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The CLRC is a joint program of the Disability Rights Legal Center & Loyola Law School Los Angeles

The HCP Manual: A Legal Resource Guide for Oncology Health Care Professionals

2nd Edition - 2011

Helping You and Your Patients Navigate Through Cancer-Related Legal Issues

INTRODUCTION

The Cancer Legal Resource Center has designed this manual to provide health care professionals with information about commonly asked questions by their patients on employment, health and disability insurance options, navigating insurance, estate planning, and legislative advocacy. We encourage patients to work with their healthcare team to resolve many of the cancer-related legal issues that arise as a result of their diagnoses. This manual should be a starting point for advocates, navigators, community health workers, nurses, physicians, social workers, and psychosocial care providers to help patients find the specific information they need. Furthermore, the information in the manual can truly be utilized by anyone assisting people coping with cancer across the nation. Please feel free to contact the Cancer Legal Resource Center at (866) THE–CLRC (866-843-2572) or visit www.CancerLegalResourceCenter.org, for additional assistance.

Funding for the preparation of this manual was provided, in part, by LIVE**STRONG**.

ABOUT THE CANCER LEGAL RESOURCE CENTER

The Cancer Legal Resource Center (CLRC) is a national, joint program of the Disability Rights Legal Center and Loyola Law School Los Angeles. The CLRC provides free information and resources on cancer-related legal issues to patients, survivors, caregivers, health care professionals, employers, and others coping with cancer.

The CLRC has a national, toll-free Telephone Assistance Line (866-THE-CLRC or 866-843-2572) where people receive information about relevant laws and resources for their particular situation. The CLRC Professional Panel of attorneys and other professionals can also provide more in-depth information and counsel to people contacting the CLRC for assistance.

Since it opened in 1997, the Cancer Legal Resource Center has assisted over 160,000 people through telephone assistance, Cancer Rights Conferences, seminars, workshops, outreach programs, and other cancer community activities.

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We extend our gratitude to those who took the time to review this guide.

DISCLAIMER

This publication is designed to provide general information on the topics presented. It is provided with the understanding that the author is not engaged in rendering any legal or professional services by its publication or distribution. It is not intended to be legal advice or establish an attorney-client relationship. Although these materials were reviewed by a professional, they should not be used as a substitute for professional services. The author of this manual has made every attempt to verify the accuracy of the information in this document but assumes no liability for use of any information or resource. The resources are provided for informational purposes only. No endorsement of any agency or individual is intended or implied. This manual is intended to include agencies and organizations in the United States, and any omissions are unintentional and do not reflect adversely on the merits of such an omitted program.

We recommend that individuals with questions or concerns about their legal options act immediately, as there may be specific legal time limitations that could affect the validity of any case and any possible legal options they may have.

We Would Like Your Feedback!

The Cancer Legal Resource Center is seeking your feedback on this manual.
Please take a few monoments to fill out our brief survey at:
www.surveymonkey.com/s/HCPManualReview2011

LIVESTRONG®

In February of 2009, the Cancer Legal Resource Center (CLRC) received a grant from LIVE**STRONG** to educate health care professionals about the legal burdens associated with cancer survivorship. The goal of the project is to empower health care professionals in the cancer community by:

1) Providing them with comprehensive cancer-related legal information in order to alleviate the psychosocial distress that may be associated with cancer survivorship;
2) Training them to identify the presence of cancer-related legal issues for the patients and to offer referral to legal resources as appropriate; and
3) Increasing the knowledge of the legal burdens of cancer survivorship to effectively advocate for cancer survivors, both within their own peer organizations and on a legislative level.

The "Cancer-Related Legal Education for Health Care Professionals" project provides frontline oncology professionals with these unique services:

- National Health Care Professionals Survey
  - Please take a few moments to complete our brief questionnaire at **www.surveymonkey.com/s/HCPsurvey**
- National Health Care Professionals Focus Groups
- Educational Seminars and In-Service Training on Cancer-Related Legal Issues for Health Care Professionals
- Cancer Rights Conferences for Health Care Professionals with continuing education units
  - Chicago, IL (Courtyard Marriott Downtown/River North) – June 24, 2011
  - Washington, DC (Georgetown University Law Center) – September 23, 2011
  - Ann Arbor, MI (University of Michigan Comprehensive Cancer Center) – October 21, 2011
- *The HCP Manual: A Legal Resource Guide for Oncology Health Care Professionals*
- Dedicated Website on Cancer-Related Legal Issues for Health Care Professionals

For more information about any of these services or upcoming events specifically for health care professionals, please visit our website at www.CancerLegalResourceCenter.org or call 213.252.8449.

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EMPLOYMENT RIGHTS

INTRODUCTION:
There are over 11.7 million cancer survivors in the United States.[1] And according to a recent study, approximately 70-80% of those survivors who are working adults return to their jobs after a cancer diagnosis.[2] Still, cancer survivors face many misperceptions about their ability to work during and after cancer treatment. As a result, their employers may treat them unfairly.

This section is designed to help employees with cancer and caregivers understand their rights, learn how to advocate for any job accommodations they may need during treatment or recovery, and effectively enforce their employment rights. It is important to understand that the federal law explained below is the bare *minimum* of what employers need to provide. However, while states must adhere to federal laws, an individual state can provide additional protections to its citizens through state laws. In addition to federal and state laws, employers may provide additional benefits to their employees. So, it is important for employees to review their employee manual or talk with their human resources representative to learn about additional employee benefits provided by employers.

I. THE AMERICANS WITH DISABILITIES ACT OF 1990

A. **Statute:** The Americans with Disabilities Act (ADA) prohibits discrimination in all employment practices against qualified employees with disabilities who can perform the essential functions of their job, with or without reasonable accommodations.[3]

1) **Employers Covered by the ADA:**
   (i) Private employers with 15 or more employees
   (ii) State and local governments, regardless of size

2) **Employment Practices Covered by the ADA:**
   (i) Job advertisements, applications, and recruiting
   (ii) Hiring and firing
   (iii) Leave and lay-offs
   (iv) Reinstatement and reassignment
   (v) Tenure and promotion
   (vi) Testing and training
   (vii) Compensation and benefits

3) The Equal Employment Opportunity Commission (EEOC) is the federal agency that enforces the ADA.

4) In 2008, the Americans with Disabilities Act Amendments Act (ADAAA) was signed into law and amended the original ADA. The ADAAA has been in effect since January 1, 2009. In several ways, the ADAAA made it easier for someone with cancer to use the ADA's protections. See below.

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[1] Center for Disease Control and Prevention. "Basic Information about Cancer Survivorship." www.cdc.gov/cancer/survivorship/basic_info
[2] Angela de Boer, PhD, Taina Taskila, PhD, Aneeli Ojajarvi, PhD, Frank J. H. van Dijk, PhD, MD, Jos H. A. M. Verbeek, Phd, MD, "Cancer Survivors and Unemployment: A Meta-analysis and Meta-regression." Journal of American Medical Association, Vol. 301, Number 7, February 18, 2009.
[3] Americans with Disabilities Act, 42 U.S.C. §12101, *et seq.*

B. **Key Requirements for Protection Under the ADA:**

1) **Who is a Qualified Individual?:** An applicant or employee with a disability who is able to perform the essential functions of the job, with or without reasonable accommodations. To be "qualified" an individual must satisfy two requirements:
   (i) Meet the skill, education, experience, and other job-related qualification standards required for the position; and
   (ii) Be able to perform those tasks that are essential to the position, with or without reasonable accommodations.
   - Example: A surgeon must be able to work as a surgeon, which requires that his/her work be done in a hospital. A surgeon cannot telecommute and conduct surgeries at home, thus being at work (in the hospital) is an essential function of the job.
   - *Note:* The ADA does not interfere with an employer's right to hire or promote the best-qualified person. While the ADA prohibits discrimination on the basis of disability, it does not impose any affirmative action obligation on an employer.

2) **What are Essential Functions?:** The essential functions of a job are the basic key job duties an employee must be able to perform, with or without reasonable accommodations.

   (i) **Factors to Consider if a Job Function is Essential:**
   - The function is the reason the job exists
   - The number of employees available to perform the function or among whom it can be distributed
   - The degree and skill required to perform that function

   (ii) **Sources to Consider if a Job Function is Essential:**
   - The written job description prepared for advertising or interviewing
   - The work experience of present or past employees in the same position
   - The time spent performing the function
   - The consequences of not requiring the employee to perform the function

3) **What is a Disability?:** Under the ADA, a "disability" is "a physical or mental impairment that substantially limits one or more of the major life activities of an individual."

   (i) **What is a Major Life Activity?:** A basic activity that the average person in the general population can perform with little or no difficulty, such as:
   - Caring for oneself
   - Speaking
   - Seeing
   - Hearing
   - Breathing
   - Walking
   - Working
   - Sleeping (new under ADAAA)
   - Concentrating (new under ADAAA)
   - Thinking (new under ADAAA)
   - Communicating (new under ADAAA)
   - Operation of major bodily functions (new under ADAAA)

- Example: A person with cancer undergoing chemotherapy treatment, who is having difficulty concentrating, thinking, sleeping or whose digestive system is being substantially limited, may qualify as having a disability under the ADA's revised definition.

(ii) **Mitigating or Corrective Measures are No Longer Taken into Account:** Corrective measures are anything that allows an individual to control, compensate for, mitigate, or alleviate a physical or mental impairment or the side effects of treatment for that impairment (e.g., eyeglasses, medications, etc).
Under the ADAAA, corrective or mitigating measures are no longer taken into account when determining if someone has a disability under the ADA.

(iii) **What is a Substantial Limitation on a Major Life Activity?:** To determine if the limitation on a major life activity is substantial, the individual is compared to an average person in the general population. Specifically, the individual must be unable to perform a major life activity that the average person in the general population can perform. Factors used to determine a substantial limitation include:

- The nature and severity of the disability;
- The duration or expected duration of the disability; and
- The permanent or long-term impact of the disability.

- Note: It is important to remember, that a substantial limitation need not be exclusive to the medical condition. The limitation may be caused by side effects from treatment.
  ⇒ Example: A patient who is undergoing chemotherapy treatment may experience "chemo-brain." In this situation, the cancer diagnosis itself may not limit the patient's ability to concentrate (a major life activity), but the side effects of the chemotherapy do substantially limit the patient's ability to concentrate and think.

4) **Who is Protected?:**

(i) **ADA Prohibits Discrimination Against Applicants or Employees Who Either:**

- Have an impairment;
  ⇒ Example: currently have cancer and going through treatment
- Have a history of an impairment; or
  ⇒ Example: childhood cancer survivor
- Are regarded as having an impairment.
  ⇒ Example: employer perceives employee as having an impairment

(ii) The ADA's protection also extends to people who "associate with" a person who has a disability.
  ⇒ Example: caregivers are protected against discrimination in the workplace, because of their "association with" a person with a disability.

(iii) The ADA also prohibits retaliation against individuals with disabilities who assert their rights or individuals who assist people with known disabilities to assert their rights.

C. **Reasonable Accommodations:**

1) **Definition:** A reasonable accommodation is any change or adjustment in the work environment, or to the way things are customarily done, that enables an individual with a disability to enjoy equal benefit and employment opportunities. An employer is required to take reasonable steps to accommodate a person with a disability, unless it would cause the employer an undue hardship.
   (i) Reasonable accommodations for people with cancer may include:
      - Making facilities accessible by changing physical space or acquiring or modifying equipment or devices;
        ⇒ Example: Providing an employee who works at a check-out counter and stands for extended periods of time with a stool to sit or lean on in order to reduce physical exertion and relieve strain on the body.
      - Flexible work hours so an employee can keep medical appointments or get treatment;
      - Telecommuting;
      - Modified or part-time work schedule;
      - Additional breaks or rest periods during the day;
        ⇒ Example: Providing an employee who is fatigued due to chemotherapy treatments with a modified lunch break from one hour to 30 minutes, in order to accommodate two additional 15-minute rest periods during the day.
      - Job restructuring to a vacant position or allocating marginal tasks to another employee;
      - Permission to use a phone to call a doctor; or
      - Extended leave time.

2) **Test to Determine What is Reasonable (case-by-case analysis):** An accommodation is reasonable if it is effective. This means that the accommodation must meet the individual's needs in that circumstance. The employer should give the employee's choice of a reasonable accommodation primary consideration, but if more than one effective accommodation is available, the employer may choose the less expensive or burdensome accommodation.
   (i) **An Employer Need Not Provide Accommodations that:**
      - Eliminate essential functions or redefine the position
      - Bump other employees from their positions
      - Create a new position
      - Lower production standards, qualitatively or quantitatively
      - Are an undue hardship on the employer (see below)

3) **Requests for Reasonable Accommodations:**
   (i) **When to Request a Reasonable Accommodation:** It is important to inform an employer of a need for a reasonable accommodation before a performance issue arises, as performance issues may lead to disciplinary action or potential termination. It is best to notify an employer as soon as the employee realizes there is a need for an adjustment in the work environment or time schedule. An employer may need advance notice to arrange for the reasonable accommodation.

   (ii) **How to Request a Reasonable Accommodation:** A request for a reasonable accommodation may be made to the employee's supervisor or to a human resources representative. Although a request for accommodation can be verbal, it

is advisable to submit it in writing, so both sides have a record of the request. Written requests may be made via email, memo or letter. The request can be in plain language and does not have to mention reasonable accommodations or refer to the ADA. Always keep a copy of all correspondence sent to or received from an employer regarding requests for reasonable accommodations. The employer may request that the employee fill out a form after an informal request has been made.

- Employers who have not been explicitly notified of an employee's disability may not be liable for failing to accommodate, or for terminating an employee based on performance problems related to the disability.

- See **APPENDIX ER1** for an example of what can be included in a letter requesting a job accommodation.

(iii) **Who May Request a Reasonable Accommodation:** A request for a reasonable accommodation may be made by the employee, a caregiver, a health care professional, or any other person acting on behalf of the employee.

- **Note:** Under the ADAAA, employers should offer an accommodation to an employee if the employer has reason to believe an accommodation is needed. Meaning, that an employee does not have to be the one to initiate the request for a reasonable accommodation. An employer can ask an employee if an accommodation is needed.

(iv) **Who is Not Eligible for a Reasonable Accommodation?:**

- Employees with a history of a physical or mental impairment
- Employees regarded as having a physical or mental impairment
- Caregivers

- Note: Only employees who currently have a physical or mental impairment that substantially limits a major life activity are entitled to a reasonable accommodation.

(v) **Both Employer & Employee Have a Duty to Engage in an *Interactive Process*:** Once a request for a reasonable accommodation is made, both the employer and the employee must engage in good faith negotiations to explore, choose, and implement the most effective accommodation for the employee.

- **Employer's obligations in the interactive process:**
  - ⇒ Respond in a timely manner to requests for reasonable accommodations;
  - ⇒ Ask relevant questions about the disability and functional limitations;
  - ⇒ Explore feasibility of suggested reasonable accommodations with the employee;
  - ⇒ Consult outside resources if not familiar with appropriate reasonable accommodations;
  - ⇒ Implement effective accommodations in a timely manner; and
  - ⇒ Maintain confidentiality about the accommodation and the process.

- **Employee's obligations in the interactive process:**
  - ⇒ Explain the disability and why accommodations are needed;
  - ⇒ Provide medical documentation, but only information relating to the "essential job functions;" and

⇒ Accept the effective accommodation offered, even if it is not the preferred accommodation.

- For more information on the interactive process visit the Job Accommodation Network at www.askjan.org/media/interactiveprocessfact.doc.

(vi) **When Does the Interactive Process End?:** Employers must continue the interactive process until an effective reasonable accommodation is found or is no longer needed. For people with cancer, the interactive process may be an ongoing process as accommodation needs may change as treatment begins, progresses, or ends. Sometimes, the most effective accommodation may only be determined through trial and error. If that is the case, the parties need to continue negotiations until they arrive at the most effective solution. Parties are also obligated to assess the effectiveness of accommodations on an ongoing basis.

4) **Employer Defenses:** The employer is not required to provide a reasonable accommodation if the reasonable accommodation poses an "undue hardship," or the employee poses a "direct threat" to himself/herself or other employees and the threat cannot be eliminated through reasonable accommodations.

(i) The required action poses an "undue hardship" for the employer if it:

- Requires significant difficulty or expense;
- Is unduly costly, extensive, substantial or disruptive considering the entire operation of the business; or
- Would fundamentally alter the nature of the operation.

(ii) An "undue hardship" is determined by assessing the nature and the cost of the accommodation against the nature, the size, and resources of the employer, the impact of the required accommodation on the facility, and the number of employees. However, even if the most effective accommodation would pose an undue hardship, the employer must still:

- Look for another effective accommodation;
- Consider funding from outside sources; and
- Give the employee an opportunity to pay for it.

D. **ADA Protections During the Job Application Process:**

1) **Disclosure of a Medical Condition and Medical Exams:** An employee does not have to disclose a medical condition or a need for reasonable accommodations on an application form or in an interview, unless the accommodation is required for the application or interviewing process. Determining the best moment to tell a potential employer about the need for reasonable accommodations is a personal decision. Often applicants do not realize that they may need accommodations until they know more about the job and the work environment, which may only arise after working there for some period of time. Some choose to inform the employer during the application process, after they understand the job requirements. If the employee chooses to reveal their cancer diagnosis or other disability, then the employer may ask if the employee will need an accommodation. If, however, an employee chooses not to disclose this information about their medical condition, then they would not be protected by the ADA, or state fair employment laws.

(i) **Pre-Offer:** During the application process, and before a job offer is made, an employer may not ask if the applicant has a disability or about the nature or the severity of a disability (even if the applicant has a visible disability), or require the applicant to take a physical exam.

- Employers may, however, ask about the applicant's ability to perform job-related functions if the questions are not designed to elicit disability-related information.
  - ⇒ Example: A potential employer may not ask an applicant if they took FMLA leave or sick time at a previous job, or how much time they took off.
  - ⇒ Note: Recently, the EEOC has recognized consistent work attendance as an essential job function.
- Employers may also ask applicants to demonstrate/describe how they will perform the essential functions of the job, with or without reasonable accommodations.

(ii) **Post Offer:** Once an employer has made a job offer, and before the employee starts work, the employer may ask the applicant to take a medical exam (but only if everyone else in the same job category must also take the exam). The employer may condition the job offer on the results of the medical exam. However, if an employee is not hired because of the medical exam results, the employer must show that:

- The reason for rescinding the offer was job related and necessary for the conduct of business; and
- There was no reasonable accommodation available to make performance of the essential job functions possible.

2) **Confidentiality of Medical Records:** Any information about an employee's medical condition or reasonable accommodations and all related documentation and medical records are confidential and must be kept in a separate file from an employee's personnel file. Information from these confidential records may only be shared with the following individuals:

(i) Managers and supervisors, if the information is necessary to determine restrictions or accommodations for a particular employee;
(ii) First aid and safety personnel, if the employee requires emergency treatment or some other assistance at work;
(iii) Government officials investigating anti-discrimination compliance; and
(iv) Workers' compensation offices and insurance carriers.

E. **Discrimination Complaint Process under the ADA:** The federal agency that enforces the ADA is the Equal Employment Opportunity Commission (EEOC). Employees who believe that they have experienced discrimination in the workplace must exhaust the administrative complaint procedures available through the EEOC, before they can file a disability-related discrimination suit in federal court. For example, employees who believe their employment rights have been violated on the basis of cancer, must first file a "charge of discrimination" with the EEOC.

1) **Mediation and Investigation:** Before conducting a formal investigation, the EEOC may refer you to the EEOC's mediation program. Mediation is an informal process whereby a third party, who is impartial to both sides, tries to resolve the issue between the employer and the employee. Both parties must agree to mediation. Participation in mediation is free, voluntary, confidential, and may prevent a time-consuming investigation or lawsuit. If mediation is unsuccessful, the EEOC will then investigate the

charge of discrimination to determine if there is "reasonable cause" to believe discrimination has occurred. If reasonable cause is found, the EEOC will then try to resolve the charge with the employer. In some cases, where the charge cannot be resolved, the EEOC will file a court action. If the EEOC finds no discrimination, or if an attempt to resolve the charge fails and the EEOC decides not to file suit, it will issue the employee a "right to sue" letter, which then allows the employee to file a lawsuit in federal court.

2) **Deadline for Submitting a Charge of Discrimination:** A charge must be filed with the EEOC within 180 days from the date of the alleged violation. But, if the charge is also covered by a state or local anti-discrimination law, the complaint must be filed with the applicable state entity first, which may also jointly file with the EEOC, and the complaint must be filed within 300 days from the date of the alleged violation, or within 30 days after the employee receives notification from the state agency that the case has been closed, whichever is earlier.

3) **Deadline for Filing a Claim in Court:** Once the EEOC issues a "right to sue" letter, the charging party has 90 days to file a court action. A charging party can also request a "right to sue" letter from the EEOC within 180 days after the charge first was filed with the EEOC and may then bring suit within 90 days after receiving notice.

II. THE REHABILITATION ACT OF 1973 (as amended in 1992)

A. **Statutes:** While the ADA applies to private employers with 15 or more employees and state or local governments, the Rehabilitation Act prohibits discrimination against qualified individuals with disabilities from federal agencies (including the U.S. Postal Service and U.S. Postal Rate Commission), contractors and their subcontractors who receive federal contracts over $10,000, and recipient of federal financial assistance.[4] For more information, or to find out about the discrimination complaint process under the Rehabilitation Act, please contact the CLRC.

B. **Disability and Reasonable Accommodations:** The definition of disability, the requirements for reasonable accommodations, and the standards for employment discrimination are the same as under Title I of the ADA outlined above.

III. STATE FAIR EMPLOYMENT LAWS

A. Many states have their own fair employment laws that provide employees with protections similar to the ADA. However, these laws vary from state to state; some have a broader definition of "disability," while some specifically list cancer as a disability, and some even provide coverage for employers with fewer than 15 employees. For more information, please contact your State Fair Employment Agency (See the **STATE APPENDICES**).

1) **States Without State Fair Employment Agencies:** Currently there are only two states in the U.S. that do not have state fair employment laws similar to the ADA. Those two states are Alabama and Arkansas. In these states, employment questions should be directed to the EEOC.

[4] The Rehabilitation Act of 1973 (as amended in 1992), 29 U.S.C. §501, §503, and §504

2) **States that Cover Employers with Fewer than 15 Employees:** Below is a chart that illustrates which state fair employment laws apply to employers with fewer than 15 employees:

State	Number of Employees
Alaska	1
Arkansas	9 (but 15 for reasonable accommodations)
California	5
Colorado	2
Connecticut	3
Hawaii	1
Idaho	5
Illinois	1
Iowa	4
Kansas	4
Kentucky	8
Maine	1
Massachusetts	6
Michigan	1
Minnesota	1
Missouri	6
Montana	1
New Hampshire	6
New Jersey	1
New Mexico	4
New York	4
North Dakota	1
Ohio	4
Oregon	6
Pennsylvania	4
Rhode Island	4
South Dakota	1
Tennessee	8
Vermont	1
Virginia	1
Washington	8
West Virginia	12
Wisconsin	1
Wyoming	2

3) **States that are Less Broad than the ADA:**
   (i) Louisiana: This state's fair employment law only applies to employers with 20 or more employees.

   (ii) Virginia: Under this state's fair employment law, a reasonable accommodation exceeding $500 in cost is presumed to impose an undue burden upon any employer with fewer than 50 employees.

4) **States that are Broader than the ADA:** The ADA defines disability as a physical or mental impairment that substantially limits a major life activity. The following states

define disability more broadly, so that people with cancer may be more likely to receive additional protections in the workplace.

(i) California: Disability is defined as a "physical or mental impairment with any limitation on a major life activity."

(ii) Illinois: Disability is defined as a "determinable physical or mental characteristic of a person which may result from disease, injury, congenital condition of birth, or a function of disorder."

(iii) Iowa: Disability is defined as a mental or physical condition or disorder that "constitutes a substantial disability," or limits a major life activity.

(iv) New York: Disability is defined as a mental or physical condition or disorder that prevents "the exercise of a normal bodily function or is demonstrable by medically accepted clinical or laboratory diagnostic techniques."

(v) Washington: Disability is defined as a sensory, mental, or physical impairment that substantially limits the ability to work generally or work at a particular job.

(vi) Wisconsin: Disability is defined as a mental or physical "impairment which makes achievement unusually difficult or limits the capacity to work."

5) **States that Specifically Identify Cancer as a Covered Medical Condition:** California, Maine, Ohio and Vermont all specifically identify cancer as a covered medical condition, which provides for protection under the state fair employment laws, in addition to protection provided under the ADA.

IV. **RESOURCES**

For questions about the ADA: U.S. Equal Employment Opportunity Commission 1801 L Street, N.W. Washington, D.C. 20507 (800) 669-4000 or (202) 663-4494 (TTY) www.eeoc.gov	**For questions about job accommodations:** Job Accommodation Network (JAN) (800) 526-7234 or (800) ADA-WORK www.askjan.org
For questions about §503 of the Rehabilitation Act (federal contractors): U.S. Department of Labor Office of Federal Compliance Program Frances Perkins Building, Room C-3325 200 Constitution Avenue, N.W. Washington, D.C. 20210 (800) 397-6251 or www.dol.gov/esa/ofccp	**For questions about §504 the Rehabilitation Act (federal financial assistance):** U.S. Department of Justice Civil Rights Division Disability Rights Section 950 Pennsylvania Avenue, N.W. Washington, D.C. 20530 (800) 514-0301 or (800) 614-0383 (TTY) www.justice.gov/crt/about/drs
For questions about the practical aspects of being an employee with cancer: Cancer and Careers (212) 685-5955 or www.cancerandcareers.org	**For state specific information:** See the **STATE APPENDICES** or contact the CLRC.

TAKING TIME OFF WORK

INTRODUCTION:
Employees with cancer may face difficulty when they need to take time off for treatment or recuperation. For example, employees may be denied time off from work or may be worried about losing their job if they do take time off from work. Caregivers may also face similar difficulties with taking time off work. Both federal and state laws allow eligible employees to take paid or unpaid leaves of absence from their work. This section provides an overview of these laws.

I. THE FAMILY AND MEDICAL LEAVE ACT OF 1993

A. **Statute:** The Family and Medical Leave Act (FMLA) was designed to balance the demands of the workplace with the needs of families, to promote the stability and economic security of the family, and to promote national interests in preserving family integrity by allowing time off from work, while keeping a job and benefits.[5]

1) **Employers Covered by the FMLA:**
   (i) Private employers with 50 or more employees, within a 75 mile radius of the employer's worksite; and
   - Number of employees is calculated for each working day during each of 20 or more calendar workweeks in the current or preceding calendar year.[6]
   - The 75 mile radius is determined by the distance it would take to drive 75 miles "using surface transportation over public streets, roads, highways and waterways, by the shortest route from the facility where the employee requesting leave is employed."[7]
   - **Note:** While companies with less than 50 employees do not qualify for FMLA leave, many have policies allowing employees similar time off from work, while allowing employees to keep their jobs and benefits. Employees should check with their human resources representative or review their employee manual for additional information about their company policies.

   (ii) Public employers, regardless of size, including federal, state and local governments.

2) **Employees Covered by the FMLA:** Employees must meet the following eligibility criteria to use the FMLA's protections:
   (i) **Work for the employer for at least 12 months**: The 12 months are calculated based on the date the leave begins. Additionally, the 12 months do not have to be continuous or consecutive, just cumulative. Under the FMLA, employees may reach a cumulative 12-month period by going back 7 years in their work history.[8] A break in work history that exceeds 7 years, does not count towards the 12-month time period required by FMLA, unless the time off is a result of the employee's service in the National Guard, reserve military training, or there is a written agreement where the employer intends to rehire the employee after a break in service.[9]

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[5] The Family and Medical Leave Act of 1993, 29 U.S.C. § 2601
[6] The Family and Medical Leave Act of 1993, 29 U.S.C. § 2611 (4)(A)(i)
[7] 29 CFR § 825.111(b)
[8] Note: Some states have similar laws to the FMLA that do not use a "7 year" limit, but allow employees to use their entire work history.
[9] 29 CFR § 825.110(b)

- **Example:** An employee could work for employer "A" for 4 months, then leave for 2 years, then return and get a job with employer "A" for another 8 months, and this would equal a total of 12 months, qualifying the employee for FMLA leave.
- **Note:** Employees maintained on payroll for any part of a week, including sick or vacation weeks taken while on unpaid leave constitutes a week of employment and therefore count towards an employee's 12-month work period.[10]

(ii) **Work at least 1250 hours in the 12 months immediately before taking leave:** To determine if any employee has satisfied the 1250-hour requirement, an employer will look at the total hours worked during the 12 months preceding the FMLA leave. Employees meet the 1250 hour requirement if they have worked:

- 24 hours in each of the 52 weeks of the year; or
- Over 104 hours in each of the 12 months of the year; or
- 40 hours per week for more than 31 weeks (over seven months) of the year.
- **Note:** If adequate records documenting the employee's total work time are not kept, the employer has the burden of showing that the employee has not met the requisite hours applicable for FMLA leave.[11]

B. **Protection under the FMLA:**

1) **Covered Leave:** A covered employer must grant an eligible employee up to 12 weeks of unpaid, job and health insurance benefit-protected leave, in a 12-month period to:
   (i) Care for a spouse, son, daughter, or parent with a "serious health condition;"
   (ii) To take medical leave when the employee is unable to work because of a "serious health condition;"
   (iii) To care for a newborn child following birth; or
   (iv) For the placement of a son or daughter in adoption or foster care with the employee.

2) **How is the 12-Month Period Determined?:** An employee may take 12 weeks of unpaid leave every 12 months. An employer must elect, and apply consistently and uniformly to all employees, one of four options to determine the 12-month period:
   (i) A calendar year;
   (ii) Any fixed 12-month period, such as a fiscal year, a year required by state law, or a year starting on the anniversary of the employee's hiring date;
   (iii) A 12-month period measured forward from the date when an employee's first FMLA leave begins; or
   (iv) A "rolling" 12-month period measured backward from the date an employee uses FMLA leave.[12]

   (v) Note: If an employer does not select one of the four options above to determine the 12-month period, then the method most beneficial to the employee is utilized.[13]

   (vi) Note: If an employer wishes to change the method utilized to calculate the 12-month period, they must provide written notice to all employees (within 60 days) of making such change.[14]

[10] 29 CFR § 825.110(b)
[11] 29 CFR § 825.110(c)(3)
[12] 29 CFR § 825.200(b)
[13] 29 CFR § 825.200(e)
[14] 29 CFR § 825.200(d)(1)

3) **How to Use 12 Weeks of Leave:** Employees may take their 12-weeks of leave in many ways, including:
   (i) By blocks of time (e.g., taking 12-weeks at once);
   (ii) By reducing their normal weekly or daily work schedule (e.g., taking every Friday off for doctor's appointments); or
   (iii) By taking short periods of leave up to 12-weeks (e.g. taking one week per month for chemotherapy).

   (iv) **Part-time employees:** Qualifying part-time employees may take FMLA leave based on a pro-rata basis by comparing their normal schedule with their new schedule. For example, if an employee works 30-hours/week but takes off 10-hours/week for FMLA time, the employee would be using one-third a week of FMLA leave each time they take the hours off.[15]

   (v) **Overtime:** If an employee is required to work overtime, but cannot do so because of qualifying FMLA leave, the hours the employee would have worked are counted against the employee's FMLA entitlement.[16]

   (vi) **Intermittent Leave:** An employee may use intermittent leave only when it is medically necessary. If the employer requests it, the employee must provide a certification by a health care provider, which states that working on this different schedule, or being able to take leave on an intermittent basis, is medically necessary for the employee or needed to provide care or psychological comfort to a family member with a serious health condition.
      - Intermittent leave may also be taken based on foreseeable medical treatment. However, the employee must make a reasonable effort to schedule the treatment to not unduly disrupt the employer's operations.[17]
      - Employers may deduct from an exempt employee's salary any hours that are taken for intermittent leave.[18]
      - The employer may temporarily transfer the employee to an alternative position with the same pay and same benefits, if the position better accommodates recurring or intermittent leave.[19]

   (vii) The time in which an employee spends performing light duty work may also be counted against the 12 week FMLA leave.
      - An employer cannot force an employee to accept a light duty assignment nor can an employer deny FMLA leave simply because light duty assignments are available to the eligible employee.

   (viii) Each extension or new block of FMLA leave time is subject to the same notification and certification requirements as the initial leave period.

   (ix) Eligibility is determined at leave commencement. FMLA leave begins with the first absence from work due to the same underlying condition each leave year. Thus, where leave is taken in a single uninterrupted block of time, eligibility is determined by the first day of missed work.

[15] 29 CFR § 825.205 (b)(1)
[16] 29 CFR § 825.205(c)
[17] 29 CFR § 825.203
[18] 29 CFR § 825.206(a)
[19] 29 CFR § 825.204

4) **What is a "Serious Health Condition?":** A "serious health condition" is any physical or mental "illness, injury, medical condition or impairment" that requires:
   (i) Inpatient care and treatment in a hospital, hospice or residential care facility; or
   (ii) Continuing outpatient treatment by a health care provider, which includes:
      - A period of incapacity of more than three consecutive calendar days, and
      - Any subsequent treatment or period of incapacity relating to the same condition that involves:
         ⇒ Two or more treatments by a health care provider (e.g., physical therapy) under the orders of, or on referral by, a health care provider; or
         ⇒ At least one treatment by a health care provider, which results in a regimen of continuing treatment under the supervision of a health care provider.
         ⇒ Note: The fact that an employee still works at a second job does not automatically indicate that the employee is not incapacitated from working at the job they are seeking time off from.[20] However, an employer may prohibit an employee from working at a second job while on FMLA leave, if that policy is applied to all employees uniformly.[21]
         ⇒ Note: Colds and flu are ordinarily not a serious health condition resulting in incapacity; however, if such illness results in more than three days of consecutive treatment, it may be treated as an incapacity requiring time off.[22]
      - Any period of incapacity due to pregnancy or prenatal care.
      - Any period of incapacity or treatment for such incapacity, which is due to a chronic, serious health condition that:
         ⇒ Requires periodic visits for treatment to a health care provider at least two times a year;
         ⇒ Continues over a period of time; or
         ⇒ May cause episodic rather than a continuing period of incapacity (e.g., asthma, epilepsy, diabetes, etc.).
      - A period of incapacity, which is permanent or long-term due to a condition for which treatment may not be effective (e.g., Alzheimer's, stroke, terminal conditions).
      - Any period of absence for the purpose of receiving multiple treatments for a condition that would likely result in a period of incapacity of more than three consecutive calendar days in the absence of medical intervention or treatment (e.g., cancer treatments such as chemotherapy and radiation).

5) **Who is a "Health Care Provider?":** Under the FMLA, a health care provider includes:
   (i) Doctors of medicine or osteopathy licensed in the state in which they practice;
   (ii) Podiatrists, dentists, clinical psychologists, optometrists and chiropractors (limited to correction of subluxations of the spine as demonstrated by x-rays), practicing within the scope of their practice and under state license;
   (iii) Nurse practitioners, nurse-midwives and clinical social workers, practicing within the scope of their practice and under state license;
   (iv) Christian Scientist practitioners listed with First Church of Christ Scientist in Boston;
   (v) Any health care provider recognized by the employer or employer's benefits manager

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[20] *Stekloff v. St. John's Mercy Health System*. 218 F. 3d 858 (8th Cir. 2000).
[21] 29 C.F.R. § 825.216(e)
[22] American Bar Association, Family Medical Leave Act: Wage and Hour Advisory Opinions, No. 87 (December 12, 1996).

6) **Medical Certification of a Serious Health Condition:**

(i) **What an employer can do:**

- An employer may require that the employee provide certification of the need to take FMLA leave from the employee's health care provider;
- The employer must allow the employee at least 15 calendar days to obtain the medical certification;
- Certification from a health care provider should include the date on which the serious medical condition began, the probable duration of the condition, and a statement that the employee is unable to perform one or more of the essential functions of the position because of a serious health condition;
  - ⇒ Note: The identity of the condition or diagnosis is not required, even if the requested time off is to care for an employee's family member
  - ⇒ Potential Issue: New Department of Labor forms include a place to list a patient's diagnosis, although it is not required to submit the form
- If the certification is for a family member, it must include a statement that the serious health condition requires the employee to provide care during a period of treatment or supervision, and an estimate of the amount of time that the health care provider believes the employee will need to provide the care;
- An employer may request a second medical opinion, at the employer's expense, if the employer doubts the medical certification is valid. If the first and second medical opinions differ, a third medical opinion is binding; and
  - ⇒ Note: The third opinion provider must be approved by both the employer and the employee; however, the employer is required to pay any expenses related to obtaining the third opinion.[23]
- An employer may ask the employee for recertification of FMLA leave only if:
  - ⇒ Circumstances have changed significantly,
  - ⇒ The employee is seeking a longer period of leave, or
  - ⇒ Information comes to the employer that casts doubt on the continuing validity of the initial certification, such as observing the employee performing activities that are inconsistent with what was previously conveyed by the health care provider.[24]
- An employer may contact the health care provider without the employee's consent to clarify (understand the handwriting or meaning) or authenticate medical certification; however no additional information may be requested.[25]
  - ⇒ Note: The employee's direct supervisor may not contact the health care provider, only a HR or a management official, leave administrator, or health care provider.[26]
- An employer may ask for medical certification even if it was not initially requested.[27] If certification is insufficient, an employer must specify in writing what information will suffice to make the certification complete and give the employee seven calendar days to comply.[28]

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[23] 29 CFR § 825.307(a),(b)
[24] 29 CFR § 825.308(b)
[25] 29 CFR § 825.307(a),(b)
[26] 29 C.F.R. § 825.307(a)
[27] *Townsend-Taylor v. Ameritech Services, Inc.*, 523 F. 3d 815, 818-819 (7th Cir. 2008).
[28] 29 C.F.R. § 825.305(d)

7) **Confidentiality of Medical Documents:** Any FMLA-related inquiries and all related documentation are confidential and must be kept in a separate file from an employee's personnel file. If employees have questions or concerns about the confidentiality of their medical information, they may contact the Office of Civil Rights.

8) **Taking Care of Family Members:** An employee can take leave under the FMLA to care for family members including:
   (i) **Care of children:** The care of children includes the employee's offspring, adopted or foster child, stepchild, legal ward, or other child that the employee is acting as "in loco parentis" for
      - "In loco parentis" includes, but is not limited to, an individual who provides daily care or financial support to the child.
      - The child must be a minor or over the age of 18 but unable to care for oneself because of a physical or mental impairment that substantially limits a major life activity.[29]
      - **Note:** Leave for birth and care, or placement for adoption or foster care of a child must conclude within 12 months of the birth or placement.
      - **Note:** Spouses who work for the same employer are jointly entitled to a combined total of 12 weeks of family leave for the birth and care of newborn child, for placement of a child for adoption or foster care.

   (ii) **Care of parents:** The care of parents includes individuals who are biologically related to the employee, adopted, step or foster parent, as well as an individual who acted as "in loco parentis" to the employee.
      - **Note:** Taking care of a parent in-law does not qualify the employee for FMLA leave.[30]

   (iii) **Care of spouses:** The care of spouses does not extend to domestic partners under the FMLA. However, care of domestic partners or common law spouses may be covered under state law.[31]

   (iv) **Care taking activities:** These activities may include, but are not limited to:
      - Providing hygienic care, meeting nutritional needs, ensuring safety, making nursing home arrangements, transportation or accompaniment to doctor visits and providing psychological comfort to the family member
      - When the employee is needed to substitute for an individual who normally cares for their family member

C. **Employee Responsibilities:**
   1) **Notice Requirement:** An employee must give the employer "reasonable advance notice" that the employee wishes to take FMLA leave.
      (i) **If leave is foreseeable:** Reasonable advance notice is 30 days in advance.
      (ii) **If leave is unforeseeable:** Reasonable advance notice is "as soon as practicable."
      (iii) **"As soon as practicable:"** typically means that the employee must give the employer at least a verbal notification within the same business day or one day after the employee learns of the need to take leave.

[29] 29 C.F.R. § 825.122 (c)
[30] 29 C.F.R. § 825.122 (b)
[31] 29 C.F.R. § 825.122 (a)

2) **Medical Documentation:** See §6(i) above to explain what a health care provider's certification should include.
   (i) Note: Upon completion of leave, a health care provider may provide notification to the employer that the employee is able to return to work.

3) **Asking for Leave:** An employee's request for FMLA leave may be in plain language and does not have to specifically mention the FMLA. However, the request must include sufficient information for the employer to understand that the reasons for the leave fall under the FMLA's definition of a serious health condition. To ensure adequate protection, it is a good idea to give notice in writing and to refer to the FMLA, although it is not required. Employees must provide at least verbal notice that makes the employer aware of the need for FMLA leave, including the time and length of leave. Additionally, it is a good idea to include reasons for the requested leave, as well as the anticipated duration of leave.
   (i) Employees should consult with their employer before scheduling treatment that would require leave, in order to best accommodate the needs of both the employer and the employee.[32]

   (ii) Note: Recently, courts have stated that employers are put on notice of a need for leave given an employee's noticeable behavior changes or deterioration in job performance.[33]

D. **Employer Responsibilities:**
1) **Notice Requirement:** An employer must notify the employee, in writing, that the requested leave is designated as FMLA leave. If an employer was not aware that the employee's leave should have been designated as FMLA, the leave can be retroactively defined as FMLA leave, but only if the leave is still in progress or within two business days of the employee's return to work.
   (i) **Notice to the employee should include:**[34]
   - The qualifying leave constitutes FMLA leave;
   - Certification requirements;
   - Leave substitution rights;
   - Health insurance premium payment requirements and consequences if payments are missed;
   - Whether the employee is a "key employee;"
   - Right to maintain benefits;
   - Eligibility to return to same or equivalent job upon conclusion of leave;
   - Potential liability to employer for paid health insurance premiums if the employee does not return to work after the conclusion of leave;
   - Other information (e.g., fitness-for-duty certification for employment to be restored, requirement of periodic status reports, etc.)

   (ii) If an employer acquires knowledge that an employee requires time off, the employer has five business days to notify the employee of their FMLA eligibility.

   (iii) If a "fitness for duty" certification is required by the employer, the employee must be given notice of this requirement within the designation notice.[35]

[32] 29 CFR § 825.302 (e)
[33] Byrne v. Avon Prods., Inc., 328 F. 3d 379 (2003).
[34] 29 CFR § 825.300 (c)(1)(2)
[35] 29 CFR § 825.300(d)(3)

2) **Unpaid Leave:** The FMLA only requires employers to provide unpaid leave; however, an employee may choose to use accrued sick or vacation leave for some or all of the FMLA period.
   (i) **Availability of Paid Leave:** The employer can require employees to take paid time off with unpaid FMLA leave; however, the employer must impose the same terms and conditions on the use of paid leave during the FMLA period as they would impose when an employee takes off for non-FMLA reasons.[36] If an employee does not wish to comply with this rule, they can still take leave, but it will be unpaid.
      - **Example:** If an employee wants to take 2 hours of FMLA leave and use substituted paid leave for the time off, but the employer's policy requires paid leave to be taken in 8 hour increments, the employer may chose to deny the 2 hours of paid leave, while granting the unpaid FMLA time off. The employer is not required to provide paid leave in smaller increments than is the normal paid leave policy. However, the employer may choose to waive their paid leave policies to allow for the shorter period of paid leave.

      - **Note:** When paid leave, such as sick or vacation leave, is substituted for unpaid leave, it may be counted as FMLA leave only if the employee is properly notified of the FMLA designation when the leave begins.

   (ii) **Bonuses:** Employers may count an employee's absence under the FMLA against attendance bonuses.[37]

3) **Job-Protected Leave:** Upon return from FMLA leave, an employee must be restored to his or her original position or to an equivalent position with equivalent pay, benefits, and other terms and conditions of employment.
   (i) **Exceptions:** There are several circumstances in which an employer does not need to reinstate an employee:
      - If an employee gives unequivocal notice that he or she does not intend to return to work;
      - If an employee's position was eliminated (e.g., in a general lay-off);
      - If the employee was terminated for a legitimate reason unrelated to the leave (e.g., for theft or misconduct);
      - If the individual is a highly paid "key employee" (e.g., in the top 10% of the pay scale whose absence would cause substantial grievous economic injury to the operations of the business). Employers must notify employees that are considered "key" and are likely to be denied reinstatement when they apply for leave, but the employer may not deny the employee the leave; or
      - If an employee is unable to return to work when he or she has exhausted all 12 weeks of FMLA leave in the designated 12-month period.

   (ii) **Additional Leave May Be Available Under Americans with Disabilities Act:** Under the ADA, an employee may be entitled to leave beyond the 12-weeks provided by the FMLA, as a reasonable accommodation, but only if:
      - The employee's serious health condition also qualifies as a disability under the ADA;

[36] 29 CFR § 825.207(a)
[37] 29 CFR § 825.215(c)(2)

- The extension is requested as a reasonable accommodation;
- The requested extension has a definite ending date and is reasonable in length; and
- The additional leave does not pose an undue hardship on the employer.

- Example: If an employee requests leave as a reasonable accommodation under the ADA, the employer may grant the requested leave, so long as it is not an undue hardship, while also advising the employee that the time-off will count towards their FMLA leave. Accordingly, the employer must maintain the employee's health coverage during the leave as required by FMLA. However, upon returning from leave, the employee's original job may be reinstated under the ADA, rather than the employee returning to an equivalent position as required under the FMLA.[38]

- Example: If an employee takes leave under FMLA, the employer is required to reinstate the employee to an equivalent position upon returning to work. If however, the employee cannot perform the essential job functions of the equivalent position, even with reasonable accommodations, the employer may allow the employee to work part-time or to be reassigned to a vacant position as a reasonable accommodation for a disability under the ADA.[39]

(iii) **How do FMLA Protections Differ From the ADA?:** Leave time under the FMLA may be used to care for the employee or a seriously ill family member. Under the ADA, only the employee can use leave time to accommodate his or her own limitations. Additionally, under the FMLA, an employee is entitled to return to his or her original or an equivalent position. If the employee is unable to return to work when the 12-week FMLA leave is over, the employer is not required to hold the employee's position. Under the ADA, an employee is entitled to return to the same position, unless it would be an undue hardship on the employer to hold the position open. FMLA also allows an employer to transfer a qualified employee with reduced hours to a temporary position to accommodate a treatment plan, whereas under the ADA the employer can only reassign an employee to an equivalent and vacant position when there are no reasonable accommodations available in the employee's current position or such accommodations would cause the employer hardship.

4) **Benefit-Protected Leave:** While on FMLA leave, an employee is entitled to receive full continued health insurance benefits from the employer, but the employer is not required to maintain any other benefit plans unless it is the employer's established policy to do so for all employees. If other benefits are discontinued during the leave, coverage must be restored when the employee returns to work and may not be subjected to any eligibility requirements or pre-existing condition exclusions.

(i) **Example**: If an employer normally pays for an employee's health insurance, then the employer has to keep paying for those benefits for up to 12 weeks, even if the employee is not working. The employer also has to reinstate the employee's other benefits when the employee returns to work.

[38] 29 CFR § 825.702(c)(2)
[39] 29 CFR § 825.702(c)(4)

(ii) **Example**: When an employee is on FMLA leave, the employer will maintain an individual's existing health coverage under any group health plan. This includes dependent or family member health coverage, dental coverage, or mental health coverage. For example, if an employer normally pays 80% of an employee's health insurance premiums, the employer must continue to pay 80% of these premiums while the individual is on medical leave. The employee would continue to be responsible for their 20% of the premiums.

5) **Discrimination or Retaliation Under the FMLA:** An employer may not take any adverse action against an employee who is asserting his or her FMLA rights, and an employer may not discharge or otherwise discriminate or retaliate against an employee for alleging a violation of the FMLA.

E. **FMLA and Short Term Disability Benefits:** Employers can impose reasonable terms and conditions on an employee's use of an employer's short term disability insurance policy. Employees need to understand that these policies may be different than FMLA policies! Employees should check their employee manual or company policy to see how the employer may treat these situations.

1) When an employee applies for short term disability benefits in conjunction with FMLA leave, the employer may:
   (i) Require a medical examination by a physician selected and regularly used by the company or a third-party administrator (in contrast to the rule under the FMLA that the physician giving a second opinion not be regularly employed by the company);
   (ii) Require more detailed information than that permitted under the FMLA;
   (iii) Require medical recertification on a regular basis or upon request without regard to FMLA limitations;
   (iv) Require the prompt return of medical certification/re-certifications as a condition of receipt of benefits (to provide incentive for employees to provide certifications earlier than required under the FMLA);
   (v) Require a signed consent by the employee permitting a physician selected by the company or third-party administrator to talk with the employee's physician and obtain medical records;
   (vi) Restrict other employment during leave (even if second jobs are permitted for active employees); and
   (vii) Restrict activities during leave that a physician selected by the company or third-party administrator concludes are inconsistent with the employee's recovery and/or plan of treatment.[40]

F. **Complaint Process for FMLA Violations:** The federal administrative agency responsible for handling FMLA-related complaints is the Employee Standards Administration (Wage and Hour Division of the U.S. Department of Labor (DOL)). The DOL will investigate claims, but filing an administrative complaint is not a pre-requisite to filing a lawsuit in federal court. The complaint must be in writing and should include a full statement of the acts and/or omissions believed to be a violation of the FMLA, including all pertinent dates.

1) **Deadline for Filing:** Administrative complaints or court actions for violations under the FMLA must be filed within two years of the date of the last alleged violation. However, complaints about willful violations may be made within three years.

[40] 29 CFR § 825.207(f)

II. STATE MEDICAL LEAVE LAWS

A. **Introduction:** In addition to federal protections, several states have enacted state medical leave laws. While most states laws are similar to the FMLA, some offer additional protections. Additionally, if a state law offers more protection than the FMLA, state law will prevail when there is an issue involving medical leave.
   1) **Example:** State A allows employees to take up to 26 weeks of leave for their own serious medical condition every two years. Although the FMLA provides for only 12 weeks of leave per 12-month period, an employer must allow the employee 26 weeks off the first year (under State A law) and 12 weeks off the second year under the FMLA.[41]

B. **States Medical Leave Laws:** The following states have enacted state medical leave laws:
   1) California
   2) Connecticut
   3) Hawaii
   4) Maine
   5) Minnesota
   6) New Jersey
   7) Oregon
   8) Rhode Island
   9) Vermont
   10) Washington
   11) Wisconsin
   12) District of Columbia

III. RESOURCES

For questions about the Family & Medical Leave Act (FMLA): U.S. Department of Labor Employment Standards Administration Wage and Hour Division 200 Constitution Ave, NW Washington, D.C. 20210 (866) 487-9243 or (887) 889-5827 (TTY) www.dol.gov/esa/whd/fmla	**For questions or concerns about the confidentiality of medical information:** Office for Civil Rights U.S. Dept. of Health and Human Services 200 Independence Avenue, S.W. Room 509F, HHH Building Washington, D.C. 20201 (866) 368-1019 www.hhs.gov/ocr
For questions about state leave laws: Contact your state's fair employment agency (See the **STATE APPENDICES**) or contact the CLRC.	

[41] 29 CFR § 825.701

DISABILITY INSURANCE

INTRODUCTION:
Employees with serious medical conditions, such as cancer, who need to take time off from work, may be concerned about maintaining their income during an unpaid leave of absence. Disability insurance is an insurance policy that pays a portion of an employee's income in the event of a temporary or permanent disability, which prevents the employee from working.

I. PRIVATE DISABILITY INSURANCE

A. **What is Private Disability Insurance?:** Private disability insurance is an insurance policy that can be provided by an employer as an employee benefit, or an insurance policy that can be purchased by an individual directly from an insurance company. It protects employees who are unable to work due to a disability, by paying them all or part of their salaries.

B. **What is Short-Term Private Disability Insurance?:** Short-term private disability insurance pays a percentage of an employee's salary if the employee becomes unable to work for a short period of time due to illness, injury, or pregnancy. Short-term disability insurance policies typically provide benefits for a short period of time (six months to one year).

C. **What is Long-Term Private Disability Insurance?:** Long-term private disability insurance pays a percentage of an employee's salary if the employee becomes unable to work for a longer period of time due to illness or injury. Long-term disability insurance policies typically provide benefits for a disability that is expected to last, or has lasted, for one year or longer. However, policies do vary on the length of coverage and the definition of a long-term disability.

D. **Policy Features:** It is important for the employee to review the terms, limitations, and exclusions in the policy to determine whether the coverage is adequate for their own future needs. It is also important to know how the insurance company defines "disability."
   1) The following information should be reviewed prior to purchasing a disability insurance policy:
      (i) The definition of "total disability" that will entitle an individual to benefits;
      (ii) The "elimination" or "qualifying" period, which refers to the period of time between the date the disability begins and when benefits are paid;
      (iii) Availability of "residual" benefits, which make up the difference in income if the individual is only able to work in a limited capacity, which results in a lower income;
      (iv) Payment for "presumptive" disabilities (such as loss of sight, hearing, or use of limbs), even if the individual still may be able to work;
      (v) The "benefit period," which means the maximum amount of time an individual can collect benefits;
      (vi) The "benefit percentage," which is the amount an individual will be paid and is usually a percentage of one's income;
      (vii) Any cost-of-living adjustments to increase benefits;
      (viii) "Waiver of premiums," so that an individual does not have to pay premiums if the disability lasts 90 days or longer;
      (ix) "Mandatory rehabilitation options," which allow the insurance company to terminate benefits if an individual does not cooperate with a rehabilitation plan;

(x) Any other limitations or exclusions (such as barring benefits for pre-existing conditions);
(xi) Any offsets against benefits (such as SSDI or workers' compensation); and
(xii) "Survivor benefit options," which is a lump sum payment to the insured's survivors if the insured dies while receiving disability benefits.

E. **Pre-Existing Conditions:** Insurance companies can refuse to sell individual disability insurance policies to people who have pre-existing medical conditions. Therefore, it is important to purchase disability insurance before an individual has a pre-existing medical condition. Some policies may offer a pre-existing condition exclusion period. This means that for a specific period of time, the insurance company will not provide benefits, if an employee is unable to work as a result of the pre-existing medical condition. Only after the pre-existing condition exclusion period ends, will the condition then be covered under the policy.

1) **Medical Examinations:** The insurance company can also require a medical examination before issuing a policy. Once they issue the policy, it generally cannot be cancelled as long as the premium is paid on time. However, if there was any misrepresentation of a disability or of pre-existing medical conditions, the insurance company may cancel the policy based on a claim of fraud. It is important to always provide accurate medical history information.

2) **Claim Denial:** If a disability insurance company denies an insurance claim, some policies require the decision to be appealed within a certain timeframe. Check with the insurance company for information on the appeals process.

F. **Private Disability Insurance vs. Workers' Compensation:** If an employee is receiving workers' compensation benefits after being injured on the job, some private disability insurance policies will deny or reduce the amount of private disability insurance benefits the employee receives.

II. STATE DISABILITY INSURANCE

A. **State Disability Insurance:** State disability insurance benefits are benefits that are offered through a state-sponsored program. State disability insurance programs have different names in each state. They can be called temporary disability insurance benefits or state short-term disability insurance benefits. They provide employees with a source of income when they are unable to work due to disabling illnesses and injuries, which are not work-related. In order to draw on these benefits while an employee is unable to work, they must have paid into the system through taxes. Typically, state disability insurance benefits are administered by the same agency that administers state unemployment insurance. Eligibility requirements for these benefits vary in each state.

1) **States and Territories That Offer State Disability Benefits:** Below is a list of the states and territories that offer disability insurance benefits and how long they offer benefits:
(i) California State Disability Insurance (SDI) – up to 52 weeks
(ii) Hawaii Temporary Disability Insurance (TDI) – up to 26 weeks
(iii) New Jersey Temporary Disability Insurance (TDI) – up to 26 weeks
(iv) New York Disability Benefits Law (DBL) – up to 26 weeks
(v) Rhode Island Temporary Disability Insurance (TDI) – up to 30 weeks
(vi) Puerto Rico Disability Insurance – up to 26 weeks

III. STATE PAID FAMILY LEAVE

A. **Paid Family Medical Leave:** Some states provide paid family leave for employees who are taking time off work to provide caregiving services to a seriously ill family member.

1) Example: California has Family Temporary Disability Insurance that provides income (up to 55% of an employee's weekly pay) for caregivers who are taking up to 6 weeks off of work.

2) Example: New Jersey has the Temporary Disability Benefits Law that provides income (up to 66% of an employee's weekly pay) for caregivers who are taking up to 6 weeks off of work.

3) Example: Washington has short term disability laws that provide income (up to $250/week) to caregivers who are taking up to 5 weeks off of work to care for a child.

IV. FEDERAL DISABILITY INSURANCE

A. **Introduction:** In addition to the disability benefits programs discussed above, the federal government offers two long-term disability benefit programs: Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI). In order to receive these benefits, an employee must apply with the Social Security Administration (SSA) and must also meet the SSA's definition of disability. The key to qualifying for benefits is to show how an employee's medical condition and the side effects from its treatment are keeping an employee from working.

1) **Requirements:** SSA defines "disability" as a "medically determinable physical or mental impairment," that:
   (i) Results in the inability to do any substantial gainful activity;
   (ii) Has lasted or can be expected to last for a continuous period of 12 months or more; or
   (iii) Can be expected to result in death.

2) **Social Security Administration Test:** The SSA has a five-step process to determine whether someone has a disability:
   (i) Is the applicant working and earning more than $1,000 per month? If so, the applicant is denied unless the applicant was precluded from working for at least one year;
   (ii) Does, the applicant have a severe impairment? The impairment must do more than minimally affect an applicant from doing basic work activities in the statute; it must significantly limit the applicant for at least one year;
   (iii) Assuming the above two requirements are satisfied, does the applicant's medical condition meet or equal a description of severity that is codified in something called a "listing" created by the SSA? If the condition is not listed, then the SSA will look at the severity of the condition;
   (iv) Can the applicant return to work or any past work done in the last 15 years? If one job is found in the applicant's last 15 years of work history that can be done, the claim is denied. If not, the applicant reaches the last step in the process; and
   (v) Finally, once the above-mentioned requirements are satisfied, the burden of proof shifts to the SSA to show that there is other work, other than past relevant work, that the applicant can now perform.

3) **Compassionate Allowances:** The Compassionate Allowances program began in 2008, as a way of quickly identifying medical conditions that qualify someone presumptively eligible for Social Security disability benefits. The following chart is a list of cancer-related conditions in the Compassionate Allowances program. For a complete list, visit www.ssa.gov and search for Compassionate Allowances.

COMPASSIONATE ALLOWANCES:

- Acute Leukemia
- Adrenal Cancer – distant metastases or inoperable, unresectable or recurrent
- Anaplastic Adrenal Cancer – distant metastases or inoperable, unresectable or recurrent
- Bilateral Retinoblastoma
- Bladder Cancer – distant metastases or inoperable or unresectable
- Bone Cancer – distant metastases or inoperable or unresectable
- Breast Cancer – distant metastases or inoperable or unresectable
- Chronic Myelogenous Leukemia (CLM) – Blast Phase
- Ependymoblastoma (Child Brain Tumor)
- Esophageal Cancer
- Gallbladder Cancer
- Glioblastoma Multiforme (Brain Tumor)
- Head and Neck Cancers – Bone Cancer – distant metastases or inoperable or unresectable
- Idiopathic Pulmonary Fibrosis
- Inflammatory Breast Cancer (IBC)
- Kidney Cancer – inoperable or unresectable
- Large Intestine Cancer – distant metastases or inoperable, unresectable or recurrent
- Liver Cancer
- Mantle Cell Lymphoma (MCL)
- Mucosal Malignant Melanoma
- Non-Small Cell Lung Cancer – metastases to or beyond the hilar nodes or inoperable, unresectable or recurrent
- Ovarian Cancer – distant metastases or inoperable or unresectable
- Pancreatic Cancer
- Peritoneal Mesothelioma
- Pleural Mesothelioma
- Salivary Tumors
- Small Cell Cancer (of Large Intestine, Ovary, Prostate or Uterus)
- Small Cell Lung Cancer
- Small Intestine Cancer – distant metastases or inoperable, unresectable or recurrent
- Stomach Cancer – distant metastases or inoperable, unresectable, or recurrent
- Thyroid Cancer
- Ureter Cancer – distant metastases or inoperable, unresectable or recurrent

B. **Supplemental Security Income (SSI):** SSI is the federal long-term disability program that makes monthly payments to people who are age 65 or older, blind, or have a disability. An applicant's income and resources are used to determine whether they meet the financial requirements for SSI.

1) **Income & Resource Requirements:** Income is money received (wages, Social Security benefits, pensions, etc.). Income can also include things such as food and shelter. Resources that SSA counts in deciding whether an individual qualifies for SSI benefits include real estate, bank accounts, cash, stocks, and bonds. Resources do not include one home and/or car; life insurance policies with a face value of $1,500 or less; burial plots; and burial funds. However, owning more than one home or car will count towards an applicant's resource level. If an applicant's resources total no more than $2,000 (or $3,000 if married), they may be able to get SSI benefits. Eligibility standards for SSI claims are usually the same as those for Medicaid. Therefore, if an applicant is found to be eligible for SSI, they may be eligible for Medicaid, under Medicaid's "aged, blind, and disabled" program.

2) **SSI Payments:** Applicants submitting a claim for SSI benefits typically receive their first benefit check after the first month of an approval of application. The amount of an SSI benefit check depends on where an applicant lives. The basic SSI check amount is the same nationwide. Effective January 2011, the SSI payment for an eligible individual is generally $674 per month and $1,011 per month for an eligible couple. For information, please visit www.socialsecurity.gov/OACT/COLA/SSI.html.

   (i) **States that Supplement the Basic SSI Amount:** The following states supplement the basic SSI amount: California, Hawaii, Massachusetts, Nevada, New Jersey, New York, Pennsylvania, Rhode Island, Vermont, and Washington D. C. Other states administer their own supplemental payments that you must apply for at the state level. The amount an applicant is eligible for depends on a variety of factors including whether the applicant lives independently, has non-medical board and care, lives in the household of someone else, or is a minor child with a disability. Check with SSA for amount of SSI benefits available in each state (www.socialsecurity.gov/pubs/statessi.html).

C. **Social Security Disability Insurance (SSDI):** SSDI is the other federal long-term disability program. SSDI benefits are based on an applicant's lifetime work history and how much money they have paid into the system through their Social Security taxes. The amount of an applicant's monthly disability benefit is based on their average lifetime earnings. The Social Security statement, that all employed individuals should receive every year, displays lifetime earnings and provides an estimate of disability benefits.

1) **Note:** If an applicant does not have a current Social Security statement, they can either request one online, call the Social Security Administration, or file the request at their local Social Security office.

2) **Eligibility Requirements:** To qualify for SSDI, an applicant must have a qualifying disability, as defined by the SSA, and be "insured."
   (i) "Insured:" Applicants who have recently worked before their disability forced them to stop working.
   (ii) "Recently Worked:" The test to determine if an applicant has "recently worked" is whether or not an applicant has worked 5 out of the last 10 years (if the applicant is older than 31) in order to collect benefits.

3) **SSDI Benefits:** It typically takes six months for an applicant to receive their first SSDI check; however, the applicant will be paid retroactively back to the date that they first became "disabled" under the SSA standards. If an applicant's disability began earlier

than the application date, an applicant will also receive retroactive payments up to 12 months before the application date, depending on the date the disability began.

(i) **Waiting Period:** The SSA has established a 5-month waiting period to ensure that all individuals applying for benefits have long-term disabilities. Benefits will not be paid during the 5-month waiting period. Accordingly, benefits are paid on the sixth full month after the onset of a qualifying disability. This waiting period does not apply to individuals applying as "children of workers."[42]

- Example: If a patient applies for SSDI benefits on September 1, 2010, with a disability that began on January 1, 2010, if approved, then they wouldn't actually receive their first benefits check until February 2011. The benefits check would have their first month's payment, plus the retroactive benefits payments from the eight months of January 2010 to August 2010.

(ii) In addition, once an applicant has been on SSDI for two years, they will receive health insurance coverage through Medicare.

4) **Private Disability Insurance vs. Social Security Disability Insurance (SSDI):** Applicants who have disabilities that prevent them from working may be eligible for both private disability insurance benefits and Social Security Disability Insurance (SSDI) benefits. Collecting private disability insurance benefits does not bar an applicant from collected SSDI benefits. However, some private disability insurance policies may require that the applicant also apply for SSDI benefits and, if SSDI benefits are received, the private disability insurance benefits will be offset by the amount of the SSDI benefits.

D. **SSI/SSDI Appeals Process:**

1) **SSA Appeals Process:** The disability insurance benefits system is set up to deny applicants, assuming that applicants will not pursue the appeals process. Therefore, applicants must not take "no" for an answer, and should appeal their decisions. Be persistent!

2) **Request for Reconsideration:** If an applicant wishes to appeal a denial of benefits, they must make their request in writing, within 60 days from the date they receive the denial letter from the SSA. This "request for reconsideration" can take approximately four to six months for the claim to be reconsidered.

(i) **ALJ Hearing:** If an applicant's request for reconsideration is denied, they can request an informal hearing administered by an Administrative Law Judge (ALJ). The ALJ who had no part in the initial denial decision will conduct the hearing. The applicant or their representative (this person does not have to be an attorney) may look at the information in their file and present new information and evidence. The ALJ will question the applicant and any witnesses, such as doctors and vocational experts. The applicant or their representative may also question the witnesses. The ALJ will make a decision based on all the information in the applicant's file, including any new information or evidence provided at the hearing. After the hearing, the applicant will be sent a letter and a copy of the ALJ's decision.

[42] Social Security Administration. "Disability Evaluation Under Social Security." www.ssa.gov/disability/professionals/bluebook/general-info.htm

(ii) **Appeals Council:** After a denial at the ALJ hearing, the applicant can file a request for review to an appeals council where the ruling of the ALJ will be upheld, unless legal error in the ALJ's decision is found.

(iii) **District Court:** Finally, an applicant can file a lawsuit with the District Court against the Commissioner of the Administration to review the administrative decision, where the final determination will be upheld as long as it is based on evidence or there is no legal error.

3) **Assistance with an Appeal:** Many people handle their own appeals with free help from the Social Security Administration. At the ALJ hearing stage in the appeals process, it is advisable to talk with an attorney who is experienced with the Social Security appeals process. Contact the CLRC for assistance finding an SSA appeals attorney.

E. **Review of Benefits:** SSA does have the right to review the status of all people receiving disability benefits to make sure they continue to have a qualifying disability and are eligible for benefits. If an applicant's health has not improved, or if their disability still keeps them from working, they will continue to receive benefits.

(i) SSA will gather any new information about an applicant's medical condition by obtaining information from their doctors, hospitals, and other health care providers; or ask an applicant to go for a medical examination or test.

(ii) SSA will look at the status of an applicant's medical condition when they last reviewed their case and for any new health problems they may have. If SSA decides an applicant's medical condition has improved, they will decide whether it has improved enough to allow the applicant to work.

(iii) If an applicant's medical condition has improved to the extent that SSA decides they can work, the applicant's benefits will be discontinued.

F. **Paying Taxes on Benefits:** Some people who get Social Security have to pay taxes on their benefits. About one-third of current beneficiaries pay taxes on their benefits. Individuals will be affected only if they have substantial income in addition to Social Security benefits.

1) If:
   (i) An applicant files a federal tax return as an "individual" and their income is more than $25,000, they have to pay taxes.
   (ii) An applicant files a joint return, they may have to pay taxes if their and their spouse have a combined income that is more than $32,000.
   (iii) An applicant is married and files a separate return, they will probably pay taxes on your benefits.

2) **Note:** An applicant's combined income is determined by adding their adjusted gross income, any non-taxable interest they receive, and half of their SS benefits.[43]

3) If an applicant does have to pay taxes on their Social Security benefits, they can either make quarterly estimated tax payments to the IRS or choose to have federal taxes withheld from their benefits.

[43] Social Security Administration. "Taxes and your Social Security benefits." www.socialsecurity.gov/planners/taxes.htm

G. **SSI/SSDI and Returning to Work:** Each federal disability program (SSI/SSDI) has different employment provisions that allow beneficiaries to test their ability to work while protecting their eligibility for cash payments and health care coverage. Special rules allow people receiving SSI or SSDI to work and still receive payment, until they can return to work permanently. While attempting to return to work, a beneficiary may keep full cash benefits, keep Medicaid or Medicare, and receive help with education, training, and rehabilitation. The trial work period lasts up to a total of 9 months, within a 60-month period. Then, a beneficiary has 36 months to work and receive benefits for any month their earnings are not "substantial." In 2011, earnings of $1,000 per month are considered "substantial."[44] If a beneficiary cannot continue working after this period, their benefits will resume.

1) **Ticket to Work Program:** The Social Security Administration has a variety of work incentives for people who receive Social Security Disability or SSI benefits, including the "Ticket to Work Program," which helps an individual obtain vocational rehabilitation, training, job referrals and other employment support services free of charge. For more information, contact the Social Security Administration.

H. **Social Security Benefits for Family Members:** Family members may be eligible for survivors benefits through the Social Security Administration.

1) **Spouses:** Surviving spouses (domestic partners are <u>not</u> covered under federal law) of a person with a sufficient Social Security work history may qualify for benefits. Surviving spouses may:
   (i) Receive full benefits at full retirement age or reduced benefits as early as age 60;
   (ii) Begin receiving benefits as early as age 50 if they have a disability; or
   (iii) Receive benefits at any age, if caring for a child under age 16, or a child with a disability who receives benefits; and
   (iv) May also switch to retirement benefits based on their own work history if the amount of the benefits would be higher.

2) **Children:** A child may also be able to receive survivor benefits if, a parent worked long enough and paid taxes into the Social Security system. In order to be eligible, the child must be: unmarried; younger than 18; 18-19 years old and a full-time student (no higher than grade 12); or 18 or older and have a disability. Within a family, a child may be able to receive 50-80% of the parent's Social Security benefits.[45] However, there is a total limit on the amount of money that a family may receive. For more information, contact the Social Security Administration.

V. <u>OTHER WAGE REPLACEMENT INFORMATION</u>

A. **Retirement Assets:** Retirement assets, including pension plans, 401K plans, and income retirement accounts (IRA's) are other sources of income. Under some of these plans, individuals can take money out of their plan to pay for certain expenses when they have a serious medical condition. The rules vary by plan, so contact the plan's administrator for more information. There may also be tax implications, so an individual may also want to consider speaking with an accountant.

B. **Life Insurance:** Many people do not consider their life insurance policies to be assets, but some individual policies can be converted to cash. If they have a whole life insurance policy, a portion of their premium is invested to create a cash value that will increase the

[44] Social Security Administration. "Significance of Earnings." www.socialsecurity.gov/OP_Home/handbook/handbook.06/handbook-0620.html
[45] Social Security Administration. "Benefits for your Children." www.ssa.gov/retire2/yourchildren.htm

total value of the policy. This type of policy usually allows an individual to borrow part of this cash value. Although it will lower the amount that is eventually paid out, it is an inexpensive way to access cash because the individual only has to repay the interest on the amount that they borrow.

1) **Note:** Some policies have a provision that allows an individual to obtain accelerated benefits, meaning they can access a portion (usually no more than 50%) of the face value of their policy. Check with the individual policy carrier for more information.

C. **Viatical Settlements:** An individual can also choose a viatical settlement, by selling a life insurance policy to a third party for cash. Often a policy can be sold for 30- 80% of the policy's value, but the buyer becomes the owner of the policy with all benefits going to the buyer instead of to the original beneficiary. It is a good idea to speak to a trusted financial planner, accountant, or attorney before making such a decision.

VI. RESOURCES

<table>
<tr>
<td>For private disability insurance questions:
See State Insurance Agencies in the STATE APPENDICES</td>
<td>For SSI and SSDI questions:
Social Security Administration
(800) 772-1213 or www.ssa.gov</td>
</tr>
<tr>
<td rowspan="2">For state disability insurance questions:
California Employment Development Department
State Disability Insurance (SDI)
(800) 480-3287 or www.edd.ca.gov

Hawaii Department of Labor & Industrial Relations
Disability Compensation Division
(808) 586-9161 (Oahu) or (808) 984-2072 (Maui)
www.hawaii.gov/labor

Rhode Island Temporary Disability Insurance Call Center
(401) 462-8000 or www.dlt.state.ri.us</td>
<td>New Jersey Department of Labor
Division of Temporary Disability Insurance
(609) 292-7060 or (800) 852-7889 (TTY)
www.state.nj.us/labor/index.html

New York State Disability Insurance Bureau
(800) 353-3092 or www.nysif.com</td>
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<tr>
<td>For viatical questions:
Dignity Resources
(877) 563-2100
www.dignityresources.com</td>
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HEALTH INSURANCE & HEALTH CARE OPTIONS

INTRODUCTION:
The best way to avoid potential issues with an insurance company is to know what is in an insurance policy and to follow the policy's procedures. This will help avoid issues before they arise. The first thing an individual should do is find out what type of health insurance coverage they have. For instance, whether or not they have a group or individual plan and whether or not an employer-sponsored group plan is insured or self-insured. This information is important because different laws apply depending on the type of plan in which the individual is enrolled.

An individually purchased plan is health insurance purchased directly from a health insurance company, and individuals pay the entire premium themselves. Most people with private insurance are covered by an employer-sponsored group health plan. This is where employees and their family members enroll in a plan through work and the employer generally pays a portion or all of the cost of coverage. If enrolled in an employer-sponsored health plan, the right to appeal disagreements about benefits through the plan's internal appeals process is determined by the federal Employee Retirement Income Security Act, or ERISA. Individuals may have other rights under state laws depending on whether the health plan is *insured* or *self-insured (a.k.a. self-funded)*.

An employer-sponsored health plan is insured if, the employer purchased health coverage from an insurance company. An employer-sponsored health plan is self-funded if the employer pays for the health care costs of its employees directly, rather than purchasing insurance from an insurance company. It is sometimes difficult for employees to know whether their employer-sponsored plan is insured or self-funded because employers often contract with third parties to administer their self-funded plan. Those third parties are often insurance companies. Sometimes these third parties are called Administrative Service Organizations (ASO). Typically, ASO services include network provisions and claims processing, and the ASO is not responsible for the payment of the costs of services. Therefore, to find out whether their employer-sponsored plan is self-funded or not, employees should ask the person who administers the employee benefits at work (i.e., an HR representative). Another way to find this information is to look in the Summary Plan Description or Evidence of Coverage (EOC), the book an employee receives from an employer when they sign up for a health plan. If an individual cannot find out from their employer, the Summary Plan Description, or the EOC, they can contact the Employee Benefits Security Administration at the U.S. Department of Labor. This agency enforces ERISA's provisions and should be able to provide additional information.

Remember, federal and state legislation regarding health care reform may provide new access to healthcare, payment, or appeals options. Look for updates to this manual online at www.CancerLegalResourceCenter.org.

I. TYPES OF PRIVATE HEALTH INSURANCE

A. **Group vs. Individual Insurance:** *Group insurance* is usually offered through an employer or some form of a trade association (e.g., a union, etc.). *Individual insurance* means that an individual purchased a policy directly from an insurance company (e.g., when an individual purchases a plan from Blue Cross or Blue Shield, etc.). People who have group or individual health insurance plans are called "members" of that insurance company.

B. **HMO, PPO, and POS Plans:** There are three types of managed care plans.
   1) **HMO Plans:** HMO stands for a Health Maintenance Organization. There are generally two forms of HMOs: independent physician associations (IPAs), and stand alone

facilities. IPAs have physicians who practice in their own offices and sometimes join with other providers to form a medical group. Examples of IPAs are Blue Cross, Blue Shield, and Aetna. Stand alone facilities are HMO's hospitals that provide all care within that HMO's facilities. Kaiser Permanente is an example of a stand alone HMO facility.

2) **PPO Plans:** PPO stands for Preferred Provider Organization. A PPO is a group of health care providers who have agreed to provide services to an insurance company's members at a reduced rate.

3) **POS Plans:** POS stands for Point of Service Plan. A POS Plan is a combination of an HMO and a PPO. Members of a POS plan decide when they want to use the PPO part of their plan or the HMO option.

HMO	PPO	POS
Participating doctors and hospitals. Generally have a primary care physician who coordinates care	Usually many health care provider and hospital choices	Can see providers in- or out-of-network
Generally have to select doctors and hospitals from within the participating group	Can select from all participating providers	If selecting within network, generally have a minimal co-pay. If selecting from larger group, member pays more
Limited choices	More choices in doctors, specialists, overall providers	More choice when needed
Usually less expensive	Usually more expensive	Cost is between that of a PPO and an HMO

C. **What to Consider When Choosing a Health Insurance Plan:**

1) **Look at the Summary of Benefits:** What benefits are included? What benefits are excluded?
2) **Look at the Cost:** How much are the monthly premiums, annual deductibles for the individual or the family, maximum out-of-pocket costs, and co-payments for different types of services?
3) **When are the Enrollment Periods?** Do they offer annual open enrollment periods for individuals to make changes to their policy?
4) **How Much Flexibility Do They Offer?** Can individuals change plans if they need to? If so, how?
5) **Guaranteed Renewability:** Under federal law and some state laws, health insurance companies are required to renew an individual's existing health coverage, as long as premium payments are made in full and on time. This is called guaranteed renewability. However, there is no cap on the rate increases companies may impose at the time of renewal. Guaranteed renewability is not portable, so the individual does not have the right to switch to another company or even another plan offered by the same company.

II. WAYS TO GET AND KEEP HEALTH INSURANCE

A. **Individual Health Insurance:** Typically when a person applies for an individual health insurance plan, they are required to go through a process called medical underwriting. During this process, the insurance company looks at the individual's past and current medical conditions in order to decide whether or not they want to issue the individual a health insurance policy. If the individual currently has, or has had in the past, a serious medical condition (known as a pre-existing condition), the insurance company will likely decide that it is not worth the risk to them to insure this person, and will deny the individual

a health insurance plan. However, under HIPAA (see below) insurance companies can only look back into medical records 6 months to impose pre-existing condition exclusions that "relate to a condition for which medical advice, diagnosis, care or treatment was recommended or received within the 6-month period ending on the enrollment date."[46] Now, even if the individual with a pre-existing condition, such as cancer, is offered an individual health insurance policy, it may be very expensive.

B. **Employment-Based Health Insurance:** The most common way that people obtain health insurance coverage is through their employer or a family member's employer. There are certain rights that are guaranteed to people who are insured through their employment. These rights pertain to the continuation of coverage during certain leaves of absence (under the Family and Medical Leave Act) or upon termination of employment (see COBRA, discussed below). Individuals with employment-based health insurance are also protected from health insurance discrimination based on their pre-existing conditions under the Health Insurance Portability & Accountability Act (see below).

C. **COBRA:** Employees who lose their jobs or have their work hours reduced are often concerned about how to keep their health insurance. COBRA is a federal law that allows employees to continue the same employment-based health insurance coverage that they had while they were employed, which means they do not have to change their health care providers.
   1) **Who can elect COBRA:** COBRA is available to an employee or family member after an employee has terminated their employment or has reduced their work hours to a point that they are no longer eligible to receive coverage from their employer. This termination or reduction in hours is referred to as a "qualifying event." Other qualifying events for COBRA are divorce or death of a spouse (when the person seeking COBRA coverage was insured by a plan provided through the spouse's employment), or a child aging out of a parent's health insurance policy. Below is a chart demonstrating the maximum coverage an individual can receive under COBRA, after a specific qualifying event:

Qualifying Event	Qualified Beneficiaries	Maximum Coverage
Termination of employment or reduction of hours	Employee, Spouse, Dependent Child	18 months
Employee enrollment in Medicare	Spouse, Dependent Child	36 months
Divorce or legal separation	Spouse, Dependent Child	36 months
Death of employee	Spouse, Dependent Child	36 months
Loss of dependent child status	Dependent Child	36 months

   2) **Requirements of COBRA:**
      (i) COBRA applies to employers with 20 or more employees;
      (ii) COBRA coverage generally lasts for 18 months;[47]
      (iii) The monthly premium paid by the employee can be up to 102% of what the employer was paying for the same benefits;
      (iv) The person insured is responsible for the full premium for the coverage;
      (v) Responsibility for notifying the health plan of the qualifying event depends on which qualifying event has occurred;

[46] Health Insurance Portability and Accountability Act of 1996, 29 U.S.C. § 701(a)(1)
[47] COBRA coverage can last up to 29 months if the person insured has a qualifying disability, or up to 36 months if the person became eligible for COBRA coverage because of certain qualifying events or a combination of qualifying events.

(vi) A health plan has 14 days after the plan administrator is notified of the qualifying event to notify the employee of the right to elect COBRA; and
(vii) Employees must elect COBRA within 60 days after being notified of their rights. Employees then have 45 days after electing coverage to pay the initial premium.

3) **State COBRA Plans:** Most states have some type of state COBRA coverage requirements for employers with 2-19 employees, but they vary greatly. Additionally, some states offer coverage for more time than under COBRA.
   (i) **Example:** In California, the state COBRA plan, called Cal-COBRA, adds an additional 18 months of coverage to federal COBRA for a total of 36 months of coverage, unless an employer is self-insured. In Texas, the state continuation of group coverage only provides an additional 6 months of coverage to federal COBRA for a total of 24 months.

D. **COBRA Premium Subsidy:** On February 17, 2009, President Obama signed the American Recovery and Reinvestment Act of 2009 (ARRA), as part of an economic stimulus plan. ARRA was amended by the Department of Defense Appropriations Act of 2010, which extended the subsidy to cover people who were involuntarily terminated from their jobs between September 1, 2008, and May 31, 2010. Although this subsidy is no longer available to those who newly elect COBRA coverage, there are some individuals who are still receiving the subsidy.

E. **Health Insurance Premium Payment Program (HIPP):** COBRA premiums can be very expensive, especially if individuals are not working. If individuals have health insurance coverage (i.e., COBRA), cannot afford to pay the premiums, and are eligible for Medicaid, then HIPP will pay their health insurance premiums to help them keep their private health insurance coverage. HIPP programs are not offered in every state and eligibility requirements vary. For more information about HIPP and to find out if the HIPP program is available in a particular state, contact the state's Department of Insurance or Medicaid program (**see the STATE APPENDICES**).
   1) The following states currently have HIPP programs:
      - Alabama
      - California
      - Colorado
      - Georgia
      - Idaho
      - Iowa
      - Kansas
      - Kentucky
      - Missouri
      - Nevada
      - New Hampshire
      - Oregon
      - Pennsylvania
      - Texas
      - Virginia
      - West Virginia
      - Wisconsin

F. **Health Insurance Portability & Accountability Act (HIPAA):** HIPAA is a federal law that prohibits health insurance discrimination against individuals based on their pre-existing medical conditions, when individuals are moving from a group health insurance plan to another group health insurance plan or from a group plan to a HIPAA guarantee issue plan.
   1) In order to take advantage of HIPAA protections, there cannot be a recent break in health insurance coverage that lasts more than 63 days.
   2) **HIPAA Protections:**
      (i) Provides a federal right to an individual health insurance plan ("guarantee issue plan");
      (ii) Reduces the maximum pre-existing condition exclusion period to 12 months; and
      (iii) Gives you credit for the time that you had health insurance coverage in the past ("creditable coverage") to eliminate or reduce a pre-existing condition exclusion period.

3) **Guarantee Issue Plan:** A guarantee issue plan, also known as a "federally insured plan" or "HIPAA plan," is an individual health insurance plan that an individual has a right to purchase under federal law. A HIPAA plan is not a specific plan – rather it is a right to purchase an individual plan. Depending on the state, there are 3 ways to access a HIPAA plan: 1) every insurance company that offers individual health policies in that state also has to offer a HIPAA plan; 2) insurance companies will allow individuals to convert their group plan to an individual plan; or 3) individuals can access a HIPAA plan through a state's major risk insurance plan or high risk pool. An insurance company cannot deny the individual a HIPAA plan, but individuals should use the "buzz" words (guaranteed issue or HIPAA plan) when applying. Otherwise the insurance company may assume the individual wants a regular individual plan and may deny them coverage based on a pre-existing condition through the medical underwriting process.

   (i) **HIPAA vs. COBRA:** A HIPAA plan is different than COBRA coverage. Under COBRA, individuals keep the same health insurance they had through their employer. Under HIPAA, individuals are buying new insurance, and need to compare all of the available plans and pick the one that is right for them. Individuals should compare the premiums, deductibles, and co-payments. Individuals should also check to make sure their health care providers accept the insurance plan they are considering, and that their prescription drugs are on the formulary list of drugs covered by the plan. Note: There is no cap on the price of a HIPAA plan.

   (ii) **Requirements:** In order to be eligible for a HIPAA plan:
   - Individuals must exhaust COBRA or state COBRA coverage, meaning that they use all 18 or 36 months of COBRA coverage, available to them;
   - There cannot be a break in their health insurance coverage longer than 63 days; and
   - Individuals must be ineligible for Medicare, Medicaid, or any form of group coverage.

   (iii) **Finding a HIPAA Plan in Your State**: In order to determine the HIPAA Plan options available in each state, individuals can contact the state insurance agency, contact the CLRC, or see the CLRC handout, "HIPAA Plan Options by State," available online at www.CancerLegalResourceCenter.org.

4) **Pre-Existing Condition Exclusion Period (PECEP):** When moving from one employer's group health plan to another employer's plan, the new plan is required to insure the individual, but may impose a PECEP, which means that for a certain period of time, the new plan will not cover any treatment or services related to the individual's pre-existing medical condition. For example, if the individual breaks their arm, those medical services will be covered; however, if they are currently undergoing cancer treatment those services will not be covered because their cancer diagnosis is a pre-existing medical condition. Before HIPAA, a two-year PECEP was common. HIPAA limited the maximum PECEP that may be imposed to 12 months. Some states have gone further. For example, in California, employers with 2 or less employees have a 12 month pre-existing condition exclusion period, but only a 6 month exclusion period can be imposed for employers with 3 or more employees.

5) **Creditable Coverage:** Creditable coverage is any previous period of health insurance coverage that was not interrupted by a break in coverage of more than 63 days. HIPAA reduces any PECEP by the length of time that an individual previously had creditable coverage.

(i) **Example:** If an individual previously had group health insurance coverage for four months, has not had a break in coverage of more than 63 days, and their new group insurance plan has a PECEP of 12 months, then they get a credit for their 4 months of previous coverage. The individual subtracts the 4 months of previous coverage from the 12 month exclusion period, leaving them with only 8 months left on their PECEP. So, if the individual has 12 months or more of previous creditable health insurance coverage, and they do not have a break in coverage of more than 63 days, they will not face a PECEP when moving between group plans or a group plan to a HIPAA plan.

12 month PECEP imposed by new group insurance plan – 4 months of previous coverage = 8 months left of a PECEP

(ii) **Example:** An individual has creditable coverage of 6 months while at a previous job. The individual is now changing jobs and the new employer's group health plan is imposing a PECEP of 6 months. Accordingly, the individual will not have a PECEP under their new health insurance policy, because the previous 6 months of creditable coverage eliminates the 6 month PECEP. .

6 month PECEP imposed by new group insurance plan – 6 months of previous coverage = 0 months left of a PCEP

(iii) **Qualifying for Creditable Coverage:** Almost all types of health insurance can qualify as creditable coverage. Medicare, Medicaid, group, individual, COBRA, and HIPAA plans can all qualify. One exception is that some student health insurance plans are not considered creditable coverage, because they do not typically provide comprehensive coverage. Also, if a particular condition was not covered by the policy that an individual is claiming as creditable coverage, then their new health plan may subject that condition to a PECEP.

(iv) **Demonstrating Creditable Coverage:** To show the health insurance company proof of creditable coverage, individuals can call their previous insurance company to request a "certificate of creditable coverage," which lists the dates that they have been insured by that company. If individuals have been insured by multiple companies, they need certificates of creditable coverage from each one.

G. **High Risk Insurance Pools/Major Risk Insurance Plans:** If an individual is not able to obtain insurance through COBRA, and is not eligible for a HIPAA plan because they did not exhaust the available COBRA coverage or if an individual had a break in coverage of more than 63 days, then they may be eligible for a state high risk insurance pool or major risk plan. These state plans provide limited health insurance for individuals who are unable to obtain health insurance coverage in the individual insurance market due to a pre-existing condition. States are not required to provide an alternative option for medically uninsurable individuals to access coverage, but many do.

1) **High Risk Insurance Pools Available in Your State:** Currently 35 states have major risk health insurance pools. Of those 35 states that offer high-risk policies, 27 states offer multiple plans for people who are unable to obtain individual health insurance policies due to a pre-existing condition. For information about plans available in each state, contact the state's insurance agency (**see the STATE APPENDICES**) or the CLRC.

2) **Applying for High-Risk Health Insurance:** Individuals can apply for high-risk pool coverage through an insurance agent or directly with the state. Generally, there is a choice of health plan options and individuals receive an enrollment card, as well as other information, just like another health plan. High-risk pools normally contract with a health insurance carrier or third-party administrator to administer paperwork and claims. Once enrolled, benefits can be used like any other health insurance plan.

3) **Pre-Existing Condition Exclusion Periods and Waiting Periods:** High-risk pools may impose pre-existing condition exclusion periods and/or waiting periods. However, many pools give individuals credit against the exclusion and/or waiting period if they have previous creditable health insurance coverage.

H. **Pre-Existing Condition Insurance Plans:** The recently enacted Patient Protection and Affordable Care Act created a way for many patients with pre-existing conditions to get insurance by mandating that states offer Pre-Existing Condition Insurance Plans. Some states have opted to administer those plans through a state agency and some states have opted to let the federal government administer their state plan. For more information, see the Health Care Reform section of this manual.

III. FEDERAL HEALTH INSURANCE PROGRAMS

A. **Introduction:** While SSI and SSDI are federal disability insurance programs, Medicare and Medicaid are federal health insurance programs.

B. **Medicare:** Medicare is a health insurance program for:
1) People age 65 or older who are eligible for Social Security retirement benefits;
2) People under age 65 with certain disabilities who have received Social Security Disability (SSDI) benefits for 2 years; and
3) People of all ages with End-Stage Renal Disease.

4) **Four Parts of Medicare:** Medicare has four parts, each with different services and coverage.

(i) **Part A:** Everyone who is eligible for Medicare will receive Part A for free unless the individual has insufficient Social Security work history. However, if they are citizens or legal residents and have lived in the U.S. for at least 5 years, they can still obtain Part A coverage by paying a monthly premium. Part A is considered "hospital insurance" and can include coverage for in-patient hospital stays, skilled nursing facilities, and some home health care or hospice care.

(ii) **Part B:** Part B is considered "medical insurance" and covers physician services, outpatient hospital services, x-rays, labs, tests, cancer screenings, ambulance rides, and other medical supplies and/or services. If the individual is eligible for Medicare Part A, they are entitled to receive this coverage; however, if they choose to elect Part B, they pay a monthly premium and an annual deductible.

- **Note:** Assuming individuals have both Part A and Part B, then Medicare usually covers 80% of the allowable charge, making them responsible for only 20% of the bill.

(iii) **Part C:** Originally called Medicare Plus Choice, Part C is now referred to as Medicare Advantage Plans with coordinated care of Part A, B and D together through a Medicare HMO or PPO. Examples of plans under Part C include Kaiser Senior Advantage and SCAN.

(iv) **Part D:** As of January 1, 2006, Medicare prescription drug plans became available to all Medicare beneficiaries. Plans vary from state to state. Some states have over 50 plans to choose from. For more information about the prescription drug plans available in each state, visit www.Medicare.gov.

5) **How Much Does Medicare Cost?**[48]:

(i) **Part A:** Medicare Part A is free unless an individual has insufficient Social Security work history. Legal residents who have lived in the U.S. for at least 5 years may also receive Part A coverage, but will have to pay a monthly premium.

- **Note:** If an individual is eligible for Part A but does not have sufficient work history, their monthly premium will be $450.
- **Note:** Although Part A coverage is free, there is a $1,100 deductible for the first day of a hospital stay.

(ii) **Part B:** As mentioned above, Part B is optional and individuals may chose to decline coverage. If individuals elect Part B benefits, then they must pay a monthly premium based on their income (see chart below) and a $110.50 annual deductible before Medicare will pay its share of the health care costs.

Individual Income	Joint (Married) Income	Your Cost:
$85,000 or below*	$170,000 or below	$115.40
$85,001 - $107,000	$170,000 - $214,000	$161.50
$107,001 - $160,000	$214,001 - $320,000	$230.70
$160,001 - $214,000	$320,001 - $428,000	$299.90
$214,000+	$428,000+	$369.10

- In addition, if individuals do not elect Part B when they first become eligible for it, they may be subject to a penalty for late enrollment (10% for each complete 12-month period that the individual could have enrolled in Part B but chose not to), unless they have creditable coverage. When an individual loses that creditable coverage, they have an 8-month special enrollment period to elect Part B without being charged a penalty.
  - ⇒ Example: An employee is eligible for Medicare because the employee has turned 65, but is still working and has health insurance through their employer. The employee chooses to stay with the employer's current plan until the employment period ends. At that point, the employee may elect COBRA, but has up to 8 months during the COBRA period to enroll in Medicare before a penalty fee is imposed.

(iii) **Part D:** Part D is optional as well, but if individuals select this benefit they will pay a national average premium of $32.34. The exact amount depends on the specific plan the individual chooses. Plans range from $14.80 - $133.40, and have an annual deductible from $0 - $310. Individuals who do not chose Part D when they are first eligible may be subject to a penalty for late enrollment, unless they have creditable prescription drug coverage. When an individual loses that creditable coverage, they have a special enrollment period to elect Part D. Those who are required to pay the penalty, pay 1% of the average national Part D premium for the year that they joined, times the number of months they were eligible to join a Medicare drug plan, but did not.

[48] Figures are based on 2011 requirements as reported by www.medicare.gov.

- **Example:** If an individual was eligible for a Medicare drug plan in January 2006, but did not sign up until January 2011, they would be required to pay the penalty. The 2011 average national Part D premium is $32.34 x 1% = 32 cents. 32 cents x 60 months = $19.20, which will be added to the individual's monthly Part D premium for life.

- **Note:** If an employee is eligible for Part D but has a prescription drug plan through private insurance (e.g., their employer, union, or COBRA), the employer/union will notify the employee each year to let them know that they have creditable prescription drug coverage and do not need enroll in a Part D plan. The employee will then have a special enrollment period to elect a Part D plan, if they chose to do so, without incurring a late penalty fee for not enrolling when initially eligible.

Additionally, beginning in 2011, Part D enrollees who have income that exceeds threshold amounts will pay a monthly adjusted amount in addition to their regular Part D premium.[49]

Estimated Part D Monthly Premium for higher income levels[50]:

Individual Income	Joint (Married) Income	Your Cost:
$85,000 or below	$170,000 or below	Your Plan Premium
$85,001 - $107,000	$170,000 - $214,000	$12.00 + Your Plan Premium
$107,001 - $160,000	$214,001 - $320,000	$31.10 + Your Plan Premium
$160,001 - $214,000	$320,001 - $428,000	$50.10 + Your Plan Premium
$214,000+	$428,000+	$69.10 + Your Plan Premium

C. **Medicaid:** Medicaid provides health insurance for certain people who have low incomes, have limited resources, and meet other eligibility requirements. Individuals with cancer often qualify for Medicaid through the Aged, Blind and Disabled Program, which provides coverage to individuals with low incomes who are over 65 or who have a disability. Medicaid may be called by other names in different states. For example, in California, Medicaid is referred to as Medi-Cal and in Tennessee, Medicaid is referred to as TennCare.

1) **Eligibility:** Applicants must meet income and asset eligibility requirements (i.e., have low income and limited resources to pay for the cost of their health care), AND fit into one of these categories:

(i) Individuals who are "aged, blinded or disabled" according to the Social Security Administration's standards;

(ii) Families with children as long as a deprivation exists. A deprivation exists if a parent is absent from the home, incapacitated, disabled, or deceased;

(iii) Children or pregnant women without regard to deprivation or poverty; or

(iv) Individuals with specific health needs. These needs include dialysis, tuberculosis services, total parental nutrition services, breast and cervical cancer treatment, certain services for minors, and nursing home care.

[49] Medicare Fact Sheet: Medicare Premiums, Deductibles for 2011, Center for Medicare and Medicaid Services (November 4, 2010). www.nasuad.org/documentation/ship/**2011Premiums**Final.pdf.
[50] Medicare Fact Sheet: Medicare Premiums, Deductibles for 2011, Center for Medicare and Medicaid Services (November 4, 2010). www.nasuad.org/documentation/ship/**2011Premiums**Final.pdf.

2) **Share of Cost:** Some states have a "Share of Cost" program that refers to the amount of health care expenses an individual must pay out of pocket each month before Medicaid begins to offer assistance. Once a recipient's health care expenses reach a predetermined amount, Medicaid will pay for any additional covered expenses that month. Share of Cost is an amount that is owed to the provider of health services, not to Medicaid.
   (i) Note: Share of Cost is not a monthly premium. It is an amount that a recipient is responsible for paying only during a month in which Medicaid's assistance with health care expenses is needed.

3) **Buy-In Program:** Some states offer a Medicaid Buy-In Program which allows people of any age with a disability and who are working, to receive Medicaid by paying a monthly premium based on income.
   (i) Example: In Texas, if an individual is eligible for the Medicaid Buy-In Program (i.e., that person has resources less than or equal to the SSI resource limit), that person is given optional dates to start their Medicaid coverage, and premium amounts depending on the date their Medicaid coverage begins. Once enrolled in the Medicaid Buy-In program, the individual will have the same services available to them as other Medicaid recipients (including office visits, hospital stays, x-rays, etc.).

IV. OTHER HEALTH CARE OPTIONS

A. **Screening Legislation:** Many states require insurance companies to cover specific cancer screening tests, such as mammography for breast cancer, prostate-specific antigen (PSA) tests and digital rectal exams for prostate cancer, pap smears for cervical cancer, and colonoscopies, flexible sigmoidoscopy and fecal occult blood tests (FOBT) for colorectal cancer. Contact the CLRC for questions about what is covered in your state.

B. **Screening and Treatment Programs:** Many states have also enacted screening and treatment programs for specific types of cancer.
   1) Breast Cancer:
      (i) Example: In Illinois, the Breast and Cervical Cancer Program (IBCCP) offers free mammograms, breast exams, pelvic exams, and pap smears to eligible, uninsured women in the state.
      (ii) Example: In California, under the Breast and Cervical Cancer Treatment Program (BCCTP) Medicaid services are provided to qualifying individuals who have been diagnosed with breast or cervical cancer.

   2) Prostate Cancer:
      (i) Example: In California, under Improving Access, Counseling and Treatment for Californians with Prostate Cancer (IMPACT), state residents who are either uninsured or underinsured are eligible to receive prostate cancer treatment.

C. **Women's Health and Cancer Rights Act (WHCRA):** WHCRA is a federal law that requires health insurance companies whose policy covers a mastectomy to also cover reconstruction of the breast on which the mastectomy was performed, surgery or reconstruction of the other breast to produce a symmetrical appearance, prostheses and/or implants, and treatment for physical complications of a mastectomy, such as lymphedema. Additionally, if a patient is between mastectomy and reconstruction and moves from one plan to another, the new plan is obligated to pay for the reconstruction if the new plan would have covered the original mastectomy.
   1) **Note:** WHCRA does not apply to federal health insurance plans, such as Medicare or Medicaid, as they have specific coverage rules.

V. HANDLING HEALTH INSURANCE DISPUTES

A. **Handling Disputes:** Disputes with insurance companies may arise over whether or not services are covered, which treatments should be provided, which providers should be used, how much a particular service should cost, difficulties dealing with specific providers, and even billing or administrative mistakes**. If an individual disagrees with a decision that their health insurance company has made regarding coverage, they have the right to appeal that decision.** Health insurance companies are required to have their own internal appeals process to handle these disagreements, and they must provide their policy holders with that information. Some states also offer policy holders with an external appeals process. In most states, individuals must first exhaust their health plan's internal appeals process before requesting an external independent medical review of the insurance company's decision.

1) **Tips on Dealing with an Insurance Company:** The following are tips for handling internal appeals with an insurance company.
   (i) Know the policy and any deadlines that apply;
   (ii) Get any decisions or denials in writing;
   (iii) Keep records of all communications;
   (iv) Get a copy of the all files from the insurance company; and
   (v) Be persistent.

2) **Different Appeal Procedures:** Health plans may have different appeals procedures for different types of disputes. For instance, a health plan may have one way to resolve a complaint about appointment times and a different way to appeal the refusal to cover a specific medical procedure.

3) **Internal Appeals Process:** If individuals disagree with an insurance company's decision, they have the right to file an appeal. ERISA requires employer-sponsored health plans to let policy holders see the documents they used to make their coverage decisions, to have no more than two levels of appeal, and prohibits insurance companies from charging a fee for the internal appeals process. For more information, contact the state insurance agency (see **the STATE APPENDICES**).

4) **External Medical Review:** Also called Independent Medical Review, this is a review of the health plan's decision by an outside, independent organization. After individuals have exhausted their plan's internal appeals process, they may be entitled to ask for an external medical review under state law. While laws vary from state to state, the process generally provides patients with the right to have an independent review of their health insurance company's decision. Reviews are conducted by independent review organizations that have medical experts in many specialty areas. The decision made by the independent medical review organization is binding on the insurance company. To find out more information about external or independent medical reviews in a specific state, contact the state's insurance agency (see **the STATE APPENDICES**).

   (i) **When is External Review Available?:** While the legal standards for review vary from state to state, many states allow external reviews when the insurance company denies care because a particular treatment is (1) not medically necessary or (2) experimental or investigational. Issues often arise when a treatment is new or a doctor prescribes a drug that was approved to treat one type of cancer and there is evidence that it will also work to treat another type of cancer, but has not yet been approved by the FDA to treat that new type of cancer (off-label drug use).

(ii) Many states allow appeals for an insurance company's decision to deny, modify, or delay treatment because it is not deemed to be medically necessary. If the insured individual can show that the treatment is medically necessary, then there is a greater chance of winning the appeal. This is a good opportunity for health care providers to help their patients demonstrate that the disputed treatment is actually medically necessary by providing letters of support, adding documentation to medical records, or providing additional medical literature to support why a particular treatment is medically necessary and/or has been successful in the past.

(iii) **External Appeals Outcomes:** Once appeals are accepted for external medical review, patients have been relatively successful in getting their insurance company's decisions overturned. However, many individuals make mistakes with their external review appeals, including filing with the wrong state agency, failing to exhaust their health plan's internal appeals process, or failing to provide all the necessary information, such as consent forms, that is needed to investigate their case.

VI. ADDITIONAL PROTECTIONS

A. States have also provided health consumers with other protections. For example, when individuals would like to receive care outside of their health insurance plan's network of providers, some states have required insurance companies to pay for these services in some circumstances. To find out about the health consumer protections available in each state, contact the state's insurance agency (see **the STATE APPENDICES**) or the CLRC.

1) **Access to Medical Records:** Individuals, or their representatives, are entitled to inspect their medical records under HIPAA, but many states also have statutes that limit what a health care provider can charge patients for copies of their medical files. In California, for example, individuals must be granted access to view their medical records within five working days after making a written request for medical records, subject to payment of reasonable clerical costs. Patients are also entitled to copies of their medical records, to be sent within 15 days of the provider's receipt of a written request, subject to copying costs not over 25 cents per page plus reasonable clerical costs. Finally providers may not withhold a patient's records for failure to settle an unpaid bill. For more information, contact the CLRC.

2) **Clinical Trials:** Some states require insurance companies to cover the routine costs of care while an individual is participating in a clinical trial. Medicare also covers routine care costs. Additionally, effective January 1, 2014, under the Patient Protection and Affordable Care Act (PPACA), insurance companies may not deny or limit or impose additional conditions on "the coverage of routine patient costs for items and services furnished in connection with participation in the [clinical] trial."[51] For more information, about the PPACA, see the Health Care Reform section of this manual.

(i) **What is a clinical trial?:** A clinical trial is a research study in which people volunteer to test new treatments, drugs, or procedures. Researchers use clinical trials to learn whether a new treatment works and is safe for people. This research is needed to develop new treatments, and clinical trials often provide patients with access to the highest quality of cancer care and new treatments before they are widely available.

[51] Public Law 111-148, 124 STAT. 893 §2709

(ii) **How are clinical trials conducted?:** Clinical trials are usually conducted in a series of four phases, or research testing steps.

- Phase I: This is the first step in testing a new drug or procedure with people. Researchers test safe dosages and methods of delivery (ex: given orally or injected into a vein or muscle). The researchers carefully observe any side effects.
- Phase II: These trials study both the safety and effectiveness of a treatment and evaluate how it affects your body. These studies are usually specific to one type of cancer, and often have less than one hundred patients.
- Phase III: These trials compare the new treatment with the current standard treatment. Participants are randomly assigned to the new treatment group or to the standard treatment group. Random assignment helps to avoid bias and ensures that other factors do not affect study results.
- Phase IV: These trials are useful in researching the long-term safety and overall effectiveness of treatment. These studies take place after a treatment has been approved for widespread use.

(iii) **Who sponsors cancer clinical trials?:** These are a few examples of agencies and companies that sponsor cancer clinical trials:

- National Cancer Institute
- National Institutes of Health
- Pharmaceutical & Biotechnology Companies
- U.S. Department of Defense
- U.S. Department of Veterans Affairs
- U.S. Food & Drug Administration

(iv) **What are the costs of participating in a clinical trial?:** Routine care costs are for care that is not dependent on a clinical trial and occurs when receiving standard treatment or participating in the study. Routine care costs can include lab tests, x-rays, blood work, and doctor visits. Costs that are typically not covered by health insurance include the drugs or procedures being tested in the clinical trial, items or services used solely for the data collection needs of the trial, and anything being provided for free by the clinical trial sponsor. Some health insurance plans will also not provide coverage for routine care costs because they consider clinical trials to be "experimental" treatment.

- **Which states require insurance coverage for clinical trials?:** Currently there are **34 states** that require health insurance plans to cover the routine care costs of a clinical trial, including: Arizona, California, Colorado, Connecticut, Delaware, Florida, Georgia, Indiana, Iowa, Kentucky, Louisiana, Maine, Maryland, Massachusetts, Michigan, Missouri, Nevada, New Hampshire, New Jersey, New Mexico, North Carolina, Ohio, Oregon, Rhode Island, South Carolina, Tennessee, Texas, Vermont, Virginia, West Virginia, Wisconsin, Wyoming, and the District of Columbia. However, each state's law is different. For more information on a state's regulation of health insurance coverage for clinical trials, please contact the CLRC or the state's insurance agency.
  - ⇒ **Example:** In **California**, health insurance plans are required to cover the routine care costs associated with cancer clinical trials (CA Health & Safety Code §1370.6). Covered costs may include, but are not limited to,

hospitalization, physician visits, X-rays, blood tests, CAT scans, and PET scans. In addition, some costs may be covered by the clinical trial sponsor, such as a pharmaceutical company.

(v) **Do Medicare and Medicaid cover clinical trials?:** Medicare Part B covers the routine costs of clinical trials. For more information visit www.cancer.gov/cancertopics/factsheet/support/medicare. Additionally, some states cover clinical trials under Medicaid. For more information, contact the state's Medicaid program (see **STATE APPENDICES**).

(vi) **What if an insurance company denies coverage for the clinical trial?:**

- Contact the health care provider team to see if they can assist the patient.
- Contact the insurance company to find out why they denied coverage.
- Go through the insurance internal appeals process.
- Contact the state insurance agency to see if the patient is eligible for an external appeals process or independent medical review.
  ⇒ Ex: California Department of Managed Health Care of California Department of Insurance
- Contact the CLRC for assistance.

(vii) **Patient Protection and Affordable Care Act (Public Law 111-148):** Also known as healthcare reform, this law was passed on March 23, 2010, and states that beginning in 2014, insurance companies will be required to cover the costs associated with routine care for individuals who are enrolled in a clinical trial to treat cancer or other life-threatening diseases.

(viii) **Current Federal Bills in Congress:** These bills are currently pending in Congress and if passed would increase access to clinical trials:

- 21st Century Cancer ALERT (Access to Life-Saving Early Detection Research and Treatment) Act (S. 717, H.R.6224)

3) **Second Medical Opinions:** Some states allow patients to have second medical opinions covered by their insurance company. If a second provider is not available within the network, the insurance company must cover a second opinion from a provider outside the network. For more information, contact the CLRC.

4) **Oral Chemotherapy Legislation:** Currently, 9 states (Hawaii, Iowa, Indiana, Oregon, Vermont, Colorado, Connecticut, Minnesota, and New Hampshire) have enacted statutes that require health insurance policies to cover oral chemotherapy at the same level as they would cover chemotherapy administered intravenously. There are also several other states with similar pending legislation. For more information about legislation in a particular state, please contact the CLRC.

5) **Fertility Legislation:** As many as 90% of young cancer patients may be at risk of permanent infertility after undergoing treatment. Although insurance plans vary in the amount of infertility treatments they cover, currently, there are fourteen states that require insurance companies to cover some form of infertility diagnosis and treatment. These states are Arkansas, California, Connecticut, Hawaii, Illinois, Maryland, Massachusetts, Montana, New Jersey, New York, Ohio, Rhode Island, Texas, and

West Virginia. For more information about specific laws, contact the state's insurance agency or visit www.asrm.org/insurance.aspx.

(i) Note: Currently, no states require insurers to cover fertility preservation methods for new cancer patients.

VII. RESOURCES

For insurance questions: State insurance agency **See the STATE APPENDICES**	**For COBRA questions:** U.S. Department of Labor Employee Benefits Security Administration (866) 444-3272 or www.dol.gov/ebsa
For state COBRA and HIPAA questions: State insurance agency **See the STATE APPENDICES**	**For major risk insurance questions:** State insurance agency **See APPENDIX HI4**
For assistance with Medicare: Center for Medicare & Medicaid Services (CMS) (800) 663-4227 or www.medicare.gov	State Health Insurance Assistance Program (SHIP) (800) 633-4227 www.medicare.gov/Contacts/staticpages/ships.aspx
For assistance with Medicaid: Center for Medicare & Medicaid Services (CMS) (800) 633-4227 www.cms.gov	State Medical Assistance (800) 633-4227 or www.cms.hhs.gov/apps/contacts/Default.aspx
For information on Pre-Existing Condition Insurance Plans (PCIP): www.healthcare.gov or www.pcip.gov	

HEALTH CARE REFORM

INTRODUCTION:
On March 23, 2010, The Patient Protection and Affordable Care Act (Public Law 111-148) was signed into law, generating significant changes to the health care system in the United States. One week later, The Patient Protection and Affordable Care Act was modified by the Health Care and Education Reconciliation Act of 2010 (Public Law 111-152). These two bills together are commonly referred to as the Affordable Care Act or the ACA. Changes mandated by this law will occur gradually from 2010 to 2020, with the biggest changes to be implemented in 2014.

As with all legislation, some details of these changes will remain undetermined until: 1) federal agencies, such as the U.S. Department of Health and Human Services (HHS) put out Federal Regulations (e.g., official rules); 2) states pass laws to implement certain provisions; and 3) insurance companies and employers re-write their policies to comply with the ACA. Furthermore, some states[52] have filed lawsuits in federal court, charging that Congress was overstepping its right to regulate commerce under Article 1 of the U.S. Constitution and that the ACA is a violation of the Tenth Amendment. The outcome of that litigation, any changes in the membership of Congress, and the actions of insurance companies, employers, and government agencies may change how the ACA is implemented over the next few weeks, months, and years.

I. WHICH POLICIES MUST COMPLY WITH THE ACA

A. **How to figure out if the ACA applies:** Different types of policies will have to comply with certain provisions of the ACA at different times. In order to determine which reforms apply to a particular health insurance plan, we must first look at when the plan was issued, and second, we must determine if the employer-sponsored health plan is self-insured (aka self-funded) or insured (aka fully funded).

1) **Date the policy was issued:**
   (i) **Policies issued on or after September 23, 2010**: These policies must immediately comply with many of the reforms discussed below.

   (ii) **Policies issued between March 23, 2010 and September 22, 2010**: These policies will be required to comply with the reforms in the next new plan year, or in other words, as soon as the policies are amended or reviewed after September 23, 2010.

   (iii) **Policies issued prior to March 23, 2010**: These policies are considered "grandfathered plans," meaning that they do not have to comply with many of the reforms discussed below. Plans may retain their grandfathered status indefinitely, so long as they do not make substantial changes to the plan.
   - Plans will lose grandfathered status if they:
     ⇒ Significantly cut or reduce benefits;
     ⇒ Raise co-insurance or co-payment changes;
     ⇒ Significantly raise deductibles;
     ⇒ Lower employer contributions;
     ⇒ Add or tighten annual limits; or
     ⇒ Change insurance companies.

[52] The following states are involved in litigation: Alabama, Alaska, Arizona, Colorado, Florida, Georgia, Idaho, Indiana, Louisiana, Michigan, Mississippi, Nebraska, Nevada, North Dakota, Pennsylvania, South Carolina, South Dakota, Texas, Utah, and Washington.

2) **Self-Insured vs. Insured Health Plans:** Employer-sponsored health plans are plans where employees and their dependants enroll in a health plan through work, and the employer generally pays a portion of all of the cost of coverage. Compare this to an individually purchased plan, which is health insurance that is purchased directly from an insurance company and the individual purchasing the policy pays the entire premium.

(i) There are two types of employer-sponsored health plans:

- Self-Insured Plan: Employers provide health care coverage by directly paying for employee's health care.
- Insured Plan: Employers contract with insurance companies to provide employees with health care coverage.

(ii) It is sometimes difficult for employees to know whether their employer-sponsored plan is insured or self-insured because employers often contract with third parties to administer their self-funded plan. Those third parties are often insurance companies. Sometimes these third parties are called Administrative Service Organizations (ASO). Because some of the reforms in the ACA do not apply to self-insured plans, it is important to find out what type of plan a person holds. To find out whether their employer-sponsored plan is self-insured or not, employees should ask the person who administers the employee benefits at work (i.e., an HR representative).

II. THE PORTAL

A. **Statute:** The ACA required HHS to create a website portal to provide consumers with information about the ACA and health insurance options at the federal and state level. By answering a few basic questions, individuals can obtain information on the health insurance options available to them based on their specific situations. The Portal went live on July 1, 2010, and is available in both English (www.healthcare.gov) and Spanish (www.CuidadoDeSalud.gov).

B. **Available Information:** Although the Portal will continue to evolve over time, it now includes detailed information about the provisions in the ACA, pricing information on insurance options available to individuals and small businesses, and state-specific information on:
   1) Individual health coverage offered by insurance companies;
   2) Medicaid coverage;
   3) Children's Health Insurance Program (CHIP) coverage;
   4) State high risk pool coverage;
   5) Federal Pre-Existing Condition Insurance Plan options; and
   6) Coverage options for small businesses and their employees.

III. HEALTH INSURANCE REFORMS

A. **Lifetime and Annual Limits**: Previously, insurance companies had the ability to establish lifetime and annual caps that limit the total dollars in benefits paid out per year or over the lifetime of an enrollee. The annual limits could be as low as $50,000. People whose claims exceeded health plan limits were forced to find other ways to pay for their medical costs. The ACA will eventually eliminate lifetime and annual limits on all insurance plans.
   1) **Lifetime Limits:** As of September 23, 2010, insurance companies may no longer impose lifetime limits on "essential health benefits."
      (i) Essential Health Benefits include:
         - Ambulatory
         - Emergency
         - Hospitalization
         - Maternity and newborn care
         - Mental health and substance abuse
         - Prescriptions
         - Rehabilitative services and devices
         - Lab services
         - Preventative and wellness services and chronic diseases management
         - Pediatrics

      (ii) Applies To:
         - Grandfathered Plans: Yes
         - Self-Insured Plans: Yes

   2) **Annual Limits:** As of September 23, 2010, insurance companies may only impose annual limits on essential health benefits. If insurance companies do impose these annual limits, they must comply with the minimum limits for all employer-sponsored plans and all new individual market plans.
      (i) Minimum Annual Limits:
         - September 23, 2010: $750,000
         - September 23, 2011: $1.25 million
         - September 23, 2012: $2 million

      (ii) Exceptions: Restrictions on annual limits do not apply to Flexible Spending Accounts (FSA), Medical Savings Accounts (MSA), or Health Savings Accounts (HAS).

(iii) Elimination of Annual Limits: On January 1, 2014, insurance companies will no longer be permitted to impose annual limits on the total dollars in benefits paid out to a beneficiary per year.

(iv) Applies to:

- Grandfathered Plans:
  - ⇒ Group: Yes
  - ⇒ Individual: No
- Self-Insured Plans: Yes

B. **Rescissions:** Previously, some insurance companies would review an individual's original insurance application to look for any mistakes or omissions, intentional or not, and then retroactively cancel (rescind) the individual's policy if they became ill, leaving them uninsured.

1) As of September 23, 2010, an insurer may not rescind an individual's policy as long as the premiums are being paid, unless the individual:
   (i) Commits fraud; or
   (ii) Makes an intentional misrepresentation of a material fact (i.e., lied) on the application.[53]

2) Applies to:
   (i) Grandfathered Plans: Yes
   (ii) Self-Insured Plans: Yes

C. **Preventative Care:** For insurance policies issued on or after September 23, 2010, health insurance plans must cover preventative services.[54]

1) A complete list of preventative services can be found at: www.healthcare.gov/law/about/provisions/services/lists.html
   (i) Examples:
   - Covered Preventative Services for Adults
     - ⇒ Colorectal Cancer screening for adults over 50;
     - ⇒ BRCA counseling about genetic testing for women at higher risk
     - ⇒ Breast Cancer Mammography screenings every 1-2 years for women over 40
     - ⇒ Breast Cancer Chemoprevention counseling for women at higher risk
     - ⇒ Cervical Cancer screening for sexually active women

2) Deductibles and Co-Payments: If the individual uses an in-network provider to receive preventative services, those services will be exempt from deductibles and co-payments.

3) Applies to:
   (i) Grandfathered Plans: No
   (ii) Self-Insured Plans: Yes

[53] ACA § 2712
[54] ACA § 1001, Amending PHSA §2712

D. **Pre-Existing Conditions:**

1) **Children:** As of September 23, 2010, children under 19 cannot be denied health insurance coverage based on a pre-existing condition.

2) **Adults:** As of January 1, 2014, adults cannot be denied health insurance coverage based on a pre-existing condition.

(i) After 2014, when considering whether to provide health insurance coverage, insurers cannot consider:
- Pre-existing condition (physical or mental);
- Health status;
- Medical history;
- Genetic information;
- Gender; or
- Age.

(ii) After 2014, in establishing premium rates, insurers may only consider:
- If the insured is purchasing an individual or family policy;
- Age of the insured;
- The insured's rating area,[55] and
- The insured's use of tobacco.

3) Applies to:
(i) Grandfathered Plans
- Group: Yes
- Individual: No

(ii) Self-Insured Plans: Yes

E. **Cancer Clinical Trials:** As of January 1, 2014, all group health plans or group or individual health insurance policies:

1) May not deny an individual's participation in a clinical trial;

2) May require the individual to use a participating provider in the network, if the provider will accept the individual;

3) Allow an individual to participate in a clinical trial out of state, unless there is a doctor in his or her network participating in the clinical trial in state and that doctor will accept the individual; and

4) May not deny, limit, or impose additional conditions on "the coverage of routine patient costs for items and services furnished in connection with participation in the trials."

(i) Routine patient costs do not include:
- Investigational item device or services
- Items and services provided solely to satisfy data collection and analysis needs and are not used in direct clinical management of the patient

5) May not discriminate against the individual for participating in the clinical trial.

[55] Rating area is a geographic area used for determining premium rates, usually by ZIP code. The premium is based on the average health care costs and the physician/hospital discounts in that area. Therefore, costs may be higher if the insured lives in a metropolitan city, as opposed to a small town. These rating areas must be approved by the HHS Secretary.

IV. **INSURANCE APPEALS**

A. **External Medical Review** (Independent Medical Review): For more information on External Medical Reviews, please refer to page 48 in the Health Insurance & Health Care Options chapter.

1) As of September 23, 2010, all plans must have an "effective" internal appeals process and provide beneficiaries an external medical review process.

2) Internal appeals process: According to the National Association of Insurance Commissioners (NAIC), an effective internal appeals process is one that:
   (i) Allows consumers to appeal when a health plan denies a claim for a covered service or rescinds coverage;
   (ii) Gives consumers detailed information about the reason a claim was denied;
   (iii) Gives consumers information about their right to appeal and how to start the appeals process;
   (iv) Ensures a full and fair review of denial; and
   (v) Provides for an expedited appeals process in urgent cases.

3) External Medical Review Process: States will also be required to enact external review policies that either, comply with the NAIC Model Act, or the HHS standards.

   (i) NAIC Model Act recommends:[56]
   - External review of denial decisions based on medical necessity, health care setting, appropriateness, level of care, or effectiveness of a covered benefit
   - Clear information be given to consumers about their rights to internal and external review
   - Expedited access to external review in emergency situations or in cases where the health plan did not follow internal review process
   - Health plans pay for the cost of the external appeal and that states may not require consumers to pay more than a nominal fee
   - Review organization be an independent body, randomly assigned by the state
   - Insurance companies abide by final decision of the independent organization[57]

   (ii) NAIC Model Act – Process for Filing an Appeal
   - Patients can file a request with the Commissioner for External Medical Review within four months of receiving a notice of a denial
   - The Commissioner notifies insurer of the request and insurer does a preliminary review to determine if patient is eligible for Independent Medical Review
   - The Commissioner randomly assigns an independent review organization
   - Independent review organization has 45 days to provide written notice of its decision to uphold or reverse the denial

4) Applies to:
   (i) Grandfathered Plans: No
   (ii) Self-Insured Plans: Yes

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[56] It is important to note that these standards are just the minimum with which states and insurance companies must comply. The federal law does not preempt more protective state laws.
[57] http://www.healthcare.gov/law/provisions/appealing/appealinghealthplandecisions.html

V. CHANGES TO MEDICARE

A. For more information on Medicare, please refer to page 44 in the Health Insurance & Health Care Options Chapter.

B. The ACA made several changes to the way that Medicare will operate.

1) **Part B:** Starting in 2007, Medicare Part B premiums were tied to an individual's income level, so that higher income Medicare beneficiaries have been paying a higher amount for their Part B premium. Each year, those income levels were decreasing so that more people were paying a higher Part B premium. The ACA froze the income threshold for Part B premiums to 2010 levels, through 2019, at $85,000 for those who are single, and $170,000 for those who are married. Although the premiums amounts may increase each year, fewer people will have to pay the higher premium rates based on their income levels.

2) **Part C (Medicare Advantage Plans):** There are no significant changes in the ACA for enrollees in Medicare Advantage Plans. However, some Advantage Plan providers were receiving a reimbursement of approximately $1,000 more per patient than Medicare fee-for-service providers. Under the ACA, those reimbursement rate gaps for Medicare fee-for-service providers and Advantage Plan providers will be closed.

3) **Part D and the Prescription Drug "Donut Hole":** For more information on Medicare Part D, please refer to page 45 in the Health Insurance & Health Care Options chapter.

(i) Starting in 2010: A $250 rebate was available for any Part D enrollee who entered the donut hole in 2010. Rebate checks were sent automatically. If you believe you should have received a rebate check, contact Medicare at (800) 633-4227.

(ii) Starting on July 1, 2010: In order for a drug to be covered by Medicare Part D, the drug company must enter into an agreement with the HHS Secretary to provide a significant discount (up to 50%) on name brand drugs to Part D enrollees who enter the donut hole.[58]

(iii) Between 2011 and 2020: The prescription drug donut hole will progressively decrease, eventually requiring enrollees to only pay 25% of the cost of their brand name and generic drugs.[59]

VI. HEALTH INSURANCE COVERAGE OPTIONS

A. Please refer to the chapter on Health Insurance & Health Care Options for more information about current options.

B. **Expansion of Coverage for Children and Young Adults:**[60] Most people who attend college graduate by the age of 23. This typically means that they lose their full time student status and are no longer eligible for health insurance coverage through their parent's health insurance plan. Finding a job after graduation that offers heath insurance can be very difficult. Under the ACA, young adults have access to health insurance coverage through their parent's health insurance policy longer than they would have previously.

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[58] www.medicare.gov/Publications/Pubs/pdf/11493.pdf
[59] www.medicare.gov/Publications/Pubs/pdf/11493.pdf
[60] §1201 of P.L. 111-148 (new PHSA §2704), as amended by §2301 of P.L. 111-152.

1) **As of September 23, 2010:** Children may remain covered under their parent's plan until they reach the age of 26 years old.

   (i) **Requirements:** Children cannot be eligible for employer-sponsored health insurance offered through their own jobs.

   (ii) **Note:** The "child" does not need to be claimed as a dependant under IRS standards. Also, the child can be married; however, the plan's coverage will not extend to the child's children or spouse.

2) **Implementation Timeline:** Although this provision went into effect on September 23, 2010, the implementation time is up to the employer.

   (i) Private employers have the option to implement this provision:
   - Immediately after March 23, 2010 (early implementation)
   - Immediately after September 23, 2010 (when the provision went into effect)
   - At the beginning of the next plan year after September 23, 2010 (e.g., when the parent's plan is renewed). Therefore, the latest possible implementation date is September 22, 2011.

   (ii) This provision will go into effect for federal employees on January 1, 2011.

   (iii) Plans must give written notice of the option to enroll children on the employee's plan by the first day of the plan year, and coverage for the dependant must start the first day of the plan year.

   (iv) If parents are not enrolled through their employers, they will be given a one-time option to enroll (or change plans) for both themselves and their dependents.

3) Applies to:
   (i) Grandfathered Plans: Yes
   (ii) Self-Insured Plans: Yes

C. **Pre-Existing Condition Insurance Plans**[61]

1) For background information on high risk insurance pools see page 43 in the Health Insurance & Health Care Options chapter.

2) If an individual currently has a pre-existing medical condition, and is over the age of 19, then he or she may not be able to purchase individual health insurance. Until the ACA protections for adults with pre-existing conditions are fully implemented in 2014, the federal government has provided high risk insurance plans to individuals with pre-existing conditions, which will remain in existence until 2014, when new options will be available.

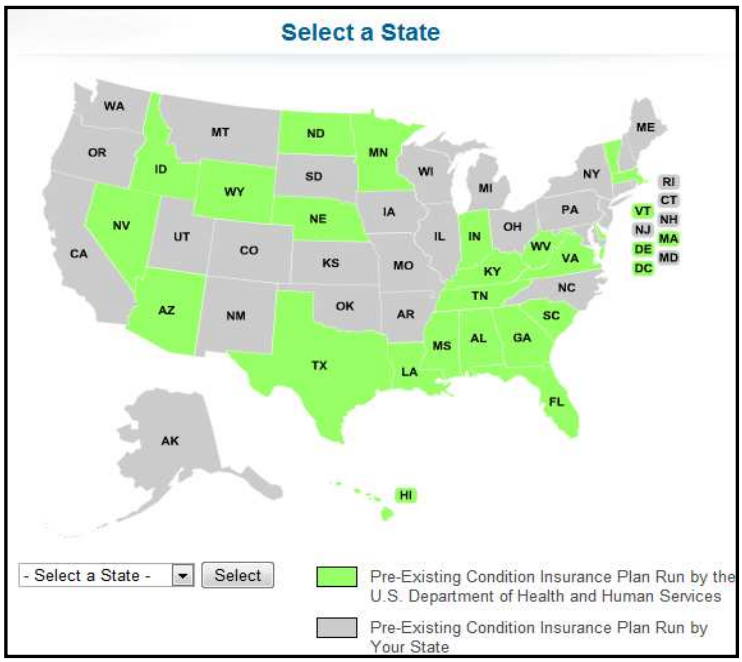
   (i) The ACA requires all states to have a Pre-Existing Condition Insurance Plan (PCIP). Some states opted to run their own plans, funded by the federal government, and some states chose to have federal government administer their state's plan.

   (ii) States began collecting applications for the PCIP plans on July 1, 2010. Coverage in some states has already begun.

[61] ACA §1101 (pg. 23)

(iii) Eligibility:

- U.S. citizens or persons who are lawfully present;
- Who have a pre-existing illness or condition; and
- Who have had no creditable coverage for 6 months or more



(iv) Maximum Out-of-Pocket Costs (excluding premiums):

- Individuals: $5,950
- Families: $11,900

(v) Premiums: Monthly premiums for the PCIP plans will vary from state to state. For example:

Age	0-34	35-44	44-54	55+
Illinois (State)	$149	$192-$269	$280-$393	$408-$562
Indiana (HHS)	$310	$372	$476	$662

(vi) For more information on PCIP plans available in each state, go to www.healthcare.gov or www.pcip.gov/StatePlans.html, or contact the CLRC.

D. **Health Insurance Exchanges:** The PCIP plans established by the ACA will only last until July 1, 2014. After this date, individuals will have the option to purchase health insurance through the health insurance exchanges. The actual details of health insurance exchanges will vary state to state, but generally, they are supposed to provide an easier way for people to research options and obtain health insurance. States are required to have a baseline plan for their exchange by January 1, 2013. Some states, such as California, have already passed legislation to implement their state health insurance exchange.

1) Generally, the exchanges will provide:
   (i) A standardized format for presenting plan options;
   (ii) An internet portal for search, selection, purchase, and enrollment;
   (iii) A toll-free telephone hotline to call for assistance;
   (iv) A calculator to determine the actual cost of coverage for each plan option.

2) Five Plan Options in the Health Insurance Exchanges
   (i) Bronze
   - Represents the minimum creditable coverage
   - Provides the essential health benefits
   - Covers 60% of the benefit costs of the plan

   (ii) Silver
   - Provides the essential health benefits
   - Covers 70% of the benefit costs of the plan

(iii) Gold
- Provides the essential health benefits
- Covers 80% of the benefit costs of the plan

(iv) Platinum
- Provides essential health benefits
- Covers 90% of the benefit costs of the plan

(v) Catastrophic Plan
- Provides catastrophic coverage to people up to age 30; or
- Those who are exempt from the individual mandate (e.g., religious objections)
- This plan will only be available in the individual market

3) Implementation Timeline:

(i) 2014: Exchanges will be open to individuals and small businesses (50 and fewer employees).
(ii) 2017: States may allow employers with up to 100 employees to participate in exchange.

E. **Individual Mandates:** As of January 1, 2014, the ACA requires all US citizens and legal residents to have health insurance or pay a penalty.[62]

1) Exceptions:
(i) A break in coverage of less than 3 months;
(ii) Religious objections; and
(iii) Financial hardship (i.e., the required contribution to pay premiums would exceed 8% of household income).

2) Penalties for Non-Compliance: Those who choose not to buy health insurance will have to pay a penalty on their taxes. The amount of the penalty increases each year:
(i) 2014: ~$325
(ii) 2015: ~$350
(iii) 2016: ~$695

F. **Early Retiree Reinsurance Program:** The ACA gives employers a way to recoup some expenses for providing insurance to certain retirees. These are individuals who retire before the age of 65 and are not yet eligible for Medicare.

1) This program allows approved companies to use federal funds to lower premiums for employees and other health care cost relief to their retirees and workers and their families, to offset increases in their own health care premiums or costs, or for combination of these purposes. This plan will reimburse employers or insurers for 80% of retiree claims between $15,000 and $90,000. This program will run until January 1, 2014, when the health insurance exchanges begin.

VII. MEDICAID ELIGIBILITY

A. For more information on Medicaid, please refer to page 46 in the Health Insurance & Health Care Options chapter.

[62] ACA §§ 1501, 1502, and 10106 adding §§ 5000A and 6055 to the Internal Revenue Code (IRC); § 1002 of Reconciliation Bill.

B. As of January 1, 2014, states are required to expand Medicaid coverage to include:

1) "Newly-Eligible" Adults: Adults at the income level of 133% of the federal poverty level (FPL).

(i) In 2010, 133% FPL for an individual was $14,403.90 per year or $1,200.33 per month. For a family of four, 133% of the FPL was $29,326.50 per year or $2,443.88 per month.

2) Children ages 6 to 19 at 133% of FPL.

C. **Notes:** States have the option to expand Medicaid eligibility beginning in 2010, but most states will not, because they cannot afford it due to budget crises. In 2014, when it becomes mandatory for states to expand their Medicaid programs the federal government will pay for the costs associated with the expansion of eligibility. However, some states, such as California, have applied for state waivers to pilot early implementation programs. For more information about state programs, contact the state's Medicaid agency. (See the STATE APPENDICES)

VIII. TAX IMPLICATIONS

A. Employer-Sponsored Health Insurance Included in W-2

1) Beginning with the 2011 tax year, in order to help the government determine who has health insurance coverage through their employer, employers will be required to include the "aggregate cost" of insurance on their employees' W-2 forms. Employers are required to report this amount, but it is not for the purpose of taxing the employee or the employer. [63]

B. **Small Business Tax Credits**[64]: Beginning in 2010, the ACA established tax credits for small businesses that are designed to encourage small employers to offer health insurance coverage for the first time or maintain coverage they already have for employees.

1) Eligibility: Small businesses with fewer than 25 full-time equivalent (FTE) employees making $50,000/year or less per employee. However, because the formula is based on FTEs, not the number of employees, a business could be eligible even if it has more than 25 individual workers.

2) Amount of Credit: The credit amount will vary depending on the size of the employer. The following maximum credits are for smaller employers (10 or fewer FTEs making $25,000/year or less).
(i) 2010 maximum credit: 35% of the premiums an employer pays for its employees.
(ii) 2014 maximum credit: 50% of the premiums an employer pays for its employees.

3) Applying for Credit: The IRS will be automatically notifying businesses that may qualify for the credit. If you have questions about this credit, contact the IRS at www.irs.gov or call 800-829-4933.

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[63] Section 9002 (pg 735 of ACA)-IRS website with this info: www.irs.ustreas.gov/newsroom/article/0,,id=220809,00.html.
[64] Information from IRS: www.irs.gov/newsroom/article/0,,id=220848,00.html.

C. **Premium Tax Credit:** Beginning on January 1, 2014, the ACA provides subsidies for individuals with incomes between 133% and 400% of the FPL, in order for them to purchase health insurance in the exchanges. Those with incomes between 100% and 133% of FPL may also be eligible for reduced cost sharing (e.g., copayments, coinsurance, & deductibles).[65]

1) Eligibility: This credit is not available to most people who have:
   (i) Employer-sponsored health insurance;
      - Unless the employer coverage is below 60% actuarial value or if premiums exceed 9.5% of their income
   (ii) Medicare or Medicaid;
   (iii) CHIP; or
   (iv) TRICARE or coverage through Veterans Affairs.

2) Process: A person will enroll in a plan offered through an exchange and report her income to the exchange. Based on that information the person will get a premium assistance credit. The federal government will then pay the credit directly to the person's insurance plan. The person is then only responsible for paying the difference between the premium tax credit and the total monthly premium.

   (i) The credit will be either:
      - The total monthly premium for the taxpayer and any covered dependents; or
      - The amount over a percentage of the household income that it costs to purchase the lowest "Silver" plan purchased through the Exchange. The percent of the household income is on a sliding scale based on FPL raging from 2% to 9.5% of income.

        ⇒ Example: Jane has an income that is 250% of the federal poverty level (FPL) (~$29,000 in 2014). The cost of the second lowest cost silver plan in the exchange in Jane's area is estimated to be approximately $5,000 per year. Under the ACA, because Jane's income puts her at 250% FPL, she would not be required to pay more than 8.05% of income for her health insurance coverage, or $2,334.50, to enroll in the second lowest cost silver plan. The tax credit available to Jane would be $2,665.50 ($5,000 premium minus the $2,334.50 limit on what Jane must pay).[66]

D. **High-Cost Excise Tax:** The ACA imposes an excise tax on "Cadillac plans," which are high-cost health insurance policies, usually with low deductibles and very good benefits.[67]

1) Beginning in 2018, insurance companies will be taxed on the amount of premiums above the established thresholds of $10,200 for an individual plan, and $27,500 for a family plan. These are not taxes to be paid by employees or employers.

IX. RESOURCES

For information about the ACA: www.HealthCare.gov	**For more information on the federal Pre-Existing Condition Plan options available in each state:** www.PCIP.gov
Kaiser Family Foundation Video, "Healthcare Reform Hits Main Street:" healthreform.kff.org/the-animation.aspx	

[65] ACA § 1401 and 10105.
[66] Note: This is only an example based on estimate figures for 2014.
[67] www.kaiserhealthnews.org/Stories/2010/March/18Cadillac-Tax-Explainer-Update.aspx; Section 9001 pg 729 of ACA.

GENETICS AND CANCER

INTRODUCTION:
Genetics is a topic of concern for many cancer survivors, people coping with genetic risk, and their relatives. It can be important to learn about risk factors for cancer so that individuals can have control over and be proactive about their health. Understanding individual risk factors, family history, or genetic predisposition for cancer lets individuals take charge of their health through potential preventative measures and early detection.

This can be very empowering, but it can also be scary, raise many questions, and pose some legal concerns. Several issues can arise from genetic information in the employment and insurance realms. For example, may an employer use genetic information to discriminate against a potential employee or current employee? Or, may an insurance company use genetic information to determine whether or not to insure someone, increase premiums, or impose a pre-existing condition exclusion period?

You may be asking yourself why an insurance company or employer would want to treat an individual differently based on their genetics. Imagine a young woman named Lucy. She has a family history of breast cancer. First, she applies for health insurance. Because her health insurance company wants to maximize profits, they could be motivated to see what risks they are taking on if they were to insure Lucy. By knowing Lucy's family medical history, they may decide that Lucy may cost the company more money in the future because she is more likely to get cancer than the average person her age. Second, Lucy applies to work at a small business. The company may want to learn about Lucy's family medical history to see if she may cost them more in insurance premiums or if she is more likely to take time off work in the future. But, can these two companies legally access Lucy's family history or use this information against her? To address these questions and concerns, this chapter will cover the basics of genetic testing and the laws that protect people against genetic discrimination.

I. UNDERSTANDING GENETICS

Scientists estimate that approximately 5% of all cancers are strongly hereditary.[67] In these cases, a gene mutation that is associated with an increased risk of cancer passes from one generation to another. The abnormal gene is not cancer itself, nor is it a guarantee that an individual will develop cancer. It is a gene abnormality, whose presence puts an individual at a higher risk for getting cancer. This increased risk is called a genetic predisposition. Although many types of cancer can run in the family, the most common of these are breast, ovarian, prostate, and colon cancer.

A. Risk Factors for Hereditary Cancer

1) **Introduction:** There are many factors that are common indicators of hereditary cancer. These include:

   (i) Multiple cases of a type of cancer within a family (e.g., if a patient's aunt and grandmother on one side of the family both had breast cancer, it could indicate that hereditary breast cancer runs in the family);

   (ii) Family members with cancer occurring at younger than average ages for that cancer (e.g. the average age of a prostate cancer diagnosis is 70 years old,

[67] American Cancer Society, *Cancer Facts and Figures 2010, page 1*.

however, if a patient is diagnosed with prostate cancer at 50, this could be an indicator that the cancer is hereditary);

(iii) Family members with cancer not commonly associated with that sex (e.g., a male patient with breast cancer is more an indication of hereditary cancer);

(iv) Family members with multiple primary tumors in the same organ or bilateral primary tumors in paired organs (e.g., a patient has multiple tumors within one organ that are not caused by the original tumor spreading or the patient has had primary tumors in paired organs such as tumors in both breasts or both kidneys).

2) Note: when examining a patient's family history of cancer, it is important to look at each side of the family separately, since the gene for increased risk for cancer can come from either a patient's mother's or father's side. Do not forget to consider both sides of the family for all types of cancer. For example, a woman can inherit a predisposition for breast cancer from either her mother's or her father's side of the family.

II. GENETIC TESTING

A. **Introduction:** For some cancers there are genetic tests available to determine whether an individual has inherited the altered gene that is associated with the increased risk for cancer. Genetic tests are laboratory tests that examine an individual's DNA to identify any changes in chromosomes, genes, or proteins. In some circumstances, the test can find alterations that are associated with an increased risk of cancer. For example, the BRCA1 and BRCA2 genetic tests are available to test for genetic predispositions for breast and ovarian cancer. Additionally, there are genetic tests available to test for genetic predispositions for colon cancer, such as the test for hereditary non-polyposis colorectal cancer (HNPCC).

1) Note: To learn more about any risks associated with an individual's family history and the genetic tests that may be available, speak to a health care provider or consider communicating with a certified genetic counselor.

B. **Costs of Genetic Testing:** The cost of genetic testing can range from under $100 to more than $3,000, depending on the nature and complexity of the test. The costs increase if more than one test is necessary or if multiple family members are tested to obtain a meaningful result. Additionally, the length of time it takes to receive results can range from a few weeks to several months. The doctor or genetic counselor who orders a particular test can provide specific information about the cost and time frame associated with that test.

1) Does insurance pay for genetic testing?

(i) Every insurance policy is different in their coverage. Some private insurers cover genetic testing, but others do not. Additionally, some insurers will cover some genetic tests, but not others. Individuals should check with their insurance company for more information.

(ii) Some state Medicaid programs also cover genetic testing. For example, 17 states currently offer coverage for a genetic test for breast and ovarian cancer. These states are Alaska, Arizona, Colorado, Connecticut, Illinois, Indiana, Iowa, Missouri, New Jersey, New York, New Mexico, Ohio, Oregon, Texas, Utah, Virginia, and Washington.[68]

[68] www.facingourrisk.org/info_research/finding-health-care/financial-help/index.php

C. **Positive Results:** In general, positive results indicate that the test has found a genetic alteration. This does not mean that a patient has cancer or that the patient will definitely develop cancer. A positive test result indicates that the patient is at a higher risk of developing cancer at some point in time. A negative result indicates that the test could not find a genetic alteration. This does not mean however that a patient's risk for developing that type of cancer is eliminated. In some situations this may be an inconclusive result, depending on whether a mutation has previously been identified in the patient's family. In other situations, this means that a patient's risk of developing cancer is the same as the risk for the general population.

1) **Managing Cancer Risks:** Knowledge about a patient's risk for cancer can help the patient manage their risk. For example, individuals with a genetic predisposition for cancer can pursue medical options such as increased surveillance or screenings, preventive drug therapy, or preventive surgery. It is important to perform regular cancer screenings in order to detect any cancer as soon as possible, as early detection is the key to improved survival rates. Prophylactic surgery, which is a preventative surgery, may also be done and involves removing as much of the "at-risk" tissue as possible in order to reduce the chance of developing cancer. Additionally, there are some FDA approved medications that help to reduce the risk of cancer in high risk patients, such as Tamoxifen for breast cancer.
   (i) Note: As indicated above, it is important to also speak with a health care provider to determine what options are best in each individual's case.

III. GENETIC DISCRIMINATION

A. **What is Genetic Discrimination:** Genetic discrimination occurs when an individual is treated differently based on their hereditary predisposition to a particular disease. There is a potential for genetic discrimination to occur in both employment and insurance contexts. Because of the fear that genetic characteristics may be used against them, some individuals decide not to disclose information to health care professionals and decline early screening and preventative measures, which may be crucial for their medical care.

B. **Genetics and the Law:** There are several federal and state laws that protect against genetic discrimination. However, these laws apply to different entities and cover different aspects of genetic discrimination. It is important to understand the complete patchwork of available protections in order to be able to weigh the legal implications of genetic testing.

Law:	Applies to:	Prohibition:
GINA	Employment/Health Insurance	Use of genetic information
ADA	Employment	Disability discrimination
EO 13145	Federal Employment	Genetic discrimination
HIPAA*	Group Health Insurance	Use of genetic information to determine eligibility

*Additionally, HIPAA covers the privacy of genetic information

C. **Genetic Discrimination in Employment:**

1) **Genetic Information Nondiscrimination Act (GINA):** In 2008, the Genetic Information Nondiscrimination Act (GINA) was signed into law. GINA prohibits genetic discrimination in both employment and health insurance. Under GINA, the definition of genetic information is broad. It includes the family medical history of an individual, the results of an individual or family member's genetic test, and the use of genetic services.

Genetic services include the use of genetic counseling, other genetic services, and participation in genetic research. An individual's current health status or manifested diseases and conditions are not considered genetic information. For example, if a patient has taken a BRCA genetic test to determine her risk of breast cancer, this is genetic information. However, if the patient has been diagnosed with cancer, the cancer diagnosis itself is not genetic information, even though the manifested breast cancer may be hereditary. In GINA, a family member includes any relative within four degrees of the individual. Examples of second degree relatives include grandparents, grandchildren, aunts, uncles, nephews and nieces and third-degree relatives include great-grandparents, great-grandchildren, great aunts, great uncles and first cousins.

(i) **GINA in Employment:**

- **Which Employers does GINA Apply To?:** GINA applies to employers with 15 or more employees. It also includes employment agencies, labor organizations, or joint labor-management committees. However, Indian tribes, and bona fide private clubs are not employers under GINA. Therefore, protections under GINA do not apply to employees under these groups. GINA applies to some federal employees, but not all.
- **What does GINA Prohibit?:** GINA offers protections to individuals in the workplace. It prohibits an employer from discriminating against an employee because of genetic information. Some examples of discrimination include firing or failing to hire an employee, or discriminating with respect to compensation, terms, and conditions. The GINA regulations make it clear that the legislation applies to current employees, applicants and former employees. Additionally, GINA does not allow limiting, segregating, or classifying employees because of genetic information. Under GINA, an employer is prohibited from misusing genetic information and acquiring genetic information. The law makes it illegal for an employer to request, require, or purchase an employee's genetic information. There are, however, a number of exceptions to this rule; if an employer does gain genetic information through one of these exceptions they are not allowed to use the information for discriminatory purposes and they must treat the information as confidential medical records.

  ⇒ Inadvertent acquisition/"water cooler exception": An employer does not violate GINA by inadvertently learning about an employee's genetic information, such as by overhearing a conversation in the break room.

  ⇒ Publicly available information: If an employee's genetic information is available publicly, such as in a newspaper article or website, an employer does not violate GINA by learning of that information.

  ⇒ Voluntary health or wellness programs: If the employer has a strictly voluntary health or wellness program, then genetic information can be gathered in this program. Genetic information cannot be gathered if there are incentives given to employees for participation in the wellness program.

  ⇒ Certification requirements of FMLA leave: An employer can ask for genetic information to determine if leave is approved.

  ⇒ Genetic monitoring of the biological effects of toxic substances in the workplace: An employer does not violate GINA by using genetic information to monitor the biological effects of toxic substances in the workplace. This

exception however has very explicit rules for when testing can be done under the circumstances.

⇒ DNA analysis conducted for law enforcement purposes: If the employer conducts DNA analysis for law enforcement purposes, as a forensic laboratory or for purposes of human remain identification, it is not a violation of GINA's protections.

- **What does GINA Protect?:** GINA also provides protections for genetic information possessed by an employer. It requires an employer that possesses any genetic information to maintain such information in separate files and treat such information as a confidential medical record. Employers are further prohibited from disclosing such genetic information, except: to the employee upon request; to an occupational or other health researcher; in response to a court order; to a government official investigating compliance with GINA; in connection with the employee's compliance with certification provisions of the Family and Medical Leave Act or state family and medical leave laws; or to a public health agency.

(ii) **GINA Enforcement in Employment:** If a patient feels that they have been discriminated against in the employment context, contact the Equal Employment Opportunity Commission (See the **STATE APPENDICES**).

2) **Americans with Disabilities Act (ADA):** Although the ADA does not explicitly address genetic information, the Equal Employment Opportunity Commission (EEOC) has interpreted the ADA to prohibit workplace discrimination of healthy persons based on genetic status. This interpretation has never been tested in court. Additionally, some individuals with genetic predispositions for cancer may fall under the ADA whereby the law protects individuals who are regarded as having a disability. (See the EMPLOYMENT RIGHTS section of this guide for more information.)

3) **Executive Order 13145:** President Clinton signed Executive Order 13145 in 2000. This order prohibits the federal government from discriminating against applicants, employees, and former employees on the basis of genetics. Although the order bans genetic discrimination, it does not provide a private right to individuals to enforce this requirement.
   (i) The Executive Order defines protected genetic information as:
   - Information about an individual's genetic tests or genetic tests of that individual's family members; and
   - Information about the occurrence of disease, or medical condition, or disorder in family members of the individual.

D. **Genetic Discrimination in Health Insurance**

1) **Genetic Information Non-Discrimination Act (GINA):** In addition to providing employment protections, GINA also provides protections in the health insurance arena. The definitions of genetic information and family member are the same for both employment and insurance (See the Genetic Discrimination in Employment section above.)

(i) **GINA in Health Insurance**

- **Which Health Insurance Companies Does GINA Apply To?:** GINA's insurance protections apply to both group and individual plans. It also applies to Medigap policies, which are Medicare supplemental policies. GINA does not apply to the Veterans Health Administration, the Indian Health Service, TRICARE military health system, or to the Federal Employees Health Benefits Plan. For those individuals who have insurance through a company that does not fall under GINA, there may be other laws or policies that would apply. For example, the United States military has set up policies against genetic discrimination.
  - ⇒ Note: The insurance provisions in GINA only apply to health insurance. Therefore, GINA does not apply to life, long-term care, or disability insurance. These insurances are regulated at the state level, but the state laws vary widely. Contact the CLRC for more information.

- **What Does GINA Prohibit?:** In the health insurance context, GINA prohibits health insurers from discriminating based on genetic information. Health insurance companies are not allowed to restrict enrollment or adjust premiums, contribution amounts, or coverage terms based on an individual's genetic information. Remember, the definition of genetic information does *not* include manifested diseases in an individual. Therefore, an insurance company cannot raise an individual's premiums because they have a family history of colon cancer, but they can raise premiums if they were to develop the disease. Health insurance companies are also limited from acquiring genetic information. They can neither request nor require an individual to take a genetic test. Also, they cannot purchase an individual's genetic information.
  - ⇒ **Exception**: A health insurer can request genetic information to determine whether to pay for a requested procedure. For example, if a patient seeks prostate cancer screenings before the standard age, the insurance company may ask for genetic information to determine whether early screening is medically necessary. However, under this exception, the insurance company can only ask for the minimum amount of information necessary to decide whether to pay for the requested procedure.
  - ⇒ **Note:** Under GINA, genetic information cannot be considered a pre-existing condition.

(ii) **GINA Enforcement in Insurance:** If a patient feels that they have been discriminated against in the insurance context, contact their state insurance commissioner's office (See **STATE APPENDIX**).

2) **Health Insurance Portability and Accountability Act (HIPAA):** Under HIPAA, group health plans and HIPAA individual plans are prohibited from using genetic information to determine insurance eligibility. However, private individual insurance is not covered under HIPAA. Additionally, asymptomatic genetic information cannot be treated as a pre-existing condition in the absence of a diagnosis or manifestation of the condition.

(i) **What Does HIPAA Prohibit?:** Although HIPAA protects against genetic discrimination during eligibility, it does not prohibit insurance plans from establishing limitations or restricting coverage or benefits. An insurance company may do this if they treat all similarly situated individuals in the plan the same. For example, a plan could exclude coverage for a particular treatment, such as prophylactic mastectomies. HIPAA also regulates patient privacy.

Note: GINA amends HIPPA to explicitly state that genetic information is confidential medical information and prohibits the use or disclosure of genetic information. Although GINA applies only to certain types of health insurance, HHS has issued proposed regulations that apply the privacy rules of GINA to:

- Long-term care policies (excluding nursing home fixed-indemnity policies)
- Employee welfare benefit plans or other arrangements established or maintained for the purpose of offering or providing health benefits to employees of two or more employers (to the extent they are not group health plans or health insurance issuers)
- State high-risk pools
- Certain public benefit programs, such as Medicare Part A and B, Medicaid, the military and veterans health care programs, the Indian Health Service program, and others
- Any other individual or group plan, or combination of individual or group plans that provides or pays for the cost of medical care

Therefore, the privacy protections of GINA apply to more entities than the other provisions of GINA.

E. **State Laws:** There is very little consistency at the state level regarding genetic information and discrimination. The majority of state legislatures have taken steps to safeguard the privacy of genetic information beyond the protections provided for under federal law. State laws that protect genetic privacy typically restrict any or certain parties (such as insurers or employers) from carrying out a particular action without consent. As mentioned above, GINA's insurance regulations only apply to health insurance companies, not to life, long-term care, and disability insurance companies. Accordingly, many states have regulated such markets by passing specific state laws. For more information about state laws, please contact the CLRC.

1) **Life Insurance:** As of January 2008, fourteen states restricted discrimination based on genetic information in life insurance.[69]
2) **Long-Term Care Insurance:** As of January 2008, fifteen states restricted discrimination based on genetic information in long-term care insurance.[70]
3) **Disability Insurance:** As of January 2008, nine states restricted discrimination based on genetic information in disability insurance.[71]

IV. **RESOURCES**

For information about GINA and the ADA with respect to employment discrimination: Equal Employment Opportunity Commission (See the **STATE APPENDICES)**	**For information about state laws that protect against genetic discrimination in employment:** State Fair Employment Agency (See the **STATE APPENDICES)**
For information about state laws that protect against genetic discrimination in insurance: State Insurance Agency (See the **STATE APPENDICES)**	**For information about GINA and HIPAA with respect to health insurance:** State Insurance Agency (See the **STATE APPENDICES)**

[69] National Conference of State Legislatures, *Genetics and Life, Disability and Long-term Care Insurance*, January 2008, www.ncsl.org/default.aspx?tabid=14283
[70] *Id.*
[71] *Id*.

MANAGING THE FINANCIAL ASPECTS OF CANCER TREATMENT

INTRODUCTION:
The financial aspects of cancer treatment can be extensive and include tests, treatment, prescriptions drugs, and appointments with healthcare providers. The purpose of this section is to provide patients with tips for understanding medical bills, negotiating payment plans, disputing a bill, options to cover health care expenses, and the consequences of unpaid medical bills.

It can be very useful for patients to start a file for the paperwork related to their treatment, including medical bills, prescriptions, explanations of benefits (EOB), and medical records. Patients should use a system that is comfortable for them, but there are a number of useful tools provided by cancer organizations, such as the American Cancer Society and LIVE**STRONG**, and there are computer programs, such as Quicken Medical Expense Manager that are also available.

When a patient receives care from a physician, there is a process for medical billing. First, the physician bills the patient's insurance company. Then the insurance company decides what they are responsible for paying and what the patient is responsible for paying. The insurance company then pays the physician and sends the patient an EOB, which indicates the amounts billed, the amounts paid by the insurance company, any amounts applied to the patient's deductible, and any amounts that the patient is responsible for paying to the physician. The EOB is not a bill, it is just an account statement provided by the insurance company. The physician should then send the patient a bill for any amount that the patient is still responsible for paying. Sometimes, a patient will receive the bill before getting the EOB. It is a good idea for patients to wait to pay the bill until receiving the EOB, to ensure that everything was billed and paid for correctly. If some time passes and patients have not received an EOB, patients can contact their insurance company directly to request another copy of the EOB.

It is also important to note that medical expenses may be tax deductible. Individuals can contact their accountant or a free tax service for information about their taxes.

I. BEFORE TREATMENT

A. **Tips to Ensure Medical Bills Get Paid:** Individuals can save time and money by avoiding medical bills in the first place. Below are a few tips to help ensure that medical bills get paid:

1) **Show Proof of Insurance to All Providers:** If patients have health insurance, they should tell all of their providers. If they have more than one kind of insurance let all providers know that as well. For example, some people have both Medicare and Medicaid or have a policy through their employer and also have an individual insurance policy. It is also the patient's responsibility to take the initiative and ask their providers to pass along their information to secondary providers like labs or imaging facilities. If the patient is in a managed health care plan, like an HMO or PPO, it is important to read their Evidence of Coverage (EOC) booklet or health plan contract, which explains the rules of the health plan. Before making an appointment, the patient can determine if their insurance will cover the services they need based on the information on the EOC. Additionally, patients should always take their insurance card to medical appointments and to their pharmacy. Patients should show the card to the billing or front office staff. This will let them know they should send any bills to the health insurance company. Patients should also ask them to make a copy of their insurance card to keep on file.

2) **Keep Contact Information Current:** Patients should make sure that all medical providers have their current address and contact information on file, including: doctors, pharmacies, and health plans. It is also important for patients to make sure that their current contact information is passed on to billing departments, labs, and other hospital departments being used by the patient. This will help ensure that all of the patient's providers are billed correctly.

3) **Check into Health Care Options:** If patients do not have health insurance, they should try to get assistance to pay for their treatment.

   (i) **Find a Hill-Burton Facility:** In 1946, Congress passed a law that gave hospitals, nursing homes, and other health care facilities grants and loans for construction and modernization. In return, these facilities agreed to provide a reasonable volume of services to persons unable to pay and to make their services available to all persons residing in the facility's area. For information on Hill-Burton facilities, visit www.hrsa.gov.

   - **Note**: Most hospitals do not disclose this payment option, so patients should be persistent to see if they are eligible.

4) **Always Read Health Forms Carefully Before Signing:** Patients should not sign anything that they do not understand. If they sign something, they may be agreeing to pay for services and treatment without knowing it. It is okay for patients to ask doctors or other providers questions about any forms they are being asked to sign.

5) **Pre-Authorization:** Patients should ask providers if a particular treatment or service requires pre-authorization from their insurance company. Most providers have a staff person who contacts an insurance company by phone to get pre-authorization. Receiving a pre-authorization does not guarantee that an insurance company will ultimately pay for the treatment. However, getting a pre-authorization in writing will help a patient make a case to the insurance company or external medical review organization that a patient's treatment should be covered.

II. AFTER TREATMENT

A. **Introduction:** Once a patient has received treatment, they are typically responsible for paying for any costs associated with that treatment. However, there are a few things that a patient can do to ensure they have been billed the correct amount, that the insurance company was charged the correct amount, that the insurance company has covered the correct amount, and that the amount the patient is responsible for is correct. Additionally, it may be confusing because the patient may receive a bill from the provider before they receive the Explanation of Benefits (EOB) from the insurance company. It is a good idea for a patient to wait for the EOB before paying the bill so the patient knows what they were billed and what their insurance company paid. If a patient does not receive an EOB, they can contact their insurance company for a copy of one.

B. **Strategies for Reading and Negotiating Hospital Bills:** It is important for patients to carefully review their medical bills, because bills may contain errors or items that are overpriced. Also, sometimes insurance companies will incorrectly deny coverage and the provider will send the bill to the patient. It is always a good idea to check a bill before paying it.

1) **Request an Itemized Copy of the Medical Bill and Review It:** When a provider submits a bill to an insurance company, the insurance company then sends the patient an Explanation of Benefits (EOB). This explains what was billed to the insurance company, how much was applied to the patient's deductible, how much the insurance company paid the provider, and how much the patient still owes to the provider. However, this is not a bill. The provider then sends the patient a bill and the patient is responsible for paying the provider. Unfortunately, it can be hard to figure out what is being billed, because the procedures are listed as codes and often do not have descriptions. Therefore, it is a good idea for patients to request an itemized copy of their medical bill from their provider(s) and review it. By obtaining an itemized bill, patients may find some errors. Patients should check for things, such as: the dates on the bill should match the dates they actually received treatment or any other data entry errors. For example, patients may have been charged for 10 x-rays when they only received one. Look for any inconsistencies; if items seem to be excessive or inappropriate for a particular condition, then they may be wrong.

2) **Request a Copy of the Medical Record and Pharmacy Ledger:** Individuals can request a copy of their medical records and pharmacy ledger. The pharmacy ledger shows all the drugs a patient has been given. The pharmacy ledger, along with their medical records, can give patients a complete picture of their hospital stay. By comparing their medical records and the pharmacy ledger to the itemized hospital bill, patients can also determine if they are being charged for goods or services that they did not receive. Additionally, check for procedures or medications that were ordered, but then cancelled. Patients have a right to copies of all of these things, but they may be charged for reasonable copying expenses.

3) **Compare the Bill to the Hospital's Standard Charges:** Some states require that hospitals make their standard charges, regardless of payer type (e.g., private insurance, Medicare, Medicaid, etc.), available to the public for all products and services. This document is typically called the "charge master." Also, some states, like California, require that uninsured patients with an income below the 350% of the federal poverty level cannot be charged more than the highest amount the hospital would receive for the same care under a public health care program, such as Medicaid. Patients can compare their bills to the hospital's standard charges to make sure they are not being over charged.

4) **Look for Items Billed Due to the Hospital's Negligence:** Generally, when a hospital makes an error, the patient usually pays for it. For example, if an x-ray is lost or the results of a blood test are misplaced, those procedures will be redone and the patient will be billed a second time. Patients may challenge these charges. Also, charges based on delays caused by the hospital can be challenged. For example, in a non-emergency situation, sometimes the hospital's own scheduling needs for tests or surgeries will result in a longer hospital stay for the patient.

5) **Hire a Professional Bill Reviewer:** If a patient has tried the techniques above, but still thinks the bill is too high, it might be time to call a professional bill reviewer, also known as a claims assistant professional. This can be helpful if patients have very high medical bills. Bill reviewers have more expertise with standard billing practices. They can check the diagnosis codes to see if a diagnosis has been "upcoded" to a more serious condition than what the medical chart states. They can determine if some charges were added that are already contained in other bundled charges and they have the expertise to know what is beyond the industry standard. Most bill reviewers will also

assist in negotiating with the provider or testifying as experts in collection defense if contracted to do so. However, bill reviewers will charge for their services, so it should make financial sense for the patient.

6) **Negotiate a Payment Plan:** Setting up a payment plan with providers can be a good option when (1) the charges are legitimate, (2) an individual can make the payments, and (3) the debt will eventually be paid. If patients pay a portion of a bill, they are essentially agreeing that they owe the amount billed, so make sure to check the charges first before setting up a payment plan. If patients decide negotiating with the hospital or provider is the best avenue, try to work out a reasonable payment plan, or if it is possible, offer the hospital a lump sum. Individuals can write out agreements, which both parties sign, for payment plans or lump sum settlements that include removing any negative reports that have been submitted to credit bureaus. Once the debt is paid off, either through a lump sum or at the completion of a payment plan, the provider should send a new statement of account that reflects a zero balance. If no one at the hospital will sign or return an agreement, the individual can write a confirmation letter to the hospital referring to the agreement made and inform the hospital that they must respond within a certain number of days if the information is correct. This should be sent by certified mail.

C. **What Can Individuals Do If They Get a Medical Bill and Did Not Have Health Insurance:** If patients did not have health insurance when they received treatment, they may be able to obtain government-sponsored health insurance, such as Medicare or Medicaid. If they are ineligible for government assistance, consider applying for free or low-cost care, ability to pay programs through local hospitals or county programs, or private financial assistance programs.

(i) **Recently Lost Insurance through Employer:** If patients recently lost their insurance through an employer, they may be able to get COBRA coverage. If patients elect this coverage within 60 days of their involuntary termination of employment, they have to pay the health insurance premiums, which are often high, but may be less expensive than paying a large medical bill. There are also assistance programs that help with COBRA premiums. (See the Health Insurance section above.)

- **Note:** If a patient decides to elect COBRA, even on the 59th day, they are still required to retroactively pay the premiums from the date of termination.
  - ⇒ **Example:** If an employee loses their employer-sponsored health insurance coverage on February 28th, they have until April 29th to elect COBRA coverage (60 days). Upon electing COBRA, the employee is then required to pay the insurance premiums for March and April.

(ii) **Retroactive Medicaid**: If a patient is on Medicaid, they may be eligible to collect benefits starting 3 months prior to their application's acceptance if the patient would have been eligible for these benefits during the retroactive 3 month period.

D. **Tips for Disputing a Bill:**

1) **Patients Who Believe Their Health Insurance Should Have Paid:** If patients believe their health insurance company should have paid the bill, and did not, patients can call the plan to determine the reason for nonpayment. The health insurance plan's contact information is usually on the patient's insurance card. The health insurance plan may have refused to pay the bill because of a mistake on the bill. Patients can also contact their providers to double-check that it was billed correctly. If patients are able to resolve

the error, then they should check with their health care provider and health insurance company to make sure the bill is paid and that their account is cleared.

(i) **Send a Letter to the Health Care Provider:** Sometimes patients need to contact their providers about their bills. It is often helpful to communicate in writing. When patients send a letter to a health care provider, the letter should include:

- Specific Information: Including any information that explains why the patient believes they should not have been billed, or why the bill they received is incorrect.
- Details: Provide as much detail as possible. This is especially important if the individual is getting medical bills for multiple services.
- Copy of the Bill: Include a copy of the bill being disputed so that the provider knows which bill is being disputed.

(ii) **Double Check that the Provider Billed the Insurance Company**: If patients have health insurance at the time they received services, make sure the provider submitted the bill to the health insurance company and that the correct billing codes were used.

(iii) **Insurance Card on Record:** Patients should send a copy of their insurance card to the provider, and be sure to show that the insurance was effective on the day(s) for which they were billed. If an individual's health insurance company needs a health care provider to fill out forms, send the forms to the provider. Always keep copies of what is sent to the health care provider and the health insurance company.

E. **How to Dispute A Health Insurance Company's Decision:** If a patient disagrees with a decision that their health insurance company has made regarding their coverage, they have the right to appeal that decision. The appeals process varies depending on the state in which they live. For more information, see "Handling Health Insurance Disputes" in the Health Insurance section of this manual.

F. **Financial Assistance Resources to Help Pay Medical Bills:** There are many financial assistance resources available to help patients with their medical bills. Unfortunately, the demand placed on these resources is high. These are just a few of the types of resources available. Some people also engage in fundraising efforts to help with medical expenses. This is a good way to engage family, friends, colleagues, and others in a support network. However, it is important that patients first check to make sure that their fundraising efforts will not disqualify them from eligibility for other income-based benefits, such as Supplemental Security Income or Medicaid.

1) **Private Financial Assistance Programs:** There are many private financial assistance programs that help patients with expenses, such as Salvation Army, Lutheran Social Services, Jewish Social Services, and Catholic Charities. Look for programs that serve the patient's local community.

2) **Non-Profit Programs:** Non-profit organizations such as the American Cancer Society, LIVE**STRONG,** and the Patient Advocate Foundation also provide patients with financial assistance for various types of treatment expenses.

3) **Cancer Specific Programs:** Some programs focus on assisting patients with a certain type of cancer, such as the Leukemia & Lymphoma Society, American Kidney Fund, and Lung Cancer Information Line.

4) **Government Benefits Programs:** Government benefits programs include state disability insurance benefits (depending on the state in which the individual lives), SSI and SSDI. These programs provide individuals with income while they have a qualifying disability and are unable to work. Please note that the eligibility requirements for these programs vary, and not all programs have income and asset restrictions. See the Disability Insurance section of this manual.

5) **Pharmaceutical Assistance:** Many pharmaceutical companies offer prescription drugs at reduced costs through a patient assistance program. For example, since 1985, Genentech has donated approximately $1.3 billion to uninsured individuals through their Access Solutions program. See the CLRC handout, "National Prescription Drug Assistance" for other available programs.[72] Some states and organizations also have prescription assistance programs. Additionally, patients can ask their doctors if generic alternatives are available and appropriate. Patients can also check into prescription drug mail order options, which can sometimes be less expensive.

6) **Local Service Organizations:** Local service organizations such as Kiwanis, Rotary Club, or Lions Club may also provide patients with financial assistance.

III. WHAT TO DO IF AN INDIVIDUAL CANNOT PAY THEIR BILLS

A. If an individual's income has been significantly reduced and/or they are having difficulty paying their bills, there are services available to help people sort out their finances.

B. **Hire a Professional:** If a patient cannot pay their bills, they can hire an accountant, lawyer, or financial planner to help solve their personal finance issues. They can also contact the Consumer Credit Counseling Services (CCCS), a national non-profit organization that helps people solve personal finance issues. A counselor at the CCCS will evaluate the patient's situation, their budget, their debts, and set up a plan to help them prepare for the future.

C. **File for Bankruptcy:** Another option is filing for bankruptcy. A patient can file for two kinds of bankruptcy – Chapter 7 or Chapter 13. Based on the type of bankruptcy filed, a patient will be able to either cancel or "discharge" their debts or debts will be reorganized to create an affordable payment plan.

1) **Chapter 7 Bankruptcy:** Also called "liquidation bankruptcy," Chapter 7 forgives most debts that are not secured by collateral or property while allowing an individual to retain certain exempt assets. Under a Chapter 7 bankruptcy, a court appointed trustee takes possession of a patient's non-exempt property, arranges for its sale or liquidation and is responsible for paying as many of the debts as possible with the proceeds. Generally, under Chapter 7, most unsecured debts are dischargeable and do not have to be paid back.

2) **Chapter 13 Bankruptcy:** A Chapter 13 bankruptcy, which is also called "reorganization" or "repayment" bankruptcy, is an option if the patient has a source of dependable income but they are unable to pay their debts. Filing for Chapter 13 bankruptcy allows the patient to pay their debts in installments over an agreed-upon period. The court must approve their plan to repay all or part of the money they owe (including unsecured debt – this includes credit cards). Under Chapter 13, a debtor proposes a 3-5 year repayment plan to the creditors, and the court approves the plan.

[72] www.disabilityrightslegalcenter.org/about/documents/NationalPrescriptionDrugAssistance2011.pdf

3) **Which Bankruptcy is Right?:** Previously, filers could choose the type of bankruptcy that seemed best for them – and most chose Chapter 7 (liquidation) over Chapter 13 (repayment). However, recent laws prohibit some filers with high incomes from using Chapter 7. Accordingly, the first step in figuring out whether a patient can file for Chapter 7 is to measure their "current monthly income" against the median income for a household of their size in their state. If their income is less than or equal to the median, they can file for Chapter 7. If it is more than the median, however, they must pass the "means test", another requirement of the new law in order to file for Chapter 7. The purpose of the test is to figure out whether the patient has enough disposable income, after subcontracting certain allowed expenses and required debt payments, to make payments on a Chapter 13 plan. If the income that is left over after these calculations is below a certain amount, the patient can file for Chapter 7. Before deciding to file for bankruptcy, the patient should always consult with an attorney.
   (i) **Note:** if a patient has incurred recent credit card debt to pay for medical bills, they will probably not be dischargeable through a bankruptcy action. They should consult with an attorney before deciding to file for bankruptcy.

IV. **RESOURCES**

For information about Hill-Burton facilities: Hill-Burton (800) 638-0742 www.hrsa.gov/hillburton/default.htm	**For credit counseling information:** Consumer Credit Counseling Service (CCCS) (800) 873-CCCS or www.cccsintl.org
For possible legal assistance with bankruptcy: American Bar Association (800) 285-2221 www.abanet.org/legalservices/lris/directory	**For assistance with tax preparation and counseling:** Volunteer Income Tax Assistance (VITA) (800) 285-2221 www.abanet.org/lsd/vita

ESTATE PLANNING

INTRODUCTION:
Estate planning is a process that involves individuals, their assets, and their wishes. Estate planning is something that many people do not want to think or talk about, but is something that everyone should consider in order to be prepared. Estate planning is necessary if an individual wants to make sure that their wishes are carried out. Individuals should consider how their assets will be managed for their benefit if they are unable to, when certain assets should be transferred (e.g., during their lifetime, at their death, or sometime later), and to whom those assets should be left. If an individual has specific wishes about the distribution of their assets, it is important to document those wishes to ensure they are fulfilled. Even if an individual thinks that everyone knows what they want, if it is not in writing, then it may not be sufficient.

Estate planning is not just about writing a will. Regardless of the amount or value of an individual's assets, it is important to have a basic plan in place. When planning, it is important for an individual to consider their medical, personal, emotional, spiritual, and financial needs and those of their family and friends. Such a plan ensures that those needs are met. For a list of common estate planning terms see our Estate Planning Glossary (**APPENDIX EP1**). Remember, laws vary from state to state, so it is important to consult with an estate planning attorney familiar with the laws in each state or contact the CLRC.

Individuals should start by taking an inventory of their assets and debts. Individuals can use the CLRC's Personal Records File and Taking Care of Business Form (see **APPENDICES EP2 and EP3**). Assets typically include bank accounts, investments, personal possessions, real estate, and business interests. Assets that have beneficiary designations (when you name a person who will receive the money at your death), such as life insurance policies, IRA's, qualified retirement plans, and some annuities are important parts of an estate, which require coordination with other assets in developing a complete estate plan.

Additionally, individuals should ask themselves a series of questions:

- Who would you want to inherit your assets?
- Who do you want to handle your financial affairs if you are ever unable to do so yourself?
- Who do you want to make your medical decisions if you could not make them for yourself?

For example, if an individual was injured in a car accident and had to spend a few weeks in the hospital recovering, the individual should consider:

- Who would pay my rent and other bills?
- Who would feed my pets?
- Who would pick up my children from school?
- If I were unconscious, whom would I want to make medical decisions for me?

Remember, estate planning is based on the idea that when individuals prepare in advance, they can prevent problems down the road.

There are four important documents to consider when planning an estate:

1. Advance Health Care Directives (including living wills, powers of attorney for health care, and organ donation)
2. Powers of Attorney for Financial Affairs
3. Wills
4. Trusts

I. ADVANCE HEALTH CARE DIRECTIVES

A. **What is an Advance Health Care Directive?:** An advance health care directive (AHCD) is a set of written instructions communicating an individual's wishes about the medical care and treatment they would like to receive if they are no longer able to make decisions for themselves. AHCD's are written in advance to inform doctors and other health care providers about patients' thoughts concerning their medical treatment. Although patients are not required to have an AHCD, nor will they be denied medical care if they chose not to have one, it may help to ensure that patient gets the treatment that they want. Through this document, an individual can make legally valid decisions about their future medical care. Every state recognizes advance directives, but the law governing directives vary from state to state.

1) **Taking Effect:** AHCD's only go into effect when individuals can no longer make their own health care decisions. As long as they are able to give "informed consent," health care providers will rely on the patient and not on the advanced directive. When the doctor determines that the patient has regained capacity to make or communicate health care decisions, then the AHCD's authority will end and the patient's consent will be required again for any treatment.
   (i) **Informed Consent:** Informed consent means that an individual is able to understand the nature, extent, and probable consequences of proposed medical treatments and they are able to make rational evaluations of the risks and benefits of those treatments. It also means that an individual is able to communicate this understanding.

B. **Parts of an Advance Health Care Directive:** Typically there are four parts, but laws vary from state to state:

1) **Power of Attorney for Health Care:** This part of the AHCD is where a patient names someone they trust (e.g., a relative or friend) to be an "agent," to make medical decisions for the patient when the patient is unable to do so. An agent makes all medical decisions unless the patient decides to limit the agent's power. For example, an agent will have access to the patient's medical records, unless the patient limits that right. It is also important to keep in mind that an individual is allowed to name an alternate agent. This means that if the first agent is not available, then an alternate agent can step in and can make decisions on their behalf. However, it is generally not a good idea to name two agents together. There is the potential for the two agents to disagree and the individual's wishes may not be carried out.
   (i) Keep in mind that the power of attorney for health care does not authorize anyone to make legal or financial decisions. That is done through a separate power of attorney for financial affairs (see below).

   (ii) Under some state laws, an individual's health care agent cannot make certain decisions for them. For example, California law prohibits an agent from committing someone to a mental health treatment facility, or authorizing convulsive treatment therapy, psychosurgery, sterilization, or abortion.

2) **Living Will:** The second part of an AHCD is commonly referred to as a living will, which outlines a patient's desires regarding life-sustaining or life-prolonging medical treatment.

   (i) **Life Treatments:** These are treatments or procedures that are not expected to cure a terminal condition or make an individual better. They only prolong one's life.

Examples include mechanical respirators to help an individual breathe, kidney dialysis to clear the body of waste, or cardiopulmonary resuscitation (CPR) to restore a heartbeat.

(ii) **Terminal Condition:** A terminal condition is defined as an incurable condition for which medical treatment will only prolong the dying process and without that treatment, death will occur in a relatively short period of time.

3) **Organ Donation:** This part of an AHCD allows a patient to express their wishes about donating specific organs or tissue.

4) **Primary Physician:** This part of an AHCD provides a space for a patient to record the contact information for their primary physician.

II. DO NOT RESUSCITATE FORM

A. **What is a Do Not Resuscitate (DNR) Form?:** This is a written order to medical personnel that resuscitation should not be attempted if an individual suffers from cardiac or respiratory arrest. A DNR can also be made using an advance health care directive in some states.

III. POWER OF ATTORNEY FOR FINANCIAL AFFAIRS

A. **What is a Power of Attorney for Financial Affairs?:** When making decisions about an estate plan, individuals may also consider appointing someone to make financial decisions on their behalf if they are unable to do so. A power of attorney for financial affairs is a legally binding document that designates a trusted person to act on a patient's behalf if they become incapacitated (incapacity is determined by a doctor or a judge). This document must be signed and notarized in most states. The power of attorney ends upon the individual's death, at which point their will would take effect. It is important to keep all of the insurance information (health, long-term care, life insurance, and special needs policies) in an accessible place for the power of attorney to locate.
   1) **Durable Power of Attorney:** This document goes into effect at its signing, and continues through any period of time when an individual is determined unable to make decisions on their own behalf.
   2) **Springing Power of Attorney:** This document only goes into effect when an individual is determined to be unable to make decisions on their own behalf.

IV. CONSERVATORSHIPS

A. **What is a Conservatorship?:** A conservatorship is a court proceeding in which the court supervises the management of an incapacitated person's finances and/or personal care, including health care. A conservatorship is usually necessary because a patient did not previously appoint someone to act as their representative through an AHCD or Power of Attorney for Financial Affairs. As a consequence of not planning ahead, a court will decide who will act on the patient's behalf, and it may not be who the patient would have wanted. This process can also be expensive, and can cause family disputes, so it is better if the patient plans in advance.
   1) **Who is the Conservator?:** A conservator is the person appointed by the court to make decisions for the patient who is not competent.
   2) **Who is the Conservatee?**: The conservatee is the person who is determined to not be legally competent to make decisions on their own.

V. WILL

A. **What is a Will?:** A will is a legal document, drafted and executed in accordance with state law, which cannot be changed after one's death. In a will, individuals can name beneficiaries (people or organizations who will receive their assets), a guardian for minor children (a person(s) who will care for their child until he/she turns 18 years old), and an executor (a person who manages and distributes their assets according to their wishes). It is important to note that a will does not cover everything that the individual owns. Wills do not cover life insurance policies, retirement plans, assets owned as a joint tenant, living trusts, or a spouse's half of any community property.

1) **Ways to Make a Will:** There are many ways to make a will. It is a good idea to consult with an attorney to ensure that estate planning documents comply with state laws.

(i) **Handwritten or Holographic Will:** Some states allow individuals to make holographic wills. A holographic will is a will completely written in one's own handwriting that is signed, dated, and expresses intent on how various assets should be distributed. This document does not need to be notarized or signed by witnesses; however, any typed material may invalidate the will.

- **Note:** Handwritten or holographic wills are not accepted in every state. For example, California accepts holographic wills, but Florida does not. For more information the validity of handwritten or holographic wills in a state, contact the state's bar association or the CLRC.

(ii) **Statutory Will:** Statutory wills, also known as fill-in-the-blank will forms, may be sufficient for an individual who does not have a large or complicated personal estate. For more information on a state's law regarding statutory wills contact the state's bar association or the CLRC.

(iii) **Will Prepared by a Lawyer:** A qualified estate planning lawyer can make sure that an individual's will conforms to state law. The lawyer can also offer suggestions about other estate planning options, explain potential tax benefits, and provide information on the many ways property can be transferred, which may be less expensive in the long run for individuals and their beneficiaries.

B. **Does an Individual Need a Will?:** If an individual dies without a will (dying "intestate"), the state's law determines the beneficiaries of their estate. This means that a court decides to whom the individual's assets will be distributed. For example, in some states there is a list of beneficiaries that courts will use to distribute one's belongings. The line of progression is automatic under the law and may not take into consideration what is best or appropriate for the individual's family. According to the line of progression, if the individual was married in a community property state, for example, the spouse will receive all of the community property. The spouse will also receive part of the individual's separate property, then the remainder of the estate would be distributed to the closest kin, including children, grandchildren, parents or siblings (in statutory order). If the individual was not married, their assets would be distributed according to the line of progression.

1) **Note:** The line of progression is automatic except for life insurance policies, joint accounts, and property held in joint tenancy (real property), which all pass without a will because a beneficiary has already been designated for those assets (typically upon purchasing a life insurance policy, opening an account, or signing a deed for the property).

C. **Can a Will be Changed?:** A will can be changed after it is signed. In fact, everyone should review their will periodically because if the will is not current, the estate may not be distributed according to one's current wishes. Individuals should also review their will when there are major changes in the family (such as births or marriages), when they purchase or sell a piece of real estate, or when the value of their assets significantly increase/decrease. If the individual moves to another state, it is a good idea to have an attorney review the will to ensure that it is in compliance with state laws.

1) **How to Change a Will:** A will can be changed through a "codicil," a legal document which must be drafted and executed in accordance with the same state laws that apply to the will. An individual should not change their will by crossing out words or sentences; rather, any changes, additions, or deletions should be done through a codicil.

D. **How is a Will Carried Out?:** The process by which the provisions in a will are carried out following one's death is called "probate." In addition to making sure that the executor correctly distributes all assets to the intended beneficiaries, probate also validates any claims by creditors. At the beginning of a probate administration, a petition is filed with the court, usually by the person named as the executor. After notice is given and a hearing is held, the will is admitted to probate and an executor is officially appointed. One disadvantage to probate is its public nature. The provisions of a will and the value of one's assets become a public record. In addition, because a lawyer's fees and executor's commission are based on a statutory fee, the expenses may be greater than the cost of a comparable estate managed and distributed under a trust.

VI. TRUST

A. **What is a Trust?:** Like a will, a trust is a written agreement where individuals can name beneficiaries who will be given, or who will inherit, their assets. A trust is a written agreement between the individual creating the trust (trustor) and the person named to manage the assets held in the trust (trustee). Depending on the type of trust, it can be revoked or changed during one's lifetime. Individuals can be their own trustee's until their death. After death, the terms of the trust cannot be changed or altered in any way. Having a trust can eliminate the need to go through the probate process. Consult with an estate planning attorney for more information about trusts. A certified state or local bar association can refer individuals to attorneys in their area.

B. **Common Types of Trusts:**
1) **Charitable Remainder Trust:** A trust where the remainder of the trust goes to a charity.

2) **Testamentary Trust:** A trust, which is set forth in a will, to provide for children or others who need management of their assets.

3) **Irrevocable Trust:** A trust that cannot be changed during one's life.

4) **Living Trust:** The most common type of trust; created while the individual is alive and allows the individual to act as their own trustee until their death when another trustee takes over. If the individual has a living trust, they may also want to consider drafting a pour over will. For example, an individual may have many possessions that are not individually listed in their trust. A pour over will covers any assets that are not contained in the trust at death.

C. **Funding a Trust:** Once a trust is created, the trust must also be "funded." The funding of a trust is simply the transfer of assets from the individual's name to the name of the trust. Deeds to real property must be prepared and recorded, bank accounts transferred, and stock and bond accounts transferred.

Whichever estate planning documents individuals choose to have, or decisions that they make, it can be a good idea to discuss their wishes with their family, caregivers, physicians, and other health care providers.

VII. RESOURCES

For estate planning information: American Bar Association Estate Planning FAQ www.abanet.org/rpte/public/home.html	**To download a state specific AHCD:** National Hospice and Palliative Care Organization Caring Connections (800) 658-8898 www.caringinfo.org/stateaddownload

LEGISLATIVE ADVOCACY

INTRODUCTION:
Legislative advocacy is an opportunity to share your voice, because you can make a difference in the lives of people with cancer and within your profession.

Legislative Advocacy is the process of working to achieve a legislative outcome. This involves taking action to change a current law, proposing an idea for new legislation, or expressing a view about a proposed bill. There are many ways to become involved in the legislative process, including writing a letter to your elected officials, scheduling a meeting with your legislators, joining an organization's advocacy efforts, communicating with the media to express an opinion, or calling fellow community members to action.

I. THE STRUCTURE OF THE U.S. GOVERNMENT

A. **Introduction:** The federal government is divided into three different branches: the Legislative, the Executive, and the Judicial branches. Each branch has its own functions, sometimes overlapping with one another, but each branch has checks on the other two. The term "checks and balances" describes this process. For example, a function of the legislative branch is to make laws. However, the executive branch has the power to veto a law passed by the legislative branch. The purpose of checks and balances is to prevent any one branch of the government from becoming too powerful, theoretically keeping the branches equal in power.

B. **Legislative Branch:** The Legislative branch is the U.S. Congress, divided into two parts, the U.S. House of Representatives and the U.S. Senate.
   1) Every state is guaranteed at least one Representative. Each additional Representative is based on the state's population; currently there are a total number of 435 Representatives. A state that has more than one Representative is divided into a number of districts equal to the number of Representatives allocated to that state. For example, California has 53 congressional districts and, therefore, has 53 Representatives, whereas Maryland has 8 congressional districts and, therefore, has 8 Representatives. Each district votes to elect their Representative. The term for a member of the House of Representatives is two years. A Speaker leads the House of Representatives and is elected by the Representatives.

   2) The Senate has exactly one hundred members. Regardless of population, each state has two Senators. Unlike the two-year term limit for Representatives, Senators serve six-year terms. The elections are staggered so that every two years, one-third of the Senators are up for re-election. The Senate was designed to be more stable, while the House of Representatives was designed to be more dynamic. The chief function of the U.S. Congress is to make laws.

C. **Executive Branch:** The Executive branch is composed of the President, Vice President, cabinet, and other various agencies and departments of the federal government (e.g., Department of Justice). The cabinet is a group of advisors nominated by the President to serve as chief officers in the departments of the federal government. The chief function of the Executive branch is to execute the laws passed by Congress.

D. **Judicial Branch:** The Judicial branch consists of the U.S. Supreme Court and all of the lower federal courts. Supreme Court Justices (one Chief Justice and Eight Associate Justices) are nominated by the President and confirmed with the "advice and consent" of the Senate. Justices serve a life term unless they resign, retire, or are removed by impeachment and conviction by a Congressional vote. The chief function of the Judicial branch is to interpret and determine the constitutionality of each law passed by Congress and executed by the Executive branch.

E. **State and Local Governments:** Under the 10th Amendment to the U.S. Constitution, all governmental powers not granted to the federal government are reserved for the states. State legislative bodies, like the federal government, are bicameral (divided into two houses), with the only exception being Nebraska, which is unicameral. Local governments are responsible for passing laws pertaining only to their county or municipality (e.g., managing water resources, funding for school districts, etc.).

Who Are Your Elected Officials?

Levels:	Executive	Legislative	Judicial
Federal	*President*	*Congress*	*Federal Courts*
State	*Governor*	*State Legislative*	*State Courts*
Local	*City Mayor & County Executive*	*City & County Council*	*City & County Courts*

II. LEGISLATIVE TERMS

A. **Abbreviations That You Often See Before a Bill Number:**
1) **AB:** Assembly Bill
2) **SB:** Senate Bill
3) **HR:** U.S. House of Representatives
4) **S**: U.S. Senate Bill
   (i) For example: S224 is a U.S. Senate Bill, number 224.

B. **Terms:**
1) **Act:** A bill passed by the legislature and approved by the Executive (e.g., Governor, President, etc.).
2) **Amendment:** A formal proposal to change the language of a bill after it has been introduced.
3) **Bill:** A proposed law introduced during a session of the Legislature for consideration by the legislators and identified numerically in order of presentation.
4) **Constituent:** A citizen residing within the district of a legislator.
5) **District:** A geographic area represented by a legislator.
6) **Lobbyist:** An individual who seeks to influence the outcome of legislation, typically on a particular issue area.
7) **Recess:** An official pause in the committee hearing or floor session, and often when the legislators return to their elected district to attend to business and conduct local meetings.
8) **Session:** The period during which the Legislature meets.

III. THE FEDERAL LEGISLATIVE PROCESS

A. **How Laws Are Made:** It is important to remember that an idea for a new law can come from anyone**.** However, in order for legislation to be officially presented, it needs to be introduced by a member of Congress. The member of Congress who introduces the bill is known as the bill's chief sponsor. If more than one member presents the bill, then the members are known as co-sponsors. You may ask your legislator to present a piece of legislation. Once the chief sponsor or co-sponsors agree to introduce the legislation, they will draft it themselves or turn it over to the Legislative Counsel's Office to formally draft the legislation. After the legislation is drafted, it is introduced in the House by placing it in the "hopper," the famous box located at the Speaker's platform. In the Senate, it is given to the presiding officer or introduced on the Senate floor.

Bills can only be introduced when Congress is in session. During this time you can encourage other legislators to support this piece of legislation and encourage the chief sponsor to reach out to colleagues for support in hopes that the legislation will become a law. After the legislation is introduced, the bill is assigned a number and sent to the appropriate committees. If the bill starts in the House, it will have an "HR" before the number and if it starts in the Senate, it will have an "S" before it.

1) **Congressional Committees:** There are several House and Senate committees. The committees are divided according to different policy issues, such as health care or defense. The committees are responsible for holding hearings where testimony supporting or opposing the bill is heard. In committee "mark-ups," changes are made to the bill, followed by a final vote to determine if the bill should be considered by the entire legislative body. In most instances if the committee decides to reject the bill, it cannot go any further. If the committee decides to accept the bill, it is presented in either the Senate or House chamber. There are rules governing the length and technique in which each bill is debated. If it passes through one chamber, it is presented to the next chamber. If there is a vast difference between the bills that pass through the Senate and the House then a conference committee containing members from both the House and Senate is formed to work out the differences. Once the issues are resolved, the bill is sent back through the voting process in both the House and Senate chambers. At this point, no further amendments to the bill are allowed.

   If the bill is passed, it is sent immediately to the President for signature. During this time the bill is considered "enrolled." The President has ten days to sign, veto, or take no action on the bill. If the bill is signed it becomes law. If the bill is vetoed, it goes back to Congress for a possible veto override vote. A two-thirds majority vote is required to override a Presidential veto. If the President decides to take no action and Congress is in session, the bill automatically becomes law in ten days. On the other hand, when Congress is not in session, if the President receives the bill and takes no action within two weeks, the bill is automatically vetoed. This is referred to as a pocket veto, because it is "put in the pocket" until Congress is back in session.

List of House and Senate Committees

House Committees	**Senate Committees:**
Agriculture	Agriculture, Nutrition, and Forestry
Appropriations	Appropriations
Armed Services	Armed Services
Budget	Budget
Education and Labor	Health, Education, Labor, and Pensions
Energy and Commerce	Energy and National Resources
	Select Committee on Ethics
Financial Services	Banking, Housing, and Urban Affairs
Foreign Affairs	Foreign Relations
Homeland Security	Homeland Security and Governmental Affairs
House Administration	
Permanent Select Committee on Intelligence	Select Committee on Intelligence
Judiciary	Judiciary
Natural Resources	Environmental and Public Works
Oversight and Government Reform	
Rules	Rules and Administration
Science and Technology	Commerce, Science, and Transportation
Small Business	Small Business and Entrepreneurship
Veteran's Affairs	Veterans' Affairs
Ways and Means	Finance
Standards of Official Conduct	
Transportation and Infrastructure	
Select Committee on Energy Independence and Global Warming	
	Special Committee on Aging
	Indian Affairs
Joint Committees of House and Senate	
Conference Committee	
Joint Economic Committee	
Joint Committee on Printing	
Joint Committee on Taxation	
Joint Commission on the Library of Congress	

2) **How to Track a Bill:** Once the bill is presented to the Legislature you can track the bill on the Library of Congress Thomas website (www.thomas.gov). This website provides details on bills, resolutions, current activity in congress, congressional records, schedules, calendars, treaties, and government resources. On the home page you can type in a bill number and you will find information about who is sponsoring this bill, bill summaries, the text of the bill, and the status of the bill. If you do not have access to the internet you can call the Office of Legislative Information on Capitol Hill to inquire about the status of a specific piece of legislation.

IV. GET INVOVLED

A. **Voting:** Voting is the duty of each eligible person. Voting is one of the most effective ways to make your voice heard. Never underestimate the power of your vote. Your vote is important and does matter, so mark your calendar for the next Election Day and cast your vote!

1) **Do I Qualify to Vote?**: To qualify to vote you must be:
   (i) A citizen of the United States,
   (ii) A resident of the state in which you are voting (unless you temporarily move to a new state to attend school),
   (iii) At least eighteen years old (most states require you to be eighteen at least thirty days prior to the election),
   (iv) Not be imprisoned or on parole for a felony, and
   (v) Not be deemed mentally incompetent by a court of law.

2) **Voter Registration:**
   (i) To obtain a voter registration form, visit your Secretary of State's website and fill out the online form. If you do not have access to the internet, you can call your Secretary of State's office or local department of motor vehicles to have a voter registration form mailed to you. Allow yourself enough time, because most states require you to register prior to the day of the election. Do not miss that deadline! For example, in California, your registration needs to be post marked at least two weeks before Election Day, whereas in Illinois, you must register twenty-five days prior to the election. After registering to vote, you will be informed of the location of your local polling place where you will go to vote on Election Day. It is important to note that sometimes the location can change so check with the Secretary of State's office before the election to confirm your polling place. Finally, when you go to the polls, bring with you a government-issued ID, just in case. If your residency address is different than what is printed on the ID, bring proof of residency with you (e.g., a piece of mail sent to you with your current address and your name on it).

   (ii) **Questions about Voting:** If you have questions at the polling place or need accommodations, ASK! If your question does not get answered, ASK AGAIN! Most of the people working at the polls are local volunteers who may not know everything about the voting process, so do not be afraid to ask more than one person until your question is answered or your accommodation is met. If you have difficulties with the polling place and would like to file a formal complaint you can call 1-800-345-VOTE.

   (iii) **Absentee Voting:** If you cannot make it to the polls on the day of the election you may qualify to vote "absentee." Contact your Secretary of State's Election Division to request an absentee ballot and ask about the requirements on voting absentee.

   (iv) **Help America Vote Act (HAVA):** Passed in 2002, the Help America Vote Act created an Election Assistance Commission to assist with Federal elections while implementing election standards for voter registration, updating voting machines and making polling places accessible to individuals with disabilities.

B. **Who are Your Elected Officials?:** It is essential to know your elected officials. For information on your federal elected officials go to www.house.gov and type in your zip code to find your U.S. Representative, and go to www.senate.gov to find your U.S. Senators. If

you do not have access to the internet, call the Capitol switchboard at (202) 224-3121 and ask who represents you. To find your local elected officials, go to www.votesmart.org.

C. **Write a Letter to Your Elected Officials:** Writing a letter is a great tool to communicate with your elected officials. You can get your point across without interruptions, and you can spend as much time as you need to be clear and articulate your point. This is an opportunity to tell your personal story, so if you are a cancer survivor or a caregiver let your legislators know. However, also remember when you are writing a letter to try to be as concise and clear as possible. Try to keep your letter to one page. This better ensures that your letter will be read in its entirety.

1) **Format:** When you are formatting your letter remember to add your own address, as envelopes often get thrown away. Also make sure that you have the proper addresses for your legislators. Before writing your letter, find out how your legislator stands on the issue that you are presenting. A good resource to find your representative's background information and voting history is Project Vote Smart at www.votesmart.org.

(i) In the first paragraph of your letter explain who you are and your main reason for writing the letter. Identify yourself as a constituent and member of the community. If you are talking about a specific bill identify it at the beginning of your letter. Use the name of legislation and the bill number, if possible. If you refer to an article published in the newspaper or another source, include a copy if possible. Always be reasonable and courteous, even if you do not agree with their position. If you have ideas on how a problem can be fixed, make suggestions. Do not be afraid to ask questions if you do not understand their point on an issue and always ask for a reply. Don't forget, your elected officials were elected to represent you!

(ii) **Fax or Email:** Faxing or emailing your letter is a better alternative to mailing. Faxing is the most popular and most legislators have their fax number posted. A benefit to faxing is that your letter will arrive within a matter of minutes. Remember to include your fax number or method in which you prefer a response. Although written letters are usually considered more personal, with heightened security at federal offices, the mail can take an extended period of time to reach the elected official.

(iii) See **APPENDIX LA1** for an example of what can be included in a letter to your elected official.

D. **Schedule a Meeting with Your Elected Official:** One of the most effective ways to lobby for an issue is to schedule an in-person meeting with your legislator. First, you will need to schedule a meeting in an advance by emailing, mailing, or faxing your legislator a letter requesting an appointment. If you do not know the name of the legislator's scheduler, call their office and ask.

1) See **APPENDIX LA2** for a sample letter requesting a meeting with your legislator.

2) **Follow-Up on Your Request:** After you send in your request via email, fax or mail, it is important to follow up with your legislator's scheduler. If you fax the request, follow up by phone within one or two days and if you submitted your request by mail, follow up within one or two weeks.

3) **Prepare for the Meeting:** You will need to prepare for the meeting, because you will have limited time to present your point. The average meeting time is between fifteen and twenty minutes. Make sure you pick one main issue to discuss. It is helpful to prepare a letter and/or materials to leave with your legislator after the meeting, recapping the issues you plan to discuss. Not only will this leave a reminder of your position with your legislator, it is great way to prepare yourself for the meeting. Before the appointment, research your legislator's position on the issue, research statistics on the issue, and plan to discuss how their position will personally affect you and/or your organization. If you are requesting that your legislator take action on an issue, be prepared to ask for a specific action. Identify other constituents or organizations that share your position. If appropriate, bring letters of their support with you to the meeting.

4) **Day of the Meeting:** On the day of the meeting dress professionally, be on time, and bring materials with you. Be aware that your legislator may become unavailable to meet with you at the scheduled date and time, so be prepared to meet in a different location or with a staff member. Do not be discouraged if you meet with the staff member instead of the legislator. Legislative staff cover specific issue areas and are more likely to be familiar with the issues you are raising and will brief the legislator on your concerns.

   (i) **At the Meeting:** When you begin your meeting, identify yourself as a constituent and start with a compliment. For example, thank them for their continued support on women's health issues or simply thank them for taking the time to meet with you. Remember to stick to the talking points you have prepared. Be informative, thorough, concise, and ask for what you want. Never argue over policies, but kindly express disappointment. If your legislator happens to ask for facts or information that you do not have, do not panic; just tell him/her that you will get back to them with the information. Do not be afraid to ask the legislator for a commitment or ask which way he/she is planning to vote on an issue. Finally, before the end of the meeting you can invite the legislator to your organization, to meet with specific members of the community, or to attend an upcoming event. Leave your materials, letter, and business card with the legislator. Also ask for the staff member's name and contact information that handles the relevant issues so that you can follow up with them if needed. Thank them again for taking the time to meet with you.

E. **Make a Telephone Call:** Making a telephone call is a great way to address your issue immediately. Most telephone calls with your legislator's office last only a few minutes, therefore, it is important to outline what you would like to say prior to the call. It is also highly unlikely that you will talk with your legislator directly; however, making a telephone call can be an extremely effective way to let your legislator know that constituents are interested in that particular issue without taking up too much time. Be prepared to leave a clear message if no one is available to talk.

   1) **What to Say on the Call:** Identify yourself as a constituent. Ask to speak to the legislator directly and if they are not available, which is likely, ask to speak to the staff person or legislative aide working on that issue. During the call be polite and concise. Let them know that you have an opinion on a certain issue or that you are supporting their position. If you are calling in regards to a specific bill, identify the bill and/or bill number. Ask for their support on the issue and ask for a response. If they ask for further information on the issue be prepared and willing to send it to them.

(i) See **APPENDIX LA3** for an example of what you can say when you call your legislator's office.

F. **Follow Up:** Always remember to follow up with your representative, whether you wrote a letter, made a telephone call, or had a face-to-face meeting. A great way of following up is to send a thank you note. When you write your thank you note, identify yourself with as much detail as possible. Tell them that you are a constituent and remind them of the time and date that you were last in contact. Make it clear exactly why you are thanking them. Include additional information if appropriate. Remember to include your contact information. If you did not receive a reply or information that was promised to you, send a letter reminding them. Following up and staying in touch will help you develop a long standing relationship with your legislator, and will keep you connected to developments or progress made regarding your concerns.

G. **Media Outreach:** Media outreach is a great way to reach many of your fellow constituents and lawmakers at the same time. One of the most basic and effective forms of media outreach is to write a letter to the editor of your local newspaper. Letters to the editor are read by community leaders and by politicians to gauge constituents' opinions on particular pieces of legislation. This is your chance to comment on articles published in the newspaper or introduce an issue that you would like to bring to public attention. Check with the newspaper for guidelines before formatting your letter. Letters that do not meet these guidelines may be disregarded. Keep your letter limited to 150 words or less. Include your name and address because most newspapers will not print anonymous letters (although they will not print this information). Always address your letter, "Dear Editor." To ensure that your letter has the best chance of being chosen for printing, talk about current issues such as pending legislation that you either support or oppose. Also be clear, brief, and to the point. Finally, do not be discouraged if your letter is not printed. Try again and remember that unpublished letters are still read by the editors, thus you are still making others aware that there is public interest in a particular issue.

1) **Talk Shows or Local Radio Stations:** Another way of reaching out to the media is calling a talk show or a local radio station. Make sure that when you call in to the show, the show's topic is relevant to your issue. Present a clear statement about the current cancer-related issue that concerns you, and talk about how it affects you and your community. If you know of public support that this concern has drawn, make others aware of this, too. You may also want to contact the producer of the show and let him/her know about the issue and urge them to cover it in their show.

2) **Press Releases:** Press releases are an effective tool to provide the media with a summarized version of your concern and relevant background information on it. Press releases are also a great opportunity for you to familiarize the media with information on your organization. For example, if your organization received an award for its public service, this would be a great way of letting other organizations and the media outlets know of your accomplishments. When writing a press release, keep your sentences short and paragraphs brief (journalistic style). Your press release should be no longer than one page. Try to write as objectively as possible. Include your contact information and a brief description of your organization at the end of the page.

(i) See **APPENDIX LA4** for a sample of a completed press release.

H. **Cancer Organizations:** Getting involved with an organization's established legislative advocacy effort is a great way to stay informed about issues that affect cancer survivors and their caregivers.

1) **Susan G. Komen for the Cure® Advocacy Alliance** is a non-partisan grassroots advocacy program designed to educate elected officials about breast cancer through community involvement. Their website, www.KomenAdvocacy.org, has information about current legislation and provides opportunities to join with them in lobbying for a change.

2) **LIVESTRONG (Lance Armstrong Foundation)** has advocacy tools to stay informed, raise awareness, and advocate for legislation that expands access to cancer screenings, treatment, and survivor care. To access their advocacy materials visit www.livestrong.org, click on the Get Involved tab, then click on Advocacy.

3) **American Cancer Society Cancer Action Network** is another non-profit, non-partisan advocacy organization dedicated to eliminating cancer as a major public health problem through voter education and issue campaigns aimed at influencing candidates and lawmakers to support laws and policies. Their website www.ACSCAN.org has the latest information and action reports on cancer-related legislative issues in your state.

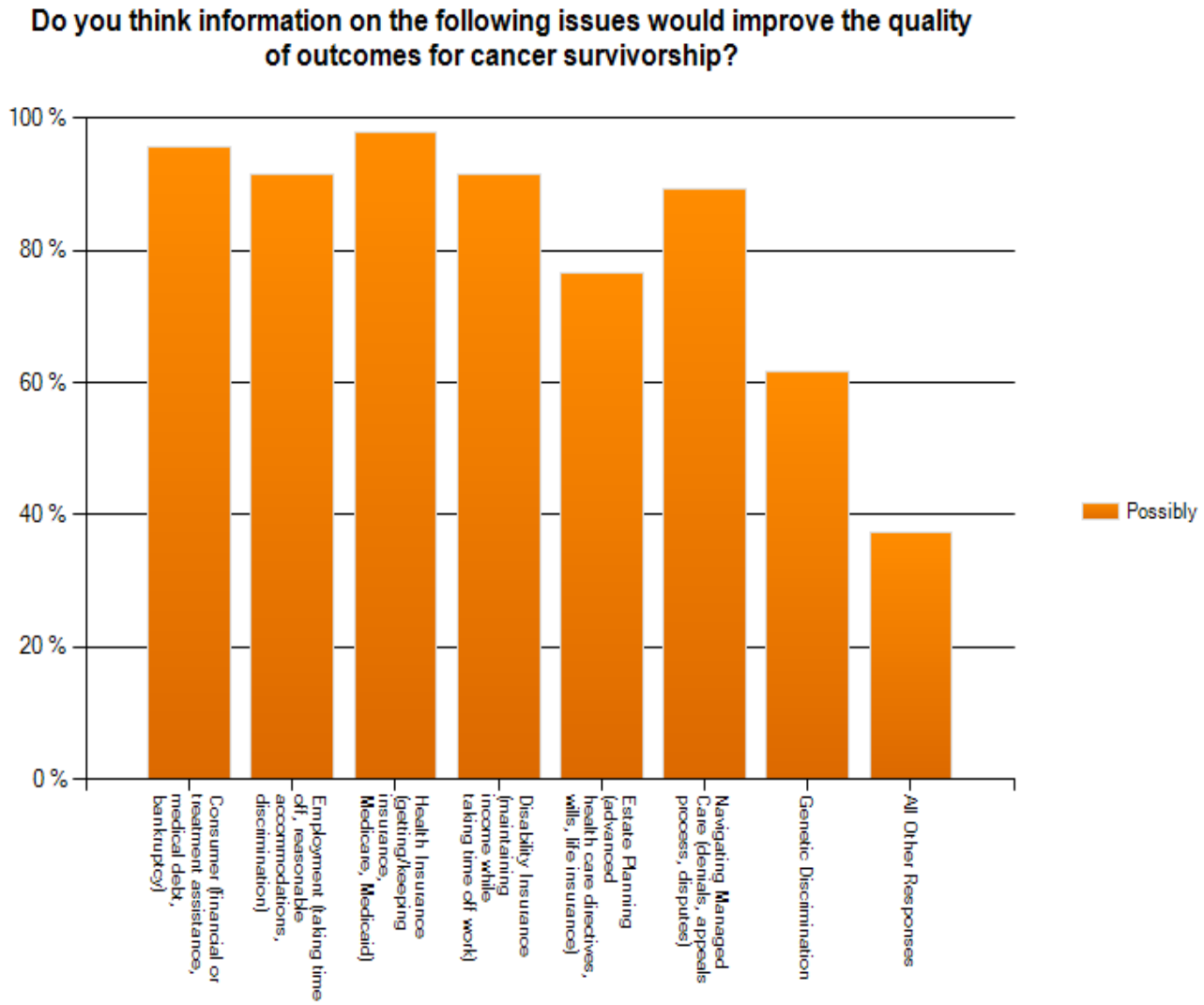
V. RESOURCES

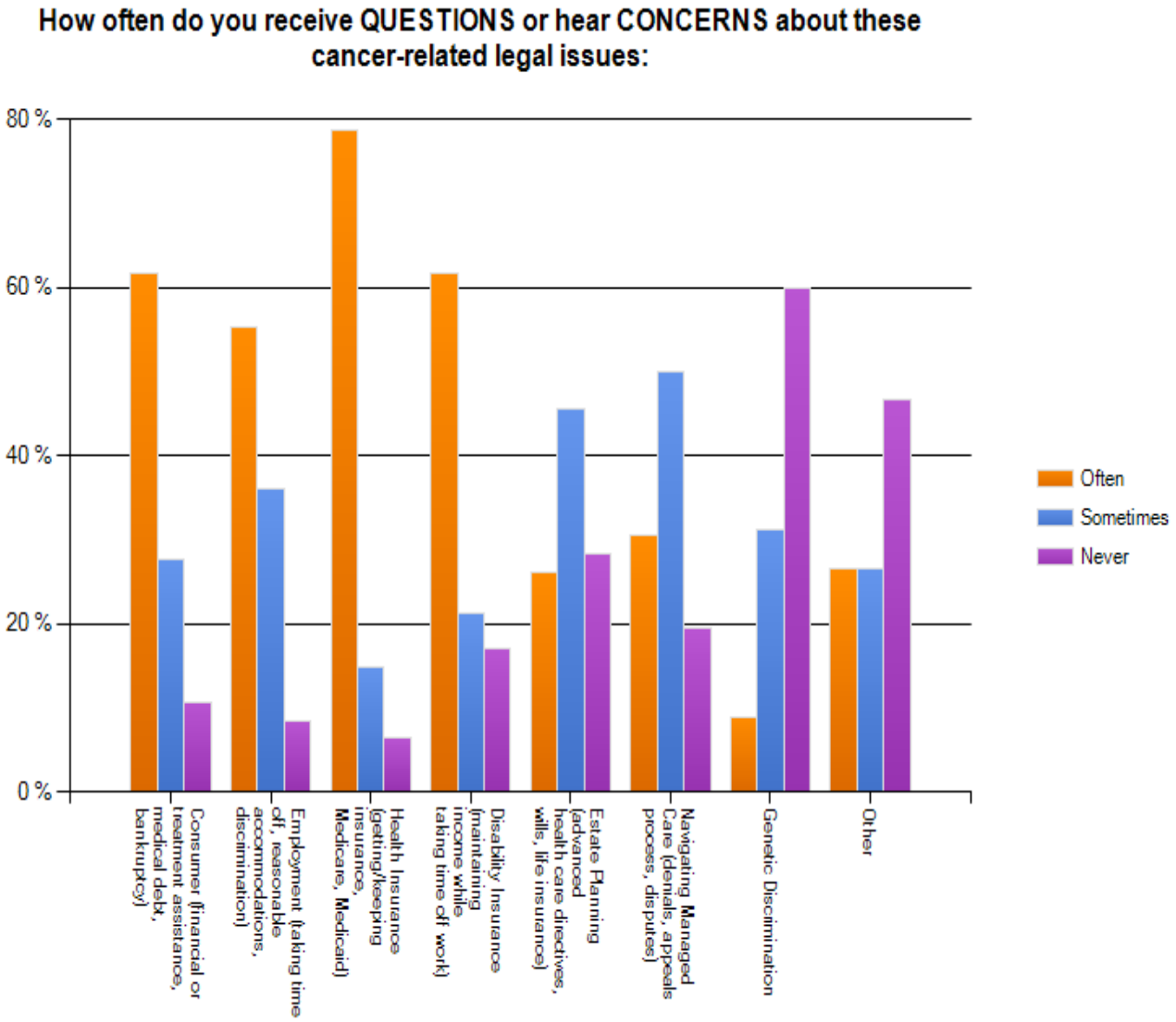
To find out who your U.S. Representatives are: www.house.gov Capitol Switchboard (202) 224-3121	**To find out who your U.S. Senators are:** www.senate.gov Capitol Switchboard (202) 224-3121
To find information about a specific federal bill: Office of Legislative Information on Capitol Hill (202) 225-7400 thomas.loc.org	**To find information about your elected officials:** Vote Smart www.votesmart.org League of Women Voters www.lwv.org
To obtain a voter registration form: www.fec.gov/votregis/vr.shtml	**For absentee voting information:** www.votesmart.org/voter_registration_resources.php
To participate in Susan G. Komen for the Cure® Advocacy Alliance efforts: www.KomenAdvocacy.org	**To participate in American Cancer Society Cancer Action Network advocacy efforts:** www.ACSCAN.org
To participate in LIVESTRONG advocacy efforts: www.livestrong.org	**To participate in Cancer Legal Resource Center advocacy efforts:** (213) 736-1455 or 1-866-THE-CLRC www.disabilityrightslegalcenter.org/about/LegislativeAdvocacy.cfm
For information on the Help America Vote Act (HAVA): www.fec.gov/hava/hava.htm	

SUMMARY

We hope that this manual will be a useful tool for you. Providing you with relevant information to help you advocate for the legal rights of your patients from a position of knowledge and strength, is our goal at the Cancer Legal Resource Center. If you or your patients have questions about cancer-related legal issues, please contact us at (866) THE–CLRC (866-843-2572) or www.CancerLegalResourceCenter.org.

Below, are graphs representing information collected from our Health Care Professional's survey on information that would improve the quality of outcomes for cancer survivorship, as well as common patient questions and concerns.





APPENDICES

INTRODUCTION:
Below are various sample letters, forms, and resources that have been referenced throughout this manual. These documents are designed to provide general information on the topics presented. They are provided with the understanding that the author is not engaged in rendering any legal or professional services by its publication or distribution. Although these materials were reviewed by a professional, they should not be used as a substitute for professional services. We recommend that individuals with questions or concerns about their legal options act immediately, as there may be specific legal time limitations that could affect the validity of any case and any possible legal options they may have. If you or your patients have additional questions, please contact the Cancer Legal Resource Center at (866) THE–CLRC or at www.CancerLegalResourceCenter.org.

APPENDIX ER1:
Sample Reasonable Accommodation Request Letter to an Employer

APPENDIX T1:
Sample Disability Determination Letter from a Health Care Provider

APPENDIX T2:
FMLA Certification for Health Care Professional for Employee's Serious Health Condition
FMLA Certification for Health Care Professional for Family Member's Serious Health Condition

APPENDIX HI1:
Sample Appeal Letter to a Health Insurance Company

APPENDIX EP1:
Estate Planning Glossary

APPENDIX EP2:
Personal Record File

APPENDIX EP3:
Taking Care of Business Form

APPENDIX LA1:
Sample Letter to Your Elected Official

APPENDIX LA2:
Sample Letter Requesting a Meeting with Your Legislator

APPENDIX LA3:
Sample Script When Calling Your Legislator's Office

APPENDIX LA4:
Sample of a Completed Press Release

APPENDIX ER1

Sample Reasonable Accommodation Request Letter to an Employer:

Date

Employer's Name
Employer's Address

Re: Request for Reasonable Accommodation

Dear (e.g. Supervisor, Manager, or Human Resources Personnel):

Content to consider in the body of the letter:
-Identify yourself as a person with cancer.

-State that you are requesting a reasonable accommodation under the Americans with Disabilities Act (ADA), § 501, 503, or 504 of the Rehabilitation Act.

-Identify your specific job tasks, which are causing you difficulty.

-Identify your accommodation idea.

-Request your employer's accommodations ideas.

*-Refer to attached medical documentation if appropriate.***

-Ask your employer to respond to your request within a reasonable amount of time.

Sincerely,

Your signature
Your printed name
Your address
Your phone number or email address

Cc: to appropriate individuals

**You may wish to attach any medical information to your letter to help establish that you are a person with a disability and to document your need for an accommodation.

APPENDIX T1

Sample Disability Determination Letter from a Health Care Provider:

March 8, 2010

Brian Smith, MD
Oncologist, State University Cancer Center
1234 University Road
Big City, State 09876

Re: Miss Jane Jones

To Whom It May Concern:

My name is Dr. Brian Smith and I am an oncologist at the State University Cancer Center. I have been treating Miss Jane Jones for over a year and know her well.

According to my records (see attachment), I first met Miss Jones on January 15, 2009. Miss Jones was originally diagnosed with breast cancer, which has since metastasized to her lungs over the last six months. On February 3, 2009, I started Miss Jones on chemotherapy (one time per week for 12 weeks), as well as radiation treatment (one time per week for 6 weeks). Based on my chart notes, the treatment temporarily stopped the growth of cancer found in Miss Jones' left breast. However, upon further assessment, including x-rays on September 15, 2009, I noticed metastatic tumors in Miss Jones' lungs. On September 29, 2009, I performed a biopsy. Approximately one week later, Dr. Renee Reed, a pathologist at State University Cancer Center, determined that Miss Jones' cancer had spread (see lab results attached). Beginning October 28, 2009, my office began administering an aggressive combination of chemotherapy and radiation therapy.

As of February 25, 2009, my last office visit with Miss Jones, the patient has several limitations in the following areas: sitting, walking, focusing, concentrating, and lifting. In assessing Miss Jones' current condition, she cannot stand for more than 20 minutes at a time. Miss Jones needs considerable rest periods throughout the day and is often too sick from her cancer treatment to attend work 3-4 days/week. Additionally, as a result of Miss Jones' secondary cancer diagnosis, she has developed severe depression, to which she has already been referred to a psychologist to help treat this condition.

It is my professional opinion that Miss Jane Jones has a disability qualifying her for Social Security disability benefits.

If you have further questions, please contact me.

Best,

Brian Smith, MD.

Dr. Brian Smith

Certification of Health Care Provider for Employee's Serious Health Condition (Family and Medical Leave Act)

U.S. Department of Labor
Employment Standards Administration
Wage and Hour Division

U.S. Wage and Hour Division

OMB Control Number: 1215-0181
Expires: 12/31/2011

SECTION I: For Completion by the EMPLOYER

INSTRUCTIONS to the EMPLOYER: The Family and Medical Leave Act (FMLA) provides that an employer may require an employee seeking FMLA protections because of a need for leave due to a serious health condition to submit a medical certification issued by the employee's health care provider. Please complete Section I before giving this form to your employee. Your response is voluntary. While you are not required to use this form, you may not ask the employee to provide more information than allowed under the FMLA regulations, 29 C.F.R. §§ 825.306-825.308. Employers must generally maintain records and documents relating to medical certifications, recertifications, or medical histories of employees created for FMLA purposes as confidential medical records in separate files/records from the usual personnel files and in accordance with 29 C.F.R. § 1630.14(c)(1), if the Americans with Disabilities Act applies.

Employer name and contact: _____

Employee's job title: _____ Regular work schedule: _____

Employee's essential job functions: _____

_____

Check if job description is attached: _____

SECTION II: For Completion by the EMPLOYEE

INSTRUCTIONS to the EMPLOYEE: Please complete Section II before giving this form to your medical provider. The FMLA permits an employer to require that you submit a timely, complete, and sufficient medical certification to support a request for FMLA leave due to your own serious health condition. If requested by your employer, your response is required to obtain or retain the benefit of FMLA protections. 29 U.S.C. §§ 2613, 2614(c)(3). Failure to provide a complete and sufficient medical certification may result in a denial of your FMLA request. 20 C.F.R. § 825.313. Your employer must give you at least 15 calendar days to return this form. 29 C.F.R. § 825.305(b).

Your name: _____
First Middle Last

SECTION III: For Completion by the HEALTH CARE PROVIDER

INSTRUCTIONS to the HEALTH CARE PROVIDER: Your patient has requested leave under the FMLA. Answer, fully and completely, all applicable parts. Several questions seek a response as to the frequency or duration of a condition, treatment, etc. Your answer should be your best estimate based upon your medical knowledge, experience, and examination of the patient. Be as specific as you can; terms such as "lifetime," "unknown," or "indeterminate" may not be sufficient to determine FMLA coverage. Limit your responses to the condition for which the employee is seeking leave. Please be sure to sign the form on the last page.

Provider's name and business address: _____

Type of practice / Medical specialty: _____

Telephone: (_____)_____ Fax:(_____)_____

CONTINUED ON NEXT PAGE

PART A: MEDICAL FACTS

1. Approximate date condition commenced: _____

   Probable duration of condition: _____

   Mark below as applicable:
   Was the patient admitted for an overnight stay in a hospital, hospice, or residential medical care facility?
   ___No ___Yes. If so, dates of admission:

   _____

   Date(s) you treated the patient for condition:

   _____

   Will the patient need to have treatment visits at least twice per year due to the condition? ___No ___ Yes.

   Was medication, other than over-the-counter medication, prescribed? ___No ___Yes.

   Was the patient referred to other health care provider(s) for evaluation or treatment (e.g., physical therapist)?
   ____No ____Yes. If so, state the nature of such treatments and expected duration of treatment:

   _____

2. Is the medical condition pregnancy? ___No ___Yes. If so, expected delivery date: _____

3. Use the information provided by the employer in Section I to answer this question. If the employer fails to provide a list of the employee's essential functions or a job description, answer these questions based upon the employee's own description of his/her job functions.

   Is the employee unable to perform any of his/her job functions due to the condition: ____ No ____ Yes.

   If so, identify the job functions the employee is unable to perform:

   _____

4. Describe other relevant medical facts, if any, related to the condition for which the employee seeks leave (such medical facts may include symptoms, diagnosis, or any regimen of continuing treatment such as the use of specialized equipment):

   _____

   _____

   _____

   _____

   _____

   _____

   _____

PART B: AMOUNT OF LEAVE NEEDED

5. Will the employee be incapacitated for a single continuous period of time due to his/her medical condition, including any time for treatment and recovery? ___No ___Yes.

   If so, estimate the beginning and ending dates for the period of incapacity: _____

6. Will the employee need to attend follow-up treatment appointments or work part-time or on a reduced schedule because of the employee's medical condition? ___No ___Yes.

   If so, are the treatments or the reduced number of hours of work medically necessary? ___No ___Yes.

   Estimate treatment schedule, if any, including the dates of any scheduled appointments and the time required for each appointment, including any recovery period:

   _____

   Estimate the part-time or reduced work schedule the employee needs, if any:

   _____ hour(s) per day; _____ days per week from _____ through _____

7. Will the condition cause episodic flare-ups periodically preventing the employee from performing his/her job functions? ____No ____Yes.

   Is it medically necessary for the employee to be absent from work during the flare-ups? ____ No ____Yes. If so, explain:

   _____

   _____

   Based upon the patient's medical history and your knowledge of the medical condition, estimate the frequency of flare-ups and the duration of related incapacity that the patient may have over the next 6 months (e.g., 1 episode every 3 months lasting 1-2 days):

   Frequency: _____ times per _____ week(s) _____ month(s)

   Duration: _____ hours or ___ day(s) per episode

ADDITIONAL INFORMATION: IDENTIFY QUESTION NUMBER WITH YOUR ADDITIONAL ANSWER.

_____

_____

_____

_____

_____

_____

Signature of Health Care Provider **Date**

PAPERWORK REDUCTION ACT NOTICE AND PUBLIC BURDEN STATEMENT

If submitted, it is mandatory for employers to retain a copy of this disclosure in their records for three years. 29 U.S.C. § 2616; 29 C.F.R. § 825.500. Persons are not required to respond to this collection of information unless it displays a currently valid OMB control number. The Department of Labor estimates that it will take an average of 20 minutes for respondents to complete this collection of information, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. If you have any comments regarding this burden estimate or any other aspect of this collection information, including suggestions for reducing this burden, send them to the Administrator, Wage and Hour Division, U.S. Department of Labor, Room S-3502, 200 Constitution Ave., NW, Washington, DC 20210. **DO NOT SEND COMPLETED FORM TO THE DEPARTMENT OF LABOR; RETURN TO THE PATIENT.**

Certification of Health Care Provider for Family Member's Serious Health Condition (Family and Medical Leave Act)

U.S. Department of Labor
Employment Standards Administration
Wage and Hour Division

OMB Control Number: 1215-0181
Expires: 12/31/2011

SECTION I: For Completion by the EMPLOYER

INSTRUCTIONS to the EMPLOYER: The Family and Medical Leave Act (FMLA) provides that an employer may require an employee seeking FMLA protections because of a need for leave to care for a covered family member with a serious health condition to submit a medical certification issued by the health care provider of the covered family member. Please complete Section I before giving this form to your employee. Your response is voluntary. While you are not required to use this form, you may not ask the employee to provide more information than allowed under the FMLA regulations, 29 C.F.R. §§ 825.306-825.308. Employers must generally maintain records and documents relating to medical certifications, recertifications, or medical histories of employees' family members, created for FMLA purposes as confidential medical records in separate files/records from the usual personnel files and in accordance with 29 C.F.R. § 1630.14(c)(1), if the Americans with Disabilities Act applies.

Employer name and contact: _____

SECTION II: For Completion by the EMPLOYEE

INSTRUCTIONS to the EMPLOYEE: Please complete Section II before giving this form to your family member or his/her medical provider. The FMLA permits an employer to require that you submit a timely, complete, and sufficient medical certification to support a request for FMLA leave to care for a covered family member with a serious health condition. If requested by your employer, your response is required to obtain or retain the benefit of FMLA protections. 29 U.S.C. §§ 2613, 2614(c)(3). Failure to provide a complete and sufficient medical certification may result in a denial of your FMLA request. 29 C.F.R. § 825.313. Your employer must give you at least 15 calendar days to return this form to your employer. 29 C.F.R. § 825.305.

Your name: _____
First Middle Last

Name of family member for whom you will provide care: _____
First Middle Last

Relationship of family member to you: _____

If family member is your son or daughter, date of birth: _____

Describe care you will provide to your family member and estimate leave needed to provide care:

_____

_____

_____

_____ _____
Employee Signature Date

CONTINUED ON NEXT PAGE

SECTION III: For Completion by the HEALTH CARE PROVIDER

INSTRUCTIONS to the HEALTH CARE PROVIDER: The employee listed above has requested leave under the FMLA to care for your patient. Answer, fully and completely, all applicable parts below. Several questions seek a response as to the frequency or duration of a condition, treatment, etc. Your answer should be your best estimate based upon your medical knowledge, experience, and examination of the patient. Be as specific as you can; terms such as "lifetime," "unknown," or "indeterminate" may not be sufficient to determine FMLA coverage. Limit your responses to the condition for which the patient needs leave. Page 3 provides space for additional information, should you need it. Please be sure to sign the form on the last page.

Provider's name and business address:_____

Type of practice / Medical specialty: _____

Telephone: (_____)_____ Fax:(_____)_____

PART A: MEDICAL FACTS

1. Approximate date condition commenced: _____

   Probable duration of condition: _____

   Was the patient admitted for an overnight stay in a hospital, hospice, or residential medical care facility?
   ___No ___Yes. If so, dates of admission: _____

   Date(s) you treated the patient for condition: _____

   Was medication, other than over-the-counter medication, prescribed? ___No ___Yes.

   Will the patient need to have treatment visits at least twice per year due to the condition? ___No ____ Yes

   Was the patient referred to other health care provider(s) for evaluation or treatment (e.g., physical therapist)?
   ____ No ____Yes. If so, state the nature of such treatments and expected duration of treatment:

   _____

   _____

2. Is the medical condition pregnancy? ___No ___Yes. If so, expected delivery date: _____

3. Describe other relevant medical facts, if any, related to the condition for which the patient needs care (such medical facts may include symptoms, diagnosis, or any regimen of continuing treatment such as the use of specialized equipment):

_____

_____

_____

_____

PART B: AMOUNT OF CARE NEEDED: When answering these questions, keep in mind that your patient's need for care by the employee seeking leave may include assistance with basic medical, hygienic, nutritional, safety or transportation needs, or the provision of physical or psychological care:

4. Will the patient be incapacitated for a single continuous period of time, including any time for treatment and recovery? ___No ___Yes.

   Estimate the beginning and ending dates for the period of incapacity: _____

   During this time, will the patient need care? __ No __ Yes.

   Explain the care needed by the patient and why such care is medically necessary:

   _____

   _____

   _____

   _____

   _____

5. Will the patient require follow-up treatments, including any time for recovery? ___No ___Yes.

   Estimate treatment schedule, if any, including the dates of any scheduled appointments and the time required for each appointment, including any recovery period:

   _____

   Explain the care needed by the patient, and why such care is medically necessary: _____

   _____

6. Will the patient require care on an intermittent or reduced schedule basis, including any time for recovery? __ No __ Yes.

   Estimate the hours the patient needs care on an intermittent basis, if any:

   _____ hour(s) per day; _____ days per week from _____ through _____

   Explain the care needed by the patient, and why such care is medically necessary:

   _____

   _____

   _____

   _____

7. Will the condition cause episodic flare-ups periodically preventing the patient from participating in normal daily activities? ____No ____Yes.

   Based upon the patient's medical history and your knowledge of the medical condition, estimate the frequency of flare-ups and the duration of related incapacity that the patient may have over the next 6 months (e.g., 1 episode every 3 months lasting 1-2 days):

   Frequency: _____ times per _____ week(s) _____ month(s)

   Duration: _____ hours or ___ day(s) per episode

   Does the patient need care during these flare-ups? ____ No ____ Yes.

   Explain the care needed by the patient, and why such care is medically necessary: _____

   _____

   _____

   _____

   _____

ADDITIONAL INFORMATION: IDENTIFY QUESTION NUMBER WITH YOUR ADDITIONAL ANSWER.

_____

_____

_____

_____

_____

_____

_____ _____

Signature of Health Care Provider **Date**

PAPERWORK REDUCTION ACT NOTICE AND PUBLIC BURDEN STATEMENT

If submitted, it is mandatory for employers to retain a copy of this disclosure in their records for three years. 29 U.S.C. § 2616; 29 C.F.R. § 825.500. Persons are not required to respond to this collection of information unless it displays a currently valid OMB control number. The Department of Labor estimates that it will take an average of 20 minutes for respondents to complete this collection of information, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. If you have any comments regarding this burden estimate or any other aspect of this collection information, including suggestions for reducing this burden, send them to the Administrator, Wage and Hour Division, U.S. Department of Labor, Room S-3502, 200 Constitution Ave., NW, Washington, DC 20210.
DO NOT SEND COMPLETED FORM TO THE DEPARTMENT OF LABOR; RETURN TO THE PATIENT.

APPENDIX HI1

Below is a sample letter appealing an insurance company's decision to deny treatment or to refuse to cover the cost of treatment:

Date
Name of Health Care Representative
Health Plan Name
Address
City, State, Zip Code

Re: Patient's Name, Type of Coverage, Group/Policy Number

Dear _____ (Health Care Representative):

On _____ (date of diagnosis), _____ (Patient's Name), a beneficiary of your health insurance policy _____ (Group Number/Policy Number), was diagnosed with _____ (diagnosis). According to _____'s (Patient's name) physician, Dr. _____ (Physician's name), _____ (Patient's name) requires _____ (treatment that the insurance company is denying coverage for) as part of the treatment for _____ (diagnosis).

According to a letter _____ (Insurance Company's name) sent to _____ (Patient's name) on _____(date of denial letter), _____ (treatment requesting) is not covered under _____ (Patient's name) insurance plan because _____ (explanation written in denial letter).

This letter serves as an appeal to _____ (Insurance Company's name) to _____ (what you are requesting Insurance company to do – e.g., pay for treatment). Dr. _____ (Physician's name) has also submitted an appeal on behalf of _____ (Patient's name), including details of his/her medical condition, copies of his/her medical records, and a thorough explanation as to why _____ (treatment requesting) is necessary. Based on the literature _____ (Insurance Company's name) sent to _____ (Patient's name) upon enrolling in this plan, _____ (Insurance Company's name) has _____ (number of days listed in Insurance Company's handbook) days to respond to this appeal.

Please reconsider your previous decision to _____ (what the Insurance company is refusing to do), as this medical procedure is necessary in _____ (Patient's name) treatment of _____ (diagnosis).

Sincerely,

Name
Address

Cc: _____ (anyone else you are sending this letter to)
Enclosures

Below is a sample of a completed letter appealing an insurance company's decision:

January 1, 2008

Mr. Joe Health Care Representative
ABC Health Care Insurance Company
100 Main Street
Big City, CA 90000

Re: Jane Smith, PPO, Group 123 / Policy Number ABC456

Dear Mr. Health Care Representative:

On April 1, 2007, Jane Smith, a beneficiary of your health insurance policy number ABC456 was diagnosed with breast cancer. According to Jane Smith's physician, Dr. Robert Feel Good, Jane requires a mastectomy as part of the treatment for her cancer diagnosis.

According to a letter ABC Health care Insurance Company sent to Jane Smith on December 1, 2007, a bilateral mastectomy is not covered under Jane Smith's insurance plan because her diagnosis is considered a pre-existing medical condition.

This letter serves as an appeal to ABC Health care Insurance Company to pay for Jane Smith's mastectomy, which was performed on October 1, 2007. Dr. Feel Good has also submitted an appeal on behalf of Jane Smith, including details of her medical condition, copies of her medical records, and a thorough explanation as to why the mastectomy is necessary and why her diagnosis should not be considered a pre-existing medical condition. Based on the literature ABC Health care Insurance Company sent to Jane Smith upon enrolling in this plan, ABC Health care Insurance Company has 30 days to respond to this appeal.

Please reconsider your previous decision to deny coverage for the mastectomy, as this medical procedure is necessary in Jane Smith's treatment of breast cancer.

Sincerely,

Fred Smith
500 S. Longroad Way
Small Town, CA 10000

Cc: Dr. Robert Feel Good

Enclosures

APPENDIX EP1

Disability Rights Legal Center
CLRC
Cancer Legal Resource Center

CLRC National Office
919 Albany Street • Los Angeles, CA 90015
CLRC Midwest Regional Office:
PO Box 31185 • Chicago, IL 60631
Toll Free: 866.THE.CLRC (866.843.2572)
TDD: 213.736.8310 Fax: 213.736.1428
Email: CLRC@LLS.edu
Web: www.CancerLegalResourceCenter.org

The CLRC is a joint program of the Disability Rights Legal Center & Loyola Law School Los Angeles

Estate Planning Glossary

The Cancer Legal Resource Center has designed this information sheet to answer commonly asked questions. However, this information may be just a starting point for you to find out additional information. Please feel free to contact the Cancer Legal Resource Center at (866) THE-CLRC if you need additional information or to answer other questions you may have.

Beneficiary: An individual who receives income or assets from a trust, life insurance policy, a will, etc.

Community Property: Generally, income or property acquired by either spouse during a marriage, except by gift or inheritance, in community property states only. Contact an attorney to determine whether the state in which you live is a community property state.

Conservatee: The incapacitated person for whom a conservatorship has been established.

Conservator: An individual who is appointed by the court to act on behalf of an incapacitated person.

Conservatorship: A court proceeding in which the court supervises the management of an incapacitated person's finances and/or personal care.

Estate: The property that is the subject of a trust or probate proceeding.

Guardian of the Person: A person appointed by the court to take care of a child under 18 years old.

Guardian of the Estate: A person appointed by the court to manage the assets and finances of a child under 18 years old. This person can be the same person who is appointed the Guardian of the Person.

Health Care Agent: A person appointed by you to make your health care decisions if you are unable to do so.

Patient Self-Determination Act (PSDA): The 1990 Patient Self-Determination Act encourages all people to make choices and decisions now about the types and extent of medical care they want to accept or refuse should they become unable to make those decisions due to illness. The PSDA also requires that all hospitals, long-term care facilities, and home health agencies that receive Medicare and Medicaid reimbursement to ask you whether you have an advance health care directive and requires them to recognize it.

APPENDIX EP2

Disability Rights Legal Center
CLRC
Cancer Legal Resource Center

CLRC National Office
919 Albany Street • Los Angeles, CA 90015
CLRC Midwest Regional Office:
PO Box 31185 • Chicago, IL 60631
Toll Free: 866.THE.CLRC (866.843.2572)
TDD: 213.736.8310 Fax: 213.736.1428
Email: CLRC@LLS.edu
Web: www.CancerLegalResourceCenter.org

The CLRC is a joint program of the Disability Rights Legal Center & Loyola Law School Los Angeles

Personal Record File

This Personal Record File will be helpful to your loved ones by gathering in one place, copies of important records and documents they will need. The items on the list can be kept in an envelope or other document holder and marked to show the contents and kept in a place known to your loved ones. Originals should be kept in a fireproof place, such as a safe deposit box, if appropriate.

1. Will, with name, address, and phone number of attorney.
2. Birth certificates for yourself, spouse, and children.
3. Marriage license and/or proof of divorce, if applicable.
4. Drivers' license and social security card.
5. Life, medical, dental, property, and auto insurance policies, with name, address, and phone number of insurance agent(s).
6. Proof of automobile ownership and registration, license plate number, and VIN number.
7. Real estate deed, title policies, mortgages, record of payments, tax receipts, receipts for improvements, etc.
8. Names of banks, savings, retirement and securities accounts, loans, and their account numbers.
9. Computer, voicemail, and internet user names and passwords for financial accounts, etc.
10. List of other assets and locations (including loans, deeds of trust and accounts receivable).
11. Safe-deposit box key, name and address of bank, and box number.
12. Name of credit card creditors and account numbers.
13. Veteran's discharge paper (DD-214).
14. Income tax returns for the last three years, and name and address of persons preparing the returns.
15. Name and address of broker or stock certificates and bonds you own (and purchase slips or other records of cost/date of purchase).
16. Receipts/appraisals for items of substantial value such as jewelry, furs, furniture, art, etc.
17. Name, address, and telephone number of your employer and/or supervisor.
18. Documentation of retirement benefits, pension plan, and profit sharing.
19. Business records.
20. List of close relatives, addresses, and telephone numbers.
21. Funeral or memorial instructions.
22. General instructions to surviving spouse or children, including a list of advisers.
23. **Any other information you would like to include.**

APPENDIX EP3

Disability Rights Legal Center
CLRC
Cancer Legal Resource Center

CLRC National Office
919 Albany Street • Los Angeles, CA 90015
CLRC Midwest Regional Office:
PO Box 31185 • Chicago, IL 60631
Toll Free: 866.THE.CLRC (866.843.2572)
TDD: 213.736.8310 Fax: 213.736.1428
Email: CLRC@LLS.edu
Web: www.CancerLegalResourceCenter.org

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"Taking Care of Business"

The Cancer Legal Resource Center has designed this information sheet so that you can collect and keep personal and financial information in one place. Keep it in a safe place known to your spouse and other loved ones. Update it as needed. And, feel free to modify and/or change it to meet your particular and special needs.

1. GENERAL INFORMATION

Name: _____

Home Address: _____

_____

Phone: (Home) _____ (Work) _____

Employer/Work Address: _____

_____

Work Telephone: _____

Date of Marriage: _____

Date of Separation/Divorce (if applicable): _____

Children of this Marriage:

Name	Date of Birth
_____	_____
_____	_____

Other Children:

Name	Date of Birth
_____	_____
_____	_____

2. INVENTORY OF ASSETS

(Assets include things like homes, real estate, investments, business interests, bank accounts, pensions, retirement benefits, life insurance policies, lines of credits, and personal property such as vehicles, jewelry and furniture.)

a. Real Property

i. **Type of Property and Address:**

_____

Lender (s) [Name and Address]: _____

Account Number: _____ Date of Purchase: _____

Amount of Debt Owed: _____

Your estimate of the current selling price: _____

Your estimate of the equity in the property: _____

What is your plan for the use or sale of the property: _____

Other issues regarding the property: _____

ii. **Type of Property and Address:**

_____

Lender (s) [Name and Address]: _____

Account Number: _____ Date of Purchase: _____

Amount of Debt Owed: _____

Your estimate of the current selling price: _____

Your estimate of the equity in the property: _____

What is your plan for the use or sale of the property: _____

Other issues regarding the property: _____

b. Financial Assets

i. Life Insurance

Name/Address of Insurance Co.: _____

Phone: _____ Policy Number: _____

Face Value: _____ Cash Surrender Amount: _____

Insured Party: _____

Beneficiaries: _____
Discussion Issues Regarding Life Insurance: _____

Name/Address of Insurance Co.: _____

Phone: _____ Policy Number: _____

Face Value: _____ Cash Surrender Amount: _____

Insured Party: _____

Beneficiaries: _____

Discussion Issues Regarding Life Insurance: _____

ii. Pensions, Retirement Benefits, Profit Sharing

Type of Benefit: _____

Name of Administrator: _____

Address: _____

Phone: _____ Plan Number: _____

Current Amount: _____ In the Name Of: _____

Beneficiaries: _____

Type of Benefit: _____

Name of Administrator: _____

Address: _____

Phone: _____ Plan Number: _____

Current Amount: _____ In the Name Of: _____

Beneficiaries: _____

iii. Bank Accounts, Investment Accounts, Lines of Credit, Stock Certificates, Etc.

Type of Account/Name of Institution/Account Number: _____

Balance: _____ Maturity Date: _____

Number of Shares (if applicable): _____

Special Circumstances/Discussion Issues: _____

Type of Account/Name of Institution/Account Number: _____

Balance: _____ Maturity Date: _____

Number of Shares (if applicable): _____

Special Circumstances/Discussion Issues: _____

Type of Account/Name of Institution/Account Number: _____

Balance: _____ Maturity Date: _____

Number of Shares (if applicable): _____

Special Circumstances/Discussion Issues: _____

iv. Business Interests

Name and Nature of Business: _____

Ownership/Partnership/Name: _____

Date Acquired: _____ Salary: _____

Buy/Sell Agreement: _____ Insurance Policies: _____

Special Circumstances/Discussion Issues: _____

Name and Nature of Business: _____

Ownership/Partnership/Name: _____

Date Acquired: _____ Salary: _____

Buy/Sell Agreement: _____ Insurance Policies: _____

Special Circumstances/Discussion Issues: _____

c. Personal Property

(Personal property includes vehicles, jewelry, furniture, appliances, art work, etc.)

Item:	Location of Item:
1.	1.
2.	2.
3.	3.
4.	4.

5. 5.

6. 6.

7. 7.

3. INVENTORY OF DEBTS, CREDIT CARDS, ETC.

Type of Account Number Name of Creditor

_____ _____ _____

Monthly Payment Amount Owed

_____ _____

Type of Account Number Name of Creditor

_____ _____ _____

Monthly Payment Amount Owed

_____ _____

Type of Account Number Name of Creditor

_____ _____ _____

Monthly Payment Amount Owed

_____ _____

Type of Account Number Name of Creditor

_____ _____ _____

Monthly Payment Amount Owed

_____ _____

Type of Account Number Name of Creditor

_____ _____ _____

Monthly Payment Amount Owed

_____ _____

APPENDIX LA1

Sample letter to your Elected Official:

Date

The Honorable (insert full name)
(Insert body of government)
(Insert address)

Dear _____(insert title) (insert last name),

I am a constituent and live at _____(insert your address). I am writing to you to ask _____ (purpose of letter – i.e. if you have a specific bill number mention it here).

_____ (describe your personal story; state why you have been affected by this situation; why the bill is important to you; etc).

Your support would make a difference in the lives of your constituents like me. Please _____ (insert purpose of letter). I would appreciate if you would let me know of your action in this matter.

Sincerely,

Your full name
Your full address (establishes that you are a constituent)
Your phone number

Sample of a completed letter to your Elected Official:

January 1, 2008

The Honorable Joe Lawmaker
U.S. House of Representatives
202 Longworth House Office Building
Washington, D.C. 20515

Dear Representative Lawmaker:

I am a constituent and live at 234 Creek Lane, in Lakeview, California. I am writing to ask you to vote in support of H.R. 405, which increases funding for cancer research through the National Cancer Institute.

I am a breast cancer survivor and many members of my family have been touched by cancer, as well. It is so important to us that we do everything that we can to support the search for a cure for cancer, so that no one else has to go through what we did.

Your support would make a difference in the lives of your constituents like me. Please support H.R. 405. I would appreciate it if you would let me know of your action in this matter.

Sincerely,

Jane Q. Public
234 Creek Lane
Lakeview, CA 90000
(888) 555-1000

APPENDIX LA2

Sample letter requesting a meeting with your legislator:

Date

VIA FACSIMILE: (enter fax number)

To: The Honorable (insert full name)
(Insert government body)
(Insert address)

Cc: Name of scheduler

Re: Meeting Request for (insert dates you are available to meet)

I am respectfully requesting a meeting with you on _____ (insert dates you are available to meet) between _____ (time you are available to meet). I am _____ (briefly introduce yourself or your organization).

_____ (discuss reasons for your meeting).

_____ (if you are bringing other advocates with you, let your representative know here).

I/We will contact your office to discuss this appointment. You can reach me at _____ (insert phone number) or _____ (email address) to arrange the appointment.

Thank you for your consideration of this request.

Sincerely,

Your Full Name
(Insert constituent or name of organization and position)
Your Full Address
Your Phone Number

Sample of a completed meeting request letter:

January 1, 2008

VIA FACSIMILE: (202) 555-1000

To: The Honorable Joe Lawmaker
U.S. House of Representatives
202 Longworth House Office Building
Washington, D.C. 20515

Cc: Ryan Scheduler

Re: Meeting Request for April 25, 2008

I am respectfully requesting a meeting with you on April 25, 2008, or April 26, 2008, between 9:00 am – 5:00 pm. I am a constituent and live at 234 Creek Lane in Lakeview, California 90000.

I would like to discuss the recently introduced H.R. 405, which increases funding for cancer research through the National Cancer Institute.

I am a breast cancer survivor and many members of my family have been touched by cancer as well. It is so important that we do everything that we can to support the search for a cure for cancer, so that no one else has to go through what we did.

I will contact your office to discuss this appointment. You can also reach met at (888) 555-1000 or at jane.q.public@email.com to arrange this appointment.

Thank you for your consideration of this request.

Sincerely,

Jane Q. Public
234 Creek Lake
Lakeview, CA 90000
(888) 555-1000

APPENDIX LA3

This is an example of what you can say when you call your legislator's office:

"Hi. My name is [name]. I am a constituent and I live [and/or work] in [town, city, county, state]. I am calling in regards to bill [bill number], [briefly describe the bill]. [Describe why the bill impacts you and your community]. I urge [name of legislator] to support bill [bill number]. Can you tell me how he/she is planning to vote on this bill?

If you have questions I can provide you with further information on this issue. Thank you for your time."

Sample telephone script:

"My name is Jane Public. I am a constituent and I live in Lakeview, CA. I am calling in regards to H.R. 405, which increases funding for cancer research through the National Cancer Institute. This bill is critical to continue effective cancer research. Cancer kills nearly 500,000 people each year. I urge Representative Lawmaker to support H.R. 405. Can you tell me how he is planning to vote on this bill?

If you have questions I can provide you will further information on this issue. Thank you for your time."

APPENDIX LA4

Sample of a completed press release:

Disability Rights Legal Center
CLRC
Cancer Legal Resource Center

For Immediate Release:
March 27, 2009

Contact:
Paula Pearlman: 213.736.8362, Paula.Pearlman@lls.edu
Joanna Morales: 213.736.8364, Joanna.Morales@lls.edu

CANCER LEGAL RESOUCE CENTER RECEIVES
LANCE ARMSTRONG FOUNDATION 2009 COMMUNITY PROGRAM GRANT

LOS ANGELES, March 17, 2009 – The Cancer Legal Resource Center (CLRC), a joint project of the Disability Rights Legal Center (DRLC) and Loyola Law School, announced today that it is the recipient of a 2009 Lance Armstrong Foundation Community Program Grant. The community program of the Lance Armstrong Foundation (LAF) provides financial support and capacity-building to community-centered initiatives that address the physical, emotional and practical challenges of cancer survivorship.

A cancer diagnosis can carry with it a variety of legal issues, including insurance coverage, employment discrimination, access to health care, government benefits, and estate planning. These legal issues can cause people unnecessary worry, confusion, and stress, and can be overwhelming. When these legal issues are not addressed, people may find that although they have survived the disease, they have lost their homes, jobs, insurance, or families.

"We are extremely delighted to receive the LAF grant and the opportunity it offers to focus on educating health care professionals about cancer-related legal issues that their patients may face," said Joanna L. Morales, Director of the Cancer Legal Resource Center. "The LAF is a generous supporter of community organizations that help people with cancer. We appreciate the foundation's recognition of our efforts to provide legal information and resources to thousands of people every year."

The CLRC provides free and confidential information and resources on cancer-related legal issues nationwide, to cancer survivors, caregivers, employers, health care professionals, and others coping with cancer. The CLRC's caring, respectful assistance helps callers resolve their legal issues, focus on their recovery, and get back to their lives. Throughout its 12-year history, the CLRC has served over 90,000 people through the Telephone Assistance Line, conferences, seminars, workshops, outreach programs, and other cancer community activities.

About the Disability Rights Legal Center
The mission of the DRLC is to promote the rights of people with disabilities and the public interest in and awareness of those rights by providing legal and related services. The Center provides legal and related services through its seven programs: Cancer Legal Resource Center, Civil Rights Litigation Program, Community Outreach Program, Education Advocacy Program, Inland Empire Program, Pro Bono Program, and the Options Counseling and Lawyer Referral Service. For more information, visit www.disabilityrightslegalcenter.org.