



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

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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; 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. 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 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

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