

**Testimony of Patty Powers to the Public Health Committee regarding *House Bill 6263, An Act Requiring The Administration Of A Screening Test For Cystic Fibrosis To Newborn Infants***

February 6, 2009

Senator Harris, Representative Ritter, members of the Public Health Committee: Thank you for giving me the opportunity to speak to you today about *House Bill 6263, An Act Requiring The Administration Of A Screening Test For Cystic Fibrosis To Newborn Infants*. My name is Patty Powers. My daughter Cameron is 5 1/2 years old and was diagnosed with Cystic Fibrosis at the age of 5 1/2 months. I am submitting this testimony to provide evidence of that newborn CF screening should be mandatory in the state of Connecticut and every other state for that matter.

Cameron's medical issues started at around 2 1/2 months of age. She began coughing which worsened as time passed. We took her to the pediatrician immediately and were sent home believing it was just a little cold. The cough persisted and we returned to the pediatrician again. This time she was given a nebulizer and Albuterol for her "cold." Her cough was a bit better for the time on Albuterol and a short time after but again her cough started to worsen. She was now coughing very violently and throwing up 2-3 times a day. We were having trouble getting her to eat, keeping any calories she was getting down, and becoming more and more stressed as time went by. We again returned to the pediatrician and were told it could be reflux. We tried a liquid antacid and no improvement occurred. We were then sent to a pediatric respiratory specialist at Danbury Hospital. He said it was perhaps the "whooping cough" since that had been popping up at the time and stated that it was considered the 100 day cough in which there is no treatment for. He stated in his notes that "because of her joules (chubby cheeks), Cameron is not a candidate for Cystic Fibrosis. Six weeks later and several more pediatrician visits, we desperately went to a different pediatrician that was available on a Sunday. Cameron was failing to thrive and coughing and throwing up regularly. This doctor heard something in her lungs and sent her for a chest x-ray. We were informed that something was showing up and that we needed to go back to the pediatric respiratory specialist the next morning. Cameron was admitted and a CF sweat test showed that in fact she did have Cystic Fibrosis.

Cameron was then 5 1/2 months old, had a partially blocked lung, and pneumonia. We were sent to Connecticut Children's Medical Center the next day and remained there for 2 weeks. She needed a bronchoscopy, intensive IV medication, intense airway clearance, and further testing. We left the hospital and remained on home IV's for another 2 weeks. Cameron has permanent lung damage today because of this. She has pseudomonas (a dangerous bacteria) and takes some medications that most 5 1/2 year olds with CF don't need yet. Can I place some blame on the physicians that she saw initially? Perhaps. But the fact remains the same.....***IF SHE WERE TESTED AT BIRTH; CAMERON MAY NOT HAVE SUFFERED NEEDLESSLY FOR 3 MONTHS AND HAVE PERMANENT LUNG DAMAGE AS A RESULT.***

Thank you for your time and consideration. Please feel free to contact me with any questions or comments that you may have.

Sincerely,

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