Chairman Lipps, Vice Chair Manning, Ranking Member Boyd, and members of the House Health Committee, thank you for the opportunity to testify today regarding House Bill 243, Madeline’s Law, with my joint sponsor, Representative Russo.

Hello, my name is Nicole White. I am a Molecular Biologist who works in Research Administration at Cincinnati Children’s Hospital, which is the best hospital in our state (sorry Nationwide Fans). Today, I’m here to talk about my daughter, Kathryn. Kate is 4.5 years old and the youngest of four children. She loves playing with dolls, her older sister, and cat, named Dawn.

As some of you may have already observed, Kate has Down syndrome. She sees many specialists for health conditions that are associated with Down syndrome. These health conditions have a huge impact on her future. Today, I’m here to talk about her hearing, the condition that will affect her future the most. To date, Kate has had fourteen surgeries on her ears for a condition called chronic otitis media, or in layman’s terms, ear infections. Chronic ear infections are common among children with Down syndrome because of their smaller anatomy. Kate has had *fourteen* surgeries to place set after set of tubes in her ears in the hope that the fluid in her ear will drain so she can hear. To understand what she hears, you can try to put your fingers in your ears and swish them around. That is about as close to what I can imitate for you what she lives with daily.

That was Kate’s life until she received a trial run at using what is called a bone conductor hearing aid. It’s a non-invasive assisted hearing device that allows for sound to travel on the bone around the base of her ear and get to her cochlear nerve, which sends sound waves to her brain to interpret sound. With the Oticon Ponto 4 hearing device, we can bypass her chronic ear infections and she can hear.

I was not prepared for the cost of these hearing aids. I had to pay more out of pocket for her hearing aides than the fourteen surgeries she had, combined. Why? Because hearing aides are not covered by health insurance, not even by my employer, who is the #3 Children’s hospital in the country. As a person who sets rates for research services at CCHMC, a position where we are mindful of the valuable NIH grant dollars our Investigators acquire, it blows my mind that fourteen surgeries cost less to me, as a parent, than a bone conductor device. All because health insurance does not cover them.

Kate has a hearing aid now; she can hear. I have been able to have a turn-taking conversation with my daughter for the first time. She is now putting together two and three word phrases. Her teachers have emailed me and told me how much improvement they have seen in her ability to follow directions, to manage her behavior in class, and to interact with her peers.

We paid almost $5,000 dollars out of our own pocket for Kate to have her hearing aids. We pulled funds from our Health Savings Account, which left us with little to cover any other expenses that may come up, but seeing Kate talk to me, her peers, and her teachers is priceless. All of these interactions will set her up for a successful future. Our goals for Kate are to graduate from high school, and be employed with a good job - possibly working with her older brother who wants to start a restaurant.

This is what this bill means to us.