

March 7, 2017

Oregon Legislative Assembly

Re: HB 2392

To Whom it May Concern:

As a native Oregonian, I am writing in support of the Bill HB 2392 in regards to expanding health benefits for those with hearing loss. Our daughter, Winnie, was born last May in Portland and she was the most beautiful thing we'd ever seen. My husband and I were shocked to learn she failed her newborn hearing screen at two days old. In the first three weeks of her life, we tried our own raw experiments of banging pots and pans and talking loudly around her to see if there was some kind of mistake. When Winnie was just three weeks old we took her in for an Echo and ABR hearing test. She passed the first test with flying colors. Sounds were piped into her ear and came back out the way it is supposed to. The audiologist told us that it was a very good sign, and that the next test was to measure how her brain responded to sounds. Sadly, the test showed that Winnie's auditory nerve was not working correctly, and that she had a very rare form of Deafness called Auditory Neuropathy Spectrum Disorder (ANSD).

We were absolutely devastated. Still in shock, we gathered from that appointment that sign language or Cochlear Implants were likely our only options for her to learn communication skills. The audiologist had limited experience with ANSD, but told us that hearing aids would not help Winnie, because her ears worked perfectly fine, and it was the nerve that wasn't firing correctly. We were also given information about Tucker Maxon Oral School and Columbia Regional Early Intervention Program. My grief was turned into motivation and drive. Besides taking care of my newborn, my mission became to research this disorder and beat the odds and try to do all that we could to give her the best shot at language. Everything I read indicated that Early Intervention is absolutely critical. It was almost like there was a ticking clock in my head and that we were in a race toward an imaginary finish line that was her ability to communicate. We were able to get a tour of the Tucker Maxon School with the EI teacher, Rebecca when Winnie was 6 weeks old.

Everything changed for us when we entered the school. We learned that there were three students who suffered from the same disorder as Winnie, and that they all are able to speak and have access to sound! We also met Shelby, the school Audiologist, and our journey with our new team had begun. We finally had hope! Unfortunately, the financial aid for the year had been already spoken for, and the tuition of \$5500/ year for the Early Intervention at Tucker Maxon needed to be paid in full. After a few trial months of the program, we knew it was absolutely essential and it was not something we could deny Winnie, even for financial reasons. Needless to say, 2016 was also our most expensive year in terms of medical bills, even with health insurance.

In the meantime, we had seen a surgeon about getting us on track for Cochlear Implant candidacy and he explained that Winnie would need to get hearing aids at six months old to see if they helped her, and to rule out surgery if need be. At the school picnic over the summer, we were introduced to parents who had children with hearing loss. Every parent we met gave us the same piece of advice: "Get Winnie hearing aids ASAP, don't wait until she's six months old! Its too late." So, we

mentioned it to Shelby, and she said that we could absolutely bypass the protocol and get her fitted at the next appointment.

Winnie received hearing aids at just 10 weeks old, and at first nothing seemed different. We honestly never believed they would work and that we were just waiting til they could operate on her. Then, after several months wearing her hearing aids upwards of 12 hours per day (even during naps), we began noticing without question that Winnie began startling at the dog barking, or the phone ringing, etc. We were skeptical at first, but now we all know that Winnie is hearing things! It has been explained that it may still be producing an unorganized response in her brain, so it is likely a scrambled signal, but the hearing aids have made her auditory nerve fire in a way that it wasn't for those first few months. We are in the process of figuring out if she still needs Cochlear Implants, but when she turned six months old, we felt so glad that we hadn't waited to get her fitted with the hearing aids! Surely all the progress that was made at that point would have resulted in a further delay.

Since her little ears are growing every day with the rest of her body, Winnie has needed at least 6 or 7 new sets of ear molds since we started this process, dozens of boxes of batteries, and each requires a visit with the audiologist. She has had 3 or 4 more booth tests to measure her progress and keep an eye on changes, and a repeated Echo Test and ABR which cost hundreds of dollars, even with a met deductible. All of these tools are absolutely essential for Winnie's future, and at nearly 10 months old we know that this will continue to be part of her standard of care for a long time.

Unfortunately, the issues (and obvious medical financial burden) don't end with the hearing portion of her health. Winnie has also been a mystery to doctors with her extreme fine motor delays, vision delay, and uncontrollable movements in her arms and legs. She may have a form of cerebral palsy, but it isn't diagnosed yet. Our full team of doctors aside from our Early Intervention Teacher and Audiologist, includes a Pediatrician, Developmental Pediatrician, Speech Pathologist, Nutrition/Lactation Expert, Pediatric Neurologist, Pediatric Endocrinologist, Ophthalmologist, Geneticist, and Physical Therapist. Each specialty requires its own unique tests, labs, and appointments. This is our life now, and each component is extremely important. We do not want to be in a position to have to choose which portion we can afford, although all of it seems ridiculously expensive. If her hearing equipment and accessories were included by insurance without regard to deductibles being met, it would have a huge impact in our financial ability to continue to get Winnie all the best care that we can. Also, having a Case Manager to help us navigate through insurance and resources would have been extremely helpful during the most difficult time of our life thus far.

We hope that consideration is made toward approving this bill. Although most people are lucky enough to never give a second thought to this issue once their child passes their hearing screen, those of us affected would stand to benefit greatly. Please keep our sweet baby, Winnie, in your thoughts when considering how to vote on this bill.

Sincerely,

Jennifer Hoyt