

## QUARTERLY REPORT

### COVER SHEET

1. Title of Project\*:

Using the “Information Rx” Process to Refer Parents of Newborns with Metabolic Conditions Identified by Screening to the Genetics Home Reference Web Site for Health Information

2. Name of Institution:

University of Utah, Department of Biomedical Informatics

3. Location of Institution:

26 South 2000 East  
HSEB Suite 5700  
School of Medicine  
Salt Lake City, UT 84112-5750

4. Name, Mailing and E-Mail Addresses, Voice and Fax Numbers, of Person Submitting Report:

Denise E. Beaudoin, mailing address as above, email address [denise.beaudoin@hsc.utah.edu](mailto:denise.beaudoin@hsc.utah.edu),  
phone 801-581-4080, FAX 801-581-4297

5. Number and Inclusive Dates of Quarterly Report:

Quarterly Report #3, covering the period from 04/16/08 through 07/15/08

6. Submission Date:

July 15, 2008

\* Note new project title:

Using the “Information Rx” Process to Refer Adults and Parents of Children with Metabolic Conditions to the Genetics Home Reference Web Site for Health Information

## NARRATIVE DESCRIPTION

1. Executive summary. Please provide a brief, one-paragraph narrative summarizing major accomplishments made during the quarter.

Patient recruitment began on April 28, 2008. Parents of two infants diagnosed with a metabolic disorder identified by newborn screening were enrolled before the study eligibility criteria were expanded to include adults and parents of older children with metabolic conditions. Changes to the protocol summary, study description, consent form and surveys were proposed to accommodate this change and a study amendment was submitted to the University of Utah IRB for review. The study was determined to be exempt from federal regulations governing human research on May 14, 2008. Modifications to question 20 in the follow-up survey were also proposed when investigators noted the need for an additional response category. A final amendment was submitted to the IRB and the study was once again deemed exempt on June 9, 2008. To date, 40 participants have been enrolled in the study. Metabolic conditions include PKU, CG, LCHAD, MCAD and MSUD, among others.

2. Description of Progress toward the Project's Major Objectives:
  - a. Administrative/Planning Activities:
    - i. Two study amendments were submitted to the University of Utah IRB and deemed 'exempt' (please see above).
  - b. Collaborations/Partnerships: Ongoing with Dr. Longo's Metabolic Clinic staff.
  - c. Publicity/Marketing Activities: Not applicable.
  - d. Product/Resource Development Activities: Not applicable.
  - e. Site Visits: None at this time.
  - f. Outreach activities: None at this time.
  - g. Web site development activities: Not applicable.
  - h. Exhibits:
    - i. Dr. Beaudoin presented a poster describing the 'Info Rx' project at the annual meeting of the Utah Library Association in April 2008.
    - ii. Drs. Mitchell, Longo, Logan and Beaudoin submitted a poster for presentation at the annual AMIA meeting in November but were notified on June 18 that the abstract was not accepted.
3. Loansome Doc/Document Delivery Activities: Not applicable.
4. Evaluation Activities: Not applicable at this time.
5. Problems/Corrective Actions (including significant changes made in implementation of the project): After discussion among study investigators, the decision was made to expand the study eligibility criteria beyond the parents of newborns to include adults and parents of older children with metabolic conditions who are seen at the Metabolic Clinic. This change will increase the number of potential study participants and allow the investigators to obtain feedback about the GHR Web site from three distinct populations: the parents of infants with a metabolic condition identified by newborn screening, the

parents of children living with metabolic conditions, and adult patients with metabolic conditions. Although a Web-based version of the initial survey was created in order to streamline the data collection process, the paper-and-pencil version has been used as it is a better 'fit' with clinic flow.

6. Lessons Learned/Significant Feedback: Not applicable at this time.
7. Projected Activities for Next Quarter:
  - (a) Dr. Beaudoin will continue recruitment of study participants from among patients seen at the Metabolic Clinic.
  - (b) Dr. Beaudoin will conduct follow-up of study participants (by e-mail and letter) to ensure that they access the GHR Web site and complete the follow-up survey.
  - (c) Dr. Beaudoin will continue data entry and begin data analysis.
8. Reports of Training/Demonstration Sessions and/or Exhibit Reports: Not applicable.

## **APPENDIX**

Include copies of: communications, materials produced, evaluation tools/instruments used or developed, press releases, advertisements, articles for newsletters, etc.

Please see attached IRB correspondence, revised study documents including the most recent (paper) versions of the study description, consent form and surveys.

**IRB: IRB\_00023554**

**Principal Investigator:** JoyceMitchell

**Title:** Using the “Information Rx” Process to Refer Parents of Newborns with Metabolic Conditions Identified by Screening to the Genetics Home Reference Web Site for Health Information

This Amendment Application (Info Rx Amendment Expanded Study 4/29/08) qualifies for an expedited review by a designated University of Utah IRB member according to University IRB policy. The designated IRB member has reviewed and approved your amendment request for this study on **5/14/2008**. The approval of this amendment request does NOT change the expiration date of this research study as noted below.

Any future changes to this study must be submitted to the IRB prior to initiation via an amendment form.

## **APPROVED DOCUMENTS**

### **Protocol Summary**

Protocol Summary Expanded Study 5/5/08 clean

### **Informed Consent Document**

Consent Form Expanded Study 4/29/08 clean

### **Surveys, etc.**

Follow-up Survey Expanded Study 5/8/08 clean

Initial Survey Expanded Study 5/5/08 clean

### **Other Documents**

Reminder Letter #2 Expanded Study 4/29/08 clean

Study Description Expanded Study 4/29/08 clean

Reminder Email #2 Expanded Study 4/29/08 clean

Reminder Letter #1 Expanded Study 4/29/08 clean

Reminder Email #1 Expanded Study 4/29/08 clean

**IRB:** IRB\_00023554

**Principal Investigator:** JoyceMitchell

**Title:** Using the “Information Rx” Process to Refer Adult Patients and Parents of Children with Metabolic Conditions to the Genetics Home Reference Web Site for Health Information

This Amendment Application ('Info Rx' Amendment, Expanded Study Revised Survey, 5/23/08) qualifies for an expedited review by a designated University of Utah IRB member according to University IRB policy. The designated IRB member has reviewed and approved your amendment request for this study on **6/9/2008**. The approval of this amendment request does NOT change the expiration date of this research study as noted below.

Any future changes to this study must be submitted to the IRB prior to initiation via an amendment form.

#### **APPROVED DOCUMENTS**

##### **Surveys, etc.**

Follow-up Survey, Expanded Study, Mod Q20, 6/6/08

## Study Description

Title: Using the “Information Rx” Process to Refer Adult Patients and Parents of Children with Metabolic Conditions to the Genetics Home Reference Web Site for Health Information

Principal Investigator: Joyce A. Mitchell, PhD  
Department of Biomedical Informatics  
26 South 2000 East  
HSEB Suite 5700, School of Medicine  
University of Utah  
Salt Lake City, UT 84112-5750

Purpose: To learn about patients and parents’ reactions to getting an “information prescription” from their/their child’s physician that directs them to a Web site where they may retrieve accurate and consumer-friendly health information about their/their child’s metabolic condition, and their assessment of the information found on this site.

Criteria for eligibility:

- Parent/caregiver of a newborn or child under the age of 18 who has been diagnosed with at least one metabolic condition
- Patient age 18 or older who has been diagnosed with at least one metabolic condition
- Diagnosis was made by Nicola Longo, MD, PhD (or medical colleague) at the University of Utah Metabolic Clinic

Potential benefits of participation:

- Increased understanding about your/your child’s medical condition
- Improved communication with your/your child’s doctor

Time commitment involved:

- Completion of initial survey at the clinic (5 to 10 minutes)
- Exploration of GHR Web site on your own (variable time)
- Completion of online survey six weeks after the clinic visit (online survey should not take more than 30 minutes to complete)

Contact: Denise E. Beaudoin, MD, MSPH, MS, Department of Biomedical Informatics, University of Utah, phone: 801-581-4080

List of Metabolic Conditions\*:

Argininosuccinic acidemia (ASA)  
Beta ketothiolase deficiency (BKT)  
Biotinidase deficiency (BIOT)  
Carnitine uptake defect (CUD)  
Citrullinemia (CIT)  
Classical galactosemia (GALT)  
Glutaric acidemia type 1 (GA I)  
Homocystinuria (due to CBS deficiency) (HCY)  
3-hydroxy 3-methyl glutaric aciduria (HMG)  
Isovaleric acidemia (IVA)  
Long-chain 3-hydroxy acyl-CoA dehydrogenase deficiency (LCHAD)  
Maple syrup disease (MSUD)  
Medium-chain acyl-CoA dehydrogenase deficiency (MCAD)  
3-Methylcrotonyl-CoA carboxylase deficiency (3MCC)  
Methylmalonic acidemia (Cbl A,B)  
Methylmalonic acidemia (mutase deficiency) (MUT)  
Multiple carboxylase deficiency (MCD)  
Phenylketonuria (PKU)  
Propionic acidemia (PROP)  
Trifunctional protein deficiency (TFP)  
Tyrosinemia type I (TYR I)  
Very long-chain acyl-CoA dehydrogenase deficiency (VLCAD)

\* Other metabolic conditions may also be included

## **Consent and Authorization Document**

### **BACKGROUND**

You are being asked to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with friends and relatives if you wish. Ask the research doctor or staff if there is anything that is not clear or if you would like more information. Take time to decide whether or not to volunteer to take part in this research study.

The purpose of the study is to learn about your reaction to getting an “information prescription” from your/your child’s doctor that contains the address of a Web site with information about your/your child’s medical condition, and your assessment of the information you find on this Web site. This study is being conducted by researchers in the Biomedical Informatics and Pediatrics Departments at the University of Utah and the National Library of Medicine’s National Network of Libraries of Medicine.

### **STUDY PROCEDURES**

If you decide to participate in this study, you will be asked to complete two surveys. The first survey will be completed by you after your clinic visit with Dr. Nicola Longo at the Metabolic Clinic located at Primary Children’s Medical Center. This survey (Web-based or paper-and-pencil depending upon the availability of Internet access at the Clinic) will ask about your computer use and some demographics (such as your age, gender, etc.) and should take you no more than 10 minutes to complete. You will then be asked to visit the Genetics Home Reference (GHR) Web site on your own using the information written on the “Information Prescription” that you receive from Dr. Longo or one of his colleagues. Three weeks after your clinic visit, you will receive a letter in the mail and an e-mail if you have an e-mail address reminding you to visit the GHR Web site. Six weeks after your clinic visit, you will receive another letter and e-mail, asking you to go to the GHR Web site to complete an online survey about your experience. The online survey will consist of 30 questions. You will be asked to complete this survey at one sitting. This survey should take no more than 30 minutes to complete. The total length of time that you will be involved in this study is approximately six weeks.

### **RISKS**

A breach of confidentiality is possible; however, every effort will be made by the researchers to keep any information that you provide confidential.

### **BENEFITS**

We cannot promise any benefits to you from your being in the study. However, possible benefits may include increased understanding about your/your child’s medical condition and improved communication with your/your child’s doctor. You will receive a summary report of the study results.

### **CONFIDENTIALITY**

Results of the study may be published; however, your name and other identifying information will be kept private. We will keep all research records that identify you private to the extent allowed by law. Records about you will be kept in locked filing cabinets, or on computers protected with passwords. Only those who work with this study will be allowed access to your information.



## **PERSON TO CONTACT**

If you have questions, complaints or concerns about this study, you can contact Dr. Denise Beaudoin at 801-581-4080. If you think you may have been injured from being in this study, please call Dr. Denise Beaudoin at 801-581-4080 during the day from 9 am to 5 pm, Monday through Friday.

## **INSTITUTIONAL REVIEW BOARD**

Contact the Institutional Review Board (IRB) if you have questions regarding your rights as a research participant. Also, contact the IRB if you have questions, complaints or concerns which you do not feel you can discuss with the investigator. The University of Utah IRB may be reached by phone at (801) 581-3655 or by e-mail at [irb@hsc.utah.edu](mailto:irb@hsc.utah.edu).

## **RESEARCH-RELATED INJURY**

If you are injured from being in this study, medical care is available to you at the University of Utah as it is to all sick or injured people. The University of Utah does not have a program to pay you if you are hurt or have other bad results from being in the study. The costs for any treatment or hospital care would be charged to you or your insurance company (if you have insurance), to the study sponsor or other third party (if applicable), to the extent those parties are responsible for paying for medical care you receive. Since this is a research study, some health insurance plans may not pay for the costs.

The University of Utah is a part of the government. If you are injured in this study, and want to sue the University or the doctors, nurses, students, or other people who work for the University, special laws may apply. The Utah Governmental Immunity Act is a law that controls when a person needs to bring a claim against the government, and limits the amount of money a person may recover. See Section 63-30d-101 through 63-30d-904 of the Utah Code.

## **VOLUNTARY PARTICIPATION**

It is up to you to decide whether or not to take part in this study. If you decide to take part you are still free to withdraw at any time and without giving a reason. Refusal to participate or the decision to withdraw from this study will involve no penalty or loss of benefits to which you are otherwise entitled. If you don't take part, you can still receive all standard care that is available to you. This will not affect the relationship you have with your doctor or other staff, nor decrease the standard of care that you receive as a patient.

## **UNFORESEEABLE RISKS**

None.

## **COSTS AND COMPENSATION TO PARTICIPANTS**

There are no costs to you if you decide to participate in this study. You will not be compensated for your time.

## **NUMBER OF PARTICIPANTS**

We expect to enroll from 60 to 120 participants from among the adult patients and the parents/caregivers of newborns/children under the age of 18 who have been diagnosed with at least one metabolic condition by Dr. Nicola Longo at the Metabolic Clinic located at Primary Children's Medical Center. This is a pilot study; the results obtained in Utah may influence whether this study is undertaken by researchers in other states.

## **AUTHORIZATION FOR USE OF YOUR PROTECTED HEALTH INFORMATION**

Signing this document means you allow us, the researchers in this study, and others working with us to use information about your health for this research study. You can choose whether or not you will participate in this research study. However, in order to participate you have to sign this consent and authorization form.

This is the information we will use:

- Your name
- Your current age
- Your date of birth
- Your gender
- Your highest level of education
- Your race/ethnicity
- Your street address, city, state and zip code
- Your telephone numbers (home and cell if available)
- Your e-mail address (if you have one)
- Your role in your child's medical care (if applicable)
- The name of your child (if applicable)
- The birth date of your child (if applicable)
- The name of your/your child's physician
- The name of your/your child's metabolic condition
- The date of your/your child's diagnosis for this metabolic condition

Others who will have access to your information for this research project are the University's Institutional Review Board (the committee that oversees research studying people) and authorized members of the University of Utah Health Sciences Center and Primary Children's Hospital who need the information to perform their duties (for example: to provide treatment, to ensure integrity of the research, and for accounting or billing matters).

If we share your information with anyone outside the University of Utah Health Sciences Center or the Metabolic Clinic located at Primary Children's Medical Center, you will not be identified by name, social security number, address, telephone number, or any other information that would directly identify you, unless required by law.

You may revoke this authorization. **This must be done in writing.** You must either give your revocation in person to the Principal Investigator or the Principal Investigator's staff, or mail it to Joyce Mitchell, PhD, Professor and Chair, Dept of Biomedical Informatics, 26 South 2000 East, HSEB suite 5700, School of Medicine, University of Utah, Salt Lake City, UT 84112-5750. If you revoke this authorization, we will not be able to collect new information about you, and you will be withdrawn from the research study. However, we can continue to use information we have already started to use in our research, as needed to maintain the integrity of the research.

This authorization does not have an expiration date.

**CONSENT**

I confirm that I have read this consent and authorization document and have had the opportunity to ask questions. I will be given a signed copy of the consent and authorization form to keep.

**I agree to take part in this research study and authorize you to use and disclose health information about me for this study, as you have explained in this document.**

\_\_\_\_\_  
Participant's Name

\_\_\_\_\_  
Participant's Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Name of Person Obtaining Authorization and Consent

\_\_\_\_\_  
Signature of Person Obtaining Authorization and Consent

\_\_\_\_\_  
Date

**Using the “Information Rx” Process to Refer Adult Patients and Parents of Children  
with Metabolic Conditions to the Genetics Home Reference Web Site  
for Health Information**

**Initial Parent Survey**

**Please select one answer to each of the following questions:**

1. How frequently do you look up sources of medical information?
  - Very frequently
  - Somewhat frequently
  - Neither frequently nor infrequently
  - Somewhat infrequently
  - Very infrequently
  
2. How frequently do you discuss the medical information that you look up with your/your child's doctor?
  - Very frequently
  - Somewhat frequently
  - Neither frequently nor infrequently
  - Somewhat infrequently
  - Very infrequently
  
3. Do you find it easy or difficult to understand the medical issues that your/your child's doctor discusses with you?
  - Very easy
  - Somewhat easy
  - Neither easy nor difficult
  - Somewhat difficult
  - Very difficult
  
4. Do you find it easy or difficult to read health information on a computer compared to a book or pamphlet?
  - Very easy
  - Somewhat easy
  - Neither easy nor difficult
  - Somewhat difficult
  - Very difficult
  
5. Where is the location of the nearest computer you can use?
  - At home
  - At the office
  - At a school
  - At a public library
  - At a hospital library
  - At another family member's location
  - Other (please fill in): \_\_\_\_\_
  
6. On average, about how many hours a day (both at home and work) do you check for email and use the Internet for all other purposes?
  - 0 to 1 hour
  - 2 to 4 hours
  - 5 to 6 hours
  - More than 6 hours

7. Had you ever visited the Genetics Home Reference Web site prior to receiving the Information Prescription from your/your child's doctor today?

- Yes
- No
- Don't know

8. If yes, approximately how many times have you visited the Genetics Home Reference Web site?

- Once
- Twice
- Three to five times
- More than five times
- I have visited the site before but don't know how many times
- I have never visited the Genetics Home Reference Web site

9. How did you first learn about the Genetics Home Reference Web site?

- From my/my child's doctor at today's clinic visit
- From another doctor
- From the staff in my/my child's doctor's office
- From an ad
- From friends and family
- From an Internet search
- From a local librarian
- From either a newspaper or a local radio/television station
- Other (please fill in): \_\_\_\_\_

**Please tell us if you agree or disagree with the following statement:**

10. I think receiving a prescription from my/my child's doctor to visit the Genetics Home Reference Web site for more information is a good idea.

- Strongly agree
- Somewhat agree
- Neither agree nor disagree
- Somewhat disagree
- Strongly disagree

11. Did you receive enough information today from your/your child's doctor to feel comfortable about using the Genetics Home Reference Web site?

- Yes
- No
- Don't know

**We'd like to know a little more about you and your child...Please go directly to question 16 if you are completing this survey about yourself.**

12. What is your child's name?

\_\_\_\_\_

13. What is your child's date of birth? For example, if your child was born on March 5, 2008 you would enter 03/05/2008.

\_\_\_\_\_

14. What is your role in this child's medical care?

- Parent
- Guardian/caretaker
- Other (please explain): \_\_\_\_\_

15. What is the name of your child's physician?

\_\_\_\_\_

16. What is your name?

\_\_\_\_\_

17. What is your age?

\_\_\_\_\_

18. What is your date of birth? For example, if you were born on March 5, 2008 you would enter 03/05/2008.

\_\_\_\_\_

19. What is your gender?

- Male
- Female

20. Which of the following best describes the highest level of education you have completed?

- Did not complete high school
- High school graduate or equivalent (GED)
- Some college or vocational school
- College graduate
- Some postgraduate school
- Graduate/professional degree

21. Which of the following best describes your race/ethnicity?

- American Indian or Alaskan Native
- Asian or Pacific Islander
- Black not of Hispanic origin
- Hispanic
- White not of Hispanic origin
- Other (please describe): \_\_\_\_\_

**We will contact you in three weeks to remind you to visit the Genetics Home Reference Web site and again in six weeks to remind you to complete the online survey. Please provide us with your home mailing address, telephone number(s) and e-mail address.**

22. What is your street address?

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23. Which city do you live in?

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24. Which state do you live in?

Utah

Idaho

Wyoming

Other (please fill in): \_\_\_\_\_

25. What is your 5 digit zip code?

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26. What is your home telephone number (including area code)?

For example, 801-332-9245.

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27. What is your cell phone number if you have one (including area code)?

For example, 801-332-9245.

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28. What is your e-mail address if you have one?

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This completes the survey. The remaining two questions are for office use only.

For office use only:

Assigned ID#: \_\_\_\_\_

Date of survey completion: \_\_\_\_\_

**Thank you very much for completing this survey. Your feedback is very important to us as it will help improve the Genetics Home Reference Web site.**

**Using the “Information Rx” Process to Refer Adult Patients and Parents of Children with  
Metabolic Conditions to the Genetics Home Reference Web site  
for Health Information**

**Patient Follow-up Survey**

ID# \_\_\_\_\_

1. I am answering the questions in this survey:

- About myself
- About a child in my care

2. For which condition(s) did you/your child receive a confirmed diagnosis?

(Please check all that apply)

- Argininosuccinic acidemia (ASA)
- Beta ketothiolase deficiency (BKT)
- Biotinidase deficiency (BIOT)
- Carnitine uptake defect (CUD)
- Citrullinemia (CIT)
- Classical galactosemia (GALT)
- Glutaric acidemia type 1 (GA I)
- Homocystinuria (due to CBS deficiency) (HCY)
- 3-hydroxy 3-methyl glutaric aciduria (HMG)
- Isovaleric acidemia (IVA)
- Long-chain 3-hydroxy acyl-CoA dehydrogenase deficiency (LCHAD)
- Maple syrup disease (MSUD)
- Medium-chain acyl-CoA dehydrogenase deficiency (MCAD)
- 3-Methylcrotonyl-CoA carboxylase deficiency (3MCC)
- Methylmalonic acidemia (Cbl A,B)
- Methylmalonic acidemia (mutase deficiency) (MUT)
- Multiple carboxylase deficiency (MCD)
- Phenylketonuria (PKU)
- Propionic acidemia (PROP)
- Trifunctional protein deficiency (TFP)
- Tyrosinemia type I (TYR I)
- Very long-chain acyl-CoA dehydrogenase deficiency (VLCAD)
- Other: \_\_\_\_\_
- Don't know **Please go directly to question 4.**
- My child had a positive screening test but was not ultimately diagnosed with one of the above conditions (false positive test) **Please go directly to question 4.**

3. When were you/was your child first diagnosed with the above condition(s)? For example, if you were/your child was first diagnosed on April 3, 2008, you would enter: 04/03/2008. If you can't remember the exact date, please provide your best estimate.

mm    dd    yyyy

4. Approximately how many times have you visited the Genetics Home Reference Web site since you received the 'Information Prescription' from your doctor?

- Only once
- Twice
- Three to five times
- More than five times
- I have visited the site but don't know how many times
- I have never visited the Genetics Home Reference Web site



**If you have never visited the Genetics Home Reference Web site, please go directly to question 27.**

5. Overall, was the information within the Genetics Home Reference Web site easy or difficult to understand?
- Very easy
  - Somewhat easy
  - Neither easy nor difficult
  - Somewhat difficult
  - Very difficult
6. Overall, how helpful was the information on the Genetics Home Reference Web site relating to your/your child's condition(s)?
- Very helpful
  - Somewhat helpful
  - Neither helpful nor unhelpful
  - Somewhat unhelpful
  - Very unhelpful
7. How did you use or do you plan to use the health information found on the Genetics Home Reference Web site? (Please check all that apply)
- Discussed, or will discuss, with my/my child's doctor
  - Discussed, or will discuss, with family or friends
  - Has improved my understanding of an illness or health condition
  - Has influenced, or may influence, future health decisions for myself or my child
  - Have contacted, or will contact, a support group in my area
  - Looked for, or will consider looking for, more health information
  - Other \_\_\_\_\_ (Please fill in)

**For questions 8 through 11, please rate your level of agreement with the statement:**

8. I trust the information on the Genetics Home Reference Web site because my/my child's doctor prescribed it.
- Strongly agree
  - Somewhat agree
  - Neither agree nor disagree
  - Somewhat disagree
  - Strongly disagree
9. A high-quality source of health information helps me talk to my/my child's doctor.
- Strongly agree
  - Somewhat agree
  - Neither agree nor disagree
  - Somewhat disagree
  - Strongly disagree
10. The health information that I find on the Genetics Home Reference Web site will help me make better health decisions for myself/my child.
- Strongly agree
  - Somewhat agree
  - Neither agree nor disagree
  - Somewhat disagree
  - Strongly disagree

11. The information I received on the Genetics Home Reference Web site added to what doctors told me about my/my child's condition.

- Strongly agree
- Somewhat agree
- Neither agree nor disagree
- Somewhat disagree
- Strongly disagree

12. Overall, how satisfied were you with the health information you found on the Genetics Home Reference Web site?

- Very satisfied
- Somewhat satisfied
- Neither satisfied nor dissatisfied
- Somewhat dissatisfied
- Very dissatisfied

13. Was it easy or difficult to find the information you were seeking?

- Very easy
- Easy
- Neither easy nor difficult
- Difficult
- Very difficult

14. Did you notice any missing information about your/your child's metabolic condition in the Genetics Home Reference Web site?

- Yes
- No
- Don't remember

If you selected "No" or "Don't remember" please go directly to [question 18](#).

15. If yes, please let us know briefly what information was missing when you searched for information on the Genetics Home Reference Web site. (Please write your comments below)

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16. In which general area of the Genetic Home Reference Web site did you notice that information was missing? (Please check all that apply):

- An overall explanation of the condition
- The genes that are related to or cause the condition
- How persons inherit the condition
- Where to find more information about treatment for the condition
- Where to find additional information about the condition
- Other names people use for the condition
- A gateway to getting specific questions answered about the condition
- Glossary definitions that help with understanding the condition
- Information about diagnosis
- All the above
- None of the above

17. Did you use these Internet sources to fill in the missing information?

(Please check all that apply)

- The WebMD.com Web site
- The MedlinePlus.gov Web site
- The MSN Health Web site
- The Genetic Alliance Web site
- The Ask the Geneticist Web site
- The Madisons Foundation Web site
- The March of Dimes Web site
- None of the above

18. **Please tell us how frequently you visited each of the following when you used the Genetics Home Reference Web site:**

How frequently did you visit pages that focus on a single genetic condition?

- Very frequently
- Frequently
- Neither frequently nor infrequently
- Infrequently
- Very infrequently
- Did not use

How frequently did you visit pages that focus on a particular gene?

- Very frequently
- Frequently
- Neither frequently nor infrequently
- Infrequently
- Very infrequently
- Did not use

How frequently did you visit pages that focus on a particular chromosome?

- Very frequently
- Frequently
- Neither frequently nor infrequently
- Infrequently
- Very infrequently
- Did not use

How frequently did you visit the 'Help Me Understand Genetics Handbook' (background information about genetics, including inheritance, genetic counseling)?

- Very frequently
- Frequently
- Neither frequently nor infrequently
- Infrequently
- Very infrequently
- Did not use

How frequently did you visit the definitions of glossary terms?

- Very frequently
- Frequently
- Neither frequently nor infrequently
- Infrequently
- Very infrequently
- Did not use

How frequently did you visit "Resources" (with links to other online genetic resources)?

- Very frequently
- Frequently
- Neither frequently nor infrequently
- Infrequently
- Very infrequently
- Did not use

19. Which of these areas was most helpful to you within the Genetics Home Reference Web site?

- "Genetic Conditions" (information about a single genetic condition)
- "Genes" (information about a particular gene)
- "Chromosomes" (information about a particular chromosome)
- "Handbook"
- "Glossary"
- "Resources"
- None of the above

20. Please answer yes or no to the following questions.

Within the Genetics Home Reference Web site:

Was "Resources" (with links to other online genetic resources) more helpful to you than "Genetic Conditions" (information about a single genetic condition)?

- Yes
- No
- Did not use area(s)

Was "Resources" (with links to other online genetic resources) more helpful to you than "Genes" (information about a particular gene)?

- Yes
- No
- Did not use area(s)

Was "Resources" (with links to other online genetic resources) more helpful to you than "Chromosomes" (information about a particular chromosome)?

- Yes
- No
- Did not use area(s)

Was "Resources" (with links to other online genetic resources) more helpful to you than the "Handbook"?

- Yes
- No
- Did not use area(s)

Was "Resources" (with links to other online genetic resources) more helpful to you than the "Glossary"?

- Yes
- No
- Did not use area(s)

21. Among the links to resources that provide other genetic information and organizations outside of the Genetics Home Reference Web site, which site was most helpful to you?

- The WebMD.com Web site
- The MedlinePlus.gov Web site
- The MSN Health Web site
- The Genetic Alliance Web site
- The Ask the Geneticist Web site
- The Madisons Foundation Web site
- The March of Dimes Web site
- None of the above

22. Please rate your level of agreement with the following statements:

The Genetics Home Reference Web site was more helpful to me than the WebMD.com Web site.

- Strongly agree
- Somewhat agree
- Neither agree nor disagree
- Somewhat disagree
- Strongly disagree
- Did not use

The Genetics Home Reference Web site was more helpful to me than the MedlinePlus.gov Web site.

- Strongly agree
- Somewhat agree
- Neither agree nor disagree
- Somewhat disagree
- Strongly disagree
- Did not use

The Genetics Home Reference Web site was more helpful to me than the MSN Health Web site.

- Strongly agree
- Somewhat agree
- Neither agree nor disagree
- Somewhat disagree
- Strongly disagree
- Did not use

The Genetics Home Reference Web site was more helpful to me than the Genetic Alliance Web site.

- Strongly agree
- Somewhat agree
- Neither agree nor disagree
- Somewhat disagree
- Strongly disagree
- Did not use

The Genetics Home Reference Web site was more helpful to me than the Ask the Geneticist Web site.

- Strongly agree
- Somewhat agree
- Neither agree nor disagree
- Somewhat disagree
- Strongly disagree
- Did not use

The Genetics Home Reference Web site was more helpful to me than the Madisons Foundation Web site.

- Strongly agree
- Somewhat agree
- Neither agree nor disagree
- Somewhat disagree
- Strongly disagree
- Did not use

The Genetics Home Reference Web site was more helpful to me than the March of Dimes Web site.

- Strongly agree
- Somewhat agree
- Neither agree nor disagree
- Somewhat disagree
- Strongly disagree
- Did not use

23. How likely are you to use the Genetics Home Reference Web site again?

- Very likely
- Likely
- Neither likely nor unlikely
- Unlikely
- Very unlikely

24. How likely are you to recommend the Genetics Home Reference Web site to others?

- Very likely
- Likely
- Neither likely nor unlikely
- Unlikely
- Very unlikely

25. Please let us know what area, or link, you found the most helpful when you used the Genetics Home Reference Web site. (Please write your comments below)

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26. Please feel free to add other comments about the Genetics Home Reference Web site:

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**Please skip questions 27 and 28 and go directly to [question 29](#). (Questions 27 and 28 are intended to be answered by those who have never visited the Genetics Home Reference Web site.)**

27. If you have NEVER visited the Genetics Home Reference Web site, please tell us the reason(s). (Please check all that apply)
- I do not have access to a computer and the Internet
  - I do not use the Internet because it is too complicated
  - It's difficult for me, at times, to understand written health information
  - English is not my first language
  - I prefer another Internet source for health information rather than the Genetics Home Reference Web site
  - It's upsetting to read about an illness that affects me/my child
  - I already know enough about the medical issues my/my child's doctor asked me to look up
  - What the doctors tell me is sufficient
  - It's just not my nature to read about medical issues
  - I forgot
  - I have not had time
  - Other: \_\_\_\_\_ (Please fill in)

28. Would it increase your interest in using the Genetics Home Reference Web site to know that many local libraries will:
- \* provide free access to the Internet for patients who do not have their own computers,
  - \* help patients locate health information using the Genetics Home Reference Web site,
  - \* demonstrate the Genetics Home Reference Web site to you?
- Very much
  - Somewhat
  - Not at all

29. Do you use any of the following health information resources? (Please check all that apply)
- Health care providers
  - Friends and/or family members
  - Other Web sites (please list): \_\_\_\_\_
  - Medical journals
  - Print media (newspapers/magazines)
  - Radio/television programs
  - Other (please list): \_\_\_\_\_

30. Did you search on any of the following Internet services to find health information about your/your child's condition? (Please check all that apply)
- Yahoo
  - Google
  - AOL
  - Answers.com
  - Other Internet services
  - None of the above

31. Compared to all other health information sources you use at this time (regardless if they are or are not located on the Internet) how frequently will you use the Genetics Home Reference Web site in the future?
- Very frequently
  - Frequently
  - Neither frequently nor infrequently
  - Infrequently
  - Very infrequently
  - Never

**Thank you very much for taking the time to complete this survey about the Genetics Home Reference Web site. Your feedback will help improve the site.**