

Advocate Work Group Meeting
Wednesday, June 10, 2009
4:30-5:30 pm—Conference Call

Summary

Members: Jeanne Egger (NE), Michelle Leeker (KS), and Donna Nale (MO) **Staff:** Shona Whitehead and Lori Williamson

Agenda Item	Discussion	Action
Welcome and Attendance		
NBS Blood Spot Retention	<p>Discussion led by Jeanne Egger. Jeanne would like to see the advocates collectively develop a position statement regarding dried blood spot (DBS) retention. A survey with a few questions will be created to gain feedback from the advocates regarding this topic. Jeanne suggestions for questions included: Should parents retain their child's card or should it be held in a national repository? What research should be done with the DBS? How long should the DBS cards be retained?</p> <p>The ACMG position statement is included.</p>	Jeanne Egger and RCC to develop survey regarding DBS.
Education resources for GINA	<p>Jeanne commented that she knows of parents who didn't want to didn't want NBS testing because they felt it could affect their chances of employment or insurance coverage.</p> <p>What can the advocates do to increase awareness of the GINA legislation in our local communities and what can the RCC do on a regional level?</p> <p>"What Does GINA Mean?" from the Coalition for Genetic Fairness is included.</p>	Please send suggestions for increasing awareness of the protections provided by GINA to Shona Whitehead at shona-whitehead@ouhsc.edu .
Financial Resource Guide	<p>No contractor has been hired to complete the financial resources guide. Several advocates had verbally indicated they were interested, but none applied to be the contractor.</p> <p>The use of two contractors working together and dividing up the remaining states is also an option. When a contractor is hired, it doesn't mean that the other advocates can't work on gathering the information for their state. In addition, advocate will still be able to invoice the RCC for the time they spend gathering information for their states.</p> <p>The status of the all information gathered is unknown. Michelle Leeker, Donna Nale and Mark Smith have submitted data they have gathered. Others have previously indicated verbally they have gathered some information, but it has not been submitted.</p>	<p>Everyone is asked to send Shona Whitehead at shona-whitehead@ouhsc.edu all information gathered for the resource guide, no matter the format.</p> <p>Please contact Shona Whitehead if you are interested in being a contractor hired to work on the Financial Resource Guide.</p>

Agenda Item	Discussion	Action
Agenda Items for face to face meeting	<p>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.</p> <p>Suggested agenda items:</p> <ul style="list-style-type: none"> • Co-chair nominations • New member nominations and introductions • Regular meeting day and time • GINA education • DBS storage position statement 	Please submit agenda items for the Advocate’s Work Group meeting at the Heartland Annual Conference to Shona Whitehead at shona-whitehead@ouhsc.edu .
Next meeting	Upcoming Meetings: Heartland Annual Conference—9/16-18/09—Little Rock, AR	Wednesday, July 8th at 7:00pm