

April 2008
Volume 2, Issue 1

PKS Kids



Board of Directors

Dawn Bergquist
Mike Zane
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Gretchen Peters
Dana Paglia
Kate Hettiger

Education~Awareness~Support

PKS Kids Face2Face 2008

What: Our 2nd PKS Medical Conference

When: June 19-22, 2008

Where: Philadelphia, PA at the [Hilton Philadelphia-City Avenue](#)

Cost: Families pay for their hotel and travel expenses and some meals. PKS Kids funding the entire conference cost, 4 meals and a family activity to the [Adventure Aquarium](#) on Saturday.

For more information including hotel and conference reservations visit:

[PKS Kids Face2Face](#)

Speakers and topics include:

Genetics
Developmental Peds

Accessible Vans
Special Needs Equipment
Displays

Financial Planning
Physical Therapy

We are also hosting a Sib Shop workshop for your child's siblings age 5-18. This Don Meyer, creator of [Sibling Support](#) runs these workshops throughout the country and gives voice to all that a sibling may think or feel. This is a unique and wonderful opportunity for your children.

Registration deadline is May 15th



Dr. Pallister with Aidan.

Dr. Pallister will again be attending our conference! We're very excited and thankful to have him be there

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 48 members on Ning. Recently a UK sub-group was created to give the families in England occasion to discuss education, medical and social aspects specific to Europe.

Please join us!

2nd Annual PKS Kids Bike Run in New York

The 2nd annual PKS Kids Bike Run will start planning the 2008 event in the next month or two. Stay tuned for information regarding this amazing fundraiser.

A motorcycle run, a family carnival,

raffles, food and fun!

The first Bike Run was held last year in September on Long Island with great success!

Contact Mike & Nicole Zane if you have questions or would like to volunteer to help.

zanehome@optonline.net



Wanted: Grant Writer

PKS Kids is looking for someone to assist who has knowledge of and experience in grant writing.

PKS Kids is hopeful of obtaining several grants in the future; however our current board is inexperienced in this area.

Whoever volunteers for this task does not have to be a parent or even a family member of a PKS

child. Maybe you know someone in your social circles, at your church or where you work who would love to help out.

Volunteering with grant writing will not assign you a place on our board and unless you ask, we will not ask you to take on any other tasks. We are grateful that anyone would help us with this

one, though very important, job.

If you're interested or know someone who is, please email Dawn at

onebuddy@comcast.net.

A letter to Michelle

Dear Michelle:

You came into my life when I was 16 years old and very shy, but it was not long before you made me understand I needed to speak for you. You made our family strong. You were the true meaning of Determination.

Through you, our family became so much bigger, coming in contact with so many different people – meeting people, going places and doing things we probably would not have done. You gave your nieces and nephews an understanding and appreciation for life like no one could.

When you walked into the room, you took over. You were the first to say “hi, what’s your name, who are you. You loved life and everyone you met.

You never asked for help and often refused it. You would propel your body through the house amazing all of us.

You were extremely thoughtful – always thinking of mommy, Mary, the kids and the rest of our family. You left every party with desert in hand for Mary. Before you would accept a piece or cake for yourself, you told the server you needed one for Mary.

You made your daily trips with Mary to Dunkin Donuts for your Coffee Coolattas, and when unable they were brought to you. Very few days went by without a trip to Dunkin Donuts.

You made shopping trips to CVS and Walgreens to buy your magazines and would have a whole list in your head of things that you and mommy needed for the house.

You were so very organized – I would often call you “Little Gloria”.

Through all your problems and

illnesses, you were always the first to ask everyone “how they were, how they felt”.

You baked cakes and brownies every day, supplying all of us.

When you saw me crying or upset, you would respond with – “its ok honey, don’t cry honey” “What’s the matter?”

You were brutally honest, saying exactly what you meant, many times making Mommy cringe. After a while we learned to laugh because we knew you were right and we felt exactly the same way, but couldn’t say it.

You were not afraid of very much and would try almost anything. I remember the first time you went go cart racing. John put you in the car with him and he couldn’t go fast enough for you. Mommy stood there looking, so worried about you.

You would come in our pool, get in a tube and manage to swim around, never hesitating to splash everyone.

While you loved people, you also loved your pocketbooks, buying at least one a week, sometimes two, when one was for Mommy.

And, we cannot forget your dolls. You took care of your dolls like they were human. When at my house, you would take out your cell phone and call home to check on them, hang up and tell me you needed to go home to take care of Alicia and Lynn.

As I approached your bed to see you, you always told me not to worry. In your hospital bed, before you could be diagnosed or treated, your first words were “I want to go home”, when am I going home, trying to get up, hanging one foot out of the bed. You never spent time dwelling on

your medical problems. As mommy put it, “you were always rearing to go”.

You never left her house without bags and goodies in tow.

Mommy would comment that “you had to pack the whole house just to come around the corner”.

You loved to make collages for every occasion. When I would call the house, mommy would say you were “breaking it up with Mary”.

You enjoyed many nicknames – the latest being “Grandma”. You also enjoyed calling the family by many names – Victor was “Vooch”, John, my brother, was “whistle”, John, my husband, was “John Hellis”, and Aidan was “the boy”.

You were determined, defying the odds over and over again until now. You had a rule no one was allowed to say bye to you. When I teased you or when people did not listen or understand, you would bang on the table three hard times and then engage mommy’s help who would say to the person “just go, don’t say bye to her”. It’s ironic, Michelle you were true to your rule and did not give us that chance to say bye to you. We love you.

Lisa



Michelle
February 21, 1977-
November 2, 2007

“You never asked for help and often refused it. You would propel your body through the house amazing all of us.”

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.

Exceptional Parent magazine. For each subscription purchased

through this link, Exceptional Parent magazine will donate \$5.00 to **PKS Kids**! Please click on the EP logo.



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.

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.