## United States Senate Judiciary Committee Hearing: The Nomination of Brett Kavanaugh to be an Associate Justice of the Supreme Court of the United States

## September 7, 2018

## Prepared Statement of Jackson Corbin

Chairman Grassley, Ranking Member Feinstein, and distinguished members of the Senate Judiciary Committee,

I am privileged to represent 130 million people with pre-existing conditions today, and I am grateful for the invitation to testify before you.

My name is Jackson Corbin, and I am thirteen years old. I am a lot like other teenagers. I love comic books, Marvel movies, and playing Minecraft and Fortnite with my friends.

Ten years ago, my brother, mother, and I were all diagnosed with Noonan Syndrome, a genetic condition that affects various systems of the body. As a result of my Noonan Syndrome, I have a lot of pre-existing conditions. Noonan Syndrome affects my growth, so I will never be as tall or as strong as other people my age. I have stomach issues, reflux, and I get really bad headaches.

My most severe condition is my Von Willebrand Disease, a form of hemophilia. This means that I cannot play contact sports, or do things like rough house, roller skate, or jump on trampolines.

I take medication to control my reflux and to clot my blood if I get hurt. Having my clotting medicine at home means that I don't have to go to the emergency room every time I lose a tooth or get a bad bruise or cut.

My brother, Henry, is my best friend. He is ten and a half, and he has Noonan Syndrome, too. We do everything together, including going to all of our specialist visits. My mom always says that the greatest thing she ever did was to give the two of us to each other.

Noonan Syndrome affects everyone differently, so in addition to having all of the same conditions as me, including Von Willebrand Disease, Henry has even more special health care needs than I do.

When Henry was a baby, he had to have life-saving stomach surgery and a blood transfusion. Now he has what's called gastroparesis, which means he vomits almost every day, sometimes even in his sleep. The medicine he takes helps, but not all the time.

We share a room, and at first it was scary to see Henry vomit in his sleep, but now I am used to it. When I hear him gagging, I roll him over so he doesn't choke and I run to get my parents. Henry also has heart problems and asthma.

I worry about Henry, a lot.

I have heard my mom and dad say that they are grateful for our insurance because the cost of our care is more than my family makes in a year. That means that if the Affordable Care Act is repealed, and Henry and I lose insurance, my parents will not be able to afford to pay for our care.

I have been fighting for health care for nearly two years. Last year, in the first speech I ever gave on the lawn of the Capitol, I compared myself to Dr. Seuss' The Lorax. The Lorax says, "I am the Lorax and I speak for the trees," and so I said, "I am Jackson, and I speak for the children." I said that because I had met so many children with special health care needs who are unable to speak for themselves. I wanted to be their voice.

But as my journey continued, I met even more children – and adults – who have pre-existing conditions, and who – like me and Henry – are scared for their future. I realize that I don't only speak for the children anymore.

Today, especially, I speak for everyone.

I speak for myself, Henry, and all the other children across the country with special health care needs.

I speak for the parents who struggle with their own health issues while caring for their children - including my own mom, who has Noonan Syndrome, too.

I speak for every person with disabilities who high fives me in the Senate hallways as they fight for our care.

I speak for every person with disabilities who will never be able to live independently.

I even speak for the man who has Lupus who altered the suit that I'm wearing today.

Most importantly, I speak for every American whose life could change tomorrow with a new diagnosis.

My Noonan Syndrome is a part of who I am. It's been a part of me since the day I was born, and will be a part of me for the rest of my life. If you destroy protections for pre-existing conditions, you will leave me and all the kids and adults like me without care or without the ability to afford our care – all because of who we are.

We deserve better than that.

I might be a kid, but I am still an American. The decisions you are making today will affect my generation's ability to have access to affordable health care. Adults talk about investing in their future. Well, we *are* your future. Invest in us.

Protections for pre-existing conditions will continue to be challenged in the Supreme Court as long as people disagree with the ACA. We must have justices on the Supreme Court who will save the Affordable Care Act, safeguard pre-existing conditions, and protect our care. Please give us the chance to be healthy, to grow up, and to lead this country one day.

I know I want that chance.

Thank you.