PRESS RELEASE



It's Official!!! Governor Tim Pawlenty Declared December 4th, 2010 PKS Awareness Day!! Following Michigan's lead

PKS Kids P.O. box 94 Florissant, MO 63032-0094
PKS KIDS
Hope and Help for those touched by
Pallister-Killian Syndrome

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FOR IMMEDIATE RELEASE

Becker, MN --- PKS Kids (<u>www.pkskids.net</u>) is announcing the declaration of PKS Awareness Day for December 4th, 2010 along with Michigan and beyond!
Governor Tim Pawlenty recently signed the proclomation, declaring December 4th, 2010 PKS Awareness Day. Pallister Killian Syndrome is a chromosome abnormality when a tetrasomy (4 copies) of the short arm of chromosome 12 (12p) occurs for no known reason.

Nicole Schmidt wrote the proclamation after a discussion last fall with Secretary of State, Mary Kiffmeyer, regarding the need for awareness to better care for our special children.

Pallister-Killian Syndrome (PKS) is a rare genetic disorder caused by a double duplication of the short arm of chromosome 12. Symptoms include hypotonia, hearing and vision impairment, seizures, diaphragmatic hernia, mild to severe developmental and cognitive delays and more.

PKS is extremely rare, affecting fewer than 300 people in the world. However, doctors at Children's Hospital of Philadelphia (CHOP), feel this number is vastly understated. Without awareness of this syndrome and how to diagnose it properly, thousands of children and young people could be going undiagnosed. Without a diagnosis, it is more difficult to obtain the proper treatments and services the child may need. Schmidt says, "My son Andrew, who will be turning 6 in December, is deaf/blind, does not walk, does not talk, needs full assistance for his entire being. Andrew needs consistent and frequent therapy to help him optimize his potential. Many of our PKS families do not have the help they need, nor the tools in their homes to take care of our children safely. Our goals for Andrew have changed over the years, but since learning of his new diagnosis last December of PKS, we now have milestones to look forward to and support for the first time in 5 years from PKS Kids." PKS Kids (www.pkskids.net) is helping families around the world receive the support and services they need. This non-profit organization, on which Nicole Schmidt serves as a board member, is assisting with research through CHOP and offering grants to families affected by PKS. In addition, they host medical and family converences where parents are able to speak with and learn from specialists and other families.

Schmidt and PKS Kids are hoping this resolution is the first step in addressing the requirements of the special needs community statewide.

Learn more about PKS and make donation s to PKS Kids by visiting www.pkskids.net

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