



The PMD Foundation E-Newsletter

Let's Join Hands to Rid the World of PMD!

PMD Foundation

Volume V, Issue I

May 2010

Remembering Alex



Alexander John LaBine

August 29, 1987 - October 16, 2009

Pembroke, ON, Canada

Survived by his parents

Brian & Pat LaBine

And sisters

Emily & Adrienne

*Nothing stops time. The world does not stop turning, and life goes on.
But for a moment, one person can force that world to stand still in our hearts.
One person can cause eyes to look toward heaven.*

And one person can leave behind the warmth of their smile with the echo in their laugh.

- Angela Hammel



Chairman's Message

In our September, 2009 issue of the PMD Foundation E-newsletter, our featured child was Li Yong. If you recall, he was a PMD affected child who was living in an orphanage in China. Many of you know Scott, Melissa, Brianna and Eli Meade from the 2009 Research Symposium at AI duPont Hospital in Wilmington, DE. They are working very hard to make Li Yong a member of their family. It takes a big heart to adopt a special-needs child, and that is multiplied when you already have one at home, as Eli is a PMD affected young man. Please keep them in your prayers as they go through this process. Melissa has also promised to write an article on the adoption process for our next issue, so be on the lookout for that, along with a family picture.

In this issue, you will read about Team Logan. Special thanks to Doris and Ben Parker for their months of hard work in organizing and running their Belton, TX barbeque and auction. They served over 200 guests and their results prove that things can be bigger in Texas. They raised a record setting excess of \$55,000 to benefit the PMD Foundation. A huge "Thank You" to the Parkers and to the Elkin's Auction Service from all those affected by PMD.

What's up with research? We are closely watching Stem Cells, Inc.'s Phase 1 clinical trial as they test the safety and efficacy of stem cell transplantation therapy for PMD. We are providing funding to help three ongoing research projects, two in the US and one in Germany. We are confident that these projects will lead to improving quality of life and also point the way to eliminating PMD. Remember our vision is "A World without PMD" and our mission is to search for ways to make it happen.

How are we operating? We remain frugal with all overhead expenses. The PMD Foundation Trustees are volunteers spread to all corners of the country. We work from our homes and have no fixed offices. Because we conduct business by email and conference calls and pay no salaries, we are able to use 95% of your hard-earned donations for family support, research and awareness. Further, it is the goal of every member of the Board of Trustees to achieve our mission and be out of business as soon as possible.

Grace and I hope to see you: at the Indianapolis Family Meeting June 11-13, at the Jones Family event in Chicago September 25 and at the New Jersey Golf Outing in late September.

Don Hobson

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Groundbreaking science. Breakthrough medicine.™

Clinical Trials Begin For PMD Patients

Phase I safety studies on a potential treatment for PMD began on February 9, 2010 at Children's Hospital at UCSF (University of California – San Francisco.) Stem Cells, Inc., the company providing the proprietary neural stem cells, is sponsoring this project. The initial trials on young males with the connatal form of PMD will determine the safety of using stem cells on patients with a myelin disorder while monitoring their potential effectiveness as a treatment for PMD. Patients will be injected with the cells and immunosuppressed for a nine month period. Evaluations will take place regularly over the following 12 months to monitor the safety of the process. Brain MRI exams will be performed post-transplant to assess any new myelin formation. Observational studies will continue for four years to analyze long term therapy results. Testing has begun on one child, with more to follow. It is still too early to provide reportable results, but we will post updates on the PMD Foundation website as progress reports are released to us. Additional information can be accessed at the UCSF website:

<http://neonatology.ucsf.edu/nbri/pmd-trial>



UPDATE

The Chairman of the PMD Foundation Scientific Advisory Board, Dr. Jim Garbern, recently resigned from his position at Wayne State University in Detroit, Michigan. In August, he'll be moving on to a new position at the University of Rochester in New York. This move will enable him to devote more of his time to PMD, myelin and neurological research. Dr. Garbern will have access to a newer, bigger research facility as well as a greater source of funding. In addition, he will be in the company of other investigators who are carrying on related neurological research including stem cell and remyelination. Luckily, this move will not change his status with the PMD Foundation. He will continue to serve on the PMD Foundation Board of Trustees and as head of the PMDF Scientific Advisory Board. We wish Dr Garbern well in his new position and look forward to the continuation of his valuable contributions of time and effort.



The New Look of the PMD Foundation

Even though we initiated a logo contest some months ago, it has taken some time to come to a consensus on a symbolic representation with significance to the group. Many creative designs were submitted, but most lacked a true visualization of what the PMDF stood for. One of the entrants went to the trouble of speaking with a Board member in an attempt to create a design that would be most meaningful to the Foundation. During that discussion, it came to light that a logo representative of PMD, the disease, is not necessarily representative of PMDF, the Foundation. The mission of the PMDF is research toward treatment and the eventual elimination of PMD, raising awareness of the existence of PMD and support for those families dealing with the disease.

The image on the left is the artist's rendition of a symbol that exemplifies many aspects of the PMD Foundation's purpose, a lighthouse situated on a firm, rock foundation. It is a beacon that brings light to dark circumstances, a guiding light to identify a new location giving direction and hope, and a bright spotlight that increases in strength the closer you get, a welcome into a safe harbor of aid and assistance. The PMDF must strive to be all this and more. Therefore, we present the lighthouse design as a most appropriate new logo. Congratulations to Maureen Manley for her efforts in developing the new design.



FUND RAISING SUCCESSES

Team Logan Barbecue Raises Over \$55K



Congratulations to the Parker Family and Team Logan for holding a spectacularly successful fundraiser!! Doris & Ben Parker and their beautiful son, Logan, joined with hundreds of hungry Texans on February 27, 2010 at the VFW Hall in Belton, TX for a BBQ lunch and auction. Food was provided by 777 Catering Co. and Elkin's Auction Service auctioned off many wonderful items to very generous bidders. The biggest auction item was a guitar autographed by C & W superstar George Strait, which sold for \$4000. Another big ticket item was a Texas-sized barbecue grill, handmade by proud Dad Ben Parker, which sold for \$1500. The event was covered on local television by KWTX. Our thanks to the Parkers for all of their hard work.

The Parkers are on a roll, continuing with more fundraising events to both benefit the PMDF and also help defray the costs of acquiring a service dog for Logan. If you have a Facebook account, become a fan of Team Logan or read their blog at <http://www.teamloganpmd.wordpress.com> to keep up with all the activity.

Taking the Plunge for PMD



Rob Gasperetti, a member of the PMD Foundation Board, braved the freezing waters off Long Beach, NY on Sunday, February 7, 2010. He participated in a Polar Bear Swim to raise funds for the PMD Foundation. Rob collected over \$1,100 in online donations for his brave feat. Nice job, Rob. Thanks for showing real dedication to the cause.



Let's Wrap It Up!



Would you like to get involved in a fundraiser for the PMD Foundation, but feel a little overwhelmed by the idea? We know of a fun and easy way to get donations without a lot of prep work. Just ask Tara Veal about her experience at the local Borders Bookstore. She collected over \$300 and the only cost was her time.

The holiday shopping season, from November through December, offers a great way to fundraise: wrapping gifts at a Borders Bookstore. Borders even provides all the gift wrapping supplies you'll need, and all the donations you collect will go to the PMD Foundation. Contact the General Manager at your local Borders Bookstore (Borders Express and Waldenbooks stores do not participate) and schedule a "gift wrapping event." Because of the popularity of this program, Borders suggests you schedule at least 4 months in advance to get a date.

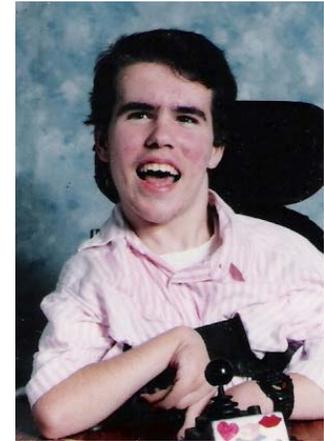
SHARING OUR GIFTS



Michael

Children are among life's most precious gifts. They fill our hearts with great joy, love and the promise of a bright future. Every parent hopes their child will be as perfect as humanly possible, inheriting our best qualities and improving on our lesser traits. We look forward to watching them grow up and develop into their own special person. Unfortunately; we don't control what our children inherit. Sometimes things don't work out the way we plan and our fondest dreams are forced to take a detour. It is then that strong love, faith, hope and determination get us through.

Both our sons, Paul and Michael Sawadzki "inherited" PMD. Although life was hectic and disheartening at times, we always looked for reasons to feel happy and thankful. In spite of life's challenges, each boy was a true blessing, perfect in his own way. Despite their physical limitations, they captured many hearts and left lasting impressions on countless people. Though they weren't blessed with "perfect" bodies, they became very special people. Let me tell you a little about them...



Paul

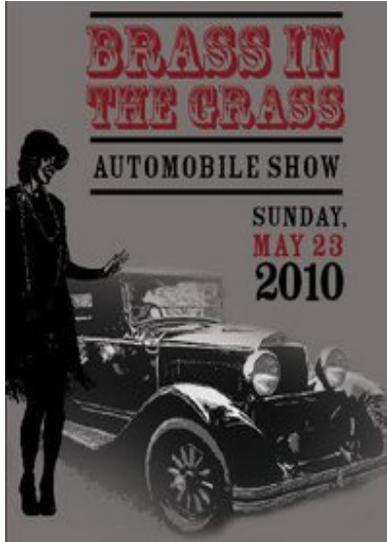
Paul, our oldest son, was loveable, charismatic and contemplative. He was a computer buff and a fan of Reggae music. He was keen on Pepsi and chocolate milk. He loved school, including the daily ride on the bus. Watches fascinated him so much that he was sometimes able to charm them right off the wrists of friends. Few people knew, but Paul had the heart of a daredevil. One time, he coaxed his sister, Erze, to take him to WaWa (a convenience store) in his wheel chair. They had to cross a major highway to get there, something he knew was not allowed. Lucky for both of us, I did not find out about this escapade until after his passing.

Michael was the cuddly, charming one, with a devilish personality. He loved chocolate and peanut butter. A real trickster, he loved to confuse and terrorize people. He got a kick out of frightening new therapists and teachers by holding his head back and pretending to choke. Other times, Michael would say he wanted to take a coffee break with them, telling them that his mom served him coffee everyday. His laugh was contagious, though at times a bit fiendish.

We learned so much from our magnificent sons. Now that they're gone, life without the boys is difficult for Frank and me. We miss them both so much, but feel their presence often. There isn't a day that goes by that we don't think of them and how we prayed and hoped for a treatment or cure. Sadly, that breakthrough did not occur in their lifetimes.

We're extremely thankful for the PMD Foundation, giving us the opportunity to meet the dedicated researchers and other affected family members. We cherish those relationships. To keep our promise of helping to find a cure, we have chosen to donate our sons' central nervous systems (brains and spinal cords) to the PMD Consortium. Although they will always live on in our hearts, they now may touch many lives. Hopefully, their contribution to PMD research may change the future for many more people.

SAVE THE DATES



Brass in the Grass

Automobile Show Fundraiser

May 23, 2010

Do you love classic vehicles (1900-1940's)? How about vintage clothing, big band music and antiques? **Tara Veal** has just the place for you! It's an automobile show and so much more, the "**Brass in the Grass**" event in Santa Rosa, CA. Expect a day of sun and fun. Stroll among the vehicles of bygone times. Relax as you picnic on the lawn and listen to music from that era. Stop and shop at the vendor booths. What an enjoyable way to support the fight against **Pelizaesus-Merzbacher Disease!** **Half of all profits from this event will be donated to the PMD Foundation.** Tara will also man a booth there to raise PMD awareness and collect any additional donations. Contributions from those living too distant to attend can be made via the donations page at www.pmdfoundation.org where there is a special category for your "Brass in the Grass" donation. If you can't be there yourself, tell your friends who live in northern California to don their zoot suits and "Lindy" over to the Redwood Academy, 385 Mark West Springs Road, Santa Rosa, CA (707) 837-9824. Adult admission \$12, seniors \$10, children under 12 free with an adult purchase. For more information, go to www.brassinthegrass.com. Thanks Tara, we wish you luck toward a successful, fun-filled event.

21ST ANNUAL RILEY PMD FAMILY CONFERENCE

June 10 – 14, 2010

The Key Is Sharing



Patti Daviau, the recognized matriarch of our (very) extended PMD family will once again host the Riley PMD Family Conference in Indianapolis, IN. Those who have attended in the past know that these meetings are based on sharing. Valuable time is spent with other PMD families, clinicians and researchers intent on providing new and helpful information. There is a sense of camaraderie unique among those who understand the challenges faced in raising a child with PMD. Both happy and heartbreaking experiences can be shared in an environment of compassion and empathy. Advice is available from those who've "been there." A central theme of the weekend is to have fun and enjoy the company of others in a little getaway from daily responsibilities. Joining planned group activities is encouraged.

If you are new to the PMD Community (or have just never made it to Indy in the past), come join the group, make new friends and share the experience.

Meet at the Crowne Plaza Hotel at Union Station, 123 Louisiana St., Indianapolis, IN, phone - 317-631-2221. Please make room reservations before Friday May 21. The special Group room rate is \$97.00 per night plus tax (mention the Riley PMD Group for this rate.) Check in after 4:00 p.m., check out by noon. If earlier check-in, later check-out, transportation from the airport or any other additional information is required, contact: Patti Daviau at 317-635-7359.

9th Annual New Jersey Golf Outing

Cranbury Golf Club

West Windsor, NJ

Las Vegas Theme

Thursday, September 30, 2010

SAVE THE DATES

(cont'd)

JOIN US FOR THE 2ND ANNUAL JONES FAMILY WALK 'N ROLL



Fresh air, exercise and great traveling companions, what more could you ask for? Save the date, September 25, 2010, to participate in the Second Annual Jones Family Walk 'N Roll for PMD. Stroll or roll along Chicago's lake-front starting at the 63rd Street Beach, around Promontory Point Park and back, on a 2.5 mile picturesque route. The Jones Family (Gina, Gordon, Garrett and Gavin) will be there to lead everyone in the fun. At the "finish line" there will be refreshments, family games and raffles. Contributions and pledges will again support the PMD Foundation in its missions of research, increasing awareness and support for PMD patients.

In addition to a repeat of last year's great activities, there are more exciting events planned. The Regular Grand Lodge is hosting a kick-off "Black-Tie" dinner gala on September 18 in Hillside, IL at the Best Western Hotel. 50% of the proceeds from this extravaganza will be donated to the PMD Foundation.

If you cannot attend, but wish to make a contribution in honor of the Jones Walk N Roll, go to the PMD Foundation site, www.pmdfoundation.org, choose your donation option in the left column (check or credit card) and then click on the Walk N Roll button on the Make a Donation page. For more information, and updates, visit www.events.org/joneswalk.



DONATING THE PAINLESS WAY

Without spending a dime

LYDIA'S UNIFORMS



The Foundation has collaborated with Lydia's Uniforms to give everyone an easy way to raise money for the PMDF. Lydia's Uniforms agreed to provide a 10% commission to the Foundation for all regular priced purchases made using our special key code, **PWPMDC10**. Plus, each buyer using our key code will receive a 5% discount on regular priced products. That's truly a win-win situation. Most PMD families work closely with medical personnel. If everyone spreads the word to their uniform-wearing friends (providing a 5% discount on items they need to buy anyway) the potential earnings are huge! You won't be asking for donations, you'll be doing your medical friends a favor. For more information, go to our website. To

place an order, login to www.lydiasuniforms.com and be sure to use our keycode. Join us in this simple, yet effective way to raise money for our cause. A promotional flyer can be downloaded at www.pmdfoundation.org.

DONATING THE PAINLESS WAY

Without spending a dime (Cont'd from pg 6)

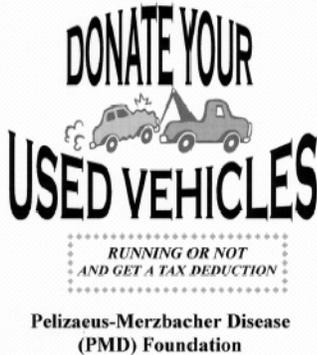
GOODSEARCH (search engine powered by Yahoo)



What if your online searching could result in a contribution to the PMD Foundation? If you use the search engine GoodSearch it can. GoodSearch donates 50% of its revenue to approved charities designated by its users. On top of that, many retailers will donate 3-20% of a "GoodShop" online purchase to the charity. Setting up GoodSearch is easy at www.goodsearch.com. It's a great way to contribute to the PMD Foundation.

iGIVE (online shopping)

Shopping or searching for purchases through iGIVE can result in a donation for the PMD Foundation. A penny or more per search, a \$5 bonus for your first online purchase and up to 26% of your purchases will be contributed to the PMDF. Over 700 stores participate in this donation program, including Amazon.com, eBay, Staples, JCPenney, Barnes & Noble, Overstock.com, Office Depot, QVC, Home Depot, HSN, Gap, & NORDSTROM. Plus, as an iGive member, you SAVE money with exclusive coupons and free shipping deals. It's easy. Select the PMDF as your favorite cause, register with iGive and shop at brand name online stores through the iGive Mall. Logon today to www.iGIVE.com and support our cause.



DONATION LINE LLC (Vehicle donation center)

Use Donation Line to donate cars, trucks, motorcycles, RVs, boats, jet skis or snowmobiles to benefit the PMD Foundation and get a tax deduction for yourself. They provide FAST, FREE pick-up of your vehicle (running or not) and have an A+ rating by the Better Business Bureau. The process can be initiated 24 hours/7 days a week by phone at 1-877-227-7487 (ext. 2434 for PMDF) or by filling out their online form. A towing agent will contact you to arrange a pick-up time, and provide you with a pick-up receipt. The vehicle will be sold at auction and the PMD Foundation will send you a tax-deduction letter upon receiving the funds. Get more information about tax deductions for donated vehicles, at www.donationline.com.

CALL TOLL FREE (have title with you)
1(877) CARS-4-US
EXT 2434



We also have Window Stickers and our latest design, 5" Magnets, available for purchase on the donations page of our website donation/purchase page: www.pmdfoundation.org for \$5.00 each plus postage.

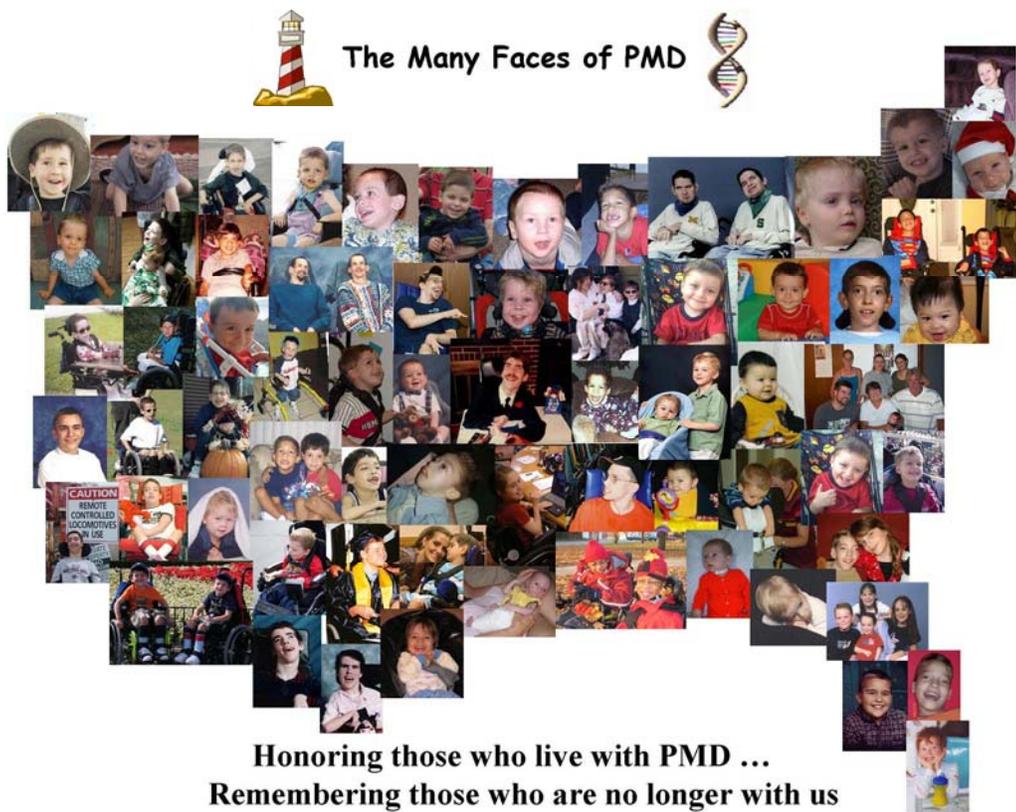


Window Sticker



Magnet

Please help us update the **COLLAGE!**



Several years ago we created this collage. We have used a large poster version at Professional meetings to raise awareness of PMD and to call attention to the fact that it is "Rare but Everywhere".

Please email a photo that you want us to include in an updated version to:

collage@pmdfoundation.org

Thank you!



Our Vision:
A World Where There Is No PMD
Our Mission:

- Provide support for families affected by PMD
- Raise public awareness and support for PMD
- Fund the research of Pelizaeus-Merzbacher Disease



If you haven't visited the PMD Foundation's Social website please visit and join us:

<http://pmdfoundation.ning.com>

We invite everyone with an interest in PMD to participate. There are many photographs of the April Scientific Symposium, the 20th Annual Riley PMD Family Conference in Indianapolis, the Manley Palooza and the Jones Family Walk and Roll in Chicago. Join, add your own PMD Events and fund raisers, post your own photos, information and ideas.



Together, we can make 2010 the year that a treatment is discovered, leading to an eventual cure!

Please make a donation either:

By visiting our website to make a safe and secure contribution or to make a purchase

www.pmdfoundation.org/donation.htm

Or

By clipping the following coupon and mailing it with you check

My Donation

I would like to support the PMD Foundation's mission of family support, awareness and research. Enclosed is my tax-deductible donation of \$_____.

Name: _____

Address: _____

City: _____ State: _____ Zip: _____

Please detach and mail with your contribution to:

The PMD Foundation
1307 White Horse Rd, Ste 603
Voorhees, NJ 08043

THANK YOU FOR YOUR SUPPORT!