

Minutes of Clinical Services Committee
October 17, 2005, Kansas City, OK

Members Present: Lisa Butterfield, Blain Bendure, Melissa Craft, Amy Brower, Dawn Peck, Sara Haslag, Brad Schaefer, Quinn Stein, Sara Copeland, Mary Riske; present via phone: Sharon McMillan, Kim Keppler, Teresa _____?

I. Introductions

II. New Chair Elected:

Quinn Stein and Blaine Bendure agreed to be the new co-chairs of the Committee

III: Reviewed Needs provided to the Committee and suggested additional Needs

1. Inadequate Funding
2. Improved Reimbursement for Genetic services
3. Ensure access to Teratogen Services
4. Ensure access to quality clinical genetic services throughout the lifespan
5. Utilize telemedicine
6. Link children with genetic conditions to a medical home

Additional Needs Committee added:

1. Appropriate subspecialty Referrals
2. Data Collection for long term follow-up: Pool resources already available in databases
3. Increased visibility including outreach
4. Improved and increased communication among Region
5. Sharing and pooling of genetic resources, laboratory services and multidisciplinary clinics
6. Genetics and Electronic Medical Records - Access Issues

Lengthy dialogue followed discussing and prioritizing the needs. In conclusion, the members decided to choose goals; that we could accomplish in one year; that would make a difference, and that would have a visible outcome. Since there was a lot of overlap in the needs discussed, we combined several and developed 2 major goals that encompassed several areas.

IV: Problem, Need, & Goal #1

A. Problem: Uneven distribution of clinical genetic services

B. Needs: Increased visibility and communication among States in the Heartland Region.
Sharing and pooling of resources

C. Goal: Establish a Dynamic Electronic Resource Reference

All inclusive with people, clinics, labs, specialty clinics, telemedicine, research projects, resources that are helpful, support groups etc.

D. Action Plan

- 1. Develop an Intake Form with Data Dictionary**
- 2. Identify Appropriate State Contacts to send intake forms to (State Genetic**

Coord)

Time frame: Beginning of October - End of January

Members responsible: Dawn, Lisa, Sarah, & State Gen Coord.

- 3. Disseminate Intake Forms with a deadline for return**

Time Frame: Beginning of February - End of April

Members responsible: State Genetic Coordinators or other appropriate officials

- 4. Compile and collate data collected from 8 States, disseminate to provide opportunity for comment and check accuracy**

Time Frame: Beginning of May - End of August

Members responsible: Blaine & Quinn

- 5. Link collected data to Heartland Genetic Website (including a contact counter)**

Time Frame: By the End of September

Members Responsible: Blaine and Theresa

Year 2 - Maintain and update info on website

V: Problem, Need & Goal #2

A. Problem: Demographic limitations and a limited or reduced genetic workforce

B. Need: Increased Communication and Sharing of Resources

C. Goal: Explore Telemedicine Collaborations

D. Action Plan

- 1. Develop an Intake Form with Data Dictionary**

- 2. Identify Appropriate State Contacts to send intake forms to (State Genetic**

Coord)

Time frame: Beginning of October - End of January

Members responsible: Brad, Blaine, Amy, Sara H. Melissa, Sharon, & State Gen Coord.

- 3. Disseminate Intake Forms with a deadline for return**

Time Frame: Beginning of February - End of April

Members responsible: State Genetic Coordinators or other appropriate officials

- 4. Compile data to determine technical assistance needs for telemedicine capabilities**

Time Frame: Beginning of May - End of August

Members responsible: Brad, Blaine, Quinn

5. Utilize collected & compiled information to develop Telemedicine Training

Time Frame: By the End of September

Members Responsible: Brad, Lisa, Kim

Year 2 - Training Webcast

VI: Budget for 2 Goals - \$3500

Data Collection & Support

Mailings

Teleconferencing

Website Developer

Printing and Dissemination

VII: Committee Issues

Membership - All states need representation on the Committee

Dawn recruiting from Arkansas

2 more from Iowa

Meetings by Conference Calls:

Schedule for 2006 - Jan, May, Aug

VIII: Next Meeting: January, 2006