

To whom it may concern,

I am a mom to a very special little boy. His name is Andrew. He is 5 1/2 and does not walk, talk, crawl, feed himself, dress self or toilet self.

Chances of him doing so are slim. At the age of 4 months, he was diagnosed with Beckwith-Wiedemann Syndrome. He proved to be much more severe than all the other children reported, which led to more studies for another diagnosis. Last December, Andrew had a skin biopsy to determine if he had Pallister Killian Syndrome, an extremely rare genetic chromosomal disorder. The test proved to be positive. Since this time, I have learned a great deal about the syndrome, have come to terms with expectations for our Andrew, for our lives and have committed myself to educating others about this syndrome. There are less than 300 known in the WORLD today, and it is unknown if there are any other children with the combination of both syndromes. Because of this diagnosis, I have been able to for the first time have the support network we as a family need. We have milestones to look forward to for the first time. We have met other families at the medical conference along with doctors and counselors. We are now a part of this small and elite little group that no one knows about. We 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.

What I am asking of you, is if we could get a day in December, preferably the 4th, and declare it PKS day. This will be a platform for us to educate, communicate families, friends, therapists, educators, doctors, nurses, ultrasound techs and more on PKS.

I look forward to hearing from you along with educating Minnesota on how beautiful our PKS kids are and how they enhance every minute of our lives!

Sincerely,

Nicole M. Schmidt, mom to Andrew Jacob