

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

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*. I am the aunt of a twenty-two year old Cystic Fibrosis patient. In the past 22 years since my beautiful niece was born into our family, I have worked vigorously to raise money to support the research for a cure for CF. In that process of raising funds I have also brought awareness about cystic fibrosis to many friends, co-workers, family members and community businesses. I have always believed that in my lifetime a cure for CF would be found. Since my niece's diagnosis, great strides have been made in understanding more about the disease, its genetic complexities and ways to treat and manage patients who have the disease. When my niece was born, we learned about her diagnosis within a week of her birth. It was devastating news at the time, but thankfully Saint Francis Hospital provided that screening when my niece was born and her parents and doctors were able to get started right away with treating my niece's health conditions. I firmly believe that as a result of the screening and the prompt diagnosis made at the time of her birth and the excellent care that her parents and physicians provided to my niece, that she not only survived with this disease but has thrived and amazed everyone with her strength and determination to live a "normal" and healthy life. She was an outstanding athlete, runner and scholar in her grammar school, high school and college years. She is now pursuing her Masters and continues to amaze us. My sister and brother in law deserve much of the credit for the fine person my niece is today and for their dedication to learning about her disease and finding ways and exploring uncharted paths to help her with her disease.

Over the course of time, I have met other CF families and am amazed to learn of the number of kids who were diagnosed late because they were not tested at birth. I feel so badly for those patients and their families because of missed opportunities for early medical and therapeutic intervention that may have helped to avoid the devastating and sometimes unavoidable complications of the disease. As my elected officials, I am asking for your help in passing this bill. It is important for you to understand the magnitude of passing the *House Bill 6263, An Act Requiring The Administration Of A Screening Test For Cystic Fibrosis To Newborn Infants*.

Infants born with CF need our help right from the beginning. Having this screening test in place gives patients and their families a chance to keep ahead of the disease and start to combat and fend off its many devastating complications.

I think you would agree with me that there is nothing more important in this world than protecting and supporting someone's life and saving children and families from the devastation of illness and disease. Therefore, I implore you to do that right thing and vote yes in favor of adopting this bill.

Thank you,

Sally Scully
52 Whitehill Drive
West Hartford, CT 06117