

Advocate Work Group Meeting

Wednesday, December 10, 2008

4:00-5:00 pm—Conference Call

Summary

Members: Jeanne Egger (NE), Stacey Montgomery (IA), Mark Smith (NE), Larry Weatherford (OK), Holly Johnson (AR) **Staff:** Shona Whitehead

Agenda Item	Discussion	Action
Welcome and Attendance		
Sookyung Shin's Financial Resource Guide		Tabled for next meeting
Resource Database update	Announcement only—Kelly Usrey, an OUHSC grad student, is updating and expanding current resource database.	
Mid-year meeting	Tentative dates are February 23-24, 2009 in Kansas City, MO. Discussed possible agenda items for work group meeting: <ul style="list-style-type: none"> • Sookyung Shin's Financial Resource Guide • MedHome Portal update • Approve mission and membership statement • Suggestions/nominations for new members • Strategic planning for Advocate Work Group 	Please send any additional suggestions for the meeting agenda to Shona Whitehead at shona-whitehead@ouhsc.edu .
External Evaluator	Announcement only—Dr Barbara Jackson, from the University of Nebraska Medical Center's Monroe Meyer Center, has been hired as the Heartland Collaborative external evaluator. She will be visiting the RCC December 16-17, 2008.	
Membership	Nominations or suggestions for new members.	To be discussed at next meeting or at February Work Group meeting in Kansas City.
Development of mission statement for work group	Reviewed and revised draft document created by Jeanne Egger.	Please review attached document defining Advocate Work Group mission statement and membership. Send any comments or suggestions to Shona Whitehead at shona-whitehead@ouhsc.edu .

Agenda Item	Discussion	Action
Advocate work/hours receipt	Announcement only—A new document for advocate work group members to submit their hours was distributed via email and is also available on the Yahoo group website.	Please use new form when submitting hours for reimbursement. Form should be sent to Shona Whitehead at shona-whitehead@ouhsc.edu .
Planning for FY 2009-10	Possible work group project: <ul style="list-style-type: none">• White paper on medical genetics home	Please send any additional suggestions for FY 2009-10 to Shona Whitehead at shona-whitehead@ouhsc.edu .
Next meeting		Wednesday, January 14, 2009 7:00-8:00pm

Mission

The Advocate Work Group of the Heartland Genetics and Newborn Screening Collaborative is committed to work to improve the health and welfare of individuals with special health care needs and their families. We initiate and support efforts to alleviate problems and improve the quality of life in a patient-centered, community-based comprehensive medical home.

Members of the Advocate Work Group can be parents or relatives of children with the special health care needs or other concerned participants in this mission.

Advocate Work Group Membership (as defined at the Heartland Annual Meeting—9/2008)

Core Work Group Member

Core members of the Heartland Work Groups agree to a two year commitment to work group membership, including participating in teleconferences, scheduled every one to two months, email communications and a work group project. Core members may also be asked to represent Heartland on national committees or groups. For core members, attendance at the annual in-person meeting, and if needed, one additional mid-year meeting, will be funded by the Heartland Regional Coordinating Center.

Work Group Members

Other members of a work group may wish to receive work group communications but not commit to active attendance and participation, or may wish to participate only on a specific project or aspect of a project.

Membership is voluntary. Heartland’s other work groups are: Newborn Screening, Clinical Services or Education

Participating

If you wish to participate, please provide the following information:

Name _____

Address _____

City _____ State _____ Zip _____

Email _____

Phone _____

Availability for conference calls Best time: _____

Mon. _____ Tues. _____ Wed. _____ Thu. _____ Fri. _____

Special interest in assisting the Heartland Collaborative: _____

