

News and Resources

August 2021

for Families of Children and Youth with Special Health Needs

The OR F2F HIC helps families of children, youth, and young adults with special health needs navigate health care and other systems. This newsletter highlights up-to-date, practical information and resources for families and is published a few times per year. [Contact us](#) to be added to the mailing list.

Let us help find resources, no matter the condition

Sometimes, you just need to talk to someone who “gets it.” Oregon Family to Family Health Information Center has connections across the state and nation and we’re here to help you find the support you seek.

There are dozens of parent-led organizations in Oregon. Some are chapters of national organizations, such as the [Autism Society of Oregon](#). There are also government-funded family programs where you can get support by phone, and there are groups that meet only through Facebook or on Zoom. Check out this [list](#) of many of these Oregon family organizations.

For families whose children experience specific or rare conditions, another excellent resource is our [Birth Anomalies Resources](#) page, which has detailed information and resources for over thirty specific conditions. These conditions can feel isolating, but you are never alone. Call us at 855-323-6744 to get connected.

Visit our [Facebook](#) page and [website](#).

[Speak with a Parent Partner:](#)

For more information, to schedule a free training, or to be added to our mailing list: contact@oregonfamilytofamily.org

Family organization spotlight:



[Northwest Kidney Kids](#) is celebrating its 15th year connecting families of children with kidney disease to resources and each other.

“There’s not a lot of regional (kidney) organizations, so we’re pretty unique that we have that out here,” said Executive Director Jill Brown, who has a “kidney kid” herself.

Northwest Kidney Kids was started in 2006 by a team of parents, doctors, and social workers. It offers blood pressure monitors and test strips to newly diagnosed families. It also offers summer camps, one of which serves about 45 families of children with end-stage renal disease (ESRD). Because children with kidney disease are particularly at risk during the pandemic, those gatherings have been on hold. But on the bright side, NWKK started some new programs, including the Young Ambassador program, for those 18 and up, and a new peer mentoring program that meet virtually. For more information, visit nwkidneykids.org

New study focuses on Oregon youth with complex medical conditions and their changing health care needs

The Journal of Pediatric Nursing [published a study](#) last month detailing how Oregon families get caught in the limbo between pediatric and adult care.

Parent interviews, conducted by the [Oregon Center for Children and Youth with Special Health Needs](#) showed that Oregon families were not prepared for the change from pediatric to adult health care.

“Families described having little to no notice about transitioning out of pediatric care and reported that their providers did not communicate with them about the steps needed to ensure a continuation of care into adulthood,” reads a summary of the study. This lack of communication and planning meant families struggled to find doctors, therapists, and other health providers for their young adults. That led to worse health

and other poor outcomes for both youth and families. The researchers urge better supports so that families know what to expect in the process of transferring to adult health care.

OR F2F HIC has [many resources](#) to help families navigate this difficult transition. We also offer free workshops and one-to-one coaching. For more information: contact@oregonfamilytofamily.org or 855-323-6744.

Make sure to get your child tax credit!

The federal government began sending out checks last month to eligible families. The IRS is paying half the total credit amount in advance monthly payments beginning July 15. You will claim the other half when you file your 2021 income tax return. Most families will receive the payments automatically. But some will need to take action, particularly those who did not file a tax return last year. If you did not file a tax return last year, you can sign up at this [IRS webpage](#). Check out <https://www.whitehouse.gov/child-tax-credit/> for more information.



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