



Central Connecticut Cystic Fibrosis Center



Testimony of Melanie Sue Collins, MD, Assistant Director, Central Connecticut Cystic Fibrosis Center and Assistant Professor of Pediatrics, University of Connecticut Health 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 6th, 2009

Senator Harris, Representative Ritter, Members of the Public Health Committee. Thank you for the opportunity to testify in support of House Bill #6263, An Act Requiring the Administration of a Screening Test for Cystic Fibrosis to Newborn Infants. My name is Dr. Melanie Collins and I am Assistant Director of the Central Connecticut Cystic Fibrosis Center and Assistant Professor of Pediatrics at the University of Connecticut Health Center.

As you may know, cystic fibrosis is the most common life-limiting inherited disease of Caucasians. It affects approximately 1 in 2,800 children in the state of Connecticut. Most patients are severely affected experiencing symptoms in almost every organ in the body. Without early, aggressive treatment, most patients with CF will die of respiratory failure. In fact, prior to introduction of newborn screening for CF in the late 1970s-early 1980s, patients with CF were malnourished, experienced frequent severe respiratory infections and died in their early teenage years. I'm proud to inform you that our state was one of the first to begin voluntary newborn screening for CF in the 1980s. However, I am embarrassed and ashamed to report that we are now one of only a handful of states who has not mandated screening for CF. While children in the state of CT benefit from the improved therapies for CF that have occurred in the last 3 decades, simply by being born in a state that does not mandate screening for CF they are placed at a significant disadvantage.

I realize that financially this is a challenging year for the state of CT. However, I believe mandating newborn screening for cystic fibrosis is worth the cost-in fact, I can guarantee it. In the July 2008 issue of Pediatric Pulmonology, I published our investigation of the efficacy of our newborn screening program at the University of Connecticut Health Center. This spanned more than 20 years of screening infants at the hospitals in CT which voluntarily screen for CF. Interestingly, there was no difference ethnically or socioeconomically between those hospitals which do and do not screen for CF. Our newborn screening program is effective, identifying CF in approximately 97% of children with the disease. As the majority of children identified by this program have chosen to continue their care at our CF center, we compared the newborn screened children with CF (about 50% of our patient population) to our symptomatically diagnosed patients with CF (also about 50% of our patient population). Most of the children screened for CF were identified and began receiving CF care by about 2 weeks of age where the children

who were diagnosed by symptoms were not diagnosed until 2 YEARS of age. We found results similar to that other states in that newborn screened children with CF grow and develop NORMALLY as would any healthy child. Unfortunately those symptomatically diagnosed children with CF are significantly behind their peers and in fact, despite receiving years of the exact same nutritional treatments, will likely NEVER catch up and have normal growth.

Most importantly, this study of our patients with CF in the state of CT and our 20+ years of voluntary screening for CF, have shown that newborn screened patients with CF not only have better pulmonary function than those symptomatically diagnosed patients, BUT as teenagers, our newborn screened patients still have NORMAL pulmonary function. This same group of patients who medical experience would have shown us would die in their teen years from their CF lung disease are thriving and still have NORMAL pulmonary function, thanks to early identification of their CF through newborn screening. Unfortunately, those symptomatically diagnosed patients with CF do not have normal pulmonary function. Furthermore, while pulmonary function continued to IMPROVE by 4% over time in the newborn screened patients with CF, those symptomatically diagnosed patients experienced a 14% decline.

As you can clearly see, our voluntary newborn screening program for CF has made a significant difference in the progression and severity of disease for those children who were fortunate enough to participate in the program. How were they so lucky? It seems silly but they were simply born in the right hospital, at the right time. Fortunately, we do not need to rely on luck or good fortune to identify ALL patients with CF in our state in the newborn period. By mandating newborn screening for cystic fibrosis, you will provide all children in the CT, the opportunity to be identified with cystic fibrosis early and immediately begin receiving early aggressive care at a CF foundation certified care center.

I implore you to mandate newborn screening for cystic fibrosis in the state of CT. Please, join us in making a difference.

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