



University of Connecticut Health Center
Health Center Administration

TESTIMONY

Public Health Committee

February 6, 2009

Raised Bill No. 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 the opportunity to provide written testimony in **support of Raised Bill No. 6263 AN ACT REQUIRING THE ADMINISTRATION OF A SCREENING TEST FOR CYSTIC FIBROSIS TO NEWBORN INFANTS**. My name is Sid Hopfer, Professor of Pathology and Laboratory Medicine, University of Connecticut School of Medicine and Director, Cystic Fibrosis Screening Laboratory at the John Dempsey Hospital at the University of Connecticut Health Center (UCHC).

The UCHC has been providing voluntary cystic fibrosis (CF) screening for babies born in the state since 1993. We screen between 22,000 and 23,000 of the approximately 44,000 babies born per year in 21 hospitals including Backus, Bristol, Charlotte Hungerford, Day Kimball, Griffin, Hartford, John Dempsey Hospital, Johnson Memorial, Lawrence Memorial, Manchester, Middlesex, New Britain, Rockville, Sharon, St. Francis, St. Mary, Stamford, Midstate, Waterbury, Windham and selected samples from Danbury.

The Neonatal Screening Program at UCHC adheres to national recommended standards. The infants tested for CF at UCHC receive prompt and appropriate care through the current relationship with the UCHC Department of Genetics and the CF Center at the Connecticut Children's Medical Center (CCMC). The comprehensive testing performed at UCHC includes a molecular panel approved by the American College of Medical Genetics and the American College of Obstetrics and Gynecology. We have developed a protocol that follows the following process: An IRT test (immunoreactive-trypsinogen) test is performed on all infants, if the test comes back with a high result a follow-up molecular test is automatically performed. These tests are completed within 2 working days of receipt of the specimen. Of the 23,000 screens approximately 800 or 3% of those infants warrant a follow up test. Of the 800 requiring the follow-up test, approximately 6% or 48 are reported to have a positive screen. It is at this stage that a confirmation sweat test is required. UCHC contacts the CF Center at CCMC who in turn contacts the pediatrician who then contacts the family with the results and need for confirmation sweat test. The confirmation sweat test is collected by and then tested at the UCHC lab. Results of the sweat test are reported to the CF Center within 4 hours of collection.

The charge to the participating hospital for the screen test has remained at \$15.00 per screen test since 1993. The cost of the sweat test is not included in the \$15.00 screening fee and is covered by the individual or insurance. Requiring all hospitals in the state to arrange for every newborn in its care to be screened for CF is good public health policy and good for families. Should this bill pass, we have the capacity at the UCHC lab to accept additional samples.

I urge your **support of Raised Bill 6263**. Thank you for your attention.

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