

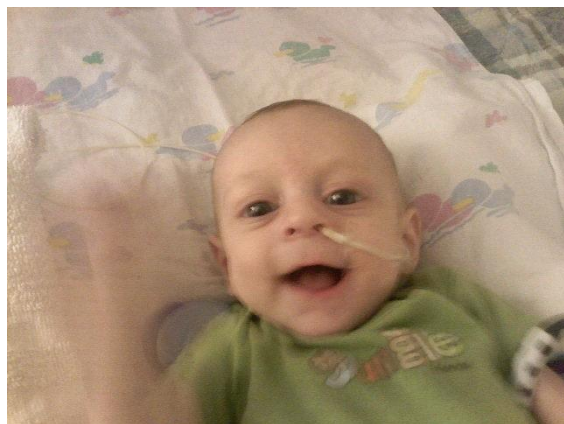
Testimony for Universal Newborn Screening for SCID

On behalf of Liam, our family and all the families living with the affects of SCID, I thank you for giving me the opportunity to speak. My name is Stacey Barrett and this is my husband, James. We are Liam's parents. Our son was diagnosed and passed away from SCID. Liam would have been one on the 30th of this month.

Liam was born on January 30, 2009 in Oregon, in the wrong state. If we had been in Massachusetts or Wisconsin, Liam would have been tested at birth for SCID. If that had been the case, his journey, our journey may have had a different ending.

Our family's journey with SCID began on June 1st when Liam was admitted to the hospital for Failure to Thrive. That was 8 months after this committee voted to delay acceptance of universal newborn screening for SCID, 10 years after the American Academy of Pediatrics (AAP) called for national newborn screening standards, 6 years after an expert on SCID, Dr. Rebecca Buckley, testified at the first meeting of this committee saying that SCID was a pediatric emergency and should be included in the uniform panel, 2 years after SCID was nominated, and 18 months after Wisconsin began screening for SCID.

At four months old he was 5 pounds below the weight for his age. During our hospital stay, the doctors ran several tests for genetic diseases; all the while Liam was gaining weight at a steady rate. Because every test came back negative, the conclusion was that Liam was behind on weight because of a common cold. After



19 days in the hospital, we were sent home with Liam on a feeding tube, antibiotics and physical therapy. We were told this would be a long haul, but he would eventually fall back into the correct percentile for his weight.

After 5 days at home and several more trips to the doctor's office, we received the call for us to take Liam back to the hospital to be admitted. His blood count was low. A few days later we received the news that he had SCID. My husband and I were numb. How could something like this happen to us? We had no genetic trace of SCID in our family. We have three healthy children that were born before Liam that did not have SCID. We started going through the process blind. We had no idea on where to take our son for care. Little did we realize that this was only the first step in our journey.



During his second hospital stay, Liam was diagnosed with three more infections. All together, he had four infections but no immune system. He was only five months old. His diagnosis was 3 months later than published articles have stated a SCID child could be successfully treated with bone marrow transplant after diagnosis at birth.



We then traveled to Seattle Children's Hospital to await a bone marrow transplant, which we hoped would come from a sibling match. Unfortunately, being diagnosed with four infections prior to admission in Seattle, the doctors were extremely cautious.

Good news came when we were told that Liam's 3-year-old sister, Rylee was a perfect match. The only obstacle in our way was the infections, which were now down to only two. But the two left, PCP and Para Influenza III were the most serious and life threatening.



Although the bone marrow transplant was a success and he was engrafting well with his sister's marrow; Liam suddenly took a turn for the worse. The infections in his lungs were getting worse. On August 16th, Liam's CO2 levels had reached over 100, more than twice the amount of an average baby. His heart rate was decreasing and he was completely sedated into a coma. As we watched his vitals decline, we believe this was his way of telling us he was tired. On the 17th of August, my husband and

I, with help from Liam, made one of the hardest decisions in our life... to let him go.

If our family were living in Wisconsin or Massachusetts at the time Liam was born, Liam would have been diagnosed with an Immune Deficiency. Shortly after birth he could have had a transplant with no infections. If that were the case, statistically my son would have had a higher success rate if diagnosed at birth, over 97% as Dr. Buckley testified before this committee in 2004. Statistics indicate our son would still be alive.



To many times our society's political infighting creates delay in progress. My son is a casualty in bureaucracy. If we have the means to test a child for a disease, the means to have a successful survival rate, what stops us from doing it? With immune deficiency, we cannot afford to wait for this board to decide whether it can be statistically proven that screening for SCID is cost effective and meets other rigid rules that focus on a population of newborns instead of on each newborn as an individual. Action needs to be taken now. While we wait for numbers and testimonies, countless children have lost their lives to this condition. It is incredible that we don't know the numbers lost to this disease because there is no national database to collect this information and the stories of these vulnerable newborns. Liam's story being one of the most recent and too familiar.

It is society's duty to protect and nourish the young children in our lives. It is the responsibility of this board to utilize its power to save lives. What are we waiting for? The statistics in Wisconsin may have shown that a classically defined SCID baby was not diagnosed in the pilot, but they identified other forms of immune deficiency that required treatment. And we know that in Oregon, it has been statistically shown that my son has died from not being diagnosed soon enough. I guess that statistic is one up on yours.

As you consider the updated nomination for SCID and other immune deficiencies, please remember that infants like Liam are born every day in the United States and around the world. We have the technology to screen and diagnose and we have a treatment that is amazingly successful. But we have not time to delay further. It may take several years to start screening in all 50 states. How many more stories like Liam's can we bear?

When I learned I could have the opportunity to speak to this committee, I thought what a wonderful way to honor my son's life and death by helping to see universal newborn screening for SCID and other immune deficiencies become a reality. Please help celebrate what would have been Liam's 1st birthday this month and support universal newborn screening for SCID. Thank you for your time.



The Barrett Family
James & Stacey
Alexis, Grace, Rylee & Liam