

Testimony of Elizabeth Nardi 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*. Let me start by being candid. My name is Elizabeth Nardi. I have a 13 year old daughter with cystic fibrosis. I believe that the health service industry is falling short on its duty to protect and watch over the safety and overall health of our fellow Americans, particularly when it comes to chronic diseases such as cystic fibrosis. Chronic diseases are responsible for 7 out of 10 deaths in this country. More than a third of our population, over 100 million men, women and children suffer from chronic diseases. These diseases cost our citizens and government, \$325 billion a year. By 2020 chronic diseases are estimated to afflict 134 million Americans and cost \$1 trillion a year. And the CDC estimates that 70% are preventable. But our federal government is not actively pursuing how to prevent this epidemic of chronic diseases.

Here and now we have the power and capability to become proactive and make the right decision to put into effect House Bill 6263 that screens for cystic fibrosis. My daughter was diagnosed at birth. I strongly believe that because she was diagnosed early on, our family, team of providers and support system committed to a health plan that would best suit the needs for optimal health. She is active in sports, a distinguished honor student, plays the flute and is active in several clubs and organizations, all because we were able to get a handle on her health issues early on.

By passing this new born screening bill, early intervention can mean the difference between life and death of a child. This is a small intrusion that can potentially save hundreds of babies per year in Connecticut from death or serious disability. Early intervention also makes a huge impact on the families and children and results in fewer hospital visits and dollars spent.

Today you have to make a decision that could impact the life of a child and many children to come. Put yourself in our situation and listen to our voices of experience and knowledge. We are advocating for our children. We have all the tools and technology to provide the best quality of life by detecting any mishaps in the beginning stages of life. We have a moral and ethic responsibility to give our children a fair chance at life. Please vote in favor of passing HB6263!

Thank you.