

PKS Kids



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Education~Awareness~Support

PKS Kids Family Reunion 2009

IT'S NOT TOO LATE!

Our 2009 **PKS Kids** Family Reunion will be held in St. Louis, Missouri.

**The dates are
June 26-28, 2009**

SHERATON WESTPORT
HOTEL

Lakeside Chalet 191
Westport Plaza

St. Louis, MO 63146
(314) 878-1500

Individual reservations (**Please tell them it's for the PKS Kids Reunion**) can be made by calling the Hotel at 314-434-5010 or by calling toll free at 1-800-822-3535. Rooms will be held until the cut-off date listed above.

All reservations must be received on or before June 12, 2009.

Reservations received after this date will be subject to room and rate availability.

Room rates are 85.00. If you'd prefer a King bed vs. 2 doubles, let them know and they reserve that for the same rate. To RSVP, click here:

<http://pkskids.ning.com/events/pks-kids-family-reunion>

Dr. Krantz will be in St. Louis early Friday afternoon to see the families!

PKS Kids Network Site

Have you visited our new social, networking, and support site? **PKS Kids** on Ning (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.

The "family" is growing! We now have over 100 members on Ning. There are mini-groups for different areas of the world: Canada, Ireland, UK, etc.

Come join the fun!

We are excited to announce our new board members

Crystal Diaz

Crystal's son Jaden is 7 years old.

PKS Kids Giving Grant

Never let
your fear
grow
greater
than your
faith

~Author
unknown



PKS Kids is now offering grants to families in need! Up to \$1000.00 will be awarded per grant and can be used to cover therapies, equipment and

medical bills that your insurance doesn't cover. Visit [this page](#) on PKS Kids for more information. Please don't hesitate to apply!

UK Meeting

Tracy Ayres is coordinating a get-together being held August 1, 2009 at Hyde Park in London.

Harley-Jae hopes to see you there!

The fun begins at 12:00 noon. Please meet at The Lido Café in Hyde Park. Click on this link for more details and to RSVP.



<http://pkskids.ning.com/events/uk-family-reunion-everyone>

PKS Kids Cookbook

You can now begin buying and selling the 1st Edition of the **PKS Kids Cookbook!**

These books have over 200 recipes and are selling for \$10.00 each.

Please visit this link to purchase!

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



BREAKING NEWS!

Dr. Francis Filloux, a pediatric neurologist with the Univ. of Utah has an interest in looking into seizures in children with PKS! He is attending the reunion in St. Louis. More information will be announced as we learn more!

PKS Kids Ballet Fundraiser!

Sunday May 31st in Chambersburg, PA, Dawn Bergquist hosted a ballet fundraiser for PKS Kids which raised more than \$1000.00!

The ballet was

Alexandra, Keeper of Dreams by Mary Alice Baumgardner.

The author was also available for book-signings also after the performance.

Thanks to Dawn and the ballet company!

A Good Deed Means A Lot!

Hi everyone,
Just a quick story for all of you that need a lift-me-up. We were on a mini-holiday this past weekend and something happened on the last day that made me think a little differently. We were backing out of our handicap parking spot at the hotel and this man waved us down. We pulled over to see what was wrong. He told me that he had something he needed to give me and then handed me an envelope. I was sort of

taken aback but proceeded to open the envelope. In it was a note that said "For your special needs baby- To those who have been honored- I honor thee". Then inside the envelope was \$200 US cash. Needless to say, I was shocked. The man was gone by now and we didn't see him again. The whole experience, even without the cash, was humbling. It reminded me and should remind all of us that we are doing the best we can with our kiddos and that

although there are many people that stare, snicker or don't seem to care- there are many people who do care.

It makes me want to do better.
So in case you haven't heard it in a while- Thank you for everything you do for your kids and for your family.

Warmly,
Tyra (Mom of Darby 2.5 yrs old with PKS)
Kelowna, Canada

ONCE YOU
CHOOSE HOPE,
ANYTHING'S
POSSIBLE.

~CHRISTOPHER REEVES

PKS Research

Dr. Ian Krantz of CHoP is diligently working on research of Pallister-Killian Syndrome. Attached you will find a letter from the genetic counselor at CHoP and the ways you can help assist them. The more families that participate the more exact the outcome. We really need you to receive the information and participate if you and your child are able.

We hope you'll *please* consider contacting CHoP in care of:

Alisha Biser
Genetic Counselor
Department of Clinical
Genetics

**Children's Hospital of
Philadelphia**

**Phone: 215-590-2920
Fax: 215-590-3298**

bisera@email.chop.edu

Additionally, if you visit [this link](#) you will see exactly the research Dr. Krantz and his team is doing and what they hope to achieve.

They are doing some very impressive things with the blood and skin biopsies they are obtaining from your child.

Without a number of specimens, they may be unable to get the data they need to apply for additional funding dollars.

For help from **PKS Kids**, please contact Kate at khettiger@pkskids.net

PKS Kids just made their first research donation to Children's Hospital of Philadelphia (CHoP)! Thanks for helping make this possible!!

PKS Kids

PO Box 94
Florissant,
MO
63032-0094

info@pkskids.net

We're on the Web!

See us at:

www.pkskids.net and
www.pkskids.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

About Our Organization...

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

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!

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

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

Conor, almost
2 years old

