

Good afternoon, my name is Tim Lenihan and I live in Granby, CT with my wife Debbie and our two children; Jason-12 and Amy-10. Both have cystic fibrosis.

I would like to thank you for the opportunity to speak to you today on behalf of new born screening tests for cystic fibrosis. I am in complete support of these tests.

My involvement with cystic fibrosis started when my son Jason was one month old. He was a healthy boy by all measures and certainly had changed our lives. My wife received a call from the CF Center located at the CT Children's Hospital in Hartford. They wanted to schedule a sweat test for Jason. When my wife asked what it was for they replied cystic fibrosis. Not being familiar with this disease my wife referred to the "What to Expect when You are Expecting" book and it simply stated "Fatal Genetic Disease". You can imagine my wife's reaction. We conducted the test and it came back positive. Our lives were changed again.

Upon further discussion with the CF Staff at the CT Children's Hospital, their call was prompted by results from a new born screening test conducted at New Britain General Hospital when my son Jason was born in 1996.

As a result of this test, we were made aware of my son's condition at a very early age and were able to start chest physical therapy and provide him digestive enzymes. This early start greatly improves their overall health and I believe adds years to their already shortened life span.

I often think about what would have happened had he not been one of the fortunate ones that was able to have this new born screening test. We would not have started any of these important therapies until we did find out he had it. Just when and how that would have happened is unknown. I imagine that he would have present one or more of the typical symptoms of CF such as weight loss, severe cough, and/or digestive problems. But I also believe it would have taken many doctors many months or even years before they would accurately diagnose it as CF. In the meantime, this delay in providing key therapies could result in a shortened life span and reduced quality of life.

I can't thank New Britain General Hospital enough for having incorporated these tests voluntarily. Making this a mandatory test would save other families from having to go forward unknowingly having a child that requires immediate medical attention. Please give this bill your support. Thank You.

Sincerely,

Tim Lenihan