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**ix: SUMMARY PROGRESS REPORT OF PROJECT YEAR 5 (FY 08-09):  
June 1, 2008 – March 19, 2009**

**1. and 2. Accomplishments, Progress on specific goals and objectives, and Barriers to progress**

Heartland Genetics and Newborn Screening Collaborative is a dynamic group of parents, patients, clinicians, researchers, industry representatives, laboratorians, and public health officials who care about the access to and quality of all genetic services in the region. The collaborative is 4 ½ years old, and is maintaining 100% participation from the clinical genetics centers, newborn screening (NBS) programs, and advocates in the region while continuing to add new members. In addition to projects that address our region's needs, Heartland contributes to projects of national significance and collaborates with other regions.

Progress and accomplishments on the goals and objectives outlined in the Year 5 Project Narrative are described below. First, the Heartland goals are provided as reference.

**Goal 1:** Promote assessment, planning, evaluation, partnering and policy activities to facilitate access to quality clinical genetic services for the citizens of the states within the Heartland Collaborative.

**Goal 2:** Promote genetics education regarding resources, clinical and laboratory services (availability, access, indications, limitations and benefit), genetic testing, teratogen services, and genomics. Facilitate integration of genetics education into the curriculum of schools (primary & secondary), vocational schools, colleges, and schools of health, such as medical schools, residency programs, midwives, nursing schools, allied health, and physician assistants.

**Goal 3:** Promote quality public health programs in the Heartland by establishing an infrastructure to facilitate networking, education, information sharing, assessment, policy activities, program development and evaluation within the region for the public health genetics programs.

**Goal 4:** The Heartland Regional Coordinating Center will provide leadership in the region and facilitate activities to promote access to quality clinical genetic services, genetic testing, collaborative research, and public health programs for the citizens of the states in the Heartland Collaborative.

Heartland projects for FY 08-09 that address **quality clinical genetic services (goal 1):**

**Strategy 1:** Contribute to Region 4's Laboratory Performance Project

**Progress to date:** 100% of states are contributing to the Region 4 Laboratory Performance Priority Project.

**Strategy 2:** Clinical long-term follow-up of children with inborn errors of metabolism

**Progress to date:** 50% of genetics centers are participating in Region 4's Inborn Errors of Metabolism Information System (IBEM-IS).

Heartland projects for FY 08-09 that **promote genetics education (goal 2):**

**Strategy 1:** Strengthening the medical home through education of primary care providers

**Progress to date:** Two diagnosis modules (Prader-Willi syndrome and Medium Chain Acyl-CoA Dehydrogenase Deficiency (MCADD) were completed; and one on fetal alcohol spectrum disorders is underway.

**Strategy 2:** Promote Leadership Education in Neurodevelopmental and Related Disabilities (LEND) programs' awareness of Heartland and genetics resources through their regional conference and incorporating aspects of clinical genetics into their curricula.

**Progress to date:** Developed educational strategy to utilize the diagnosis modules on genetic disorders as a practicum opportunity for LEND fellows.

**Strategy 3:** Pilot project award to Missouri Department of Health and Senior Services (MDHSS), Genetics Program to conduct a state-wide conference for primary care providers and families about expanded newborn screening (addresses HRSA Office of Performance Review (OPR) action plan key step).

**Progress to date:** PI, Sharmini Rogers, met with Heartland evaluator to review project's evaluation plan. The conference is scheduled for April 17<sup>th</sup> in Jefferson City, MO and 75 people are registered. Physicians can earn 7 AMA PRA Category 1 Credits™.

**Strategy 4:** Pilot project award to Beth Conover (NE) to develop, promote, and disseminate a Heartland Pregnancy and Breastfeeding Exposure Information resource manual.

**Progress to date:** The award was made in FY 07-08 (carried forward due to funding logistical issues) and completed on time when funding was available. The original award, per HRSA requirement, targeted federally funded family planning clinics and providers who worked with pregnant women and/or delivered infants. The project was presented by poster and roundtable session at the 2008 Heartland annual meeting. Attendees advised the PI about other providers in need of this information. Given the overwhelming response, Heartland Regional Coordinating Center (RCC) agreed to extend and fund the project one more year (FY 08-09). The project was also accepted as a poster presentation at the 2009 American College of Medical Genetics (ACMG) meeting (March 2009, Tampa FL).

Heartland projects for FY 08-09 that **promote infrastructure (goal 3):**

**Strategy 1:** Genetic Systems Assessment (GSA)

**Progress to date:** Evidence table completed; manuscript of literature review for *American Journal of Medical Genetics-Part C* on quality issues in genetics; abstract of preliminary data accepted for poster presentation at ACMG Annual Meeting (March 2009, Tampa, FL); Expert Panel membership expanded; organized ancillary meeting held January 2009 in Bethesda regarding the four quality projects coming out of the regions and whether or not the Council of Regional Networks (CORN) guidelines (See Attachment 13) need revising; Expert Panel meeting scheduled for May 7-8, 2009 to complete Delphi process (selection of measures).

**Strategy 2:** Exchange between NBS programs.

**Progress to date:** 100% of states requesting to visit another state have complied with the guidelines to conduct a Program Evaluation and Assessment Scheme (PEAS) pre-visit assessment, develop an agenda around needs and deficiencies identified through the pre-assessment, and complete a post-assessment with PEAS 12 months later.

- 1) AR visited NE: post-assessment completed;
- 2) ND visited IA: post-assessment due in April 2009;
- 3) KS visited IA: post-assessment due April 2009;
- 4) SD scheduled to visit OK April 2009: draft agenda and PEAS pre-assessment submitted to RCC for review, which is pending.
- 5) MO requests to visit IA. MO pre-visit documentation not yet submitted.

**Strategy 3:** Pilot project award to MDHSS to pilot a database linkage project in a large, urban pediatric practice (Swope Health Center, Kansas City MO).

**Progress to date:** Access has been granted internally to MDHSS and training conducted for >200 Swope employees.

**Strategy 4:** Heartland NBS Back-up Testing and Quality Assurance Project. Conduct 3-day drills in FY 08-09 and report on progress from FY 07-08 at Heartland annual meeting.

**Progress to date:** PIs, Berberich (IA) and Hopkins (MO) presented their work at 2008 Heartland annual meeting. Details of their 1-day drills can be found at <http://www.heartlandcollaborative.org/annualconference/conference08.htm>. A manuscript of their work is in progress. One 3-day drill has been conducted, and the second is scheduled for April 2009. The third annual Heartland NBS workshop is scheduled for April 30 – May 1 in Lincoln, NE. Proposal submitted for FY 09-10 to conduct drills with remaining Heartland states.

**Strategy 5:** Sarah Lawrence Scholarship for certificate in Public Health Genomics.

**Progress to date:** Two applicants tied and were thus awarded (for consecutive years) the scholarship. These recipients were Kim Piper (FY 07-08/08-09) and Sharmini Rogers (FY 08-09/09-10). Piper completed the course and presented her capstone project at Heartland annual meeting. Capstone project presentation can be found at:

<http://www.heartlandcollaborative.org/annualconference/conference08.htm>.

**Strategy 6:** Build linkage to resources for transitioning individuals from pediatric to adult healthcare.

**Progress to date:** Invited speaker, Patti Hackett, Co-Director of Healthy and Ready to Work (HRTW) National Resource Center, to present at 2008 Heartland annual meeting. Presentation and resources can be found at:

<http://www.heartlandcollaborative.org/annualconference/conference08.htm>. Ad hoc work group on Transition issues formed and met once.

Heartland Regional Coordinating Center activities that **demonstrate leadership and facilitate access to clinical and public health services as well as collaborative research (goal 4):**

**Strategy 1:** Revise regional plan.

**Progress to date:** Regional plan reviewed by Heartland Advisory Board at September meeting. All but one change was minor; the content change was to add “collaborative research” to Goal 4. Updates have been incorporated and revised plan posted on Heartland website.

**Strategy 2:** Developed project evaluation plan (see Attachment 14).

**Progress to date:** External evaluator retained and plan developed. Plan approved by Advisory Board at the January 2009 meeting and posted on Heartland website (OPR action plan key step).

**Strategy 3:** Disseminate information and resources, and enhance regional communication using multiple strategies (website, e-newsletter, list serve, work group meetings, and conferences).

**Progress to date:**

**a. Website (<http://www.heartlandcollaborative.org>)**

The Collaborative completed a major overhaul and expansion of its two websites ([www.heartlandcollaborative.org](http://www.heartlandcollaborative.org) and [www.heartlandfamilyhistory.org](http://www.heartlandfamilyhistory.org)) at the end of July, 2008. The goal was to re-energize the Collaborative’s web presence with the aim of dramatically increasing usage of the two sites through improved content, organization, and functionality. That goal has been met.

Average daily usage rates for the eleven-month period before August 1, 2008 and the five-month period after the cut-over to the new sites were compared. Data show that the average visits-per-day after the cut-over were 575% of what they had been. Daily visits-per-day for both sites combined grew to 119/day, up from 21/day. Looking at the average visits-per-day indicator, improvement was somewhat stronger for the Collaborative’s main site (new rate is 600% of old rate) than for the family history site (where the new rate is 453% of the old rate.)

The data for page views-per-day also grew significantly, indicating that visitors, when they reached our websites, viewed more content. Average page views-per-day before the cut-over were 63; after the cut-over they were 1,046, a rate of increase of 983%.

Top 10 pages on Heartland Website (August 1-December 31, 2008)	Number of visitors
Heartland Regional Genetics and Newborn Screening Collaborative, Arkansas, Iowa, Kansas, Missouri, Nebraska, North Dakota , Oklahoma, and South Dakota (homepage)	3,335
Calendar - Heartland Collaborative (month view)	2,186
Calendar - Heartland Regional Genetics (specific event)	1,105
Heartland Annual Collaborative Meeting - Heartland Regional Genetics	805
News - Heartland Regional Genetics	635
Calendar - Heartland Collaborative (specific event)	609

<b>Top 10 pages on Heartland Website (August 1-December 31, 2008)</b>	<b>Number of visitors</b>
Advisory Board - Heartland Regional Genetics	560
Newborn Screening - Heartland Regional Genetics	502
Advocate - Heartland Regional Genetics	437
Research Funding Opportunities - Heartland Regional Genetics	431

**b. E-newsletter**

Heartland began publishing its quarterly newsletter electronically since September 2008. The newsletter is disseminated electronically to 210 subscribers. A copy of the December newsletter is included in Attachment 8. The March 2009 issue focuses on “how to” include genetic counseling as a component of a state NBS follow-up program (OPR action plan key step).

**c. List serve**

Heartland now has 81 subscribers to the list serve. Between June 1, 2008 and March 2009, 84 original messages were posted, which is comparable to the same time frame last year. Postings include announcements, clinical questions, other requests for information, discussion of regional issues, and dissemination of RCC and HRSA information. In addition, a web-based Yahoo group and list serve is used by the Advocate group for communication from the RCC, discussion, posting documents, links, and photos. There are currently fifteen members of this group.

**d. Work Group meetings**

All work groups and the advisory board meet monthly by teleconference with few exceptions. Since June 2008, 25 work group meetings have been held and three ad hoc work group meetings (6 clinical, 3 Education, 8 Advocate, 8 NBS, 2 Genetics Education for Nurses and 1 Transition). Additionally, the advisory board met seven times, including our first face-to-face meeting in September 2008. The meeting summaries, call-in information, and agendas are posted on our website calendar and in the Work Group sections. All meetings are open.

**e. Conferences**

The 2008 annual meeting was held September 11-12, 2008 in Sioux Falls, SD (agenda included in Attachment 7). The meeting was attended by 83 people from 16 states and one foreign country. Five vendors attended and supported the conference. Conference information, including agendas, speaker slide sets, references and other materials, are available on our web site <http://www.heartlandcollaborative.org/annualconference/conference08.htm>.

NBS Workshop scheduled for April 30 – May 1, 2009 in Lincoln, NE. (Agenda included in Attachment 10)

GSA Expert Panel scheduled for May 7 – 8, 2009; location TBD.

Additional activities of the RCC and Heartland collaborative that were a continuation from the previous year or occurred in response to a stimulus during the project year are listed below.

- 100% of Heartland states have implemented expanded NBS.
- 100% of NBS laboratories have accessed the additional training opportunities for their staff (offered at Mayo and Baylor).
- 100% NBS programs have accessed the additional training opportunities for their staff (offered at Duke).
- 25% of Heartland states have licensure for genetic counselors (OK and SD).
- Funding development and dissemination of the KS state genetics plan.
- North Dakota state genetics plan dissemination.
- Regular meetings as required by the cooperative agreement (e.g.: monthly NCC/PI calls; quarterly HRSA/NCC/RCC calls; ACHDNC meeting; biannual NCC/PI meeting (DC area and Chicago)).
- Representation on all NCC work groups.
- Mulvihill leading RCC publications work group.
- Inter-regional collaborations (Western States, Mountain States, NEGC, and Region 4).
- Promoted abstract submission/presentations from our region at Association of Public Health Laboratories Newborn Screening and Genetic Testing Symposium (APHL/NBSGTS) (2 oral); ACMG (2 posters); and American Telemedicine Association (ATA) conferences (1 poster).
- Purchased “tree” magnets to promote family health history website. MO has disseminated approximately 400 at health fairs and 2000 were disseminated with an OK family health history project (project was funded by Genetic Alliance grant).
- Provided two letters of support for grants submitted by sections of genetics in the region (AR and OK).
- Invited participation of Early Hearing Detection and Intervention partners through newsletter submission and roundtable discussion at the annual meeting.
- Data collection continues for NBS town hall meeting pilot project.
- Data collection continues for parental stress in NF1 pilot project.

### **Barriers to Progress**

The only barrier during FY 08-09 was loss of a key RCC team member, the assistant project manager (Byerly) and the external evaluator (Joens-Matre). Thankfully, a new position for project coordinator was created and filled during the year (Whitehead), which has helped us maintain most of the momentum while we are down one staff member. A new evaluator has been retained (Jackson), and in a short period of time, the project evaluation plan was developed and approved by the Advisory Board. We look forward to the implementing the evaluation plan in FY 09-10. The absence of an assistant project manager mostly affects progress on detailed projects such as the development of the diagnosis modules and completing the CME application.

**Office of Performance Review Action Plan** (see Attachment 12)

All items in the action plan will be completed by May 31, 2010. The key steps are incorporated into our Heartland Evaluation Plan. Progress has been made in three areas of the action plan. First is the pilot project in MO that will offer pediatrician and family education in NBS. Second is the publication of a “how-to” newsletter issue. The March 2009 issue compares how each state offers (or does not) genetic counseling as part of their NBS program. Finally, the Heartland Evaluation Plan is completed.

### **3. Current Staffing**

The RCC team located at the University of Oklahoma Health Sciences Center (OUHSC) consists of a PI (Mulvihill), a Co-PI and project manager (Williamson), and program coordinator (Whitehead). Whitehead joined the team August 1, 2008 as the program coordinator. She assists Williamson in consolidating and streamlining the administrative activities that were previously spread among several individuals and across campus: monitoring, subcontracts, budgets, invoicing, reporting, planning meetings, communication (website, newsletter), and facilitating and summarizing the work group meetings. Additionally, Dr. Ann Chou at OUHSC leads the GSA project, and one of her graduate students (Norris) assists her on the project. The external evaluator (Jackson) was sub-contracted through University of Nebraska Medical Center, effective December 1, 2008. We are currently recruiting for a part-time assistant project manager to assist Williamson with content-heavy projects. Current staff efforts total 1.9 FTE.

### **4. Technical Assistance (TA) Needs**

We will continue to request TA from the HRTW National Resource Center, RAND Corporation, Emergency Management Assistance Compact (EMAC), and National Committee for Quality Assurance (NCQA) in the FY 09-10 project year.

### **5. Linkages with other Programs:**

Heartland has partnered, reached out to, or sought technical assistance from LEND, EMAC, Agency for Healthcare Research and Quality (AHRQ), Genetic Alliance, National Newborn Screening and Genetics Resource Center (NNSGRC), HRTW, RAND Corporation, and NCQA in the FY08-09 project year. Additionally, Heartland has current activities involving four other regions.

## **2. PROGRAM NARRATIVE SECTIONS for FY09-10:**

### **a) Purpose of the Project (proposed activities for June 1, 2009 – May 31, 2010)**

The major purpose of the Heartland Genetics and Newborn Screening Collaborative is to improve and expand the capacity of state public health genomics programs and clinical genetics service programs to provide quality screening, testing, diagnostic, counseling, treatment, and management services to newborns, children and adults having or at risk for heritable disorders in a way that is culturally sensitive, collaborative, and responsive to our states’ and regional needs. To this end, the region developed a strategic plan (revised Fall 2008) based upon needs assessments, established a collaborative of key stakeholders, created lines of communication which did not previously exist, launched regional projects with national impact, and catalyzed collaborations within and beyond the Heartland region. Building on these accomplishments, the Heartland collaborative will maintain existing activities and inter-regional collaborations (Genetic Systems Assessment, Laboratory Performance Project, IBEM-IS, Back-up testing project, Sarah Lawrence Scholarship Program); initiate new activities in education and clinical

services that improve the resources in our region and strengthen the medical home (Metabolic rounds, Family Financial Resources Guide, and Genetics in Nursing modules); and implement the Heartland Evaluation Plan.

Decisions to pursue these activities are based on a) goals of the Heritable Disorders Program; b) Heartland needs assessment and strategic plan; c) findings of completed projects; d) HRSA OPR Action Plan; e) projects nominated by the work groups, and f) prioritization of activities by the Heartland Advisory Board.

#### **b) Needs Assessment**

According to the latest US Census estimates more than twenty-one million people live in the Heartland states; with half of them (55%) in rural areas. (Attachment 13) Though varying from state to state, the average population density in the region is 39 persons per square mile, as compared to the US average of 80 persons per square mile. The racial and ethnic mixture consists of Whites (87%), African Americans (6%), Hispanics (5%), and Native Americans (3%). Although Native Americans make up only 3% of the population, Native Americans exert a strong cultural influence in Oklahoma and the Dakotas.

Twelve clinical genetics centers provide clinical services for the entire region. The medical genetics clinical staff ranges from one geneticist in North Dakota to nine medical geneticists in Missouri. Three states (Missouri, Arkansas, and Iowa) have regionally based clinics with a provider (genetic counselor, coordinator, or nurse) at that location. These regionally based services are linked to a genetics center. Similarly, variability exists among the public health genetics resources and in the nature of the relationships between the clinical centers and their respective public health genomics programs.

The Heartland Collaborative developed, over a two-year period, the *Heartland Regional Collaborative Strategic Plan*. This plan was informed by an inclusive process that involved: a) regional needs assessment; b) review of state genetics plans; and c) prioritization of needs by state genetic coordinators and regional committees. The *Heartland Regional Collaborative Strategic Plan* therefore represents a regional consensus of the strengths, weaknesses, and gaps within the Heartland region. Revised in 2008, the plan outlines four goals, as stated in the previous section.

Heartland Work Groups and Pilot Projects are engaged in and plan activities to meet the goals. Each activity addresses a goal in the regional plan or is a priority of the Heritable Disorders Program, or responds to the OPR Action Plan.

#### **c) Goals and Objectives**

***Goal 1) Promote assessment, planning, evaluation, partnering and policy activities to facilitate access to quality clinical genetic services for the citizens of the states within the Heartland collaborative.***

Heartland projects that respond to Goal 1 of the *Heartland Regional Strategic Plan* include:

- Laboratory performance project with Region 4
- IBEM-IS project with Region 4

- Metabolic rounds via telehealth technology

Laboratory Performance Project: **100%** of Heartland states are contributing data to this inter-regional project. Heartland will provide travel support to any state that cannot otherwise send a representative to the required, in-person meeting of this project (APHL meeting, May 2010, Orlando, FL). However, due to base budget constraints and timing of the required meeting, this budget request will come in our carry forward request rather than the base budget request.

IBEM-IS Project: Treatment of children with rare, metabolic conditions varies among practitioners for a variety of reasons, but the absence of scientific evidence on which to base management is chief among them. One strategy to improve treatment and clinical management for these patients is to collect treatment plans and clinical and developmental data longitudinally. Region 4 has developed the IBEM-IS. Currently, six centers (**50% of clinical genetics centers**) in the Heartland are participating in this activity (Children’s Mercy (MO); University of MO (MO); Sanford Children’s Hospital (SD); St. Francis Medical Center (OK); University of Iowa (IA); and University of Nebraska Medical Center (NE). These centers will present their collective experience in poster or oral format at the 2009 and 2010 annual Heartland meetings. Their experiences may stimulate participation by some or all of the six remaining genetics centers in the region. Once again, we will request carry forward funding for their work rather than request from base budget.

Promote use of telehealth strategies for clinical genetics: Heartland RCC will disseminate the “TeleGenetics How to Guide” to all clinical genetics centers in the region, collaborative members, other regional centers and post on our website.

Metabolic Rounds using Telehealth technology: The primary purpose is to provide a forum for primary care providers to consult with metabolic experts about their difficult cases (diagnosed or undiagnosed). Secondary purposes are to promote genetic services in that state and to provide support and education around expanded newborn screening (NBS). Metabolic Rounds will be promoted among American Academy of Pediatrics (AAP), American Academy of Family Practice (AAFP), and the National Association of Pediatric Nurse Practitioners (NAPNAP) chapters as well as with pediatric neurologists and endocrinologists in four Heartland states. North Dakota has volunteered to be the first state. Metabolic consultant panels will be comprised of boarded metabolic geneticists in the region, but not necessarily geneticists from the host state, as some of our states do not have boarded metabolic geneticists. Thus, a potential outcome may be further sharing of resources (e.g., metabolic specialists) in the region. We do not anticipate a budget request for this item.

***Goal 2) Promote genetics education regarding resources, clinical and laboratory services (availability, access, indications, limitations and benefit), genetic testing, teratogen services, and genomics. Facilitate integration of genetics education into the curriculum of schools (primary and secondary), vocational schools, colleges, and schools of health, such as medical schools, residency programs, nursing schools, and allied health.***

Heartland projects that relate to Goal 2 of the *Heartland Regional Strategic Plan* include:

- MedHome Portal Evaluation

- LEND partnership Implementation and Evaluation
- Family Financial Resources Guide
- Genetics in Nursing modules

MedHome Portal Evaluation: This project is an ongoing activity of Heartland's Clinical and Education Work Groups. The purpose is to educate primary care providers using a "just-in-time" strategy. Usage of the modules is incentivized by continuing education credits paid for by Heartland. This project collaborates with Dr. Chuck Norlin at the University of Utah Health Sciences Center (Mountain States Region). Heartland is creating additional diagnosis modules for genetic conditions and metabolic disorders (Prader-Willi syndrome and MCADD) are completed; fetal alcohol syndrome and Phenylketonuria (PKU) are in progress) and providing continuing medical education units for the project. In turn, the MedHome Portal (<http://www.medhomeportal.org/>) provides an existing platform within a medical home context.

Completion of the five remaining diagnosis modules (Heartland will have contributed a total of seven modules) will occur in FY 09-10, and any expenses will be covered by carry forward funds. Evaluation of this project will begin as soon as providers begin to access the continuing medical education component.

In summary, this project strengthens the medical home for children and families with genetic conditions by providing genetics information targeted at primary care providers at the point-of-service; develops partnerships with local AAP chapters in the region by involving them in selecting disorders for which they desire modules and through promoting the CME activity; and exposes pediatricians in the region to the Heartland collaborative.

LEND Partnership: Six of the eight Heartland states have LEND programs. Nebraska has integrated genetics into their LEND program and Oklahoma has identified core faculty in genetics. Representatives from the NE and OK LEND programs presented at the 2007 annual Heartland meeting. The discussion following the presentation made clear that awareness of LEND is minimal. To the extent that over half of the LEND programs in the region do not interact with genetics programs signals poor awareness, few opportunities to interact, and little understanding of programs' capacity to enhance one another. The Heartland has identified two activities to promote mutual awareness of LEND and the regional collaborative as well as increased knowledge of genetic services. These are to offer the MedHome Portal diagnosis modules as a practicum experience for LEND fellows and respond to the "Call for Presentations" for the regional AUCD/LEND conference in 2009. Heartland will evaluate the extent to which these strategies increase knowledge and awareness. Prior to any of these activities, however, Heartland will arrange an introductory call with the LEND directors before May 31, 2009.

Family Financial Resources Guide: A version of this guide, developed by a parent and LEND fellow in Oklahoma, was presented at the 2008 Heartland annual meeting. The Advocate Work Group proposed creating guides for each state in our region. Some progress has been made, but has been quite slow for two main reasons: 1) the information is difficult to find, even on the internet; and 2) parents on this work group are volunteer, care for children with special health care needs, and work outside of the home. Therefore, we propose hiring an advocate (not

necessarily a member of the work group) to compile the guides for each state. This will ensure the project is completed in a timely manner.

Genetics Nursing Modules: The University of Iowa, College of Nursing has developed on-line genetics modules targeted for nurses. Heartland learned of the potential opportunity to collaborate during our state visit to Iowa in FY 07-08. Two planning and exploratory teleconference calls have occurred and both parties (Heartland collaborative members and University of Iowa College of Nursing) are interested. The project is straightforward: use Heartland's network to promote and disseminate an existing resource. In rural areas, nurses provide a great deal of the medical care, so this strategy could potentially educate a significant work force. Finally, Heartland will incentivize participation in the project by offering Continuing Education Units (CEUs) to the nurses.

***Goal 3) Promote quality public health programs in the Heartland by establishing an infrastructure to facilitate networking, education, information sharing, assessment, policy activities, program development and evaluation within the region for the public health programs of genetics, newborn screening, birth defects registry, Children with Special Health Care Needs, Maternal and Child Health, and other programs related to genetic services, such as Chronic Disease.***

Heartland projects that relate to Goal 3 of the *Heartland Regional Strategic Plan* include:

- Genetic System Assessment
- Evaluation of NBS Program Exchange
- Create capacity for back-up NBS in the Heartland--Phase 3
- Transitioning specialty medical care from pediatrics to the adult healthcare system
- Sarah Lawrence Scholarship Program

Genetic System Assessment: Measures will be selected by the end of the current project year. Thus, in FY 09-10, the measures will be assigned weights, the assessment tool developed, and two pilots conducted. The GSA team will also submit an abstract and/or manuscript about the measures selection process. A Steering Committee and Expert Panel combined meeting will take place at the March 2010 ACMG meeting. Implementation of the tool in the Heartland region will take place in FY 10-11.

Evaluation of NBS Program Exchange: NBS programs (short-term follow-up (STFU) and long-term follow-up (LTFU)) in the region conducted a "program exchange" during parts of the past two project years. Five states requested exchanges: North Dakota (visited Iowa); Arkansas (visited Nebraska); Kansas (visited Iowa); South Dakota (scheduled to visit Oklahoma) and Missouri (scheduled to visit Iowa). Evaluations of the exchanges occurring during FY 07-08 (ND and KS) are due soon and AR is complete. In addition to the PEAS post-assessment, the Heartland evaluator will also interview stakeholders to collect qualitative data about the effectiveness of this project. No budget request.

Create capacity for back-up NBS system in the Heartland—Phase 3: The Heartland Back-up Testing and Quality Assurance Project is an ongoing project within the Heartland Region to ultimately provide backup NBS services across our region in the event that a natural disaster or

other hardship would render a state NBS program inoperable. The critical nature of the disorders and requirement for time critical interventions make it essential that contingency backup services be available to prevent interruption of routine NBS services. This project, now into its second year, has been very successful in planning, practicing and validating a contingency plan between the Iowa and Missouri NBS laboratories. Iowa also provides the NBS laboratory support for the North Dakota and South Dakota NBS programs; so, this project has resulted in the establishment of NBS backup services not only for Missouri and Iowa, but for North Dakota and South Dakota as well. During FY 09-10, we propose to expand the project to Nebraska, Kansas, Oklahoma and Arkansas to ensure backup NBS services are in place and validated throughout the Heartland Region.

In FY 09-10, the Missouri State Public Health Laboratory (MSPHL) and the University of Iowa Hygienic Laboratory (UHL) will work with the remaining four states in the Heartland Region (MSPHL will work with the Oklahoma State Department of Health and the Kansas Department of Health and Environment; UHL will work with the Arkansas Department of Health and the Nebraska Department of Health and Human Services) to plan and implement a one-day functional preparedness drill to establish emergency NBS backup services for each state NBS program. Utilizing the EMAC process between each of our state emergency management departments, we will stage mock disasters that would require their NBS samples to be sent off site for testing. We will use pre-tested and completely reported two-week-old samples. The drills will include full testing and reporting of the NBS results back to the original state NBS programs using protocols similar to the drills between IA and MO. These drills will address not only the testing of the specimens, but the whole system, ensuring the screening results are interfaced with necessary follow-up services to ensure that abnormal screen results will receive timely and appropriate action. Additionally, as demonstrated in past drills, the number of specimens used in these drills provides an excellent opportunity for several quality assurance comparisons between our laboratories. MSPHL and UHL will each hold a drill with one state in the Fall 2009 and with one state in the Spring 2010. (Letters of Support from the participating states can be found in Attachment 11).

Upon completion of the drills, Heartland NBS programs will convene their annual workshop to review data collected, necessary changes to be made based on the drills, and identify next steps. The Heartland RCC will organize this Spring 2010 meeting and will pay for it from carry forward funds. Therefore, a budget request is not made for this meeting in the base budget.

In response to the OPR Action Plan, Heartland RCC will work with Berberich and Patrick to explore resources and establish links with the Federal Emergency Management Agency (FEMA) and Homeland Security Exercise and Evaluation Program (HSEEP), as appropriate. This may also be an activity that NCC's consultant, Bill Perry, can assist us with. These links could prove vital in a catastrophe.

Transitioning specialty medical care from pediatrics to the adult healthcare system: A stated goal within *Healthy People 2010* plan is for all young people with special health care needs to receive the services required to successfully transition into all aspects of adult life: healthcare, work, and independent living. (Attachment 13) Medical care has helped children with conditions survive longer. Their survival created a demand for adult health care providers knowledgeable about the

genetic condition, but those providers are rare. To date, our region participates on the national ad hoc Transition Work Group and invited speakers to two annual meetings to present practice models and resources to promote the application of transition practices. As a result, a regional ad hoc work group formed to further discuss the topic and share information. This ad hoc group has had one meeting to date and will continue to meet regularly. One task for this group is to develop a project proposal FY 10-11. No budget request.

Additionally, Heartland is a co-applicant in a Department of Defense grant to educate primary care providers about NF1. One aspect of the proposal is to increase appropriate transition of children with NF1 to adult primary care and specialty providers.

Sarah Lawrence Scholarship Program: A long-term goal for the Heartland region is to have a cadre of decision-makers educated in public health genomics. Increased knowledge and understanding in the field are likely to promote change within health departments and within programs. Policy and programmatic changes ultimately affect the consumer and public.

Providing a competitive scholarship, to a public health genomics program, is the strategy Heartland has employed to reach this long-term goal. Three scholarships have been awarded to individuals from three different states, all of whom are in positions to effect change in their states. This scholarship program receives strong support from the Heartland collaborative, the Sarah Lawrence Public Health Genomics program, and HRSA.

***Goal 4) The Heartland Regional Coordinating Center will provide leadership in the region and facilitate activities to promote access to quality clinical genetic services, genetic testing, and public health programs for the citizens of the states in the Heartland collaborative.***

Heartland projects that relate to Goal 4 of the *Heartland Regional Strategic Plan* include:

- Continual assessment, evaluation, and modification
- Maintain regional communication and disseminate information and resources
- Expand regional communications to federally qualified health centers and other primary care organizations

Continual assessment, evaluation, modification and strategic planning: The RCC maintains vitality of the collaborative through assessment, planning, evaluation, communication, consumer partnerships, clinical and public health partnerships, and advocacy. A functional and cohesive organization with meaningful participation from all stakeholders has the power to impact services, programs, infrastructure, and policy, all of which ultimately affects the individuals and families affected by genetic conditions.

The Heartland Regional Strategic Plan outlines the region's original goals and plan for the collaborative. The Advisory Board reviewed the plan in Fall 2008 and recommended only minor revisions. The current version can be found on the Heartland website (<http://heartlandcollaborative.org>).

An external evaluator, Dr. Barbara Jackson (University of Nebraska Medical Center) was contracted to develop a regional evaluation plan (FY 08-09) and implement the evaluation plan

(FY 09-10). A major activity for the RCC in FY 09-10 will be implementation of the evaluation plan. (See Attachment 14).

Maintain regional communication and disseminate information and resources: Heartland RCC uses multiple communication strategies, including: website (<http://heartlandcollaborative.org/>); list serve; work group meetings; annual conference; and quarterly e-newsletter. We will continue to utilize these modes of communication unless evaluation data indicates a strategy(ies) should be modified.

Heartland will also utilize the new services of ACMG Public Relations Director, Kathy Beal, MBA. Ms. Beal’s strategy for the RCs is forthcoming.

Expand regional communications to federally qualified health centers and other primary care organizations: This strategy came from the OPR action plan. These entities in our region will be added gradually (there are many) to the mailing list beginning June 2009 through May 31, 2010. Primary Care Associations will also be added to the e-newsletter mailing list for the June 2009 issue (OPR action plan key step).

**d) Project Methodology**

Implementation Objectives	Activities/ Task Assignment	Implementation Evaluation Measures	Outcome Evaluation Questions	Outcome Evaluation Measures	Outcome Data Collection Timeline <sup>1</sup>
<b>Goal 1: (short form) Facilitate access to quality clinical genetics services</b>					
Maintain participation of Heartland states at 100% for FY 09-10.	State NBS labs/programs enter data into Laboratory Performance database.  Heartland Regional Coordinating Center (RCC) assures that all participants attend required meetings.	Document # of states who contribute data to the project.			Ongoing

<sup>1</sup> Year 6 is 06/01/2009 through 05/31/2010  
Year 7 is 06/01/2010 through 05/31/2011

<b>Implementation Objectives</b>	<b>Activities/ Task Assignment</b>	<b>Implementation Evaluation Measures</b>	<b>Outcome Evaluation Questions</b>	<b>Outcome Evaluation Measures</b>	<b>Outcome Data Collection Timeline<sup>1</sup></b>
<p>50% of Heartland's Clinical Genetics centers will participate in the IBEM-IS project for FY 09-10.</p>	<p>Six centers (50%) currently participating will enter data into IBEM-IS, attend monthly project teleconference calls, attend face-to-face required project meeting in Fall 2009, and present data/experience at Heartland annual meeting.</p> <p>Heartland RCC facilitates participation; mediates in any issues that arise; and assures reimbursement for travel to face-to-face, required meeting.</p>	<p>Document participation in the study and # of data entries reimbursed.</p> <p>Presentation of findings/experience at 2009 Heartland Annual Meeting.</p>			<p>Ongoing</p>

Implementation Objectives	Activities/ Task Assignment	Implementation Evaluation Measures	Outcome Evaluation Questions	Outcome Evaluation Measures	Outcome Data Collection Timeline <sup>1</sup>
<p>Promote use of telehealth strategies for clinical genetics</p> <p>Implement metabolic rounds using telehealth technology</p>	<p>Heartland RCC disseminates “TeleGenetics How To Guide” to all genetics centers.</p> <p>Heartland will fund, if requested, a pilot telegenetics service.</p> <p>Heartland RCC will: 1) identify 4 participating states; 2) promote the rounds with local AAP/AAFP/ NAPNAP chapters; and 3) identify metabolic specialists willing to serve as the consultant(s).</p>	<p>Document states’ use of telehealth for clinical genetics services.</p> <p>Document participants attending rounds and describe their characteristics.</p>	<p>Does the information support providers in the treatment and management of clients in their practice?</p> <p>To what extent does it increase knowledge of state resources?</p> <p>Do new inter-state systems collaborations result from participation?</p>	<p>Survey of participants who participate in forums.</p>	<p>Ongoing</p> <p>Year 6, 7, and 8</p>

**Goal 2: (short form) Promote genetics education**

<p>Partner with Utah MedHome Portal to strengthen medical home through education of primary care providers via web-based modules.</p>	<p>Heartland RCC identify authors for remaining 3 modules as prioritized by AAP chapters.</p>	<p>Document completion of seven diagnosis modules.</p>	<p>To what extent do the providers find the content and format of the modules helpful?</p>	<p>Satisfaction survey tool completed by providers who finish modules</p>	<p>Year 6</p>
<p>Establish continuing education credits (CME) and assessment requirements and identify demographic data for future evaluation analyses.</p>	<p>Evaluator to conduct analyses of data from CMEs submitted.</p>	<p>Document # of providers that complete CME.</p> <p>Describe characteristics of providers that completed the CME.</p>	<p>What percentage of providers who complete the knowledge assessment meet the set criteria?</p>	<p>Completion of module knowledge assessments</p>	<p>Year 6</p>

<b>Implementation Objectives</b>	<b>Activities/ Task Assignment</b>	<b>Implementation Evaluation Measures</b>	<b>Outcome Evaluation Questions</b>	<b>Outcome Evaluation Measures</b>	<b>Outcome Data Collection Timeline<sup>1</sup></b>
<p>Partner with LENDs to evaluate the potential use of Diagnosis Modules as a training option for LEND Trainees.</p> <p>Submit abstract to Fall 2009 AUCD/LEND regional meeting.</p>	<p>RCC arrange conference call with LEND directors to inform them of the practicum opportunity for their fellows and about the Heartland collaborative.</p> <p>RCC respond to “Call for Presentations” for Fall 2009 AUCD/LEND regional meeting.</p>	<p>Document faculty and students who participated in collaborative project and determine from them the usefulness of modules.</p> <p>Submission of abstract.</p>	<p>To what extent are the diagnosis modules a useful educational tool for LEND students?</p> <p>To what extent are new collaborations formed between Heartland and LEND programs and between genetics and LEND programs?</p>	<p>Completion of module ratings by LEND faculty and students.</p> <p>Interviews of key stakeholders from both programs</p>	<p>Year 6</p> <p>Year 6</p>
<p>Develop and disseminate a Family Financial Resource Guide.</p>	<p>Hire advocate as independent contractor to complete remaining sections of the guide by August 30, 2009.</p>	<p>Document completion of the Guide.</p> <p>Document dissemination of the guide to stakeholders.</p>	<p>To what extent are the genetic nurses and counselors using the Family Financial Resource Guide with families?</p>	<p>Survey of genetic nurses and counselors on the utility of the Financial Resource Guide.</p>	<p>Year 7</p>
<p>Create a partnership with the University of Iowa to allow for nurses in the Heartland to have access to online genetics modules.</p>	<p>RCC and ad hoc nursing education group develop CEUs for the modules.</p> <p>RCC fund the CEUs on a first-come, first-served basis.</p>	<p>Document partnership agreement with University of Iowa College of Nursing.</p> <p>Document number and characteristics of the nurses who enroll in the online genetic modules.</p>	<p>To what extent do nurses in the region complete the online genetics course?</p>	<p>Number of courses passed by enrolled nurses.</p>	<p>Year 6</p>

Implementation Objectives	Activities/ Task Assignment	Implementation Evaluation Measures	Outcome Evaluation Questions	Outcome Evaluation Measures	Outcome Data Collection Timeline <sup>1</sup>
<b>Goal 3: (short form) Infrastructure support to facilitate networking</b>					
<p>Genetics System Assessment (GSA) tool developed.</p> <p>GSA tool piloted in HI and OR.</p>	<p>Independent contractor, Johann Chanin, and Project Leader, Chou, assign weights for the measures selected in the Delphi process (FY 08-09).</p> <p>Chou and RCC develop pilot tool by August 30, 2009.</p> <p>Chou and Williamson pilot tool in HI and OR.</p>	<p>GSA tool is established based on scientific approach.</p> <p>Document evidence review and Delphi and pilot experiences in a manuscript.</p> <p>GSA tool is modified based on feedback from pilot.</p>	<p>To what extent was the GSA a helpful approach to assessing a quality system?</p>	<p>Survey tool completed by pilot sites.</p>	<p>Year 6</p>
<p>Evaluate the NBS program exchange.</p>	<p>Evaluator will analyze data from PEAS post-exchange and conduct key informant interviews.</p>	<p>Site visits completed.</p>	<p>To what extent did the site visit contribute to adoption of or modification of a practice, policy or system procedure?</p>	<p>Pre-post analysis of PEAS (post test at 12-month follow-up).</p> <p>Interviews of stakeholders.</p>	<p>Years 6 - 7</p>

<b>Implementation Objectives</b>	<b>Activities/ Task Assignment</b>	<b>Implementation Evaluation Measures</b>	<b>Outcome Evaluation Questions</b>	<b>Outcome Evaluation Measures</b>	<b>Outcome Data Collection Timeline<sup>1</sup></b>
<p>The Heartland NBS Back-up Testing and Quality Assurance Project complete drills with remaining Heartland states, to finalize implementation of the back-up system.</p> <p>Implement one NBS workshop per year related to NBS back-up project process and regional laboratory harmonization.</p> <p>Establish links with FEMA and HSEEP regarding NBS Back-up Project.</p>	<p>Hopkins (MO) and Berberich (IA) will conduct drills in Fall '09 and Spring '10.</p> <p>RCC will convene NBS workshop in Spring '10.</p> <p>Berberich, Hopkins, and RCC contact FEMA and HSEEP.</p>	<p>Document completion of NBS Back-up project drills.</p> <p>Document protocol and process of the EMAC procedures in a manuscript.</p> <p>Document the # of states that could implement NBS Back-up project protocol.</p> <p>Document contacts with FEMA and HSEEP.</p>	<p>How effective was the implementation of the back-up system?</p> <p>To what extent did the workshop meet its goal(s)?</p>	<p>Data from the NBS Back-up project sites with comparative analysis of results.</p> <p>Completion of survey evaluating effectiveness of the workshop.</p>	<p>Year 7</p> <p>Year 6</p> <p>Year 6</p>
<p>Heartland provides resources on website related to youth transition.</p> <p>Heartland sponsors speakers to increase network knowledge on youth transition.</p> <p>Heartland links state participants who are interested in addressing youth transition issues.</p>	<p>RCC and ad hoc transition group meet quarterly to share resources.</p> <p>RCC to increase visibility of ad hoc group by inviting Healthy and Ready to Work programs, practice model coordinators, and youth to participate.</p>	<p>Document # of posted resources on website.</p> <p>Document # of awareness activities, including # of states and participants impacted.</p>			<p>Ongoing</p>

<b>Implementation Objectives</b>	<b>Activities/ Task Assignment</b>	<b>Implementation Evaluation Measures</b>	<b>Outcome Evaluation Questions</b>	<b>Outcome Evaluation Measures</b>	<b>Outcome Data Collection Timeline<sup>1</sup></b>
Sarah Lawrence Scholarship is granted for one student per year to obtain a Public Health Genomics Certificate.	RCC to announce scholarship competition Summer/Fall 2009.  RCC to assist past and current recipients with developing a manuscript on their capstone project.	Document selection of scholarship recipient and completion of course.  Document presentation of Capstone project at annual conference and in manuscript.	To what extent did completion of the certificate help the participant contribute to the field?	Interview with participants at course completion and one year post course completion.	Ongoing

**Goal 4: (short form) Leadership strategies**

Implement Evaluation Plan.	Evaluator to conduct evaluation and submit report to RCC/HRSA.	Summary Report	To what extent do the leadership activities reflect the priorities and needs of the Heartland Collaborative?	Focus group satisfaction survey on group meetings.	Ongoing for implementation measures.
Disseminate educational resources using multiple strategies (i.e., website, e-newsletter, list serves, meetings, conferences).	RCC will utilize multiple communication strategies to disseminate information.	Document type and # of participants per strategy.  Post minutes of meetings.  Document conference schedules.	What are the contributing and inhibitory factors that influence the success of the Heartland Collaborative?	Measure of collaborations (i.e., Working Together, Tent exercise).	Focus group at 2009 Annual meeting.  Measure of collaborations at Advisory Board September 2009 meeting and work group meetings during Annual meeting.
Contact Primary Care Associations (PCA) and Federally Qualified Health Centers in Heartland Region to determine interest in being added to e-newsletter mailing list.	RCC will identify and contact PCAs and FQHCs by July 2009 so that they can be made aware of the annual regional meeting.	Document e-newsletter mailing list subscribers.	To what extent have the Heartland Advisory Board and Work Groups formed a collaborative partnership?		

**e) Collaboration and Coordination**

Our collaborations with clinical geneticists/genetic counselors, state genetics coordinators, and newborn screening programs are strong. Advocates are involved in every activity and at every organizational level in the collaborative. We are hiring a parent advocate to draft the financial resources guide and we are formally inviting the federally funded Family-to-Family Health Information Centers to join the Advocate Work Group. Heartland currently has relationships with March of Dimes, AHRQ, Genetic Alliance, NNSGRC, HRTW, RAND Corporation, and NCQA. By the end of FY 09-10, we expect to have strengthened relationships with advocacy organizations, AAP chapters in our region, LEND directors in our region, and developed new relationships with FEMA, HSEEP, EMAC in AR, OK, KS, and NE.

**f) Administration and Organization**

The Heartland Regional Coordinating Center is located within the Section of Genetics, Department of Pediatrics at the University of Oklahoma Health Sciences Center (OUHSC). The PI (Mulvihill), Co- Pi and project manager (Williamson), and project coordinator (Whitehead) are located in the section of Genetics. GSA project leader (Chou) resides in the School of Public Health at OUHSC. External evaluator (Jackson) resides in Nebraska. Heartland Advisory Board and Advocates provide guidance and expertise to the RC. Heartland Work Groups and other centers in the region are sub-contracted to accomplish the specific projects. The Heartland Genetics and Newborn Screening Collaborative organizational chart is located in Attachment 6.

**g) Attachments**

Position Descriptions for New Personnel	Attachment 1
Bio Sketches for New Key Employee	Attachment 2
Updated Logic Model	Attachment 3
LIST of New MOA, LOA, or contracts	Attachment 5
Revised Organizational Chart	Attachment 6
Annual Meeting Agendas	Attachment 7
Current Newsletter	Attachment 8
Pilot Projects Summary Table	Attachment 9
Agenda NBS	Attachment 10
Letters of Support	Attachment 11
OPR Action Plan	Attachment 12
References	Attachment 13
Evaluation Plan	Attachment 14