



# NOTES

## Genetic Expertise Workgroup Telemeeting Notes Friday, February 6th, 2009

### **Upcoming Genetic Access Survey:**

A survey for families was developed to examine access to genetic services. The plan is to distribute the survey in Michigan, Minnesota and Ohio. The survey will be brought to the workgroup at the next meeting for review. It was requested that a question about hearing loss/newborn screening be added to the survey.

### **Workgroup Face-to-Face Meeting on May 1, 2009**

The Genetic Expertise Workgroup will be convening for a face-to-face meeting to further develop priorities and next steps.

- Sarah emailed a survey to all group members to indicate your availability on May 1<sup>st</sup> at two locations, Lansing and Chicago. Please respond to the survey ASAP so we can plan the meeting and also reserve that date on your calendar.
- The meeting will include hearing about the efforts of other regional collaboratives to expand telemedicine to serve children with heritable disorders; reviewing the results of a family survey about access to care; and holding a conversation with pediatricians/primary care providers about their needs.
- We will be asking primary care providers from each state in our region to join us. Sarah will be composing an email to use to inform primary care physicians/pediatricians of the meeting and related details. If you know of or are a pediatrician/primary care provider who would be able to contribute to our discussion, ideally in person (or by telephone/webcast), forward their names to Sarah.
- Sarah will be contacting each workgroup member who was not on the call today or has not responded via the Doodle survey by phone to ask about your availability for our upcoming face-to-face meeting
- We are trying to get all of our members listed in their respective workgroups on the Region 4 website. If your name is below, please take a few moments to add your contact information to the Genetic Expertise website. Thank you! The link is <http://www.region4genetics.org/region4/members/search.aspx>
  - Carolyn Bay
  - Nancy Leslie
  - Shawn McCandless
  - Suzanne O'Neill
  - William Rhead
  - Helga Toriello
  - Jodi Wallace

**NEXT MEETING IS FRIDAY, MARCH 6<sup>TH</sup>**