



**NORD**  
National Organization for Rare Disorders

February 24, 2015

*Sent via email*

Dear Ms. Sharon Agli-Pageau and the SMARD community:

The National Organization for Rare Disorders (NORD) is heartened by the work you and your supporters are doing to raise awareness about Spinal Muscular Atrophy with Respiratory Distress (SMARD). In the spirit of Rare Disease Day 2015, we are proud to support the passage of House Bill (HB) 6100, "An Act Designating Spinal Muscular Atrophy With Respiratory Distress Awareness Day."

Held on the last day of February every year, Rare Disease Day is an important opportunity to bring widespread recognition of rare diseases as a public health challenge. The immense challenges faced by the SMARD community are no exception.

As is all too often the case with rare diseases, people living with SMARD struggle to find providers and medical professionals who are familiar with the disorder and can guide them through care. Moreover, like most rare diseases, there are no FDA-approved treatment options available for SMARD. As a result of these challenges, individuals with this disease must endure the hardship of meeting daily challenges with minimal outside support.

HB 6100 is an important first step in beginning to address these issues. By raising awareness about SMARD and all rare diseases, we can increase opportunities for community education and research for a cure.

Thank you for your continued advocacy on behalf of people living with SMARD and all rare diseases.

Sincerely,

Tim Boyd, Associate Director for State Policy  
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