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, phone 801-581-4080, FAX 801-581-4297

5. Number and Inclusive Dates of Quarterly Report:
Quarterly Report #2, covering the period from 01/16/08 through 04/15/08

6. Submission Date:
April 15, 2008

NARRATIVE DESCRIPTION

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

   Progress continues to be made in several key areas of the study. Two rounds of survey pre-testing were conducted with parents of children with special health care needs. Proposed changes to the initial and follow-up surveys were discussed with members of the GHR team. The initial parent survey was changed from a paper-and-pencil survey to a Web-based survey to streamline the data collection process. Both surveys were finalized and a study amendment was submitted to the IRB for review. The study was again determined to be exempt from federal regulations governing human research on April 7, 2008. Formatting changes were made to the data file in order to facilitate data entry and analysis. Dr. Beaudoin met with Dr. Longo and the staff of the Metabolic Clinic on March 31, 2008 to discuss logistics of recruiting parents into the study. Dr. Beaudoin obtained additional "Info Rx" prescription pads for use at the clinic.

2. Description of Progress toward the Project's Major Objectives:
   a. Administrative/Planning Activities:
      i. A study amendment was submitted to the University of Utah IRB for review.
   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. Drs. Mitchell, Longo, Logan and Beaudoin submitted a poster for presentation at the Utah Library Association meeting in April. Dr. Beaudoin was notified that the poster was accepted and will present it on April 30, 2008.
      ii. Drs. Mitchell, Longo, Logan and Beaudoin submitted a poster for presentation at the annual AMIA meeting in November and are awaiting notification by the submission review committee.

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): No significant changes have been made in project implementation to date. However, discussion is ongoing regarding the possibility of expanding 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. Expansion of the eligibility criteria would increase the number of study participants and allow data collection from three different patient populations. Additional review of the literature and

further discussion of how this proposal may affect the study results is ongoing.

6. Lessons Learned/Significant Feedback: Not applicable at this time.

7. Projected Activities for Next Quarter:
   (a) Dr. Beaudoin will attend the Metabolic Clinic at Primary Children's Medical Center and begin recruitment of the parents of newborns into the study.

   (b) Dr. Beaudoin will continue to work with Phill Wolf, NLM contractor, to format the data file and check the accuracy of 'test data' received by the system.

   (c) Dr. Beaudoin will present a poster describing the "Info Rx" study at the ULA meeting.

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 abstract accepted for poster presentation at the ULA meeting in April, and the abstract submitted for consideration as a poster presentation at AMIA in November.

Please see attached revised study documents including study description and surveys with highlighted changes in yellow. Web-based versions of the surveys may be viewed in the attachments to this e-mail.

Abstract for ULA Meeting

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

Mitchell JA[1], Beaudoin DE[1], Longo N[2], Logan R[3]

Parents of children with a possible genetic diagnosis need help to access information.[1] Providers also report not feeling competent to discuss conditions included in newborn screening panels.[2] The Genetics Home Reference Web site (GHR) offers consumers and providers accurate information about genetic conditions, including disorders identified by recommended screening tests. This study seeks to determine parental reaction to receipt of an "information prescription", and the perceived usefulness of information found on GHR. Key questions include whether use of GHR increases parental understanding of conditions, encourages parent-provider communication, or prompts further information seeking behaviors. Parents of affected newborns will receive a prescription to visit GHR and be invited to participate. After obtaining informed consent, participants will be asked to complete a demographic survey and visit the site. At six weeks, participants will complete an online survey about their user experience. Results will be analyzed using descriptive statistics and frequency responses. Referral to GHR may optimize medical management of affected newborns, ultimately improving outcomes.

Author affiliations:
1. University of Utah, School of Medicine, Department of Biomedical Informatics
2. University of Utah, School of Medicine, Department of Pediatrics
3. Office of Communications and Public Liaison, National Library of Medicine

References:
1. Skirton H. Parental experience of a pediatric genetic referral. MCN Am J Matern Child Nurs 2006;31(3):178-84.
2. Kemper AR, Uren RL, Moseley KL, Clark SJ. Primary care physicians' attitudes regarding follow-up care for children with positive newborn screening results. Pediatrics 2006;118:1836-41.

Funding: Project is funded through an agreement between the NN/LM MidContinental Region and the Department of Biomedical Informatics at the University of Utah.

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

Denise E. Beaudoin, MD, MSPH, MS[1], Nicola Longo, MD, PhD[1], Robert Logan, PhD[2], Joyce A. Mitchell, PhD[1]

[1]University of Utah, Salt Lake City, UT; [2]National Library of Medicine, Bethesda, MD

Abstract

The Genetics Home Reference Web site (GHR) offers consumers and providers accurate information about genetic conditions, including disorders identified by recommended newborn screening tests. This pilot study seeks to determine parental reaction to receipt of an "information prescription", and the perceived usefulness of information found on GHR. Study participants will visit GHR and complete a Web-based survey about their user experience. Referral to GHR may optimize medical management of affected newborns, ultimately improving outcomes.

Introduction

Parents of children referred for a possible genetic diagnosis need help to access additional information.[1] Providers also report not feeling competent to discuss conditions included in newborn screening panels.[2] The GHR is a commercial-free Web site (http://www.ghr.nlm.nih.gov) developed by the National Library of Medicine that offers consumers and providers accurate and reliable information about genetic conditions. This pilot study will assess parental reaction to the receipt of an "information prescription", and the perceived usefulness of information found on GHR. Key questions to be addressed include whether use of GHR increases parental understanding of medical conditions, encourages communication with providers, or prompts further information seeking behavior(s).

Methods

Parents of newborns diagnosed at the University of Utah Metabolic Service Clinic with one of 22 metabolic conditions (Table 1) will receive an "information prescription" from their child's provider to visit GHR and be invited to participate. After obtaining informed consent, participants will complete a demographic survey at the clinic and visit GHR at least once during a six-week period. At six weeks, participants will complete a follow-up survey about their user experience. Results will be analyzed using descriptive statistics and frequency responses.

Metabolic Condition	Acrony
Argininosuccinic acidemia	ASA
Beta ketothiolase deficiency	BKT
Biotinidase deficiency (BIOT)	BIOT
Carnitine uptake defect (CUD)	CUD
Citrullinemia (CIT)	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 dehyd. def.	LCHAD
Maple syrup disease	MSUD
Medium-chain acyl-CoA dehyd. def.	MCAD
3-Methylcrotonyl-CoA carboxylase def.	3MCC
Methylmalonic acidemia	Cb1 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 dehyd. def.	VLCAD

Table 1. List of selected metabolic conditions.

Progress to Date

The surveys have been pre-tested by parents of children with special health care needs. Study enrollment will begin once the surveys are finalized.

Anticipated Results and Conclusion

Parents will likely be eager to access information from a reliable resource. Referral to GHR may optimize medical management of affected newborns.

References

1. Skirton H. Parental experience of a pediatric genetic referral. MCN Am J Matern Child Nurs. 2006;31(3):178-84.
2. Kemper AR, Uren RL, Moseley KL, Clark SJ. Primary care physicians' attitudes regarding follow up care for children with positive newborn screening results. Pediatrics. 2006;118:1836-4.

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

Thank you for submitting your amendment application (Info Rx Amendment 3/17/08). The IRB has administratively reviewed your amendment and again determined that your study is exempt per IRB Chair as of 4/7/2008, under 45 CFR 46.101(b), from the Federal regulations governing human research. Before implementing any changes in the study, you must submit an application to the Board and secure either approval or a new determination of exemption.

It is the policy of the University of Utah that all human subject research which is exempt under this section will be conducted in accordance with (1) the Belmont Report (http://ohrp.osophs.dhhs.gov/humansubjects/guidance/belmont.htm), (2) this institution's administrative procedures to ensure valid claims of exemption, and (3) orderly accounting for such activities.

This determination of exemption only applies to the research study as submitted to the Board. Since this determination is not an approval, it does not expire or need renewal. Remember that all research involving human subjects must be approved or exempted by the Board before the research is conducted.

If you have any questions, please contact our office and we will be glad to assist you. Thanks again for submitting your proposal.

Study Description

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

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 parents' reactions to getting an "information prescription" from their child's physician that directs them to a Web site where they may retrieve accurate and consumer-friendly health information about their child's metabolic condition, and their assessment of the information found on this site.

Criteria for eligibility:

- Parent/caregiver of a child who has been diagnosed by newborn screening with at least one of 22 specified metabolic condition(s)
- Child's diagnosis was made by Nicola Longo, MD, PhD at the University of Utah Metabolic Clinic during the enrollment phase of the study

Potential benefits of participation:

- Increased understanding about your child's medical condition
- Improved communication with 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 Specified 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)

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

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 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 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 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 doctor at today's clinic visit
- ❑ From another doctor
- ❑ From the staff in my 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 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 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...

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 gender?

    - ❑ Male
    - ❑ Female

19. 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

20. 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.

21. What is your street address?

_____

22. Which city do you live in?

_____

23. Which state do you live in?

- ❑ Utah
- ❑ Idaho
- ❑ Wyoming
- ❑ Other (please fill in): _____

24. What is your 5 digit zip code?

_____

25. What is your home telephone number (including area code)?
For example, 801-332-9245.

_____

26. What is your cell phone number if you have one (including area code)?
For example, 801-332-9245.

_____

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

_____

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 Parents of Newborns with Metabolic Conditions Identified by Screening to the Genetics Home Reference Web site for Health Information

Patient Follow-up Survey

ID#_____

1. For which condition(s) did 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 3.**
- ❑ 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 3.**

2. When was your child first diagnosed with the above condition(s)? For example, if your child was first diagnosed on April 3, 2008, you would enter: 04/03/2008.

____ ____ _____
mm dd yyyy

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

- ❑ Only once (when my child was first diagnosed with a metabolic condition)
- ❑ 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 Web site

If you have never visited the Genetics Home Reference Web site, please go directly to question 26.

4. 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

5. Overall, how helpful was the information on the Genetics Home Reference Web site relating to your child's condition(s)?
   - ❑ Very helpful
   - ❑ Somewhat helpful
   - ❑ Neither helpful nor unhelpful
   - ❑ Somewhat unhelpful
   - ❑ Very unhelpful

6. 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 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 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 7 through 10, please rate your level of agreement with the statement:

7. I trust the information on the Genetics Home Reference Web site because my doctor prescribed it.
   - ❑ Strongly agree
   - ❑ Somewhat agree
   - ❑ Neither agree nor disagree
   - ❑ Somewhat disagree
   - ❑ Strongly disagree

8. A high-quality source of health information helps me talk to my doctor.
   - ❑ Strongly agree
   - ❑ Somewhat agree
   - ❑ Neither agree nor disagree
   - ❑ Somewhat disagree
   - ❑ Strongly disagree

9. The health information that I find on the Genetics Home Reference Web site will help me make better health decisions for my child.
   - ❑ Strongly agree
   - ❑ Somewhat agree
   - ❑ Neither agree nor disagree
   - ❑ Somewhat disagree
   - ❑ Strongly disagree

10. The information I received on the Genetics Home Reference Web site added to what doctors told me about my child's condition.
    - ❑ Strongly agree
    - ❑ Somewhat agree
    - ❑ Neither agree nor disagree
    - ❑ Somewhat disagree
    - ❑ Strongly disagree

11. 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

12. Was it easy or difficult to find the information you were seeking?
    - ❑ Very easy
    - ❑ Easy
    - ❑ Neither easy nor difficult
    - ❑ Difficult
    - ❑ Very difficult

13. Did you notice any missing information about 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 17.

14. 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)

_____
_____
_____
_____
_____
_____
_____

15. 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

16. 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

17. **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

18. 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

19. 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 information about a single genetic condition?

- ❑ Yes
- ❑ No

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

- ❑ Yes
- ❑ No

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

- ❑ Yes
- ❑ No

Was "Resources" (with links to other online genetic resources) more helpful to you than the 'Help Me Understand Genetics Handbook'?

- ❑ Yes
- ❑ No

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

- ❑ Yes
- ❑ No

20. 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

21. **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

22. How likely are you to use the Genetics Home Reference Web site again?
    - ❑ Very likely
    - ❑ Likely
    - ❑ Neither likely nor unlikely
    - ❑ Unlikely
    - ❑ Very unlikely

23. How likely are you to recommend the Genetics Home Reference Web site to others?
    - ❑ Very likely
    - ❑ Likely
    - ❑ Neither likely nor unlikely
    - ❑ Unlikely
    - ❑ Very unlikely

24. 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)

_____
_____
_____
_____
_____
_____

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

_____
_____
_____
_____
_____
_____
_____
_____

Please skip questions 26 and 27 and go directly to question 28. (Questions 26 and 27 are intended to be answered by those who have never visited the Genetics Home Reference Web site.)

26. 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 my child
- ❑ I already know enough about the medical issues my 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)

27. 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

28. 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):_____

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

30. 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.