Dear Members of the Public Health Committee:

I urge you to pass **SB 543 An Act Providing Newborn Screening for Severe Combined Immunodeficiency Disease**. Please read our story below about how Severe Combined Immunodeficiency Disease (SCID) impacted our family. I feel this is very important for the welfare to other families so others do not need to go through what we went through. Thank you for your consideration.

My son, Jake was born on January 21,2009 as a healthy, happy little baby weighing 7lbs,14 ounces. As a new mother I enjoyed the first six months of his healthy life marking the various mile stones a new baby achieves. On July 21, we celebrated his six month birthday, but noticed that something was different with his breathing and he couldn't seem to get in enough air. I decided to call the pediatrician to get him checked out. When entering the doctor's office, they did a test and his oxygen level was poor and they said that he should go to Yale New Haven hospital to make sure everything was alright. As soon as he entered Yale, they decided to put him on oxygen and started running tests to see what was wrong with him. After one test came back positive for pneumonia, they figured that was the reason his oxygen level was low. After two weeks and his oxygen level wasn't improving, they decided to run more tests and take numerous x rays. They called in a pneumunologist to see what was wrong and they then thought he had trachea malaise.

After another couple of weeks, my regular pediatrician was looking at an x-ray and noticed that she wasn't able to see the thymus gland, so she decided to call in an immunologist just in case. They then ran numerous tests, took more x-rays and after a total of 5 weeks in the hospital and many misdiagnoses, I found out the devastating news that my son was born with a rare disease, Serve Combined Immune Deficiency (SCID) also known as the bubble boy. In order to save his life, he needed a bone marrow transplant. Since there is not a hospital in Connecticut that does this, we would have to pick another hospital out of state. After some research, I found that Dr. Rebecca Buckley at Duke University Medical Center was very knowledgeable and dedicated to SCID. We immediately left Yale and drove down 11 hrs to North Carolina, with my son on an oxygen tank. After I got tested, we found that I would be a match for his transplant and on Sept. 3, 2009 the procedure was done. After the transplant Jake and I had to relocate our lives and stay in North Carolina while his father had to go back and work in our home state of Connecticut since we still needed income to survive. We had to go to Duke weekly for blood tests and check- ups, and unfortunately his father missed most of the milestones that I child goes through after 6 months. During that long time away from home and trying wait to and see if the transplant would even work, Jake had two cases of Graft vs. host and was hospitalized for a week each time. After 5 months, we were blessed with the happy news that yes the transplant worked and he now has functioning T cells. That wonderful news meant we could at last go home and be a family again. Jake still needed to be isolated at our home for another 6 months, and is slowly working his journey into the big world waiting for him. I hope our story will make an impact so that others will not have to experience what our family did. It is our hope that one day soon a newborn screening for SCID will be available for the state of Connecticut so that this agonizing experience will not happen again to another family.

Please support **SB 543 An Act Providing Newborn Screening for Severe Combined Immunodeficiency Disease**.

Thank you,
Lisa Forrest
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