

****EMBARGOED UNTIL THURSDAY, AUGUST 16, 2018, AT 10:00a.m.****

**Testimony of Elena Hung
DPCC Hearing – August 16, 2018**

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.

In a few weeks, my daughter Xiomara will be going back to school, starting pre-K 4, at the inclusive, special education program that she loved so much last year. We have had a lot of fun this summer: going to the pool, the playground, the library, and our favorite, to baseball games.

This was not always a given. 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 was born with ten pre-existing conditions and spent the first five months of her life in the Neonatal Intensive Care Unit.

She uses a tracheostomy 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, talk, and eat by mouth.

I am thrilled to tell you that today, Xiomara is thriving. She is happy; she is kind and smart and funny, and she is the greatest joy of my life.

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

The threats have come from every angle with ongoing Congressional repeal efforts, harmful regulations, a federal lawsuit in Texas, a budget that cuts funding to life-saving Medicaid programs, and most recently, a Supreme Court nominee with a hostile record against those with pre-existing conditions and people with disabilities.

Xiomara has made incredible progress, and I am terrified that that progress will be taken away.

Families like mine, families with medically complex kids, are terrified. That is why we started speaking up, so we can share what is possible with access to health care and what is at stake without it.

As the Little Lobbyists families and I watched the news of repeal efforts unfold last year, we asked ourselves: How can the party that claims to be “pro-life” and “pro-family” be leading the charge to repeal the protections that saved our babies’ lives and saved our families from bankruptcy?

How can lawmakers talk about supporting our children but cast votes to take their health care away? How is that “pro-life”?

Choosing life, like I did, is not a decision you make once; it is a decision you make over and over and over again, every single day. It is a decision you make with the support of your government, with the support and protections of the Affordable Care Act, that says your baby’s ten pre-existing conditions will never prevent her from getting the care that she needs to survive and thrive.

In every decision before me, I chose life for Xiomara.

I chose life throughout my prenatal care, as I attended one maternal-fetal specialist appointment after another.

I chose life every single one of the 169 days that I spent at her NICU bedside.

I chose life with every medical procedure.

Every surgery, starting with her heart surgery at 11 days old.

Every discharge to go home, and every 911 call, ambulance ride, and hospital readmission that followed.

Every medical appointment.

Every therapy session.

Every piece of life-saving medical equipment.

Every box of medical supplies that gets delivered to our home on the first of the month.

Every medication.

Every specialist.

Every second opinion.

I chose life for Xiomara every single day.

That is what “pro-life” is. That is what health care is.

Health care is coverage for her ten pre-existing conditions without penalty.

Health care is insurance that does not put a lifetime cap on her care, which cost over \$3 million before she turned one.

Health care is emergency care, hospitalizations, and specialists: all essential health benefits.

Health care is Medicaid that pays for the therapies that support her independence.

Health care is long-term services and supports that tells people with disabilities that they have a right to live their lives in their communities as they choose.

I co-founded the Little Lobbyists because these are stories that desperately need to be told and heard. There are thousands of children like Xiomara in each of your states -- that's millions of children with pre-existing conditions across the country -- who deserve a shot at life. There are millions of families being harmed right now, filled with anxiety about our future because of our government's ongoing attacks on our health care.

I am asking the members of Congress to work together so I can watch my daughter Xiomara grow up, so all the Little Lobbyists families can watch their children reach their greatest potential.

I am here to remind every member of Congress that you work for us. At the end of the day, if you are not working to protect our kids, we will work to elect those who will.

Children's health should not be a partisan issue.

I know we can be better. Let's do better. For our children.

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