



Region 4 Genetics Collaborative Advisory Group

February 23, 2009

9 am CST/ 10 am EST

Call in number: 1/866/489-0573; *4545164*

Agenda

- I) Welcome and Introductions Cameron
Please provide your name, state and role in the R4 Collaborative

- II) Updates
 - A) National Connections Cameron/Berry/Rinaldo
 - 1) National Newborn Screening Translational Research Network Cameron
 - 2) Guidelines for becoming a National Project

 - B) Region 4 Cameron
 - 1) Region 4 Re-application
 - 2) Updates
 - (a) Base Funding
 - (1) Medical Home Education Deising/Griffin/Turner
 - (2) Care Coordination Arveson/Hiner/Wood
 - (3) Genetic Expertise Mendelsohn/Wedepohl
 - (4) Follow-up – EHDI Hoffman/Hiner
 - (5) Parent Coordinator Report Wedepohl
 - (b) Carry-forward activities
 - (1) Endocrine
 - (i) CAH & DSD Registry Hiner
 - (ii) CH 3-year follow-up Hiner
 - (iii) CAH 2nd tier testing Hiner
 - (iv) Access to Genetic Services Survey Wedepohl
 - (v) Family Functioning and Chronic Disease Hiner
 - (vi) State Site Visits Griffin/Cameron
 - (c) Priority Projects
 - (1) Priority 1 – NBS by MS/MS Rinaldo
 - (2) Priority 2 – IBEM-IS Anderson/Berry

 - III) Workgroup Products – EHDI State-to-State UNHS Follow-up Protocol Hoffman
*Action Item (Handout 1)

 - IV) Reminders Cameron
 - A) Please enter your contact information <http://Region4genetics.org>
 - B) Quarterly reports due 03/15/09 for quarter ending 02/28/09

 - V) Other news and issues Advisory Group



Region 4 Genetics Collaborative Advisory Group

November 17, 2008

Participating: Claudia Nash, IL; Bob Bowman, IN; Joyce Robl, KY; Janice Bach, MI; Carolyn Anderson, MN; Anna Starr, OH; Murray Katcher, WI; Piero Rinaldo, Priority 1; Susan Berry, Priority 2; Kathy Wood, CCWG Co-Lead; Jennifer Arveson, CCWG Co-Lead; Jane Turner, MHWG Co-Lead. Region 4 Staff: Cindy Cameron, Sally Hiner, Sarah Wedepohl and Jodi Griffin.

I) Updates – Cameron

1) New Advisory Group members & new Region 4 Staff (Handout 1)

Cindy Cameron introduced and welcomed workgroup leads joining the Advisory Group and Jodi Griffin, new Region 4 staff.

2) Regional meeting feedback (Handout 2) – Cameron

- Overall, 36 evaluations were completed (87 participants), and the general feedback was positive. Primary comments include:
 - Families wish to connect with people from their state but did not feel they were able to;
 - too many abbreviations/acronyms were used in presentations and discussions; and
 - color code name badges by state – this will be implemented for the next Regional meeting

3) Carry-forward Request Discussion (Handout 3)

Information was emailed to Advisory Group members prior to submitting the carry-forward request to HRSA. Project details were discussed as follows:

- Region 4 staff site visits with each state – State leads expressed support for the activity and would like to be able to tailor the visit to their needs. Site visits must be completed by the end of May, 2009 and coordination of schedules will begin immediately. The purpose will be to strengthen connections across state partners, between state partners and Region 4 and identify opportunities to extend partnerships in each state.
- Endocrine Projects: Conference calls regarding participating in these activities will be scheduled to provide all Region 4 states an opportunity to discuss involvement and responsibilities.
- The Michigan Genetic Service Survey is nearly ready to be sent out. The Region 4 budget supports the participation of the three states expressing interest in participating when the idea was presented at the Regional Meeting. (Michigan, Minnesota, and Ohio)
- Priority 1 – this request will support additional representatives from each Region 4 state to participate in the MS/MS training on site at Mayo. State leads should contact Cindy as soon as possible with their designees.
- Priority 2 – Darin Erickson is drafting a project proposal that the Sally Hiner will use as a basis for a workplan. Focus groups with family members of children with heritable disorders will be held in 3 or more of the Region 4 states to obtain qualitative data

from which to design the survey to assess the impact of chronic disease on family functioning.

4) HRSA Office of Performance Review Site Visit – Cameron & Bach

- Overall the HRSA representatives were very impressed with the progress Region 4 has made towards its goals and offered positive feedback on plans for future activities
- HRSA reviewers recommended quarterly visits for Cindy Cameron with Jill Shugar and Michelle Puryear
- HRSA reviewers encouraged using Region 4 as a model for national projects
- Two areas were selected to focus on for our improvement plan: education for primary care providers, specialists and families on the importance of medical homes for children with heritable disorders and the promotion of care coordination for children with heritable disorders

5) Base Funding – Hiner

We have 5 workgroups established, meeting and working on activities outlined in the Region 4 Action Plan. Endocrine was carried over from work initiated with supplemental funding in the first 3-year grant cycle. We have been cycling in “new workgroups” as described in our current 5 year plan.

(a) Medical Home Education Workgroup – Sarah Wedepohl

The Medical Home Guide is ready for copy-edit and formatting for both hard copy and web-based production.

(b) Care Coordination Workgroup – Hiner, Arveson, & Wood

The workgroup has been meeting since January. Early on in the process, we split into 3 subcommittees to tackle the 3 types of care plans: Emergency, Medical care coordination, and Medical Home care plans – recognizing that the emergency and medical care plans should be integral parts of the comprehensive medical home care plan.

- Emergency plans committee has completed their work. Kathy Wood will be providing a formal recommendation following this update.
- Medical care coordination committee focused on a plan to coordinate the medical/health care activities. To date, the committee has:
 - Identified and reviewed existing plans
 - Compared components of plans
 - Drafted a medical care coordination plan for children with heritable disorders; and
 - Obtained feedback on the draft plan from Region 4 parent/family member partners
 - The committee is preparing to obtain feedback from additional stakeholder groups by working to engage Region 4 partners – primary care providers and specialists – in a structured review of the draft plan.
- Care plans subcommittee finalized a draft “care plan component review” tool. Their next step is to identify and select templates for each of the components identified in the review tool. The tool and components will be built into a web-based, menu driven format that will allow users to identify and select components essential to their personal child/family care plan and then obtain the corresponding template to assemble their plan.
- **ACTION ITEM** – Kathy Wood brought forth the recommendation on behalf of the Care Coordination Workgroup to **Support, promote and encourage the use of MEMSCIS (Midwest Emergency Medical Services for Children Information system MEMSCIS) throughout Region 4 as a clinical tool for improving**

emergency care to individuals with heritable disorders. The recommendation included the following activities: 1) *Restructuring the MEMSCIS Advisory Board to reflect a broader group of Region 4 stakeholders to provide input, oversight, and access to expertise as MEMSCIS is expanded to include additional heritable disorders and a broader geographic region,* 2) *Develop and implement a process to respond to inquires about MEMSCIS to engage interested parties in a timely fashion* and 3) *Develop and implement a marketing plan, including recruiting clinics to enroll their patients.*

- Region 4 has set aside funds for MEMSCIS software development and marketing; however, there are no funds to support enrollment activity. A motion to approve the Care Coordination Workgroup recommendation as submitted was made by Sue Berry and seconded by Claudia Nash. The motion carried unanimously.

(c) Endocrine (CAH Disease Registry) – Hiner

Endocrinologists met at the Regional Meeting and reviewed the most recent draft of data elements for Congenital Adrenal Hyperplasia (CAH) and Disorders of Sex Development (DSDs). A process was developed to solicit additional input from colleagues throughout the Region. Electronic copies were emailed to our liaisons in the seven Region 4 states. Kiki Sarafoglou, lead endocrinologist for the CAH & DSD Registry project, is receiving comments. A series of discussions are scheduled to occur over the next 3 weeks via telemeeting to finalize the elements with the endocrinologists. Strategies are being developed to solicit input of urologists on the data elements for the urogenital disorders. The group plans to examine follow-up algorithms next and Kupper Wintergerst, endocrinologist from Kentucky, has agreed to provide leadership for related project activities.

(d) Genetic Expertise – Wedepohl

Activities of this recently formed workgroup include:

- comparing Region 4 genetic service locations to www.genetest.org clinic listings
- examining population density data for each state to identify and locate rural/underserved populations; and
- exploring organizing states into regions of multiple counties in lieu of identifying disorder populations by county (which may have privacy violation implications).

6) Priority 1 (NBS by MS/MS) – Rinaldo

Sixty-five workgroup members participated in the meeting in San Antonio. The meeting featured the launch of the new data program which was very well received by those in attendance.

7) Priority 2 (IBEM-IS) – Anderson & Berry

To date, 47 patients have been entered into the information system, mostly MCADD. We have 5 sites IRB approved and trained to use the information system. Heartland Region requested carryforward funds to support participation of clinicians in the registry. Sally Hiner held a telemeeting with the Heartland clinicians to explain the process and expectations.

II) National Connections

A) National Evaluation (Handout 5) – Wedepohl

Sarah has received state responses. State leads were asked to review handout 5 and advise Sarah if anything has changed or any information needs to be updated. Sarah will initiate contact as necessary if additional information is needed.

B) National Newborn Screening Translational Research Network – Berry & Rinaldo
The NCC has received funding to function as the National Newborn Screening Translational Research Network. A national group of Regional Genetics Collaboratives has been formed and Region 4 is represented by Sue Berry and Piero Rinaldo. The network is in infancy and beginning to identify details of it's role to be worked out.

III) Opportunities – Bach

A) Collaboration with University of Michigan on regional conference

Region 4 was approached by Beth Tarini of UM who would like us to co-author a proposal and partner with University of Michigan CHEAR to host a conference. The group discussed pursuing this opportunity. It was suggested a topic for the conference be identified and then we decide which funding source, if any, to pursue.

B) Other grant opportunities

Region 4 staff have researched and identified additional grant funding for Conferences: CDC (non-research based) and NIH (research based). Suggestions included conducting proactive funding searches to promote networking and sharing of best practices – perhaps it would be best to focus on activities of Region 4

IV) Reminders – Cameron

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Notes by Hiner & Griffin