

Advocate Work Group Meeting
Wednesday, March 11, 2009
7:00-8:00 pm—Conference Call

Summary

Members: Jeanne Egger (NE) and Larry Weatherford (OK) **Guest:** Sookyung Shin **Staff:** Shona Whitehead, Lori Williamson

Agenda Item	Discussion	Action
Welcome and Attendance		
Sookyung Shin's Financial Resource Guide	<p>Lori Williamson has received secondhand feedback indicating support for continuing the Financial Resources project, but also hearing from advocates that gathering the information and completing the guide is stressful and time consuming. Ironically this feedback shows the actual need for the guide. Others have commented the information is hard to find.</p> <p>During the HRSA Office of Performance Review it was suggested that the RCC hire advocate to be a part of the RCC team. It was not pursued at the time because of the cohesiveness and momentum of the current advocate members.</p> <p>The Advisory Board ranked project ideas for FY 09-10 as suggested by the work groups. The Financial Resource was the top ranked project under the Education goal (see attached rankings). This shows support for project outside of advocate work group.</p> <p>Lori's idea for moving forward with the Financial Resources Guide is to subcontract with either a current advocate or someone outside the group to complete the guide. This person would earn \$20 per hour and have specific requirements to complete the project. The plan is to complete this needed project without losing work group members or momentum. Since there is a clear need for the guide it is too important not give up the project either. Lori could hire a graduate student; but a parent would have a different perspective. This idea has been discussed with John Mulvihill and he approves.</p> <p>The finished product will then be disseminated to genetic counselors, advocates and other Heartland members. Potential for pilot test in region. Pilot test data could then be used by Sookyung for her dissertation if she chooses to do so.</p> <p>This idea is not set in stone, but the RCC is seeking quick feedback from the Advocate work group. Budget for FY 09-10 is to be finalized by noon on March 18, 2009.</p>	<p>Please read discussion and provide feedback to Shona at shona-whitehead@ouhsc.edu or Lori at lori-williamson@ouhsc.edu by Monday, March 16, 2009.</p>

Agenda Item	Discussion	Action
	<p>Sookyung commented that she finished the Oklahoma section because of her personal reasons. She has received requests from other states for similar products. Hiring someone could relieve the stress of advocates. This person would fill in the main information and the advocates confirm the details.</p> <p>How does Advocate work group feel? Are any Advocates interested in being paid to complete the guide? This hired person will have specific deliverables and timeline. The advocate work group would stay actively involved and will have a role in the completion of the guide.</p>	
<p>Review Heartland proposal and budget for FY 09-10</p>	<p>The Advisory Board was asked to prioritize activities that had been suggested by all the work groups. Lori organized the suggestions under each of the Heartland goals, provided description of the activity and included estimated budget costs. The list not only included new activities but also ongoing and required activities. This was a new process for selecting Heartland activities for the upcoming project year. The results of the Advisory Board rankings are attached.</p>	
<p>Review Family to Family Health Information Center contact list</p>	<p>As was discussed on the previous call, HRSA is urging the regional collaboratives to reach out to the federally funded Family to Family Health Information Centers (F2FHIC) in our region. In some states the, F2FHIC is also the Parent to Parent organization or it is the Family Voices organization. The attached list is not meant to be exhaustive or correct, but rather a starting place. If you know which organization in your state received HRSA funding as the F2FHIC, please let the Heartland RC know. If you have a personal contact at the F2FHIC please also provide the contact information to the Heartland RC. The plan is to send these organizations a packet of information introducing them to the Heartland Collaborative and invited them to become involved.</p>	<p>Please review the information for your state and make any corrections. Please send updates to Shona at shona-whitehead@ouhsc.edu.</p>
<p>Meeting Schedule</p>	<p>Are the Wednesday evening calls still a good time for everyone in the work group? Would a different day be better?</p>	<p>Please visit http://www.doodle.com/vs3bnpzitt7fhbea to indicate if Wednesday evening calls will continue to work for your schedule.</p>
<p>Other</p>	<p>Jeanne Egger commented that Julie Miller (State Genetic Coordinator in Nebraska) had identified a potential new advocate. An invitation to join the next call will be extended to this person.</p>	
<p>Next meeting</p>		<p>April 8, 2009 4:30 pm</p>