1. Title of Project:
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

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 #4, covering the period from 07/15/08 through 10/15/08

6. Submission Date:
October 15, 2008
1. Executive summary. Please provide a brief, one-paragraph narrative summarizing major accomplishments made during the quarter.

Patient recruitment continued during this quarter. To date, 76 participants have been enrolled in the study. A total of 61 eligible participants (i.e., those for whom at least six weeks have passed since they were enrolled in the study) have been reminded to complete the online follow-up survey. Of these, 24 have done so for an online survey response rate of 39.3%. Follow-up efforts are ongoing to enhance the online survey response rate. In addition, the decision was made by Drs. Mitchell, Longo and Beaudoin to enroll 80 individuals into the pilot study.

2. Description of Progress toward the Project's Major Objectives:
   a. Administrative/Planning Activities: Arrangements were made for payment of obligated funds to Dr. Nicola Longo, Director of the Metabolic Clinic.
   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: Not applicable.


4. Evaluation Activities: Not applicable at this time.

5. Problems/Corrective Actions (including significant changes made in implementation of the project): The current response rate for completion of the online survey by study participants is approximately 39% (please see above). In order to enhance the response rate, Dr. Beaudoin is conducting follow-up activities as described in the study protocol, i.e., additional ‘reminder’ e-mails are being sent to participants who do not complete the online survey within the specified amount of time (six weeks from the date of study enrollment), and the date by which the online survey must be completed is emphasized at the time of patient enrollment.

During this quarter, it was noted that a study participant neglected to provide a user ID number when he/she completed the online survey. In order to prevent this occurrence in the future, an instruction was added to the top of the survey, explaining that the participant should enter the user ID number contained in the six-week reminder letter in the designated field on the survey (please see Appendix). In addition, the participant user ID number has now been incorporated into the link that allows access to the online survey. This information remains available in the NLM’s Web server logs for several days, allowing identification of study participants who neglect to complete the user ID number field in the future.
6. Lessons Learned/Significant Feedback: Not applicable at this time.

7. Projected Activities for Next Quarter:
   (a) Dr. Beaudoin will complete recruitment to achieve a final enrollment of 80 study participants.

   (b) Dr. Beaudoin will continue to conduct follow-up activities to ensure that study participants access the GHR Web site and complete the online survey.

   (c) Dr. Beaudoin will complete data entry, verify data accuracy and consult with a statistician regarding 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 the additional user instruction that was added to the online survey below:

![Genetics Home Reference](http://genet1.53080/ghr/page/SurveyOnline?idnum=abcd)

**InfoRx Patient Follow-up Survey**

University of Utah    IRB #00023554

Please enter the four-digit User ID number that you received in your six-week reminder e-mail/letter in the ID# box below.

**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)