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March 10, 2012

The Honorable Clark Shultz
Chairman, Insurance Committee
Kansas House of Representatives
300 SW 10th Street
Room 166-W
Topeka, Kansas 66612

Dear Chairman Clark:

I am writing to tell you why I support HB 2764, and ask you to do the same.

My wife Emily and I are the proud parents of three children; Hannah , Benjamin and Samuel. One of our twin boys, Benjamin, has been diagnosed with Autism. This journey to a diagnosis started at around 14 months, when Emily and I noticed that something was not quite right with Ben's development. Over the course of the next four years we utilized every possible public means provided to help Bens development; Infant Toddler Services, Special Education Preschool, and now Level 1 Special Education Kindergarten through our school district. We have been truly blessed to continually encounter caring and loving individuals in this season of Benjamin's life.

However, the one recurring theme throughout Bens' first five years has been cost. Benjamin, like many autistic children, has also been diagnosed with a myriad of allergies. Food and environmental allergies are very common among autistic children, and research is pointing to auto immune issues as a possible contributor to the disorder. Ben is no exception. He is allergic to over two dozen food items, including things like milk, eggs, beef, and wheat. This means that Ben is on a very restricted diet, which in turn is a huge expense for our family. Ben also needed to receive allergy shots every three days to help with his environmental allergies. He started these shots at about age two. This was our first encounter with private insurance and Autism.

Bens Medical Doctor who prescribed the shots, treats many autistic children and adults. These shots are very beneficial for their quality of life, and we noticed a great improvement in Benjamin's overall development. Ben had not been medically diagnosed with Autism at the age of two but all the indicators were present. We were told by the office where Ben got his shot's that if we pursued an official diagnosis some insurance companies would not cover Benjamin's shots, blood work, and lab work. They would consider this an "experimental treatment for autism". It would not matter that Ben had tested positive through scientific lab workups that he had these allergies. The difference in our family incurring many thousands of dollars in medical expenses was simply one word on Benjamin's chart.....Autistic.

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Benjamin has done very well while in school, and I am happy to say that he is starting to say a few words now. This is offset by his twin brother who never seems to run out of things to say. It is hard as a parent to see Ben so far behind Samuel, and Sam is now realizing that his twin brother is “different” than him in many ways. Emily and I had hoped to place Ben in some supplemental programs during the Summers that he was not in school. Benjamin has tended to regress while out of his routine, again, this is very common in autistic children.

If we decided to place Ben in a full time school that specifically dealt with autism we would be looking at a cost of nearly \$40,000.00 out-of-pocket annually. If we were to place Ben in a supplemental program to his current schooling over the summer, we would be looking at around \$6000.00 for 12-16 weeks and that is only part time. I know these costs are real, because Emily and I have pursued those avenues, only to realize we can't afford it. There is an option for being placed on a Medicaid waiver through the state. This requires a medical diagnosis of Autism, which we recently just went through the process of acquiring. I went down to fill out the proper paper work for the waiver the very next day and was told the wait time for Ben would be approximately six years because of the waiting list in front of him.

Autism Spectrum Disorder is now diagnosed in 1-100 children in the U.S. Two decades ago it was 1-10,000. I do not know what has caused this epidemic, but I do know what it is like to live with an autistic child. I have held him while he screams because he can't communicate what he wants to say. I have seen him sit and stare for hours with no ability to recognize his mother and I from a complete stranger. One thing that I have yet to do, is hear my son tell me that he loves me. Ben is a sweet, loving, and caring little boy just as his brother Samuel is. I am asking you to support House Bill 2764 to give families like ours, and thousands of others, the chance to receive some much needed help in allowing all of our children the same opportunities.

Thank you for your time and I pray the Lord richly bless your life. Thank you too for your service to our state and your country.

Sincerely,

Kirk M. Keller

Paola, Kansas

