

# MEETING NOTES

## Region 4 Genetics Collaborative Transition Workgroup

June 14, 2010

**Meeting documents** – Meeting Agenda, Inherited Illness Transition Resources, Transition Workgroup Materials Table, Meeting Notes 5-10-10

**Attendees:** Kathy Bachmann (OH), Bob Cook (IL), David Entwistle (OH), Holly Elliot (IN), Claudia Nash (IL), Beth Carne (MI), Ceci Shapland (MN), Michelle Kempf-Weibel (WI), Kara Van Vooren (WI), Sondra Gilbert (KY), Anne Weaver (KY), Abby Shannon (Region 4), Sarah Wedepohl (Region 4)

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### Overview of the National Transition Workgroup Meeting (Sarah)

Sarah gave an overview of the national transition workgroup May call. NYMAC Region is doing a competency in transition for physicians training to raise awareness. This will be a team of a professional and parent. The PowerPoint will be posted and Sarah will send the link when it is available. Region 5 (west coast) is doing a "Tickets to Adult Healthcare Independence" project with a movie theme that uses "tickets"/information sheets. These tickets will be handed out to young adults through pediatricians to bring to adult healthcare providers. Northeastern region has developed a guide for young adults transitioning that Sarah will forward to everyone after this call.

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### Region 4 Website and Results of Transition Survey (Abby)

- Abby went over the Region 4 website [www.region4genetics.org](http://www.region4genetics.org) including the home page and how the transition resources that were highlighted and reviewed by our workgroup can fit into the website so they are easily accessible and useable to families. Our meeting materials are also available on the website under our transition page. The group decided it's best to put the materials in the family resources page so families can better access the links and information.
- Abby went over the results of the survey she sent out to workgroup members to prioritize transition issues in order of importance. The top four issues were: Healthcare/Insurance; Moving from Pediatric Medical Home to an Adult Medical Home; Treatment Adherence; and Achieving Self-Support. This will help us guide the development of the website and posting of the resources. If you have more resources in those areas please send them to Abby. Abby will be posting resources on a regular basis until they are all posted.

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### Thoughts about Transition/David Entwistle Document on Transition (David and all)

- The workgroup made positive comments about the document and its context of transition throughout life's stages. David suggested writing a paragraph about each of the issues (described above) to go on the website when we are listing resources. Group members can volunteer to write paragraphs. The group discussed that the reading level for our publications should be kept between 5<sup>th</sup> and 6<sup>th</sup> grade.
- The group talked about the social-emotional issues involved in transition and how David's document touches on that issue. Instead of focusing on the "business" part of transition instead of the "social-emotional/intangible" part of transition. It's an area that is harder to capture but makes a big difference. The group mentioned "resilience" of a young person and parents not being over protective, giving their children chores/responsibilities. The group talked about helping parents to learn more about the mental health needs of transitioning kids and issues facing parents, including fear that something will happen with more responsibility/freedom. Group members spoke about their experiences with the social-emotional aspects of transition and forwarded Sarah websites that she in turn forwarded to the workgroup during the call.

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### Next Steps:

- Sarah will forward the links and information described above to the workgroup after the call.

*Notes by Sarah Wedepohl*