

## BENJAMIN SIRMON

March 2013

My name is Hillary Sirmon, and I have a beautiful, bright, and delightful one year old son named Benjamin. Benjamin is diagnosed with Myotubular Myopathy, a muscle disease that has a survival rate of 60% past the age of 1 and 10% past the age of 10. He is able to live at home, but not without an extensive supply of medical equipment and nursing (multiple pieces of equipment in our home cost more than my college tuition). Although Benjamin lives on a ventilator and has limited movement, he is able to touch hearts and change lives.

Benjamin is currently covered by private insurance and Medicaid, but there are expenses that can cripple any family financially that are not covered by insurances. Since having Benjamin, I am no longer able to work, and since I made most of the money for our family, these times have been difficult. My daily walk to the mailbox is painful, and gives me great anxiety, wondering whether there is a bill or more paperwork I have to sort through. This is time I should be spending with my son.



Benjamin has been on the NOW waiting list since May 2012. At this time, the waiting period for a waiver exceeds my son's medical life expectancy. A waiver could provide our family with home and car modifications as well as additional equipment that could assist us in taking care of Benjamin. Without appropriate funds, I am afraid that Benjamin, as well as his older sisters, will be negatively affected by the stress that our family must endure concerning financial, mobility, and home limitations.

Before Benjamin came into our lives, I worked as a pediatric physical therapist. I thought I had an idea of what the families I worked with went through, but I was wrong. You can't quite understand until you walk in our shoes... until you have a year without a full night's sleep, until you feel like your closest friends are medical professionals, and until you realize every decision you make can literally mean life or death. I am not here to complain, I am here to make changes. I am not looking for pity, I am here to open your eyes and offer a voice for those who may not have one. I tell my family and friends that, for me, I wouldn't change a thing about Benjamin. He has taught me so much and made me who I am today. For him, I would and will do everything I can to make him comfortable, happy, and a participating member of our society. With or without your help, I will make this happen for my son. We are only requesting the benefits of a system that our families have paid into for so many years. I want to spend more time being a mom for my children, instead of constantly fighting for them. Thank you.