

## Clinical Services Workgroup

Annual Heartland Meeting  
September 7, 2007

**Present:** Kyna Byerly (RCC Staff), Sharon Vaz, (OK), Anne Gramiak (AAP), Becky Butler, Brad Schaefer, Carol Saunders, Cheryl Freeman, Christina Trout, Dani Johnson, Delphine Dorsey, Dewey Scheid, Erica Cole, Fred Schaefer, Gary Gottesman, Gene Hallford, Gina DiRenzo-Coffey, James O'Leary (Genetic Alliance), Jamie Kim, Jayne Brown, Jeanne Egger, Jennifer Kussmann, Judy Welch, Julie Keeth, Lisa Butterfield, Melissa Craft, Merlin Butler, Nicole Rose, Quinn Stein, Ralph Vogel, Robin Troxell, Sharmini Rogers, Stacey Montgomery, Susan Hassed, Tiffany Lepard, Valentina Dalili

## Introductions Presentations

- Larry Mullins – **Assessing Parenting Capacities and Stress in Neurofibromatosis 1**  
Heartland Funded Pilot Project see *web site for slides*  
[http://heartland.ouhsc.edu/conf\\_information.asp](http://heartland.ouhsc.edu/conf_information.asp)  
goal is to identify parenting styles, types of parenting stress, levels of overprotectiveness, perceptions of their child's vulnerability, and how these variables influence the emotional, behavioral, and psychosocial adjustment in children with NF1.  
Two sites identified: OK, TX  
Difficulties holding groups due to rural area  
Requesting other Heartland sites: **contact Larry if interested in participating**
- Susan Hassed – Genomic Disorders  
See *web site for slides* [http://heartland.ouhsc.edu/conf\\_information.asp](http://heartland.ouhsc.edu/conf_information.asp)  
Determine the true incidence of certain disorders  
Use NBS dots to do sequential analysis to determine true incidence  
Question – how many do we actually need?  
Response – Not sure yet  
CGH – customized chip for only the conditions that we want to look for.  
Questions rose about cost, informing parents of positive results, testing methodology on known positives first, alternative testing methodology for Prader Willi
- Delphine Dorsey – Healthy and Ready to Work Transition Program  
Model transition program in sickle cell disease - HRSA/MCH Block grant  
See *web site for slides* [http://heartland.ouhsc.edu/conf\\_information.asp](http://heartland.ouhsc.edu/conf_information.asp)  
Addresses goal of healthy people 2010; children with special health care needs transition to a medical home as they transition to adulthood  
Overview of program – case management to assist in transitioning healthcare, education and employment- and results so far given  
Successful with some barriers identified
- Brad Shafer- Kansas Nebraska telemedicine Connection for Metabolic Disorders  
Heartland funded Pilot Project  
See *web site for slides* [http://heartland.ouhsc.edu/conf\\_information.asp](http://heartland.ouhsc.edu/conf_information.asp)  
Review of project to provide tele-health link between NE/KS metabolic programs due to regional misdistribution of services  
Dr. Majed Dasouki, metabolic geneticist now working in KS  
Plan altered; to include site visit to KS, technical assistance and capacity building w/ implementation of expanded NBS; nursing/nutrition  
Metabolic grand rounds planned – 8 states

## Discussion

### What has already happened in the clinical subcommittee?

Telemedicine Survey completed

Telemedicine Manual for genetics – How do you set up a telegenetics system. 6 sections, 30 questions, need to fill in the blanks and finish. Quinn Stein has collected all info written to date: suggested individuals who to telegenetics needed to pull together and edit.

**Action item:** Brad Schafer and Becky Butler identified to finish editing telegenetics manual

## Planning

### Medical Home

**Action Item:** Develop and complete medical home related project by May 2008: address at next meeting

### Discussion

Medical home activity required as contingency of our funding.

Identification of models and resources in our region: convening “expert panel” , identify current barriers and strategies, opportunities for collaboration with AAP, AAFP, Title V etc.

Identify what is already out there in terms of Medical Homes, make connections

Anne Gramiak from AAP-has two staff members focused on technical assistance for medical home: Angela and Amy. Also can provide connections to local AAP chapters

MedicalHomeinfo.org – literature review.

Pediatric supplement that focuses on the Medical Home available

### Transition

**Action Item:** plan for a transition project for next fiscal year (2008-2009)

### Discussion:

Bring adult side in; lots of existing resources already developed, including from the dept of Education; as well as model programs, as presented.

Adult health care is not family centered, only individual centered.

Two separate models of care, need to bring the two models together. Address gap or difference. CF, Sickle cell and CAD/CHD .

Develop a brochure for parents on how to talk to parents on transitioning your child

### Cancer genetics

Previous cancer genetics services directory project, headed by Melissa Craft, put on hold due to feedback from HRSA. However, it has been clarified that addressing “genetics through the life span” is included in regional collaboratives mission. It was agreed to revise and address this issue in the future, year 2 or 3.

### Membership

Membership open

Core membership- commit to:

Actively participate on a project

Attend calls every 4-6 weeks

2 year commitment

Face to face meeting if needed

National Workgroup nomination possible

Expertise related to projects

Core membership identified:

- Becky Butler (AR) [ButlerBeckyB@uams.edu](mailto:ButlerBeckyB@uams.edu)
- Brad Schaefer (NE) [gbschaef@unmc.edu](mailto:gbschaef@unmc.edu)

- Carol Saunders (MO) [csaunders@cmh.edu](mailto:csaunders@cmh.edu)
- Fred Schaefer (OK) [fvschaefer@saintfrancis.com](mailto:fvschaefer@saintfrancis.com)
- Jeanne Egger (OK) [jegger@agr.ne.gov](mailto:jegger@agr.ne.gov)
- Judy Welch (IA) [judy-welch@uiowa.edu](mailto:judy-welch@uiowa.edu)
- Lisa Butterfield (KS) [lbutterfield@kumc.edu](mailto:lbutterfield@kumc.edu)
- Mary Riske (ND) [mriske@medicine.nodak.edu](mailto:mriske@medicine.nodak.edu)
- Melissa Craft (OK) [mcraft@breastok.com](mailto:mcraft@breastok.com)
- Merlin Butler (MO) [mgbutler@cmh.edu](mailto:mgbutler@cmh.edu)
- Quinn Stein (SD) [STEINQ@sanfordhealth.org](mailto:STEINQ@sanfordhealth.org)
- Ralph Vogel (AR) [vogelralphj@uams.edu](mailto:vogelralphj@uams.edu)
- Stacey Montgomery (IA) [lewnstacey@yahoo.com](mailto:lewnstacey@yahoo.com)

**Future Meetings**

Friday morning best time for conference calls – Kyna will communicate with group via email.