



Board of Directors

Dawn Bergquist
Mike Zane
Cammie Gray
Gretchen Peters
Dana Paglia
Kate Hettiger

Education~Awareness~Support

PKS Kids Face2Face 2008

June 19-22 was a fabulous few days in Philadelphia!

We had 20 families attending the second PKS conference, many meeting for their first time.

Dr. Ian Krantz and Dr. Mary Pipan from CHoP both presented excellent talks about Pallister-Killian Syndrome and about

the research they're working on for PKS and PKS Kids. See copies of their presentations at <http://www.pskkids.net/pskkidsface2face2008.htmworkshops> .

Dr. Krantz also has asked for as many PKS parents as willing to consider submitting a blood and skin biopsy

sample to him at CHoP to do some new research and testing with. Contact Dinah Clark at clarkd2@email.chop.edu to get the details on how to submit your samples.

LOOKING FOR BOARD MEMBERS!

PKS Kids cannot grow and succeed without dedicated, enthusiastic volunteers. We are adding 2-3 board positions which will start in October. Please consider helping this worthy foundation!

Visit

<http://www.pskkids.net/whatsnewonpskid.s.htm?blogentryid=36>

[71132](#) to download the interest form. Please email this form to Dawn by Sept 1st!



SAVE THE DATE!

We are planning the PKS Family Reunion tentatively the weekend of August 8-9, 2009 in Ohio.

Please plan to join us!

Have you visited our new social, networking, and support site? (www.pkskids.ning.com) was created to give us an opportunity to socialize, post photos and videos of our children and families, and most important, to make a difference in the lives of all of us through friendship and encouragement.

2nd Annual PKS Kids Bike Run in New York

The 2nd annual **PKS Kids** Bike Run will be held Saturday, September 6, 2008. Registration is at 9:00 and kickstands up at 12:00 noon at 24 Lowell Ave, Islip Terrace. Like last year, the family friendly after-party is from 1:00-6:00 at Eastern Athletics in Bluepoint. There will

be Food and Drinks, DJ entertainment, Moonbounce, Face Painting and much more! We will also repeat the very successful Chinese Auction and 50/50 Raffle! The first Bike Run was held last year in September on Long Island with great success!

For more info contact Mike & Nicole Zane at zanehome@optonline.net or

Chris at 631.767.7431

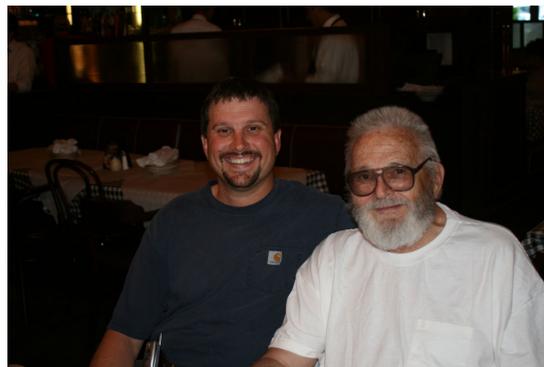


Equipment Exchange

Do you have a piece of equipment that your child no longer uses? We have equipment and supply exchange on our website and we'd like to get it going. Instruction for the exchange can be found at:

<http://www.pkskids.net/equipmentssupplyswap.htm>

Can you help another family??



Dr. Pallister and his grandson Joshua attended the conference. We are so blessed that he made the long trip east for us. Thanks O' Phil!

PKS Kids website

It is essential that in between newsletters you check in on our website www.pkskids.net. Often, we post updates, announcements and new information on the site. We are not allowed to post any of this information on or via the Yahoo support group, so you'll not find updates there. Please check in with us often for news and more!

PKS Kids Contacts

We would like to add PKS contacts for every state and country onto our website. On <http://www.pkskids.net/resources> we list locations of families affected by PKS. If you're willing to help

people in your country with questions, resources etc, please email gpeters@pkskids.net to have your name added. Long-term, **PKS Kids** plans on being able to provide state and

country resources to all our families, but in the meantime, having a "friendly name" out there for help can mean the world to a new family facing the journey.



Where are the parents?

They are on the phone to doctors and hospitals and fighting with Insurance Companies, wading through the red tape in order that their child's medical needs can be properly addressed. They are buried under a mountain of paperwork and medical bills, trying to make sense of a system that seems designed to confuse and intimidate all but the very savvy.

Where are the Parents?

They are at home, diapering their 15 yr old son, or trying to lift their 100lb. daughter onto the toilet. They are spending an hour at each meal to feed a child who can not chew, or laboriously and carefully feeding their child through a g-tube. They are administering medications, changing catheters and switching oxygen tanks.

Where are the parents?

They are sitting blearily eyed and exhausted, in hospital rooms, waiting for test results to come back and wondering; is this the time when my child doesn't pull thru?

They are sitting patiently, in hospital rooms as their child recovers from yet another surgery to lengthen hamstrings or straighten backs or repair a faulty internal organ.

They are waiting in long lines in county clinics because no insurance company will touch their child.

Where are the parents?

They are sleeping in shifts because their child won't sleep more than 2 or 3 hours a night, and must constantly be watched, lest he do himself or another member of the family harm.

They are sitting at home, with their child because family and friends are either too intimidated or too unwilling to help with child care and the state agencies that are designed to help are suffering cutbacks of their own.

Where are the parents?

they are trying to spend enough time with their non-disabled children, as they try to make up for the extra time and effort that is critical to keeping their disabled child alive. They are struggling to keep a marriage together, because adversity does not always bring you closer.

They are working 2 and sometimes 3 jobs in order to keep up with the extra expenses.

And sometimes they are a single parent struggling to do it all by themselves.

Where are the parents?

They are trying to survive in a society that pays lip service to helping those in need, as long as it doesn't cost them anything.

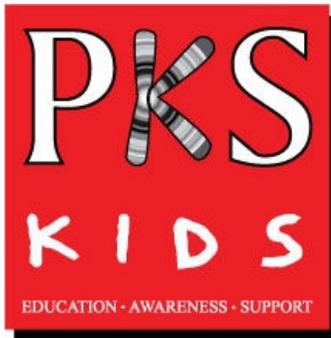
They are trying to patch their broken dreams together so that they might have some sort of normal life, for their children and their families.

They are busy, trying to survive.

this was written by Sue Stuyvesant.. .on 12/15/96...and it still applies today!

PKS Kids

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We're on the Web!

See us at:

www.pskkids.net and
www.pskkids.ning.com

How you can help!

Are any of you Facebook users? PKS Kids has a cause on Facebook. Please join the cause and invite your friends to join too. Try using this link or simply go to Facebook and search **PKS Kids**. Please join! I can't think of a faster way to spread the word!!
http://apps.facebook.com/causes/view_cause/15870?recruiter_id=5066734

Are you GoodSearching for PKS Kids??? PLEASE, PLEASE consider doing so!

Simply go to www.goodsearch.com. In the box where it asks "Who do you GoodSearch for?" type in **PKS Kids** and hit enter. This choice will save and all your searches will benefit **PKS Kids**. You might want to download their search toolbar to make your searching easier. You can even make GoodSearch your default search engine for your browser.

Don't forget to GoodShop also. Click on GoodShop via GoodSearch and choose your

online store. Just by clicking through this site, GoodShop pays PKS Kids a percentage of your sale—at no additional cost to you!

Visit CafePress at www.cafepress.com/pskkids to buy shirts, buttons, magnets and more with our **PKS Kids** logo on them! We earn 15% on each item purchased.

The Phoneraiser campaign. Collect and donate your old cell phones and empty inkjet printer cartridges (laser jet cartridges are not accepted). Phones must have the ability to power up and have an undamaged LCD. Contact gertyp@sbcglobal.net for information.

HOW ARE YOU
PROMOTING **PKS**
KIDS?

Check out Cammie
Gray's car!



We need your help in promoting this organization. Please let us know what you can do to promote **PKS Kids** and how you can help with fundraising!

About Our Organization...

PKS Kids is a 501c3 organization and the only registered non-profit created to benefit those affected by Pallister-Killian Syndrome.

Donations are tax-deductible and used to promote education and raise awareness as well as help those touched by PKS.