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 F2Fs 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

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.

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• 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)

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

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

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<th>State</th>
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<th>FFCMH</th>
<th>PTI/CPRC</th>
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<tr>
<td>Texas</td>
<td>Texas Parent-to-Parent 512-458-8600 or 866-896-6001</td>
<td>Texas Parent-to-Parent 512-458-8600 or 866-896-6001 <a href="https://www.txp2p.org/services/talk-to-another/">https://www.txp2p.org/services/talk-to-another/</a></td>
<td>Texas FFCMH 512-944-9972 E-mail ffcmh <a href="mailto:texas@gmail.com">texas@gmail.com</a></td>
<td>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</td>
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<td>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></td>
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<td>Contact a neighboring state</td>
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<td>Allies with Families 801-433-2595 or 877-477-0764 <a href="http://www.allieswithfamilies.org">www.allieswithfamilies.org</a></td>
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<td>Wyoming</td>
<td>SAO: UPLIFT 800-492-3199 <a href="http://www.upliftwy.org">www.upliftwy.org</a></td>
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<td>Parent Information Center 800-660-9742 307-684-2277 <a href="http://www.wpic.org">www.wpic.org</a></td>
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We strive to keep this information up-to-date. Please send updates/corrections to [bdworetzky@familyvoices.org](mailto:bdworetzky@familyvoices.org)