

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

The [National Genetics Education and Family Support Program](#) (Family 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 Family Center works to ensure that all individuals and families who have, or are at-risk of having, a genetic condition:

- Understand the implications of a genetic diagnosis
- Have access to genetic services
- Be engaged in their own care
- Have opportunities to engage in a meaningful way in national, regional, and local genetic healthcare delivery system

In addition to the above goals, the Family Center supports the RGNs by providing training, tools, and resources to facilitate family engagement in genetic services.

The following family-led organizations can help families navigate the system of care 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 [Family Voices: Leadership in Family and Professional Partnerships \(LFPP\)](https://familyvoices.org/lfpp/) 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 <https://familyvoices.org/affiliates/> if your RGN or families need help:

- Finding services for CYSHCN and the family
- Understanding eligibility for Title V, Medicaid or other state agency services
- Understanding private health insurance
- Communicating with doctors
- Understanding a child’s medical condition
- Connecting to a disability-specific support organization or group
- Finding support for a caregiver
- Building leadership skills and partnering with professionals to improve systems of care
- Creating family-friendly, plain language materials
- Reaching out to and recruiting families, including families of diverse race, ethnicity, geographic and socio-economic diversity, to participate in RGN advisory or other roles

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](https://www.p2pusa.org/parents/) at <https://www.p2pusa.org/parents/> if families:

- Need emotional and/or informational support
- Want to talk to someone who has similar life experiences and shares an understanding of a specific diagnosis, topic, and/or challenge.
- Are stressed, facing barriers or challenges, and want to talk to someone who understands your life.
- Are ready to share their own family circumstances, leadership skills, positive attitude, etc and want to support other parents.

If there is no P2P program in your state, contact a neighboring state’s P2P or P2P USA.

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.

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 <https://www.ffcmh.org/our-affiliates> if your RGN or families:

- Are worried about a child's emotional health and behaviors
- Need help identifying a mental health provider
- Need help supporting a caregiver who is experiencing mental health stress

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 26.

CPRCs help families who need additional language supports.

Use this link to identify the [PTI and/or CPRC](#) in your state at <https://www.parentcenterhub.org/find-your-center/> if your RGN or families need 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: NEW ENGLAND REGIONAL GENETICS NETWORK (NERGN)

	F2F/SAO	P2P	FFCMH	PTI/CPRC
CT	Path 203-234-9554 800-399-7284 http://pathct.org/	Path 203-234-9554 800-399-7284 http://pathct.org/	FAVOR, Inc. 860-563-3232 866-630-6055 http://www.favor-ct.org/	PTI: Connecticut Parent Advocacy Center (CPAC) 860-739-3089 800-445-2722 http://www.cpacinc.org/ CPRC: AFCAMP 860-548-9959 https://www.afcamp.org/
MA	Federation for Children with Special Needs 617-236- 7210 800-331-0688 https://fcsn.org/family-to-family-health-information-center/	Family Ties of MA 617- 624-5563 1-800-905-TIES (8437) http://massfamilyties.org/index.php	Parent Professional Advocacy League (PPAL) 866-815-8122 http://ppal.net/	Federation for Children with Special Needs 617-236- 7210 800-331-0688 https://fcsn.org/pti/
ME	Maine Parent Federation 207-588-1933 800-870-7746 https://www.mpf.org/programs/f2f/	Maine Parent Federation 207-588-1933 800-870-7746 https://www.mpf.org/programs/family-network/	There are 2 FFCMH affiliates in Maine Maine Parent Federation 207-588-1933 800-870-7746 http://www.mpf.org/ G.E.A.R. Parent Network 207- 223-9993 800-264-9224 www.gearparentnetwork.org	Maine Parent Federation 207-588-1933 800-870-7746 https://www.mpf.org/programs/pti/

NH	New Hampshire Family Voices 603-271-4525 800-852-3345 http://nhfv.org/	New Hampshire Family TIES 603- 225-4153 800-499-4153, ext. 241 https://www.communitybridgesnh.org/services/nh-family-ties/	NAMI New Hampshire 603-225-5359 800-242-6264 http://www.naminh.org/	Parent Information Center (PIC) 603-224-7005 800-947-7005 https://www.picnh.org/
RI	Rhode Island Parent Info Network (RIPIN) 401-270-0101 800-464-3399 www.ripin.org	Contact a P2P program in a neighboring state	Parent Support Network 401-467-6855, Ext. 101 800-514-3489 https://www.psnri.org/	Rhode Island Parent Info Network (RIPIN) 401-270-0101 800-464-3399 www.ripin.org
VT	Vermont Family Network 802-876-5315 800-800-4005 http://www.vermontfamilynetwork.org/	Vermont Family Network 802-876-5315 800-800-4005 http://www.vermontfamilynetwork.org/	Vermont FFCMH 802-876-7021 800-639-6071 https://www.vffcmh.org/	Vermont Family Network 802-876-5315 800-800-4005 www.vermontfamilynetwork.org