# 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 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, resources, and support services they may need. In addition, RGNs should partner family-led organizations 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**](http://www.familyvoices.org) **(FV)**

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](http://familyvoices.org/lfpp/) (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[[1]](#footnote-1) 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](http://familyvoices.org/affiliates/) (or see the list of FVAOs/F2Fs in your region on the last page) 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**](http://www.p2pusa.org/) **(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](http://www.p2pusa.org/parents/) at\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ (or see the list of the P2P programs in your region on the last page) 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 any neighboring statewide P2P program or P2P USA.

### [**National Federation of Families for Children’s Mental Health**](https://www.ffcmh.org/) **(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](https://www.ffcmh.org/our-affiliates) at \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ (or see the list of NFFCMH programs in your region on the last page) 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**](http://www.parentcenterhub.org/) **(CPIR)**

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](http://www.parentcenterhub.org/find-your-center/) in your state at \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ (or see the list of PTIs/CPRCs in your region on the last page) if your RGN or families need help:

        Understanding educational issues related to a genetic diagnosis

        Understanding a 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 a infant, child, or adolescent

        Finding support groups, educational specialists, legal assistance and other resources

### **Family-led organizations: New York-Mid Atlantic Consortium for Genetics and Newborn Screening Services (NYMAC)**

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|  | **F2F/FVAO** | **P2P** | **FFCMH** | **PTI/CPRC** |
| DC | F2F: **Advocates for Justice and Education** 202-678-8060 888-327-8060<http://www.aje-dc.org/>  |  | Total Family Care Coalition 202-758-3281[www.totalfamilycarecoalition.org](http://www.totalfamilycarecoalition.org)  | Advocates for Justice and Education202-678-8060888-327-8060[www.AJE-DC.org](http://www.AJE-DC.org) |
| DE | Delaware Family Voices 302-669- 3031/3033877-235-3588[www.delawarefamilytofamily.org/](http://www.delawarefamilytofamily.org/)  | Delaware Family Voices 302-669-3030[www.delawarefamilytofamily.org/](http://www.delawarefamilytofamily.org/)  | There are 2 FFCMH affiliates in DEDelaware Family Voices 302-669- 3030 877-235-3588[www.delawarefamilytofamily.org/](http://www.delawarefamilytofamily.org/) andChampions for Children’s Mental Health302-892-6408<https://www.championsde.org/>  | Parent Information Center of Delaware (PIC) 888-547-4412302-999-7394 (New Castle) 302-856-9880 (Sussex) [www.picofdel.org](http://www.picofdel.org/) |
| MD | Parents’ Place of Maryland, Inc.410-768-9100800-394-5694[www.ppmd.org](http://www.ppmd.org/) | Parent to Parent of Maryland @ The Arc MD 301-576-9035 410-571-9320 [www.p2pmd.org](http://www.p2pmd.org/) | There are 2 FFCMH affiliates in MDMD Coalition of Families for CMH 410-730-8267888-607-3637[www.mdcoalition.org](http://www.mdcoalition.org) andMontgomery County FFCMH301-879-5200 ext. 27[www.mcfof.org](http://www.mcfof.org)   | Parents’ Place of Maryland, Inc.410-768-9100800-394-5694[www.ppmd.org](http://www.ppmd.org/) |

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| NJ | Statewide Parent Advocacy Network (SPAN) 973-642-8100800-654-7726[www.spanadvocacy.org/](http://www.spanadvocacy.org/) | Statewide Parent Advocacy Network (SPAN) 973-642-8100<http://www.spanadvocacy.org/content/nj-statewide-parent-parent>  | There are 9 FFCMH affiliates in NJStatewide Parent Advocacy Network (SPAN) 973-642-8100[www.spanadvocacy.org/](http://www.spanadvocacy.org/)Camden Co. Family Support Org.856-662-2600[www.camdenfso.org/CCFSO.html](http://www.camdenfso.org/CCFSO.html)Family Based Services Assn of NJ732-542-4502[www.fbsanj.org/](http://www.fbsanj.org/)Family Support Org. of Bergen County 201-796-6209[www.fsobergen.org](http://www.fsobergen.org)Family Support Org. of Burlington County 609-265-8838Email: familyvoices@fsoburlco.orgFamily Support Org. of Essex Co. 973-395-1441[www.fsoec.org](http://www.fsoec.org)Family Support Org. of Hunterdon, Somerset & Warren Counties 908-223-1191[www.fso-hsw.org](http://www.fso-hsw.org)New Jersey Alliance 609-310-1120[njfamilyalliance.org](http://njfamilyalliance.org/)New Jersey Parents Caucus, Inc. 908-994-7471[www.newjerseyparentscaucus.org](http://www.newjerseyparentscaucus.org) | PTI: Statewide Parent Advocacy Network (SPAN) 973-642-8100800-654-7726[www.spanadvocacy.org](http://www.spanadvocacy.org)CPRC: Association for Special Children and Families973-728-8744 <http://ascfamily.org> This link works, if you copy and paste it into your browser |

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| NY | **Parent to Parent of NYS** 518-381-4350800-305-8817<http://parenttoparentnys.org/>  | **Parent to Parent of NYS** 518-381-4350, ext. 27800-305-8817<http://parenttoparentnys.org/>  | There are 5 FFCMH affiliates in NYFamilies Together in NYS (State Org)518-432-0333, ext.12888-326-8644[www.ftnys.org](http://www.ftnys.org)Families on the Move of NYC, Inc. 347-682-4870<http://fotmnyc.org/> Parsons Child and Family Center 518-426-2600[www.parsonscenter.org/](http://www.parsonscenter.org/) Finger Lakes Parent Network, Inc. 607-776-2164[www.flpn.org/](http://www.flpn.org/)MHA of Rochester & Monroe Co.585-325-3145[www.mharochester.org](http://www.mharochester.org/) | There are 5 PTIs in NY Starbridge585-546-170[www.starbridgeinc.org](http://www.starbridgeinc.org/)Advocates for Children of New York212-947-9779866-427-6033[www.advocatesforchildren.org](http://www.advocatesforchildren.org/)INCLUDEnyc 212-677-4650 212-677-4660 [www.includenyc.org](http://www.includenyc.org)Sinergia/Metropolitan Parent Center212-643-2840866-867-9665[www.sinergiany.org](http://www.sinergiany.org/)Long Island Advocacy Center516-248-2222631-234-0467[www.theliac.org](http://www.theliac.org)There are 4 CPRCs in NYParent Network of WNY716-332-4170866-277-4762[parentnetworkwny.org](http://parentnetworkwny.org/)United We Stand of New York718-302-4313/4314 [www.uwsofny.org](http://www.uwsofny.org)INCLUDEnyc212-677-4650 212-677-4660 [www.includenyc.org](http://www.includenyc.org/)Community Inclusion & Development 718-224-8197[www.cidainfo.com](http://www.cidainfo.com/) |
| PA | Parent Education and Advocacy Leadership Center (PEAL)866-950-1040 412-281-4404215-567-6143[www.pealcenter.org](http://www.pealcenter.org/) | Parent-to-Parent of PA717-649-4861888-727-2706 <http://www.parenttoparent.org/>  | Allegheny Family Network412-438-6102[www.alleghenyfamilynetwork.org](http://www.alleghenyfamilynetwork.org/) | PTI: Parent Education and Advocacy Leadership Center (PEAL)866-950-1040 412-281-4404215-567-6143[www.pealcenter.org](http://www.pealcenter.org/)There are 2 CPRCs in PAHispanos Unidos para Niños Excepcionales 215-425-6203[huneinc.org](http://huneinc.org/) Mission Empower814-825-0788844-370-1529[www.missionempower.org](http://www.missionempower.org) |
| VA | **Family to Family Network of Virginia - Center for Family Involvement** 804-828-0352877-567-1122<https://partnership.vcu.edu/programs/health/family-to-family-health-information-center/> | **Center for Family Involvement**877-567-1122<https://centerforfamilyinvolvement.vcu.edu/> |  | PTI: Parent Educational Advocacy Training Center (PEATC) 703-923-0010800-869-6782 [www.peatc.org](http://www.peatc.org/)CPRC: Formed Families Forward 703-539-2904[www.formedfamiliesforward.org](http://www.formedfamiliesforward.org) |
| WV | FVAO: West Virginia Parent Training and Information 304-472-5697 800-281-1436[www.wvpti.org](http://www.wvpti.org) **F2F:** [West Virginia University’s Center for Excellence in Disabilities](http://www.f2f.cedwvu.org/)304-205-6434<http://www.f2f.cedwvu.org> |  | Mountain State Parent Children & Adolescent Network 304-428-0365800-244-5385[www.mspcan.org](http://www.mspcan.org/) | West Virginia Parent Training and Information (PTI)304-624-1436 800-281-1436[www.wvpti.org](http://www.wvpti.org) |

1. 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. [↑](#footnote-ref-1)