

Potential Young Adults Discussion Groups Information

The Region 4 Genetics Collaborative Transition Workgroup is seeking groups of young adults to talk with us about transition issues. We hope to meet with a few different groups and ask a variety of questions around young adults' opinions about transitioning, including their experiences, hopes, fears and other thoughts. We are looking for groups of youth already in existence who we can visit and engage in a guided discussion in a comfortable environment. If you know of any groups of youth who might be able to meet with us, please complete the table below, then resave the document and email it to Sarah Wedepohl, Region 4 Parent Coordinator at swedepohl@me.com. We will then contact you and discuss details and feasibility, and answer any questions you might have. Please complete one line for each group of which you are aware. For more information about Region 4 Genetics Collaborative, visit www.region4genetics.org.

What is the group's name?	What is the purpose of the group?	What is the age range of group Members?	How many youth are in the group?	Where does the group meet? (City/State)	What organization sponsors/hosts the group?	How often does the group meet?	When is the next scheduled meeting date?
PKU Organization of Illinois							
Sickle Cell Disease Association of Illinois							
Chicago Center for Jewish Genetic Disorders							
KASA Kids as Self Advocates Website: www.fvkasa.org	For youth and young adults with special health care needs	Not sure, but think teens into the 20s	This is a national group		It is the youth arm of Family Voices, Inc.		This group would have access to state KASA groups. I think they are an important resource.

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Additional Question:

Will it be possible to conduct a discussion group around transition issues during your regularly scheduled group session, or will we have to schedule another, separate group discussion to cover our questions?

Is there anything else that would be helpful for us to know about the group?

NOTE:

- I can respond to 2. In Illinois we have the PKU Organization of Illinois, the Sickle Cell Disease Association of IL, and the Chicago Center for Jewish Genetic Disorders, all of which engage youth and have numerous social events planned. Another means may be to contact all of the various pediatric subspecialists (hematology, cystic fibrosis, endocrinology, genetics) and have them solicit input from the youth they have as patients. Also CSHCN programs can assist with a survey. Could have a facebook site and publicize that through these channels... (Claudia Nash, IL)
- For CSHCS in Michigan we may be able to ask permission to do a mailing to a group of youth on the program based on their diagnosis. We have done this in the past, but we'd need permission from our Director/possibly IRB approval. Last time we did something like this we mailed out a survey to youth on our program with diabetes and they were able to complete the survey on paper. We put it on-line using survey monkey and they could complete it that way. We had good results because we offered a raffle for those who responded to win an ipod. I think the ipod raffle made the difference for the response rate! So I would definitely suggest we do some sort of incentive. That is a way to get some feedback on-line. After the holidays the CSHCS program is going to be hiring a Youth Consultant (someone on the program) to help us create a social networking presence for issues such as this. We are hoping to get a facebook page or something similar and send out notification to young adults on our program about this. We can look at using this when something is up and running. (Gina Gembel, MI)
- I would think the best way is to reach out the genetics clinics themselves. Transition is a very hot topic in many medical settings, therefore I would imagine that collaborating with genetics clinics/medical professionals to spread the word to patients and families about future programs would be well received and helpful.
- I am recommending a national group. Not sure if someone has mentioned them yet. Also, I would suggest speaking with Ann Wall at the newly funded National Transition Health Center-Got Transition! Her contact info is: Ann.Walls@crotchedmountain.org please tell her I told you to contact her. I am on their advisory board and we are meeting in person in Feb. in DC. I am sure they would be interested in the work of this group and we could collaborate with them if you are interested. Thanks, Ceci

Sondra – commission

Gina - hired a youth consultant for the state of MI – looking for a wide range of groups