

Heartland Education Workgroup
 Thursday, Oct 4th 2007
 Conference call 1:15pm-2:00 pm

Members present: Merlin Butler (KS), Patricia Burk (OK), Jayne Brown (ND), Robin Troxell (MO), Lori Williamson (OK), Sharon Vaz (OK)

Item	Discussion	Action
Welcome / Introduction / Review of minutes from the Heartland Education Workgroup	Members on the phone call introduced themselves. Minutes from the Heartland education workgroup were reviewed and only one correction/clarification made. This is reported in the next item below.	
AAP – “Just in time” information	AAP “just in time” information discussed at the annual meeting was described erroneously. The actual project is to have a one/two click access on the AAP website or the heartland web site, where a pediatrician seeking more information about a genetic disorder can get credible information that they need. The workgroup will assess various websites, for specific disorders and resources for credibility and accuracy. New materials will not be created in this first year, if ever. It was decided to include AAFP in this project.	RCC will organize a conference call with representatives from all eight (heartland states) AAP and AAFP chapters, regarding their desire to have access to genetic information in a “just in time” manner. Conference call will be open to any member of the Heartland Education Workgroup.

<p>Review of resources received, with examples of National and State resources</p>	<p>Existing resources that have been sent in were reviewed. Discussion ensued regarding National versus State resources. The decision was made to collect and collate both National and state resources simultaneously. Lori from the RCC went to the ACHDGDNC meeting and went to the education workgroup meeting. That workgroup is currently working on a repository of foreign language resources. Nebraska has newborn screening information translated into various languages.</p>	<p>Lori will provide contact information of the ACHDGDNC education workgroup for collaboration. Include existing repositories, such as Genetic Alliance, KUMC genetic resources etc.</p>
<p>Other examples discussed- Down Syndrome, March of Dimes, Sickle Cell, Cystic Fibrosis, William Syndrome etc</p>	<p>Collect support groups information for different genetic disorders to see if there are gaps in support group services in the 8 states. Examples of some support groups – Prader Willi, Angelman’s syndrome, Autism, Huntington’s disease, 22q deletion syndrome. The workgroup would like to identify support groups that are active and those that are not and to find out what limitations are present to these groups, so that barriers can be identified and discussed.</p>	<p>Send in support group information to Sharon Vaz. Send in contact information as well as meeting times etc.</p>
<p>Research Interest</p>	<p>Access to research studies was discussed. There are many families in the Heartland region that are willing to participate in research studies and are willing to travel in the Heartland region but may not be willing to travel to NIH, for example. Information about ongoing research can be placed on the Heartland website, thus increasing access.</p>	<p>Message to the Heartland listserv asking members to send in current research studies with IRB approval for inclusion to the website. (Sharon Vaz) Members on the conference call will seek out current studies and send information in to Sharon Vaz to be placed on the Heartland website.</p>

Lay Advocates	None were present on the phone conference, but at the annual meeting the Lay Advocates would collaborate with the Education Workgroup by collecting Family-to-Family/ Parent – to- Parent support information and send it in to the Education workgroup for inclusion in the database	Contact Lay Advocates
Next meeting – First Thursday of the month	November 1st – 1:15pm – 2:00 pm	Contact : Sharonav@health.ok.gov