OREGON FAMILY TO FAMILY HEALTH INFORMATION CENTER

You are not alone. The organizations on this list are led by families, for families, and they welcome your call. This is a partial list. For help finding support organizations in other states and countries, or to connect with families whose children experience rare conditions, call 855-323-6744 or email contact@oregonfamilytofamily.org

Oregon Family to Family Health Information Center - 855-323-6744 (English) 503-931-8930 (Spanish) www.oregonfamilytofamily.org Coaching and support to navigate health systems and other state, federal, and community services. Offers training, toll-free phone line, website, toolkits, and other publications by families, for families..

Autism Society of Oregon - www.autismsocietyoregon.org - 1-888-288-4761

Autism-specific resources and information, "Take a Break" funding, support and guidance. Resource directory of autism-related services and supports. Calendar of trainings and support groups for all types of disability.

Epilepsy Foundation - https://epilepsyoregon.org/support-groups/ - 503-205-1404

Offers parent support group every month via Zoom. For Zoom link and to be added to our parent list please contact oregon@efa.org.

FACT (Families and Communities Together) - www.factoregon.org - 1-503-786-6020

Oregon's Parent Training & Information Center. Supporting families navigating disability, special education, and whole life planning through a support line, trainings and community building. Empowering Families.

Hands and Voices of Oregon - www.handsandvoicesor.org 541-241-6048

Support and information for all Oregon families raising children who are Deaf or Hard of Hearing. All communication methods and technologies are supported.

NAMI Oregon Online Support Groups: www.namior.org

Peer-led support groups for parents, adults, and family members of children and adolescents with mental health and behavior issues.

Northwest Kidney Kids - www.nwkidneykids.org (503) 893-5671

Support and education for children/young adults with chronic kidney disease and their families. Camps, family/sibling support, clinical Support, Young Ambassadors, and mentoring for ESRD, dialysis, and transplant.

Northwest PANDAS/PANS Network - www.nwppn.org 971-645-0842

Northwest nonprofit serving OR, WA and ID. Offers support to families diagnosed with, or suspecting, post-infectious neuroinflammatory disorders (PANDAS/PANS). Referral services to knowledgeable PANDAS/PANS providers and parent/caregiver support groups.

Oregon Deafblind Project - https://www.crisoregon.org/site/Default.aspx?PageID=536 Provides technical assistance, training and information to enhance services for children in Oregon who are DeafBlind. The Oregon DeafBlind Project supports families, school teams, and individuals who are DeafBlind to access high quality, evidenced based supports and services birth through age 21. Housed at Columbia Regional Inclusive Services, the Oregon DeafBlind Project serves all of Oregon. https://www.facebook.com/groups/oregondb

Oregon Family Support Network - www.ofsn.org - 503-363-8068

Supports families raising a child/youth experiencing complex emotional, behavioral and/or mental health needs. Trainings, workshops, and advocacy throughout Oregon by certified Family Support Specialists (peers).

Reach Out Oregon - www.reachoutoregon.org 833-732-2367

Warmline, live chat, or <u>email</u> support for parents of youth with emotional, behavioral or mental health needs. ROO can connect families to regional support groups; call for locations

Swindells Resource Center - http://oregon.providence.org/our-services/s/swindells-resource-center/

541-732-5958 (Spanish) 503-215-2429 (English)

Books, resources, free care notebooks for families, telephone support, statewide trainings on topics related to pediatric special needs, parenting classes, and much more.

Tourette Association of Oregon - https://tinyurl.com/ehuj6ewt ts.salemor@gmail.com

Support for families raising children who experience Tourette Syndrome and co-occurring conditions. Educational materials, new patient/family/teen materials, teacher/provider materials, family-to-family connections and more.

United Cerebral Palsy - http://www.ucpaorwa.org/our-services/family-support - 503-777-4166 x332 Serves families whose children experience disabilities that mimic Cerebral Palsy as well as those with the diagnosis of CP. Conferences, trainings, parent support, "Respitality" program, and more.

Oregon Family Networks

Sometimes it can be hard to see past tomorrow. Oregon Family Networks help families do just that: to help them map out a life for their children and themselves, full of meaningful relationships and experiences, and to connect them with resources that can help. Oregon Family Networks are supported by the Oregon Council on Developmental Disabilities.

Multnomah, Washington Counties

FACT Oregon

Phone: 503-786-6082 or 888-988-3228

Website: <u>www.factoregon.org</u>

Yamhill, Polk, Marion Counties

Creating Opportunities

Phone: 503-559-0424

Website: www.creatingops.org

Lane and Douglas Counties

Families Connected

Phone: 541-343-5256
Website: https://arclane.org/

Crook, Deschutes, Grant, Harney, Jefferson, Klamath, Lake, Wheeler Counties

Central Oregon Disability Support Network

Phone: 541-548-8559

Website: http://www.codsn.org/

Clatsop, Tillamook, Lincoln Counties

Oregon COAAST Network

Phone: 503-739-2240

Website: <u>www.sammysplace.info</u>

Jackson and Josephine Counties

Bridging Communities

Phone: 541-690-8542

Website: https://livingopps.org/bridging-communities

Community (in-person or virtual) support groups

(This is a partial list, kept current to the best of our ability. For additions or changes, email contact@oregonfamilytofamily.org

Rogue Valley

CARE (Compassion Answers Rest Encouragement)

Meets at Jacksonville Presbyterian Church

Website: https://jvillepres.churchcenter.com/groups/small-groups/c-a-r-e

Contact: rachelolstad@gmail.com

Portland Metro

NAMI Multnomah (*Free*, *online peer support group for parents & caregivers of children with mental health barriers.*) Meets 1st & 3rd Wednesdays, 4:00 - 5:15 PM

To register, call 503-228-5692 or email info@namimultnomah.org

Autism Family Support Group

Autism Society of Oregon (For families of children/youth aged birth – 22.)

Meets 3rd Wednesdays during school year, 6:00 - 7:00 pm

To register: https://us02web.zoom.us/meeting/register/tZEvfu-hpzsiHNU1sBEFsbN3XyRBdGVYGLNC

Talk it Over Support Group

NAMI Oregon For parents/caregivers with school-age children and young adults living with behavioral health challenges)

Meets 2nd Sundays, 4:00 - 6:00 pm

To register: https://zoom.us/meeting/register/uJUrcOGvpjkicxpCt2YAHaBOLSHYAxA_Ow

Grandparent Support Group

Oregon Kinship Navigator For grandparents raising grandchildren.

Meets 1st Tuesdays 10-11 am OR 3rd Tuesdays 7 - 8 pm

Online: meet.google.com/swz-uorx-jkj or call in: +1 314-666-1828 PIN 291 586 204#

Keep for Kin Support Group

Oregon Kinship Navigator: For grandparents, aunts, uncles, siblings, and others caring for related youth who are not actively involved with Oregon DHS. Call to find out if you are eligible.

www.keepfostering.org/keep-for-kin or call 541-780-3808

The Oregon Family to Family Health Information Center is affiliated with the Oregon Center for Children and Youth with Special Health Needs (OCCYSHN), Oregon Health & Science University (OHSU), 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 OHSU, OCCYSHN, HRSA, HHS, the US Government, or OHSU.