



The Honorable Debbie Dingell  
United States House of Representatives  
Washington, DC 20515

Dear Representative Dingell:

We understand there will be a hearing before the Energy & Commerce Health Subcommittee on June 6, and that one of the subjects of the hearing will be the Family-to-Family Reauthorization Act of 2019 (H.R. 2822). As the co-Project Directors of the Family-to-Family Health Information Center (F2F) in Michigan, we would like to provide you with some information about Michigan Family to Family. We are housed at the Michigan Public Health Institute in Okemos, just outside of Lansing and we serve families in the entire state. Our federal grant is \$96,750 per year.

Like other F2Fs, we are staffed by family members of children or youth with special health care needs (CYSHCN). Our Family & Community Outreach staff are all parents of CYSHCN and use their lived experience parenting and advocating for their children to inform our work. We are also growing a state-wide Family Leadership Network, made up of parents of CYSHCN in each of Michigan's 10 prosperity regions. Our local family leaders are our ambassadors to reach the many diverse communities across our state, including traditionally underserved families in urban centers, rural areas, and tribal communities.

Michigan F2F partners closely with the Family Center for Children and Youth with Special Health Care Needs. They are the statewide parent-directed center within the Title V Children's Special Health Care Services (CSHCS) and the Michigan Department of Health and Human Services (MDHHS). This close partnership has allowed both organizations to accomplish more together than either could do independently in supporting Michigan's families. Below are examples of our outreach work:

- **Online resource repository available at [f2fmichigan.org](http://f2fmichigan.org)** where families can search over 400 organizations and resources. The repository can be searched by county and key words so families can find what they need efficiently.
- **Care Coordination: Empowering Families training** was developed at the request of and with family stakeholders who reported being the only consistent managers of care for their children with special health care needs. The training is facilitated by a parent-professional team and offered in partnership with agencies around the state. The eight-hour, one-day training covers topics that are critical for caregivers, including Medical Home, transition to adulthood, and navigating insurance.

- **Family Leadership Network** is a group of parents of CYSHCN representing each of the 10 prosperity regions in Michigan. Family leaders receive training and support from MI F2F and the Family Center to provide local outreach to families and the professionals who serve them.
- **Speaking Engagements** are an important part of our outreach work. MI F2F staff and Family Leadership Network members attend conferences, parent support meetings, professional groups, and university classrooms to share the experience of raising a CYSHCN, resources, and information on how to best partner with families so children can attain optimal health.
- **Michigan Family Connections Newsletters** are an important outreach tool to inform families and professionals about current events, important changes in policies, and highlighted resources. Our spring family stories edition is very popular—we encourage you to read some **stories from Michigan families** on our Family Stories page on the website.
- **Social Media Outreach** has become an increasingly important part of our outreach strategy. We maintain an active twitter and Facebook account to engage families and professionals and direct them to some of our resources.

The website for our F2F can be found at [f2fmichigan.org](http://f2fmichigan.org). There you can learn more about us and our work and discover some of the resources available to your constituents. You can find more information about children and youth with special health care needs and F2Fs in general on the [Family Voices website](#). We would more than happy to provide additional information about our F2F (contact information below).

Sincerely,

Kristen Reese, Co-Project Director  
Family & Community Outreach  
[kreese@mphi.org](mailto:kreese@mphi.org)  
517-324-7396

Julie Moore, Co-Project Director  
Design, Evaluation, & Data  
[jamoore@mphi.org](mailto:jamoore@mphi.org)  
517-324-8331

cc:

The Honorable Frank Pallone  
The Honorable Greg Walden  
The Honorable Anna Eshoo  
The Honorable Michael Burgess, MD



The Honorable Fred Upton  
United States House of Representatives  
Washington, DC 20515

Dear Representative Upton:

We understand there will be a hearing before the Energy & Commerce Health Subcommittee on June 6, and that one of the subjects of the hearing will be the Family-to-Family Reauthorization Act of 2019 (H.R. 2822) which you introduced with Representative Mikie Sherrill. As the co-Project Directors of the Family-to-Family Health Information Center (F2F) in Michigan, we would like to provide you with some information about Michigan Family to Family. We are housed at the Michigan Public Health Institute in Okemos, just outside of Lansing and we serve families in the entire state. Our federal grant is \$96,750 per year.

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The website for our F2F can be found at [f2fmichigan.org](http://f2fmichigan.org). There you can learn more about us and our work and discover some of the resources available to your constituents. You can find more information about children and youth with special health care needs and F2Fs in general on the [Family Voices website](#). We would more than happy to provide additional information about our F2F (contact information below).

Sincerely,

Kristen Reese, Co-Project Director  
Family & Community Outreach  
[kreese@mphi.org](mailto:kreese@mphi.org)  
517-324-7396

Julie Moore, Co-Project Director  
Design, Evaluation, & Data  
[jamoore@mphi.org](mailto:jamoore@mphi.org)  
517-324-8331

cc:

The Honorable Frank Pallone  
The Honorable Greg Walden  
The Honorable Anna Eshoo  
The Honorable Michael Burgess, MD



May 30, 2019

The Honorable Ann M. Kuster  
United States House of Representatives  
Washington, DC 20515

Dear Representative Ms. Kuster

I understand there will be a hearing before the Energy & Commerce Health Subcommittee on June 6, and that one of the subjects of the hearing will be the Family-to-Family Reauthorization Act of 2019 (H.R. 2822). As the Co-Director of the Family-to-Family Health Information Center (F2F) in New Hampshire, I would like to provide you with some information about our F2F project.

We receive a federal grant of \$96,750 and serve the families across the entire state. Like other F2Fs, we are staffed by family members of children or youth with special health care needs (CYSHCN). Our F2F provides assistance to other families whose children have special health care needs or disabilities of any sort, including developmental disabilities, serious or chronic health conditions, and mental illness. We help them navigate the complex health care system so they can get the care their children need and find ways to cover the often very-high costs of that care. We serve families in a culturally and linguistically appropriate manner, and reach out to underserved communities.

Examples of assistance we have provided:

We recently assisted a family from Manchester whose child has a genetic condition. The parents had been trying, to access Medicaid based on the child's condition. After two tries, with encouragement and support from our staff to get them through the paperwork and understanding of the institutional level of care, they were successful. The help from us continued as we followed up with education regarding the use their private insurance and Medicaid together to obtain in-state medically necessary services for their child. This on-going support has led to the family becoming involved in a regional genetics training program so they can "give back" by sharing their experiences with others.

A family in Contoocook has been a "repeat customer" with our F2F as they transitioned their daughter from pediatric services to adult care. Our staff supported them through the

129 Pleasant Street – Thayer  
Concord, NH 03301  
(603) 271-4525

54 Old Suncook Road  
Concord NH 03301  
(603)224-7005

application for guardianship, adult Medicaid and Social Security benefits by answering questions regarding process and sometimes explaining the intent behind confusing questions. We assisted them when they “aged out” of their pediatricians’ office and had to find adult care. In this instance we were able to help them define what they wanted from a primary care practice and then connect them to other families who could speak to the quality of care at various practices from personal experience.

For more information about the work of the New Hampshire Family to Family Health Information Center I would encourage you to [view the 2016-2017 New Hampshire F2F Data Report](#).

Sincerely,



Terry Ohlson-Martin  
NHFV Co-Director

Sincerely,



Martha-Jean Madison  
NHFV Co-Director



## NAVAJO FAMILY VOICES

Office: (505) 716-3030  
Fax: (888) 263-2051

P O Box 744, Farmington, NM 87499  
<https://navajofamilies.org>

Helpline: (505) 226-3073  
Email: [info@navajofamilies.org](mailto:info@navajofamilies.org)

May 30, 2019

The Honorable Ben Ray Lujan  
United States House of Representatives  
2323 Rayburn House Office Building  
Washington, D.C. 20515

*Ya'at'eeh* Congressman Lujan:

I understand there will be a hearing before the Energy & Commerce Health Subcommittee on June 6, and that one of the subjects of the hearing will be the Family-to-Family Reauthorization Act of 2019 (H.R. 2822). As the Program Administrator of the Family-to-Family Health Information Center (F2F) on the Navajo Nation, I would like to provide you with some information about our F2F, Navajo Family Voices.

We are a tribally-controlled non-profit organization, founded by retired Navajo Nation judges, including Chief Justice Herb Yazzie, who have family members with chronic healthcare needs and all continue to serve on our board. Our F2F federal grant is \$96,750 per year.

A model that supports leadership growth among those most in need, the F2F concept efficiently and cost-effectively empowers families of children with special needs to help each other in accessing services, partnering with health providers in planning medical care, personal and family supports, and transition to adulthood. On the Navajo Nation reservation, family-based leaders empowered to access and plan services themselves are too often the only resort. Having visited our reservation so often and provided so much assistance to our communities over the years, you know the challenges our families face. These include rural and remote environments lacking basic services like water, electricity, heat, and convenient trash removal, roads impassable and homes trapped in bad weather. Infrastructure and the challenges of culture and language make it both cost prohibitive and also very often invasive for workers unfamiliar with local ways and methods to come in and tell local families what they should do, how they should do it, and what they need.

It routinely takes hours in the best of weather conditions to get to a health care facility, let alone a pediatric subspecialist, with scattered transportation help provided by limited non-profits. With families frequently lacking a vehicle to get to medical appointments, building family networks becomes doubly important for transportation support. In addition, our families must navigate complex facility and eligibility systems that include Indian Health Service, PL93-638, private foundation, and state services which are limited to within state borders, yet the reservation spans three states. We are helping to map how these service systems work together, for the first time.

Navajo Family Voices is among the first tribal F2Fs to obtain federal funding, and is the first tribal affiliate organization of Family Voices. We are community-based in Twin Lakes and Naschitti with an office in Farmington, our goal to empower families through methods that our communities are

most comfortable with, nurture our own arc of learning, and grow networks of informed families whose children have special health care needs or disabilities of any sort, including developmental disabilities, serious or chronic health conditions, and mental illness.

Our Family Mentor, Elvira Dennison, is a single mother of two children with special healthcare needs, and herself recovered from a stroke three years ago which required her to re-learn how to read. Elvira is a force of nature, having taught herself how to access services for her children and deal with healthcare providers for fifteen years in the Naschitti community. Having experienced the despair of isolation and knowing the urgency of providing for her children's needs both for immediate care and transition to a supported future, Elvira became a volunteer First Responder through which she gained connections with other families and became known throughout the Newcomb region. She overcame shyness and her own disability to become a voice for her children and other families on school and community committees. We know there are no better and more compassionate advocates for disabled children than parents and families.

You know firsthand our challenges of basic food nutrition. We are pulling in passionate families through collaborations with other non-profits on nutritious food access and already joining with Indian Health Services health promotion teams in hosting Family Nights at which information booths and presentations are given together with healthy, abundant meals and games, which is the unique Navajo method for all family learning. We have already jointly hosted two such evenings and are organizing an all-day Family Event for youth and especially young parents in Shiprock this coming month at an event that normally draws 750 people. For this event, we are bringing in F2F partners from Arizona, Utah and New Mexico as well as the Children's Medical Services unit of the New Mexico Department of Health. According to the NMDOH CMS, they have long offered case coordination services throughout the state, but have never before been able to offer information to tribal communities on the Navajo Nation directly.

Federal funding through the F2F program having got us started in 2018 with three part-time staff, we were able to leverage our F2F funds and gained a fourth staff member through funding from the Kellogg Foundation. Hazel James, who has cared for her deaf brother at Mexican Springs since childhood and is now in her sixties, came to us with grant funding that at first didn't include our F2F. After explaining our mission and need to the funder, and seeing Hazel's enthusiasm, the grant now helps pay for Hazel's participation in this project as our Diné wellness community coordinator.

Our website can be found at <https://navajofamilies.org>. We are getting enthusiastic help from state F2Fs in generating material and resources for our site, which we are presenting in ways that are tailored to tribal families and also our healthcare providers. Since we only formed in October 2018, data about our tribal F2F's services is still in early stages. You can find more information about children and youth with special health care needs and F2Fs in general on the [Family Voices website](#). I would be more than happy to provide additional information about our F2F. I can be reached at [josey@navajofamilies.org](mailto:josey@navajofamilies.org), phone (505) 716-3030.

Sincerely,



Josey Foo  
Program Administrator



cc: The Honorable Frank Pallone  
The Honorable Greg Walden  
The Honorable Anna Eshoo  
The Honorable Michael Burgess, MD



# Parents Reaching Out

May 29, 2019

The Honorable Ben Ray Lujan  
United States House of Representatives  
Washington, DC 20515

Dear Representative Lujan,

I understand there will be a hearing before the Energy & Commerce Health Subcommittee on June 6, and that one of the subjects of the hearing will be the Family-to-Family Reauthorization Act of 2019 (H.R. 2822). As the Executive Director of Parents Reaching Out (PRO), home to the Family-to-Family Health Information Center (F2F) in New Mexico and a tribal Family-to-Family Health Information Center covering seven tribal entities in New Mexico and Arizona], I would like to provide you with some information about the importance our F2F projects.

As background, Parents Reaching Out is a non-profit organization serving the entire state of New Mexico since 1981. Our federal grant is for each F2F is \$96,500 per year.

Like other F2Fs, we are staffed by family members of children or youth with special health care needs (CYSHCN). Cathy Salazar, our lead F2F staff member, is a parent of nine children, six of whom she adopted with complex medical needs. Our F2F provides assistance to other families whose children have special health care needs or disabilities of any sort, including developmental disabilities, serious or chronic health conditions, and mental illness. We help them navigate the complex health care system so they can get the care their children need and find ways to cover the often very-high costs of that care. We serve families in a culturally and linguistically appropriate manner, including Native American and monolingual Spanish-speaking family members and reach out to rural, frontier and other underserved communities.

Examples of assistance we provide includes supporting families in the neonatal intensive care unit (NICU), providing information about and assistance with applying for Medicaid waivers, helping parents get much-needed medical equipment for their child or provide strategies to help parents or grandparents communicate with their child's/grandchild's physician or managed care organization.

Furthermore, we work to educate professional communities on issues impacting children and youth with special health care needs, including connecting with all medical students at UNMH during their pediatrics rotation during which they visit with a family of a medically fragile child in the family home. Our staff have sat on committees relating to Centennial Care 2.0, those relating to addressing physician shortages and the impact of the opioid crisis on newborns.

We are also available to assist congressional caseworkers when they are contacted by constituents trying to secure assistance for their children with special health care needs. The website for our F2F can be found at [www.parentsreachingout.org](http://www.parentsreachingout.org). There you can find some of the resources available to your constituents. Data about our F2F's services can be found at <http://familyvoices.org/wp->

[content/uploads/2018/02/2016\\_NM\\_StateDataReport\\_final.pdf](#). You can find more information about children and youth with special health care needs and F2Fs in general on the [Family Voices website](#). I know that you are concerned about access to health care in New Mexico and if I can provide any additional information about our F2F and our impact, I can be reached at [nsandweiss@parentsreachingout.org](mailto:nsandweiss@parentsreachingout.org) or 505-247-0192.

Sincerely,

A handwritten signature in cursive script that reads "Naomi Sandweiss".

Naomi Sandweiss, M.A.  
Executive Director



May 30, 2019

The Honorable Kurt Schrader  
United States House of Representatives  
Washington, DC 20515

Dear Representative Schrader,

I understand there will be a hearing before the Energy & Commerce Health Subcommittee on June 6, and that one of the subjects of the hearing will be the **Family-to-Family Reauthorization Act of 2019** (H.R. 2822). As the manager of the Family-to-Family Health Information Center (F2F HIC) in Oregon, I would like to provide you with some information about it.

The Oregon F2F HIC is housed at Oregon Center for Children and Youth with Special Health Needs (OCCYSHN) which is our state's Title V program. Although we are physically housed at Oregon Health & Science University, we serve families in the entire state of Oregon. Our federal grant is \$96,700 per year. With that funding, we reach more than 1,000 Oregon parents annually, providing coaching, education, resources, and information to help them make healthcare decisions for their children with disabilities.

Like all of the F2F HICs around the country, we are staffed entirely by family members of children or youth with special health care needs (CYSHCN). We believe that those who have navigated multiple, complicated systems are best suited to help others. Our team of six Parent Partners (five moms and one dad) have extensive knowhow and experience with the major Oregon CYSHCN systems, including mental/behavioral Health, developmental disabilities, Social Security, Medicaid, early intervention, special education, public health, commercial insurance, newborn screening, and much more.

Professionals call on the OR F2F HIC as well, and frequently use our comprehensive website, [www.oregonfamilytofamily.org](http://www.oregonfamilytofamily.org) to find resources for the families they serve. This website, developed and maintained entirely by parents of children with disabilities, is considered Oregon's clearinghouse of information about pediatric special needs.

When a parent or professional calls our toll-free line, they will be served by one of our Parent Partners, usually within one working day. We will listen carefully to their question or concern and provide them with a variety of ideas, resources, or referrals. We reliably send follow-up resources and information by email or postal mail, whichever the family prefers. Examples of calls within the last 60 days include

- helping a parent of a 10-year-old who requires seven medications a day feel confident speaking to her provider about a second opinion and possible genetic testing.

OCCYSHN

Oregon Center for Children and  
Youth with Special Health Needs

t 503 494-8303  
t 877 307-7070  
f 503 494-2755  
e [occyshn@ohsu.edu](mailto:occyshn@ohsu.edu)  
w [www.occyshn.org](http://www.occyshn.org)

Mail code CDRC  
707 SW Gaines St  
Portland, OR 97239

- coaching the parent of a six year old in Southern Oregon who received a 'surprise' bill resulting from a referral to an out-of-network referral
- educating a parent about the availability of Exceptional Needs Care Coordinators in their Coordinated Care Organization (CCO) and providing them a "script" to help them request one
- helping a parent of two children with hearing loss get connected to family support and information about cochlear implants
- coaching a family of a medically complex child who is seeking to move from California to Oregon and is unclear on the service system here
- helping a professional find resources about traumatic brain injury for a client who wishes to attend a conference.

In just the last 30 days we have also:

- conducted family trainings about health care advocacy and resources in eight rural and two urban communities
- sponsored a workshop for parents of Spanish-speaking families of children with cerebral palsy
- met with a grandparents' support group about managing their grandchild's transition from pediatric to adult health care

Our team is grateful to be able to do this meaningful work. For more information about us and our "sibling" F2Fs around the country, please visit <http://familyvoices.org/affiliates/>

In closing, please know that our team is more than happy to be a resource for your staff and/or constituents and am attaching a referral form for that purpose. We look forward to stopping in to your Oregon offices to meet your staff in the near future.

Most Sincerely,



Tamara Bakewell  
Family Involvement/OR F2F HIC Manager

cc:

The Honorable Frank Pallone  
The Honorable Greg Walden  
The Honorable Anna Eshoo  
The Honorable Michael Burgess, MD



May 30, 2019

The Honorable Greg Walden  
United States House of Representatives  
Washington, DC 20515

Dear Representative Walden,

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Youth with Special Health Needs

t 503 494-8303  
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e [occyshn@ohsu.edu](mailto:occyshn@ohsu.edu)  
w [www.occyshn.org](http://www.occyshn.org)

Mail code CDRC  
707 SW Gaines St  
Portland, OR 97239

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In closing, please know that our team is more than happy to be a resource for your staff and/or constituents and am attaching a referral form for that purpose. We look forward to stopping in to your Oregon offices to meet your staff in the near future.

Most Sincerely,



Tamara Bakewell  
Family Involvement/OR F2F HIC Manager

cc:

The Honorable Frank Pallone  
The Honorable Anna Eshoo  
The Honorable Michael Burgess, MD



Providing support and information for families of children with disabilities, chronic illness and other special health care needs

February 6, 2019

The Honorable Michael Burgess, MD  
United States House of Representatives  
Washington, DC 20515

Dear Representative Burgess,

I understand there will be a hearing before the Energy & Commerce Health Subcommittee on June 6, and that one of the subjects of the hearing will be the Family-to-Family Reauthorization Act of 2019 (H.R. 2822). As the Executive Director of the Family-to-Family Health Information Center (F2F) in Texas, I would like to provide you with some information about our F2F, Texas Parent to Parent.

Texas Parent to Parent (TxP2P) is a free-standing family-led nonprofit organization and an affiliate of the national organizations, Family Voices and Parent to Parent USA, located in Austin. We serve over 8,000 families across the state. Our federal grant is \$95,000 per year.

Like other F2Fs, we are staffed by family members of children or youth with disabilities, chronic illness and children with special health care needs (CYSHCN) and young adults with disabilities. My son was born at 24 weeks gestation, 33 years ago. As a physician, you know the odds for a 24-weeker that long ago. Fortunately, my boy surprised everyone and not only survived, but thrived and only has mild Cerebral Palsy and learning difficulties. He even got his Texas driver's license. Unfortunately, most families are not this fortunate. Because of all we went through (6 months in the NICU, another 8 months of medical fragility, etc.), I knew I needed to help other families by the time he was 3-years-old. I have worked in family support for 30 years now.

Our F2F assists families whose children have special health care needs or disabilities of any sort, including developmental disabilities, serious or chronic health conditions and mental illness. We help them navigate the complex health care system so they can get the care their children need and find ways to cover the often very-high costs of that care. We serve families in a culturally and linguistically appropriate manner, and reach out to underserved communities. We have four Spanish bilingual staff. We also serve military families and have done some outreach to Ft. Hood.

Examples of assistance we have provided:

TxP2P provides one statewide 2-day conference and three 1-day conferences, with local partners, across the state each year using funding from our F2F grant. We had one in Fort Worth for the past seven years. We had 75 to 175 parents and professionals attend over the years with some great speakers, both parents and professionals. We provide specialized child care, Sibshop

**Texas Parent to Parent**

1805 Rutherford Lane • Suite 201 • Austin, TX 78754 • 866-896-6001 • 512-458-8600  
Website: [www.txp2p.org](http://www.txp2p.org) • Email: [info@txp2p.org](mailto:info@txp2p.org)



and lunch during the conferences. Here is what some of the parents had to say about the conference:

- Thank you for not having a cost associated with these conferences!!! Great exhibitors and speakers.*
- As an educator, I enjoy coming to these conferences. Keep up the good work.*
- This event always delivers on information and resources. Good networking opportunity.*
- The event was very informed and obtain a wealth of knowledge*

We are also available each workday to help families on the phone and email with insurance concerns, information on caring and advocating for their child, helping a new parent navigate their stay in the NICU or finally coming home with their baby, getting healthcare assistance in schools, etc. All our families receive information on the services available to their children, including the Medicaid waivers. We also have 40+ social media venues for parents who wish to communicate that way.

TxP2P also has a transition program, Pathways to Adulthood, for parents whose children are reaching 14-years-old or over. We provide a 1-day training covered the pertinent topics parents need to consider in transition, including what to do when school ends, insurance and financial issues, where will your child live, work and play, etc. We take this across the state to help families prepare for a transition to a good life for their young adult.

We are also available to assist congressional caseworkers when they are contacted by constituents trying to secure assistance for their children with special health care needs. Another excellent resource is the state website, [Navigate Life Texas](#). TxP2P also assists with resources and family stories on this website.

TxP2P website is [www.txp2p.org](http://www.txp2p.org); our F2F page is <https://www.txp2p.org/services/family-to-family-health-info>. On these sites, you can find some of the resources available to your constituents. Data about our F2F's services can be found at [http://familyvoices.org/wp-content/uploads/2018/02/2016\\_TX\\_StateDataReport\\_final.pdf](http://familyvoices.org/wp-content/uploads/2018/02/2016_TX_StateDataReport_final.pdf). You can find more information about children and youth with special health care needs and F2Fs in general on the [Family Voices website](#). I would more than happy to provide additional information about our F2F. I can be reached at [laura@txp2p](mailto:laura@txp2p) or 512-458-8600, direct line: 737-484-9040

Sincerely,



Laura J. Warren, Executive Director

cc:

The Honorable Frank Pallone

The Honorable Greg Walden

The Honorable Anna Eshoo

## Texas Parent to Parent

1805 Rutherford Lane • Suite 201 • Austin, TX 78754 • 866-896-6001 • 512-458-8600

Website: [www.txp2p.org](http://www.txp2p.org) • Email: [info@txp2p.org](mailto:info@txp2p.org)

May 29, 2019

The Honorable Morgan Griffith  
United States House of Representatives  
Washington, DC 20515

Dear Representative Griffith:

One of the topics scheduled for discussion at a June 6<sup>th</sup> Energy & Commerce Health Subcommittee hearing is the Family to Family Reauthorization Act of 2019 (H.R. 2822). We serve as Virginia's federally funded Family to Family Health Information & Education Center, or F2F. Below is some information that might be helpful for that June discussion.

The F2F Network of Virginia is housed within the Center for Family Involvement (CFI) at the Partnership for People with Disabilities. The Partnership is Virginia's university center for excellence in developmental disabilities located since 1985 at Virginia Commonwealth University. The CFI is comprised of 22 people with disabilities and family members of children and adults with developmental disabilities, mental health needs, and/or special health care needs. In addition to federal funds, the CFI is funded by the Virginia Departments of Aging & Rehabilitative Services, Behavioral Health & Developmental Services, Education, and Health. To ensure we have depth and spread across the Commonwealth, the F2F Network team works from six regional offices (Bristol, Charlottesville, Fairfax County, Richmond, Newport News, and Virginia Beach) and is supported by over 100 culturally diverse volunteer Family Navigators. We provide enhanced one-to-one emotional, informational and systems navigational support to over 1,000 families each year in addition to annual educational opportunities to about 6,000 families and professionals (educators, health care workers, community services workers).

In the districts that you represent, the F2F Network regional coordinator, Lisa Richard, also serves as our rural outreach specialist. Among the many things Lisa does each year, she has worked with local faith based organizations to write grants to design sensory friendly rooms, held community-wide family networking events, received her certification to provide telehealth coordination, helped local businesses hire and support young adults with disabilities, and participated in the mobile RAM clinic and Care Connection for Children clinics to ensure families of children and adults with disabilities have a parent of children with disabilities to connect with to discuss concerns and needs they may not feel comfortable sharing with providers. Other CFI team members in your region work with hospital newborn hearing screening teams and audiology clinics to ensure infants/toddlers with hearing loss are diagnosed quickly and referred for early intervention services; provide training and career counseling to over 400 adults working in sheltered work settings for subminimum wage; help families navigate special education services (particularly immigrants); and serve on committees such as the Virginia Rural Healthcare Association and Medicaid Member Advisory Committee.

You can find information about the CFI and Virginia's F2F at [www.centerforfamilyinvolvement.org](http://www.centerforfamilyinvolvement.org). Please do not hesitate to reach out to me ([dvyarbrough@vcu.edu](mailto:dvyarbrough@vcu.edu)) or Lisa ([lrichard3@vcu.edu](mailto:lrichard3@vcu.edu)) through email or our toll free help line (877.567.1122) if you need stories of our support to rural families in Virginia, data snapshots, and/or connections to other team members who are working with aging families, refugees and immigrants, and those waiting for long term Medicaid waiver or mental health services.

Sincerely,



Dana Yarbrough, Director



The Honorable Eliot L. Engel  
United States House of Representatives  
Washington, DC 20515

Dear Representative Engel:

I understand there will be a hearing before the Energy & Commerce Health Subcommittee on June 6, and that one of the subjects of the hearing will be the Family-to-Family Reauthorization Act of 2019 (H.R. 2822). As the Executive Director of the Family-to-Family Health Information Center (F2F) in New York, I would like to provide you with some information about our program.

We are housed at Parent to Parent of NYS in Schenectady, but we serve families in the entire state. We have ten regional offices, including Westchester (located within the Westchester Institute for Human Development) and Manhattan. Our federal grant is \$96,750 per year.

Like other F2Fs, we are staffed by family members of children or youth with special health care needs (CYSHCN). Our F2F provides assistance to other families whose children have special health care needs or disabilities of any sort, including developmental disabilities, serious or chronic health conditions, and mental illness. We help them navigate the complex health care system so they can get the care their children need and find ways to cover the often very-high costs of that care. We serve families in a culturally and linguistically appropriate manner, and reach out to underserved communities.

Examples of assistance we have provided:

A mother whose teenage son suffered a spinal cord injury after a swimming accident relies on in-home nursing services to meet his daily health needs. She was paying these costs out of pocket as the family's health insurance plan doesn't cover long-term in-home nursing care, but eventually declared bankruptcy and could no longer afford to do so. The family applied for a Medicaid waiver but had received some misinformation which led to the young man nearly losing all insurance coverage. We connected the mother to her local CYSHCN program who helped the mother obtain eligibility for Medicaid. The mother is now an active contributor to our Medically Fragile Families e-group.

We assisted a family whose teenage son needed intensive day treatment for an orthopedic condition but lacked transportation to the hospital. The family could not afford daily taxi fare and bus transportation wasn't an option due to the distance the young man would need to walk to and from the hospital from the bus stop. The young man had been approved for an Office of People with Developmental Disabilities (OPWDD) waiver but

had never used it. We provided assistance to the family in obtaining reimbursement for cab fare through the waiver and helped them understand the available benefits.

We are also available to assist congressional caseworkers when they are contacted by constituents trying to secure assistance for their children with special health care needs.

The website for our F2F can be found at <http://parenttoparentnys.org/index.php/healthcare/>. There you can find some of the resources available to your constituents.

Data about our F2F's services can be found at <http://familyvoices.org/affiliates/states/ny/> (click on the View Data Report link found on that page.)

You can find more information about children and youth with special health care needs and F2Fs in general on the [Family Voices website](#).

I would more than happy to provide additional information about our F2F. I can be reached at [mjuda@ptopnys.org](mailto:mjuda@ptopnys.org) or (518) 381-4350 ext. 27.

Sincerely,



Michele Juda  
Executive Director

cc:

The Honorable Frank Pallone  
The Honorable Greg Walden  
The Honorable Anna Eshoo  
The Honorable Michael Burgess, MD