



Proposed Activities to be supported with Carry Forward

Base Funding

Carry forward funds from the Base Funding budget resulted from the following:

- Better use of telemeetings and fewer face-to-face meetings led to a reduction in travel costs and cost of honoraria for workgroup leads.
- Fewer cases than anticipated entered into the Midwest Emergency Medical Services Children's Information System
- Funds set aside for product development and distribution were not used because work group products were not yet finalized
- Not all funds were expended by the website developer

Activities to be supported by carry forward

1. **EHDI Disease Registry** (Short Term Follow-Up page 15 of grant application) – The State of Minnesota EHDI program has contracted with MPHI to work with DocSite to create a disease registry. **Carry forward funds will be used to pay for case entry and for staff to develop contracts/letters of agreement with those entering cases, coordinate training and assist with IRB documents.**
2. **CAH Disease Registry** (Endocrine Project, pages 35-36 of the grant application) – Region 4 endocrinologists are in the process of finalizing data elements for a disease registry which will use the platform created by the Priority 2 Project. **Carry forward funds will be used to support the development of the registry, support state coordinators in recruiting additional endocrinologists, pay for case entry, and for staff time to develop contracts/letters of agreement, coordinate training, negotiate with the software provider and assist with IRB documents.**
3. **Improved Communication with Region 4 States** – (Page 10 of grant application) State leads have indicated a need for additional communication with Region 4 staff (Director, Co-Director, Project Coordinator and Parent Coordinator). In order to respond to this need, Region 4 staff will make site visits to each state. Meeting participants can include current Region 4 members and additional parties who are interested in Region 4 activities. The objectives of the meetings are to (1) provide updates on regional and national activities; (2) disseminate Region 4 products and best practices developed by the Region 4 Collaborative; and (3) recruit additional members. It is anticipated that meetings will begin in the morning and adjourn in the early afternoon. **Carry forward funds will be used to pay for travel expenses for Region 4 staff and to cover breakfast and lunch for meeting participants.**
4. **3 year follow-up of CH** (Endocrine Project, page 9 of grant application) – As part of Region 4 activities, the Michigan Newborn Screening Program has undertaken a limited pilot to determine the feasibility of locating and evaluating the CH diagnosis and treatment status of diagnosed cases after three years. Indiana, Kentucky, Michigan, Minnesota and Wisconsin, have indicated an interest in exploring the feasibility of conducting the evaluations on a

routine basis. The Michigan Department of Community Health has offered to provide 5% of Newborn Screening Manager and Newborn screening epidemiologist (in kind) during this pilot. **Carry forward funds will support up to 5 conference calls among the participating parties and a .10 FTE project coordinator.**

5. **Modified Second-Tier CAH Protocol** (Endocrine project, page 9 of grant application) – Based on previous work done in Michigan, the goal of this project is to develop and publish a two tiered screening algorithm for CAH that reduces the false positive rate by at least 80% and increases the positive predictive value by three fold. Indiana, Wisconsin, and Michigan will participate in this study. Michigan's Department of Community Health will provide project leaders in-kind (2% Newborn Screening Manager and Newborn screening epidemiologist) during this pilot. **Carry forward funds will be used to conduct up to 5 conference calls among the participating parties and a project coordinator at .15 FTE.**
6. **Midwest Emergency Medical Services for Children Information System (MEMSCIS): Sickle Cell Initiative** (Care Coordination Workgroup, pages 33-34 of grant application) – Sickle cell programs in Illinois are already working with Region 4 to adapt MEMSCIS to meet the needs of sickle cell patients. **Carry forward funds will be used to engage additional sickle cell programs in Region 4, hold a face-to-face meeting with sickle cell providers, make necessary revisions to software and support staff to coordinate training.**
7. **Genetic Services Survey** (Access to Genetic Expertise Workgroup, pages 29-32 of the grant application)– The Michigan Birth Defects Registry (MBDR) and the Children's Special Health Care Services (CSHCS) program are preparing to survey families of children with heritable disorders to assess families' knowledge of and perceived need for clinical genetic services. Minnesota and Ohio expressed an interest in joining this effort. **Carry forward funds will be used to (1) support conference calls for participating states; (2) coordinate survey development across states, (3) develop an electronic format; (4) provide participant incentives; and (5) summarize survey results from across the region.**
8. **Marketing and dissemination of Region 4 products and best practice guidelines** (Pages 15, 18 & 20 of grant application) Region 4 has developed multiple products and best practice guidelines that, if marketed and disseminated successfully, can improve practice in both the newborn screening and genetic services arenas. This includes newborn screening short-term follow-up guidelines, the on-line course in newborn screening for prenatal providers, and the soon to be completed Family is the Center of a Medical Home: A Guide for Families with Children with Heritable Conditions, and care coordination plan templates.
9. **Expanded evaluation to measure change in practice** (pages 36-68 of the grant application) – Additional evaluation activities are needed to determine the use and impact of products and best practice guidelines created by the Region 4 Genetics Collaborative. Carry forward funds will be used to complete an evaluation of the following:
 - Online course on newborn screening for prenatal providers – over 500 people have completed the Newborn Screening online course. An email survey will be used to assess how they found out about the course (to inform future marketing efforts) and how they have used that they learned.
 - NBS Short-term Follow-up Guidelines – Telephone interviews will be used to determine how the guidelines have been distributed and used within each Region 4 state.

- MS/MS Training provided by Mayo – A survey will be developed to assess how the experience has impacted practice.
- Evaluation of Priority 2 Activities – This evaluation will be modeled on the previously completed evaluation of Priority 1 and will consist of telephone surveys of workgroup members to assess impact of the project to date.

Priority 1

Carry forward funds are available from a contract with the State of Kentucky lab for coordinating the sample exchange.

10. **MS/MS Training at Mayo** (pages 6-8 of Priority 1 application)– Week-long training is provided by Mayo at no cost to participants except travel. **Carry forward funds will be used to support at least one person from each Region 4 NBS lab to attend training.**

Priority 2

Due to delays in finalizing the data platform and processing IRB forms, fewer cases were entered into the information system than anticipated. This resulted in carry forward of funds that had been set aside to support case entry.

11. **Chronic Disease and Family Functioning** (page 6 of the Priority 2 application) - Darin Erikson, PhD, a parent member of the Priority 2 Workgroup, will identify parents of children with inborn errors of metabolism using the IBEM-IS. Parents will be asked to participate in focus groups to identify and assess the impact of stressors on families who have a child with a heritable disorder. Ohio and Michigan have expressed interest in joining this effort. **Carry forward funds will be used to support 1) focus groups in each of the 3 states to provide qualitative data on stressors 2) analyze data obtained 3) develop a survey and 4) staff support to coordinate, schedule and facilitate focus groups. Additional funding will be sought to support implementation of the survey.**