

June 8, 2006

Heartland Education Committee Meeting

1-2 pm Teleconference

Present: Piper, Kim (IA) - Chair, Brown, Jayne (ND), Collins, Debra (KS), Schweitzer, Barb (ND), Vaz, Sharon (OK), Rayburn, Julie (MO), Kyna Byerly & Lori Williamson, Regional Coordinating Center Staff

Absent: Conover, Beth (NE) Ferkol, Thomas, (MO) Hess, Norm (KS) Kenney, Linda (KS), Rogers, Sharmini (MO) Tinker, Kayla (SD), Tinley, Sue (NE), Wagner, Kerri (SD), Julie Miller (NE)

Introductions were made. It was announced that the Heartland Web site www.heartland.ouhsc.com has been extensively revised and is ready for use. Each committee has a page with information, minutes, members, and meeting dates. Please review and use the web site.

Committee priorities from 3-27-05 were reviewed and discussed. It was noted that educational information availability in multiple languages was still being addressed, while having a centralized location (Heartland Web Site) and a service directory have been addressed. Discussion of the service directory included the overlap between this project and clinical services committee listing of clinical genetics services, and updating the information on a regular basis. Materials have been written by recognized experts so far, and the committee will continue to work towards this goal, as well as having a consistent message in materials. Policy statements and legislative advocacy network will now be addressed by the Public Policy Committee. Revised priorities are posted on the Education committee page on the heartland web site.

Family History Project was discussed at length. A copy of year 3 continuation narrative sent to HRSA with the sections relevant to Education Committee's Family History Project highlighted along with the proposed budget was sent prior to the meeting for review. Final funding levels will be determined in the next few weeks. Several issues were discussed.

Deciding on what day or month to use for the educational campaign was discussed. Determining what would be the best time for Native American and Latino populations was discussed. The committee wants to determine what would be culturally appropriate. Jayne Brown states Melanie Antonio is a Native American contact in ND who can be consulted. Lori Williamson also states she has Native American contacts in OK who can be consulted. Re-taping the PSA with Native American and Latino families was discussed. Ideas for times to launch the campaign included Thanksgiving, coordinating with the national effort; MO has used the month of Nov, along with a proclamation by the governor; Iowa has focused on summer months, when family reunions are happening; and targeting Jan-Feb after the winter holidays are over. Participants were asked to

respond via email regarding which dates would be appropriate for which populations.

Working with local genealogy groups to help promote the Family Health History project was discussed. It was decided each member should make a list of genealogy groups in their state, starting with the web site for United States Genealogy Societies: <http://www.daddezio.com/society/hill/> Sharon Vaz also stated public libraries have listings of these groups; she has compiled a list for OK. The lists can then be further refined. It was also pointed out that we need to have an outcome measurement for the project. Currently there is no one on the committee from AR-Sharon Vaz will contact Ralph Vogel who was interested in both the Education and Policy committees.

All members were asked to put together documentation and resources they have and send them to Kim. She will have her summer intern sort and compile these materials; a final "Tool Kit" can then be assembled. This can be posted on the web site by Kyna Byerly. Julie Rayburn stated MO had numerous materials from November "Family History Month", including radio spots, a tool kit, available on their web site, and a CD on how to take a family health history, which she will forward to Kim.

Contacting the genealogy societies was discussed, and it was decided to use both email and one page letter, and multiple contacts. Four points were to be included: a short paragraph they can cut and paste into a newsletter, a link to the tool kit on the Heartland website, asking them to focus on November Family History Day and asking them to give us feedback on how they have used the information provided. It was suggested we recruit members of the genealogy groups to join or at least consult with the committee. Kim will do this. Promoting this project to family support units was also discussed.

Having a list of speakers available to give presentations on Family Health History Day for each state was also discussed. The committee will have a template or outline for a presentation available for speakers; this will be based on the information in the tool kit.

It was suggested that the PSAs be added to the web site as well. Deb Collins pointed out that in her area (Kansas City) TV stations needed about 3 months lead time in order to have the PSAs aired. This will need to be taken into account in planning, although each locality may have varying deadlines for submission of materials.

Curriculum development for grades 7-10 was discussed. It was determined the committee will focus on planning this project this year, with implementation next year (2007). A consultant will be hired to assist with this project. Deb Collins stated she has a contact who has submitted a bid on a similar project, which may be helpful. Having a power point presentation for local public health nurses was

also discussed; this can be done in conjunction with the Family Health History Project. "I Lecture" software from IA was discussed. It is currently under development, but may be available. This program takes slides and tapes a voice over discussing them, making a video of the whole presentation.

Summary of assignments:

- Each state to collect listing of genealogy groups and begin contacting them
- Native American and Latino contacts to be consulted by Lori and Jayne Brown. Any other with appropriate contacts to solicit input as well
- All members to send info to Kim Piper for compilation and review