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Quarterly Report

National Network of Libraries of Medicine - MidContinental Region Region 4

November 1, 2007 - January 31, 2008

Contract No. N01-LM-6-3504

Spencer S. Eccles Health Sciences Library
University of Utah

Submitted July 7, 2008

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Executive Summary

Personnel

Recruitment continued for the RML Director and Wyoming Liaison positions. Four candidates traveled to the University of Utah and were interviewed for the director position. The Associate Director spoke with two candidates applying for the Wyoming Liaison position.

The shared position pilot is progressing with without major problems. The MCR has hired Susan Roberts in the position of Technology Associate to help accomplish the activities stipulated in the logic model and to assume some of the day to day responsibilities that were being carried out by the Technology Coordinator and Technology Liaison. These include managing the listserv and web site and teaching. A mid-point report was presented at the RML Directors meeting on January 16, 2008.

Advocacy

Major progress was made on the design and implementation of the study on the impact of library-provided information in health care institutions. Implementation documents were written and two libraries, one academic health sciences library and one hospital library, were recruited as pilot sites.

Dana Abbey, Consumer Health/Colorado Liaison, is a member of the Colorado Medical Society CME committee. CME surveyors for the Colorado Medical Society noted that sites that

have librarians have better CME programs and are more apt to be in compliance with ACCME standards than sites that do not have librarians.

Community Outreach

Siobhan Champ-Blackwell, Community Outreach Liaison, has organized the MCR Collaboration Working Group to contribute to a guide for libraries and community groups wishing to collaborate. Members include librarians, Regional Advisory Board members, and staff of community based organizations from the region.

In December, following the year 3 budget announcement, RML staff discussed holding a symposium for librarians and staff of community based organizations on the topic of emergency planning. We decided to revisit this discussion next year after more emergency planning activities have taken place.

Gretchen Healy, Winnebago Public Library Director, and Ms. Champ-Blackwell finalized the design for a poster that Ms. Healy will use to promote health information resources and services at tribal events. The Winnebago Public Library will be the first of the tribal libraries to create a personalized poster for outreach to their community. The poster is funded by the RML.

Ms. Champ-Blackwell shared information on MedlinePlus en español and offered the “¿No Comprende?” class to state library staff in Nebraska, Utah, Kansas, and Missouri. Each of

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these states is participating in the WebJunction Spanish Outreach Project.

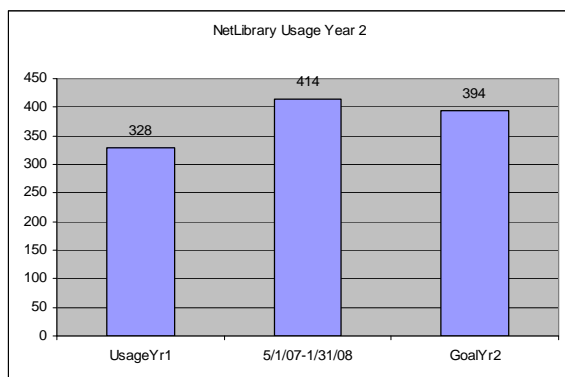
Consumer Health

Ms. Champ-Blackwell attended the ALA Mid-Winter meeting in Philadelphia, Pennsylvania in January. As a member of the ALA Wellness in the Workplace Task Force, she participated in planning the web site and participant resources including the use of Web 2.0 applications for this ALA 2008 event. She met with co-presenter Lois Dye to plan their ALA 2008 class: "The Healthy Librarian: Cultivating Wellness in the Workplace."

The Utah Library Association/Mountain Plains Library Association meeting organizers accepted three workshops proposed by the RML for their joint meeting this spring. PubMed will be taught by the NTCC and RML staff will present "From Snake Oil to Penicillin" and "¿No Comprende?."

Education

We have already exceeded our indicator set for usage of NetLibrary for this year.



We worked with the NTCC and scheduled their classes in the region through 2008.

Creighton University health sciences librarians and the RML liaison were part of the Creighton Public Health Network developing a multidisciplinary public health curriculum. At this meeting they determined the collection that would support course work. This is part of the RML effort to incorporate informatics into public health curricula.

Network Membership

The Reference Continuity Project was described to the Resource Library Directors at their bimonthly meeting. They asked for a written project description and recommended that discussion on the role of Resource Libraries be postponed until the next meeting. The Reference Continuity web page has been drafted.

An inquiry is going out to Network members to determine why they are not participating in EFTS. Staff contributed the barriers they had heard about. These identified barriers formed the basis of the inquiry. The results will help formulate the strategy for promoting EFTS among non-participants.

DOCLINE statistical reports from the region were reviewed. Of concern are the 56% of DOCLINE users who haven't updated their serial holdings within the past year. Staff is following up on the ten members that have fewer than 25 current serial subscriptions. These full members will be encouraged to increase the number of serial titles listed in DOCLINE. If they don't make the minimum, they will be changed to Affiliate member status.

We are pleased that desktop document delivery is pervasive in the region. After following up with Network members appearing on the DOCLINE report, full Network members not offering desktop document delivery dropped from nineteen to eight. Having members update their institutional records provided a more

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accurate picture of this service in the region. We agreed that the number is now low enough that no further efforts are needed to encourage this service.

The Regional Licensing Consortia Advisory group promoted EBSCOHost and Elsevier products this quarter. Following the trial period no members decided to license either of the products.

State Outreach

Progress continued in working with the Prevention Information Center, a Network member, to pilot making their online resources available to a group at the Colorado Department of Public Health and Environment. The site has been established and they are now tackling a firewall issue.

Technology

A number of Network members consulted with the RML as they tried to use new technologies: using a camera with Skype, using a wiki vs. a blog, options for holding a virtual journal club and an online class, and using SurveyMonkey. These consults are indications that regional librarians are adopting the new technologies that we have been promoting.

Sharon Dennis, Technology Coordinator, followed up with two members who had consulted with her about blogs earlier this contract year. One of the members, at an academic library, has implemented 3 blogs with another 2 in development. The other, at a hospital library, has plans to “revisit the idea in the spring.”

Rebecca Brown, Technology/Kansas Liaison demonstrated social bookmarking applications at the Technology Work Group meeting. The group decided to implement a pilot project adding and tagging useful bookmarks using Magnolia.

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Network Infrastructure

Table 1: Quarterly Infrastructure Data

	Current quarter	Previous quarter
Network members – full	177	153
Network members – affiliate	273	262
Libraries providing services to unaffiliated health professionals	106 (60%)	106 (69%)
Libraries providing services to public users	116 (66%)	118 (77%)
Average fill rate for resource libraries	78%	79%

A membership renewal letter was mailed to all affiliate members in mid-December. In January, state liaisons were provided a list of non-renewing members and were asked to personally contact them. Among our affiliate members, 102 have renewed and 172 need to renew.

Regional Advisory Board Activities

Marty Magee, Education/Nebraska Liaison, provided an overview of the RAB meeting for Roxanna Jokela, Director Rural Health Education Network, who had a conflict and could not attend.

Ira Combs, Community Liaison Nurse Coordinator, will appear in the 2008 Aetna African American History Calendar. His name was submitted by NLM at the suggestion of the MCR.

Needs Assessment and Evaluation Activities/Data

In the spring of 2007, the RML made available two podcasts from its web site interviewing individuals who work in health outreach. In August 2007, we sent out messages through the mcmla-l asking subscribers to answer questions about our podcasts. Of the 46 respondents, only six (13.3%) had listened to one or both of the podcast episodes. Most were not aware that we had produced podcasts. Those who had listened to them found them interesting and informative. The podcasts are a medium worth continuing but we need to do a better job of promoting their availability. For a more detailed report see page 3 in our newsletter

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(http://nmlm.gov/mcr/services/comm/newsletter/P TPP_February_2008.pdf)

Claire Hamasu, Associate Director, interviewed Resource Library Directors on the benefits of being a Resource Library in the NN/LM MCR. This was her project as a participant in the “Marketing as if Your Library Depended on It” workshop. Benefits that they identified that currently exist are networking, their connection to NLM, recognition and influence. Benefits that they would like to see implemented are further networking, additional resources, and more

continuing education. (See Attachment 3 for the report)

Ms. Brown also participated in the marketing workshop. Her project involved asking members of the Kansas Biomedical Librarians about their preferences in learning about technology. Most preferred receiving their technology updates from mcmla-l, the listserv that is shared between the RML and the MLA chapter. (See Attachment 4 for the report)

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Outreach

Table 2: Newly Funded Awards and Projects

Start/ end dates	Title of award/ project	PI institution	PI last name	Funding amount	Project type
10/1/2007- 4/1/2009	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: Feasibility Study in Utah	University of Utah	Mitchell	\$67,945	Evaluation

In December, the outreach RFP was revised to simplify the application process by using an online express form. The amount of the award was reduced from \$8,000 to \$6,000 to attract smaller projects.

The Hospital Library Award RFP was announced. Deadline for proposals is February 1, 2008.

A letter of support was submitted for Creighton University's grant proposal to NLM to set up a "Healthy Internet Café"

in the Omaha Tribe of Nebraska's Wellness Center. This project is a collaboration between the university and the tribe and includes the health sciences library.

Update of Ongoing, Major Projects

No Activity

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Table 3: Exhibits

Dates	Organization name	Meeting name	Location (city, state)
RML NATIONAL EXHIBITS			
1/15-19/2008	National Western Stock Show	Annual Stock Show and Rodeo	Denver, CO
RML REGIONAL/STATE/LOCAL EXHIBITS			
11/8-10/2007	Colorado Association of Libraries	Conference	Denver, CO

Actionable Feedback received from Exhibit Visitors

None

MedlinePlus Go Local

Ms. Abbey presented a poster at the Colorado Association of Libraries meeting to promote the benefits of Go Local and stir up sponsoring libraries.

Table 4: Presentations and Training provided by RML Staff

Date	Last name of staff responsible	Title of presentation/training	Location (city, state)	Number of participants	In-person or distance education
11/8/2007	Abbey	Preparing for Disaster (poster)	Denver, CO	32	In-person
11/9/2007	Kelly, Jones	Measuring Your Impact	Kansas City, KS	10	In-person
11/12/2007	Jones	Health Information Resources	Kennett, MO	10	In-person
11/13/2007	Abbey	Consumer Health Resources/PubMed	Aurora, CO	9	In-person
11/14/2007	Brown, Jones	Library Advocacy, RML Update	Wichita, KS	14	In-person
11/16/2007	Champ-Blackwell	Cultural Considerations	Omaha, NE	70	In-person

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Date	Last name of staff responsible	Title of presentation/training	Location (city, state)	Number of participants	In-person or distance education
11/21/2007	Jones, Kelly	Breezing Along with the RML	Salt Lake City, UT	Synchronous 19 Asynchronous Not available	Distance
11/28/2007	Jones	Consumer Health Resources	Columbia, MO	34	In-person
12/7/2007	Abbey	MedlinePlus, reliable web sites	Denver, CO	45	In-person
12/7/2007	Magee	DailyMed, Podcasting	Omaha, NE	30	In-person
12/14/2007	Abbey	CAM Resources	Aurora, CO	2	In-person
1/2008	Magee	Thinking like an MBA	Omaha, NE	9	Distance
1/8/2008	Magee	Health Disparity	Omaha, NE	25	In-person
1/16/2008	Magee, Dennis, Brown	Breezing Along with the RML	Salt Lake City, UT	Synchronous 28 Asynchronous 35	
1/17/2008	Jones	Map to Success: Using Logic Models to Reach Desired Outcomes	Columbia, MO	15	In-person

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Other Staff Activities

Table 5: Publications and Resources Developed by RML Staff

Date completed/published	Last name of staff responsible	Title	Medium	Submitted to Clearinghouse ("yes" or "out of scope")
11/12/2007	Champ-Blackwell	Community Outreach Pages Updated	Internet	Out of Scope
11/30/2007	Abbey	Colorado State Page Updated	Internet	Out of Scope
11/30/2007	Abbey	Wyoming State Page Updated	Internet	Out of Scope
1/1/2008	Brown	Kansas State Page Updated	Internet	Out of Scope

Notable Staff Activities

November 5-7, 2007

All librarians participated in the year 3 planning meeting hosted by the Assessment and Evaluation Liaison at the Bernard Becker Medical Library. The staff completed the logic model for year 3.

December 5-7, 2007

Ms. Hamasu attended the Scholarly Communication Institute in Chicago, Illinois with Ruth Holst, Associate Director for NN/LM

GMR, and Kathel Dunn, Associate Director for NN/LM MAR. Following the institute they continued planning how scholarly communication could be promoted to librarians in clinical settings.

January 23, 2008

Ms. Brown organized a presentation by librarians from Ebling Library on RSS Journal Service via Adobe Connect.

January 23, 2008

Year 3 budget documents were submitted to NLM.

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Photographs



NN/LM New Employee Orientation

MidContinental Region Attendees: Joan Stoddart (5th from the left) and Rebecca Brown (6th from the left)

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Attachments

Attachment 1: Quarterly OARF Summary Data - RML Staff Activities

Outreach Activities Report MidContinental Region 2006-2011 - Project

RML Q3, 2007-2008

Generated: Tuesday, June 10, 2008

7 Total Outreach Activities

The following information is based on outreach reports of training activities.

Activities Summary

Total number of estimated participants:	160 participants
Average number of participants:	22.86 per activity
Average length:	1.93 hours
Under 1 hour:	0 activities
Between 1 and 2 hours:	6 activities (85.71%)
Over 2 hours:	1 activity (14.29%)
Hands-on practice:	4 activities (57.14%)
Conducted remotely:	1 activity (14.29%)
Offering continuing education:	0 activities
Significant number of minorities:	1 activity (14.29%)

Type(s) of Organization(s) Involved in Activities

Health sciences library:	7 activities (100.00%)
Public library:	0 activities
Government agency:	0 activities
Hospital:	1 activity (14.29%)
Clinical/Health care:	1 activity (14.29%)
Academic Institution:	7 activities (100.00%)
Community-Based:	1 activity (14.29%)
Faith-Based:	1 activity (14.29%)
Public Health Agency:	0 activities
Other:	0 activities

Session Content

PubMed:	3 activities (42.86%)
MedlinePlus:	5 activities (71.43%)
ClinicalTrials.gov:	1 activity (14.29%)
NCBI:	0 activities (0.00%)
NLM Gateway:	0 activities (0.00%)
TOXNET:	0 activities (0.00%)
Other technology content:	2 activities (28.57%)
Other, non-technology content:	2 activities (28.57%)

Significant Minority Population Present

(>=50% of participants)

African American:	1 activity (14.29%)
Alaska Native:	0 activities (0.00%)
Asian and Pacific Islander:	0 activities (0.00%)
Hispanic:	1 activity (14.29%)
Native American:	0 activities (0.00%)

136 Participants Completed Participant Information Sheets

The following information is based on Participant Information (PI) sheets collected during training activities.

Participants Summary

Activities at which PI sheet collected:	100.0%
Health care or service providers:	10 participants (7.35%)
Health science library staff members:	55 participants (40.44%)
Public Health worker:	2 participants (1.47%)
Public/Other library staff members:	2 participants (1.47%)
Members of general public:	67 participants (49.25%)



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Attachment 2: Promotional Materials Provided

Date	Who	Items Provided	Purpose
11/27/2007	North Colorado Medical Center <i>Colorado</i>	– 50 MedlinePlus Bookmark	Training handouts
11/29/2007	St. Louis Public Schools – Spanish Class <i>Missouri</i>	– MedlinePlus Bookmarks (Spanish) – PubMed Bookmarks – Consumer Health Bookmarks – 1 Health Hotlines directory for the school nurse	Spanish language materials for students
12/5/2007	Utah Valley Regional Medical Center <i>Utah</i>	– 200 MedlinePlus Bookmark – 50 MedlinePlus Bookmark (Spanish) – 250 PubMed Card	Promoting medical library tools awareness in employee orientation which will ripple to others in the community
1/21/2008	Keene Memorial Library <i>Nebraska</i>	– 25 MedlinePlus Bookmark – 25 MedlinePlus Bookmark (Spanish) – 25 MedlinePlus Card (English & Spanish) – 25 NLM Pocket Card – 25 Consumer Health Card – 25 Health Information for Senior Citizens Card – 25 Tox Town Card – 25 Tox Town Brochure – 1 Tox Town Poster – 25 Household Products Database Card – 25 Good Health Information on WWW card – 25 Our Collection/Our Databases Card – 25 How to Use NLM Card – 25 PubMed Card	Promote health resources available through the library/on the web in a lunch & learn sponsored by a local wellness committee
1/25/2008	Intermountain Medical Center <i>Utah</i>	– 100 MedlinePlus Bookmark	For patients and their families interested in their health
1/25/2008	Utah Valley Regional Medical Center <i>Utah</i>	– 200 PubMed Card – 200 Medline Plus Bookmark	We are getting them out the new employees and to the administration

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Attachment 3:
The Benefits of Being a Resource Library

NN/LM MidContinental Region
The Benefits of Being a Resource Library
Claire Hamasu, Associate Director
March 31, 2008

Introduction

Resource libraries are the larger health sciences libraries in the National Network of Libraries of Medicine. They are usually at academic institutions hosting medical schools. Resource Libraries are selected by the Regional Medical Library because they are larger and have resources, expertise, and leadership that can be shared with other Network members. If we categorize Network members into the “haves” and “have nots”, Resource Libraries would generally fall into the “haves” group.

Since the mission of the NN/LM is to equalize access to health information, much of the RML programming concentrates on the “have nots”. Resource Libraries are asked to support this effort because they have access to more resources.

By interviewing Resource Library Directors, the Associate Director of the NN/LM MCR hoped to answer the following questions: What efforts would Resource Library Directors like the RML to implement that would benefit Resource Libraries?

Methodology

The NN/LM MCR has 9 Resource Library directors. The Associate Director scheduled interviews with each Resource Library Director in the region over a 3 week period October 25 – November 7, 2007. Interviews varied in length from 15 – 60 minutes as some directors took the opportunity to talk about other topics related to the RML or their own institutions. The following questions were asked:

1. What do you identify as the benefits of being a Resource Library?
2. Are there additional benefits you’d like the RML to provide?
If yes--What suggestions do you have as a Resource Library director for new benefits for RLS?
3. Is there a question I haven’t asked that you’d like to comment on?

Participating Resource Library Directors:

Jerry Perry, Director, Health Sciences Library, University of Colorado at Denver and the Health Sciences Center

Karen Cole, Director, A.R. Dykes Library of the Health Sciences, University of Kansas Medical Center

Deborah Ward, Director, J. Otto Lottes Health Sciences Library, University of Missouri – Columbia

Paul Schoening, Director, Bernard Becker Medical Library, Washington University School of Medicine

Jim Bothmer Assistant Vice President for Health Sciences and Director of Creighton University Health Sciences Library/Learning Resources Center

Nancy Woefl, Director, McGoogan Library of Medicine, University of Nebraska Medical Center

Joan Stoddart, Interim Director, Spencer S. Eccles Health Sciences Library, University of Utah

Lori Phillips, Associate Dean of Libraries, University of Wyoming [Ms. Phillips was interviewed because she is the university's representative to the Resource Library Directors group.]

Current Resource Library Benefits

The benefits recognized by the library directors fit into four categories: networking, recognition, influence and their connection to NLM.

Networking

The networking that occurs among the directors because each leads a Resource Library was a frequently mentioned benefit. As a director of a Resource Library they had access to other directors and the opportunity to learn from each others' experiences and exchange ideas. The regular meetings that the RML coordinates for the directors foster a collegial relationship that can provide the opportunity to work on collaborative efforts.

Connection to NLM

Directors also felt that being a Resource Library gave them a closer connection to NLM. They could use the NN/LM staff to funnel information to NLM or consult with the staff on how to approach NLM. They felt NLM's recognition of their library as a Resource Library was helpful in establishing relationships with divisions within NLM.

Recognition

Another frequently mentioned benefit was the prestige that comes from being selected a Resource Library. The recognition comes at all levels, from within the university and by libraries of all types around the state. With this recognition comes an expectation that the Resource Library is a leader in the state.

Influence

Resource Libraries are in a role to influence the RML and the NN/LM program and indirectly the NLM. Directors saw this influential position as a benefit. Two of the directors attributed the increased engagement as a characteristic of the distributed model. In the work that they do, liaisons represent NLM and the NN/LM. They also represent their Resource Library. This incorporates multiple influences to be expressed through one individual's activities.

New Benefits for Resource Libraries

Suggestions of additional benefits for Resource Libraries fell into three major categories: more networking, developing additional resources, and offering more continuing education.

Networking

Directors wanted the RML to facilitate networking at a more mature level resulting in more collaboration among the libraries, calling attention to the strengths and programming at their

libraries. They asked for more communication about the directions being taken by the National Library of Medicine.

Resources

The Resource Library Directors wanted the opportunity to increase the amount of funding to their libraries. They suggested increasing the number and the dollar amount of competitive subcontracts to make it more attractive for their staff to apply. Another suggestion was to provide basic funding to each of the Resource Libraries and create a pot of money for which the Resource Libraries would submit proposals. In the area of staff as a resource, a request was to allow greater flexibility in the use of liaisons within their own libraries.

Continuing Education

Resource Library Directors asked for more support in increasing the technology skills and awareness of library staff. They wanted more events for support staff development as well as professional librarian development. One idea was to have the directors as presenters in Breezing Along with the RML.

Additional Recommendations for the RML

Resource Library Directors took this opportunity to comment on areas of the RML that did not directly impact Resource Libraries. They provided advice on the MCR's operations, outcomes and activities.

Operations

- Funded projects should have a post-funding plan
- The MCR's logic model should focus on depth rather than breadth
- Consider additional academic health sciences libraries for Resource Libraries

Recommended Outcomes

- Network members know what's available on the MCR web site
- Go Local is in all of the region's states
- NN/LM MCR members can articulate the benefits of membership

Activities

- Coordinate regional disaster planning
- Coordinate identification of historical and unique materials
- Provide training of membership on how to do assessment
- Support recruitment into the profession
- Support diversity of the profession

Additional Comments

There are fewer problems in working out the logistics of awarding of subcontracts to Resource Libraries with accounting and sponsored projects offices.

NN/LM has been valuable throughout this professional career

Resource library needs are being well met

Conclusion

The benefits that Resource Library Directors identified were non-tangible: networking opportunities among themselves and with NLM, recognition, and influence.

Additional efforts that they would like to have the RML make on their behalf included facilitating increased collaboration among the Resource Libraries, more communication about the National Library of Medicine, the opportunity for increased funding and increased training for staff at all levels.

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Attachment 4:
Communicating Technology Developments in Kansas

Communicating Technology Developments in Kansas
Rebecca Brown, Kansas/Technology Liaison

What did I hope to discover?

The National Network of Libraries of Medicine MidContinental region has approximately seven different communication outlets by which we communicate technology developments to our members. As one of Technology Liaisons for the MidContinental Region of the NN/LM, I wanted to learn which methods of communications are preferred by our members.

What method did I use?

Using Survey Monkey, I asked people to rank all seven different communication methods. I also included an open-ended question with a text box for responses.

Survey Question:

How do you prefer to receive updates about technology developments, such as information about freely available software tools, from the MidContinental Region of the NN/LM? Please rank the following choices from 1-7 (1 is the highest rank).

MCR web site at <http://nnlm.gov/mcr/>

MCMLA Listserv

MCR Blog Technology Category

Plains to Peaks Post

Breezing with the RML Showcase Sessions

RSS

Podcast

Other: What is your idea? What would you like to tell us that we haven't asked?

Who did I include in the survey?

I limited the survey to a subset of NN/LM members. I sent the survey link to 32 Kansas NN/LM members who are members of the Kansas Biomedical Librarians (KBML) group. The invitation to respond to the survey was sent over the KBML listserv. Initially, only 10 people responded, so I sent out a reminder email a few days later and 3 additional members responded, a 40% response rate.

What did I learn?

77% of respondents ranked the MCMLA Listserv as their number one choice to receive technology updates. One member stated that she likes having information sent to her via email; she does not want to have to search for information on a website.

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Attachment 5:
Go Local Quarterly Report

University of Nebraska
Nebraska Go Local

**Quarterly Report
October - December 2007
Submitted by Marie Reidelbach, McGoogan Library of Medicine,
University of Nebraska Medical Center, Omaha, NE**

Current primary staff and their roles

- No changes to report at this time

Major changes or additions made to the database

- Two mailings have been sent to clinics throughout the state. All cities from A – L have been mailed with roughly 25% return. Our assumption is going to be that no response means the information is current. The majority of responses received have come through the GoLocal@unmc.edu email address and the library toll free number. The mailings have provided an excellent way to update the records as well as promote the project to health care providers. Two more mailings remain to cover all 2500+ clinics located in Nebraska.

Outreach and promotion efforts

- **Exhibit and presentation at 10th Annual Omaha Women’s Health & Wellness Conference, October 5, 2007, 8:00am – 3:00pm – total attendance approx. 300.** Roxanne Cox and Teri Hartman exhibited Go Local Nebraska and MedlinePlus at this established women’s health fair that took place in the convention center in Council Bluffs, IA. Exhibit was set up and attracting visitors from 7:00am until 3:00pm, with the best times between 7 and 10:30 am, when direct information contact about Go Local Nebraska was made with 63 individuals. Go Local Nebraska and MedlinePlus were also presented to approximately 25 attendees in an afternoon break out session that included live Internet demonstrations.
- **Meet & Greet on UNMC campus, November 8, 2007, Noon – 2:00pm – total attendance approximately 115.** Six librarians from the McGoogan Library of Medicine, including the library director, hosted the second annual Meet & Greet in the private dining rooms of the University of Nebraska Medical Center. Event attendees were introduced to or reminded of library services for UNMC and The Nebraska Medical Center, including Go Local Nebraska and MedlinePlus.
- **The National Network/Libraries of Medicine Education and Nebraska Liaison shared information about Go Local Nebraska and the CHIRS program at the following events:**

Go Local promotions by NNLM MCR liaison		
Oct.-Dec. 2007		
Event	Contact	Date
Health Policies Class-UNO School of Public Administration	Alice Schumacker	Oct. 1, 2007
Children's Hospital Librarian	Jessy Covert	Oct. 2, 2007
Wellness Works - Outreach from St. Francis Medical Ctr. - Grand Island	Doreen Folland	Oct. 24, 2007
St. Francis Medical Center - Director of Education	Shery Huffman	Oct. 24, 2007
Nebraska Library Association conference -Exhibit and presentation on Sr. Resources		Oct. 25, 2007

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Fremont library receives 'Go Local' recognition

The Keene Memorial Library in Fremont was presented the first Go Local Nebraska Recognition Award last week by Marie Reidelbach, associate director of the UNMC McGoogan Library of Medicine.

The librarians and staff of the Keene library received the award for their work on completing a comprehensive listing of the Fremont community health services in the [Go Local Nebraska database](#).

"Thanks to their work, Fremont and Dodge County area residents can access up-to-date health services information directly through Go Local Nebraska," Reidelbach said during a ceremony on Wednesday at the Keene library.

Jennifer Wright, a library aide at the Keene Memorial Library, was the principal staff member involved with the 2007 project.

Go Local Nebraska was launched in 2006 and contains health services directory information for the state of Nebraska. It was created by staff at the McGoogan Library. The directory is managed by a team of librarians and a citizen advisory group.

In addition to funding through UNMC, Go Local Nebraska also is supported by the National Network of Libraries of Medicine and the [Nebraska Library Commission](#).

Nebraska public libraries in Blair, Oakland, Hooper and Wahoo are currently reviewing and updating their community's health services



Marie Reidelbach, associate professor and associate director of user services at UNMC-McGoogan Library of Medicine, second from left, presents the Go Local Nebraska Recognition Award to Ann Stephens, director of Keene Memorial Library, second from right, as Teresa Hartman, associate professor and head of education at the McGoogan library, and Keene library assistant Jennifer Wright look on.

information for the Go Local Nebraska database.

The [McGoogan Library of Medicine](#) is directed by Nancy Woelfl, Ph.D., and has served Nebraska consumers with access to free health information since 1984. The library's mission is to serve the biomedical information needs of UNMC faculty, staff and students and to support quality health information access for all Nebraskans.

Date Published: Monday, January 7, 2008

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Attachment 6:
Subcontractor Quarterly Report

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

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 #1, covering the period from 10/01/07 through 01/15/08

6. Submission Date:

January 15, 2008

NARRATIVE DESCRIPTION

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

This is the first reporting period for this project. Progress has been made in several key areas. The NLM approved the revised project budget and an agreement between the NN/LM MidContinental Region, University of Utah and the Department of Biomedical Informatics was signed. The study was reviewed by the University of Utah's Institutional Review Board and determined to be exempt from federal regulations governing human research, allowing the study to move forward. The study surveys (initial and follow-up) were developed. A prototype of the online follow-up survey was created by NLM systems development staff. Planning for survey pre-testing is underway.

2. Description of Progress toward the Project's Major Objectives
 - a. Administrative/Planning Activities:
 - i. A study application was submitted to the University of Utah IRB for review on October 25, 2007. The study was deemed exempt on November 11, 2007. (Please see attached IRB notification.)
 - ii. The Department of Biomedical Informatics was notified on November 19, 2007, that the revised budget of \$67,945 had been approved by the NLM.
 - iii. An agreement between the NN/LM MidContinental Region/U of U and the Department of Biomedical Informatics was signed on December 11, 2007.
 - b. Collaborations/Partnerships:
 - i. Dr. Beaudoin has contacted Ms. Gina Pola-Money, Director of Utah Family Voices, for assistance with recruitment of parents to pre-test study surveys.
 - c. Publicity/Marketing Activities: Not applicable.
 - d. Product/Resource Development Activities: Not applicable.
 - e. Site Visits: None at this time.
 - f. Outreach activities:
 - i. Dr. Joyce Mitchell provided information about the Genetics Home Reference resource to Eccles Health Sciences librarians on January 14, 2008. Dr. Beaudoin summarized the "Info Rx" evaluation project following Dr. Mitchell's presentation. Enrolled parents requiring access to the Internet or assistance in viewing the GHR site will be referred to reference staff at the Eccles Library or to local public libraries as appropriate.
 - g. Web site development activities: Not applicable.
 - h. Exhibits: Not applicable.
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.

6. Lessons Learned/Significant Feedback: Not applicable at this time.
7. Projected Activities for Next Quarter:
 - (a) Pre-testing of both surveys will be conducted with a small number of parents. Two rounds of pre-testing are planned. Revisions to the surveys will be made based on feedback from parents and comments from project partners.
 - (b) The revised surveys will be resubmitted to the IRB for review (per protocol).
 - (c) Following IRB review, the surveys will be finalized and either printed (initial paper-and-pencil survey) or made available online (follow-up survey) via the “mock” GHR site developed by NLM.
 - (d) Dr. Beaudoin will meet with study co-investigator Nicola Longo, MD, and staff at the Metabolic Service Clinic to review the logistics of study implementation and begin recruitment of parents into the study.
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 study description and surveys (original versions).

IRB_00023554

PI: Joyce Mitchell

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 request for approval of this study. The IRB has administratively reviewed your application and a designated IRB member has determined that your study is exempt, under 45 CFR 46.101(b), Category 2, from the Federal regulations governing human research. Before implementing any changes in the study, you must submit an amendment application to the IRB and secure either approval or a 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 IRB. 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 IRB before the research is conducted.

If you have questions about this, please contact our office at 581-3655 and we will be happy to assist you. Thank you 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” 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 paper-and-pencil survey at the clinic (5 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 Patient Survey

1. How frequently do you look up sources of medical information? (Check one please)
 - Very frequently
 - Somewhat frequently
 - Neither frequently or infrequently
 - Somewhat infrequently
 - Very infrequently

2. How frequently do you discuss the medical information that you look up with your doctor?
(Check one please)
 - Very frequently
 - Somewhat frequently
 - Neither frequently or infrequently
 - Somewhat infrequently
 - Very infrequently

3. Do you find it easy or difficult to understand the medical issues that your doctor discusses
with you? (Check one please)
 - Very easy
 - Somewhat easy
 - Neither easy or 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? (Check one please)
 - Very easy
 - Somewhat easy
 - Neither easy or difficult
 - Somewhat difficult
 - Very difficult

5. Where is the location of the nearest computer you can use? (Check one please)
 - 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? (Check one please)
 - 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? (Check one please)
- Yes
 - No
 - Don't know
8. If yes, approximately how many times have you visited the Genetics Home Reference Web site? (Check one please)
- 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? (Check one please)
- 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!)
10. I think receiving a prescription from my doctor to visit the Genetics Home Reference Web site for more information is a good idea.
(Please tell us if you agree or disagree with this statement. Check one please)
- Strongly agree
 - Somewhat agree
 - Neither agree or 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? (Check one please)
- Yes
 - No
 - Don't know
12. What is your role in this child's medical care?
- Parent
 - Guardian/caretaker
 - Other: _____ (please explain)

Please provide the following demographic information about yourself:

13. Name _____

14. Date of birth: _____/_____/_____
(month) (day) (year)

15. Gender: (Please check the appropriate box)

- Female
- Male

16. Street address: _____

17. City: _____

18. State: _____

19. Zip code: _____

20. Telephone number: (____) – (____) _____

21. E-mail address (if available): _____

22. Name of your child's physician _____

23. Which of the following best describes the highest level of education you have completed? (Please check the appropriate box)

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

24. Which of the following best describes your race/ethnicity? (Please check the appropriate box)

- American Indian or Alaskan Native
- Asian or Pacific Islander
- Black, not of Hispanic origin
- Hispanic
- White, not of Hispanic origin

Assigned ID number _____

Thank you very much for completing this survey. We will contact you in approximately six weeks to ask you to complete an online survey about the Genetics Home Reference Web site. Your feedback is very important to us as it will be used to improve the 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. Approximately how many times have you visited the Genetics Home Reference Web site since you received the ‘Information Prescription’ from your doctor? (Check one please)

- 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.

2. For which condition(s) did your child receive a confirmed diagnosis? (Please indicate below)

- 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
- My child had a positive screening test but was not ultimately diagnosed with one of the above conditions (false positive test)

3. When was your child first diagnosed with the above condition(s)?

____/____/____
(day) (month) (year)

4. Overall, was the information within the Genetics Home Reference Web site easy or difficult to understand? (Check one please)
- 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)? (Check one please)
- 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!)
7. I trust the information on the Genetics Home Reference Web site because my doctor prescribed it. (Please tell us if you agree or disagree with this statement. Check one please)
- 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. (Please tell us if you agree or disagree with this sentence. Check one please)
- 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. (Please tell us if you agree or disagree with this sentence. Check one please)
- 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. (check one please)

- 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? (Check one please)

- 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? (Check one please)

- 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

14. If yes, 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

15. 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)

16. Did you use these Internet sources to fill in the missing information? (please check all that apply)

- WebMD.com
- MedlinePlus.gov
- MSN Health
- Genetic Alliance (<http://geneticalliance.org/>)
- Ask the Geneticist (<http://www.askthegen.org/>)
- Understanding Genetics : A guide for patients and professionals
(http://geneticalliance.org/ws_display.asp?filter=pubs.understanding.genetics.download)
- Madison's Foundation (<http://www.madisonfoundation.org/>)
- March of Dimes (<http://www.marchofdimes.com/pnhec/4439.asp>)
- None of the above

17. When you used the Genetics Home Reference Web site, how frequently did you visit:

Pages that focus on a single genetic condition? (check one please)

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

Pages that focus on a particular gene? (check one please)

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

Pages that focus on a particular chromosome? (check one please)

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

The 'Help Me Understand Genetics Handbook' (background information about genetics, including inheritance, genetic counseling)? (check one please)

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

Definitions of glossary terms? (check one please)

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

Resource lists (that link to other online resources)? (check one please)

- 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? (check one please)

- "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. Within the Genetics Home Reference Web site, were the resource lists and links more helpful to you than...

Information about a single genetic condition?

- Yes
- No

Information about a particular gene?

- Yes
- No

Information about a particular chromosome?

- Yes
- No

The 'Help Me Understand Genetics Handbook'?

- Yes
- No

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? (check one please)

- WebMD.com
- MedlinePlus.gov
- MSN Health
- Genetic Alliance (<http://geneticalliance.org/>)
- Ask the Geneticist (<http://www.askthegen.org/>)
- Understanding Genetics : A guide for patients and professionals (http://geneticalliance.org/ws_display.asp?filter=pubs.understanding.genetics.download)
- Madison's Foundation (<http://www.madisonsfoundation.org/>)
- March of Dimes (<http://www.marchofdimes.com/pnhec/4439.asp>)
- None of the above

21. The following resources for genetic information were more helpful to me than the Genetics Home Reference Web site:

WebMD.com (check one please)

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

MedlinePlus.gov (check one please)

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

MSN Health (check one please)

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

Genetic Alliance (<http://geneticalliance.org/>) (check one please)

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

Ask the Geneticist (<http://www.askthegen.org/>) (check one please)

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

Madison's Foundation (<http://www.madisonsfoundation.org/>) (check one please)

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

March of Dimes (<http://www.marchofdimes.com/pnhec/4439.asp>) (check one please)

- 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? (Check one please)

- 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? (Check one please)

- 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:

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?

(Check one please)

- 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 these Internet services to find health information about your child's condition?

Yahoo

- Yes
- No

Google

- Yes
- No

AOL

- Yes
- No

Answers.com

- Yes
- No

Others

- Yes
- No

Not applicable to me

- Yes
- No

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? (check one please)

- 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.

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