

HEARTLAND PROJECT PRIORITIES FOR 2008-2009

- Genetics report card
- Disaster preparedness
- LTFU—participating in Sue Berry’s project
- Continued participation in Region 4 true positive data collection and ms/ms training
- PCP education—diagnosis modules and state mirror portals
- Transition
- LEND
- Update strategic plan

HEARTLAND PROJECTS—Version 2

New and High Priority

Transition to Adult care

PCP education

Genetics Report Card

Strengthening medical home

(SD and AR state plans)

Disaster preparedness (*this was originally under “started and hi priority...but, it’s more appropriate here)*

Long-term follow-up (*this was originally under “started and hi priority...but, it’s more appropriate here)*

Comments:

Transition to adult care is important to advocates and there may be existing activities at the state level (through special health care needs programs and maternal child health programs) we could link to or support.

PCP Education is a priority. We proposed a web-based, “just-in-time” educational approach for PCPs in collaboration with state AAP chapters. CMEs would be a strategy for promoting the site and getting physicians to use the resource. We need to have existing PCP educational programs linked to our website.

Disaster Preparedness: our region has already invested in this activity through planning and gathering information; the next step is to set up a demonstration (including practice drills); this is do-able within the project year

State Plans: SD may not need a state plan at the moment, but when Dr. Hoyme arrives, this may be something to consider in the future; not this year. Since AR is expanding NBS and has a shortage of medical geneticists, maybe AR should consider revising an old or creating a new state plan.

Genetics Report Card: no discussion around this topic. HRSA loves the topic, so we will pursue it, for at least one year and see if it takes off; it seems to have significant potential.

Strengthening Medical Home: HRSA is requiring that we have some activity in this vein; the PCP educational project is a good example

Long-term follow-up: since we were not funded, this project will take a bit to get off the ground—even if we participate with another region. Given our time frame, maybe it's best to complete disaster preparedness this year and look at LTFU for the next year

New and Low Priority or Optional

Family health history multicultural and educational campaign

Family health history curriculum

TeleMetabolic Rounds

Emergency cards for kids with metabolic disease

Hereditary cancer resource assessment

Research collaboration for external funding

Comments:

Family Health History: the advocates emphasized the importance of this continued work

Emergency cards for kids with metabolic disease: both advocates and clinicians supported this project and strongly recommended it be made a high priority. It's a very do-able project within the year, doesn't cost much and will have a positive impact for children and families. Further justification: many of the metabolic conditions are rare so little is known about the disorder and therefore an emergency physician would most likely not know how to treat; shortage of metabolic geneticists; and increasing language barrier for many of our families....the card would educate the emergency physician in treatment for the disorder and would inform appropriate care when a language barrier existed; sickle cell programs use these cards and we are simply applying that model to a population of kids with metabolic conditions.

TeleMetabolic rounds: Important for educating PCPs and strengthening medical home.

Hereditary cancer resource assessment: No discussion. As was stated by Williamson, the activity can continue, we just cannot fund it.

Research collaboration for external funding: No discussion.

Additional comments, overall:

- **Williamson should check with other regions to find out if the “low priority” projects may be going on in other regions; could we join together for greater impact?**
- **Willige asked if advocates from other regions could come together to set a national agenda for how the advocates can participate and benefit from these collaboratives; we should also start bridging with condition-specific parent organizations in our states/region and nationally**
- **The public health genomics scholarship has the potential of being very beneficial and ultimately building capacity in states; we should evaluate Jamie Kim’s experience**

Project Finished (or will be by fall meeting)

Family health history toolkit for genealogy groups

Family health history article for rural electric coop magazines

Telemedicine guide

NBS card retention white paper

Genetics education at the capitol (AKA: DNA DAY) toolkit

NBS education to prenatal population

ND state plan

Started and High Priority

Website revisions

KS state plan

KS-NE telemed project

Lab workshop project

Started and Low Priority

Teratogen pilot project

NF pilot project

Town hall pilot project

MSUD project

Public health genomics scholarship

Pilot project program