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<td>42</td>
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</tbody>
</table>
Executive Summary

Personnel

Jean Shipman accepted the position as Director of the RML and the Spencer S. Eccles Health Sciences Library. Her start date is October 1, 2008.

Orientation for Jim Honour, Wyoming Liaison, proceeded throughout the quarter.

Sandy Drollinger was hired as Financial Analyst. Her start date is August 4, 2008.

The final report on sharing the Technology Coordinator position was submitted to NLM. (See Attachment 3)

Advocacy

Barb Jones, Missouri/Library Advocacy Liaison, completed follow-up interviews with participants in the MCMLA Library Advocacy Task Force Survey. She gathered more data on the services the libraries provide to administrators; the existence of a marketing plan; and whether budget and staffing had gone up, down or remained level.

Ms. Jones has started recruiting hospital librarians in Missouri and Colorado for the value of librarians/libraries research study. This is a research effort being led by the J. Otto Lottes Library. A core set of questions is asked by every participating library so comparisons can be made. The additional benefit to participation is that librarians can add questions to customize the questionnaire to their local environment.

Community Outreach

Rebecca Brown, Kansas/Technology Liaison, contributed health information items to the US Department of Health and Human Services Region VII Office of Minority Health Weekly Update.

Siobhan Champ-Blackwell, Community Outreach Liaison; Claire Hamasu, Associate Director; and John Bramble, Utah/Network Membership Liaison; as members of the TC4C Effective Practices work group, reviewed the proposals submitted for TC4C community partnerships. They approved the Arizona project and developed questions for the projects submitted by Utah and New Mexico for areas that were unclear.

Consumer Health

Ms. Champ-Blackwell and Dana Abbey, Colorado/Consumer Health Liaison, attended the American Library Association Annual Conference. Ms. Champ-Blackwell was very involved in wellness activities developed for the conference. She helped run the Wellness Fair that attracted about 500 people and spoke in the Membership Pavilion about ALA’s Wellness Initiative. Both Ms. Abbey and Ms. Champ-Blackwell were presenters during the main...
conference program and Ms. Champ-Blackwell was on a health disparities panel.

Ms. Brown established a Kansas consumer health wiki based on the comments of the Kansas public library focus group held in April. It started with five subscribers and is now up to seventeen.

Education

Marty Magee, Nebraska/Education Liaison, weeded and selected new technology and management titles for the NetLibrary collection.

Network Membership

In preparation for the RML Directors meeting at MLA, data was collected from the region. Resource Libraries were asked to respond to questions on their transition to electronic collections. All but two Resource Libraries responded to the questions. Resource Library Directors, Regional Advisory Board members, and Eccles Library faculty were invited to respond to questions about trends and the impact of those trends on the NN/LM program for 2011-2016. One director and two advisory board members contributed to the response from the MCR. Both reports were submitted for the minutes of the RML Directors’ meeting.

Regional Licensing Consortium

The Regional Licensing Consortium Advisory Group prepared the 2008-2009 fiscal year offering of electronic resources. Resources from the Future Science Group, Sage Publications, EBSCOHost, and Elsevier will be negotiated for the region. Renewal negotiations were started for ACP Pier.

The Pacific Southwest Region decided to initiate a collaboration with a licensing group in California and will not be participating in the consortium with BCR. Under a new CEO, BCR continues to clarify with the RML expectations of its role in negotiating license agreements for the region. Ms. Hamasu and Mr. Bramble held a meeting with Brenda Bailey-Hainer, President and CEO for BCR. BCR expected increased revenue with additional RMLs and increased MCR member participation. Under the agreement between BCR and the RML, BCR feels that it is not being financially compensated for the work that is required to make electronic resources available to MCR members. BCR and MCR will continue negotiations.

Reference Continuity Service

In July, the first two libraries were matched through the Reference Continuity Service Project: the medical libraries of the Poudre Valley Health System in Colorado and Campbell County Memorial Hospital in Wyoming. Mr. Bramble facilitated the agreement between the librarians on their backup service points. They decided to work under an informal, unsigned agreement.

Emergency Preparedness

Ms. Brown is one of a three-person committee to create an emergency preparedness plan for the Dykes Library. The final output is a continuity of operations plan.

All staff participated in the day long event planned by Dan Wilson, coordinator for the NN/LM National Emergency Preparedness Plan, and Susan Yowell, project assistant. Staff agreed to carry out the following activities:

- spread the word through consortia in the region as well as the state organizations
- publish a briefing about the plan and the services available
- encourage applications for awards to fund implementing the plan
- address the MLA chapter meeting about the plan
- host a Moodle class
include information about the plan in personal site visits

− offer something (e.g., dPlan, etc.) that members can start at the meetings

− create promotional materials for the plan (e.g., a brochure) for use within the region

− create promotional materials for the Toolkit site (e.g., baseball cards) to hand out at meetings, etc.

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**Technology**

The Health Sciences Library at the University of Colorado Denver joined other Resource Libraries in PIG testing this quarter. There was a successful event on June 18, 2008, when Dan Wilson’s presentation on emergency planning was broadcast from the Eccles Health Sciences Library to Resource Libraries in Colorado, Nebraska, Kansas, and Missouri (Washington University). Other libraries did not have their PIGs set up and heard the presentation via teleconference.

Ms. Brown organized the first informal meeting of the Technology Coordinators to discuss current projects, collaboration opportunities, and generally assist each other. This serves a different purpose from the sessions organized by Web-STOC.
Network Infrastructure

Table 1: Quarterly Infrastructure Data

<table>
<thead>
<tr>
<th></th>
<th>Current quarter</th>
<th>Previous quarter</th>
</tr>
</thead>
<tbody>
<tr>
<td>Network members – full</td>
<td>166</td>
<td>168</td>
</tr>
<tr>
<td>Network members – affiliate</td>
<td>150</td>
<td>146</td>
</tr>
<tr>
<td>Libraries providing services to unaffiliated health professionals</td>
<td>102 (61%)</td>
<td>105 (63%)</td>
</tr>
<tr>
<td>Libraries providing services to public users</td>
<td>111 (67%)</td>
<td>115 (69%)</td>
</tr>
<tr>
<td>Average fill rate for resource libraries</td>
<td>76%</td>
<td>78%</td>
</tr>
</tbody>
</table>

- Closed: Lutheran Community Hospital, NE
- Full to Affiliate Membership: St. John’s Medical Center, WY
- New Affiliate Members:
  - University of Saint Mary, KS
  - Topeka and Shawnee County Public Library, KS
  - Utah College of Dental Hygiene, UT

Ms. Jones learned that the library at St. Joseph Hospital in Kirkwood, Missouri is being asked to eliminate all its holdings. This is part of the reorganization of the Sisters of St. Mary’s Hospital system. All system hospitals in the St. Louis area will fall under one of two managers. Several of the hospitals are expanding into new facilities, and there is a potential for growth of library services throughout the system.

Ms. Jones presented a proposal at the July DOCLINE Coordinators’ meeting to collect data on closed libraries throughout the country. Pat Devine, Network Coordinator from the Pacific Northwest Region, and Mr. Bramble will work with her on this effort.
Regional Advisory Board Activities

Ms. Hamasu gathered suggestions for new board members from the liaisons and composed a Regional Advisory Board representative of the diversity in the region. All candidates accepted their invitations to serve on the board, and letters confirming their appointments were mailed in July. An orientation session for board members, conducted by Joan Stoddart, Acting Director, and Ms. Hamasu, is being scheduled.

Needs Assessment and Evaluation Activities/Data


Ms. Kelly and Mr. Bramble emailed a draft of the Network Member Questionnaire to testers from the Regional Advisory Board. The questionnaire collects information about the resources and services available from our health sciences library members.

Usability tests for the MCR web site were conducted by AIR from May 7-15, 2008. Ms. Brown and Sharon Dennis, Technology Coordinator, reviewed the recordings. They gleaned additional action items from the viewings to add to the recommendations of the final report.

On July 11, 2008, Ms. Hamasu participated in an orientation for site visit team members to the New England Region (NER) held by Angela Ruffin. Others on the team are Harold Schoolman (chair), Holly Buchanan (University of New Mexico), and Michelle Brewer (New Jersey Hospital Association). NER's proposal, newsletters, and reports were reviewed in preparation for the visit. The site visit took place on Thursday, July 24, 2008. It was very well organized, and Ms. Hamasu got ideas on how to structure the MCR site visit and adapt the NER advocacy program for this region. She drafted her report as a team member addressing the strengths of the NER, challenges and recommendations for the NER, recommendations for NLM, and other comments.

A Network member from Missouri reported that DOCLINE did not have the current records for a journal title change. This was reported to NLM who appreciated being told of the problem and fixed it.
Outreach

Table 2: Newly Funded Awards and Projects

<table>
<thead>
<tr>
<th>Start/end dates</th>
<th>Title of award/project</th>
<th>PI institution</th>
<th>PI last name</th>
<th>Funding amount</th>
<th>Project type</th>
</tr>
</thead>
<tbody>
<tr>
<td>No new projects</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

In year 2, the RML administered a questionnaire about our funding efforts. Participants could indicate whether they wanted liaisons to contact them. Ms. Jones and Ms. Magee followed up with Missouri and Nebraska members.

Ms. Champ-Blackwell consulted with the Nebraska AIDS Project, the University of Nebraska Medical Center (UNMC) Center for Health Disparities, and the UNMC McGoogan Library of Medicine on their proposal for the NLM HIV/AIDS Outreach RFP. They were not able to meet the proposal deadline. She also advised the Cardiac Center of Creighton University about funding agencies and opportunities.

The RML forwarded three proposal summaries in response to the NICHSR funding for public health projects. Two were from Kansas and one was from Nebraska. None were funded.

Update of Ongoing, Major Projects
No Activity
Table 3: Exhibits

<table>
<thead>
<tr>
<th>Dates</th>
<th>Organization name</th>
<th>Meeting name</th>
<th>Location (city, state)</th>
</tr>
</thead>
<tbody>
<tr>
<td>6/9-12/2008</td>
<td>USPHS</td>
<td>Scientific and Training Symposium</td>
<td>Tucson, AZ</td>
</tr>
<tr>
<td>6/29-7/1/2008</td>
<td>National AHEC</td>
<td>NAO 2008 Conference</td>
<td>Denver, CO</td>
</tr>
<tr>
<td>RML REGIONAL/STATE/LOCAL EXHIBITS</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5/7/2008</td>
<td>St. John’s Medical Center</td>
<td>Teton County Health Fair</td>
<td>Jackson, WY</td>
</tr>
<tr>
<td>5/13/2008</td>
<td>CIMRO of Nebraska</td>
<td>Nebraska Healthcare Quality Forum</td>
<td>Lincoln, NE</td>
</tr>
<tr>
<td>5/28/2008</td>
<td>Creighton University</td>
<td>AgeWell Senior Center Health Fair</td>
<td>Omaha, NE</td>
</tr>
<tr>
<td>6/18/2008</td>
<td>Omaha Public Library, Washington Branch</td>
<td>June Family Fair</td>
<td>Omaha, NE</td>
</tr>
<tr>
<td>6/19-20/2008</td>
<td>Colorado Rural Health Center</td>
<td>Colorado Rural Health Conference</td>
<td>Copper Mountain, CO</td>
</tr>
</tbody>
</table>

Actionable Feedback received from Exhibit Visitors

No suggestions or recommendations were received from exhibit visitors this quarter.

MedlinePlus Go Local

The Utah/TC4C Go Local coordinator moved to another state. Mr. Bramble assisted the library to complete its portion of the TC4C questionnaire. Discussion is being held within the library about Go Local responsibilities.

Table 4: Presentations and Training provided by RML Staff

<table>
<thead>
<tr>
<th>Date</th>
<th>Last name of staff responsible</th>
<th>Title of presentation/training</th>
<th>Location (city, state)</th>
<th>Number of participants</th>
<th>In-person or distance education</th>
</tr>
</thead>
<tbody>
<tr>
<td>5/2/2008</td>
<td>Bramble</td>
<td>Quality Health Information for School Nurses</td>
<td>Ogden, UT</td>
<td>16</td>
<td>In-person</td>
</tr>
<tr>
<td>5/7/2008</td>
<td>Bramble</td>
<td>Quality Consumer Health Information</td>
<td>Jackson, WY</td>
<td>6</td>
<td>In-person</td>
</tr>
<tr>
<td>Date</td>
<td>Last name of staff responsible</td>
<td>Title of presentation/training</td>
<td>Location (city, state)</td>
<td>Number of participants</td>
<td>In-person or distance education</td>
</tr>
<tr>
<td>------------</td>
<td>--------------------------------</td>
<td>-----------------------------------------------------------------------------------------------</td>
<td>--------------------------------</td>
<td>------------------------</td>
<td>---------------------------------</td>
</tr>
<tr>
<td>5/9/2008</td>
<td>Magee</td>
<td>Health Resources for Diverse Populations</td>
<td>Bellevue, NE</td>
<td>7</td>
<td>In-person</td>
</tr>
<tr>
<td>5/13/2008</td>
<td>Bramble, Salmond</td>
<td>DOCLINE Routing Tables</td>
<td>Salt Lake City, UT</td>
<td>Synchronous 8</td>
<td>Distance Education</td>
</tr>
<tr>
<td>5/17/2008</td>
<td>Abbey, Champ-Blackwell, Sahali (PNR)</td>
<td>Getting Started with Information Outreach in Minority Communities</td>
<td>Chicago, IL</td>
<td>11</td>
<td>In-person</td>
</tr>
<tr>
<td>5/18/2008</td>
<td>Dennis, Sandstrom (PSR)</td>
<td>High Tech High Touch: Sharing Staff at a Distance</td>
<td>Chicago, IL</td>
<td>80</td>
<td>In-person</td>
</tr>
<tr>
<td>5/19/2008</td>
<td>Hamasu, Kelly</td>
<td>Demonstrating Effectiveness: One RML’s Story</td>
<td>Chicago, IL</td>
<td>80</td>
<td>In-person</td>
</tr>
<tr>
<td>5/20/2008</td>
<td>Jones, Kelly</td>
<td>ROI Calculator</td>
<td>Chicago, IL</td>
<td>80</td>
<td>In-person</td>
</tr>
<tr>
<td>5/21/2008</td>
<td>Dennis</td>
<td>Blogs and Wikis</td>
<td>Chicago, IL</td>
<td>14</td>
<td>In-person</td>
</tr>
<tr>
<td>5/27/2008</td>
<td>Bramble, Salmond</td>
<td>DOCLINE for Beginners</td>
<td>Salt Lake City, UT</td>
<td>Synchronous 1</td>
<td>Distance Education</td>
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<tr>
<td>5/29/2008</td>
<td>Brown</td>
<td>Social Bookmarking: Bookmarking for the Greater Good</td>
<td>Kansas City, KS</td>
<td>Synchronous 14</td>
<td>Distance Education</td>
</tr>
<tr>
<td>6/5/2008</td>
<td>Salmond</td>
<td>DOCLINE Routing Tables</td>
<td>Salt Lake City, UT</td>
<td>Synchronous 4</td>
<td>Distance Education</td>
</tr>
<tr>
<td>6/11/2008</td>
<td>Champ-Blackwell</td>
<td>National Library of Medicine Resources for Minority Summer Research Interns</td>
<td>Omaha, NE</td>
<td>2</td>
<td>In-person</td>
</tr>
<tr>
<td>6/12/2008</td>
<td>Jones, Kelly</td>
<td>Measuring Your Impact</td>
<td>Traverse City, MI</td>
<td>21</td>
<td>In-person</td>
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<tr>
<td>6/13/2008</td>
<td>Magee</td>
<td>Thinking Like an MBA</td>
<td>Wilson, NC</td>
<td>22</td>
<td>In-person</td>
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<tr>
<td>6/18/2008</td>
<td>Brown, Dennis</td>
<td>Breezing Along with the RML</td>
<td>Kansas City, KS</td>
<td>Synchronous 42</td>
<td>Distance Education</td>
</tr>
<tr>
<td>6/26/2008</td>
<td>Brown</td>
<td>Spanish Language Online Resources - Reaching Out to Spanish Speaking Communities</td>
<td>Kansas City, KS</td>
<td>Synchronous 6</td>
<td>Distance Education</td>
</tr>
<tr>
<td>6/30/2008</td>
<td>Champ-Blackwell</td>
<td>The Healthy Librarian: Cultivating Wellness in the Workplace</td>
<td>Anaheim, CA</td>
<td>78</td>
<td>In-person</td>
</tr>
<tr>
<td>6/30/2008</td>
<td>Champ-Blackwell</td>
<td>Partnering to Help Reduce Health Disparities in our Communities</td>
<td>Anaheim, CA</td>
<td>17</td>
<td>In-person</td>
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<tr>
<td>6/30/2008</td>
<td>Abbey</td>
<td>Take Two Aspirin: Helping Librarians Meet the Public Demand for Consumer Health Information</td>
<td>Anaheim, CA</td>
<td>43</td>
<td>In-person</td>
</tr>
<tr>
<td>July 2008</td>
<td>Magee</td>
<td>Thinking Like an MBA</td>
<td>Omaha, NE</td>
<td>5</td>
<td>Distance Education</td>
</tr>
<tr>
<td>Date</td>
<td>Last name of staff responsible</td>
<td>Title of presentation/training</td>
<td>Location (city, state)</td>
<td>Number of participants</td>
<td>In-person or distance education</td>
</tr>
<tr>
<td>------------</td>
<td>-------------------------------</td>
<td>---------------------------------------------------------------------------</td>
<td>-------------------------</td>
<td>------------------------</td>
<td>---------------------------------</td>
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<tr>
<td>7/8/2008</td>
<td>Dennis, Anderson (GMR)</td>
<td>Unwrapping New Technologies</td>
<td>Elkhart Lake, WI</td>
<td>40</td>
<td>In-person</td>
</tr>
<tr>
<td>7/10/2008</td>
<td>Dennis, Anderson (GMR)</td>
<td>Twitter</td>
<td>Salt Lake City, UT</td>
<td>15</td>
<td>Distance Education</td>
</tr>
<tr>
<td>7/11/2008</td>
<td>Abbey</td>
<td>NIH Public Access Policy and New Roles for Libraries in the Open Access Arena</td>
<td>Denver, CO</td>
<td>34</td>
<td>In-person</td>
</tr>
<tr>
<td>7/14/2008</td>
<td>Magee</td>
<td>Health Resources from the National Library of Medicine and more!</td>
<td>Norfolk, NE</td>
<td>9</td>
<td>In-person</td>
</tr>
<tr>
<td>7/15/2008</td>
<td>Champ-Blackwell</td>
<td>Research Resources from the National Library of Medicine for Minority High School Summer Students</td>
<td>Omaha, NE</td>
<td>45</td>
<td>In-person</td>
</tr>
<tr>
<td>7/16/2008</td>
<td>Abbey, Honour</td>
<td>Breezing Along with the RML</td>
<td>Denver, CO Laramie, WY</td>
<td>Synchronous 30, Asynchronous 51</td>
<td>Distance Education</td>
</tr>
<tr>
<td>7/17/2008</td>
<td>Brown</td>
<td>National Library of Medicine Consumer Health Resources</td>
<td>Iola, KS</td>
<td>14</td>
<td>In-person</td>
</tr>
<tr>
<td>7/17/2008</td>
<td>Magee</td>
<td>Health Resources from the National Library of Medicine and more!</td>
<td>Chadron, NE</td>
<td>9</td>
<td>In-person</td>
</tr>
<tr>
<td>7/19/2008</td>
<td>Abbey</td>
<td>Public Health Information Resources</td>
<td>Ft. Collins, CO</td>
<td>7</td>
<td>In-person</td>
</tr>
<tr>
<td>7/19/2008</td>
<td>Abbey</td>
<td>NLM Consumer Health Resources</td>
<td>Red Feather Lakes, CO</td>
<td>4</td>
<td>In-person</td>
</tr>
<tr>
<td>7/23/2008</td>
<td>Jones</td>
<td>Snake Oil to Penicillin</td>
<td>St. Louis, MO</td>
<td>13</td>
<td>In-person</td>
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</table>
### Other Staff Activities

#### Table 5: Publications and Resources Developed by RML Staff

<table>
<thead>
<tr>
<th>Date completed/published</th>
<th>Last name of staff responsible</th>
<th>Title</th>
<th>Medium</th>
<th>Submitted to Clearinghouse (&quot;yes&quot; or &quot;out of scope&quot;)</th>
</tr>
</thead>
<tbody>
<tr>
<td>May 2008</td>
<td>Champ-Blackwell</td>
<td>Consumer Health Information in Many Languages Resource update</td>
<td>Web site</td>
<td>Out of Scope</td>
</tr>
<tr>
<td>5/13/2008</td>
<td>Abbey</td>
<td>Clinical Inquiries: Patient Education 'Worrying About Memory Loss' (Editor)</td>
<td>Tear sheet–Evidence-Based Practice newsletter</td>
<td>Out of Scope</td>
</tr>
<tr>
<td>6/2/2008</td>
<td>Magee</td>
<td>Health Information on the Internet</td>
<td>Brochure</td>
<td>No</td>
</tr>
<tr>
<td>6/5/2008</td>
<td>Bramble</td>
<td>DOCLINE Classes update</td>
<td>Web site</td>
<td>Out of Scope</td>
</tr>
<tr>
<td>6/10/2008</td>
<td>Abbey</td>
<td>Clinical Inquiries: Patient Education 'Shin Splint Injuries' (Editor)</td>
<td>Tear sheet – Evidence-Based Practice newsletter</td>
<td>Out of Scope</td>
</tr>
<tr>
<td>6/26/2008</td>
<td>Dennis</td>
<td>Materials for Loan update</td>
<td>Web site</td>
<td>Out of Scope</td>
</tr>
<tr>
<td>7/15/2008</td>
<td>Abbey</td>
<td>Clinical Inquiries: Patient Education 'Arthritis and Exercise' (Editor)</td>
<td>Tear sheet–Evidence-Based Practice newsletter</td>
<td>Out of Scope</td>
</tr>
<tr>
<td>7/22/2008</td>
<td>Abbey</td>
<td>Standardized modules for MedlinePlus, Genetic Home Reference, NIH Senior Health, Household Products Database, ClinicalTrials.gov, and National Center for Complementary and Alternative Medicine</td>
<td>PowerPoint</td>
<td>No</td>
</tr>
</tbody>
</table>

One of our Missouri members sent an appreciative email to Ms. Brown. “I really enjoyed and profited from your Plains to Peaks [sic] article on social bookmarking, Rebecca. It was so clearly written and the imbedded links so apt that I really ‘got it’.”

The MCMLA-listserv had 357 subscribers at the end of the quarter.
Notable Staff Activities

May 7, 2008
Ms. Champ-Blackwell attended the board meeting for the Center for Human Diversity, a community-based organization.

May 9, 2008
Ms. Abbey attended the webcast “Tools of Engagement: Attracting and Engaging Library Users,” sponsored by BCR.

Ms. Hamasu added the description of the TC4C Public Library Project to the Outreach Connections: Native Health Information wiki.

May 16, 2008
All RML librarians attended the RML Directors’ meeting in Chicago and participated in the break out sessions.

May 17, 2008
Ms. Brown and Ms. Dennis attended the NN/LM Web-Dev meeting before MLA.

May 27, 2008
Mr. Honour emailed all Network members in Wyoming, introducing himself, providing his contact information, and inviting them to contact him.

May 28, 2008
Eduardo Crespi of Centro Latino invited Ms. Jones to participate in a meeting with other community and government organizations to explore ways that Centro Latino could collaborate and qualify for larger grants.

Ms. Abbey attended a planning meeting of the Culture of Data conference.

May 30, 2008
Ms. Brown attended a REFORMA meeting where she learned of BiNational Health Week activities planned for Kansas.

June 4, 2008
Ms. Hamasu, Ms. Dennis, and Mr. Bramble participated in the Eccles Health Sciences Library strategic planning retreat to look at the work that faculty is carrying out in relationship to the mission, values, and vision of the library and university.

June 6, 2008
Ms. Abbey attended “Taking Neighborhood Health to Heart: Partners for Health Project” a collaboration that includes the University of Colorado at Denver and Health Sciences Center to learn more about and improve the health of the neighboring communities.

Ms. Abbey attended the “Foundation of Cultural Dimensions” workshop to better understand what it is like to be part of a minority group. The workshop was sponsored by the university Office of Diversity and the Colorado Health Outcomes

June 9, 2008
Ms. Champ-Blackwell and Ms. Magee attended the Future Search Conference for librarians and city administrators, sponsored by the Nebraska Library Commission. They looked at trends for libraries and literacy.

June 26, 2008
Ms. Magee and Ms. Champ-Blackwell attended a web conference “Addressing Health Literacy” featuring Dr. Paul Smith, a physician from Wisconsin. The web conference was sponsored by CIMRO of Nebraska.

July 2, 2008
Ms. Champ-Blackwell attended the quarterly meeting of the Nebraska Minority Public Health Association.

July 10, 2008
Mr. Honour visited Affiliate member, University of Wyoming Institute for Disabilities Library. He was given a tour that included an overview of resources and description of the population that the library serves.
July 10, 2008
Mr. Honour attended training on Dreamweaver.

July 18, 2008
Ms. Magee presided over the State Advisory Council on Libraries meeting where she distributed materials on NLM and NN/LM resources.

July 22, 2008
Ms. Champ-Blackwell attended the meeting of the Nebraska C.A.R.E.S Omaha Cancer Health Disparities and recommended that they partner with McGoogan Library of Medicine and incorporate Go Local and the Consumer Health Information Resource Service into the resources they promote.

July 24, 2008
Mr. Honour visited Lesley Boughton, Wyoming State Librarian, and the State Library’s outreach librarian. They discussed opportunities for collaboration.

July 25, 2008
Ms. Brown attended the Latino Health Issues Conference sponsored by the Kansas City, Missouri Health Department.

July 28-29, 2008
Mr. Honour visited libraries at the Wyoming Medical Center, Campbell County Memorial Hospital, Gillette VA Medical Center, University of Wyoming Family Medicine Residency Program, University of Wyoming Family Medicine Program, and Sheridan College.

July 29, 2008
Ms. Jones attended the ALA webinar “Congress: Coming Soon to a Community near You!”
Photographs

Dan Wilson presenting on emergency planning - June 18, 2008
Attachment 1:
Quarterly OARF Summary Data - RML Staff Activities

Outreach Activities Conducted by MCR RML Staff

RML Q1, 2008-2009

Generated: Wednesday, October 15, 2008

22 Total Outreach Activities

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

Activities Summary

<table>
<thead>
<tr>
<th>Activity</th>
<th>Number of Activities</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total number of estimated participants</td>
<td>441</td>
<td></td>
</tr>
<tr>
<td>Average number of participants</td>
<td>26.65</td>
<td></td>
</tr>
<tr>
<td>Average length:</td>
<td>1.72 hours</td>
<td></td>
</tr>
<tr>
<td>Under 1 hour:</td>
<td>2 activities (9.09%)</td>
<td></td>
</tr>
<tr>
<td>Between 1 and 2 hours:</td>
<td>10 activities (72.73%)</td>
<td></td>
</tr>
<tr>
<td>Over 2 hours:</td>
<td>4 activities (18.18%)</td>
<td></td>
</tr>
<tr>
<td>Hands-on practice:</td>
<td>12 activities (64.56%)</td>
<td></td>
</tr>
<tr>
<td>Conducted remotely:</td>
<td>4 activities (18.18%)</td>
<td></td>
</tr>
<tr>
<td>Offering continuing education:</td>
<td>2 activities (9.09%)</td>
<td></td>
</tr>
<tr>
<td>Significant number of minorities:</td>
<td>5 activities (22.73%)</td>
<td></td>
</tr>
</tbody>
</table>

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

<table>
<thead>
<tr>
<th>Organization</th>
<th>Number of Activities</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health sciences library</td>
<td>22 activities (100.00%)</td>
<td></td>
</tr>
<tr>
<td>Public Library</td>
<td>2 activities (9.09%)</td>
<td></td>
</tr>
<tr>
<td>Government agency</td>
<td>0 activities</td>
<td></td>
</tr>
<tr>
<td>Hospital</td>
<td>1 activity (4.55%)</td>
<td></td>
</tr>
<tr>
<td>Clinical/Health care</td>
<td>0 activities</td>
<td></td>
</tr>
<tr>
<td>Academic Institution</td>
<td>22 activities (100.00%)</td>
<td></td>
</tr>
<tr>
<td>Community-Based</td>
<td>2 activities (9.09%)</td>
<td></td>
</tr>
<tr>
<td>Faith-Based</td>
<td>4 activities (18.18%)</td>
<td></td>
</tr>
<tr>
<td>Public Health Agency</td>
<td>1 activity (4.55%)</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>5 activities (22.73%)</td>
<td></td>
</tr>
</tbody>
</table>

293 Participants Completed Participant Information Sheets

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

Participants Summary

<table>
<thead>
<tr>
<th>Participant Category</th>
<th>Number of Participants</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Activities at which PI sheet collected:</td>
<td></td>
<td>81.8%</td>
</tr>
<tr>
<td>Health care or service providers:</td>
<td>5 participants</td>
<td>1.71%</td>
</tr>
<tr>
<td>Health science library staff members:</td>
<td>84 participants</td>
<td>28.67%</td>
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<tr>
<td>Public Health worker:</td>
<td>7 participants</td>
<td>2.39%</td>
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<tr>
<td>Public/Other library staff members:</td>
<td>100 participants</td>
<td>64.61%</td>
</tr>
<tr>
<td>Members of general public:</td>
<td>37 participants</td>
<td>12.63%</td>
</tr>
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</table>
### Attachment 2:
Promotional Materials Provided

<table>
<thead>
<tr>
<th>Date</th>
<th>Who</th>
<th>Items Provided</th>
<th>Purpose</th>
</tr>
</thead>
<tbody>
<tr>
<td>5/19/2008</td>
<td>Primary Children's Medical Center Utah</td>
<td>− 1 MedlinePlus Poster &lt;br&gt;− 2 Genetics Home Reference Card &lt;br&gt;− 1 Tox Town Poster &lt;br&gt;− 2 Connecting Native Americans To Health Information Card &lt;br&gt;− 2 NLM Worlds Largest Medical Library Card &lt;br&gt;− 2 Our Story Card &lt;br&gt;− 20 PubMed Card &lt;br&gt;− 20 DOCLINE Card &lt;br&gt;− 2 Telemedicine Card</td>
<td>Display as information for our patrons</td>
</tr>
<tr>
<td>5/28/2008</td>
<td>Rocky Mountain University of Health Professions Utah</td>
<td>− 100 MedlinePlus Bookmark &lt;br&gt;− 100 Haz-Map Occupational Health Database</td>
<td>Information for advanced degree students during formal library instruction class</td>
</tr>
<tr>
<td>6/17/2008</td>
<td>Jackson Hole High School Media Center Wyoming</td>
<td>− 150 MedlinePlus Bookmark &lt;br&gt;− 2 MedlinePlus poster &lt;br&gt;− 2 Consumer Health Card &lt;br&gt;− 1 Consumer Guide to NIH HIV/AIDS Information Services Brochure &lt;br&gt;− 3 Genetics Home Reference Card &lt;br&gt;− 2 Tox Town Brochure &lt;br&gt;− 1 Household Products Database Card &lt;br&gt;− 1 NLM Worlds Largest Medical Library Card &lt;br&gt;− 1 Our Story Card</td>
<td>To assist in collaborative projects between the librarian and the health and biology teachers - Student research projects</td>
</tr>
<tr>
<td>7/31/2008</td>
<td>Longmont United Hospital Colorado</td>
<td>− 50 MedlinePlus Bookmark &lt;br&gt;− 50 MedlinePlus Bookmark (Spanish) &lt;br&gt;− 100 NLM Pocket Card &lt;br&gt;− 200 ClinicalTrials.gov Card &lt;br&gt;− 200 Health Information for Senior Citizens Card &lt;br&gt;− 10 Household Products Database Card &lt;br&gt;− 50 NLM Worlds Largest Medical Library Card &lt;br&gt;− 10 Our Collection/Our Databases Card &lt;br&gt;− 100 PubMed Card &lt;br&gt;− 50 NLM Gateway Card &lt;br&gt;− 50 Public Health Resources &lt;br&gt;− 50 WISER Card &lt;br&gt;− 10 Specialized Information Services Card &lt;br&gt;− 10 Telemedicine Card &lt;br&gt;− 10 The Visible Humans Card</td>
<td>handouts for: &lt;br&gt;- new employee orientation &lt;br&gt;- cardiac rehabilitation groups &lt;br&gt;- consumer handouts &lt;br&gt;- nursing students &lt;br&gt;- attachments with information packets &lt;br&gt;- promotion of tax dollars in use for positive results &lt;br&gt;- new physician tours/orientation &lt;br&gt;- physician CME committee &lt;br&gt;- cancer committee participants &lt;br&gt;- public awareness/ library week</td>
</tr>
</tbody>
</table>
Attachment 3:  
Technology Position Sharing Final Report
NATIONAL NETWORK OF LIBRARIES OF MEDICINE

MidContinental Region and Pacific Southwest Region
Shared Position Evaluation
Final Report
July 1, 2007 to April 30, 2008

Sharon Dennis, Technology Coordinator
Claire Hamasu, Associate Director
Heidi Sandstrom, Associate Director

Submitted July 29, 2008
The proposal for the Shared Technology Coordinator Position between the MidContinental Region (MCR) and Pacific Southwest Region (PSR) of the National Network of Libraries of Medicine (NN/LM) states the project will be deemed a success based on nine criteria. Each of these is addressed in this evaluation as follows:

1. Activities of the joint logic model (see Attachment 1) are completed.
   Activities were completed as planned for 6 of 11 PSR activities and 9 of 12 MCR activities as outlined in the joint logic model. There were problems implementing some of the activities and staffs are developing new strategies.

   It should be noted that the quality of Sharon’s work has been excellent in all activities; the level of activity far exceeded expectations in the areas of training and consultation with Network members and NN/LM PSR staff.

2. Indicators of the logic model are met. (see Attachment 2)
   Five of the eleven indicators were met as written. Progress was made on most of the indicators.

3. If either is not accomplished, there is an explanation which both Associate Directors find satisfactory.
   At least half of the measures of success have been met, according to the responses outlined in questions 1 and 2 (above). Some of the activities and indicators have not been completed within the scheduled time frame due to an ambitious schedule or to external reasons. The Associate Directors are very satisfied with the achievements of the technology logic model in both regions.

4. Staff members at both RMLs are satisfied with support from, and interaction with, the Technology Coordinator.
   PSR staff members are satisfied with the nature and quality of support from Sharon Dennis. Interactions have been perceived as very positive and supportive. The level of interaction has been less than expected, likely due to an “out of sight, out of mind” dynamic. Ways to increase the level of interaction have been proposed to PSR staff: adjusting settings on Skype so that it automatically opens on logon so Sharon knows who is available throughout the day; Sharon sending an email once a week to PSR staff as an inquiry and reminder of her availability to assist and consult on technology-related issues; Sharon spending more days at the Regional Network Office during her visits in order to increase opportunities for “face time” and casual interaction. Discussion with other RML Associate Directors are being held to learn how they integrated telecommuting staff into the communication patterns of the co-located staff.
MCR liaisons still receive excellent support from the Technology Coordinator. They have noticed that she is less available which reduces impulse contacts and favors contacting the Technology Liaison or someone else. The Technology Liaison, who works most closely with the Technology Coordinator, finds no change in Sharon’s availability. They still have regularly scheduled meetings and her presence is noted on Skype whether she is in Salt Lake City or Los Angeles.

5. Each Region recognizes Sharon Dennis as the Technology Coordinator for the Region. A questionnaire was sent to all MCR Network members in April 2008 asking for their perception of the service from the RML supporting the technology project area. We received 61 responses (not statistically significant but useful). The survey results assure us that Sharon Dennis continues to be recognized as part of the technology team.

[Note: The MCR has two librarians leading the technology project area—Sharon Dennis and Rebecca Brown. Some members may work with Rebecca Brown and may recognize her as the technology person in the MCR.]

Sharon has gotten a great response to the messages she has sent on the PSR electronic mailing list, her classes have filled immediately in response to invitations to register, and she has received calls from Network members following article publication in Latitudes. In lieu of surveying its Network members during the pilot period, PSR used feedback they provided on evaluations following Sharon’s instructional sessions, and during individual consultations with her. We also received Network member feedback during our Resource Library Directors Meeting in October 2007, during the Joint MLA Chapters meeting in February 2008, and from our Technology Advisory Group, which met on May 9, 2008. In summary, when Sharon has announced classes in the region, she has consistently gotten a level of response that necessitates multiple offerings in the region. Class participants have indicated that they have acquired knowledge that they can apply to their work environments, and several have contacted Sharon afterwards to consult with her on specific technology issues/problems. Sharon’s February 2008 Communications Questionnaire had a good response rate, and included comments such as the following, “Thanks to Sharon Dennis for the RSS, blog, Wiki classes.” I have heard only positive comments about Sharon’s extensive knowledge, skill and experience related to technology and her ability to translate technology-related content into understandable and actionable information.

6. In addition, the MCR members will be asked if they’ve noticed a change in level of service in our technology program.

A questionnaire was sent to all Network members in April 2008 asking for their perception of the service from the RML supporting the technology project area. We received 61 responses (not statistically significant but useful). The majority of the participants perceive that our service has either remained at the same level or increased.

7. If technology support staff were hired in the MCR, the Technology Coordinator and the technology support staff would jointly accomplish the logic model indicators and activities. Technology Associate, Susan Roberts, started December 1, 2007 at .4 FTE. Sharon supervises this position. Susan is highly experienced in communication technologies and web design. Susan worked on a color redesign for the web site, assisted with the PIG / Access Grid set up and tests, wrote a manual for the Utah Access Grid operation, and
performed routine web site maintenance. She worked with several liaisons to assist them in creating or editing web pages and provided answers to web site questions as needed. In addition, she taught two distance education classes related to web site and image design using Adobe Connect; 24 members attended the classes.

8. The administrative overhead is not too burdensome as determined by the Associate Directors.

The administrative overhead has not exceeded that associated with any other coordinator position. Setting up the program required more coordination than was expected for a new project. Outlining the project and agreeing on policies and procedure was negotiated in a day-long meeting that included Heidi Sandstrom, Claire Hamasu, and Sharon Dennis. It took a reasonable amount of time to write the proposal. However, getting the subcontract through the approval processes of NLM, UCLA, and University of Utah took much longer than expected. Grants offices at all institutions involved are short staffed and overworked. Diligent follow up was required to verify that all necessary documents were provided and that the paperwork received priority handling and proceeded expeditiously. Whenever the ADs attention was required elsewhere progress slowed. After several months, NLM required that the start date originally established be changed from July 1 to August 14, 2007, requiring an amendment to the proposal. The subcontract required by UCLA was very formal and required involvement by more than the University of Utah’s Office of Sponsored Projects before it could be approved and signed.

Because of the success of the pilot, both MCR and PSR agreed to extend the position-sharing arrangement for Year 03 of the contract, and to subsequently decide on a year-to-year basis to extend the arrangement for the remaining years of the contract. The extension has required only an amendment to the original subcontract agreement between the two RML institutions, a process that has been much simpler, involving minimal time and effort.
We anticipated being able to answer the following questions by conducting the pilot:

1. What is the best way to handle salary and benefits, as well as other costs associated with the position, between two NN/LM Regions?
   Salary and benefits are administered through Eccles Health Sciences Library; the PSR portion is paid to MCR through the subcontract mechanism. Travel expenses are split evenly between MCR and PSR. Both provide office space, supplies, and equipment for the position. With salary as the only budget item in the subcontract both RMLs use their regular budgets for all other items providing them with flexibility in how they support the work of the position.

2. Can sharing be established with a “Handshake Agreement” among the RMLs involved?
   Until the subcontract could be executed, sharing proceeded on a “good faith” agreement between the Associate Directors of MCR and PSR. However, since funds need to be exchanged between institutions, a “handshake agreement” would not work for a permanent arrangement. RMLs looking to share positions should consult with their grants office to determine the most simple way to execute an agreement for the shared position.

3. Can duties be shared or be fulfilled by one person for multiple regions?
   The requirements of time and effort for the split MCR/PSR position have been met and seem reasonable based on the first 10 months.

4. Can support staff perform some of the duties currently being performed by professional staff?
   Yes. Support staff have assisted the PSR Technology Coordinator for some time with the more routine activities associated with the position (e.g. equipment, web site maintenance, etc.)
   Yes, a support position has taken over the responsibility of administrator for the listserv, promoting pages from the development to the public web site, teaching classes using Adobe Connect, and revising the web site.

5. How does administration of the regional program have to be modified to accommodate shared staff positions?
   UCLA and the University of Utah required the subcontract funding mechanism for the shared position pilot, which required a bit more initial overhead of time and effort. Communication between the ADs must be consistent and clear relative to supervising and scheduling activities for this position. Cost savings must be reallocated within the program, while leaving open the possibility of terminating the shared position if circumstances in either MCR or PSR necessitate this.

6. What modifications need to occur in the operations of each RML to accommodate shared staff positions?
   Each RML needs to ensure adequate access to IT software/hardware/files needed for the position in each region and feasible mechanisms for working remotely and communicating regularly.
Centralized staff needs to make an extra effort to be inclusive when the technology coordinator is working remotely. The online reporting system for the MCR was adapted to record and report out work done for the PSR.

For the RML sharing the position, responsibilities that could be allocated to a part time person and finding someone to take the position needed to happen in order to accomplish all that was planned for the technology project area.

7. What are the technology coordinator activities that done once serve both regions?
   Almost all, with the exception of one or two activities, fall under program elements not exclusive to either region. These include developing classes; researching and disseminating knowledge about new technologies. Sharon has done these activities once and applied them to both regions. The “Introduction to Blogs and Wikis” class is a good example. After updating the workshop in October for the MCR, she had only had to do a small update in December to offer it to the PSR. Projects that both RMLs see as beneficial such as testing and working with the NTCC to develop a national training web system and coordinating a web usability study for both regions also are carried out once.

8. Is the number of Network members related to the number of Network member contacts with the Technology Coordinator? PSR has more Network members than MCR. Does this result in more work for the Technology Coordinator?
   It is definitely true that any activity conducted for the PSR involving members results in an increased time commitment (for instance, offering more sessions of classes to meet demand, responding to more questions, etc.) However so far this has been manageable in the time allotted for PSR work.

9. How much in-person time is necessary for Sharon Dennis to be integrated into the NN/LM PSR staff?
   At least 2-3 days every other month seems optimal.

10. What are the major benefits and levels of satisfaction with the position-sharing arrangement— for the Regions, for the NN/LM staff (ADs, Technology Coordinator, other coordinators/liaisons), and for the institutions/RMLs (U of U Eccles Health Sciences Library, UCLA Louise Darling Biomedical Library)?
    The major benefits and levels of satisfaction are related to the unique qualifications and characteristics that Sharon Dennis brings to the shared position and to the collaboration between the regions that result from this arrangement. Feedback from PSR Network members has been very positive thus far. Not only is NN/LM PSR staff pleased with the arrangement, but UCLA Biomedical Library staff who work in the area of technology are as well.
    Sharing a position offers additional opportunities for staff without the individual having to leave a position and relocate. Sharon has enjoyed working with both regions. She enjoys teaching and consultations, so has appreciated the opportunity to expand these activities with the PSR members.
    Sharing a position with another RML has had no impact on the MCR project areas or on Eccles Health Sciences Library.
11. What are the major challenges of such an arrangement?

The major challenges are integrating this position into the UCLA Library organization, and the limited opportunity for “face time” with the technology coordinator. For the RML sharing the position, the challenge has been identifying the responsibilities that can be reallocated from professional staff to support staff in order that the technology project progresses as planned.

The success of the pilot has been driven to a significant degree by the individuals involved. Both Associate Directors have worked together before, on an intraregional level at PSR and on an interregional level between MCR and PSR on various other projects, so they are familiar with each other’s work and communication styles. In addition, Claire is familiar with the culture and characteristics of the region and UCLA, so is an additional resource to Sharon in this regard when questions arise.

Sharon Dennis not only brought her knowledge, expertise, and experience related to technology with her on Day 1 of the pilot, but also her knowledge of the NN/LM and its operations, and the relationships she has developed with NN/LM staff nationally. This has been of tremendous benefit to PSR; hiring an individual from outside of the NN/LM for the shared position would pose a significant orientation and training challenge for each of the regions.

As a staff member of two RMLs, discretion is required when she is involved in sensitive issues for either RML. Knowing what can and what should not be shared with the other RML librarians.

One of the big questions for PSR is whether .4 FTE is adequate for the needs of the region, which is larger in terms of Network membership than MCR, which has a combined total of 1.2 FTE (two .4 FTE professional and one .4 FTE) allocated for technology for that region.

The MCR now divides technology responsibilities among 3 people. It was a challenge for other staff to learn who to contact for a particular task and to remember each one’s schedules. The MCR has resolved the issue by having staff send technology requests to all three. The 3 technology staff members have worked out a response procedure.

Termination of the Pilot:

The mid-year evaluation of the pilot coincides with the start (at the end of 2007) of the NN/LM annual budget renegotiation process. The evaluation indicates that the pilot has approached at least half of the measures of success, so the effort to share the Technology Coordinator position will be continued on a year to year subcontract.
### ATTACHMENT 1

<table>
<thead>
<tr>
<th>NN/LM Goal</th>
<th>GOAL</th>
<th>OUTCOMES</th>
<th>INDICATOR</th>
<th>ACTIVITY</th>
<th>MCR: Notes</th>
<th>PSR: Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Develop collaborations among network members and other organizations to</td>
<td>Assist NLM with the development and implementation of a plan to</td>
<td>More historical and unique materials related to the health sciences will be identified and accessible to the public</td>
<td>There will be an increase in resources identified and added to NLM’s “Directory of History of Medicine Collections” or another publicly accessible database</td>
<td>Follow NLM's lead to arrive at a practical definition of and scope for “historical and unique materials related to the health sciences”</td>
<td>No activity expected in Year 2.</td>
<td>No activity expected in Year 2.</td>
</tr>
<tr>
<td>improve access to and sharing of biomedical information resources</td>
<td>identify collections of historical and unique materials related to the health sciences</td>
<td></td>
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<tr>
<td>throughout the nation</td>
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</tr>
<tr>
<td>Develop collaborations among network members and other organizations to</td>
<td>Assist NLM with the development and implementation of a plan to</td>
<td>More historical and unique materials related to the health sciences will be identified and accessible to the public</td>
<td>There will be an increase in resources identified and added to NLM’s “Directory of History of Medicine Collections” or another publicly accessible database</td>
<td>Collaborate with NLM and the other regions in the development of a national plan to identify these collections</td>
<td>No activity expected in Year 2.</td>
<td>No activity expected in Year 2.</td>
</tr>
<tr>
<td>improve access to and sharing of biomedical information resources</td>
<td>identify collections of historical and unique materials related to the health sciences</td>
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<tr>
<td>throughout the nation</td>
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<tr>
<td>Develop collaborations among network members and other organizations to</td>
<td>Enter into a formal agreement with at least one institution in</td>
<td>Members adopt new technologies to increase access to biomedical information</td>
<td>Each resource library with a PIG is a participating site for at least one event using the PIG</td>
<td>The RML organizes Access Grid events and helps install PIGs at Resource Libraries</td>
<td>Year 1: 3 PIGs were installed at Creighton, UNMC, and Kansas. Year 2: install at Colorado, Wash. U, and Columbia. Coordinate events to be held in Year 2.</td>
<td>No activity expected in Year 2.</td>
</tr>
<tr>
<td>improve access to and sharing of biomedical information resources</td>
<td>each state in the region to serve as a Resource Library</td>
<td></td>
<td></td>
<td></td>
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<td></td>
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<tr>
<td>throughout the nation</td>
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<tr>
<td>NN/LM Goal</td>
<td>GOAL</td>
<td>OUTCOMES</td>
<td>INDICATOR</td>
<td>ACTIVITY</td>
<td>MCR: Notes</td>
<td>PSR: Notes</td>
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<tr>
<td>Develop collaborations among network members and other organizations to improve access to and sharing of biomedical information resources throughout the nation</td>
<td>Establish and maintain channels for effective communication with current and potential NN/LM participants, other RMLs, NLM, and other state and multi-type library networks within the region</td>
<td>Increased collaborations and access to biomedical information via effective communication mechanisms</td>
<td>75% of members responding to surveys on periodic web surveys indicate increased knowledge of biomedical information due to reading the MCR’s website</td>
<td>Develop and maintain a regional Web site as an integral component of the NN/LM Web site.</td>
<td>Routine web work to be handled by Rebecca. Continue to make improvements based on Year 1 usability study. Baseline survey to be conducted in late summer 2007; follow-up survey in April 2007. CMS implementation not likely in Year 2. Investigate other web technologies such as Google Gadget or other personalized options.</td>
<td>Involvement in routine web work to be determined according to PSR's needs. Continue to make improvements based on Year 1 usability study. Baseline survey to be conducted in late summer 2007; follow-up survey in April 2008. CMS implementation not likely in Year 2. Investigate other web technologies such as Google Gadget or other personalized options.</td>
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<td>Establish and maintain channels for effective communication with current and potential NN/LM participants, other RMLs, NLM, and other state and multi-type library networks within the region</td>
<td>Increased collaborations and access to biomedical information via effective communication mechanisms</td>
<td>At least three video on demand events per year provided by the RML.</td>
<td>Participate in/testing/using other methods of communication, such as videoconferencing, computer conferencing, podcasts.</td>
<td>Offer on demand video via multiple delivery methods (this may include traditional streaming events, Flash streaming on demand videos on our server, or audio or video podcasts).</td>
<td>Offer on demand video via multiple delivery methods (this may include traditional streaming events, Flash streaming on demand videos on our server, or audio or video podcasts). PSR anticipates creating 3 video events; members create 1 event.</td>
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<td>Increased collaborations and access to biomedical information via effective communication mechanisms</td>
<td>At least one on-demand video provided by those trained.</td>
<td>Participate in/testing/using other methods of communication, such as videoconferencing, computer conferencing;</td>
<td>Training on how to create on-demand videos or podcasts offered to members, including those not covered by the sub-contract.</td>
<td>Training on how to create on-demand videos or podcasts offered to members, including those not covered by the sub-contract.</td>
</tr>
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<td>Develop collaborations among network members and other organizations to improve access to and sharing of biomedical information resources throughout the nation</td>
<td>Establish and maintain channels for effective communication with current and potential NN/LM participants, other RMLs, NLM, and other state and multi-type library networks within the region</td>
<td>Increased collaborations and access to biomedical information via effective communication mechanisms</td>
<td>One on-demand video per sub-contract</td>
<td>Participate in/testing/using other methods of communication, such as videoconferencing, computer conferencing;</td>
<td>Training on how to create on-demand videos or podcasts offered to sub-contract awardees</td>
<td>PSR offers funding opportunities for members to receive training and create on-demand video.</td>
</tr>
<tr>
<td>Develop collaborations among network members and other organizations to improve access to and sharing of biomedical information resources throughout the nation</td>
<td>Establish and maintain channels for effective communication with current and potential NN/LM participants, other RMLs, NLM, and other state and multi-type library networks within the region</td>
<td>Increased collaborations and access to biomedical information via effective communication mechanisms</td>
<td>One new technology adopted by the RML per year.</td>
<td>Participate in/testing/using other methods of communication, such as videoconferencing, computer conferencing.</td>
<td>Test videoconferencing options to replace Festoon. Explore new methods of delivering content (might include new multimedia formats, virtual reality, web 2.0, new publishing models)</td>
<td>Provide training and support for PSR adoption of Skype, as needed. Share results of videoconference tests with PSR. Develop communication plan for electronic communications. Provide RML web-based interactive session (open discussions, topics to be determined): 2/ year using Connect</td>
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<td>Develop collaborations among network members and other organizations to</td>
<td>Establish and maintain channels for effective communication with</td>
<td>Increased collaborations and access to biomedical information via</td>
<td>All workgroups use alternative form of communication to meet</td>
<td>Participate in testing/using other methods of communication, such as</td>
<td>Research and test videoconferencing options to replace Festoon.</td>
<td>Survey Resource Library capability</td>
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<td>improve access to and sharing of biomedical information throughout the</td>
<td>current and potential NN/LM participants, other RMLs, NLM, and other</td>
<td>effective communication mechanisms</td>
<td>Note: PSR indicator probably relates to Resource Libraries</td>
<td>computer conferencing.</td>
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<td>Research, test and implement best method for videoconferencing with</td>
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<td>nation</td>
<td>state and multi-type library networks within the region</td>
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<td>Resource Libraries.</td>
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<td>Spring 2008 videoconference with RL’s.</td>
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<td>Develop, promote, and improve electronic access to health information</td>
<td>Develop an information technology and policy program to improve</td>
<td>Under-connected Network Members have increased access to biomedical</td>
<td>Technology liaisons efforts will contribute to an increase in connectivity</td>
<td>Review the adequacy of the Internet connections of network members on an</td>
<td>In Year 2, two institutions in two different states other than Utah will</td>
<td>At least 2 (and up to 5) institutions will participate in the</td>
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<td>by network members, health professionals, and organizations providing</td>
<td>access to biomedical information</td>
<td>information and to communication tools</td>
<td>of at least one institution per state over the contract period</td>
<td>annual basis, reporting the results to the region and to NLM, and</td>
<td>participate in under-connected project. Note: Rebecca will coordinate this</td>
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<td>health information to the public</td>
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<td>assisting the &quot;under connected&quot; in maintaining and upgrading their</td>
<td>for the MCR.</td>
<td>for the under-connected project in PSR.</td>
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<td>connections</td>
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<td>Develop, promote, and improve electronic access to health information</td>
<td>Develop an information technology program and policy issues to</td>
<td>In conjunction with other RMLs, Network members, health professionals,</td>
<td>50% of network members surveyed indicated that have adopted at least one</td>
<td>Identify, evaluate and monitor the best authoritative sources for new</td>
<td>This activity refers to time spent &quot;keeping up&quot; with new technologies; i.e.,</td>
<td></td>
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<td>by network members, health professionals, and organizations providing</td>
<td>improve access to biomedical information</td>
<td>and organizations providing health information to the public are able to</td>
<td>showcased new technology per year</td>
<td>technology information</td>
<td>learning about and &quot;playing with&quot; new technologies as they come to my</td>
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<td>health information to the public</td>
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<td>to learn about new technology developments that will help them to</td>
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<td>attention. If the technologies look useful for members, these are</td>
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<td>increase access to biomedical information</td>
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<td>showcased to members under the &quot;showcase information technologies...&quot;</td>
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This activity refers to time spent "keeping up" with new technologies; i.e., learning about and "playing with" new technologies as they come to my attention. If the technologies look useful for members, these are showcased to members under the "showcase information technologies..." activity.
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<td>Develop, promote, and improve electronic access to health information by</td>
<td>Develop an information technology program and policy issues to</td>
<td>Members adopt new technologies to increase access to biomedical information</td>
<td>50% of network members surveyed indicated that have adopted at least one</td>
<td>Investigate and showcase information technologies and policies affecting</td>
<td>Offer regular updates on technology website and newsletter</td>
<td>Offer regular updates on technology website (to be created for PSR) and newsletter. 2 newsletter articles by Sharon and 1 by workgroup member Offer updates to members via Connect as deemed appropriate by PSR Participate in Web Developer’s Group</td>
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<td>network members, health professionals, and organizations providing health information to the public</td>
<td>improve access to biomedical information</td>
<td></td>
<td>showcased new technology per year</td>
<td>their use on a regular basis.</td>
<td>Offer update at Wyoming Symposium</td>
<td>Offer updates to members via Connect as deemed appropriate by PSR Participate in Web Developer’s Group</td>
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<td>Develop an information technology program and policy issues to</td>
<td>Members adopt new technologies to increase access to biomedical information</td>
<td>75% of class participants indicate increased knowledge about technologies</td>
<td>Hold classes focused on the use of information technology to improve access</td>
<td>Offer 12 classes per year on technology topics (see separate list).</td>
<td>Offer 4 technology classes in Year 2: two through distance, two in person (one at chapter meeting in Feb. 08, the other in-person to be determined)</td>
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<td>improve access to biomedical information</td>
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<td>to biomedical information and on policy issues affecting production,</td>
<td>MCR classes are taught using Connect.</td>
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<td>distribution, and access to biomedical information</td>
<td>Develop and offer Networking class using Moodle, with Rebecca.</td>
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<td>Develop, promote, and improve electronic access to health information by network members, health professionals, and organizations providing health information to the public</td>
<td>Develop an information technology program and policy issues to improve access to biomedical information</td>
<td>Working groups contribute to the technology project activities</td>
<td>At least one new idea generated by working group is integrated into the program each year</td>
<td>Hold regular meetings with Technology working group</td>
<td>Hold quarterly meetings with Technology working group. Working group members are solicited to write newsletter articles and teach classes, as well as provide information about technology projects in their state and advice to liaisons about the direction of the MCR technology project.</td>
<td>Form PSR Technology Working group. Hold quarterly meetings. Determine charter of the working group, perhaps the same as MCR's.</td>
</tr>
<tr>
<td>Develop an information technology program and policy issues to improve access to biomedical information</td>
<td>Access to knowledge based health information is available to support healthcare during and after an emergency.</td>
<td>2 tests using different communications methods for 2 different scenarios are successfully conducted</td>
<td>Explore and test communication tools based on emergency scenarios.</td>
<td>Sharon is responsible for leading the Emergency Planning &quot;web presence&quot; working group.</td>
<td>No activity related to PSR for this activity.</td>
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</table>
Indicator / Activity #1: Access Grid / PIGs

Indicator: Each Resource Library with a PIG is a participating site for at least one event using the PIG.

Activity: The RML organizes Access Grid events and helps install PIGs at Resource Libraries

Progress: This activity is an MCR activity only. Progress was made on the activity, but the indicator as written was not met. Sharon worked with the Resource Libraries to continue setting up and testing the PIGs. An event (Dan Wilson’s Emergency Preparedness presentation) will be held on June 17, but we did not hold an event during the 10 month pilot period.

Indicator / Activity #2: Web site

Indicator: 75% of members responding to periodic web questionnaires indicate increased knowledge of biomedical information due to reading the regional web site.

Activity: Develop and maintain a regional Web site as an integral component of the NN/LM Web site.

Progress: Web site evaluation questionnaires were conducted for both regions. The indicator was met; over 75% of members in both regions said they increased their knowledge due to reading the web site. For PSR, the questionnaire asked broader questions about communications that will be used to inform a communications plan. For MCR, the questionnaire will be used in conjunction with the upcoming usability tests to determine what improvements should be made to the web site. In addition, Sharon assisted other staff in both regions with routine maintenance of the web site.

Indicator / Activity #3 - 5: Video on Demand

Indicators: At least three video on demand events per year provided by the RML. At least one on-demand video provided by those trained. One on-demand video per subcontract.

Activity: Participate in/testing/using other methods of communication, such as videoconferencing, computer conferencing, podcasts.

Progress: The indicator was not met. Neither region offered a video on demand event. There were no applicants for the video on demand subcontract, so no members offered an event.
Indicator / Activity #6: New communications technologies

Indicator: One new technology adopted by the RML per year.

Activity: Participate in/testing/using other methods of communication, such as videoconferencing, computer conferencing.

Progress: The indicator was met for both regions. Sharon continued to test new videoconferencing products, and the MCR used Skype and Adobe Connect routinely for meetings and distance education. MCR staff adopted other new technologies for communication (small group wikis). Sharon also worked with the PSR staff to communicate via Skype and to offer distance education through Abode Connect. In addition, Sharon and PSR staff had regular distance meetings using a Polycom videoconferencing system.

Indicator / Activity #7: New communications technologies for workgroups and Resource Libraries

Indicator: All workgroups use alternative form of technology to meet note: PSR indicator probably relates to Resource Libraries

Activity: Participate in testing/using other methods of communication, such as videoconferencing, computer conferencing.

Progress: This indicator was met for MCR; the technology workgroup met using Adobe Connect. Sharon tested Adobe Connect with the PSR Resource Library directors, but a meeting using the technology was not held in the 10-month period.

Indicator / Activity #8: Under-connected Project

Indicator: Technology liaisons efforts will contribute to an increase in connectivity of at least one institution per state over the contract period

Activity: Review the adequacy of the Internet connections of network members on an annual basis, reporting the results to the region and to NLM, and assisting the "under connected" in maintaining and upgrading their connections

Progress: The indicator was not met for either region. In the MCR, the technology liaisons held an Adobe Connect forum to discuss connectivity issues with hospital librarians (particularly firewalls and information filters).

Indicator / Activity #9 & 10: Evaluating and Showcasing New Technologies

Indicator: 50% of network members surveyed indicated that have adopted at least one showcased new technology per year

Activities: Identify, evaluate, and monitor the best authoritative sources for new technology information. Investigate and showcase information technologies and policies affecting their use on a regular basis.
Progress: The indicator was not met since we did not conduct a survey. Sharon regularly monitors and evaluates new technology developments and posts the information to the MCR news. She wrote two articles for the PSR Latitudes newsletter. She gave technology updates at the Wyoming Symposium in July 2007 as well as for the MCR’s “Breezing Along with the RML” session. Anecdotal feedback from members in both regions indicated they appreciated the technology updates and classes.

Indicator / Activity #11: Technology Classes

Indicator: 75% of class participants indicate increased knowledge about technologies.

Activity: Hold classes focused on the use of information technology to improve access to biomedical information and on policy issues affecting production, distribution, and access to biomedical information.

Progress: The indicator was met for both regions. In each class session below over 75% of the participants indicated they had increased their knowledge. Classes offered via distance education using Adobe Connect are listed below:

*The “New” Current Awareness Service: Introduction to RSS (One Hour Class):* Six sessions were taught from August – October 2007, with a total of 92 participants from PSR.

*Introduction to Blogs and Wikis (4 Hour MLA CE class):* One session was taught in October 2007 for MCR, with 7 participants. Two sessions were taught in December 2007 – January 2008 for PSR, with a total of 23 participants.

*Introduction to Personalized Google / iGoogle (One Hour Class):* Two sessions were taught in April 2008 for MCR and PSR simultaneously. Twenty-four participants attended from MCR; 51 from PSR.

In addition, Sharon consulted with both PSR and MCR members after the classes about various technology issues related to the class materials or other technology questions.

Indicator / Activity #12: Workgroups

Indicator: At least one new idea generated by working group is integrated into the program each year.

Activity: Hold regular meetings with Technology working group.

Progress: The indicator as written was not met. Sharon met remotely using Adobe Connect with the MCR Technology Working Group on a quarterly basis throughout the 10 month period. Several ideas were generated by the group but none were integrated into the program yet. Sharon formed the PSR Technology Advisory Group in March 2008; the first meeting was held at UCLA on May 9, 2008.
Indicator / Activity #13: Emergency Planning

Indicator: 2 tests using different communications methods for 2 different scenarios are successfully conducted.

Activity: Explore and test communication tools based on emergency scenarios.

Progress: Sharon set up a draft emergency planning web page, which was then turned over to Dan Wilson’s group.
Attachment 4:
Go Local Quarterly Report

University of Kansas
Kansas Go Local
Go Local Project Report

Go Local Project Name: Kansas Go Local

Submitted by
• Name: Amy Ritterskamp
• e-mail address: aritterskamp@kumc.edu

Date Submitted: July 8th, 2008

Dates covered: April-June 2008

If currently receiving NN/LM funding, Contract number (optional): 2507044-09

A. For Sites not yet released:
Estimated release month/year: January 2009

Progress on project timeline
• Held virtual training for Selectors in early June.
• Selectors began inputting records from their region.
• Continuing review of imported data.
• Two State Library Regions have met their goal to receive grant money.

B. For all projects:
1. Major staff leaving or joining the project this quarter (name and role)
   • Mary Lou Chard, Selector from SEKLS
   • Gail Santy, Selector from CKLS
   • Jo Ann Warman, Selector from NWKLS
   • Brandi Seamon, Selector from NWKLS

2. Database Development & Maintenance
Over 2,500 records in the database.
   • 90% of batch-imported data has been completed and is ready for review.
   • Selectors from across the state have entered close to 200 records.

3. Website Development & Maintenance
   • No development on the web site at this time due to focusing on database

4. Outreach and promotion efforts
   • Sent partnership proposal to Emporia University’s School of Library and Information Management program to assist with review and selection. Cataloging class would provide review of records; Collection Development class would assess ‘collection’ for deficiencies and fill in the gaps.
• Working on partnership proposal to Kansas Regents Institutions to provide record review. Each Institution would be assigned a Region and would be responsible for reviewing records from that area.
• Still encouraging a partnership with Kansas Biomedical Librarians (Particularly Via Christi) to review records.
• Planning for KHO Days and focus groups which involves traveling around the state teaching librarians and consumers about Kansas Health Online, MedlinePlus, and Go Local Kansas as well as gathering information from consumers about their health needs. Also provides opportunity for face-to-face training of Selectors. First KHO Day will be July 16th in Iola, Kansas.

5. Other
• None at this time.
Attachment 5:  
Go Local Quarterly Report

University of Nebraska  
Go Local Nebraska
Go Local Project Name: Go Local Nebraska

Submitted by: Marie Reidelbach mreidelb@unmc.edu

Date Submitted: July 3, 2008

Dates covered: April-June 2008

B. For all projects:
1. Major staff leaving or joining the project this quarter (name and role)
   • No change in staffing

2. Database Development & Maintenance
   • Over 840 dental clinics were sent a letter in April requesting that the dentists verify the contents of their individual records. The letters also included a brochure about the McGoogan Library of Medicine’s consumer programs and a baseball card of Go Local Nebraska. The dentists have been very responsive in contacting the library to update their information.
   • Hospitals, clinics, and dental clinics are being audited for the current year.
   • Respite care resources, mental health clinics, and veteran services are currently being added or updated.

3. Website Development & Maintenance
   • No changes.

4. Outreach and promotion efforts
   • Marie Reidelbach and Teri Hartman attended the Republican Valley/Meridian Library Systems' Joint Annual Meeting in Hastings, Nebraska on June 6. They presented information on Go Local Nebraska, the Consumer Health Information Resource Service [CHIRS], and other support offered by the McGoogan Library of Medicine to all public librarians in the state.
   • Marie and Teri also exhibited Go Local Nebraska and the CHIRS program at the 2008 Cattleman's Ball on June 7 near Albion, Nebraska. The Ball is a major fund raiser to support cancer research at the Eppley Cancer Center at UNMC. Meeting and talking about high quality health information sources such as Go Local Nebraska, CHIRS, and MedlinePlus with some of the 3000 attendees was exciting. This exhibit was held outdoors in a tent! Lucky for the team, the weather was beautiful that day.
   • CHIRS and Go Local Nebraska were discussed at the Nebraska Libraries Future Search event that was held in Schuyler, Nebraska on June 10 and 11. Nearly 100 Nebraska citizens, elected officials, librarians, and trustees agreed that having quick access to evaluated, reliable, local health information is and will continue to be important to Nebraskans.
   • Go Local Nebraska and CHIRS teamed up with the National Network of Libraries of Medicine to exhibit at the Washington Branch of the Omaha Public Library on June 18 in
Omaha, Nebraska. The Omaha World Herald published a story about the event at this site: http://omaha.com/index.php?u_page=3940&u_sid=10362060. Health information resources were presented to the adults in the crowd as they watched the kids and young people ride the rides. This was a great community event!

- The Go Local Nebraska team exhibited at the Eastern Library System Annual Meeting, held in Bellevue, Nebraska on June 20. Public, school, and special librarians attended the meeting, and stopped by the booth to catch up on the news about Go Local Nebraska and CHIRS. This was also a great opportunity to show the Go Local/CHIRS display that can be checked out by any library in Nebraska. Additionally, brochures were given to representatives of the Soul Desires and Confluence bookstores, so their customers would know about the health information services offered to them.

5. Other

- **A testimonial showing how CHIRS/Go Local Nebraska make a difference**
  
  - My father has a rare disease. I needed to find the singular specialist in Omaha for a second opinion and treatment consultation. But who? And how would I find this doctor? Could there even be someone in our area?
    
    I emailed my request to Teresa Hartman at Go Local Nebraska, and within hours I had the name of a doctor with the subspecialty in neurology. Within a few days, we were sitting in his office. We are most grateful to the medical librarians at the McGoogan Library who know everything! You just have to ask.
    
    Submitted by Sandra Wendel

- More information about members of the Advisory Committee and pictures from various events is linked from the Go Local Nebraska blog: http://golocalne.blogspot.com/
Attachment 6:
Subcontractor Quarterly Report

University of Utah
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
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 #3, covering the period from 04/16/08 through 07/15/08

6. Submission Date:
July 15, 2008

* Note new project title:
Using the “Information Rx” Process to Refer Adults and Parents of Children with Metabolic Conditions to the Genetics Home Reference Web Site for Health Information
NARRATIVE DESCRIPTION

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

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

2. Description of Progress toward the Project's Major Objectives:
   a. Administrative/Planning Activities:
      i. Two study amendments were submitted to the University of Utah IRB and deemed 'exempt' (please see above).
   b. Collaborations/Partnerships: Ongoing with Dr. Longo’s Metabolic Clinic staff.
   c. Publicity/Marketing Activities: Not applicable.
   d. Product/Resource Development Activities: Not applicable.
   e. Site Visits: None at this time.
   f. Outreach activities: None at this time.
   g. Web site development activities: Not applicable.
   h. Exhibits:
      i. Dr. Beaudoin presented a poster describing the ‘Info Rx’ project at the annual meeting of the Utah Library Association in April 2008.
      ii. Drs. Mitchell, Longo, Logan and Beaudoin submitted a poster for presentation at the annual AMIA meeting in November but were notified on June 18 that the abstract was not accepted.


4. Evaluation Activities: Not applicable at this time.

5. Problems/Corrective Actions (including significant changes made in implementation of the project): After discussion among study investigators, the decision was made to expand the study eligibility criteria beyond the parents of newborns to include adults and parents of older children with metabolic conditions who are seen at the Metabolic Clinic. This change will increase the number of potential study participants and allow the investigators to obtain feedback about the GHR Web site from three distinct populations:
the parents of infants with a metabolic condition identified by newborn screening, the parents of children living with metabolic conditions, and adult patients with metabolic conditions. Although a Web-based version of the initial survey was created in order to streamline the data collection process, the paper-and-pencil version has been used as it is a better ‘fit’ with clinic flow.

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

7. Projected Activities for Next Quarter:
   (a) Dr. Beaudoin will continue recruitment of study participants from among patients seen at the Metabolic Clinic.

   (b) Dr. Beaudoin will conduct follow-up of study participants (by e-mail and letter) to ensure that they access the GHR Web site and complete the follow-up survey.

   (c) Dr. Beaudoin will continue data entry and begin data analysis.

8. Reports of Training/Demonstration Sessions and/or Exhibit Reports: Not applicable.

APPENDIX

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

Please see attached IRB correspondence, revised study documents including the most recent (paper) versions of the study description, consent form and surveys.
IRB: IRB_00023554

Principal Investigator: 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

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

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

APPROVED DOCUMENTS

Protocol Summary
Protocol Summary Expanded Study 5/5/08 clean

Informed Consent Document
Consent Form Expanded Study 4/29/08 clean

Surveys, etc.
Follow-up Survey Expanded Study 5/8/08 clean
Initial Survey Expanded Study 5/5/08 clean

Other Documents
Reminder Letter #2 Expanded Study 4/29/08 clean
Study Description Expanded Study 4/29/08 clean
Reminder Email #2 Expanded Study 4/29/08 clean
Reminder Letter #1 Expanded Study 4/29/08 clean
Reminder Email #1 Expanded Study 4/29/08 clean
IRB: IRB_00023554

Principal Investigator: Joyce Mitchell

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

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

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

APPROVED DOCUMENTS

Surveys, etc.

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

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

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

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

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

Potential benefits of participation:
- Increased understanding about your/your child’s medical condition
- Improved communication with your/your child’s doctor

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

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

* Other metabolic conditions may also be included
Consent and Authorization Document

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

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

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

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

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

CONFIDENTIALITY
Results of the study may be published; however, your name and other identifying information will be kept private. We will keep all research records that identify you private to the extent allowed by law. Records about you will be kept in locked filing cabinets, or on computers protected with passwords. Only those who work with this study will be allowed access to your information.
PERSON TO CONTACT
If you have questions, complaints or concerns about this study, you can contact Dr. Denise Beaudoin at 801-581-4080. If you think you may have been injured from being in this study, please call Dr. Denise Beaudoin at 801-581-4080 during the day from 9 am to 5 pm, Monday through Friday.

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

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

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

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

UNFORESEEABLE RISKS
None.

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

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

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

This is the information we will use:

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

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

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

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

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

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

________________________
Participant’s Name

________________________
Participant’s Signature       Date

________________________
Name of Person Obtaining Authorization and Consent

________________________
Signature of Person Obtaining Authorization and Consent   Date
Using the “Information Rx” Process to Refer Adult Patients and Parents of Children with Metabolic Conditions to the Genetics Home Reference Web Site for Health Information

Initial Parent Survey

Please select one answer to each of the following questions:

1. How frequently do you look up sources of medical information?
   - Very frequently
   - Somewhat frequently
   - Neither frequently nor infrequently
   - Somewhat infrequently
   - Very infrequently

2. How frequently do you discuss the medical information that you look up with your/your child’s doctor?
   - Very frequently
   - Somewhat frequently
   - Neither frequently nor infrequently
   - Somewhat infrequently
   - Very infrequently

3. Do you find it easy or difficult to understand the medical issues that your/your child’s doctor discusses with you?
   - Very easy
   - Somewhat easy
   - Neither easy nor difficult
   - Somewhat difficult
   - Very difficult

4. Do you find it easy or difficult to read health information on a computer compared to a book or pamphlet?
   - Very easy
   - Somewhat easy
   - Neither easy nor difficult
   - Somewhat difficult
   - Very difficult

5. Where is the location of the nearest computer you can use?
   - At home
   - At the office
   - At a school
   - At a public library
   - At a hospital library
   - At another family member’s location
   - Other (please fill in): _________________________________________________________

6. On average, about how many hours a day (both at home and work) do you check for email and use the Internet for all other purposes?
   - 0 to 1 hour
   - 2 to 4 hours
   - 5 to 6 hours
   - More than 6 hours
7. Had you ever visited the Genetics Home Reference Web site prior to receiving the Information Prescription from your/your child’s doctor today?
   - Yes
   - No
   - Don’t know

8. If yes, approximately how many times have you visited the Genetics Home Reference Web site?
   - Once
   - Twice
   - Three to five times
   - More than five times
   - I have visited the site before but don’t know how many times
   - I have never visited the Genetics Home Reference Web site

9. How did you first learn about the Genetics Home Reference Web site?
   - From my/my child’s doctor at today’s clinic visit
   - From another doctor
   - From the staff in my/my child’s doctor’s office
   - From an ad
   - From friends and family
   - From an Internet search
   - From a local librarian
   - From either a newspaper or a local radio/television station
   - Other (please fill in): ___________________________________________________________________

Please tell us if you agree or disagree with the following statement:
10. I think receiving a prescription from my/my child’s doctor to visit the Genetics Home Reference Web site for more information is a good idea.
   - Strongly agree
   - Somewhat agree
   - Neither agree nor disagree
   - Somewhat disagree
   - Strongly disagree

11. Did you receive enough information today from your/your child’s doctor to feel comfortable about using the Genetics Home Reference Web site?
   - Yes
   - No
   - Don’t know

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

12. What is your child’s name? __________________________________________

13. What is your child’s date of birth? ______________________________________

14. What is your role in this child’s medical care?
   - Parent
   - Guardian/caretaker
   - Other (please explain): ___________________________________________________________________

15. What is the name of your child’s physician? ____________________________________
16. What is your name? _________________________________________________________

17. What is your age? _________________

18. What is your date of birth? ____________________________________

19. What is your gender?
   ❑ Male
   ❑ Female

20. Which of the following best describes the highest level of education you have completed?
   ❑ Did not complete high school
   ❑ High school graduate or equivalent (GED)
   ❑ Some college or vocational school
   ❑ College graduate
   ❑ Some postgraduate school
   ❑ Graduate/professional degree

21. Which of the following best describes your race/ethnicity?
   ❑ American Indian or Alaskan Native
   ❑ Asian or Pacific Islander
   ❑ Black not of Hispanic origin
   ❑ Hispanic
   ❑ White not of Hispanic origin
   ❑ Other (please describe): ________________________________________________________

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

22. What is your street address? ______________________________________________________

23. Which city do you live in? ______________________________________________________

24. Which state do you live in?
   ❑ Utah
   ❑ Idaho
   ❑ Wyoming
   ❑ Other (please fill in): ______________________________________________________

25. What is your 5 digit zip code? __________________________________________

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

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

28. 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 Adult Patients and Parents of Children with Metabolic Conditions to the Genetics Home Reference Web site for Health Information

Patient Follow-up Survey

ID#_____

1. I am answering the questions in this survey:
   - About myself
   - About a child in my care

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

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

   mm  dd  yyyy

4. Approximately how many times have you visited the Genetics Home Reference Web site since you received the ‘Information Prescription’ from your doctor?
   - Only once
   - Twice
   - Three to five times
   - More than five times
   - I have visited the site but don’t know how many times
   - I have never visited the Genetics Home Reference Web site

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

5. Overall, was the information within the Genetics Home Reference Web site easy or difficult to understand?
   - [ ] Very easy
   - [ ] Somewhat easy
   - [ ] Neither easy nor difficult
   - [ ] Somewhat difficult
   - [ ] Very difficult

6. Overall, how helpful was the information on the Genetics Home Reference Web site relating to your/your child’s condition(s)?
   - [ ] Very helpful
   - [ ] Somewhat helpful
   - [ ] Neither helpful nor unhelpful
   - [ ] Somewhat unhelpful
   - [ ] Very unhelpful

7. How did you use or do you plan to use the health information found on the Genetics Home Reference Web site? (Please check all that apply)
   - [ ] Discussed, or will discuss, with my/my child’s doctor
   - [ ] Discussed, or will discuss, with family or friends
   - [ ] Has improved my understanding of an illness or health condition
   - [ ] Has influenced, or may influence, future health decisions for myself or my child
   - [ ] Have contacted, or will contact, a support group in my area
   - [ ] Looked for, or will consider looking for, more health information
   - [ ] Other __________________________ (Please fill in)

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

8. I trust the information on the Genetics Home Reference Web site because my/my child’s doctor prescribed it.
   - [ ] Strongly agree
   - [ ] Somewhat agree
   - [ ] Neither agree nor disagree
   - [ ] Somewhat disagree
   - [ ] Strongly disagree

9. A high-quality source of health information helps me talk to my/my child’s doctor.
   - [ ] Strongly agree
   - [ ] Somewhat agree
   - [ ] Neither agree nor disagree
   - [ ] Somewhat disagree
   - [ ] Strongly disagree

10. The health information that I find on the Genetics Home Reference Web site will help me make better health decisions for myself/my child.
    - [ ] Strongly agree
    - [ ] Somewhat agree
    - [ ] Neither agree nor disagree
    - [ ] Somewhat disagree
    - [ ] Strongly disagree
11. The information I received on the Genetics Home Reference Web site added to what doctors told me about my/my child’s condition.
   - Strongly agree
   - Somewhat agree
   - Neither agree nor disagree
   - Somewhat disagree
   - Strongly disagree

12. Overall, how satisfied were you with the health information you found on the Genetics Home Reference Web site?
   - Very satisfied
   - Somewhat satisfied
   - Neither satisfied nor dissatisfied
   - Somewhat dissatisfied
   - Very dissatisfied

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

14. Did you notice any missing information about your/your child's metabolic condition in the Genetics Home Reference Web site?
   - Yes
   - No
   - Don’t remember

   If you selected “No” or “Don’t remember” please go directly to question 18.

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

________________________________________________________________________________
________________________________________________________________________________
________________________________________________________________________________
________________________________________________________________________________

16. In which general area of the Genetic Home Reference Web site did you notice that information was missing? (Please check all that apply):
   - An overall explanation of the condition
   - The genes that are related to or cause the condition
   - How persons inherit the condition
   - Where to find more information about treatment for the condition
   - Where to find additional information about the condition
   - Other names people use for the condition
   - A gateway to getting specific questions answered about the condition
   - Glossary definitions that help with understanding the condition
   - Information about diagnosis
   - All the above
   - None of the above
17. Did you use these Internet sources to fill in the missing information? 
(Please check all that apply)
- The WebMD.com Web site
- The MedlinePlus.gov Web site
- The MSN Health Web site
- The Genetic Alliance Web site
- The Ask the Geneticist Web site
- The Madisons Foundation Web site
- The March of Dimes Web site
- None of the above

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

How frequently did you visit pages that focus on a single genetic condition?
- Very frequently
- Frequently
- Neither frequently nor infrequently
- Infrequently
- Very infrequently
- Did not use

How frequently did you visit pages that focus on a particular gene?
- Very frequently
- Frequently
- Neither frequently nor infrequently
- Infrequently
- Very infrequently
- Did not use

How frequently did you visit pages that focus on a particular chromosome?
- Very frequently
- Frequently
- Neither frequently nor infrequently
- Infrequently
- Very infrequently
- Did not use

How frequently did you visit the ‘Help Me Understand Genetics Handbook’ (background information about genetics, including inheritance, genetic counseling)?
- Very frequently
- Frequently
- Neither frequently nor infrequently
- Infrequently
- Very infrequently
- Did not use

How frequently did you visit the definitions of glossary terms?
- Very frequently
- Frequently
- Neither frequently nor infrequently
- Infrequently
- Very infrequently
- Did not use
How frequently did you visit “Resources” (with links to other online genetic resources)?

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

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

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

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

   Within the Genetics Home Reference Web site:

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

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

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

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

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

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

   Was “Resources” (with links to other online genetic resources) **more** helpful to you than “Handbook”?*

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

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

   - [ ] Yes
   - [ ] No
   - [ ] Did not use area(s)
21. Among the links to resources that provide other genetic information and organizations outside of the Genetics Home Reference Web site, which site was most helpful to you?
   - The WebMD.com Web site
   - The MedlinePlus.gov Web site
   - The MSN Health Web site
   - The Genetic Alliance Web site
   - The Ask the Geneticist Web site
   - The Madisons Foundation Web site
   - The March of Dimes Web site
   - None of the above

22. Please rate your level of agreement with the following statements:
   The Genetics Home Reference Web site was more helpful to me than the WebMD.com Web site.
   - Strongly agree
   - Somewhat agree
   - Neither agree nor disagree
   - Somewhat disagree
   - Strongly disagree
   - Did not use

   The Genetics Home Reference Web site was more helpful to me than the MedlinePlus.gov Web site.
   - Strongly agree
   - Somewhat agree
   - Neither agree nor disagree
   - Somewhat disagree
   - Strongly disagree
   - Did not use

   The Genetics Home Reference Web site was more helpful to me than the MSN Health Web site.
   - Strongly agree
   - Somewhat agree
   - Neither agree nor disagree
   - Somewhat disagree
   - Strongly disagree
   - Did not use

   The Genetics Home Reference Web site was more helpful to me than the Genetic Alliance Web site.
   - Strongly agree
   - Somewhat agree
   - Neither agree nor disagree
   - Somewhat disagree
   - Strongly disagree
   - Did not use

   The Genetics Home Reference Web site was more helpful to me than the Ask the Geneticist Website.
   - Strongly agree
   - Somewhat agree
   - Neither agree nor disagree
   - Somewhat disagree
   - Strongly disagree
   - Did not use
The Genetics Home Reference Web site was more helpful to me than the Madisons Foundation Web site.

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

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

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

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

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

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

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

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

____________________________________________________________________________________
____________________________________________________________________________________
____________________________________________________________________________________
____________________________________________________________________________________

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

____________________________________________________________________________________
____________________________________________________________________________________
____________________________________________________________________________________
____________________________________________________________________________________

Please skip questions 27 and 28 and go directly to question 29. (Questions 27 and 28 are intended to be answered by those who have never visited the Genetics Home Reference Web site.)
27. If you have **NEVER** visited the Genetics Home Reference Web site, please tell us the reason(s). (Please check all that apply)

- I do not have access to a computer and the Internet
- I do not use the Internet because it is too complicated
- It’s difficult for me, at times, to understand written health information
- English is not my first language
- I prefer another Internet source for health information rather than the Genetics Home Reference Web site
- It’s upsetting to read about an illness that affects me/my child
- I already know enough about the medical issues my/my child’s doctor asked me to look up
- What the doctors tell me is sufficient
- It’s just not my nature to read about medical issues
- I forgot
- I have not had time
- Other: ________________________________ (Please fill in)

28. Would it increase your interest in using the Genetics Home Reference Web site to know that many local libraries will:

* provide free access to the Internet for patients who do not have their own computers,
* help patients locate health information using the Genetics Home Reference Web site,
* demonstrate the Genetics Home Reference Web site to you?

- Very much
- Somewhat
- Not at all

29. Do you use any of the following health information resources? (Please check all that apply)

- Health care providers
- Friends and/or family members
- Other Web sites (please list):______________________________
- Medical journals
- Print media (newspapers/magazines)
- Radio/television programs
- Other (please list):______________________________

30. Did you search on any of the following Internet services to find health information about your/your child’s condition? (Please check all that apply)

- Yahoo
- Google
- AOL
- Answers.com
- Other Internet services
- None of the above

31. Compared to all other health information sources you use at this time (regardless if they are or are not located on the Internet) how frequently will you use the Genetics Home Reference Web site in the future?

- Very frequently
- Frequently
- Neither frequently nor infrequently
- Infrequently
- Very infrequently
- Never

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