

October 15, 2012

Hello Senator Nofs,

I am writing as one of your constituents. I live in Marshall with my husband and our five children. Thank you for your service to the state of Michigan.

My youngest son, Simon, has a very rare chromosome disorder called Pallister-Killian Syndrome. PKS causes global delays/disabilities: vision and hearing impairments, physical impairments, cognitive disabilities and many medical problems often including seizures and structural abnormalities. All that said, my Simon (who is almost 8 years old) is a total joy and delight. He is hugely affected by PKS and will never be independent, but his giggles and cuddles always make my day.

We (our organization and other medical groups) know of fewer than 300 cases in the world, but due to previous poor testing techniques, doctors believe there should be as many as 2000 cases in the US alone. PKS Kids (501c3) was formed to provide research dollars and is currently affiliated with Children's Hospital of Philadelphia and a pediatric neurologist at the University of Utah as well as other professionals. We raise awareness through our website, social network and through email and physical mailings around the country. Additionally, we are providing grants to our families affected by PKS to help offset costs of medication, equipment and therapies. We hold a bi-yearly medical conference as well to provide families emotional, educational and medical support.

While individual families do try and fundraise for PKS Kids, it is hard to draw enough attention and support because 1) no one knows anyone with PKS and 2) we are spread out throughout the country. Nearly everyone knows someone affected with autism or cancer and so that makes it easier to fundraise for those, and other, organizations. Additionally, as there is no cure for PKS, I feel that may encourage people to choose what they feel is a better avenue for their money. Just because our children are mentally handicapped doesn't mean they shouldn't have every opportunity for success their way!

The past two years I've worked with Representative Jase Bolger's office to pass a proclamation declaring December 4th "PKS Day" in MI. This year instead, I ask you to propose a bill to designate December 4 as PKS Awareness Day forevermore in Michigan. {PKS is a tetrasomy 12p which is where the idea of December (12 month) 4th (4 copies of the short arm on the 12th chromosome) came to be. }

Our main website is www.pskskids.com and our social network is www.pskskids.ning.com and can be reached from our main home page. Simon's website is www.simonpeters.org, if you'd like to read a little bit of personal information about our journey with PKS. *Families touched by PKS need help. We need awareness. We need to educate others how to help. We need better diagnosis measures, techniques and awareness to the clinical features.*

I've also attached our brochure and you'll find lots more information, including a video, on our website at www.pskskids.com. If I've left any questions unanswered, please feel free to contact me via email or phone. I look forward to your reply.

Thank you so much.

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