ROBIN BERLIN

1815 WILNELLA SE • GRAND RAPIDS • MICHIGAN • 49506

616.245.3017

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Michigan House of Representatives
Health Policy Committee
c/o Representative Robert Dean

Dear Members of the Health Policy Committee,

My name is Robin Berlin and I am the over-worked, stress-overloaded, sleep-deprived working mother of three amazing boys. My oldest son Benjamin, is 15 and a freshman at Grand Rapids Catholic Central High School on a full-ride four year academic scholarship, he played football this past fall and is now playing basketball. My middle son (in the Superman jimmies), Sam is 8 and is in the third grade at Immaculate Heart of Mary School in Grand Rapids. Sam has severe ADHD, which impedes his ability to learn as quickly as the other children in his class, but what he lacks in academic performance, he makes up for in sheer energy. However, today I am writing to you to tell you the story of my baby boy, Luke and my family's personal struggle with Autism and the lack of insurance coverage for much of the care and therapy that he needs.

Luke has been a gift from God since the day he was born. He is going to 6 years old in just 13 days, and was born on the day after Christmas in 2001, when we buried in snow to our waists from a blizzard! He was induced two weeks early, as I had gestational diabetes while pregnant with him, and was the smallest of my boys, only weighing in at 8 pounds. My two other boys were 9 ½ and 11 pounds at birth. Almost immediately he was a mama's boy, I was the only one that could soothe him, I was the only one he would let hold him, and I was also the only one that could have him in my arms 24 hours a day, because if he was put down for more than about 30 seconds he would scream until I picked him up again. He would also cry if he wasn't being held very tightly or swaddled tightly in a blanket. He never seemed to notice anyone else in his world except for me...

As Luke grew, he seemed to emotionally develop much slower than my two older boys, we spent over two and a half years dealing with ear infections and tubes and finally being told that he had a hearing lose of 80%, we were sent for a special hearing test in which they sedated him, placed electrodes all over his sweet little head and conducted a hearing test, by sending sounds through headphones to his ears, but measuring his brain waves to see if they were responding to the sounds, since he would not respond to them physically. This test actually came back that he had no hearing loss at all. At this point the ear, nose and throat specialist could do no more for us and we were sent to Kenosha. Kenosha is the first step in the process of discovering what a child's special educational needs might be here in Kent County. After filling out reams of forms, and being interviewed by multiple specialists, along with Luke being observed and tested by many of the specialists at Kenosha, it was determined that he had Auditory Processing Disorder. At this point, he qualified for early childhood special education and was placed in a special education pre-school, where we were told they would coax him out of his shell and work towards minimizing the affects of the Auditory Processing Disorder. He began school in February of 2005 and quickly became extremely agitated in

the classroom; he would dart from activity to activity, barely speak to anyone, and generally cause problems when things weren't done the way he wanted them to be. Since he still was barely speaking at this point, he would get even more frustrated as no one discipher what he wanted. The next school year, he was placed into a different class, and again was easily agitated, very disruptive and very hyperactive. His speech had improved dramatically, but he still couldn't covey to the staff what he wanted, or what was bothering him. In a classroom of 8 children with one teacher and one full-time aide, he was still difficult to handle, and the aide had to spend 75% or more of her time with Luke, trying to get him to follow directions, sit still, interact with the other children... The school social worker and teacher decided to test Luke for ADHD. Again we filled out reams of forms and interview and waited. The school felt that he had all the markers of having ADHD and that we should take him to the family doctor. Since our family doctor does not test for ADHD, we were sent to the ADHD Institute at Pine Rest, which is one of the premier facilities in Michigan for the testing and diagnosing of ADHD. In short, we were told by the doctor in charge of his case, that he had a 'disabling' case of ADHD, and that they had never seen a child his age with such a severe case, and that he would never be able to truly function in society and would be able to receive SSI as his condition was so dibiltating. Since the Institute doesn't treat ADHD, we were sent back to the family doctor for medication. After 6 months of trying every ADHD medication on the market, we were finally sent to a child psychiatrist that specializes in pediatric psychopharmacology. Within the first few minutes of observing Luke in his office, he wanted us to go to yet another specialist, as he felt there was more to the picture than ADHD... By this time we had been told he was 80% deaf, had Auditory Processing Disorder, and had debilitating ADHD, and was by then he was being heavily medicated with the maximum dosages available to treat his ADHD...

The pediatric psychiatrist sent us to a developmental psychologist and an occupational therapist. We met with the occupational therapist, and within minutes she pulled in the psychologist, who within seconds told us he felt Luke needed to be tested for Autism. We were devastated, one because all we knew about Autistic children was that they sat in the corner and banged their heads on the wall, and that yet again, most of the costs for the testing would not be covered by our medical insurance. By that time we had already spent thousands of dollars on testing and medications, and special daycare. After more form filling out, more interviewing, more question answering, more observing and more money, we were given a diagnosis of Moderate to Severe Autism, but the good news was he has a very high IQ... This sent both myself and my husband into a free-fall of depression, blame, anger, frustration, and more. It upset our other children, as they didn't understand what Autism was, and thought he was sick and going to die.

Our lives had changed again with the birth of our third son, but it changed forever the day we were told he has Autism. In many ways, once the initial shock has worn off, it is a relief to actually know what is wrong, rather than being strung along not knowing. But now that Luke has been diagnosed with Autism, we have had to kiss any insurance coverage, besides his ADHD medications, goodbye. If we followed the course of treatment recommended by Luke's psychologist, psychiatrist, and occupational therapist, we would be spending over $4,000 a month in out-of-pocket expenses, on a myriad of different intensive therapies. Our family financial situation is not one in which we can afford expenses this high. Nor could one of us quit our jobs to be able to take him from place to place for all of his treatments. We tried to do as much as we could after his initial diagnosis of Autism, but we quickly drained all of our savings, our children's college savings, and changed our entire family's lifestyle drastically to try to keep from drowning in debt. We have even gotten to the point that we are on the verge of foreclosure on our home.

This is unfair. If Luke had been diagnosed with cancer, or diabetes or some other physical, meaning medical, problem our insurance would cover almost everything. If he had been in an accident that

left him paralyzed, insurance would cover therapies to help him learn to walk again, to learn to function in his daily life. If he had childhood cancer, his chemo would be covered, his medical needs would be met. But since Autism is labeled as a "Developmental Disability" it is not even recognized by medical insurance as a true medical or even mental condition. So now we have to rely on the school system to give him the treatments that he needs. And I refuse to speak ill of the school system, as they have done everything that they can to help our baby, but they do the minimum. It is a fight to get more occupational therapy or speech therapy or life skills training. Things he needs to live in this world that doesn't revolve around him and his special needs.

I haven't even begun to tell you about the impact his Autism has had on our entire family. The day to day struggles to meet his particular needs, our family's inability to go on family outings, as Luke's behavior can turn on a dime if something isn't the way he needs it to be, or a fire alarm goes off, or aisle 7 at Meijer is closed so we can't check out in aisle 7... Finding daycare had been a struggle, as many centers and even home based caregivers don't have the time or the resources to deal with him. Our oldest son often has to bear the burden of taking care of his younger brothers because we can't get a teenager to babysit, as they wouldn't understand him the way Ben does. We haven't been on a family vacation since he was born, my husband and I have only been able to get away for one over-night getaway, we have to attend church at different times, going out to eat is a tremendous challenge. Life at home is difficult, in that Luke can not be left alone for a second, and with his ADHD he is constantly into everything, including writing on walls, pulling up carpet, venturing outside alone... He also uses biting and hitting as a way to fight back with his brothers, and children with Autism don't always necessarily understand discipline. Luke doesn't understand that he should or shouldn't do particular things. We have tried time out, Love and Logic, 1-2-3 Magic, you name it, we've tried it. As a mother, simple tasks such as doing laundry, cleaning a toilet or making dinner are huge challenges, as the second you concentrate on the task at hand Luke is into something else, or having a tantrum because his last red crayon broke and we don't have anymore in the house...

Over the past year since Luke's diagnosis, the burden of dealing with the costs of his therapies, the 24 hour a day, 7 days a week of responsibility of caring for an Autistic child, not to mention two other children, has lead to severe tension in our marriage, finding myself on the brink of suicide – only stepping away from the edge after three weeks of inpatient mental health hospitalization and continued outpatient therapy and medications, additional reactionary behavioral problems with our 8 year old son, Sam, and feelings of extreme responsibility for Luke in his oldest brother Ben.

If Luke could get the therapies he needed, if our other children and my husband and I could receive counseling/education/respite for living with a child with Autism, maybe our lives would be less difficult. If insurance would pay for the therapies that he needs to function in the world outside of our family and his school, his quality of life, and that of the rest of the family would improve greatly.

Like many other families of children with Autism, we have seriously considered moving to another state, where his needs would be met by insurance, where getting therapy for one child wouldn't mean spending the college savings of another. Where both my husband and I would be able to get better paying jobs, where our other children might be able to feel less burdened by having a sibling with Autism.

Our goal for not only Luke, but all of our children, is that they learn to live happy and productive lives. That they embrace the differences in others and have empathy for their challenges. That their lives aren't forever labeled with Autism, but richer because they have lived a life in which challenge has been something to embrace and overcome, instead of something to despise. To not lose their faith in God, because their lives have been affected in so many ways by Autism. To know that they are loved, and that if they need help they will find it.

So I am asking you as a constituent of Representative Robert Dean, as a citizen of Michigan, and most of all as a mother, to both fight for and vote for Mandated Insurance Coverage for Individuals with Autism. Not only will you be helping those with Autism, you will be helping those who love them.

I would also like to extend an extra thank you to both Representatives Kathy Angerer and Richard Ball for sponsoring this bill. As caring for those with Autism, especially as children, will allow many to live better lives, and hopefully be less of a concern of the State once they reach adulthood.

Thank you,

Robin Berlin
and James, Benjamin, Sam, and especially Luke.