

Dear Senator Greenleaf,

We are writing to ask if you would sponsor the legislation required to have the Commonwealth of Pennsylvania officially recognize December 4th as Pallister-Killian Syndrome (PKS) Awareness day.

The reason for this request is that our son, Ricky, has a genetic disorder recognized as Pallister-Killian Syndrome Tetrasomy 12P. PKS is identified by a “chromosome abnormality when a tetrasomy of the short arm of chromosome 12 (12p) occurs for no known reason”. This is a rare syndrome and at the time of his birth his mother and I were told that he was the first ever prenatally diagnosed case for this syndrome, he would be the 51st known case worldwide ... and that we should select a name and a burial plot for him. Granted, we had a lot of doctor’s visits and emergency room runs in the early years, but Ricky is a fighter and will now be celebrating his 16th birthday on the 29th of this month.

As with every parent of a special needs child with a rare syndrome, we felt we were alone in understanding and providing for his care. We spent several hours every day searching the internet, reading medical journals and nursing periodicals while referencing a medical dictionary time and time again to decipher all of the terminology. We learned about CVI (Cortical Vision Impairment), gastro-esophageal reflux, reactive airway disease, seizures and myoclonic jerks, silent aspiration, obstructive sleep apnea, hyperactive gag reflex, hearing impairment and severe mental retardation as part of the listed neurologic and developmental delays that can be expected for a Pallister-Killian child.

A few years back, a group of parents who have Pallister-Killian children organized and formed PKS Kids. This is an organization devoted to providing education, awareness and support for families with PKS children. The organization helps generate ideas to sponsor fundraisers and organizes a biennial Face to Face where our families are able to get together to share ideas, concerns and resources. You may visit the website at www.pkskids.net to learn more about the organization and what it has been able to accomplish thus far.

Ricky’s Pennsylvania PKS siblings include, Mckenna Granahan from Exeter, Aidan Bergquist from Greencastle, Conor Small from Downingtown, Melinda Heibert from Aliquippa and Gracie Isabella Westover from Fairmount City. PKS children all face different special medical anomalies but there is one constant – the tetrasomy (4) of the 12th chromosome hence the request for December 4th. Michigan was the first state to recognize the date and Minnesota is currently in the process. We are hoping Pennsylvania will be next and help guide the way for other states to follow.

We hope you accept this request on behalf of Ricky, Mckenna, Aidan, Conor, Melinda and Gracie and are successful in your endeavor.

Thank you for your consideration to this request,