

February 25th, 2015

To: Government Administrations and Elections Committee

Re.: House Bill #6100 An Act Designating a Spinal Muscular Atrophy  
with Respiratory Distress Awareness Day

From: Lauren Lyga, Burlington, CT

Dear Members of the Committee,

I am writing to advocate in strong support for the passage of proposed House Bill 6100, An Act Designating a Spinal Muscular Atrophy With Respiratory Distress Awareness Day. Hunter Pageau is my cousin, my hero, and a true inspiration to everyone he meets. As a member of Hunter's extended family, I cannot emphasize enough how very proud and thankful we are to have Hunter in our lives. His unique journey has taught us many valuable lessons about the world and has truly opened our eyes to the vast struggles that the SMARD community faces daily.

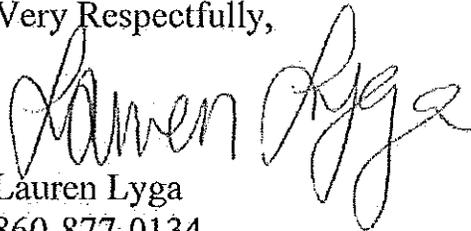
Hunter was born in 2005, with he being only the 3rd documented person with SMARD in the United States at that time. Naturally, I did what most concerned family members would do and began to conduct my own research online about this disease. Much to my dismay, there was little to be found online or in libraries about this disease; 11 published articles to reference, to be exact, offering us very little opportunity to educate ourselves about SMARD. Our entire family, along with all of our friends, and most of the medical professionals we had inquired with, had never heard of SMARD, rendering us virtually unable to help appropriately pursue the needed care and support planning to best help our sweet Hunter battle this unknown disease most effectively. Hunter truly IS a SMARD pioneer.

With Hunter having received the needed 24-7 care and dedicated advocacy of his family care providers, he has continued to defy the published medically noted odds, choosing to "thrive and not only survive," in his words, and inspire numerous others with his consistent personal message of hope and kindness. However, this has come with deep and consistent struggles

and hardships for Hunter and his family, since he was born, due to the rarity of SMARD and general lack of awareness in our communities about this disease. Our family has truly done as much as we possibly can within the last decade to assist with raising SMARD awareness and pursue research for a cure funding. The thing which has stood out definitively for me in this effort has been the continual need to explain SMARD to each person I've spoken to, in an effort to garner their support. Absolutely no one I have ever encountered has heard of SMARD. Although Hunter and our entire family has made a huge and decade long effort to spread awareness of this disease, our personal reach can only bring us so far, towards reaching our goal for overall general SMARD awareness and securement of funding assistance for research for a cure. Please note that due to this disease being a virtual unknown to most, there are no formal organizations for SMARD support yet created and Hunter's family is mostly on their own to find their way through their mystery maze in living with this disease.

This is why we are here today, in the highest hopes of assisting with the passing of House Bill 6100, in order to make our dreams of a quality life for Hunter and the entire SMARD community become a reality, which requires state level support. With support from the State of Connecticut in the form of a Spinal Muscular Atrophy With Respiratory Distress Awareness Day, we are confident we will then be able to begin the necessary larger outreach required in ascertaining the needed educational and research opportunities for SMARD. Your respected support is greatly appreciated by both our family and the entire SMARD community and we cannot thank you enough for considering this life changing legislation for our hero, Hunter, a true Connecticut pioneer and inspiration. Please join us in supporting Hunter, so he and his family do not have to battle SMARD in the isolated manner which has prevailed in his first decade of life.

Very Respectfully,



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