

Advocate Work Group Meeting
Wednesday, February 11, 2009
4:30-5:30 pm—Conference Call

Summary

Members: Larry Weatherford (OK), Michelle Leeker (KS), Jane Nelson (ND), Jeanne Egger (NE), Holly Johnson (AR)

Staff: Shona Whitehead, Lori Williamson

Agenda Item	Discussion	Action
Welcome and Attendance		
Announcements	<ol style="list-style-type: none">1. Heartland can send 3-4 advocates who would like to attend the Genetic Alliance Annual Conference--July 16-19, 2009 in Bethesda, MD. More information can be found at: http://www.geneticalliance.org/conference09 http://www.geneticalliance.org/geneticsday09 Michelle Leeker has expressed interest in attending.2. Congratulations to Larry Weatherford on his acceptance to the Genetic Alliance Advocate Partnership Program to attend the American College of Medical Genetics (ACMG) Conference in March in Tampa Bay.3. Holly Johnson notified the HRCC that Paula Conway is resigning from the Advocate Work group due to health reasons. Paula was recently diagnosed with acute myelogenous leukemia. Her previous contributions are appreciated.	If you are interested in attending the Genetic Alliance Conference, please contact Shona at shona-whitehead@ouhsc.edu by Friday, February 20, 2009

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Financial Resource Guide	<p>Feedback:</p> <ul style="list-style-type: none"> Michelle Leeker said that it is hard to find contact info for the waiver, but she finally just emailed the head of the department requesting help filling in the missing info. It took a couple of weeks, but she was able to get a response with the completed information. She took 2-3 hours of uninterrupted work to complete what she has already done. As a member of the Kansas Newborn Screening Committee, Michelle was able to reach out to other parents willing to help gather information. Language from Michelle's email will be distributed to work group members. Jeanne Egger said she has gathered info but has no access to email from home to submit information online. She commented that wavier programs are "moving targets" and can change. <p>Lori Williamson reminded the advocates about reimbursement for their time working on this project.</p> <p>In addition, Lori reminded the Advocates that projects evolve; and that initial feedback is positive for the project, but provide to feedback if at some point the project needs to be refreshed or revised. This project should be tailored to the needs of the collaborative and the parents in the region.</p> <p>The final product will most likely need to be revised annually as programs in each state are changed or updated.</p> <p>Lori also suggested that advocates utilize the resources of their State Genetics Councils to expand involvement, highlighting the potential benefit to the parents in their state.</p>	<p>Please provide feedback on your progress, success, struggles or need for assistance gathering information for this project to Shona at shona-whitehead@ouhsc.edu.</p>
Membership	<p>HRSA is encouraging each region to develop a partnership to increase the involvement of the Family-to-Family Health Information Centers (F2FHIC) in each state. Jane Nelson indicated that F2FHIC and Parent-to-Parent organizations are the same.</p> <p>The F2FHIC could become a member of the Advocate Work Group and designate a person to represent their organization at the meetings. Lori Williamson indicated that the Western States Region has a good working relationship the F2FHICs in their states.</p> <p>The question posed to the Advocates is do the members want the additional core member from their state to be a parent/adult patient or a F2FHIC representative? It is</p>	<p>If you have a contact at a F2FHIC (or equivalent) in your state please send the information to Shona at shona-whitehead@ouhsc.edu.</p>

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	<p>important to continue to grow the membership so that the work done by the Advocates has greater impact through partnerships.</p> <p>Jane Nelson said that if the second core member from each state was a parent who was already involved with F2FHIC that would be good as well.</p> <p>The advocates agreed that the 2nd core member from each state should be a parent/adult patient or a non-professional advocate and that the F2FHIC representatives should be ancillary work group members.</p> <p>The HRCC, with input from the Advocates, will develop a packet of information to accompany an invitation letter for the F2FHIC in each state. A list of F2FHIC contacts will be distributed to the work group members.</p>	
<p>Advocate Budget for Participation Expenses</p>	<p>Other regions have “professional” advocates who are paid by their employers to participate in the collaborative meetings and activities. The question then becomes—should they receive a “stipend” for their time the same as a parent/volunteer who takes unpaid time from a job and pays for childcare to attend meetings? The prevailing thought in other regions is that no “stipend” is given to the “professionals” but is paid to the parent/volunteer. (Travel expenses are still paid by the collaborative for both.)</p> <p>Michelle Leeker indicated that she would use personal days from work to participate in Heartland activities, but has few opportunities to do so with her work schedule. She also said it isn’t about the money, but needs the Heartland funding to participate.</p> <p>Jeanne Egger mentioned that for some state employees, including Nebraska, employees are on travel restriction and have to use vacation days to participate in non-work activities. In addition, not all vacation requests are approved.</p> <p>It was decided that at this point “stipends” would be viewed on a case by case basis; but that a group decision may be requested at a later date if the need arises. This has the potential to become an “issue”.</p> <p>Thoughts and feedback is requested by the HRCC. Feedback will be kept anonymous.</p>	<p>Please send any thoughts regarding “advocate participation reimbursement” to Shona at shona-whitehead@ouhsc.edu by Friday, February 20, 2009.</p>
<p>Next Meeting</p>		<p>March 11, 2009 7:00 pm</p>