

February 19, 2015

**RE: Bill # HB6580, AN ACT ESTABLISHING AN ADVISORY COUNCIL ON RARE DISEASES**

Chairman Ritter, Chairman Gerratana and Members of the Public Health Committee,

Hello. I am Christina's mother, not Maria. Yes, 'Christina's mother,' that how countless doctors have referred to me. My identity does not lie with me, yet with my daughter since my life revolves around her health, schedule, endless doctor's appointments, therapies, and hospital visits. All while trying to fit in some normalcy, like a play-date to go swimming with a friend and praying to God to let this week of "healthy" Christina, last. Then it ends and the week of laughs turns into cries as once again we find ourselves in the place we dread, a hospital emergency room. Where the medical staff try to understand the complexity of my child's condition, its implications and what can be done to stabilize her, but in reality most have limited knowledge of exactly what her medical profile means or how to effectively treat it. All I can do is sit there and comfort her and pray that this team of doctors will have the answers. But, more often than not, they do not and the search continues.

Unfortunately, this is a common theme across all environments, i.e., school, medical, insurance, etc. At school, it is a struggle to get medically necessary services so that Christina can be 'available to learn' and have 'access' to a public education. Another critical area is in finding doctors that understand the sheer scope and complexity of symptoms Christina has suffered since birth. We have seen countless doctors and often have had to travel outside of Connecticut to receive care because in-state resources are so limited. Our insurance company is not equipped to understand cases that don't fit neatly into a box. We were assigned a Case Manager in their "Escalation Unit," but complex cases are not understood by insurance, therefore are denied. We have traveled to Wisconsin and will be traveling to North Carolina to see highly specialized, sub-specialists, in hopes of getting answers and effective treatment--both costing thousands of dollars and are not covered by insurance. And, many of her medications are not covered.

I have been unable to work because managing a child with a Rare Disease and its unpredictability is a full-time job and these out of pocket costs effect us deeply. The reality is, we have to make hard choices of where our limited dollars will be spent (food or medical, education or medical). It's a losing battle with no winner.

I am Christina's mother. Yes, she has a Rare Disease and she deserves so much more than a mother that is committed to finding answers and resources but is finding little to none. An important first step in helping us find answers is in passing this bill to form a Rare Disease Advisory Council. I would implore you to please pass this bill, for Christina and countless others like her.

Sincerely,  
Maria