

### Advocate Work Group Meetings

Thursday, September 17, 2009--3:30-4:45 pm  
Grampas Room (Level 2)

Friday, September 18, 2009—12:30-2:00 pm  
Neosho Room (Level 1)

### Meeting Summary

**Members:** Jeanne Egger (NE), Michelle Leeker (KS), Michelle Black (KS), Larry Weatherford (OK), Donna Nale (MO), Holly Johnson (AR), Leisha Suckstorf (NE), Mark Smith (NE) **HRCC:** Shona Whitehead **Thursday Guests:** Amy Brower, Melva Wilson, Gloria Weissman, Kathy Harris **Friday Guests:** James O’Leary, Jill Shuger

Agenda Item	Discussion	Action
Welcome/Attendance		
Update on Financial Resources Guide Project	<p>After receiving no objections from the Advocates, the HRCC decided to contract with Sookyung Shin to complete the Financial Resources Guide for all 8 Heartland states.</p> <p>Thanks to Michelle and Michelle for their hard work on collecting information for Kansas. A draft of the Kansas information is on the conference display table.</p> <p>Once more of the Guide is completed, a plan for dissemination will need to be discussed. Should it be web based? Who is the target audience? Should it be a hard copy booklet?</p>	
Nominations for Work Group Co-Chair	<p>Jeanne Egger opened the discussion of a co-chair. Jeanne commented that her availability is restricted since she doesn’t have internet access at home, so in the best interest of the group a co-chair is needed.</p> <p>The work load of the co-chair is not heavy, participation on conference calls, assist with development of meeting agendas, and review of meeting summaries.</p> <p>Leisha Suckstorf indicated she would be willing to serve as a co-chair with Jeanne.</p>	

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Advisory Board Representation	<p>There are three positions for Advocates to fill on the Advisory Board. Holly Johnson has one more year to serve. Larry Weatherford is willing to serve again, leaving at least one additional position open. Amy Brower commented that the Advocates serve an important role and provide key perspective on the activities of the Collaborative. Larry commented that it is not an over-bearing about of work; monthly conference calls and email correspondence. New advocates were encouraged to serve on the Advisory Board and not to defer to advocates with more experience.</p>	
New Member Recruitment and regular meeting day/time	<p>Additional core advocates are needed, in addition to more advocates. New members do not need to be parents, representatives of advocacy groups can join. Core members are expected to be parents or an effected adult.</p> <p>Donna Nale asked if there had been response from her nominee form Missouri. The nominee had not responded to the HRCC.</p> <p>New member nominees are invited and welcome to participate in upcoming conference calls.</p> <p>It was decided that the during the week evening calls were no longer working and that switching between days and times was also causing problems. The suggested solution was to move the call day/time to the second Sunday of the month at 9:00 pm. Many commented this might be the best time since it is after their kid’s bedtime. It was agreed that this new time would be tested and re-evaluated after 6 months.</p>	<p><b>New Meeting Time: 2<sup>nd</sup> Sunday of the month, 9:00 pm</b></p>

Agenda Item	Discussion	Action
<p>NBS Dried Bloodspot Retention Position Statement</p>	<p>The landscape is constantly shifting, especially with political and government involvement in health issues. This is a key issue at Genetic Alliance and ACMG.</p> <p>What are the ethical questions surrounding screening for carrier status or adult onset diseases? Education about genetics is expanding to all age groups. Mark Smith commented that as more people are educated, parents have more questions and choices; so it would be good to look at the broader public policy.</p> <p>Amy Brower commented that NBS looks for chemicals, not “genes”. And, historically DBS are used to look for markers of disease or conditions and are retained for analytical research for quality assurance in the lab, to make sure the correct diagnosis was made. She said there are at least two visions for DBS retention:</p> <ol style="list-style-type: none"> <li>1. Proficiency in the lab</li> <li>2. ultimately develop a test to conduct outcomes based research</li> </ol> <p>The emphasis should be on validation, measured outcomes, benefit to research, anonymous, focus on positive health outcomes and save children’s lives.</p> <p>James O’Leary commented that a future statement from the Advocates would be a valuable and balanced perspective. Genetic Alliance is also conducting a survey of expectant mothers and recent mothers to gage knowledge and perspective.</p>	<p>After this discussion, it was decided to take a step back and start again on a DBS/NBS statement from the Advocates.</p>

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Education resources for GINA)	<p>Where are we now? GINA implemented in two phases</p> <ul style="list-style-type: none"> <li>• Health insurance (not life insurance)—May 2009</li> <li>• Employment protections—September 2009</li> </ul> <p>Large insurance companies and major employers now in compliance. Law doesn't apply to small companies with 50 or fewer employees.</p> <p>GINA is similar to other discrimination laws. It doesn't cover diagnosed conditions, but does protect family health history and predictive screening.</p> <p>Website with more info:  <a href="http://www.geneticfairness.org">www.geneticfairness.org</a>  <a href="http://www.geneticalliance.org">www.geneticalliance.org</a>  <a href="http://www.genome.gov">www.genome.gov</a>  <a href="http://www.dnapolicy.org">www.dnapolicy.org</a></p>	James O'Leary to send HRCC additional information for dissemination.
New Initiatives or Projects	<p>Should HRCC budget for Advocate to attend: ACMG, NSGC or Genetic Alliance meetings? YES</p> <p>Michelle L. and Larry commented that attending the national meetings was valuable, educational and encouraged other advocates to attend if possible.</p> <p>Michelle commented that the Genetic Alliance meeting was great to attend and to meet and talk with other advocates was beneficial.</p>	
MedHome	<p>Not discussed during the meeting, However Mark did remind everyone that a Medical Home is important to remember when reviewing a projects and policies. Handout from American Academy of Pediatrics was provided.</p>	
Reports from Advisory Board and other Work Group meeting	<p>Tabled for next meeting.</p>	

<b>Agenda Item</b>	<b>Discussion</b>	<b>Action</b>
Independent Contractor Forms	Disseminated to the group, completed and returned	
Next Meeting		<b>9:00 pm, Sunday, October 11, 2009</b>