

Fundraising and Donations

Fundraisers are being conducted for **PKS Kids** by individual families. Learn about these fundraisers or make donations through our website at www.pskkids.net or by mail to:

PKS Kids
PO Box 94
Florissant, MO 63032-0094

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

Visit www.pskkids.net for more information on Pallister-Killian Syndrome and **PKS Kids**. Thank you for your support!

Are you a medical professional with questions? Please contact Alisha Wilkens, Genetic Counselor at The Children's Hospital of Philadelphia.

215-590-2920
wilkens@email.chop.edu



Jake 6 years old with PKS

"Jake and all these kids have a positive impact on everyone they meet. Their love is 100% pure."

Jake's Parents

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 Rarity of this syndrome means information available is scarce and outdated. **PKS Kids** decided to raise awareness themselves to ensure early diagnoses for all children born with Pallister-Killian Syndrome. Since its formation we've hosted a medical conference, done a nationwide mailing to geneticists and created an online network for parents.

Board of Directors

Chairperson: Dawn Bergquist
Vice-Chair: Mike Zane
Treasurer: Cammie Gray
Secretary: Gretchen Peters

Finance Chair: Cammie Gray
Promotion/Education Chair:
Gretchen Peters
Medical Advisory Chair: Kate Hettiger
Fundraiser Chair: Christine Strahm
Members at large: Kim Hudson, and Nicole Schmidt.



PKS Kids
PO Box 94
Florissant, MO 63032-0094
www.pskkids.net

Email: Info@pskkids.net

www.pskkids.ning.com

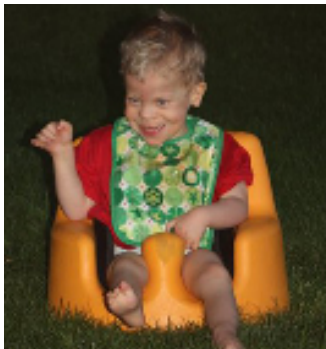


Our mission is to promote research, provide education and raise awareness within the medical community in order to ensure early diagnoses of children with Pallister-Killian Syndrome (PKS). To provide resources and support to families, therapists and caregivers of children with PKS.

Did you know?

- That a buccal smear (cheek swab), a skin biopsy or a new blood test using DNA ARRAY technology shows the most accurate results? A regular genetic blood screening will often result in a false negative.
- That PKS is so unheard of that no one knows exactly how many cases there are in the world? Doctors at CHoP believe that the frequency should be as high as 2,000 cases in the US alone, while only about 200 cases in the world are currently known.
- That PKS Kids has contributed to research at CHoP and has been instrumental in the upcoming papers that are being published on Pallister-Killian Syndrome

Educating the public on these facts and others will help children who are affected by PKS get diagnosed earlier and get the treatments and therapies they need.



Simon 5 years old with PKS

What is Pallister-Killian Syndrome?



Kelsey 5 years old with PKS

“Our hopes and dreams are different than we thought, but we haven’t given up on them.”

Mom and Dad of Kelsey

Pallister-Killian Syndrome is a double duplication of the short arm of chromosome 12. It occurs at conception and there is no known cause. Children with this syndrome suffer low muscle tone, seizures, global developmental delays, hearing and vision loss among other delays.

PKS Kids raises awareness of this rare disorder by educating doctors, genetic offices, NICU’s, Early Intervention providers, therapists and other professionals by funding research and promoting recognition of the characteristics and traits of PKS.

HOW **PKS KIDS** WILL HELP

PKS Kids is a non-profit organization providing support and education for Pallister-Killian Syndrome.

PKS Kids provides resources to families affected by PKS as well as offer emotional support and help to those who need it.

PKS Kids also supports research of Pallister-Killian Syndrome through the Children’s Hospital of Philadelphia (CHoP).

“Hope writes its own story.”

Gretchen Peters



Aidan 6 years with PKS

EDUCATION

AWARENESS

SUPPORT