



The PMD Foundation E-Newsletter

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

PMD Foundation

Volume IV, Issue IV

December 2009

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Chairman's Message



As we prepare for the Holidays, please take a moment to remember those that we lost in the past year. The hardest thing for any parent to do is to attend your own child's funeral. Fortunately, I have not had to do that, but with a rare disease such as PMD, too many of my friends have.

We supported three major successful awareness and fund raising events this year. Congratulations to the Manley's for their Palooza, the Joneses for their Chicago Walk and Roll and to Linda Leonard for the 8th annual New Jersey Golf Tournament.

We are honored to welcome three very talented and experienced volunteers to the Foundation team. They are committed to doing whatever it takes to rid the world of Pelizaeus-Merzbacher Disease and to supporting the PMD community. They each bring many skills that have made them successful in their careers.

Kathy Kanous is our Director of Business Development. Kathy's two nephews have PMD, one of whom, Bradley Widdop, passed away earlier this year.

Fran Sargent is our Director of Financial Operations. Fran's nephew, Jeffrey Rogers, has PMD. Fran is also serving as our Board Recording Secretary..

Ann Ventura joined the Board of Trustees and is our Director of Contributor Relations. Her son Daniel is memorialized as our PMD child. A photo of Daniel appears above. A Ventura Family remembrance appears on page 4.



Patti Daviau Honored for 20 Years of Service

On November 4, 2009, Patti Daviau, PMD Foundation Board Member and "Mama Bear" to just about every family in the United States who is afflicted with PMD, received an award from the Mayor of her hometown.

At the Indiana Historical Society in downtown Indianapolis, Mayor Greg Ballard presented her with the Mayor's Community Service Award. This is in recognition of her volunteer contributions and commitment to community service. This year, Patti hosted the 20th Annual PMD Family Conference in Indianapolis. This annual gathering and celebration of life has been the first affirmation for dozens of PMD families that they are not alone with their rare disease. Those families affected by PMD who have never attended this event should make it a point to "stop by" the next one. All are welcome and many return year after year.

No date has been set for the 2010 Family Conference as of yet, but you can rest assured that a collection of PMD families will be in downtown Indianapolis for a four-day weekend in June or July for many years to come. Congratulations Patti and Thank you!



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In the past two years, the PMD Foundation has sponsored research on two continents in our continued mission to help find treatments and an eventual cure for PMD. Additional research dollars have been granted by the National Institute of Health / National Institute of Neurological Diseases and Stroke, which is a U.S. governmental agency. Together, every dollar counts.

As PMD, the disease, comes from an assortment of causes, such as a duplication, mutation, or lack of a specific gene, treatment options and research therapies also will vary. Some of the projects currently being researched include natural history studies, pharmacologic expressions, and cell transplantation. It is hoped that this wide variety of studies will lead to a treatment within the next few years.

Stem cell therapy seems to be the treatment option that is getting all the press lately. Stage One trials for the treatment of PMD will be beginning soon. We will be watching closely to see how it affects members of our community. It is an invasive process which does have its risks, but we will see what its rewards may be. That project, along with other research that is taking place worldwide, can only give us a reason to be optimistic.



Logo Design Contest



In 2010, the PMDF will celebrate its 10th anniversary. In observance of that special occasion, the Foundation would like to renew its look with the generation of a new, inspiring logo. Currently, the Foundation uses two logos familiar to those involved with our programs. Our hope is to incorporate one, consistent image in all future promotional material. The Foundation Board is sending out a call to those of you who are creative (or have creative family/friends/contacts) to design a memorable logo representative of the PMD Foundation and its mission. The PMD Foundation mission/vision can be found at www.pmdfoundation.org, on the PURPOSE page, for those who need clarification/inspiration. This logo design contest will begin immediately with entries accepted through January 20, 2010. Like all good contests, there will be a **prize, a \$200 Visa gift card**. Rules and guidelines for submissions can be found at www.pmdfoundation.org/logocontest and anyone is eligible to participate. We ask that each individual limit themselves to a maximum of three entries. If identical/similar designs are entered by multiple participants, only the one received earliest will be considered. So, fire up those creative juices and let's launch a new decade with a new image!



How to HELP without Trying

GoodShop/GoodSearch/I-Give

This Holiday season, please remember to use Goodshop or I-Give when shopping online from your favorite retailers. It costs nothing extra and only requires that you visit their website first.

To help even further, use Goodsearch every time you surf the internet. Just go to www.goodsearch.com and choose the PMD Foundation as your chosen cause. Then download the Goodsearch toolbar and it will automatically use Goodshop when you type the name of your retailer in the Search Box. The search engine is powered by Yahoo, so you know that you are using the services of a reputable program

AVON

Katherine Robson is the step-mother of a young adult with PMD. She is also an Avon representative. She recently started an online event to benefit the PMD Foundation. To assist in this event, just go to www.youravon.com/krobson and click on the *Online Events* tab. A full 25% of your purchase will go to the PMD Foundation. They are even offering Free Shipping with any \$30 order this Holiday season.

Please visit Katherine's website and help bring her closer to her goal of raising \$2500 for the Foundation. We are very grateful to her for organizing this event, and would like to encourage everyone to support it.

A Win-Win Fundraiser With Lydia's Uniforms



Raising funds is a necessary activity for sustaining the PMD Foundation. Organizing large events is a daunting task for many, when time and energy are hard to come by. The Foundation has collaborated with **Lydia's Uniforms** to devise an easy program to give everyone a way to help raise money with very little effort. **Lydia's Uniforms** retails quality medical scrubs, lab coats, etc. nationwide through their catalogs and website. They have agreed to provide a 10% commission to the Foundation for all purchases made utilizing our special keycode, **PWPMDC09**. In addition, each buyer using our keycode will receive a 5% discount on products. That is truly a win-win situation. Most PMD families are closely allied with a variety of medical personnel. If each family spreads the word to their uniform-wearing contacts (doing them a favor by providing a 5% discount on items they need to buy anyway) the potential earnings are great. You won't be asking for donations, you'll be doing your medical friends a favor. If the results are positive, this can become an ongoing program, providing a consistent stream of cash flow for the PMDF. We will provide more information at www.pmdfoundation.org/uniformprogram and create a link from the PMD websites. We hope to develop promotional materials (flyers and catalogs) that you can distribute in the near future. Join us in this simple, yet effective way to raise money for our cause.

September Fund Raisers

8th PMD Golf Outing

The 8th New Jersey Golf Outing was held on location at the Cranbury Golf Club in West Windsor, NJ. The good weather (warm and dry), a spirited round of golf, a fun Hollywood atmosphere with raffle, auction and good food made for a festive and fun day. We are grateful for Linda Leonard and all of the volunteers for their hard work and contribution to helping Rid the World of PMD!

Jones Family Walk & Roll



Led by Garrett, Gavin, Gina, and Gordon Jones, the 2009 Jones Family Walk and Roll took to the Chicago lakefront on Saturday, September 19, 2009. Approximately one hundred walkers and rollers completed the course supported by volunteers along the route and at the Start/Finish. Walkers and rollers paid a registration fee and obtained donations and sponsors in order to raise funds for the PMD Foundation. Approximately \$10,000 was raised for the Foundation. After walk activities included the prize raffles, snacks, games, and a hotly contested tug-of-war with the fire department.

The event was held in honor of Garrett and Gavin Jones who live in Chicago, Illinois. Garrett, 11 years old, and Gavin, 7 years old, both have Pelizaeus-Merzbacher disease, and both did a fine job of leading the event. Helping the boys and their parents kick off the start was the Grand Marshal of the walk, George Flores. George, a professional Harp Technician, suffered a spinal cord injury in 2004. He spends much of his time and energy as an advocate and supporter of charitable programs to better our world; and, the Jones Walk and Roll was honored to have him as the Grand Marshal.

Financial and organizational support for the walk was provided by sponsor Permobil Power Wheelchairs, as well as the Evergreen Fire Fighters Association, the Knights of Columbus Council 3323, Kenwood Liquors, Hyde Park Bank, and La Rabida Hospital.

SAVE THE DATES

9th Annual New Jersey Golf Outing

Ramblewood Country Club, Mt Laural, NJ
Tuesday, September 14, 2010

Parker Texas BBQ Lunch

On Saturday, February 27, 2010, Doris Parker and family will host a fundraiser in honor of her son Logan (PMD), who is two years old. This will take place at the VFW Hall in Belton, TX. It will feature a Texas style BBQ lunch, followed by an auction. Come and join the Parkers and support the Foundation. Details will follow on our website



Daniel Ventura with his older brother Noah

Dearest All:

I thought that I'd take a brief moment to share with you how Noah, Ann and I are doing. Not a day has gone by that each of us has not missed or thought of our lil' Daniel. I was most concerned with how Noah would understand and cope with our family's loss, but his maturity and resilience has surprised both Ann and I. Perhaps it shouldn't. Noah knew that his lil' brother was special, and loved, cared, and played with him in their own special way. I remember how Daniel would keenly look and listen for his very loud, very active, older brother. Daniel would always smile at the sight and sound of his brother. And when Noah would cuddle up and "chat" quietly with him, it would soothe and calm Daniel. That's one of the family moments that I miss, and one that Noah misses, too. When we visit Daniel, Noah still shares with his lil' brother a whispered, brother-to-brother chat. I know that still brings a smile from our lil' Angel.

Ann was (and still is to a much smaller extent) at a loss during the immediate weeks and months that followed. Ann was fighting for Daniel. She'd fight to beat the recurring, monthly illnesses. She'd fight to keep Daniel healthy for a week, hopefully two, so that we could all enjoy each other's company. Ann would fight to get Daniel the medical appointments, therapy sessions, and assistive devices he needed. She would fight the bureaucracy that would stand in Daniel's way. When Daniel passed away, Ann took it very hard. She felt that she had lost the fight for Daniel. That was her role, she thought, her responsibility. It took awhile for Ann to break out of her deeply ingrained routine of waking up in the wee hours of the morning to take the shift of taking care of Daniel. It took our family to help Ann cope. It took our extended PMD family to help Ann recover. I can't thank all of you enough for the comfort and counsel that you gave her.

A big test was Daniel's birthday on August 5th. I was away, and couldn't be with Ann and Noah. I worried about how they would be. They were fine. Ann had e-mailed me a picture of Daniel blowing out his birthday cake's candles. (One of the pictures we have of Daniel is a 10x14 with his mouth wide open as if saying, "Oooh" or "Aaah".) Ann is doing as well as can be expected, though, in the back of her mind she wonders if she could've fought to get Daniel through this year's flu season.

As for me, it's tough when it's quiet and I'm alone. I miss the evenings that I would have with Daniel while everyone was off to sleep. I remember talking to him, stroking his hair, and rocking him to sleep. I can even remember the "tennis elbow" that I would get. In fact, the feeling that I have right now as I write this is like the feelings I would have with Daniel when I would have him all to myself. Thank you for letting me share this moment with you -- thank you for having me share these feelings with my lil' Daniel once more.

With all our love,
Phil, Ann & Noah



Treasurer's Audited Reports for fiscal year:
January 1 to December 31, 2008

Net Income

<u>Income</u>		<u>Expenses</u>	
Available		Fund Raisers	
NJ Golf Outing-Income	40,813.24	NJ Golf Outing-Expenses	18,389.59
Bonus Eligible		Bonus Eligible Expenses	
Hawaian Trip Raffle	2,350.00	Walk 'n Rolls	4,074.19
Total Walk & Roll	5,423.00	Ex Dir Expenses	1,970.61
YearEnd Newsletter/Appeal	3,911.00	Palooza	610.00
Personal Donations	3,415.00	Ex Dir 15% Bonus - Paid	223.81
Window Stickers	75.00	Total Fund Raisers	<u>25,268.20</u>
Corporate Matching		Program Expense	
Walk & Roll	1,000.00	Research	61,000.00
Personal	600.00	Newsletter	1,719.49
Donated Expenses	159.72	ASHG - Nov 2008	1,577.43
Foundation Grants		Promotional Materials	1,237.50
Fidelity Charitable Gift Fund	2,500.00	Merchant Account Charges	872.32
2007 Gasperetti Block Party	170.00	Indianapolis Reilly Conference	486.54
GoodSearch	400.79	PAY PAL transaction costs	63.10
Interest Income	340.07	Total Program Expense	<u>66,956.38</u>
I-Give	90.73	Operating Expenses	
Just Give	0.60	ED, 1099 Contract	18,000.00
Manley Pig Palooza	3,940.00	Research Symposia	3,000.00
Total Available	<u>65,189.15</u>	Exec Dir Operational Expenses	2,403.43
Restricted		Insurance	1,603.00
Research		Accounting	550.00
Personal Donations	18,660.55	Board Meetings	532.03
Corporate Matching	2,500.00	Web Site Consulting	314.76
PayPal Contributions	2,438.40	Software Upgrades	195.85
United Way	499.23	GoToMyPC	179.40
Corporate Donation	300.00	Bank Fees	169.50
IMO Contributions	130.00	Postage	116.93
Total Restricted	<u>24,528.18</u>	Web Hosting	107.40
Total Income	<u>89,717.33</u>	Legal	50.00
		Registration, Licenses, Permits	25.00
		Total Operating Expenses	<u>27,247.30</u>
		Total Expenses	<u>119,471.88</u>
		Total Net Income	<u>-29,754.55</u>

Balance Sheet

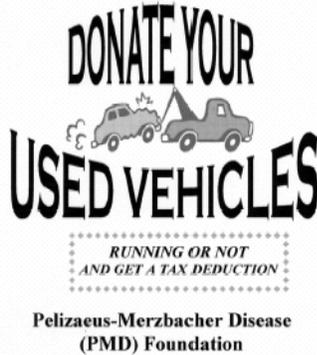
<u>Assets</u>		<u>Liabilities</u>	
Money Market Account		Retained Earnings	72,448.79
Available	16,468.87	Net Income	-29,754.55
Restricted	13,714.25	Total Equity	<u>42,694.24</u>
Designated	2,960.00		
Operating Account	7,926.80		
Pay Pal-Restricted	925.45		
Merchant Credit Card Account-Restricted	653.62		
Ex Dir Expense Account	45.25		
	<u>42,694.24</u>		

Supporting the Foundation

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

Please visit our website to make a safe and secure contribution or purchase online.

www.pmdfoundation.org/donations.htm



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

Didn't get cash for your clunker? Not a problem, you can still help the PMD Foundation and get a tax donation by donating your car or boat.

Donate your car, boat, truck, RV, Jet Ski or snowmobile to the PMD Foundation and receive a tax deduction. This no cost, no hassle process begins when you contact our fundraising partner, Donation Line LLC at 877-227-7487. Make sure to ask for our extension, 2434. Or you visit the "Donate Your Car Now" website:

http://www.donationline.com/newvehicle_donation_form.shtml and complete the Vehicle Donation Form on line. Make sure to select the PMD Foundation from the dropdown list. Please have your title in hand when you donate.



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



Window Sticker



Magnet



PMD Community Site

Open Community for Pelizaeus Merzbacher Disease



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

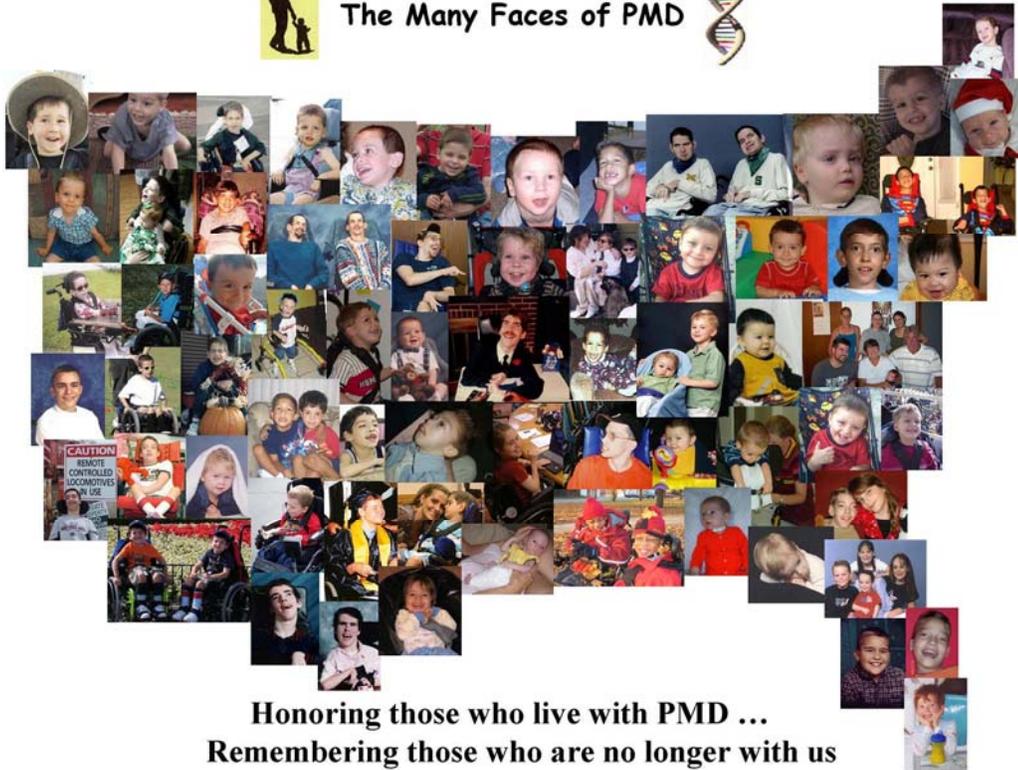
<http://pmdfoundation.ning.com>

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.

Please Help us update the COLLAGE!



The Many Faces of PMD



**Honoring those who live with PMD ...
Remembering those who are no longer with us**

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

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

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

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
1059 Mosefan St
Franklin Square, NY 11010**

THANK YOU FOR YOUR SUPPORT!