

Alpha Resource Center of Santa Barbara 4501 Cathedral Oaks Road Santa Barbara. CA 93110

(805) 683-2145 info@alphasb.org

Eastern Los Angeles Family Resource Center

1000 South Fremont Ave. Suite 6050, Unit 35 Alhambra, CA 91803 (626) 300-9171 info@elafrc.org

Family Resource Navigators

291 Estudillo Ave San Leandro, CA 94577 (510) 547-7322 eileenc@frnoakland.org

Support for Families of Children with Disabilities

1663 Mission Street, Suite 700 San Francisco, CA 94103 (415) 282-7494 info@supportforfamilies.org

FAMILY VOICES OF CALIFORNIA

1663 Mission Street, Suite 700 San Francisco, CA 94103 (415) 282-7494

info@familyvoicesofca.org www.familyvoicesofca.org May 29, 2019

The Honorable Nanette Barragán United States House of Representatives Washington, DC 20515

Dear Representative Barragán:

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 Project Director of the Family-to-Family Health Information Center (F2F) in California, I would like to provide you with some information about our F2F, Family Voices of CA.

We are housed at Support for Families of Children with Disabilities in San Francisco, but we serve families throughout 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 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. We promote partnerships with families, professionals and the community at large, because it is through partnerships that we create a community where our children can flourish. We also work with partners around the state to develop and implement innovative Parent Leadership trainings that prepares parents to make their voices heard on issues important to families of children with special needs.

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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.

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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 pipmarks@familyvoicesofca.org. Phone: (415)282-7494 ext. 123

Sincerely,

Pip Marks

Popland

Project Director, Family Voices of California

cc:

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



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The Honorable Tony Cárdenas United States House of Representatives Washington, DC 20515

Dear Representative Cárdenas:

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The Honorable Anna Eshoo United States House of Representatives Washington, DC 20515

Dear Representative Eshoo:

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 Project Director of the Family-to-Family Health Information Center (F2F) in California, I would like to provide you with some information about our F2F, Family Voices of CA.

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The Honorable Doris O. Matsui United States House of Representatives Washington, DC 20515

Dear Representative Matsui:

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 Project Director of the Family-to-Family Health Information Center (F2F) in California, I would like to provide you with some information about our F2F, Family Voices of CA.

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The Honorable Raul Ruiz, MD, MPH United States House of Representatives Washington, DC 20515

Dear Representative Ruiz:

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 Project Director of the Family-to-Family Health Information Center (F2F) in California, I would like to provide you with some information about our F2F, Family Voices of CA.

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Project Director, Family Voices of California

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



May 30, 2019

The Honorable Gus Bilirakis
United States House of Representatives
Washington, DC 20515

Dear Representative Bilirakis:

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 Project Director of the Family-to-Family Health Information Center (F2F) in Florida, I would like to provide you with some information about our F2F, Family STAR.

We are a free-standing nonprofit organization, Family STAR Florida's F2F is a project of Family Network on Disabilities located in Pinellas County, but we serve families in the entire state. Our federal grant is \$95,000 per year.

Like other F2Fs, we are staffed by family members of children or youth with special health care needs (CYSHCN). Working on a peer model, families we work with know when they talk with our staff they are talking to family members just like them who know what they are going through. We use our lived experience we have gained in life as family members of children with health care needs to now help other parents navigate this difficult field. 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. We provide our presentations in English, Spanish, and Haitian Creole. Our resources developed under this grant are available in 5 languages on our website in an easy to read format for families. We are working with military families to help them navigate Tri-care and help coordinate services for their child as they are moved from one installation to the next.

Examples of assistance we have provided:

There are two stories I'd like to share with you about our work supporting your constituents. The first is of the family who is taking a vacation out of state in Vermont. The pregnant mother was not due for another couple of months but suddenly went into premature labor. Their child survived but, having been several months' premature, was hospitalized in an incubator for over eight months not able to return home to Florida. This family spent the first precious months with their child in the hospital. When the child was finally discharged, they went back to their house in Vermont with tubes, machines, and more paperwork than they could know what to do with, not knowing what to do next. The hospital told them to reach out to their Florida F2F. We quickly worked with the family, helping them understand how to transfer from the Medicaid in which their child was instantly enrolled in Vermont to the Medicaid system in Florida. We were able to help them with information on making a smooth transition back home after some of the most terrifying months of their life. We are happy to say the family is back home in Florida and we will be doing follow-up check-ins, making sure they are adequately connected to services throughout their community for the success of their child.

The second story is about one of my favorite activities that we host here in Pinellas and Hillsborough County. Every month, we host a support group, called Coffee Talks, for families who have children with disabilities. The support group is a way for families to be able to come together to share their stories and gain information about how they can better support the needs of their children. As part of the support group that we host, we bring in other agencies from around the different counties that provide services free of cost or out of sliding scale for families to be able to access. We have heard time and time again from families in the support group the benefit they've received and their desire to keep this program running.

The website for our F2F can be found at https://fndusa.org/special-healthcare-needs-resources/. There you can find some of the resources available to your constituents. Data about our F2F's services can be found at http://bit.ly/2VYABrn. I would be more than happy to provide additional information about our F2F. I can be reached at Jwells@fndfl.org (727) 523-1130.

Sincerely,

Janell Wells

Director of Family STAR, Florida Family to Familie Health Information Center

CC:

The Honorable Frank Pallone

The Honorable Greg Walden

The Honorable Anna Eshoo

The Honorable Michael Burgess, MD



May 30, 2019

The Honorable Kathy Castor United States House of Representatives Washington, DC 20515

Dear Representative Castor:

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 Project Director of the Family-to-Family Health Information Center (F2F) in Florida, I would like to provide you with some information about our F2F, Family STAR.

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The Honorable Greg Walden

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May 31, 2019

The Honorable John Sarbanes United States House of Representatives Washington, DC 20515

Dear Representative Sarbanes:

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 Maryland, I would like to provide you with some information about our F2F, The Parents' Place of MD.

We are a free-standing nonprofit organization; Family Voices of MD and we serve families for the entire state. Our federal grant is \$96,700 per year.

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In MD there are 200,000 children who meet the definition of a child with a special healthcare need. This means that this would fill 5,545 schools uses that would span the Bay Bridge 9 times! PPMD is here to help families navigate the complex world of the healthcare and educational system so that children with special healthcare needs have the best outcomes to live their fullest lives.

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Sincerely,

Rene Averitt-Sanzone Executive Director

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



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 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 eighthour, 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. 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
517-324-7396

Julie Moore, Co-Project Director Design, Evaluation, & Data <u>iamoore@mphi.org</u> 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 Debbie Dingell 116 Cannon House Office Building Washington, DC 20515

Dear Representative Dingell,

Michigan Family Voices is an organization that works in partnership with decision-makers at all levels to make a positive impact on policy for children and youth with special health care needs. We are reaching out to you because you are a champion for children and families, especially those with special health-care needs.

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).

This Act will extend funding for Family-to-Family Health Information Centers (F2FHIC) in the country through FY 2024. There has been an F2F in each state (including Michigan) and the District of Columbia since 2009, when the program was fully phased in. And thanks to a 2018 amendment to the program, there are now additional F2Fs in American Samoa, Guam, Puerto Rico, the Northern Mariana Islands, and the U.S. Virgin Islands, plus three F2Fs dedicated to serving American Indian and Alaska Native families.

F2Fs support families helping families of children with complex needs to obtain and find assistance, information, and education to care for their children. Despite their modest budgets, F2Fs served nearly one million families in 2018.

Michigan has over 2,256,400 children. Of which 18.4% have special health care needs (above the national average of 15.1%). The percentage of households with one or more children with special health care needs is 26.8%. Again, above the country's average of 23%. The statistics for children in southeast Michigan are even higher.

Because of our state's and your districts need; we ask that you consider supporting or even co-sponsoring the Family-to-Family Reauthorization Act of 2019 (H.R. 2822), bill with Representatives Upton and Representative Sherrill.

If you have any questions please don't hesitate to contact us at (313) 408-3867,

Coltra Co-Director

Co-Director



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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Sincerely,

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517-324-7396

Julie Moore, Co-Project Director Design, Evaluation, & Data <u>iamoore@mphi.org</u> 517-324-8331

cc:

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



The Honorable Susan Brooks United States House of Representatives Washington, DC 20515

Dear Representative Brooks:

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 Indiana, I would like to provide you with some information about our F2F, Family Voices Indiana.

We are a free-standing nonprofit organization located in Fishers, but 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 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. One of our staff is a bilingual, bi-cultural Spanish speaker and all of our materials are available in both English and Spanish.

We recently assisted a family from the Fort Wayne area who child's epilepsy was escalating to the point where he was in danger of losing his applied behavior analysis (ABA) therapy. Family Voices Indiana was able to help the child's mother sift through her options and eventually define a course of action. Mom was able to identify a new ABA provider who took her insurance and welcomed her son. As a result, her son is thriving, she was able to keep working and the family maintained stability.

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.

There are approximately 1.6 million children ages 0-17 years in Indiana of whom 22.6% have special health care needs (vs. 19.8% U.S.). Family Voices Indiana is committed to assisting as many of these families as possible. We do this through one-on-one support and through partnership with state and community organizations across the Indiana. Among the organizations with which we partner are Covering Kids & Families of Indiana, the Indiana State Department of Health, About Special Kids and IN*Source (the state's Parent Training Information Center). We share with these organizations a commitment to family-centered care.

The website for our F2F can be found at www.fvindiana.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/affiliates/. 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 holly@fvindian.org, 12175 Visionary Way, Suite 1360, Fishers, IN, 46038, or 317-374-7857.

Sincerely,

Holly Wheeler

Executive Director

Holly Wheden

cc:

The Honorable Frank Pallone The Honorable Greg Walden The Honorable Anna Eshoo

The Honorable Michael Burgess, MD



The Honorable Larry Bucshon, MD United States House of Representatives Washington, DC 20515

Dear Representative Bucshon:

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 Indiana, I would like to provide you with some information about our F2F, Family Voices Indiana.

We are a free-standing nonprofit organization located in Fishers, but 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 www.fvindiana.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/affiliates/. 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 holly@fvindian.org, 12175 Visionary Way, Suite 1360, Fishers, IN, 46038, or 317-374-7857.

Sincerely,

Holly Wheeler

Executive Director

Holly Wheden

cc:

The Honorable Frank Pallone The Honorable Greg Walden The Honorable Anna Eshoo

The Honorable Michael Burgess, MD

Mass Family Voices F2F HEALTH INFO CENTER

– A project of the Federation for Children with Special Needs

May 28, 2019

The Honorable Joseph Kennedy United States House of Representatives Washington, DC 20515

Dear Representative Kennedy,

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 Project Director of the Family-to-Family Health Information Center (F2F) in Massachusetts I would like to provide you with some information about our Massachusetts Family Voices/F2F.

We are housed at the Federation for Children with Special Needs (FCSN) in Charlestown, MA but we serve families in the entire state. Our federal grant is \$96,750.00 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. The Federation for Children with Special Needs has a robust outreach staff that works in the Vietnamese, Chinese, Hispanic, Portuguese, and Somali and Haitian-Creole communities.

The MA F2F, as part of the FCSN, collaborates extensively with these outreach specialists to empower and educate families in these communities. An example of this collaboration occurred in 2018 when the Massachusetts Family Voices/F2F and the Vietnamese Health and Education Outreach Coordinator spent several months with representatives from Mass Health explaining the need for communication with the Vietnamese community in their native language. Highlights of the collaboration include the translation of the Mass Health enrollment guide into Vietnamese and a community event that included representatives of Mass Health, Mass Family Voices/MA F2F, interpreters and parents from the Vietnamese community with children with special health needs including mental health. The Mass Health representatives, with the help of the interpreters were able to provide 1:1 assistance to the Vietnamese parents and solve issues they were facing with ACO (Accountable care Organization) selection and continuity of care for their child. A Vietnamese mother stated tearfully this was the first time she had someone respectfully listen and help her with insurance issues. This event empowered these Vietnamese parents to work with Mass Health in the future and to help other members of their community.

Recently the MFV/F2F helped a single Hispanic mom from Newton resolve an issue caused by communication barriers. Mom's current Mass Health program was ending and she was having great

difficulty finding a new Mass Health plan that would address all of her child's behavioral health needs. This change in Mass Health status would potentially cause a disruption of services for her young child. Because of the language barriers, mom was unable to communicate her problem to the Mass Health or Health plan customer service. Through MA/F2F relationship with the plan provider, we were able to connect mom with our professional partner to resolve the issues for this child.

The Massachusetts F2F continues to collaborate with the outreach specialists at the Federation for Children with Special Needs to bring essential information to communities in which language and culture are barriers. After attending an F2F training and calling for one-to-one assistance, a mother from the Chinese community emailed "Mass health premium is available to us as of today. I want to thank you for helping our family".

Mass family Voices /F2F often helps families navigate the complicated Mass Health Common Health application system. One parent emailed, "I really cannot thank you enough for your wealth of knowledge. I mean it when I say our short conversation was more beneficial than any other avenue I have taken this far to understand mass health."

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 MA Family Voices/F2F Listserv facilitates a problem solving forum for families and professional partners throughout the state. The questions posted receive accurate answers and often creative solutions. This provides families an opportunity to share and learn from lived experience. For many this listserv is an entry point into family leadership. It is recognized by state agencies and organizations across Massachusetts as a valuable tool for parents. At a recent Panel Discussion at Boston Children's Hospital the participant from AANE (Asperger/Autism Network) highlighted the MFV/F2F listserv as one of the best ways in the state for parents to share experiences and find solutions.

MA Family Voices/F2F provides trainings on health care financing, health care transition, care coordination, and family leadership. The MA F2F has a conference annually for about 100 families. In addition the MA Family Voices/F2F is part of the annual FCSN Vision of Communities Conference. Over 1000 families attend this one day conference in March. The Conference presents a full day program in English, Chinese, Vietnamese, Arabic, Haitian-Creole, Spanish and Portuguese. Free buses help families from around the state attend the conference including families in Southern Massachusetts.

The Mass Family Voices/ F2fF collaborates with many professional partners and state agencies throughout Massachusetts. The includes Department of Public Health, Department of Mental Health, Health Care for All, ARC, Mass League, Boston Children's Hospital, Mass General Hospital, Fetal Alcohol Syndrome, Children's Health Access Coalition, Medicaid Advocates Committee, New England Regional Genetics Network, MA Chapter of the American Academy of Pediatrics, Community Catalyst and many community health centers.

The website for our F2F can be found at https://fcsn.org/mfv/f2fhic. 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_MA-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 pnemia@fcsn.org or 617-236-7210.

Sincerely,

Pat Nemia

Pat Nemia Program Coordinator MassFamily Voices/F2F Health Information Center The Federation for Children with Special Needs The Schrafft Center 529 Main Street 1M3, Boston MA 02129

Phone: 617-236-7210, ext. 301

Fax: 617-241-0330

www.fcsn.org

cc:

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

Mass Family Voices F2F Health Info Center. The Family to Family Health Information Center is federally funded through a grant (6 H84MC08005-03-03) from the
Integrated Services Branch, Division of Services for Children with Special Health Needs (DSCSHN) in the Federal Maternal and Child Health Bureau (MCHB), Health Resources and Services Administration (HRSA), Department of Health and Human Services (DHHS). HRSA/MCHB Project Officer: The opinions expressed herein do not necessarily reflect the policy or position nor imply official endorsement of the funding agency or working partnerships
The opinions expressed herein do not necessarily reject the policy of position nor imply official endorsement of the funding agency of working partnerships
The Schnefft Center Tee Mair Street Switz area Deet Mary 1
The Schrafft Center 529 Main Street, Suite 1102 Boston, Massachusetts 02129



May 31, 2019

The Honorable John Sarbanes United States House of Representatives Washington, DC 20515

Dear Representative Sarbanes:

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 Maryland, I would like to provide you with some information about our F2F, The Parents' Place of MD.

We are a free-standing nonprofit organization; Family Voices of MD and we serve families for the entire state. Our federal grant is \$96,700 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. Maryland is considered in the top ten of highest concentration of military families due to compassionate reassignment and because of our excellent medical facilities; Johns Hopkins, Kennedy Krieger and University of MD to name just a few.

In MD there are 200,000 children who meet the definition of a child with a special healthcare need. This means that this would fill 5,545 schools uses that would span the Bay Bridge 9 times! PPMD is here to help families navigate the complex world of the healthcare and educational system so that children with special healthcare needs have the best outcomes to live their fullest lives.

The website for our F2F can be found at www.ppmd.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/wpcontent/uploads/2018/02/2016_MD_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 rene@ppmd.org or 410.768.9100 ext 101.

Sincerely,

Rene Averitt-Sanzone Executive Director

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