



**Advocating for Kids with Complex
Medical Needs & Disabilities**

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TESTIMONY OF STACY STAGGS BEFORE THE SENATE JUDICIARY COMMITTEE

I want to thank the members of this committee for the opportunity to raise my voice against the nomination of Amy Coney Barrett and in support of the Affordable Care Act and to share my family's story.

While I appear alone in this room, I bring with me millions of families, including 130 Million Americans who live with pre-existing conditions, and millions of Americans who dissent from this hearing and any confirmation to the Supreme Court before Inauguration Day.

My name is Stacy Staggs, though I'm more frequently addressed as "mommy" (with ASL sign). I live in North Carolina with my husband and twin girls, who both have complex medical needs and disabilities. I advocate for their health care, education and community inclusion with Little Lobbyists, a family-led organization advocating for children like my own. I am here today because Judge Barrett has repeatedly made statements hostile to the Affordable Care Act. A vote for Judge Barret is a vote to take away health care. A vote for Judge Barrett is a vote to strike down the law that saved the lives of my daughters. And my family is one of many.

Studies confirm the ACA has saved thousands of lives, especially in states that accepted Medicaid expansion. My family is a real-life example of the ACA's success. My twin daughters, Emma and Sara, are adorable and active 7 years olds. They are the lights of my life as we balance a busy schedule of therapies and distance learning. Sara Bean is a nature lover, happiest when she's splashing in the water or digging in the dirt. Emma has a smile that lights up her entire face! Her favorite day is Tuesday when we go to the farm for therapeutic horseback riding! I look at them with love and amazement, as I'm sure you do for your own children. But, seven years ago, their recent birthday would have been too much to hope for.

My husband and I were excited to learn we were expecting. We were surprised to learn we were having twins. I had excellent prenatal care -- one of the ten essential health benefits under the Affordable Care Act. My pregnancy was going great...until one day, it wasn't.

I was experiencing pain, so my doctor suggested I come down to the hospital for monitoring. Within hours my vital signs faded and I was rushed to the operating room. Our small wonders were born via emergency c-section at 28 weeks and rushed to the Neonatal Intensive Care Unit where their survival was far from assured. We sat in vigil for weeks, learning an entirely new language of medical terms and holding our breath between



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heartbeats on their monitors. I wasn't able to hold either girl for the first several weeks, but they were about the size of my hand, with IVs in every extremity and skin so fragile you could see through.

Emma's birth weight was 11b 9oz. She has never taken an unassisted breath or made a sound, due to vocal cord paralysis. She has an artificial airway through a breathing tube, and she eats through a feeding tube that was surgically placed when she was 3 months old.

Her twin sister Sara was the bigger newborn at 2lbs. She needed heart surgery at 2 weeks old, and that was the day percentages took on a new meaning for me. The surgeon told us his success rate for Sara's procedure was 98%. Then he said, and I will never forget, "but that doesn't mean much to the parents of the 2%." To this day, when I hear data points and discussion (about recovery rates from COVID-19, for example), I am transported immediately back to that moment in the surgical waiting room.

When I was finally able to bring my babies home from the hospital the first time, after 110 days, we received an Explanation of Benefits with total claims nearly one million dollars. In their first 7 years, our combined claims have surpassed four million dollars. Without the protections of the ACA, my daughters would have already hit their lifetime cap and would now be uninsurable.

We have primary insurance through my husband's employer, and Medicaid support which has been a lifeline for Emma, who needs 24hr "eyes on" care. Medicaid provides Emma with home and community based services, including nursing, that helps us keep her home, where she belongs, instead of living in a hospital or other medical facility.

Our country is in a public health crisis right now, one that gets worse by the day. In this moment, we need our legislators to protect our families; to provide relief and support; to do the job we elected them to do. We do not need to rush through the nomination of a Supreme Court Justice who is on the record as hostile to the law that provides our health care protections. Shifting the focus away from a relief package for families, during a pandemic, tells me that this committee's priorities are not aligned with those of the American people. I urge you to listen to us and address the immediate need for COVID relief.

Thank you for the opportunity to give my testimony: to say "health care is a human right" and "decency matters." And to remind you that as your constituents, my children and children like mine are your children, too. I hope that you will remember your duty to all our children as you cast your vote to protect - or take away- the health care they depend on to survive and thrive.