

WHO IS PKS KIDS?

Our non-profit organization, PKS Kids was organized in 2006 by the parents of children affected by PKS. Rarity of this syndrome means information available was scarce and outdated. PKS Kids decided to raise awareness themselves to ensure early diagnoses for all children born with Pallister-Killian Syndrome.

Since our formation we've hosted medical conferences, done nationwide mailings to geneticists and pediatricians, offered financial grants for families and created an online network for parents as well as donating research dollars to CHOP.



pkskidsTM
Education, Awareness, Support

**PALLISTER-KILLIAN
SYNDROME**



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WHAT IS PALLISTER-KILLIAN SYNDROME?

Pallister-Killian mosaic syndrome (PKS) is typically caused by the presence of two copies of the short arm of chromosome 12 (12p). It occurs at conception and there is no known cause.

Children with this syndrome suffer low muscle tone, seizures, diaphragmatic hernias, global developmental delays, intellectual disorders, hearing and vision loss among other traits.

PKS Kids has partnered with a genetic team, led by Dr. Ian Krantz, at Children's Hospital of Philadelphia to provide research funding for and insight into Pallister-Killian Syndrome. At least nine research papers have been published during this collaboration.

EDUCATION

Individuals with PKS need extensive therapies. Routinely, they will have occupational, physical, vision and hearing therapy, but there are other therapies that can offer a great deal of help such as, hippotherapy, aquatherapy and more.

Those affected by PKS, typically require care throughout their lives. Without a proper diagnosis, these children may not receive the care and help they need.

AWARENESS

Because Pallister-Killian Syndrome has no known cure, PKS Kids focuses on helping children and young adults to achieve their highest potential. We fund research being conducted at Children's Hospital of Philadelphia (CHOP) and travel around the country in efforts to educate medical professionals about PKS.

In addition we offer grants to families caring for children with PKS. As parents ourselves, we understand the needs and difficulties families face. We run an online forum where families can exchange advice and support.

Because of the rarity of this genetic condition (fewer than 300 known cases in the world), online support is crucial.

SUPPORT

Your donations make a difference!

Donate through our website at www.pkskids.com or by mail to:

PKS Kids

PO Box 12211

Green Bay, WI 54307

As PKS Kids is a 501(c)3 organization, your donation is tax deductible.

VISITING OUR WEBSITE will help you see the unique physical characteristics those with PKS have. On our medical page, you'll find more information and resources as well as stories of many children with PKS.

You'll also see our events and fundraisers for PKS Kids.

www.pkskids.com