

Genetic Expertise Workgroup Telemeeting Notes
Friday, March 6th, 2009

Upcoming Genetic Access Survey:

- Region 4 is partnering with the Michigan's Birth Defects Registry and Children's Special Health Care Services programs to survey families of children with heritable conditions in Michigan. The survey will assess families' knowledge of and perceived need for clinical genetic services. Region 4 will provide incentives to parents to complete the survey. The survey will be sent to a sample of families in Michigan.
- Other states are invited to talk with us about conducting the survey in their state. Illinois and Ohio expressed an interest and we will talk with them further about this opportunity. Carry-forward funds must be used before May 31st so we need to move quickly.
- Incentive for families to complete the survey will be a raffle--this has worked successfully in the past in Michigan.
- Region 4 parent partners will be reviewing the survey at a telemeeting on March 13th. After all changes have been made we will be moving quickly to get the survey distributed.
- The workgroup discussed suggestions for changes in survey including lowering the reading level of the survey, translating it into Spanish and other languages prominent in each state, clarifying what "genetic services" are so that families understand the question (it was decided this would be best done in a cover letter to families), look at questions 10 and 11 and decide if both are needed/differences between the two
- There is not question that asks all respondents about their perceived need for genetic services such as, "Do you feel that you could benefit from clinical genetic services or do you feel you have access to clinical genetic services?" This question is asked at the end of the survey but at that point not everyone is asked.
- Workgroup hoped to have MI be the pilot for the survey then move to other states, but noted time limitations as well to use carry-forward funds
- Carrie Langbo, Clinical Services Coordinator in MI and developer of the survey was present on today's call and will be working on the group's suggestions for the survey

Upcoming Workgroup Face-to-Face Meeting on May 1st in Chicago:

- The meeting will be held in Chicago, most likely near the O'Hare Airport on Friday, May 1st. We are actively recruiting primary care providers/pediatricians to attend the meeting and talk with us about access to genetic services (especially those in rural areas) and telemedicine. Sarah has heard from MN and KY but needs names of providers from the other five states. Please forward those names asap to Sarah and she will contact them.
- Group discussed inviting physician assistants as well in case they have more contact/better idea of access for families
- Sarah will contact AAFP (Frederick Chen, Chair of Genomics Subcommittee) for help in distributing announcement about the meeting to primary care providers
- Group discussed time on meeting and suggested 10:00am to 4:00pm so that people can fly in and out in one day.
- Group discussed agenda topics and goals for the meeting such as:
 - Hearing from primary care providers about the process of identifying children with metabolic conditions and how they interact with genetic centers, what works and doesn't work. Also, same questions about children with complex diagnoses and known diagnoses.

- Has there been a difference because of the fewer number of genetic counselors who feel comfortable doing a metabolic diagnosis—has there been a difference in getting this service? Do they have concerns about the future of this service?
- What do the primary care physicians perceive as the role of the geneticists and counselors in their practice?
- Need a clear agenda and clear goals. Goals include deciding what we want out of this meeting, identifying three major concerns to approach and where is our group going? Starting with what is the charge from this grant by brainstorming/having a conversation with this grant narrative then in the afternoon discussing our goals and plans and a time frame
- We will also be studying the access survey's results and looking at past studies that can inform us about questions that we need to ask, WI survey will be a good place to start looking at questions to ask PCPs.
- The workgroup feels that this needs to be a facilitated discussion with PCP run by a moderator
- Sarah will draft an agenda in partnership with the Region 4 staff and email it to workgroup before the next workgroup meeting on April 3rd. It will be discussed at the April 3rd meeting and a packet will then be sent to all participants for the May 1st meeting.
- Meeting location and time will be announced soon.

NEXT MEETING IS FRIDAY, APRIL 3rd 11:00-1:30 CENTRAL, 12:00 – 1:30 EASTERN

Notes by Sarah Wedepohl