OREGON FAMILY TO FAMILY HEALTH INFORMATION CENTER

News and Resources

February 2022

for Families of Children and Youth with Special Health Needs

Table Talks: Families sharing ideas and learning from each other

Oregon Family to Family Health Information Center hosts monthly Table Talks - small, informal discussions with family members of children with special health needs. It's not a support group or a focus group, but families report learning a lot from each other, and their feedback helps ORF2FHIC learn what matters to families.

You earn a \$20 gift card to thank you for sharing your time and expertise with other parents and caregivers like you. Each group has space for about 10 participants. We currently meet on Zoom. We plan to host some in-person meetings when it's safe to do so. Sign up by writing to contact@oregonfamilytofamily.org.

February: School Nursing, 504s, and Partnering with Schools

March: Service and Support Animals: Who, What, and How

April: Getting Ready for Summer: Programs, Camps, Childcare and Supports

ORF2FHIC helps families of children, youth, and young adults with special health needs navigate health care and other systems. This newsletter offers up-to-date, practical information and resources. <u>Contact us</u> to be added to the mailing list.

Visit our <u>Facebook page</u> and <u>website</u>. Get more information, talk to a <u>Parent Partner</u> or schedule a free training: <u>contact@oregonfamilytofamily.org</u>



Parent spotlight: Katherine

Q: What is the biggest myth about this life?

When my son was born with a disability, I mistakenly thought that we would receive all of the support we needed for both of us to live our best lives. I had no idea the battles that we would have to fight, the digging that we would have to do and the trials and tribulations that would add to an already incredibly stressful life. I don't know if it gets any easier, I just think we get better at dealing with it.

Q: What is your hope for the future?

Both of us hope that "disability" will become mainstream and that all people will be seen as equal and deserving of having a happy, fulfilling life where we are all supported by one another and that people with disabilities will have the same access, opportunities and accommodations as everyone else. We would love to see all families coming together to advocate for justice and equality in our community. We are all so tired and burnt out that adding another thing to the pile can be challenging.

Katherine Ball is the Family Support Director at UCP Oregon. See their list of classes and support groups here.



OCCYSHN Oregon Center for Children and Youth with Special Health Needs

www.oregonfamilytofamily.org

Internet discounts for eligible families



The Federal Communications Commission just launched the Affordable Connectivity Program. The program aims to help connect families and households struggling to afford internet service.

Those who qualify can receive a discount of up to \$30 per month for broadband service, or up to \$75 per month on Tribal lands. The program also offers a one-time discount of up to \$100 for a laptop, desktop computer or tablet purchased through a participating vendor. For that program, applicants will need to contribute between \$10-\$50 of the purchase price.

Eligibility includes people at or below 200 percent of the federal poverty level, participation in SNAP, TANF or other benefit programs, and those on Medicaid. The Affordable Connectivity Program is limited to one monthly service discount and one device discount per household

For more info visit <u>www.fcc.gov/ACP</u>.

New family-friendly blog from the AAP

The American Academy of Pediatrics started a new blog for parents and caregivers. *Family Connections* will take articles from the AAP's medical journal *Pediatrics* and repackage them in family-friendly language.

Families will write the blog posts and each will include information on how health professionals and caregivers can work together.

Recent topics include how to talk to teens with heart disease about endof-life care and teaching young children emergency life support.

Did you know, for example, that 92 percent of teens want their doctor to tell them if they are "sick and not going to get better," whereas only 46 percent of families wanted them to be told? That is the type of research *Family Connections* breaks down.

You can read this new blog by visiting the AAP pages <u>"Family</u> <u>Connections with Pediatrics"</u>.

Join the Community Partners Council

Your experience is valuable! The University Centers for Excellence in Developmental Disabilities (UCEDD) at Oregon Health & Science University is looking for advisory group members Make a difference and partner with your peers and colleagues. Enhance the health and quality of life of Oregonians with disabilities and their families. <u>More info</u> and application here.

The Oregon Family to Family Health Information Center is affiliated with the Oregon Center for Children and Youth with Special Health Needs, Oregon Health & Science University, and supported by the Health Resources and Services Administration (HRSA) of the US Department of Health and Human Services (HHS). (Grant #H84MC21658/Family Professional Partnership/\$95,700). This information, content and conclusions are those of the author(s) and should not be construed as the official position or policy of, nor should any endorsements be inferred by, HRSA, HHS, the US Government, or OHSU.

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