

**Testimony of Sean and Michelle Crowley 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*. We are the parents of a five year old girl with Cystic Fibrosis and believe that newborn screening will result in adding years and potentially decades to the life of our daughter.

At the time of our daughter Paige's birth we were living in Rochester, NY. Paige was diagnosed at 15 days old through newborn screening. At the time of her diagnosis, she was already exhibiting complications due to cystic fibrosis that required her to start taking pancreatic enzymes and Zantac. Without this early diagnosis, we may have gone on for months or years' not understanding what was wrong with our daughter. We spoke with many parents in NY that had children prior to the required newborn screening for CF. Many spent years trying to determine why their child was not gaining weight and suffering repeatedly with upper and lower respiratory infections and at the time of final diagnosis, they now had significant health issues resulting in permanent lung function loss. We were able to be proactive in our daughters care and feel that this is the reason she has continued to remain in the 50<sup>th</sup> percentile for weight and maintained adequate lung and respiratory function. We had the fortunate opportunity to learn about the disease and prepare for daily regimens before problems arose.

CF is a genetic disease therefore there is a 25% chance that any biological child of ours would be born with CF. Due to our knowledge of Paige's diagnosis of CF we were able to make an informed decision in growing our family, and adopt our second child. We have met many parents that have either had more children without knowing the diagnosis of an older child or have been pregnant at the time of diagnosis of an older child. Some of these parents now have multiple children with CF. Knowledge is power and although we currently reside in Connecticut we are ultimately thankful that we gave birth to our child in New York which is one of the other 47 states that conduct newborn screening for CF. As residents of Connecticut we would like every parent of a child with CF to benefit from early diagnosis with early intervention. We strongly urge you to pass this bill requiring mandatory newborn screening for Cystic Fibrosis in infants. Thank you for your time and consideration.

Sincerely,

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