

Minutes
September 29, 2006
Education Committee
Heartland Regional Genetics & Newborn Screening Collaborative
Omaha, Nebraska

Present: Julie Miller, Nebraska (Secretary)
Sara Jackson, Arkansas
Carol Saunders, Missouri
James O'Leary, Genetic Alliance, Washington D.C.
Michelle Leeker, Kansas
Jayne Brown, North Dakota
Lori Williamson, RCC, Oklahoma
Julie Raburn-Miller, Missouri

Connected via Phone:
Barb Schweitzer, North Dakota
Sharon Vaz, Oklahoma

Lori Williamson re-oriented the Committee to the previous discussions regarding the family health history initiative. The Committee had originally thought to do a 4 prong approach by building on the PSA's already done to promote use of the family health history tools available, address health professional education about the use of family health history information, focus on regional and state multicultural populations more unique to our region in particular Native American Indian and Hispanic population, and then address getting genetics education more integrated into school curricula at all levels.

Because of the extent of the approaches discussed for addressing each element, the Committee decided this was far too ambitious for the first year, and would identify more specifically year one activities, and then re-group in a few weeks to address years 2, 3 and 4.

This year the plan will be to promote public awareness in November and December via: a print (newspaper), radio and TV PSA will be sent from the RCC to each State for a consistent message. The PSA's will use existing (Deb Collins & Missouri) formats/content so as not to reinvent the wheel. Contact information from the State Genetic Coordinators (SGC's) for who to contact within each State to obtain toolkits, (possibly the SGC) and who to contact for more information about how to use them (possibly a genetic counselor) will be obtained for State customization. The RCC will print toolkits for distribution to those without web-access. The web-version will be linked via the Heartland web-page. State Genetic Coordinators will be encouraged to identify one or two lay-advocates for media contacts for the personal story of how completing a family health history benefited an individual or family member. It was felt the lay advocate should be someone with a family history of a common chronic condition such as heart disease or cancer rather than a rare disorder, in order to peak the attention of the general public.

Next summer efforts to promote the tool with the roughly 600 Genealogy groups in our 8 State region will be done so that summer family reunions could make use of the family health history toolkits. This will include providing a letter, and identifying how they can obtain the toolkit. If they request hard-copies, the RCC will supply those.

The following year the Education Committee would like to focus on education of health care professionals so they support the use of the tools, and make referrals.

The year after that, efforts will support genetics education targeting our Native American Indian populations and Hispanic/Latino populations.

The 4th year will address integrating genetics education into all levels of education curricula. Schools of Public Health will be added to the list already generated.

It was felt this was a more realistic plan, since this is just one of 5 objectives, but is cross cutting. The Committee will need to further discuss at the next conference call the other objectives regarding genetic testing, CGS Referral, attracting students to careers in genetics, and integrating genetics into the curriculum at every level.

Julie Miller will no longer be serving on the Education Committee, and so an appeal was made for another Executive Secretary to serve for the upcoming year.

Respectfully submitted:
Julie Miller