

**Advisory Board Meeting**  
**Monday, August 9, 2010**  
**9:45-10:45 am—Conference Call**

**Meeting Summary**

**Members:** Leslie Himstedt (AR), Amy Brower (SD), Julie Luedtke (NE), Mary Riske (ND), Holly Johnson (AR), Larry Weatherford (OK), Sharon Vaz (OK) **Guests:** JoAnn Bolick (AR), Barb Hemmelman (SD)  
**HRCC:** John Mulvihill, Brad Schaefer, Mary Ann Coffman and Shona Whitehead

Agenda Item	Discussion	Action
Welcome/Attendance		
Annual Meeting	<p>Agenda is set and speakers are confirmed. Online registration is open and over 35 people have registered. Please contact Shona Whitehead <a href="mailto:shona-whitehead@ouhsc.edu">shona-whitehead@ouhsc.edu</a> with any questions about conference logistics or items for the Advisory Board agenda.</p>	<p><a href="http://www.heartlandcollaborative.org/annualconference/conference10.htm">www.heartlandcollaborative.org/annualconference/conference10.htm</a></p>
Transition Project	<p>Mary Ann Coffman gave a progress report on the transition project. It is obvious that it is a big project with many areas to cover. She has had calls with Dr Laura Pickler and Dr Wendy Parent to seek advice on the potential direction of the project. Dr Pickler suggested contacting Dr Carl Cooley, who was recently awarded a federal grant for the National Health Care Transition Center, to seek technical assistance. Mary Ann has spent time reviewing transition projects in the other regions and Heartland’s proposed project will be systems based, targeting the areas of education, health care, employment and work place training, rather than mimicking other current projects.</p> <p>She indicated that the pilot project proposal will be drafted in time for discussion by the Transition work group at the September meeting in Des Moines. Initial thoughts are to identify 2-3 clinics, through a competitive process, to provide them technical assistance or trained parent advocates. Estimated amount for the pilot project is \$40,000-60,000.</p> <p>Dr Mulvihill asked about the scope of Dr Cooley’s project and would genetics be given due attention or is its focus decided by disease prevalence?</p>	

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	<p>Dr Schafer asked the group if they feel this is the right direction for the project. Julie Luedtke commented that she felt using a parent advocate was good idea, but wants to know more about the training they would receive. She also wanted to know how the Heartland advocates felt about this direction. Mary Ann said that she has had several discussions with Mark Smith, both as a parent and as someone with experience in working on youth transition. From those conversations it is clear that medical home model will be used within the project.</p> <p>It is clear that a specialist may not always be available to the patients, but the family and PCP need to be involved with the medical home model. This project will not be designed to have an effect on the availability of specialists. Dr Schafer commented that one goal should be to explore ways to find available resources and this isn't just a one-year pilot program. If successful it could be expanded into all the states in the region.</p> <p>Dr Mulvihill commented that it might be helpful to look at the model developed for long-term care for survivors of childhood cancer.</p> <p>Amy Brower commented that there has been an increased focus on transition care through the life span.</p> <p>Dr Schafer asked the group again if they feel this is the right direction for the project. There were no objections.</p>	
Other	<p>Dr Schaefer announced that the work is still being done with HRSA to finalize the changes.</p> <p>Mary Ann Coffman commented that Sandy Daack-Hirsch will be visiting Briar Cliff College in the next few weeks as a part of the genetics nursing project.</p>	
Next Meeting	Save the Date: Heartland Annual Meeting—September 22-24, 2010—Des Moines	Wednesday, September 22, 2010 5:00-8:30 pm in Des Moines, IA