

Statement of
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Mother of son with severe food allergies

Before the Senate HELP Committee

Hearing on “Addressing the Challenge of Children with Food Allergies”

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Good afternoon Chairman Dodd, Ranking Member Alexander and distinguished Members of the Committee. It is my privilege to appear before my home state Senator from Tennessee today. I deeply appreciate the opportunity to help the Committee gain a greater understanding of the personal difficulties that food allergic children and their families face every day. The number of children suffering from life-threatening food allergies is dramatically increasing nationwide, and I am thankful to the Committee for taking the time to address this alarming national children’s health issue.

As an educator – I teach music education to elementary school children at Apison Elementary School in Ooltewah, Tennessee – I would also like to express my support for Senator Dodd’s bill, S. 1232, and applaud the bill’s focus in providing our nation’s schools with the necessary resources to protect children who suffer from life-threatening food allergies. Senator Dodd’s bill, and the Committee’s recognition of the importance of childhood food allergies, is encouraging, but there remains much to be done in the effort to prevent and cure food allergies.

When people hear the word “allergy,” they may think of a runny nose or the sniffles. As I learned when my son Ryan was 3 months old, life-threatening food allergies are something very different than hay fever – and parents like me literally fear for our children’s lives every day because an allergic individual’s reaction to food can be so severe. Probably the scariest aspect of an allergic reaction to food is that each reaction can manifest in a different way. While one reaction might begin with a rapid succession of sneezing, another reaction may begin with lethargy, or hives. It’s difficult enough for a parent to sometimes realize that their own child is having a reaction. Imagine a teacher who now needs to distinguish between the common cold and an allergic reaction. Our experience has been that many teachers just haven’t been given the proper amount of education to understand how to identify a reaction and then how to treat one.

At 3 months old, Ryan was given milk formula and immediately began to vomit. Within minutes, he was covered head to toe in hives. Without hesitation, we took him to the emergency room. With Ryan being so young, and it being the height of flu season, the ER told us it was likely the flu and to just take him home and feed him like normal. Since I was mostly breast feeding at the time, it took probably another week before Ryan was fed another formula bottle. At that time, he reacted in the exact same way. We

again rushed to the ER. This time, the doctor confirmed that a milk allergy was the likely culprit. Ryan needed to stay in the ER for several hours and be monitored to ensure a secondary reaction didn't occur. My husband and I were overwhelmed, as neither of our families had any members with food allergies. We spent the next several months educating ourselves as much as possible how to live with food allergies. We thought we had things covered, only to find out at about 10 months that Ryan was also allergic to egg. We had fed him a baby food jar that contained egg. This time, Ryan first swelled up around his mouth and broke out into hives. We recognized this reaction, even though it started a bit differently and immediately gave him the Benadryl. Thankfully, he had only had a bite and we were able to contain that reaction at home. It wasn't until a year old that Ryan was finally able to be formally tested for food allergies. The tests confirmed that he was severely allergic to both milk and egg. With Ryan now eating table food, we sprung into action to educate everyone around us. We carried cards that contained key words to identify the proteins for egg and milk that would help us with reading ingredients. Often times, we find that when people hear that a child has a food allergy, they only look for that main word (i.e.-milk or egg) to tell whether a food includes that allergen. What they don't realize is that an allergy to milk for example, means that the child cannot come into contact with any food containing any one of the 19 some odd milk proteins that exist. When reading labels, we must be diligent to look for all the variations of these protein words.

There is no "treatment" for life-threatening food allergies. Instead, children and their families must maintain a constant level of vigilance to avoid any kind of contact with the allergenic food. My child is allergic to milk, egg and peanut and avoiding these staples of the American food supply is a constant struggle. Here's an experiment you can try at home – go to your pantry and try to find even five foods that do not contain milk, egg or peanut. Now imagine that if you didn't read the label correctly, your child's life could be at risk. It is heart-wrenching from a parent's perspective to know that even with a high level of individual and parental responsibility, my child could still be endangered by a well-intentioned but uneducated teacher, caregiver, sports coach or even a server in a restaurant.

As you can imagine, mitigating risk for an infant is far simpler than when they enter the school system. When Ryan began preschool and then grade school, we were faced with a whole new world of complications for managing his medical condition. While some school systems have a broad program for handling medication, many individual schools have discretion to develop further, their own protocol for handling individual situations. My personal experience with schools is that the focus is primarily on peanut food allergies. While I am grateful that there is some awareness for the impact of a peanut allergy in a social/public situation, I think it's important for schools to understand that the potential for a life threatening reaction is also present for those with other food allergies. When registering my children for our current school, I was told that the school nurse is only in the building two days/week. This school's protocol is such that they lock medication in the nurse's office. All staff members are trained to use an epi-pen, of which we were thankful. The problem, as I explained to the staff, was that in the time it would take for a staff member to go to the nurse's office, unlock the

medication, and bring it to him, Ryan could die. Often times, I get looked at and even remarks that I am being overly dramatic. They fail to realize that the rapid progression of anaphylactic reaction is a clearly documented medical emergency and should be treated as such. I insisted that Ryan needed to have the medication with him at all times. Time is of the essence in the event of any reaction. Going from a mild to a severe reaction can take seconds. I asked the school how they handle the lunchroom for children with allergies. This was the first year that our school has had a child with food allergies. There was another child enrolled who has a severe peanut allergy and the school accommodated him by allocating a "Peanut-Free" table. There is very limited space in the cafeteria, so this was the only exception made. I was told that Ryan could and should sit at the peanut-free table. While the school saw this as a safety precaution, I saw it as just as large a risk as if Ryan were integrated with all the other kids at any other table. The reason being, Ryan is allergic to more than just peanuts. He was now sitting at a table with a child who certainly wouldn't have peanuts, but did bring cheetos and egg products daily to the table and was sitting within inches of Ryan. This solution didn't help mitigate the risk for Ryan and it separated him from his own class. I will never feel entirely comfortable with the cafeteria situation, but I do know that I've educated the students in Ryan's class enough that they truly look out for him at lunch. Ryan now eats lunch with his class. He brings a "placemat" to put his food on, as the tables just get wiped off and not washed. Ryan's teacher delivers his medication to the lunchroom with Ryan each and every day.

As I said earlier, time is of the essence with any reaction. We learned this the very hard way. I share my story of Ryan's anaphylactic reaction to everyone who is willing to listen. We are his parents and we almost waited too long. Ryan had what one ER doctor we saw called a "perfect storm" reaction. He had contact with both milk and Bermuda grass, to which he is also allergic. Contact with these allergens caused an anaphylactic reaction. Ryan came in and just said he needed to sit down. He looked pale. We sat him down and he immediately started coughing. Now, Ryan had been playing outside, so we initially thought he could just be tired. Well, only seconds passed and we decided we better give him benadryl, as we thought he was starting to have a reaction. Within a couple of minutes, Ryan started sneezing uncontrollably and could hardly breathe. We have a peak flow meter with which to test Ryan's breathing. When he is healthy, Ryan's peak flow is at 225. At the time of his reaction, he could barely hit 25. At this point, we decided we had to give Ryan the epinephrine. While my husband injected, I called 911. Epinephrine saved our son's life that day. We spent the night in the ER and came home more afraid than ever, but in a way, more empowered that we were able to handle the reaction.

The first thought that entered my mind when I came home was how fearful I am that if it took me, his mother, that long to react, how long will it take if the reaction happens at school? Do educators know enough to be able to handle such a life threatening situation in a timely manner? Do the kids know enough to tell that something is not right with Ryan?

Parents have to rely on everyone around their child to manage his food allergy. That's a scary scenario. Even simplicities such as playing on a playground are concerns for those with food allergies. While there isn't always food present on the playground, the risk is still present. Imagine a child who ate peanut butter and jelly and got peanut butter on their hands. They have not washed their hands and then go out to the playground. When the child who now has peanut residue touches the playground equipment, my child now becomes at risk. Ryan can react simply by touching something that contains the food residue to which he's allergic. Food allergy awareness and education needs to encompass the many different ways a child can be exposed. Many parents, myself included, with children who have severe food allergies carry wipes around and clean areas where their children play. We walk around perceived as being overly-protective, or perhaps even crazy, paranoid parents – just to try and reduce risk wherever possible. We're NOT crazy. We're scared. Allergen protein can be as life threatening to my child as a gun in the hands of a toddler.

Each and every day Ryan is placed in scenarios beyond his or our control. Children like Ryan are vulnerable to allergic reactions not only at school cafeterias and restaurants, but in any public setting, from childhood parties to an afternoon spent at a friend's house. Ryan has been invited to a sleepover at a classmate's home. I could not allow him to attend, because of his food allergies. There's just not enough understanding by the general public as to how serious this is. Ryan recently attended a birthday party where kids were jumping on a trampoline. The birthday boy had a bag of cheetos in his hand and decided to jump on the trampoline with them. Ryan immediately told the boy he couldn't be around him if the child was going to have cheetos on his hand, as it could hurt him. Ryan proceeded to get off the trampoline and would not go back on. Seems like such a simple thing to most people. To me, that was a huge victory. I've educated Ryan enough that he is able to stand up for his own safety. I can only hope and pray that this will continue. As children grow up, they are going to test boundaries and push limits – a natural part of the maturation process. With the food allergic child, the teenage years can be particularly frightening as the kids struggle to fit in and “prove” their normalcy. One of my greatest fears is that my son will play down or try to hide his allergy from his peers out of a desire to not want to be “different.” If the people around him do not understand his allergies, they cannot help him in an emergency situation.

Efforts to protect our children in school, and other social settings are very important. However, what we need more than anything else is research to find a cure for life-threatening food allergies. Ryan participated in an exciting research study based at Duke University Medical Center in North Carolina. On each visit, Ryan was given small amounts of milk protein, exposing him to the very thing to which he is deathly allergic. The first visit caused an anaphylactic reaction that came on with rapid speed. The doctors and nurses were very well prepared, as they expected this type of reaction. I was asked by a friend who has a child with a peanut allergy how I could sit there and purposely cause my son to have that reaction. Well, my answer is simple. How could I not afford him the opportunity for a lifetime without the risk of this type of reaction occurring again? The hope was that, over time, he would build up a sort of immunity – they call it desensitization – and would be able to tolerate milk later in his life. Our

participation in the Duke study is a good example of just how desperate parents of food allergic children are to find any kind of relief for our children. We drove 7 ½ hours each way to get to Duke because there are no facilities that we know of closer to home that are doing this kind of work. We stayed in town near Duke when we would have to make the visits and there was a constant danger that my son would have a severe, adverse reaction to the treatment. In fact, numerous times, Ryan had little mini reactions, like hives on his back or a few coughs. The doctors are, after all, feeding him something that could kill him.

Why are we willing to subject our son to this risk? Because he faces a greater risk every single day of his life simply by being surrounded by foods that can harm him. Research is our only hope for a long-term solution to these deadly allergies. There's no distance I wouldn't travel for the possibility of alleviating the daily risk Ryan faces. You know, the old saying "No Risk, No Reward" is how I feel about the research. There's never a guarantee that these research studies are going to "cure" my child. To not participate is almost guaranteeing the status quo – enrolling in the study offers hope. At the very least, we've contributed to the research. At best, we may have found a way to live without fear that our child could die from food.

You can help us. Millions of parents just like me are counting on the US Congress to increase the amount of research that is conducted on life-threatening food allergies. There are only a handful of research centers like Duke around the country that are currently doing any kind of food allergy research. After 11 months of participation in Duke's Research Study, Ryan is now able to tolerate milk. This is a huge victory for both Ryan and the study itself. Ryan can now come into contact with any milk protein and not have to reach for the epi-pen. The study has proven to work in his case. There is still much more research to be done. For example, we know that as long as Ryan has a daily dose of milk protein, he's ok. What we don't know is what happens if he goes without for days on end. This is where the research still needs to continue. We are a unique glimpse at what can be accomplished. The federal government currently spends under \$10 million a year funding research on food allergies. That is simply not enough. We need new research studies, more researchers and doctors investigating the disease, and funding to allow the best scientific minds in the field to find a cure.

Like any parent, I simply want my child to have the opportunity to grow and flourish in his life, and to reach his potential without limitations. On behalf of Ryan and the millions of other kids just like him, I am begging for your help.

Thank you!