

Young Adults Transition Plan

*Your Future/  
Your Life*



DOH 970-153 October 2011

# *Time To Make a Plan*

**T**he transition to adulthood is an exciting time for teens and young adults. Transition may include changes in where you go to school, where you work, or where you live. Health care transition may include changing from pediatric care and services to adult care and services.

Teens and young adults with special health care needs, and their families, need to know that health care transition takes a lot of thought and planning. The materials and forms you will find in this binder are designed to guide you as you take steps toward adult life and additional responsibility, with a focus on your healthcare in the transition from youth to adult.

You and your family will get ideas to help you make your own successful health care transition plan by learning about new choices and new ways of getting health care services for you.

*We hope that you and your family will read these materials and will begin to talk about this important part of your future.*

# About Transition

**A** smooth health care transition is very important to your health and well being. Now is the time to start planning.

One important change that will happen over the next few years is saying good-bye to your pediatrician and going to see doctors who take care of adults instead. This process of leaving pediatrics and getting ready to go to adult-oriented medical providers is called health care transition. Health care transition is important because it supports the activities that you want to do in life such as living on your own, going to college, having a job or being as independent as you can be. In practical terms, health care transition means more than getting medical care from health care providers trained to treat adults. It also means becoming knowledgeable about your health condition, being responsible for carrying out your health tasks, and making good health care decisions.



Growing up with a special health care need presents you with many challenges. Many people, including your parents, doctors, care coordinators, and therapists have helped to take care of you and have seen that you got the medical care that you need. However, now that you are getting older, you get to be more in charge of your health care. This will involve new responsibilities and privileges.

*Between now and when you legally become an adult, it will be important for you to become responsible for managing your chronic illness or disability.*

This guide will give you some ideas about what you can do to help make your health care transition easier, and presents information about what you can do to become more independent in managing your health care.

Don't forget to share this guide with your parents since they can be a big help in getting you started.

# Your Future. Your Life.

Your future is just ahead of you and now is the time to start thinking about what you want to be and want to do when you get older. Health care transition is a process that will help you realize your dreams. To begin, answer the following questions:

After high school, do you want to get vocational training or go to college?

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What type of job would you like to have?

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Do you want to be able to drive a car?

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Where do you want to live when you are an adult?

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Do you want a family of your own?

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Now, think about how your health and medical independence will help you reach these goals.



# Transition Checklist

Check the items that are true for you.

- I keep a personal health notebook or medical journal.
- I reorder my medications when my supply is low and call my doctor when I need a new prescription.
- I tell my doctors I understand and agree with the medicines and treatments they suggest.
- I can tell someone the difference between a primary care doctor and a specialist.
- I can tell someone the effects that getting older may have on my disability or health condition.
- I can tell someone about medications that I should not take because they might interact with the medications I take.
- I am alone with the doctor(s) or choose who is with me during health care visits.
- I answer all the questions during a health care visit.
- I have identified adult doctors and facilities that I will go to when I leave my current doctors and facilities.
- I manage all of my regular medical tasks outside the home (school, work).
- I can tell someone what new legal rights and responsibilities I have when I am 18 years old (sign medical consent forms, make medical decisions by myself).
- I can tell someone how long I can be covered under my parent's health insurance plan and what I need to do to maintain coverage (such as be a full-time student).



# Are You Considering Vocational Training or College?

**H**ealth care transition is all about providing you with a healthy foundation on which to build your life goals. Going away to college or vocational training may be part of your plans for the future. If so, there are some things you can do to help make this transition to a new school and to new health care providers easier. Even if you are not going away to school, some of the tips can be helpful.

The transition to a college away from home takes some planning. Once on campus, your parents will not be there to help you with your care, make decisions, or solve problems. Therefore, it will be important to plan ahead and make sure you are as prepared as possible to be in charge of your health care.

*Let's begin with some questions:*



1. What medical care do you need when you are away from home?

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2. Do you need physical assistance?

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3. Will you be using personal assistants to help you complete activities of daily living?

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Once you have determined what you need, you will have to check to see if these services are available at the colleges you are considering. All colleges have an Office for Students with Disabilities. Contacting this office is a good place to begin. Some colleges have worked hard to make their campus and educational programs very accessible. These colleges tend to have more comprehensive programs to help you adjust and succeed in college life. In addition, if you decide to attend vocational school, their admissions staff might be able to provide you with some guidance about resources in their area.

# Tips For Young Adults

*When you turn 18 years old, you legally become an adult.*

Now is the time to find out how your legal rights and responsibilities will change when you turn 18. As an adult, you have the right to vote, sign contracts and control who has access to your medical information.

Most medical and other information about you will be kept private from everybody, including your parents. Doctors can't talk with anyone else about you, unless they have your written permission to do so. If there is an emergency, doctors cannot share information with your parents or talk with them about what things you do and do not want to be done to your body (*remember – when you turn 18, you are in charge*) unless you have signed a "release of information" form ahead of time.

You will also be the one who signs the medical consent forms. By signing these forms, you say that you understand what the doctors have told you and agree to certain tests, surgeries or procedures.

The resource list in this document has more information about your new legal rights, your rights to privacy, and how to give permission to doctors to share information with your parents or others who you want involved in decisions about your care.

If you think that you will need special housing arrangements at college because of your health care needs, be sure to talk with your school's Office for Students with Disabilities.

Many colleges have only a few dorm rooms that are specially equipped for students with special needs and these spaces fill up quickly. Let your school know about your needs as soon as possible, so that they can make your living arrangements as comfortable, accessible, and safe as possible.

*In addition to making arrangements with your new school, you will also need to make arrangements for getting the health care you will need while you are away at college.* Even if you are still receiving services from pediatric providers, you should not expect to get care from pediatric providers in your new location. To make arrangements for health care,

begin by talking to the college or student health center to find out if they can or cannot meet your medical needs.

If the student health center is unable to meet all your health needs, you will need to find a local health care provider. Finding a new provider may take some effort on your part so you will want to start this process as early as possible. After you have found a new provider, arrange an introductory meeting so you can discuss your care, ask questions, and learn about the doctor's treatment approach. You may want to ask your current provider and new provider to talk directly with each other. Once this has been arranged, have your medical records sent to your new provider.

It's also a good idea to let your academic advisor at college know about your special health needs or disability and how this might affect your ability to take a full course load.

When you are in high school, your guidance counselor and other staff are supposed to take the first steps to get you the accommodations you need. When you are in college, it is up to you to let the Office for Students with Disabilities and other school officials know about your needs.





*Don't wait until you get behind to let them know you need help and support.* Under some circumstances, students with chronic health conditions or disabilities are allowed to take a reduced course load, but still be considered "full-time students" by the health insurance company.

This overview can't tell you everything you need to know about transitioning your health care services to a college setting, but it does show how you will need to use the transition skills you have been working on. Now, work hard in high school to get the grades needed for the college of your choice so you can put your transition skills to work.



# Taking Charge

**T**he time you have been preparing for is now here. You have become more knowledgeable about your health care condition, you are more independent in carrying out or directing others to carry out the health care tasks that keep you healthy, and you know when you will leave the pediatric doctors that you have been seeing. *Completing the transition process will involve a few more steps: transferring to adult-oriented providers, developing a good relationship with these new providers, establishing your new leadership role in managing your health care, and ensuring that you have ongoing health insurance coverage.*

You might have asked for a referral from your pediatrician, talked with friends, or received assistance from a local support group to find an adult-oriented doctor who will be responsible for providing your care. As part of the process of finding the right adult-oriented doctor for you, meet with the doctor when you are in good health to discuss your understanding of your special health care need and any treatment preferences. Adult-oriented medical procedures are frequently different from treatment practices in pediatrics. It is important to discuss these differences and express your preferences, and to also consider the suggestions of your new doctors.

This give and take around medical decisions is part of building a new working relationship. You and your parents trusted your pediatric provider because of the many years you worked together. Now you have to build new trusting relationships. *Remember this will take some time.* A very important part of developing a new relationship is saying good-bye to the doctors, nurses, and therapists who you worked with while growing up. It can be hard to leave the people and places you have known for a long time. You will probably miss seeing these individuals who have worked closely with you and your family. As part of saying good-bye, ask if it is okay to keep in touch after you are no longer a patient. Most pediatric providers enjoy hearing about how their patients are doing after they “graduate” from their practice. You can send an email or letter or drop in for a personal visit. However, it is important to remember that you do have a new doctor and your old doctors can no longer give you medical care or advice.

*Another big change is that you are now responsible for making decisions about your care.* This can be an important and sometimes difficult change for your parents. After all, helping to take care of you has been one of their major concerns for a long time. Encourage your parents to think of the change in decision-making as a promotion. They have been promoted from managers to consultants. For your part, remember that your parents have a lot of experience with your health and they can be a great source of information and support as you take charge of making your own health care decisions.

Paying for health care can be very challenging. At this point you may still be covered by your parents' health insurance or some combination of public or private plans. Most likely this will change over the next few years. Keeping health insurance is very important over the next few years. If your insurance coverage depends on you being in college, then you need to be successful in school. Not only for the short-term, but also for the long-term. This will help you get a job that has health insurance benefits. If you qualify for a public health insurance plan such as Medicaid, it is important to be aware of the rules and requirements that need to be met in order to continue receiving it. You do not want to find yourself sick with no way to pay for the care you need.





# The Conclusion

Growing up with a special health care need can present you with many challenges. However, young people with chronic health conditions and disabilities have met these challenges and been able to reach their goal of being independent and having a good job by:

- taking responsibility for themselves
- managing their own health care
- being as physically fit and healthy as possible

And so can you!

You have learned that getting ready to go to adult-oriented health care providers is important because it helps you to do the things you want to do in life, such as living on your own, going to college, and having a job. You have learned that health care transition takes time, planning, and practice. It involves becoming knowledgeable about your health condition, being responsible for doing health care tasks for yourself, and making health care decisions. It is about taking on new responsibilities, practicing independence and finally, taking charge. It is important to remember that this guide is only an introduction and does not cover all aspects of health care transition. *Health care transition is also an individual process and there is no one right way to transition.*



Well, you've done it. You are now an adult and are learning how to exercise your new privileges and responsibilities. As you become more independent, think about all the efforts your family and pediatric health care providers have invested in you. It is now your job to take good care of your body and your health by making good decisions in all aspects of your life. *This will let you not only envision your future but make it actually happen.*



# Family Coverage

Some employers offer family health insurance coverage, so you may be covered under the health insurance that one of your parents has through their place of work. While coverage usually ends when a child turns 19, some programs might allow you to be covered until you are older (24, 25, 26) if you are a full or part-time student, or if you are disabled and your parents help to support you. More information about family coverage can be found in the resources section in the binder.

# Health Coverage through Work

Some employers offer health insurance to their workers, but most require that employees pay for part of the cost of the insurance. When starting out, it may seem like a lot of money is deducted from your pay check to pay for insurance. However, it is a lot less expensive than having to pay the full costs of a visit to the ER or a day in the hospital all by yourself. Picking the right insurance plan can be a hard decision.



# On The web

## *Children With Special Health Care Needs Program Web Site*

<http://www.doh.wa.gov/cfh/mch/cshcnhome2.htm> This web site has information about Children With Special Health Care Needs Program.

## *Health Care Transition Training Web Site*

[hctransitions.ichp.ufl.edu](http://hctransitions.ichp.ufl.edu) This web site was developed by the University of Florida for teens, parents and professionals. It has lots of information about transition and some videos about teens who have taken charge of their health.

## *Jim's Story*

[video.ichp.ufl.edu/JimStory2.htm](http://video.ichp.ufl.edu/JimStory2.htm) This 10-minute on-line video is about a young man with Cystic Fibrosis.

## *College and Beyond*

[video.ichp.ufl.edu/collegeandbeyond.htm](http://video.ichp.ufl.edu/collegeandbeyond.htm) This 20-minute on-line video is about Jeff, a young man who has a severe physical disability. As he grew up, Jeff learned how to be in charge of his health and make medical decisions with his doctors. This helped him be able to be independent and successful at college. Now he is about to graduate and get a job!

## *Health and Ready To Work Web Site*

[www.hrtw.org](http://www.hrtw.org) This web site has lots of information about being healthy and getting ready for the future!



# Now That You are Eighteen

<i>Health</i>		Things I need to know or do	Will someone else have to do this for me?	I will finish by (date)	Done
1. I sign my own release of information forms or have a plan in place for guardianship or healthcare surrogate.	Y N		Y N		
2. I make my own medical decisions or have other arrangements in place.	Y N		Y N		
3. I have transitioned to an adult healthcare provider or know that my current physician can continue seeing me.	Y N		Y N		
4. I have been referred to adult specialty physicians and have made initial appointments to establish care with them.	Y N		Y N		
5. If I am no longer eligible for medical care under my family's insurance, I have looked at my options and applied for other funding sources.	Y N		Y N		
6. I am aware of support groups in my area to supplement family support.	Y N		Y N		
7. I have a medical history summary that I carry and that can be given to my new doctors.	Y N		Y N		
8. I manage my schedule of medical appointments and make arrangements for transportation to attend, if needed.	Y N		Y N		
9. I know what to do for minor ailments, like a cold, and health emergencies.	Y N		Y N		
10. I have chosen a pharmacy where my current and new prescriptions can be filled.	Y N		Y N		

<i>Independent Living</i>		Things I need to know or do	Will someone else have to do this for me?	I will finish by (date)	Done
1. I have plans for after high school.	Y N		Y N		
2. I can take care of my personal needs or have identified someone to help.	Y N		Y N		
3. I have plans for independent living, housing and transportation.	Y N		Y N		
4. I know how to manage money and budget household expenses.	Y N		Y N		
5. I know what to do to enroll in school or training or apply for work.	Y N		Y N		
6. I know how to get any accommodations I need for work or school.	Y N		Y N		
7. I have a driver's license or State ID.	Y N		Y N		

# Suggested Timelines for Teens With Disabilities

## *Before Age 14*

1. Develop your transition plan for school to post-school for your IEP.
2. Receive invitation to participate in your IEP.

## *Before Age 17*

1. Learn about healthcare funding options available for you after you turn 18.
2. If full or limited guardianship is being considered, begin procedures two months before turning 18.
3. Discuss your legal rights and responsibilities upon turning 18 (legal adulthood).



## *Before Age 18*

1. During the month you turn 18, find out if you are eligible for SSI.
2. If you are eligible for SSI, learn about their work incentive programs.
3. If you will be living away from home (such as college), request any accommodations you will need.



# Medical Home Key Messages

## *What is a Medical Home?*

A Medical Home is an approach to delivering primary health care through a 'team partnership' that ensures health care services are provided in a high quality and comprehensive manner.

## *Who can provide a Medical Home?*

A primary care provider (physician or nurse practitioner) leads the medical home with the support and direction of the patient, the patient's family, clinic staff, community agencies, and other specialty care service providers.

## *What are the core components of a Medical Home?*

### *Accessible & Continuous*

- Care is provided in the community.
- Change in insurance providers or carriers are accommodated by the medical home practice.

### *Coordinated & Comprehensive*

- Preventive, acute care, specialty care, and hospital care needs are addressed.
- When needed, a plan of care is developed with the patient, family, and other involved care providers and agencies.
- Care is accessible 24 hours a day, 7 days a week.
- The patient's medical record is accessible, but confidentiality is maintained.

### *Family-Centered*

- Families and individual clients are involved at all levels of decision-making.

### *Compassionate & Culturally Effective*

- The patient's and family's cultural needs are recognized, valued, respected, and incorporated into the care provided.
- Efforts are made to understand and empathize with the patient's and family's feelings and perspectives.



# *What are the benefits of a Medical Home?*

## *Promotes Health through Prevention*

- Preventive services such as annual physical exams, developmental screening, health education, immunizations, well-child care, and other medical and community-based services help maintain optimal health.
- Women who have a regular source of health care are more likely to access prenatal care.<sup>1</sup>
- Regardless of age, sex, race, or socioeconomic status—all people can receive an array of acute, chronic, and preventive medical care services through a medical home.<sup>2</sup>

## *Healthier Children and Families*

- Among children with special health care needs (CSHCN), children with a medical home have less delayed care, less problems getting care, fewer unmet health needs, and fewer unmet needs for family support services.<sup>3</sup>
- In a study of medical home among CSHCN, parents reported improved care delivery, a decrease in the number of missed work days, and a decrease in hospitalizations.<sup>4</sup>

## *Reduce Health Care Costs*

- Children who receive care in a medical home are half as likely to visit an emergency room or be hospitalized.<sup>4</sup>
- Having health care access through health insurance is not enough to avoid acute care and treatment costs—other issues such as quality of care and the relationship with a primary care provider also influence the use and cost of health care services.<sup>5</sup>

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1 Braveman, P., Marchi K., Egerter S, Pearl M, Neuhaus J, Barriers to timely prenatal care among women with insurance: the importance of prepregnancy factors. *Obstetrics and Gynecology*. 2000; 95:874-880

2 Kahn, Norman (2004). *The Future of Family Medicine: A Collaborative Project of the Family Medicine Community*.

3 Strickland, B., et al. (2004). Access to the Medical Home: Results of the National Survey of Children With Special Health Care Needs. *Pediatrics* 113:5 (1485-1992).

4 Palfrey, J., et al (2004). The Pediatric Alliance for Coordinated Care: Evaluation of a Medical Home Model. *Pediatrics*. 113:5 (1507-1516).

5 Starfield, B & Shi, L (2004) *The Medical Home, Access to Care and Insurance. A Review of Evidence*. *Pediatrics*. 113: 1493-1498 Revised: July 2007

# Transition Resource List

<i>Type</i>	<i>Title or Description</i>
Magazine	Exceptional Parent, vol. 38, Issue 11, "What To Do When Your Child Turns 18," Harry S. Margolis and Eric Prichard, pp. 24 – 26
Magazine	Exceptional Parent, vol. 38, Issue 10, "Transition Planning, Special Education Law and Its Impact On Your Child," Terry Schmitz, pp. 37 – 39
Magazine	Exceptional Parent, vol. 39, Issue 01, 2009 Annual Resource Guide
Website	<a href="http://depts.washington.edu/healthtr">http://depts.washington.edu/healthtr</a>
Website	<a href="http://hctransitions.ichp.ufl.edu">http://hctransitions.ichp.ufl.edu</a>

## *National Resources*

**CHADD** (Children and Adults with Attention Deficit Disorder) 1-301-306-7070; [www.chadd.org](http://www.chadd.org)

**National Hemophilia Foundation;** 1-800-424-2634; [www.hemophilia.org](http://www.hemophilia.org). Includes programs sponsored by Pharmaceutical and Homecare Companies to provide factor to patients without insurance who meet eligibility requirements.

**National Cystic Fibrosis Foundation;** 1-800-344-4823; [www.cff.org](http://www.cff.org). Includes patient assistance programs through Cystic Fibrosis Services

**National Organization for Rare Disorders;** [www.rarediseases.org/#](http://www.rarediseases.org/#); has Patient Assistance Programs for uninsured or underinsured to obtain prescription medications; provides medical foods assistance program for patients with PKU that meet eligibility requirements. Call 1-866-924-0100.

**NeedyMeds.org.** Includes disease-based assistance programs to help patients affected by a specific disease or condition. May provide a range of assistance including medicine co-pays, medical supplies or services. State and government assistance programs also listed.

**Arthritis Foundation.** [www.arthritis.org](http://www.arthritis.org). Resources to help pay for assistive devices and link to directory for medications at reduced or no charge.

**Little People of America.** [www.lpaonline.org](http://www.lpaonline.org). Support and information to people of short stature and their families.

**FACES — The National Craniofacial Association.** [www.faces-cranio.org](http://www.faces-cranio.org).

**Forward Face.** [Forwardface.org](http://Forwardface.org). Family assistance funds for those with financial need with craniofacial conditions.

**Children’s Tumor Foundation.** [www.ctf.org](http://www.ctf.org). Patient assistance programs for children with neurofibromatosis.

**National Tay-Sachs and Allied Diseases Association.** 1-800-906-8723; [www.ntsad.org](http://www.ntsad.org). Member supports.

**Tourette Syndrome Association.** 1-718-224-2999; [www.tsa-usa.org](http://www.tsa-usa.org). Information and referral.

**National Parent to Parent Network.** [www.lookingglass.org/ppn.php](http://www.lookingglass.org/ppn.php). Connects parents with others who may have shared similar experiences or face common barriers as parents of children with disabilities.

**Genetic and Rare Conditions Site.** [www.kumc.edu/gec/support/#e](http://www.kumc.edu/gec/support/#e). Each condition links to a page with many web sites and organizations specifically for that condition.



# About PSI (Patient Services Inc.)

*PSI is the "ground breaking" 501(c)(3) non-profit, charitable organization of its kind. For nearly two decades, PSI has helped people who live with certain chronic illnesses or conditions locate suitable health insurance coverage and access ways to satisfy expensive co-payments.*

PSI provides assistance with the cost of health insurance premiums associated with COBRAs, State High Risk Pools, Open enrollment, Guaranteed Issue policies, HIPAA conversion policies; and prescriptions co-payments associated with private insurance as well as with Medicare Parts B and D.



**PSI is an advocate for families with expensive chronic illnesses. The assistance programs offered include:**

- Subsidizing the cost of health insurance premiums, COBRA coverage, HIPAA conversion policies, state high-risk insurance pools and open enrollment insurance plans.
  - Working with Medicare patients to satisfy their 20% co-payment threshold.
  - Helping Medicare Part D patients cover out-of-pocket costs (TrOOP) until the appropriate level is met for Medicare Catastrophic Coverage to begin.
  - Identifying and accessing health insurance mechanisms on behalf of our clients in all 50 states and territories.
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- Offering assistance to cover certain pharmacy costs and treatment co-payments, especially as they relate to Medicare Part B and D.
  - Supplying certain medically-necessary items and services to the Bleeding Disorders Community that home care companies and specialty pharmacies can no longer provide, due to the Office of the Inspector General (OIG) requirements or because they are not covered by insurance.
  - Providing Medical Expense Programs for specific chronic conditions not covered by insurance which help with things such as assistance with medical evaluation testing, assisted devices, and transportation and lodging.

## *About PSI (continued)*

- Advocating public policy initiatives that promote greater access to health care, encourage innovative approaches to healthcare, and continue the federal government's commitment to research for better treatments and cures.
- Enter into public/private partnerships with States and the Federal Government to assist individuals' in accessing health insurance and comprehensive healthcare coverage.

PSI programs can help families avoid financial ruin or a reliance on public assistance programs like Medicaid. Our end goal is simple – offer services that provide peace of mind to a patient and his/her family by helping them afford the medical treatment they need in order to facilitate well-being and prevent financial devastation.



### *Did you know?*

- Most of those who have been helped by PSI programs have averaged 16-22 months of assistance and 70 percent have transitioned into a better situation in life due to our assistance. These better situations are: obtaining group or individual private insurance plans, improving financially to assume premium or co-payment responsibility, and going back to work.
- Of the donations received, over 80 percent of the funds contributed to PSI go directly to customers enrolled in our programs to help them pay insurance premiums, pharmacy bills and the cost of recurring treatment co-payments.
- Over the last two years, PSI has helped over 30,000 people.
- In the last three years, PSI has seen a marked increase in the number of programs it provides. The number of programs have grown 14 percent since 2004 and the number of people we have helped increased 101 percent since 2004.
- Personal service is the cornerstone of our business. To better support clients, PSI has grown its infrastructure. Staff has increased by 57 percent since 2004 to accommodate your needs.

# About Rx Assist

*RxAssist is a pharmaceutical access information center created by Volunteers in Health Care (VIH), a national resource center for safety net organizations.*

VIH operates out of the Brown University Center for Primary Care and Prevention, based at Memorial Hospital of Rhode Island, a Brown Medical School teaching and research facility located in Pawtucket, Rhode Island. VIH was established in 1997 originally to assist and connect organizations across the country using volunteer clinicians to deliver health care to the uninsured. VIH quickly realized that pharmaceutical access is a key problem. Safety net organizations were struggling to meet their patients' medication needs; applying to the pharmaceutical companies' patient assistance programs was cumbersome and purchasing medication was expensive. As the years progressed, with each year bringing rising costs of medications, safety net health care providers were stuck with a dilemma: how could their patients receive the highest quality of care if they couldn't purchase medicine?

In 1999, with input from organizations across the country, VIH launched our website, RxAssist.org. RxAssist.org streamlines the application process for the pharmaceutical industry's patient assistance programs. Combined with our staff's extensive knowledge of pharmaceutical access issues and the creation of technical assistance tools, VIH and RxAssist are nationally recognized as expert resources for safety net organizations, policymakers, clinicians and the media.







**Through RxAssist.org, Volunteers in Health Care offers:**

- A comprehensive database of pharmaceutical company patient assistance programs. RxAssist was the first website to make application forms available online
- Extensive resources on using and understanding pharmaceutical company patient assistance programs
- Materials and information tailored to providers and consumers on medication access, including fact sheets, FAQs and “how to” guides
- Connections to programs and professionals across the country who are wrestling with issues of medication access, including a dynamic listserv
- Staff who are able to assist organizations starting or operating programs providing medication or pharmacy assistance
- Staff who are able to provide a national perspective on pharmaceutical access issues and strategies

Volunteers in Health Care received support from the Robert Wood Johnson Foundation to update RxAssist. We continue to look for funding and sponsors for ongoing operations. If you would like to support our work through a grant, donation or sponsorship please contact Janet Walton, Deputy Program Director at [janet\\_walton@mhri.org](mailto:janet_walton@mhri.org).



# Some FAQs

## *What are patient assistance programs?*

Patient assistance programs (PAPs) are programs set up by drug companies that offer free or low cost drugs to individuals who are unable to pay for their medication. These programs may also be called indigent drug programs, charitable drug programs or medication assistance programs. Most of the best known and most prescribed drugs can be found in these programs. All of the major drug companies have patient assistance programs, although every company has different eligibility and application requirements. Companies offer these programs voluntarily; the government does not require them to provide free medicine.



## *How do patient assistance programs work?*

An individual gets an application for the drug company program that has the medicine the patient needs. Information on medication available through patient assistance programs and the company programs offering these drugs may be found on the RxAssist.org. Many application forms are available on RxAssist.org and can be filled out directly on the computer or printed out.

Some company programs require that a physician or health care advocate (someone working in a physician's office or in a clinic) get the form by calling the program. Many times in these cases, the patient assistance program will screen for eligibility before sending out the form. The form that is sent will have a patient specific identification number on it.

After the form is filled out and submitted to the company, the drug company will decide whether the patient is eligible to receive the medication for free. If the patient is eligible, the medication may be sent to the patient's home, the physician's office or a local pharmacy depending on the program. Some, but not all, companies send letters letting patients and/or physicians know whether the patient has been approved for their patient assistance program.

## *What are the eligibility requirements for patient assistance programs?*

Eligibility varies program by program. Generally, individuals must have incomes under 200% of the Federal Poverty Level, cannot have prescription coverage

from any public or private source and must be a U.S. resident or citizen. Some companies require that the patient has no health insurance.

### *What do I have to do to apply for a patient assistance program?*

You must follow the directions on the application exactly, answer every question and include any documents the program asks for. Usually, programs will ask about prescription coverage, veteran's status, eligibility for public insurance programs and income and asset information. Companies also may ask for:

- Proof of income, such as federal income tax statements or pay stubs
- Medicaid or insurance denial letters
- A prescription from your doctor
- Patient consent forms that are included with the application.



Most applications will request information about the physician. Applications may require the signature of the physician, the patient or both.

### *What does my doctor need to do to help me apply for a patient assistance program?*

This depends on the specific patient assistance program. Usually the physician only has to fill out a few brief questions on the application form and/or sign it. The physician may also be asked to:

- Call the program for an application
- Write out a prescription
- Include information about the patient's diagnosis on the application

### *Do I need to pay anything to participate in a patient assistance program?*

Most programs make their medications available for free. A few that require pharmacy pick-up have up to a \$25 co-pay.

*How long does it take for my medicine to arrive?*

It can take anywhere from 2 days to 6 weeks for medication to arrive after approval for participation in the program.

*What do I do if I need a medication refill?*

This depends on the program. Some companies require that the physician's office call to request a refill while others allow the patient to call directly. Every company has a different policy on how many refills it will allow.

*I have health insurance, but no prescription insurance; am I eligible for patient assistance programs?*

In most cases, the answer is yes. Some companies, however, require that a patient has no health insurance.

*I have coverage for prescriptions with my health insurance but I have reached my coverage limit. Am I eligible for patient assistance programs?*

Technically, if you have reached your coverage limit you no longer have prescription coverage, but we suggest attaching a letter with your application that indicates this. If you have a letter from your insurer stating that you have used up your benefits, send that along as well.

*I have Medicare Part D. Do I qualify for these programs?*

This will vary depending on the particular patient assistance program that carries your medication and that company's policy. In general, companies do not allow Part D enrollees who are eligible to receive the full low income subsidy (LIS or extra help) to apply for their programs. If you have Part D, it is a good idea to get a letter from Social Security indicating that you are not eligible for the low income subsidy.

Although RxAssist does its best to keep its information as current as possible, companies can and do make changes without notice. Companies may also be willing to review cases on a case by case basis, where financial hardship is involved. It always makes sense to call the program to check on its policy. Click [here](#) to see a chart of PAP's and their Medicare Part D policies



## *Some FAQs (continued)*

*What do I do if the company decides that I do not qualify for its patient assistance program?*

It is up to each company to decide who can have medication for free and who cannot. For a variety of reasons, some patients are turned down for these programs. In that case, the best thing to do is ask your physician or health care advocate to make an appeal directly to the manager of the patient assistance program that explains exactly why you cannot afford to buy your medication. We suggest a letter followed by a phone call. Click [here](#) for an example of an appeal letter to a patient assistance program.

*Are there patient assistance programs for generic medications?*

Yes. Both Rx Outreach and Xubex Pharmaceutical Services offer patient assistance programs for generic drugs. These programs differ from all other patient assistance programs in that they are not offered by the pharmaceutical manufacturer of the drug. They are programs that include several different generic drugs which are purchased by the company and then made available for a fee to low income individuals. Both companies have income requirements to be eligible and both charge a fee to receive the medication. Xubex charges shipping and handling as well.





# More Stuff About Transition

**B**y reading this guide and completing the activities, you have started to be more in charge of your life and your health and are better prepared to do more of the things you want to do now and in the future.

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