

Region 4 Family News



Region4
Genetics Collaborative

NEW GUIDE FOR PROVIDERS ABOUT HEARING LOSS

NEW INFORMATION...

The Family Voices Board of Directors is seeking individuals to serve on the national Board of Directors. Applications are due on December 17th. For more information and to apply go to geneticalliance.org/sites/default/files/ksc_assets/pdfs/FV_Board_Applicationrev2010.pdf

The *New York Times* published "Putting Patients at the Center of the Medical Home" which explores patient-centered medical homes. bit.ly/djUiol

UPCOMING WORKGROUP DATES

For meeting dates click on your workgroup name at this page: region4genetics.org/region4/region4_home.aspx

WE NEED YOUR UPDATED CONTACT INFORMATION!

If you have not entered your contact information or need to update it, please go to region4genetics.org/region4/members/search.aspx then click on "Add my contact information." Keep in mind that your new information will not appear immediately, it needs to be released first. Thank you!

Region 4 Genetics Collaborative Early Hearing Detection and Intervention (EHDI) Workgroup recently published "Increasing Genetic Referrals for Children Identified Through EHDI: An Action Guide for Providers Serving Children Who Have Hearing Loss".

Region 4 Genetics Collaborative strives to improve outcomes for children who have genetic conditions. Research has shown that more than 50% of hearing loss in infants is genetically related. Of those, about one-third are affected with a complex medical syndrome.

In response, the Early Hearing Detection and Intervention (EHDI) Follow-up Workgroup was established and charged with improving access to genetic services for families whose children have been diagnosed with hearing loss through Universal Newborn Hearing Screening (UNHS).

The workgroup engaged in a series of activities to: learn how state EHDI and genetics programs interact; examine the EHDI follow-up system to identify encounters with families that provide opportunities for offering a genetic referral; and explore materials for educating parents and professionals about the importance of obtaining a genetic assessment for children who are diagnosed with hearing loss.

The workgroup developed this guide to help providers increase genetic referrals for children with hearing loss. The guide also includes tools to facilitate appropriate referrals to genetic services.

To access the guide please go to www.region4genetics.org/region4_products/follow_up.aspx

WikiGenetics

Are you familiar with Wikipedia, the free encyclopedia? WikiGenetics provides information on human genetics. It is a web-based encyclopedia on human genetics for the public. Categories include basic science, understanding the human genome, understanding health and disease, and genetic services. Readers can view and edit pages. The site has an advisory and editorial board and was created by Genetic Alliance in 2007.

For more information go to wikigenetics.org

Meet One of Our Region 4 Families

David is a professor of psychology at Malone University in Ohio. He and his wife, Debbie, have been married for 27 years, and have three children who are 20, 17 and 14 years old. His oldest daughter has cystic fibrosis, and their experiences have spurred his interest in transition to adulthood, which has become a focus of some of his research. David is a co-lead for the Region 4 Genetics Transition Workgroup, which formed last winter.

Prior to taking a job in academia, I worked as a clinical psychologist providing psychotherapy. My work often involved chronic mental illness, and sometimes brought me into contact with people who dealt with chronic physical illness. My father was a medical doctor, so I was often intrigued with the difficulties of coping with physical infirmity. These issues became personal for us when our oldest daughter was diagnosed with cystic fibrosis (CF) as an infant, and we began to face the transitions involved in raising a child with a chronic medical condition.

When parents learn that their child will likely have a shortened life expectancy, the fear of losing the child can translate into over-protection on one extreme or abandonment on another. The CF specialists that we have seen over the last twenty years have encouraged us to avoid the extremes, to raise our daughter to live with CF and to keep life as normal as possible. Every child needs love and limits; and that does not change just because a chronic illness enters the mix.

Several years after leaving clinical practice for academia, I decided to focus some of my research on chronic illness and transition issues. About five years ago, a doctor at our CF clinic asked me to look over a survey he was creating. I helped him revise the survey so that its items were clearer and its measurement scales would provide meaningful data. That initial project led to several other projects that

we have collaborated on, mostly focusing on coping and adjustment issues. Our research has mostly been with adolescents. We are currently looking at how adolescents with CF make decisions about what to do after high school. Having a chronic illness like CF can affect this transition in many ways. Someone may be too ill to go to college or get a job, or they may have extended absences from work or school due to periodic exacerbations of their symptoms. People with chronic illnesses also need to be especially careful about making sure that they have time to do their medical treatments; that they get adequate rest; and a host of other issues, all while trying to have a life that is as “normal” as possible.

We are currently interviewing young adults with CF about their post high school experiences. Although we are still in the early stages of the study, one theme that seems to be emerging is the importance of being willing to seek out and use accommodations that are available, whether in academic or work settings. College students with chronic illnesses can often receive academic accommodations due to their illness, but only if they have filed the correct paperwork with the disability support services office of their colleges. It is also important to know how to defend your rights legally if a school or workplace fails to provide adequate accommodations for a documented disability.

Another interesting finding from our research is that the ability to be successful in college or a post high school job often involves how well a person has been able to manage his or her own treatment and accept his or her illness. Treatment adherence is a very important issue. As people with chronic illness move from childhood towards adulthood, they need to become increasingly independent in their ability and willingness to do their own treatments and participate in their own medical care. Many young adults manage that transition very well, but there are also many who struggle with these issues.

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Knowing about many of these issues, we decided very early on to raise our daughter in a way that would allow her to develop as much independence and responsibility as was developmentally appropriate. As soon as she was old enough to open up a medicine bottle, it became her job to open the bottle, count the pills out and take them with our encouragement and supervision. By age 4 she was

handling some of her own medicine. We never held her back from living life as normally as possible. She competed in sports, played flute in the school band, went on trips with our church, and worked hard at school. She is now majoring in biology and chemistry, competing in collegiate swimming, and living a very successful life, albeit with the challenges of having a chronic illness.

RESOURCES FOR FAMILIES ON TRANSITION FROM REGION 4 TRANSITION WORKGROUP

Health Care Transitions

This website is produced by The Institute for Child Health Policy at the University of Florida and has a variety of print resources, videos and links to other resources for families.

<http://hctransitions.ichp.ufl.edu/hct-promo>

Transition to Adult Health Care: A Training Guide in Two Parts

University of Wisconsin-Madison, Waisman Center published this guide through the Wisconsin Healthy & Ready to Work project. Part one of the guide is a workshop for parents and part two is a workshop series for teens and young adults.

http://www.waisman.wisc.edu/hrtw/Adult_Teen.pdf

National Center for Medical Home Implementation

This website was developed and is maintained by the American Academy of Pediatrics. It has a number of resources including "Transition Tools" to assist in the process of transition from childhood to adulthood.

http://www.medicalhomeinfo.org/how/care_delivery/transitions.aspx

This website helps families build a medical care notebook for their child. The care notebook helps parents and caregivers maintain an ongoing record of their child's care, services, providers and notes.

http://www.medicalhomeinfo.org/tools/care_notebook.html

HRTW National Resource Center

Healthy & Ready to Work's website focuses on understanding systems, access to quality health care and increasing the involvement of youth. It includes provider preparation plus tools and resources needed to make more informed choices.

<http://www.hrtw.org/>

Highlighting... Family Resources

Illinois - Management of Sickle Cell Disease Annual Christmas Gift Giving Parents of children with sickle cell disease ages 0-12 years are invited to come and receive a Christmas gift. For additional information call 773-526-5016 or sicklecelldisease-illinois@scdai.org or visit their website at www.sicklecelldisease-illinois.org

Indiana - CYACC (Center for Youth and Adults with Conditions of Childhood) CYACC is a program through Riley Children's Hospital for youth ages 11-22 with special health care needs. The program helps prepare youth for their adult life. rileychildrenshospital.com/parents-and-patients/programs-and-services/cyacc/index.jsp

Kentucky - Lexington Family Magazine recently published an article about self-advocacy and the Kentucky Self-Advocates for Freedom Chapters throughout the state. www.lexingtonfamily.com/exceptional_family/2010/Ex%20Fam%202010%20.pdf

Michigan - MetroParent magazine's October issue outlines free or for a small fee, nine smart phone applications for children with special needs metroparent.com/Metro-Parent/September-2010/Special-Needs-iPhone-Apps/

Minnesota - Creating the Independent Living Plan Jan. 11, 2011 What is your son/daughter's vision for independent living? Come hear the person-centered planning process and begin to create your son/daughter's housing plan. To register and for more information contact PACER at 800-537-2237, PACER@PACER.org or www.PACER.org/workshops

Ohio - Youth Leadership Forum for Students with Disabilities (YLF) July 18 - 21, 2011 in Columbus. A four day leadership training program for 11th and 12th grade high school students with disabilities. There is no cost for students/participants to attend this forum. www.gcpd.ohio.gov/YLF/index.html

Wisconsin - Parent to Parent Wisconsin provides support, resources and training to Wisconsin parents. The Making Connections program provides parent support to parents of children with special needs through a one-to-one connection with another parent who has similar experiences. p2pwi.org

National - United Way 2-1-1 Program is currently available in 80% of the country. 2-1-1 helps people assess their needs and links them directly to the resources that will help. Whether a person is contemplating starting a small business, looking for volunteer opportunities in his/her community or seeking information on essential services, 2-1-1 is there to help.

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