

**Advancing Care for Exceptional Kids Act of 2015**

**Energy and Commerce Committee**

**Subcommittee on Health**

*Testimony*

*by*

*Letitia "Tish" West*

*Parent of a Medically Complex Child*

*and Volunteer*

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Room 2322 of the Rayburn House Office Building

Washington, DC

## **Summary Points**

Letitia “Tish” West, parent of a medically complex child

\*Families are completely unprepared in every way for the enormous task of caring for a child with complex medical problems.

\*Most doctor offices are unprepared for advising families and for caring for children with complex medical problems and are not qualified to diagnose rare conditions.

\*Parents cannot continue to work and provide for their families when there is a medically complex child in the home.

\*I have seen first-hand how beneficial it is to have a clinic that coordinates care for my daughter, other children, and families through the Chronic-Complex Clinic at St. Joseph’s Children’s Hospital of Tampa. It is an exceptional model that should be replicated around the country and used as the standard for providing a medical home for children with complex medical conditions.

## **Written Testimony**

Submitted July 5, 2016

Letitia “Tish” West, parent of a medically complex child and volunteer

### **The Journey of the Family of Caroline West**

My name is Tish West. I am the mother of Caroline West. On behalf of my daughter and the millions of medically complex children in Florida and across the country, I thank you for devoting time to discuss how we can better serve the most medically vulnerable children in our county. I would particularly like to thank Congresswoman Kathy Castor, our long time champion and original sponsor of this bill. I'd also like to thank Congressman Gus Bilirakis, another Tampa Bay member, who cares deeply about this issue. Additionally, I would like to thank Ranking Member Frank Pallone. Congressman Pallone travelled to Tampa to see the Chronic-Complex Clinic, where Caroline and nearly a thousand other children receive life saving care at St. Joseph's Children's Hospital. Chairmen Upton, Pitts, Ranking Members Green and Pallone, and the entire subcommittee on Health, I am deeply honored to be here today to testify.

My daughter, Caroline, was born on January 7, 1997. She is 19 years of age. Caroline has a rare neurological condition known as, Alternating Hemiplegia of Childhood. This disease affects approximately 800 people worldwide. Her condition affects every aspect of her life. She has seizures, cannot eat by mouth, is confined to a wheelchair, is developmentally delayed and has cerebral palsy. She has been

hospitalized for full spinal fusion, chronic pneumonia and seizures that have been uncontrolled for as long as 12 hours. She is currently on seizure medicine that she takes three times a day, does breathing treatments twice a day, has physical and speech therapy twice a week, is on a specialized diet to control seizures and attends a specialized school. It takes 29 different specialty care providers to maintain her health and welfare.

In the early part of Caroline's illness she would cry for hours on end. She had uncontrolled seizures and could not eat or participate in outdoor activities. Her sensory system was so delicate that the slightest change in her environment would cause seizures, posturing and pain. Through the advice of many doctors and therapists, and medicine and diet, her condition has improved over the years. Currently, Caroline is a happy child with an infectious smile and a happy disposition. Her improved health over the years is largely due to the wonderful health care that we have received from the doctors and staff at St. Joseph's Children's Hospital of Tampa.

Before Caroline was born I was working in an executive job at Barnett Banks of Florida and was on an advanced promotional track. As is the case of many parents of children with complex illnesses, I did not have the luxury of continuing to work. Her care was extensive and rigorous and required constant monitoring. Further, she did not have a diagnosis at the time so we were very busy visiting doctors and running tests to identify her illness. The first step in treatment is identifying a diagnosis. This diagnostic process took us to Boston Children's Hospital, Miami Children's Hospital, Columbia Medical Center and The University of Chicago Children's Hospital to see various specialists and experts on rare diseases. All this travel and testing was funded personally. Insurance would not cover the expenses at the various hospitals out of our area.

During this time our family was under an enormous amount of stress both emotionally and financially. I had just left a high paying job. We were paying out of pocket for travel. We were paying for expensive medicines that were not covered by insurance. Many of her necessary therapies were not covered by insurance. There were expensive tests at out of state hospitals that were not covered by insurance and we had been denied by Florida's Medicaid Waiver Program. Our family was in an emotional crisis. We were unprepared for the isolation that having a child with disabilities presents. Since all my friends were primarily my past coworkers, I did not have a strong support system. We were navigating uncharted territory alone.

The ACE Kids Act is important in many ways, but one critical component is that it will hopefully establish more medical homes or health homes for this population of children. A medical home for complex kids is a rarity. We know first hand. Our primary pediatrician was a highly educated individual who we respected greatly. However, he was not experienced in dealing with children with chronic and complex illnesses.

We were an unusual site in the doctor's office and did not always feel comfortable visiting the doctor. Our questions would often go unanswered. We were a puzzle to our doctors. We were visiting many specialty doctors and had a difficult time getting the doctors to consult with each other. There was an occasion in the diagnostic process that we had to be admitted to the hospital just to get our various providers to talk with each other. After years of bouncing around with doctors, we learned about a new clinic, the Chronic-Complex Clinic at St. Joseph's Children's Hospital of Tampa. Moving to this Clinic was life changing for Caroline and for our family.

The Chronic-Complex Clinic has been in existence for 14 years. The doctors and nurses are very experienced in treating children with complicated medical problems and severe disabilities. All 800 patients of this Clinic are categorized at the highest levels of complexity. The Clinic is co-located on the campus of St. Joseph's Children's Hospital of Tampa with every sub-specialty on the same floor. The doctors in the Clinic are also Hospitalists, which means that if Caroline is admitted into the hospital she will see the exact same doctors that she sees as an inpatient and they in turn will be familiar with her. This structure is highly efficient and effective and has the benefits of a true medical home. This means faster treatment, less time in the hospital and better outcomes. If specialists are needed during our office visit that appointment is made at the time of her visit or the consult is often accomplished during the same visit. This means less time in between seeing the attending and seeing the specialist which again means faster treatment and better outcomes. This Clinic is one of two of its kind in Florida and only a handful in the county. ACE Kids will hopefully incentivize, through financial reimbursement and outcomes-based reporting, the establishment of more medical homes for kids like Caroline across the county.

We are the "normal" at our Clinic. We are not an outlier. Since coming to the Clinic, Caroline's health has improved and her hospitalizations have been reduced tremendously. Our family feels welcome and embraced at the Clinic. All the nurses and staff know Caroline and our family. There is support through family activities and holiday events. Through the Clinic we have made many friends and have received support in every aspect of our caregiving of Caroline. Our entire family has benefited from this Clinic.

As you review ways to deliver medicine to children with chronic and complex issues I would urge to look closely at the model and structure of this Clinic. Our Clinic works because of the high degree of specialization. The criteria you put into place for ACE Kids needs to ensure that these medical homes are for the most medically complex and the institutions (like St. Joseph's Children's) have all of the clinical and psychosocial resources to support this approach to care. Diluting this care to every pediatrician would not accomplish the outcomes that we have experience through this model.

We were finally approved for the Medicaid Medical Waiver Program which allowed us to augment our private insurance with Medicaid. This was a lifesaver for us. We are hard workers and have always believed in taking care of ourselves and not relying on the welfare of others. We would never have imagined that we would have needed to rely on a government program for the health care of one of our children. However, I am grateful and thankful for the program.

Lastly, I am not here only testifying for myself and for Caroline. I am here for the thousands of families that are not able to speak for themselves. This legislation is urgently needed.

My daughter Carline is approaching adulthood. We had a lot of misfires and missteps along the way. I can only hope that through stories like mine and through the ACE Kids Act that families with young children will have more ease in navigating a health care system not designed for our most medically complex children.

Respectfully,

Letitia "Tish" West