Our non-profit organization, PKS Kids was started 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 Rarity of this syndrome means information available was scarce and outdated.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 and created an online network for parents.

Meet our Board of Directors at http://www.pkskids.net/boardofdirectors.php

PKS Kids
PO Box 12211
Green Bay, WI 54307

info@pkskids.net
www.pkskids.com

What is PKS?

Pallister-Killian mosaic syndrome 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, mental retardation, hearing and vision loss among other traits.

How do you recognize PKS?

Visual characteristics include: a full lower lip, flat nasal bridge, high forehead, extra nipples, short fingers, high arched palate, hypopigmentation, and a unique hair pattern early in life. Children with PKS look very much alike!

Diagnostic testing should include a skin biopsy, buccal smear or an array blood test.

Are you a medical professional with questions?

Please contact Alisha Wilkens, Genetic Counselor at The Children's Hospital of Philadelphia. 215-590-2920 or wilkens@email.chop.edu

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

PALLISTER-KILLIAN SYNDROME

Family Brochure

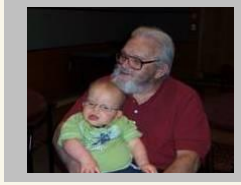
Education, Awareness, and Support for those touched by Pallister-Killian Syndrome.

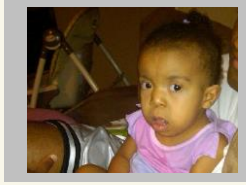
www.pkskids.com

PALLISTER-KILLIAN SYNDROME

EDUCATION ~ AWARENESS ~ SUPPORT

www.pkskids.com





Our mission is to promote research, provide education and raise awareness within the medical community in order to ensure early diagnoses of children with Pallister-Killian Syndrome (PKS). To provide resources and support to families, therapists and caregivers of children with PKS.

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 at the University of Utah 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.

www.pkskids.com

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.

Your donations <u>will</u> make a difference!

Make donations 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.

Visit www.pkskids.com for more information on Pallister-Killian Syndrome and PKS Kids.

Thank you for your support!