

Susan K. Kresnye – Proponent Testimony

Senate Bill 143

House Health Committee

December 6, 2017

Good morning Chairman Huffman, Vice-Chair Gavarone, Ranking Member Antonio, and colleagues of the House Health Committee. My name is Susan Kresnye and I thank you for the opportunity to give testimony on Senate Bill 143, which will designate September 25th as International Ataxia Awareness Day (IAAD) in Ohio.

Ataxia is a very rare and solitary disorder. In this country, there are approximately 150,000 individuals diagnosed with this incurable disorder. No one wants to be labeled as different. And for those with Ataxia, it is much easier to sit back and watch the days, weeks, or even years go by without encouraging attention to this horrible disorder. I believe I am able to walk without the assistance of an external device and am able to speak clearly for a reason. This is the reason. It is my sincerest hope that I respectfully represent those that no longer have the ability to speak for themselves due to Ataxia.

The main resource that Hereditary and Sporadic Ataxia patients have is the National Ataxia Foundation (NAF). This is a non-profit organization established in 1957 to provide support to the families and caregivers as well as those affected with Ataxia. The foundation also provides grant money for research studies that will ultimately find an effective treatment and possibly a cure. Funding for NAF comes in 3 main forms, private donations, matching donations, and grass roots fundraising. In 2016, NAF awarded more than \$1.1 million dollars in research grant funds. I like to think that the day of the cure is just around the corner. Maybe even today.

The first IAAD occurred on September 25, 2000 and was the first time that Ataxia organizations throughout the world declared and recognized September 25th as IAAD. The goal of IAAD is for everyone who is impacted by Ataxia to participate in some activity, creating awareness about Ataxia. Awareness is key. It is that solid foundation that International Ataxia Awareness Day is built upon. The second component is Education. Awareness hopefully leads to education, which then leads to funds, which leads to research, which leads to an effective treatment and the possibility of a cure. This cure may not happen in my lifetime, but with encouraging awareness, it can immediately improve the quality of life.

Thank you for giving me the opportunity to provide testimony on Senate Bill 143. I know that, so far, I have 32 Senators that back this bill and I believe there are 18 members on the House Health Committee so 50 more people are aware of Ataxia.

I have provided this year's flyer for International Ataxia Awareness Day, and the 2016 Annual Report for the National Ataxia Foundation.

Thank you again for the opportunity and now I welcome the chance to answer any questions you may have.