



Region 4 Genetics Collaborative Advisory Group
Wednesday July 21, 2010
1:30 PM CST/2:30 pm EST
Call in Number 1.866.489.0573 *4545164*

Participating: Bob Bowman (IN), Joyce Robl (KY), Kupper Wintergerst (KY), Janice Bach (MI), Carolyn Anderson (MN), Piero Rinaldo (MN), Kathy Bachman (OH), David Entwistle (OH), Anna Starr (OH), Murray Katcher (WI), Michelle Kempf-Weibel (WI), Abby Shannon (R4), Cindy Cameron (R4), Sally Hiner (R4), Sarah Wedepohl (R4).

National Connections

4 National Conferences Presentations

- Partnering with Your Doctor – Medical Home Guide for Parents
 - AMCHP Annual Meeting, Washington DC, March 8, 2010
 - NICHQ Conference, Atlanta Georgia, March 8-10, 2010
- Promoting the Genetic Referral – An Action Guide for EHDI Providers
 - Annual National EHDI Conference, Chicago IL, March 1-2 2010
- Care Coordination for Children with Genetic Conditions
 - Genetic Alliance Annual Conference, Washington DC, July 15-18 2010

HRSA Genetics Branch Strategic Planning

HRSA has asked Cindy to facilitate the process of developing a strategic plan to guide future activities for the next 10 years. R4 will lead a strategic planning meeting in Washington on October 21st. Input gained through the strategic planning process will be used by HRSA to develop funding criteria for future grant opportunities.

Leveraging Funds Priority 2 – RO1 Natural History (Handouts 2 & 3)

MPHI as applicant - Two proposals are in development and will be submitted to National Institute of Health in response to RO1 grant opportunities around natural history of rare disorders. The first proposal is based on the R4 Priority 2 project (IBEM-IS) lead by Sue Berry. Sue and Cindy will function as Co-PIs with Cindy coordinating the project and Sue leading the scientific research. MPHI will be the applicant to take advantage of lower indirect rates which allow for the participation of additional clinics. The plan is to include 13 clinics (3 from the Heartland, 1 from Mid-Atlantic States and the remaining clinics from Region 4. The grant is 1 million per year for 5 years and will overlap the current grant by one year. We are not guaranteed continued funding from HRSA so this grant could be very important.

FAOD Project - R4 has been asked to partner with the FAOD consortium in the submission of a separate proposal concentrating on Fatty Acid Oxidation Disorders. The Region 4 infrastructure will be used for preparing IRB applications, training clinics on data entry, and working with the software provider on development of new data collection instruments.

Piero Rinaldo expressed concern about possible lack of communication surrounding development of the proposal. He felt that the proposal could have been strengthened if additional disorders beyond IBEM

were targeted. Cindy Cameron was never contacted by Kiki Sarafoglou concerning inclusion of CAH or possible development of a separate proposal for CAH/DSDs.

Action taken: David Entwistle expressed support of what has been completed so far. Action was taken by the participating Advisory Group to approve submission of the NIH grants.

Region 4 Updates

Insight Media Marketing Proposal (Handouts 3 & 4)

Insight Public Television has approached R4 to create and distribute a 3-5 minute educational segment to Public Television in all 50 states on the topic of Newborn Screening. The proposal also includes the production of a 6-8 minutes documentary tape, internet distribution with a feature on Web MD, email campaign, and commercial segment on Discovery Health, MSNBC, FOX and other networks. Region 4 would have total control over the script. The piece would be geared toward an average citizen and likely include an interview with a R4 family. Cindy has gotten very positive feedback from previous clients of Insight and plans to contact additional references.

There is a cost involved (\$23,000). Janice Bach reported that a recent video she was involved with had a considerably higher cost. Others agreed that there seems to be a lot of product for the cost. Interest in raising awareness of NBS was discussed at the Secretary's Advisory Committee meeting held recently. This would give Region 4 the opportunity to help shape the message. Funds would come out of our marketing line. We may also be able to request carryover funds as we are about to close our current year.

Group Discussion:

- Since the campaign would run nationally maybe the NCC would be willing to offer money.
- Do the other regions have an interest? Could we ask the other regions to chip in?
- It would be nice to be able to take advantage of this opportunity but it is not "a must have"
- Bob Bowman expressed concern about the public's reaction. An educational campaign about NBS might lead to negative reactions from the public. There were some marked examples of people who were very upset to learn that their children's bloodspots were stored by the state without their knowledge.
- Janice Bach that the issue is out there and felt Bob was making some good points. We need to be careful not to create more problems for states that don't have the infrastructure to field all the questions.
- Cindy pointed out that the campaign would appeal to a large audience and have a human interest feel and a positive message. For example, featuring a family who had a child who benefitted from NBS. It would not be about biobanks.
- If states did not want the campaign to air in certain locations, Insight most likely will be able to accommodate.
- Cindy also emphasized that the advisory group would have input throughout the process of creating the message, we would not do anything on our own.

Action: Cindy will approach HRSA about the media marketing campaign as well as the NCC at the request of the group.

Priority 1 Updates

- Participants met in May 2010 in Orlando for a face to face meeting. Ninety-nine people attended and overall the meeting went well. Presentations highlighted new developments and the progress that has been made.
- Data collection continues to increase with >10,000 true positives. Data is coming from 80 labs in 44 countries.
- The training course continues to increase in popularity and demand is beginning to exceed resources available to provide it. Interested individuals have requested some kind of training via the internet. This would open up more opportunities and allow those who cannot travel to participate.
- Cindy suggested a carryover request for funds to do a webinar? We have the facilities. It could be done in weekly segments. *The Advisory Group supported this use of carryforward funding, if approved.*

Priority 2 Updates

- Participated in a telemeeting hosted by NYMAC to show potential participants in the IBEM-IS how the system works and what services and supports are in place via the Region 4 infrastructure to support participation.
- Finalized and added additional surveys to the IBEM-IS.

Base Funding Updates

Blood Disorders WG

- This is a new workgroup that came out of the regional meeting. The group that met at the regional meeting wanted to continue to meet and expand to include disorders beyond Sickle Cell.
- The first meeting will be held next week and members will concentrate on prioritizing issues and reaching a consensus.
- Not all R4 states are represented. State leads already have been asked to identify members. Workgroup members will be asked to recommend members and then Sally will work with state leads. State leads will be contacted as needed to identify workgroup members.

Care Coordination WG

- A team consisting of a Provider, Parent and R4 staff presented at Genetic Alliance on the Care Coordination Tools under development by Region 4 Workgroup and engaging parents as partners in the collaborative process. Was well received.
- Preparing to pilot the Integrated Care Plan - a tool to facilitate coordination of care across providers. It includes a template for developing goals, strategies to reach the goals and specify the role of each provider involved in the child's care.

State Systems Follow-Up WG

- Workgroup is working to identify or develop one or more models for follow-up systems that assure linking/referral to services, facilitate surveillance, support communication and increase access to services for children with genetic conditions and their families.

Genetic Expertise WG

- The workgroup designed a survey to gather information from genetic clinicians. The survey focuses on learning about practice models, time use and clinician shortages.
- To date, 42 interviews have been completed. By September we will begin analyzing data and pull genetic specialists together to interpret and discuss how it might be used.

MEMSCIS WG

- Current efforts center on re-branding to make it more identifiable. A meeting will be held in August with key stakeholders and a marketing consultant.
- SERC developed and implemented a tabletop exercise using MEMSCIS. Lee Pyles and Sally Hiner participated by phone. We anticipate information that will be provided in a written report will influence some changes and improvements to the system.

Transition WG

- The workgroup selected as its focus the social and emotional issues surrounding transition to adulthood. This idea was presented to the National Transition WG and was well received.

CAH WG

- The intake and interval surveys have been added to DocSite.
- David Sandberg is leading a subgroup to develop psychological data elements.
- We will be asking workgroup members to identify psychologists to participate in the subgroup.

Products

Medical Home Guide – The Medical home guide has been disseminated to states. Jodi Griffin contacted state leads to discuss distribution. The guide has been very well received. Many states requested additional guides to distribute.

EHDI Guide (Handout 5) – A copy of the Action Guide was distributed to the Advisory Group with the meeting materials. The Workgroup is requesting Advisory Group endorsement of this product. The workgroup will be meeting in August to discuss dissemination strategies. The guide lends itself nicely to an electronic format. The electronic version will be designed so that users can easily identify and access relevant information.

Action: The members of the advisory group endorsed the EHDI action guide.

Next step: The guide will go to HRSA for approval.

Other news

- Anna Starr announced that Jim Bryant the Ohio Title V Director is retiring next week and they are sad to see him go.
- Piero Rinaldo reported that someone has published information about the VLCADD tool without R4 Priority 1 permission. Piero consulted with the Priority 1 steering committee and contacted the editorial office at the Journal of Pediatrics to ask them to respond. Apparently the issue was brought to the attention of the editor by a reviewer but the feedback was ignored.