

**Advocate Work Group Meeting**  
**Wednesday, August 12, 2009**  
**7:00-8:00 pm—Conference Call**

**Summary**

**Members:** Jeanne Egger (NE), Michelle Black (KS), Mark Smith (NE) and Donna Nale (MO) **Staff:** Shona Whitehead

Agenda Item	Discussion	Action
Welcome and Attendance		
Report from Genetic Alliance Meeting	Michelle Leeker submitted a written summary of the Genetic Alliance Meeting in Washington DC in July. Report attached.	
NBS Blood Spot Retention	Jeanne Egger wrote a rough draft of a position statement regarding dried blood spot retention and research. Advocates are asked to suggest revisions. Some revisions were made during the meeting and have been incorporated in the draft attached. Additional discussion and revisions will take place during the September meeting.  The ACMG position statement is included.	Please read and suggest changes for the DBS position statement. Any revisions can be sent to <a href="mailto:shona-whitehead@ouhsc.edu">shona-whitehead@ouhsc.edu</a>
Education resources for GINA	Tabled for September meeting.	
Annual Conference	Similar to last year's meeting in Sioux Falls, the advocates will have two meeting times during the Heartland Annual Conference in Little Rock in September. Find draft Work Group agenda attached.  Current agenda Items for face to face meeting: <ul style="list-style-type: none"> <li>• Co-chair nominations</li> <li>• New member nominations and regular meeting day and time</li> <li>• GINA education</li> <li>• DBS storage position statement</li> <li>• Update on Financial Resources Guide project</li> </ul> Suggestions: <ul style="list-style-type: none"> <li>• New initiatives/projects</li> <li>• MedHome</li> </ul> Information about reimbursement can be found along with other conference information, including online registration at: <a href="http://www.heartlandcollaborative.org/annualconference/conference09.htm">http://www.heartlandcollaborative.org/annualconference/conference09.htm</a>	Please submit agenda items by August 28 <sup>th</sup> for the Advocate's Work Group meeting to Shona Whitehead at <a href="mailto:shona-whitehead@ouhsc.edu">shona-whitehead@ouhsc.edu</a> .

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Genetic Alliance Advocates Partnership Program	<p>The Genetic Alliance provides scholarships for advocates to attend various national meetings throughout the year. Two Heartland advocates have received these scholarships—Larry Weatherford to attend ACMG in March 2009 and Michelle Leeker to attend the Genetic Alliance Conference in July 2009. The scholarship provides:</p> <ul style="list-style-type: none"> <li>• waived, full registration to the meetings</li> <li>• up to \$250 reimbursement for transportation, hotel room, or airfare</li> <li>• participation in every aspect of the conference</li> <li>• amazing access to the genetics community</li> <li>• exclusive daily briefings with professionals</li> </ul> <p>The HRCC plans to budget funds for the additional expenses, not covered by the scholarship, for one interested advocate (per meeting) to attend NSCG in November 2009 and ACMG March 2010. (At this time we can't provide funding for the ASHG meeting in October 2009). The advocate is expected to provide a written report to the HRCC/Advisory Board, an oral report to the Advocate Work Group and possibly and oral report at the annual Heartland meeting.</p> <p>Mark Smith indicated he is interested in attending the NSGC meeting.</p> <p>Application and more information regarding the NSCG conference opportunity can be found at: <a href="http://www.geneticalliance.org/advocates.opportunities">http://www.geneticalliance.org/advocates.opportunities</a> Application deadline is September 11, 2009.</p>	
Next meeting	Upcoming Meetings: Heartland Annual Conference—9/16-18/09—Little Rock, AR	

**Attachments:**

- Draft Dried Blood Spot Position Statement
- ACMG Position Statement
- Michelle Leeker's report
- Draft Advocate Work Group Meeting agenda