

REFERRAL TO SUPPORT AND PARTNERING WITH FAMILY-LED ORGANIZATIONS: A REFERENCE GUIDE

The National Genetics Education and Family Support Center (Genetics Education & Family Support Center) is a companion project to the Regional Genetics Networks (RGNs). RGNs link medically underserved populations to quality genetic services and provide resources to genetic service providers, Primary Care Physicians, public health officials, and families. In many cases though, linking isn't enough. Individuals and families need direct support and assistance.

The Genetics Education & Family Support Center works to:

1. Assist the RGNs in their efforts to develop meaningful partnerships with families and family-led organizations and reach medically underserved and diverse families.
2. Provide emotional, informational, and navigational support for individuals and families who have, or are at-risk of having a genetic condition;
3. Provide education and resources on genetic conditions;
4. Link individuals and families to services and supports, especially those families in underserved areas
5. Help families develop skills to partner with professionals and improve systems of care

The following family-led organizations can help families navigate the system of care system and connect families to the information, resource, and support services they may need. In addition, family-led organizations can partner with RGNs and other families to help build capacity for family leadership and engagement to improve genetic educational materials, services, and programs.

OVERVIEW OF FAMILY-LED ORGANIZATIONS

The four national, family-led organizations described below have chapters in each state. In many states, one or more of these projects are co-located. In other states, the projects are located in different places. Each project has a specific area of expertise: health care, emotional support, mental health supports and services, and special education laws. The family members who staff the state projects are parents/guardians of children and youth with special health care needs (CYSHCN); some are siblings to CYSHCN. They understand families' concerns about their children and will connect them with the organization that can best advise them. Staff at these organizations come from diverse backgrounds, so they are able to connect with families of like backgrounds in their own native languages. In other instances, staff can connect families from diverse backgrounds to cultural brokers.

In many states, the families who staff each of these projects work at the same agency. As a result, they connect families with each other's programs so they get all needed information and support. Even if they are located in different agencies, they routinely refer families to the organization that has the expertise to help resolve a family's issues.

[FAMILY VOICES \(FV\)](#)

FV is a national, family-led organization that works to keep families at the center of children’s health care. Its [National Center for Family/Professional Partnership](#) (NCFPP) provides training and technical assistance to family leaders and professional partners. This training includes skill-building workshops to help families increase skills and build confidence to work with professionals to improve systems of care. FV has developed a national network of family-led State Affiliate Organizations (SAOs) and Family-to-Family Health Information Centers (F2Fs) in every state and the District of Columbia (DC). SAOs are statewide, family-led, non-profit organizations that work to advance the mission, vision and principles of Family Voices, Inc. Often, the SAO and the F2F are co-located. F2Fs, funded by the federal Maternal and Child Health Bureau, provide free, confidential support and training to families of CYSHCN and their professional partners. Both SAOs and F2Fs¹ help families navigate health care and community supports; partner with health providers; and build leadership skills.

Use this link to identify the [SAO/F2F in your state](#) at _____
(or see the list of SAOs/F2Fs in your region on the last page) if your family needs help:

- Finding services for your CYSHCN and family
- Understanding eligibility for Title V, Medicaid, or other state agency services
- Understanding private health insurance
- Communicating with doctors
- Understanding your child’s medical condition
- Connecting to a disability-specific support organization or group
- Finding support for yourself
- Building leadership skills and partnering with professionals to improve systems of care
- Finding culturally and linguistically appropriate services

[PARENT TO PARENT USA \(P2P USA\)](#)

P2P USA is a national organization committed to assuring access and quality in parent to parent support for families who have children of any age (pre-birth through aging), who have a special health care need, including a genetic condition. P2P USA provides technical assistance and support to state programs by encouraging use of evidence-based and best practices, including the capacity to “match” families with diverse experiences, ethnicity, culture, race, language, socio-economic, disability and other child/family related life experiences.

Use this link to identify the [P2P program in your state](#) at _____
(or see the list of the P2P programs in your region on the last page) if your family:

- Needs emotional and/or informational support
- Wants to talk to someone who has similar life experiences and shares an understanding of a specific diagnosis, topic, and/or challenge

¹ Note, SAOs and F2Fs are often part of larger non-profit organizations, Department of Public Health Title V programs, or universities. Therefore, the names of each SAO and/or F2F vary, depending on the vendor organization.

- Is stressed, facing barriers or challenges, and wants to talk to someone who understands your life
- Is ready to share your own family circumstances, leadership skills, positive attitude, etc and wants to support other parents

IF THERE IS NO P2P PROGRAM IN YOUR STATE, CONTACT ANY NEIGHBORING STATEWIDE P2P PROGRAM OR P2P USA.

[NATIONAL FEDERATION OF FAMILIES FOR CHILDREN'S MENTAL HEALTH \(NFFCMH\)](#)

The NFFCMH is a national, family-run organization that works to ensure children and youth with emotional, behavioral, and mental health needs and their families can get the supports they need. The NFFCMH provides leadership and technical assistance to state affiliates.

Use this link to identify the [NFFCMH affiliate in your state](#) at _____
(or see the list of NFFCMH programs in your region on the last page) if your family:

- Is worried about a child's emotional health and behaviors
- Needs help identifying a mental health provider
- Is experiencing mental health stress and needs support

[THE CENTER FOR PARENT INFORMATION AND RESOURCES](#)

The Center for Parent Information and Resources is a central hub with information about Parent Training and Information Centers (PTIs) and Community Parent Resource Centers (CPRCs)

PTIs, funded through the federal Individuals with Disabilities Education Act (IDEA) help families understand special education services for CYSHCN to age 22.

CPRCs help families who need additional language supports.

Use this link to identify the [PTI and/or CPRC](#) in your state at _____
(or see the list of PTIs/CPRCs in your region on the last page) if your family needs help:

- Understanding educational issues related to a genetic diagnosis
- Understanding a child's rights to special education services
- Communicating with teachers, nurses, and other school staff
- Working with school staff to create an Individualized Educational Plan (IEP) for a child
- Finding support groups, educational specialists, legal assistance and other resources

FAMILY-LED ORGANIZATIONS: MOUNTAIN STATES

	F2F/SAO	P2P	FFCMH	PTI/CPRC
Arizona	Raising Special Kids 602- 242-4366 or 800-237-3007 http://www.raisingpecialkids.org/	Raising Special Kids 602- 242-4366 or 800-237-3007 http://www.raisingpecialkids.org/	Family Involvement Center 602-412-4095 http://www.familyinvolvementcenter.org/ (Link works, but must copy and paste into your browser)	Raising Special Kids 602- 242-4366 or 800-237-3007 http://www.raisingpecialkids.org/
Colorado	Family Voices Colorado 303-733-3000 or 800-881-8272 https://familyvoicesco.org/	Ability Connection Colorado 303.691.9339 Hispano 877-472-7201 http://www.abilityconnectioncolorado.org/p2p-co/	Colorado FFCMH 888-429-3369 http://www.coloradofederation.org/	PEAK Parent Center 719-531-9400 or 800-284-0251 719-531-9403 (TTY) www.peakparent.org
Montana	Parents, Let's Unite for Kids (PLUK) 800-222-7585 or 406-255-0540 http://www.pluk.org/	Parents, Let's Unite for Kids (PLUK) 800-222-7585 or 406-255-0540 http://www.pluk.org/	Family Support Network (406) 256-7783 http://mtfamilysupport.org	Parents, Let's Unite for Kids (PLUK) 800-222-7585 or 406-255-0540 http://www.pluk.org/
New Mexico	Parent Reaching Out 505-247-0192 or 800- 524-5176 http://parentsreachingout.org/ http://parentsreachingout.org/es/	Parent Reaching Out 505-247-0192 or 800- 524-5176 http://parentsreachingout.org/ http://parentsreachingout.org/es/		Parent Reaching Out 505-247-0192 or 800- 524-5176 http://parentsreachingout.org/education/ http://parentsreachingout.org/es/sped/
Nevada	Family TIES of Nevada 775-823-9500 or 866-326-8437 https://www.facebook.com/familytiesnv/	Family TIES of Nevada 775-823-9500 or 866-326-8437 https://www.facebook.com/familytiesnv/	Nevada PEP, Inc. 702-388-8899 http://www.nvpep.org/	Nevada PEP, Inc. 702-388-8899 or 800-216-5188 http://www.nvpep.org/
Texas	Texas Parent-to-Parent 512-458-8600 or 866-896-6001	Texas Parent-to-Parent 512-458-8600 or 866-896-6001 https://www.txp2p.org/services/talk-to-another-	Texas FFCMH 512-944-9972 E-mail ffcmhtexas@gmail.com	There are 3 PTIs in Texas. Identify the PTI for your region TX at http://prntexas.org/about-prn/find-your-pti/ PATH Project

	https://www.txp2p.org/services/family-to-family-health-info	parent/peer-parent-mentor-program		409-898-4684 or 800-866-4726 http://prntexas.org/texas-ptis/path-project/ PEN Project 915-259-8717 833-847-2686 http://prntexas.org/texas-ptis/pen-project/ TEAM Project 281-969-5944 877-832-8945 http://prntexas.org/texas-ptis/team-project-2/
Utah	Utah Parent Center 801.272.1051 or 800.468.1160 http://www.utahparentcenter.org/projects/ufv/	Contact a neighboring state	Allies with Families 801-433-2595 or 877-477-0764 www.allieswithfamilies.org	Utah Parent Center 801.272.1051 or 800.468.1160 http://www.utahparentcenter.org/projects/pti/ info@utahparentcenter.org
Wyoming	SAO: UPLIFT 800-492-3199 www.upliftwy.org F2F: Wyoming Institute for Disabilities (WIND) 307-766-2761 or 888-989-9463 http://www.uwyo.edu/wind/f2f/	Contact a neighboring state	UPLIFT 800-492-3199 www.upliftwy.org	Parent Information Center 800-660-9742 307-684-2277 www.wpic.org