

Advocate Work Group Meeting
Wednesday, April 8, 2009
4:30-5:30 pm—Conference Call

Summary

Members: Donna Nale (MO), Michelle Leeker (KS), Jeanne Egger (NE), Larry Weatherford (OK), Holly Johnson (AR), Leisha Suckstorf (NE)
Guest: Sookyung Shin (OK) **Staff:** Shona Whitehead

Agenda Item	Discussion	Action
Welcome and Attendance		
New Member Introduction	<p>Leisha Sucksortf is from Nebraska and is a mother of 7 children, two who have been diagnosed with MCADD. Both were diagnosed as a result of expanded NBS. She wants to be involved as much as possible. She is currently working on her Master's degree.</p> <p>Other potential new members, who were not on the call, are: Michelle Black from Kansas, Susanne Heutter from Arkansas and Carla Sandwell from Missouri.</p>	Welcome Leisha!
Report from ACMG Conference	<p>Larry Weatherford was the recipient of a Genetic Alliance scholarship to attend the March 2009 American College of Medical Genetic (ACMG) conference. Larry was one of seven advocates to attend under this Genetic Alliance program. He encouraged and recommended it to all the advocates. Each of the five days during the conference, the advocates had meetings with the professionals in attendance, including ACMG Board members, like Dr Mulvihill.</p> <p>Other advocates that Larry met included: another Collaborative advocate, a member of a Canadian PKU group, a member of a Down Syndrome organization and a deaf program.</p> <p>Two sessions were of particular interest to Larry: Direct to Consumer Genetic Testing and Ethics of Genetic Testing.</p> <ul style="list-style-type: none"> • Direct to Consumer Genetic Testing—available on the internet, used by most consumers for genealogy, but also for disease traits. One company, for \$400 and a cup of spit, they will provide results from 28 clinical tests, ranging from type of ear wax you have to determining your CF carrier status. It is not clear who does the medical follow-up if you are a gene carrier for a disease, which could potentially lead to over or under reaction to the results. 	

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	<ul style="list-style-type: none"> • Ethics of Genetic Testing—Issues discussed included: <ul style="list-style-type: none"> ○ What if NBS shows that the infant is a carrier? ○ What if a parent tests a child for adult onset diseases (like breast cancer, Alzheimer’s disease or prostate cancer)? Surveys show that most adults don’t want to know these types of results. ○ What should be done about genetic testing over a lifetime? Who keeps the results or information on a child? ○ What about screening for untreatable diseases? How does this relate to false positives? 	
<p>Financial Resources Guide</p>	<p>In the Heartland Collaborative project renewal, the RCC proposed and included in base funding to pay an independent contractor, preferably a parent/advocate, to finish the Heartland’s Financial Resources Guide. This person would be paid contingent on completion, in a timely manner, of each section. The goal is to have a draft (including information from all eight states) in time for the Heartland Conference in September. The final document will need to be ready for printing and dissemination by Spring 2010.</p> <p>So far, two advocates have indicated they are interested in being the contractor to complete the guide. Anyone who is interested should complete the attached application and return it to the HRCC by April 24, 2009. All applications received will be reviewed by external reviewers, not Heartland RCC staff. Contract will begin June 1, 2009.</p> <p>Sookyung asked if it would be possible to pay two people instead of one in the hopes of speeding up the process. However, this is not in the Heartland budget. Even though someone will be hired to complete the guide, this doesn’t mean that others are prevented from providing assistance in gathering the information.</p> <p>Michelle Leeker is concerned that it will be hard to receive feedback from other states as a non-resident. In addition, she doesn’t have time during the day to make follow-up call until school is out for the summer. Sookyung said that the best way to get information from across state lines is to call, then email and mention that you are a parent Advocate from the Heartland Collaborative.</p> <p>Leisha indicated she is willing to help anyway she can. Sookyung will contact her to provide more information about the project.</p> <p>Holly Johnson commented that when she worked on a similar project, it was important to have time during the day to make calls, especially to state agencies.</p>	<p>Please return the attached application to Shona (shona-whitehead@ouhsc.edu) by April 24th if you are interested in being the independent contractor hired to complete Heartland’s Financial Resources Guide.</p>

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Nomination of Co-Chair	<p>Jeanne Egger and Teresa Willige were nominated to be co-chairs during the Omaha, NE meeting in 2007. It was suggested at that time the term of service would be two years. Since then, Teresa has stepped down as co-chair. It is up to the group whether to have a chair or co-chairs. Jeanne commented that she loves the position, but since she doesn't have access to personal email, she feels she can't be as accessible or as responsive as she would like to be. The next discussion for nominations or volunteers for the co-chair position will be during the annual meeting in Little Rock.</p> <p>Larry Weatherford commented that the advocates play a critical role in providing a different perspective on policy and collaborative projects. He also said that co-chairs are probably the best solution, since all the advocates have obligations at home that require attention.</p>	If you are interested in serving as a co-chair of the Advocate Work Group, please contact Shona at shona-whitehead@ouhsc.edu .
Meeting Schedule	With the addition of new members, a discussion of the meeting schedule needs to be revisited by the group. Is Wednesday the best day of the week for everyone? What about rotating the times from 4:00 pm and 7:00 pm.	Please email Shona shona-whitehead@ouhsc.edu the best days and times that fit your schedule.
Announcement	Sookyung's son is being discharged on Friday, April 10. His recovery has from surgery has been slow, but is now ready to go home.	
Next meeting		May 13, 2009