



Care coordination Workgroup Telemeeting Notes ~ Tuesday, June 24th, 2008

Participating: Jennifer Arveson, co-lead MN; Kelly Jackson (KY); Sandy LaPrad (MI); Kristi Bentler (MN); Alex (Meyer) Yuncker WI; Sarah Wedepohl, Parent Coordinator; Sally Hiner, Region 4 Genetics Collaborative Coordinator.

I. Announcements

- A. Family Member/Parent Meeting at Regional Meeting – Sarah Wedepohl provided a recap of the May family member meeting. A face-to-face meeting of Region 4 Family Members is scheduled on the evening of September 15th in conjunction with the Regional meeting. The agenda is being finalized but will include opportunities to get input from the family members on products, processes and recommendations coming out of the Region 4 workgroups. Sarah Wedepohl will be contacting each family member representative about the upcoming meeting and participation in Region 4 activities.
- B. Website and member directory – the Region 4 website is “live”. Workgroup information is routinely posted to the website. Members were asked to enter their member information. www.region4genetics.org
- C. MEMSCIS and Sickle Cell Meeting in Illinois – With the help of CCWG member Linda Drawhorn, a small workgroup has been established to explore adapting MEMSCIS for use with persons with sickle cell disease. Kristi Bentler shared her expertise with MEMSCIS, and Sally Hiner and Cindy Cameron provided information on Region 4 at a face-to-face meeting in Chicago at the end of May. Participants in the meeting included representatives from the state health department, Sickle Cell Disease associations and organizations, family members and a pediatric hematologist. The group is very interested in using MEMSCIS and will be working with Kristi Bentler and Jehad Adwan to make necessary modifications to the information users would be prompted to provide in an emergency information form unique to sickle cell disorders. The Sickle Cell Disease Association requested a presentation of MEMSCIS at their upcoming statewide conference (September 18th) to generate statewide interest in using MEMSCIS.

II. Sub-Committee Updates

A. Emergency Plans

a. Progress to Date:

- i. The group has settled on promoting MEMSCIS. Helpful feedback was received from presentation to the IL Sickle Cell group and issues and recommendations raised by that group are being addressed.
- ii. MEMSCIS originated as a research project. University of MN has developed a revised protocol to submit to their IRB that would allow enrollment and consent to be done in the MEMSCIS web platform introduction. This would allow families, primary care providers, emergency service providers to be able to consent and enroll families vs. requiring paper consent at specified clinical sites. The consent would facilitate the use of MEMSCIS as a clinical tool, but will

clearly advise participants that they could be contacted in the future for participation in research studies and that their health data is accessible to the University of Minnesota, who owns MEMSCIS and ImageTrend, the company that developed and maintains the website.

- iii. The group agreed formalizing a process for getting feedback on and into MEMSCIS could serve to 1)improve the clinical tool, 2)improve the implementation process and 3)entice clinicians, families, primary care providers, etc. to consider using it. As a result, the group has identified stakeholders and will be drafting survey tools to gather input on MEMSCIS. The survey tools will be specific to each stakeholder group. Jehad Adwan, University of MN, has provided focus group questions University of MN used previously to elicit input on MEMSCIS for the group to consider.
- iv. Indiana is looking into piloting MEMSCIS in their clinic. Kathy Wood has taken the lead on this initiative.
- b. Need from CCWG – nothing at this time. The CCWG will be asked to provide input into the survey tools and participate in the survey process. The group intends to have Region 4 family members participate in the survey process at the September meeting.
- c. CCWG Reactions/Recommendations
 - i. Present MEMSCIS to the family members either via telemeeting or face-to-face. One of the family members who has a child enrolled could present or Jehad. Jehad should be present at the meeting to hear feedback and be able to respond to questions that require knowledge of functionality and program capacity.

B. Care Plan –

- a. Progress to Date – the group has reviewed many care plans and through that process has identified stakeholders that should know about care plans and components that should be included. The group has been developing a tool to assess care plans and is looking into making it more comprehensive to assess – components, recommendations for use, process for implementation (initiation, updating), why stakeholders do/do not use care plans for their child/in their practice, and how current the care plan information and/or template available for use is. The group discussed needing to understand if care plans have been evaluated and demonstrated to be a best practices tool, if they are monitored and continue to evolve, or if they were developed, published, and have not evolved since publication. This will help the group determine how much effort should be given to promoting care plans that exist and how much effort given to developing a new product.
- b. Need from CCWG – the CCWG will be asked to assist with finalizing the assessment tools – their will be an assessment tool specific to each stakeholder group, to provide care plans for assessment, and to conduct an assessment, representing his/her stakeholder group. Goal is to have the Family member assessment ready for implementation by the group meeting in September.
- c. CCWG Reactions/Recommendations – Sandy LaPrad volunteered to join this subcommittee.

C. Care Coordination – no report

III. Next Steps:

Sarah will be scheduling telemeetings of the workgroups.

Notes by Hiner