

Birth Anomalies

Support and Information for Families

Fetal Diagnosis

Fetal Health Foundation
fetalhealthfoundation.org/

Brain or Spinal Cord Conditions

Carter Centers for Brain Research
Holoprosencephaly and related disorders
hperesearch.org/support.html

Foundation for Children with Microcephaly
childrenwithmicro.org

Spina Bifida Association
spinabifidaassociation.org

Digestive System Conditions

Pull Through Network Anorectal
Anomalies
pullthrough.org

United Ostomy Association of America
ostomy.org

Children's Liver Association for Support
Services (CLASS)
classkids.org

Liver Families
liverfamilies.net

Esophageal Atresia and
Tracheoesophageal Fistula (EA-TEF)
eatef.org

Bone or Limb Conditions

Clubfoot Club
Clubfootclub.org

Lucky Fin Project: Hand and/or
Arm differences
luckyfinproject.org

Helping Hands Foundation: Upper Limb
Loss
helpinghandsgroup.org

Children's Craniofacial Association
ccakids.org

Muscle Conditions

Congenital Diaphragmatic Hernia
International
cherubs-cdhi.org

Breath of Hope, Inc.: Congenital
Diaphragmatic Hernia
breathofhopeinc.com

Avery's Angels: Gastroschisis
averysangles.org

Mothers of Omphaloceles
omphalocele.net

OREGON FAMILY TO FAMILY
HEALTH INFORMATION CENTER
oregonfamilytofamily.org

Oregon
Health
Authority

Reproductive or Urinary Conditions

Association for the Bladder Exstrophy Community
bladderexstrophy.com

Courage to Shine Foundation Support: Bladder Exstrophy
couragetoshine.org

Hypospadias and Epispadias Association
heainfo.org

Conditions of the Mouth or Face

Children's Choanal Atresia Foundation
babynose.org

American Cleft Palate-Craniofacial Association
acpa-cpf.org/acpa-family-services/

Children's Craniofacial Association
ccakids.org/family-networking

Chromosomal Conditions

Chromosome Disorder Outreach
chromodisorder.org

Chromosome 22 Central: Chromosome 22 deletion
c22c.org

22q: Chromosome 22 deletion
22q.org

Turner's Syndrome Society
turnersyndrome.org

Eye Conditions

Wonderbaby: Microphthalmia, Anophthalmia Parent Support
wonderbaby.org/maps

Childhood Cataracts Network
childhoodcataracts.org.uk

Pediatric Glaucoma and Cataract Family Association
pgcfa.org

Heart Conditions

American Heart Association (AHA)
supportnetwork.heart.org/about-heart-defects

American Heart Association (AHA)
Supportnetwork.heart.org/connect-with-someone-like-me/

Mended Hearts
mendedhearts.org

Little Hearts - membership
Littlehearts.org/become-a-member

Ear Conditions

Ear Community: Microtia, Atresia, and Hearing Loss
earcommunity.org

Hands and Voices: Hearing Loss and Deafness
handsandvoices.org

Alexander Graham Bell Association: Hearing Loss and Deafness.
agbell.org

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