



AGENDA

Genetic Expertise Workgroup
Telemeeting Agenda
Friday, November 7th, 2008 11am CT/12pm ET

Toll-free - 1/866/489-0573; at the prompt, enter *4545164*

Roll Call & Introductions
Sarah Wedepohl, Facilitator

- Review of Agenda

Review of Research on Genetic Services to Underserved Populations
Sarah Wedepohl

- Update on findings from research from other regions and states in our region

Next Steps
Nancy Mendelsohn

Ideas about:

- Where do we go from here?
- Next steps and responsibilities

Other Announcements:
All members

- Next meeting is December 5th
- No meeting in January – next meeting in 2009 is February 6th

Adjourn 12:30 p.m. Central, 1:30 p.m. Eastern

**REGION 4 GENETIC EXPERTISE WORKGROUP MEETING
SEPTEMBER 17, 2008**

The meeting was held during the Region 4 Genetics Collaborative Regional Meeting 2008.

In attendance

Cathy Wicklund (IL), Courtney Eddy (IN), Jody Wallace (KY), David Stockton (MI), Helga Toriello (MI), Allison Lapointe (MN), Renee Temme (MN), Nancy Leslie (OH), Murray Katcher (WI), Sarah Wedepohl (MPHI)

Handouts

Region 4 Genetics Collaborative Organizational Chart
Genetic Expertise Workgroup Survey September 2008
Base Funding Logic Model
Genetic Expertise Workgroup Year 1 Workplan
Genetic Expertise Workgroup Workplan
Regions 1 - 7 Efforts in Improving Access to Genetic Services, Expertise and Technology for Underserved/Rural Populations

Monthly Telemeetings

First Friday of every month 11am - 12:30pm Central/12 - 1:30pm Eastern

Discussion of Region 4 and the workgroup process

- Explained Region 4 overview and how workgroups typically function with one facilitator from MPHI and 1-2 leaders
- History - the logic model and action plan were developed, then the workgroup was identified to tackle those issues
- Action plan is a guide - it's used to keep us on track

Discussion of Year 1 plan:

- The group discussed rural health service delivery including telemedicine networks, communication systems (i.e., list serves, education, webcasts)
- Small community hospitals are a good source of communication and might be helpful to have them as collaborative partners (teleconferencing and telecasting)
- Using avenues such as non-genetic systems (i.e., x-rays) was also discussed

Areas to explore/research:

- Start with what we know and have in place already; what works in the current system; Do the PCPs want it? (An example is Mansfield Clinic in northern WI - they are connected by telemedicine system - go to site, be examined by a physician/nurse practitioner, geneticist on site as well - Georgia also has a model to explore)
- Need to map rural health initiatives and look at where the gaps are, what is needed, what would be effective to meet those needs and find ways to accomplish them.
- Collaborate with AAP and contact them with the idea about telemedicine being used this way

Other regions' work in this area:

Jill Shugar discussed what other regions are doing in their efforts. Encouraged the workgroup to contact other regions to find out more specifically Becky and Han also Ken (Oregon) and Sylvia (Hawaii):

- Region 1 - They mapped out treatment centers and looked at the population and distance between to see how far patients would have to go

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- Region 3 - Hans Anderson/Co-Chairs of NCC Workgroup - Region will be expanding to do clinical services two states at a time, David Flannery good contact
- Region 5 - Becky Butler, co-chair for NCC Workgroup - In Missouri there is a woman doing outreach genetic services
- Region 7 - They surveyed PCP, patients and providers - Care Coordination being done by community public health nurses and social workers
- Recommended websites www.acmg.net and www.nccrcg.com

Steps needed:

- To examine telemedicine and see what's out there/barriers; we need to talk with PCPs in rural areas (look at Murray Katcher's survey in WI)
- Talk with PCPs about whether they see value in this - how does this affect care? Are they handling genetic issues adequately? Would they like something like this?
- Figure out what it would take to meet the needs identified by PCPs in rural areas
- Look at national survey from National Coordinating Center (NCC) (Sarah contact Judith)
- Look at Birth Defects Registry to see the distribution of birth defects across the state and what the distances are like
- Contact Genedx - lab providers - list by zip code and find out what tests have been ordered and map it
- Newborn screening programs with genetics can be mapped with distance
- Ask, Where are genetic tests being conducted and where are the services? (Kathy Harris, Project Director - software questions)
- Who gets genetic counseling once they are diagnosed across the state?
- Helga in MI can find out how many molecular tests they send out a year

Other issues:

- What equipment do they have for telemedicine?
- What are the gaps in service?
- Would it help to have a coordinator in place to help pull everything together?
- Issues of reimbursement

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Agenda and call-in information will be provided ahead of time.