

Clinical Services Work Group

August 15, 2008 8:30-9:30 am

Teleconference Summary

Attendees: Becky Butler, Jeanne Egger, Judy Welch, Melissa Craft, Merlin Butler, Quinn Stein, Ralph Vogel, and Donna Nale

Heartland Staff: Kyna Byerly and Shona Whitehead

Meeting Summary:

| Agenda Item | Discussion | Action |
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| New Heartland Staff | Shona Whitehead, Heartland Program Coordinator was introduced. Please note her contact is listed on the Contact Us page of the web site. Contact Shona for any questions related to the conference, travel or reimbursement. | Note Shona Whitehead contact: 405-271-8001 x42190 Shona-Whitehead@ouhsc.edu |
| Telemedicine Resource Manual Project Update (Schaefer, Nale, Butler): Working draft from Schaefer | Working draft of manual, edited by Schaefer, was sent with meeting agenda. The plan is to have workgroup and state genetic coordinators review, discuss at annual meeting, then send final product to the National Coordinating Center (NCC) for the regional collaboratives Telemedicine in Genetics Taskforce. Becky Butler and Dr. Anderson are co-chairs of this task force. Discussed dysmorphology exam, equipment needs for telemedicine, training on-site staff (ultrasonographers in AR), and the need for a nurse on-site; is this info included in the draft? Dr. Laura Davis-Keppen has used telemedicine for dysmorphology exams, and will be at conference; Butler would like discussion with a geneticist who has used this technology for dysmorphology exams. Other geneticists in the region using telemedicine for genetics are: Dr. Miles, Dr Gorski (Columbia, MO) Dr. Copeland (Iowa City, IA) Dr. Schaefer (Little Rock, AR) Feedback requested on manual in advance of conference, so more detailed discussion can be held during the work group meeting. Telemedicine will be a roundtable discussion topic at Sioux Falls Conference | Byerly to send draft of manual to Heartland State Genetics Coordinators for review and feedback. Members please send any comments on review of draft to group, and be prepared to discuss at meeting. Byerly to collect names of contributing authors Donna Nale and Becky Butler will be the facilitators of Telegenetics Roundtable |
| Prader Willi Syndrome (PWS) Module: discussion of completion | Judy Welch: Initial Diagnosis section is almost complete; she is working on Ongoing Assessment. Judy to have these complete within a week or so. Drafts of sections will be sent to PWS group for review. All other sections are complete and have been sent to Utah MedHome Portal Project for review and feedback. Plan to have final draft version from Utah for review in Sioux Falls. Merlin is working on update of a Prader Willi brochure for PWS Association to be used in coordination with Heartland; he will communicate with PWS organization regarding our module. | Byerly will request final version with all feedback and comments from Utah for distribution to PWS work group members. Timeline for having module live on Utah MedHome Portal to be discussed with Utah |

Heartland Regional Genetics and Newborn Screening Collaborative

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| <p>Annual meeting: Sept. 11-12, Sioux Falls SD</p> | <p>Schaefer, Welch and Craft not attending. Reminder to register and make travel arrangements if not already done. Agenda items for Work Group in person meeting include: Review of Telemedicine Project, Transitional Care and planning for future projects.</p> | <p>Please submit any suggestions for the Clinical Services Work Group meeting agenda to Byerly; think about potential partners who could be interested in transitional care</p> |
| <p>Transition</p> | <p>Plenary session will include a presentation from Patti Hackett about Transitional Care. Transition resource from Brad Schaefer is now on the new Heartland website. Melissa Craft discussed OK Genetics Advisory Committee (OGAC) is establishing a standing sub group on transition. OGAC will meet in Sept.; so more info available then. Ralph Vogel is working on incorporating pediatric transition into the nursing curriculum in AR.</p> | <p>Melissa Craft will keep work group updated on Oklahoma OGAC committee on Transitional Care in Oklahoma.</p> |
| <p>Clinical Genetics Services Listings</p> | <p>Updates for database have been received from all states; Online searchable database is at the new website: www.heartlandcollaborative.org. It is still a work in progress. List of categories is different than NCC's list, which is more extensive.</p> | <p>Members to review each respective state's listing for errors or updates and send changes to shona-whitehead@ouhsc.edu. An online form for updates is coming soon.</p> |
| <p>Other items</p> | <p>Discussed Heartland collaboration with Iowa nursing education program about their on-line programs on nursing genetics; will have roundtable on this topic at meeting</p> <p>Merlin Butler has begun new position at KU Medical Center.</p> <p>Discussion of status Dr. Virginia Johnson in SD: Update after meeting from Stein-She has retired and Dr. Patricia Crotwell now runs the cytogenetics lab in SD.</p> | <p>Note new contact info: Merlin G. Butler, MD, PhD, FFACMG Professor of Psychiatry, Behavioral Sciences and Pediatrics Departments of Psychiatry & Behavioral Sciences and Pediatrics Kansas University Medical Center MS 4015, 3901 Rainbow Boulevard Kansas City, Kansas 66160 Phone: (913) 588-1800 Fax: (913) 588-1305 E-mail: mbutler4@kumc.edu</p> |
| <p>Next meeting</p> | | <p>September 12, 2008 at annual meeting In Sioux Falls.</p> |