

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

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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 National 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

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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.

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

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FV is a national, family-led organization that works to keep families at the center of children’s health care. Its [Leadership in Family Professional Partnerships](#) (LFPP) project 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 Family Voices Affiliate Organizations (FVAOs) and Family-to-Family Health Information Centers (F2Fs) in every state, the District of Columbia (DC), 5 territories and 3 tribal nations. FVAOs are statewide, family-led, non-profit organizations that work to advance the mission, vision and principles of Family Voices, Inc. Often, the FVAO 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 FVAOs and F2Fs<sup>1</sup> help families navigate health care and community supports; partner with health providers; and build leadership skills.

Use this link to identify the [FVAO/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

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

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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

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<sup>1</sup> Note, FVAOs and F2Fs are often part of larger non-profit organizations, Department of Public Health Title V programs, or universities. Therefore, the names of each FVAO 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.

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

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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

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

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The Center for Parent Information and Resources (CPIR) is a central hub with information about Parent Training and Information Centers (PTIs) and Community Parent Resource Centers (CPRCs) and other information for families and professionals. The CPIR provides universal technical assistance to the network of PTIs and CPRCs.

PTIs and CPRCs, funded through the federal Individuals with Disabilities Education Act (IDEA), help families understand early intervention (EI), special education, and transition services for CYSHCN from birth to age 26. PTIs are often statewide, except in larger states where there may be more than one PTI, while CPRCs are community-based organizations serving particular geographic regions or targeted racial/ethnic/language populations.

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 your child’s rights to early intervention, special education, or transition services
- Communicating with EI providers; teachers, nurses, and other school staff; and agencies serving adults with disabilities
- Working with professionals to create an Individualized Family Support Plan (IFSP), Individualized Educational Plan (IEP) (including a transition plan) for your infant, child, or adolescent
- Finding support groups, educational specialists, legal assistance and other resources

## FAMILY-LED ORGANIZATIONS: MOUNTAIN STATES

	F2F/FVAO	P2P	FFCMH	PTI/CPRC
<b>Arizona</b>	Raising Special Kids 602- 242-4366 or 800-237-3007 <a href="http://www.raisingpecialkids.org/">http://www.raisingpecialkids.org/</a>	Raising Special Kids 602- 242-4366 or 800-237-3007 <a href="http://www.raisingpecialkids.org/">http://www.raisingpecialkids.org/</a>	Family Involvement Center 602-412-4095 <a href="http://www.familyinvolvementcenter.org/">http://www.familyinvolvementcenter.org/</a> (Link works, but must copy and paste into your browser)	Raising Special Kids 602- 242-4366 or 800-237-3007 <a href="http://www.raisingpecialkids.org/">http://www.raisingpecialkids.org/</a>
<b>Colorado</b>	Community Voices by CBR YouthConnect 303-733-3000 <a href="https://www.cbryouthconnect.org/community-voices/">https://www.cbryouthconnect.org/community-voices/</a>	Ability Connection Colorado 303.691.9339 Hispano 877-472-7201 <a href="http://www.abilityconnectioncolorado.org/p2p-co/">http://www.abilityconnectioncolorado.org/p2p-co/</a>	Colorado FFCMH 888-429-3369 <a href="http://www.coloradofederation.org/">http://www.coloradofederation.org/</a>	PEAK Parent Center 719-531-9400 or 800-284-0251 719-531-9403 (TTY) <a href="http://www.peakparent.org">www.peakparent.org</a>
<b>Montana</b>	The Rural Institute for Inclusive Communities 406-243-4570 <a href="http://ruralinstitute.umt.edu/current-projects#mtfamilytofamily">http://ruralinstitute.umt.edu/current-projects#mtfamilytofamily</a>	Contact a neighboring state	Family Support Network (406) 256-7783 <a href="http://mtfamilysupport.org">http://mtfamilysupport.org</a>	Guided by the South Dakota Parent Connection (877) 870-1190 <a href="http://www.sdparent.org">www.sdparent.org</a>
<b>New Mexico</b>	Parent Reaching Out 505-247-0192 or 800- 524-5176 <a href="http://parentsreachingout.org/">http://parentsreachingout.org/</a> <a href="http://parentsreachingout.org/es/">http://parentsreachingout.org/es/</a>	Parent Reaching Out 505-247-0192 or 800- 524-5176 <a href="http://parentsreachingout.org/">http://parentsreachingout.org/</a> <a href="http://parentsreachingout.org/es/">http://parentsreachingout.org/es/</a>		Parent Reaching Out 505-247-0192 or 800- 524-5176 <a href="http://parentsreachingout.org/education/">http://parentsreachingout.org/education/</a> <a href="http://parentsreachingout.org/es/sped/">http://parentsreachingout.org/es/sped/</a>
<b>Nevada</b>	Family TIES of Nevada 775-823-9500 or 866-326-8437 <a href="https://www.facebook.com/familytiesnv/">https://www.facebook.com/familytiesnv/</a>	Family TIES of Nevada 775-823-9500 or 866-326-8437 <a href="https://www.facebook.com/familytiesnv/">https://www.facebook.com/familytiesnv/</a>	Nevada PEP, Inc. 702-388-8899 <a href="http://www.nvpep.org/">http://www.nvpep.org/</a>	Nevada PEP, Inc. 702-388-8899 or 800-216-5188 <a href="http://www.nvpep.org/">http://www.nvpep.org/</a>

<p><b>Texas</b></p>	<p>Texas Parent-to-Parent 512-458-8600 or 866-896-6001 <a href="https://www.txp2p.org/services/family-to-family-health-info">https://www.txp2p.org/services/family-to-family-health-info</a></p>	<p>Texas Parent-to-Parent 512-458-8600 or 866-896-6001 <a href="https://www.txp2p.org/services/talk-to-another-parent/peer-parent-mentor-program">https://www.txp2p.org/services/talk-to-another-parent/peer-parent-mentor-program</a></p>	<p>Texas FFCMH 512-944-9972 E-mail <a href="mailto:ffcmhtexas@gmail.com">ffcmhtexas@gmail.com</a></p>	<p>There are 3 PTIs in Texas. Identify the PTI for your region TX at <a href="http://prntexas.org/about-prn/find-your-pti/">http://prntexas.org/about-prn/find-your-pti/</a> PATH Project 409-898-4684 or 800-866-4726 <a href="http://prntexas.org/texas-ptis/path-project/">http://prntexas.org/texas-ptis/path-project/</a> PEN Project 915-259-8717 833-847-2686 <a href="http://prntexas.org/texas-ptis/pen-project/">http://prntexas.org/texas-ptis/pen-project/</a> TEAM Project 281-969-5944 877-832-8945 <a href="http://prntexas.org/texas-ptis/team-project-2/">http://prntexas.org/texas-ptis/team-project-2/</a></p>
<p><b>Utah</b></p>	<p>Utah Parent Center 801.272.1051 or 800.468.1160 <a href="http://www.utahparentcenter.org/projects/ufv/">http://www.utahparentcenter.org/projects/ufv/</a></p>	<p>Contact a neighboring state</p>	<p>Allies with Families 801-433-2595 or 877-477-0764 <a href="http://www.allieswithfamilies.org">www.allieswithfamilies.org</a></p>	<p>Utah Parent Center 801.272.1051 or 800.468.1160 <a href="http://www.utahparentcenter.org/projects/pti/info@utahparentcenter.org">http://www.utahparentcenter.org/projects/pti/info@utahparentcenter.org</a></p>
<p><b>Wyoming</b></p>	<p>SAO: UPLIFT 800-492-3199 <a href="http://www.upliftwy.org">www.upliftwy.org</a>  F2F: Wyoming Institute for Disabilities (WIND) 307-766-2761 or 888-989-9463 <a href="http://www.uwyo.edu/wind/f2f/">http://www.uwyo.edu/wind/f2f/</a></p>	<p>Contact a neighboring state</p>	<p>UPLIFT 800-492-3199 <a href="http://www.upliftwy.org">www.upliftwy.org</a></p>	<p>Parent Information Center 800-660-9742 307-684-2277 <a href="http://www.wpic.org">www.wpic.org</a></p>

<p><b>Tribal Communities in NM &amp; AZ</b></p>	<p>Parents Reaching Out in NM and Raising Special Kids in AZ jointly serve as a F2F for tribal communities in these states  Parents Reaching Out  Parent Reaching Out  505-247-0192 or  800- 524-5176  <a href="http://parentsreachingout.org/">http://parentsreachingout.org/</a>  <a href="http://parentsreachingout.org/es/">http://parentsreachingout.org/es/</a></p> <p>Raising Special Kids  602- 242-4366 or  800-237-3007  <a href="http://www.raisingpecialkids.org/">http://www.raisingpecialkids.org/</a></p>			
<p><b>Navajo Nation</b></p>	<p>Navajo Family Voices at Indian Country  505-326-2650  <a href="https://navajofamilies.org/team.html">https://navajofamilies.org/team.html</a></p>			