

Advocate Work Group Meeting
 Wednesday, January 14, 2009
 7:00-8:00 pm —Conference Call

Summary

Members: Jeanne Egger NE, Julie Briggs SD, Holly Johnson AR, Donna Nale MO, Mark Smith NE **Guest:** Sookyung Shin
Staff: Shona Whitehead

Agenda Item	Discussion	Action
Welcome and Attendance		
Announcements	<ol style="list-style-type: none"> 1. Resource Database update—Kelly’s current version is now online. It is still in progress. Search function by category also available. 2. Mid-year meeting—February 23-24 in Kansas City—Expenses for Core members of the work groups participating in this meeting will be covered. Hotel and travel information will be sent a later date. 3. Teresa Willige—regrettably announced she will be stepping down as co-chair of the Advocate Work Group. She will still be involved, but her role will be reduced. She is also stepping down as a member of the Advisory Board. 	<p>A draft agenda for the KC meeting is attached. Please send agenda items for the Advocate meeting to shona-whitehead@ouhsc.edu.</p> <p>Discussion regarding the co-chair position will take place in Kansas City.</p>
Genetic Alliance Annual Conference	<p>July 16-19, 2009 in Bethesda, MD—Heartland can send 3-4 advocates who would like to attend this conference. More information can be found at: http://www.geneticalliance.org/conference09 http://www.geneticalliance.org/geneticsday09</p>	<p>If interested in attending, please contact Shona at shona-whitehead@ouhsc.edu.</p>
Advocate Participant Fee	Lori Williamson was not on call to discuss.	Tabled for later discussion.

Agenda Item	Discussion	Action
<p>Sookyung Shin's Financial Resource Guide</p>	<p>Sookyung reminded everyone to begin their search for information with the State Waivers and remember that waivers can vary by state. The most relevant information for a parent should be included. The categories within the template were selected based on feedback from other parents; financial qualification is key information for parents when seeking eligibility. The Notes section is for general information.</p> <p>Feedback on progress: Jeanne is planning to ask the staff at DHHS in NE for help; Julie has started gathering info and is planning to get additional info from the SD Parent Connection, (the SD Parent Connection is also developing a similar tool); Holly is gathering info and Mark has previously sent information he collected to Sookyung.</p> <p>It was suggested that the group investigate if it would be worthwhile and effective to partner with other organizations that are collecting similar information within their state. It could reduce the work load and provide more outside exposure to Heartland. (Discussion on this topic will take place in Kansas City).</p> <p>Sookyung expressed gratitude to everyone for working on this project. Everyone agreed this resource guide will be a valuable tool for both parents and professionals.</p>	<p>Please send any information, including any weblinks, you have collected to this point to Sookyung at sk@ou.edu and Shona at shona-whitehead@ouhsc.edu.</p> <p>The working templates are also being distributed with these minutes.</p>
<p>Next Meeting</p>	<p>It was suggested that another conference call be held in advance of the February meeting in Kansas City. It could be held on February 11, 2009 at 4:00 pm (this would be the next regularly scheduled call)</p>	<p>Please let Shona know if you would be interested in a conference call on 2/11/09 at 4:00pm.</p> <p>February 23-24, 2009--Heartland Mid-Year Meeting in Kansas City</p>