

## **HEARTLAND NEWS—July 2007**

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**Annual Regional Meeting:** The 2007 Heartland regional meeting will be held **September 6-7** in Oklahoma City, Oklahoma at the Skirvin Hotel. See the Heartland website (<http://heartland.ouhsc.edu>) for details and registration (no fee). Special features at this meeting include:

- Advocacy training the afternoon of September 5. Although we cannot pay travel expenses, any support groups, parents, or advocates are welcome to attend the training at no charge.
- Dinner at and tour of the Oklahoma City Art Museum sponsored by the Children's Medical Research Institute, a major sponsor of Pediatrics at the University of Oklahoma Health Sciences Center.

**Family Health History:** The family health history is the “cheapest genetic test,” according to Dr. Mulvihill. Thus, it has been a major thrust of our educational mission. The Education committee has completed a family health history toolkit, adapted from one developed in Utah. The toolkit will be available on the website: [www.heartlandfamilyhistory.org](http://www.heartlandfamilyhistory.org) by September 1. An article about the family health history was submitted to state rural electric cooperative journals. And, state genetics coordinators are contacting genealogy societies regarding the family health history resources currently available. Good work, education committee!

**Genetics Services Report Card:** If your state received a grade for its achievements in public health genetics, clinical and laboratory genetics services, what would it be?

The Heartland region proposed a five-year plan to develop, pilot, and assess the feasibility of a *Genetics Services Report Card* (GSRC), in consultation with national colleagues. The anticipated outcome from this project will be enhancement of genomics capacity in the Heartland and, if feasible, other participating states.

In the area of newborn screening, the National Foundation—March of Dimes has published a report card based on the number of disorders screened by the 50 states and the District of Columbia. The Centers for

Disease Control and Prevention (CDC) graded state Birth Defects Registries in the early 2000s. The National Newborn Screening and Genetics Resource Center (B. Therrell, San Antonio) offers in-depth review of Newborn Screening Laboratories and Programs by invitation, usually by genetic program coordinators of state departments of health. Finally, the CDC offers, on request, laboratory proficiency testing for analytes in Newborn Screening Laboratory. But, no objective summary rating of genetics clinical and laboratory services exists in the U.S.

Specific aims and tasks are as follows: 1a) Achieve consensus among stakeholders on the objectives, specific aims and tasks, risks, and benefits of the GSRC; 1b) Determine criteria for deciding if the pilot has been feasible and deserves implementation across the U.S. and perhaps beyond; 2) Develop the pilot instrument, including its data elements, the composite factors, their relative weights, and the exact form of the instrument; 3) Agree on criteria for desirable pilot states and pilot the instrument in two states outside the Heartland Region; 4) Implement the revised instrument in all eight Heartland states and analyze, interpret, and disseminate the results; and, 5) Re-evaluate the instrument in the ten original states approximately 24 months later, and implement the GSRC in additional jurisdictions.

\*\*Please see website for past monthly updates.