



FAMILY-LED ORGANIZATIONS: A REFERENCE GUIDE

Family Voices is a national family-led organization of families and friends of children and youth with special health care needs (CYSHCN) and disabilities, including genetic disorders. We connect a network of family organizations across the United States that provide support to families of CYSHCN.

We work to develop and promote meaningful partnerships with families and family-led organizations and reach medically underserved and diverse families.

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.

FAMILY VOICES (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](#) (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

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.

and their professional partners. Both FVAOs and F2Fs¹ 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](#) (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 \(P2P USA\)](#)

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 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.

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.

NATIONAL FEDERATION OF FAMILIES (NFF)

The NFF 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 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 (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](#) 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 CARIBBEAN REGIONAL GENETICS NETWORK (NYMAC)

| | F2F/FVAO | P2P | NFF | PTI/CPRC |
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| 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 | Advocates for Justice and Education 202-678-8060 888-327-8060 www.AJE-DC.org |
| DE | Delaware Family Voices 302-669- 3031/3033 877-235-3588 www.delawarefamilytofamilily.org/ | Delaware Family Voices 302-669-3030 www.delawarefamilytofamilily.org/ | There are 2 FFCMH affiliates in DE Delaware Family Voices 302-669- 3030 877-235-3588 www.delawarefamilytofamilily.org/ and Champions for Children’s Mental Health 302-892-6408 https://www.championsde.org/ | Parent Information Center of Delaware (PIC) 888-547-4412 302-999-7394 (New Castle) 302-856-9880 (Sussex) www.picofdel.org |
| MD | Parents’ Place of Maryland, Inc. 410-768-9100 800-394-5694 www.ppmd.org | Parent to Parent of Maryland @ The Arc MD 301-576-9035 410-571-9320 www.p2pmd.org | There are 2 FFCMH affiliates in MD MD Coalition of Families for CMH 410-730-8267 888-607-3637 www.mdcoalition.org and Montgomery County FFCMH 301-879-5200 ext. 27 www.mcfof.org | Parents’ Place of Maryland, Inc. 410-768-9100 800-394-5694 www.ppmd.org |

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| NJ | <p>Statewide Parent Advocacy Network (SPAN) 973-642-8100 800-654-7726 www.spanadvocacy.org/</p> | <p>Statewide Parent Advocacy Network (SPAN) 973-642-8100 http://www.spanadvocacy.org/content/nj-statewide-parent-parent</p> | <p>There are 9 FFCMH affiliates in NJ Statewide Parent Advocacy Network (SPAN) 973-642-8100 www.spanadvocacy.org/</p> <p>Camden Co. Family Support Org. 856-662-2600 www.camdenfso.org/CCFSO.html</p> <p>Family Based Services Assn of NJ 732-542-4502 www.fbsanj.org/</p> <p>Family Support Org. of Bergen County 201-796-6209 www.fsobergen.org</p> <p>Family Support Org. of Burlington County 609-265-8838 Email: familyvoices@fsoburlco.org</p> <p>Family Support Org. of Essex Co. 973-395-1441 www.fsoec.org</p> <p>Family Support Org. of Hunterdon, Somerset & Warren Counties 908-223-1191 www.fso-hsw.org</p> <p>New Jersey Alliance 609-310-1120 njfamilyalliance.org</p> <p>New Jersey Parents Caucus, Inc. 908-994-7471 www.newjerseyparentscaucus.org</p> | <p>PTI: Statewide Parent Advocacy Network (SPAN) 973-642-8100 800-654-7726 www.spanadvocacy.org</p> <p>CPRC: Association for Special Children and Families 973-728-8744 http://ascfamily.org This link works, if you copy and paste it into your browser</p> |
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| NY | Parent to Parent of NYS 518-381-4350 800-305-8817 http://parenttoparentnys.org/ | Parent to Parent of NYS 518-381-4350, ext. 27 800-305-8817 http://parenttoparentnys.org/ | There are 5 FFCMH affiliates in NY Families Together in NYS (State Org) 518-432-0333, ext.12 888-326-8644 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/ Finger Lakes Parent Network, Inc. 607-776-2164 www.flpn.org/ MHA of Rochester & Monroe Co. 585-325-3145 www.mharochester.org | There are 5 PTIs in NY Starbridge 585-546-170 www.starbridgeinc.org Advocates for Children of New York 212-947-9779 866-427-6033 www.advocatesforchildren.org INCLUDEnyc 212-677-4650 212-677-4660 www.includenyc.org Sinergia/Metropolitan Parent Center 212-643-2840 866-867-9665 www.sinergiany.org Long Island Advocacy Center 516-248-2222 631-234-0467 www.theliac.org There are 4 CPRCs in NY Parent Network of WNY 716-332-4170 866-277-4762 parentnetworkwny.org United We Stand of New York 718-302-4313/4314 www.uwsofny.org INCLUDEnyc 212-677-4650 212-677-4660 www.includenyc.org Community Inclusion & Development 718-224-8197 www.cidainfo.com |
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| PA | <p>Parent Education and Advocacy Leadership Center (PEAL) 866-950-1040 412-281-4404 215-567-6143 www.pealcenter.org</p> | <p>Parent-to-Parent of PA 717-649-4861 888-727-2706 http://www.parenttoparent.org/</p> | <p>Allegheny Family Network 412-438-6102 www.alleghenyfamilynetwork.org</p> | <p>PTI: Parent Education and Advocacy Leadership Center (PEAL) 866-950-1040 412-281-4404 215-567-6143 www.pealcenter.org</p> <p>There are 2 CPRCs in PA</p> <p>Hispanos Unidos para Niños Excepcionales 215-425-6203 huneinc.org</p> <p>Mission Empower 814-825-0788 844-370-1529 www.missionempower.org</p> |
| PR | <p>Cas Rosada, calle Palmatum, Jardín Botánico de Río Piedras-Sur https://rcm2.rcm.upr.edu/</p> | | | <p>PTI: APNI, Inc. (787) 763-4665 (787) 250-4552 centroinfo@apnivr.org http://www.apnivr.org</p> <p>CPRC: El Centro Margarita, Inc. (787) 739-6030 centromargarita@yahoo.com http://www.centromargarita.com/</p> |
| VA | <p>Family to Family Network of Virginia - Center for Family Involvement 804-828-0352 877-567-1122 https://partnership.vcu.edu/programs/health/family-to-family-health-information-center/</p> | <p>Center for Family Involvement 877-567-1122 https://centerforfamilyinvolvement.vcu.edu/</p> | | <p>PTI: Parent Educational Advocacy Training Center (PEATC) 703-923-0010 800-869-6782 www.peatc.org</p> <p>CPRC: Formed Families Forward 703-539-2904 www.formedfamiliesforward.org</p> |

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| VI | Virgin Islands Developmental Disabilities Council, Inc. http://www.dhs.gov.vi/disabilities/dd_counsel.html 202-615-6369 | | | PTI: Disability Rights of the Virgin Islands (340) 772-1200 (340) 772-1280 (340) 776-4303 http://drcvi.org |
| WV | FVAO: West Virginia Parent Training and Information 304-472-5697 800-281-1436 www.wvpti.org F2F: West Virginia University's Center for Excellence in Disabilities 304-205-6434 http://www.f2f.cedwvu.org | | Mountain State Parent Children & Adolescent Network 304-428-0365 800-244-5385 www.mspscan.org | West Virginia Parent Training and Information (PTI) 304-624-1436 800-281-1436 www.wvpti.org |