



Central Connecticut Cystic Fibrosis Center



**Testimony of Ginny Drapeau, BSN, RN, CCRP Clinical Research Coordinator,
Cystic Fibrosis Center at Connecticut Children's Medical Center 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 Ginny Drapeau and I am a nurse clinician and the clinical research coordinator for the Cystic Fibrosis Center at Connecticut Children's Medical Center. I am here to provide testimony in support of Bill 6263. I would like to express my appreciation to this committee for considering the importance of Newborn Screening for Cystic Fibrosis.

Cystic Fibrosis is a genetically inherited disease, which affects many systems within the body. Due to abnormally thick and sticky mucus, the digestive and respiratory systems are adversely affected. At the Central Connecticut Cystic Fibrosis Center, we care for approximately 160 people with CF – children and adults. CF is the most common genetic illness among Caucasians, and occurs approximately once in every 2500 births. The carrier rate of the CF gene is very high – 1 in 25 Caucasians carry the defective gene.

I have been the clinical coordinator of the Cystic Fibrosis Center for over 16 years. I have a strong commitment to the children and families whom I serve. While attending the North American Cystic Fibrosis meetings in Orlando last October, I was shocked and somewhat embarrassed to see that my home state of Connecticut is one of only two states in the union who have not mandated new born screening for cystic fibrosis. This testing has been available in Connecticut on a voluntary, hospital by hospital basis since 1993, but, in spite of frequent raising of this issue before various committees of the legislature and testimony by many of us involved with this chronic illness, we have not yet succeeded in mandating this extremely important test.

Early diagnosis is essential for children with CF in order to prevent malnutrition and severe lung disease. Infants diagnosed at birth have much less risk for these early health problems. People who come to a CF diagnosis later in life face a potentially poorer prognosis. Due to the voluntary Newborn Screening Program in Connecticut, we have been able to greatly decrease the number of infants requiring admission to the hospital at the time of diagnosis.

I encourage you, for the sake of the children and adults for whom I provide care, to recommend the passage of this bill, on an urgent basis. The quality of life for people with Cystic Fibrosis will be greatly enhanced by mandated newborn screening. Thank you very much for your time and attention.

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