

Testimony of Elena Hung, Co-founder of Little Lobbyists
Hearing: Texas v. U.S.: The Republican Lawsuit and Its Impacts on Americans with Pre-Existing Conditions
Subcommittee on Health (Committee on Energy and Commerce)
February 6, 2019

Good morning. Thank you for the opportunity to tell my story and share my concerns with you today.

My name is Elena Hung, and I am a mom. I'm a proud mom of an amazing 4 year old.

My daughter Xiomara is a happy child; she is kind and smart and funny, and a little bit naughty. She is the greatest joy of my life.

She is at home right now, getting ready to go to school. She attends an inclusive, special education Pre-K program. I asked her if she wanted to come with me today, and she said she wanted to go to school instead.

It has been a long road to this moment.

Xiomara was born with chronic, complex medical conditions affecting her airway, lungs, heart, and kidneys.

She spent the first five months of her life in the Neonatal Intensive Care Unit.

She uses a tracheostomy tube to breathe and a ventilator for additional respiratory support. She relies on a feeding tube for all of her nutrition.

She participates in weekly therapies to help her learn how to walk and talk.

I am thrilled to tell you that Xiomara is thriving today.

This past year was her best year yet, health-wise. Ironically, it was also when her access to health care has been the most threatened.

I sit before you today because families like mine -- families with medically complex children -- are terrified of what this lawsuit may mean for our kids.

You see, our lives are already filled with uncertainty -- uncertainty about diagnoses, uncertainty about the effects of medications and the outcomes of surgeries. The one certainty we have is the Affordable Care Act and the health care coverage protections it provides.

We don't know what Xiomara's future holds, but with the ACA's protections in place, we know this:

We know Xiomara's ten pre-existing conditions would be covered without penalty even if we switched insurance plans or employers.

We know a ban on lifetime caps means that insurance companies cannot decide her life isn't worth the cost and cut off her care just because she met some arbitrary dollar amount.

We know we won't have to worry about losing our home as a result of an unexpected hospitalization or emergency.

We know Medicaid will provide the therapies and long-term services and supports that enable her independence.

I sit before you today on behalf of families like mine who fear that the only certainty we know could be taken away pending the outcome of this lawsuit -- this lawsuit that seeks to eliminate protections for people with pre-existing conditions. And if that happens, our children's lives will then depend on Congress, where every so-called "replacement plan" proposed over the past two years has offered far less protection for our kids than the ACA does.

I sit before you today on behalf of:

Isaac Crawley, who lost his insurance in 2010 after he met his lifetime limit just a few weeks after his first birthday, but got it back after the ACA became law.

Myka Eilers, who was born with a pre-existing congenital heart defect and was able to obtain health insurance again when her dad opened his own business after being laid off.

Timmy Morrison, who spends part of his childhood in hospitals (both inpatient and outpatient) because his insurance plan covers what is essential to his care.

Claire Smith, who has a personal care attendant and is able to live at home with her family and be included in her community thanks to Medicaid.

Simon Hatcher, who needs daily medications to prevent life-threatening seizures -- medications which cost over \$6,000 a month without insurance.

Colton Prifogle, who passed away on Sunday, was able to spend his final days pain-free, with dignity, surrounded by love, because of the hospice care he received.

These are my friends. These are Xiomara's friends. This is our life.

I co-founded the Little Lobbyists -- this group of families with medically complex children -- because these are stories that desperately need to be told and heard alongside the data and numbers and policy analysis.

There are children like Xiomara in every state -- that's millions of children with pre-existing conditions and disabilities across the country.

I sit here before you today on the eve of another trip to the children's hospital. Tomorrow, I will hold my daughter's hand as I walk her to the OR for her procedure. As I have done every time before, I know I will drown in worry (as a mother does), but the thing that has always given me comfort is knowing that my government believes my daughter's life has value and that the cost of the medical care she needs to survive and thrive should not financially bankrupt us. It is my plea for that to always be true.

Thank you.

Elena Hung is Xiomara's mom, the co-founder of [Little Lobbyists](#), and a national co-chair of [Health Care Voter](#).