The PMD Foundation Newsletter

Striving for a World Without PMD

Vol. XII Issue 2

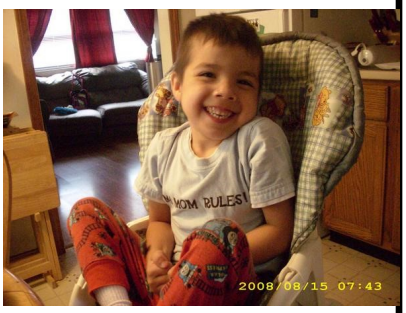
Fall 2017

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Devin Joseph Bell — Kansas City, MO



Devin Joseph is a 14-year-old young man who loves school, sports, his family, and really, just life in general. Devin was born on a cold February afternoon to a young mother in 2003. Though just bringing a new baby into the world was life changing already, I had no idea how much my world was about to flip.



I noticed general floppiness and nystagmus by a few months old. Several tests and a few years later he was referred to a genetic specialist. An MRI and F.I.S.H. blood test confirmed a PMD diagnosis in 2005. Devin was 2 years old.

Devin is high functioning when it comes to PMD. He is able to talk, feed himself, and is completely toilet trained. Devin attends public school at Oak Park High School in a contained class setting, meaning he is among peers with abilities close to his. He receives therapy services through the school; which include speech, vision, occupational therapy and physical therapy. Devin has an IEP that insures all of his needs and goals are met. His class goes on several outings into the community to learn how to do everyday life skills, like grocery shopping, ordering at restaurants and working at a job.



Devin has had a few surgeries over the past few years. He had a Bilateral Femoral Osteotomy and Adductor release to correct his hips from being 50% out of the sockets in 2015.



Devin also had a Baclofen Pump placed that same year. He had several complications with the catheter in his spinal column causing a slow leak of CSF. This ultimately led to Devin contracting bacterial meningitis. He spent 10 days in the hospital receiving IV antibiotics. His baclofen pump had become infected by the meningitis and the pump had to be removed. Devin was diagnosed with scoliosis in August 2017. He has a double curve. His lumbar curve is 52 degrees and his thoracic curve is 48 degrees. Doctors are monitoring the progression, and corrective surgery is planned for the future.



Devin may be held back by physical limitations, but he has had the opportunity to taste life more richly than most. Devin has been a co-pilot for Challenge Air for Kids since 2010. Challenge Air is a program for kids with disabilities to have the chance to be a co-pilot and help fly an actual airplane! Devin and his family visited Disney World, Orlando Studios and Sea World in 2013 through Make-A-Wish. In 2014 Devin participated in a study for PMD at Wayne State

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Devin Joseph (continued)



University in Detroit, MI. In the spring/summer of 2017 Devin played baseball for YMCA challengers.

Beginning in the summer of 2017 Devin has gotten involved with a local charity called Variety Children's Charity of Greater Kansas City. It is an amazing organization that helps children with a variety of needs. While being a part of the awesome Variety family, Devin has had the chance to play ice hockey, meet local sports celebrities and talk on the radio! Devin was on the radio with other Variety kids to help raise money to buy adaptive bikes for 20 special needs kids in the community. Devin was one of the 20 kids. The bike was delivered, and Devin has enjoyed the new sense of freedom it has brought to him. For his whole life, he has wanted to do something as simple as ride a bike by himself. What may seem a small thing to others, was life changing for him. It empowered him!



Devin is a big sports fan. He enjoys watching NASCAR, baseball and football. He loves the Kansas City Royals and the Kansas City Chiefs. Devin and his family were selected by Variety KC and the local grocery store Hy-Vee, to go to the home opener for the Kansas City Chiefs. Not only did we get surprised with tickets to the game, but we were given a VIP experience! We got to watch the game from an Airstream trailer that was fully catered with snacks and delicious food from Hy-Vee. To top off that great experience, Devin was invited on the field during pre-game warm ups. He rubbed elbows with some players and even a few Chiefs cheerleaders! The gift of attending the Kansas City Chiefs home opener was so cool, it grabbed the attention of 2 local news stations. Devin and his family were interviewed and it aired on the evening news!



Devin has an amazing personality and an infectious smile. Despite the challenges that he has faced in his 14 years of life, he has always remained happy. Of course, there are days where Devin feels saddened by the limitations that PMD gives. I am quick to remind him of all the great experiences and opportunities PMD has given him. Devin continues to be a true inspiration to all. Yes, PMD has flipped Devin's family's world upside down, but we wouldn't change it for anything.

Kelli Marie Curtiss
(Devin's Mom)

Letter from the Chair of the PMDF



As we enter Fall and begin to feel the seasons change, I am reflective of how time and the seasons are ever changing with our children. The challenges we all face. They don't go away they just change. Some of those changes like the seasons are better than others and easier to navigate. Some are more difficult. As I think about the changes and adversity we face I wanted to remind everyone why The PMD Foundation exists.

We exist for newly diagnosed families searching for answers after receiving likely the most devastating news of their lives. As parents and family members search for answers, The PMD Foundation is a beacon out in the abyss of misinformation. We are here to provide correct, current and valid information on PMD for those that are searching. We provide hope by letting them know they are not alone. We are here to provide support to those newly diagnosed families and all of our families throughout the years to help them navigate available resources and do whatever we can do to help them provide the best possible care for their children. The PMD Foundation is also here to lead the charge for research, to push for, promote and fund research that will help lead to better therapies and increased quality of life and longevity for all of our children.

At times we can all lose sight of what is most important in our lives because we are too busy. However, it is my goal that The PMD Foundation will never lose sight of why we're here and why we do what we do. We are here for all those afflicted with PMD and their families. My hope is that we can unify all families affected by PMD, that all families will work together to assist The PMD Foundation in our mission to help their PMD Child. The PMD Community is too small for us all not to work together. We need YOUR help. You can help through your donations or by getting involved to help us achieve our goals. If you would like to learn more about how you can help please contact us.

www.pmdfoundation.org
contact@thepmdfoundation.org
Phone: 1-254-313-9107

Dave Manley
PMD Foundation Board Chair

Research Update; Why We Do What We Do

By Don Hobson

The PMD Foundation was incorporated as a 501c3 non-profit advocacy organization in 1999. During the past 17 years you have contributed and we have provided PMD researchers and clinicians with $413,000 exclusively for PMD Research. All of the research proposals have been peer reviewed and selected for their contribution either to basic research, development of PMD natural history or improvement of quality of life. Two of the projects provided proof of concept that was critical to receiving NIH Funding. Before the end of 2017, we will be issuing an invitation to Leukodystrophy researchers to submit PMD treatment proposals to compete for Foundation funding.

There are over 7000 rare diseases and over 40 known Leukodystrophies. 20% of Leukodystrophy patients do not yet have a genetic diagnosis and we don't know how many patients with PMD have a Cerebral Palsy diagnosis. The prevalence of all Leukodystrophies is now estimated to be 1 in 6000 live births. All of which are competing for awareness, rapid and early diagnosis, research investigators, and funding with the goal to improve the quality of life or cure the disease.

A few Leukodystrophies have been successful in arresting the development of the disease…BUT ONLY IF the treatment is used before symptoms appear. Notably Krabbe Disease, spear headed by Hunter's Hope; Adrenal Leukodystrophy, by STOP ALD; and Metachromatic Leukodystrophy, by the MLD Foundation. PMD is among the rarest Leukodystrophies, with an estimated worldwide prevalence between 1 in 200,000 and 1 in 500,000 live births.

The PMD Foundation's Mission includes: raising awareness, providing family support and funding PMD Research. One means of fulfilling the Mission has been by participating in the following three Leukodystrophy organizations:

- The Global Leukodystrophy InitiAtive (**GLIA**), (http://theglia.org/)
- The Leukodystrophy Care Network (**LCN**), (https://huntershope.org/family-care/leukodystrophy-care-network/) and
- The World Leukodystrophy Alliance (**WLA**) (http://leukodystrophyalliance.org/)

Please visit their websites to find out more about their roles, the existing international Centers of Excellence for patient care, cutting edge Leukodystrophy research and the PMD Foundation's participation.

I have been personally involved in the work of these three organizations from their beginning. The week of October 3, I attended the Child Neurology Society's (**CNS**) conference in Kansas City, MO. Each year the Neurobiology of Disease in Children (**NDC**) offers a one day seminar for the 600+ child neurologists, program officers from the National Institutes of Health, and members of dedicated patient advocacy foundations.

These seminars have preeminent clinicians, researchers and members of patient advocacy groups present the status of diagnosis, research and treatment of a specific disease or a class of diseases. This year's symposium was the opportunity of a life time to raise awareness, focus attention on patient care, the need for early diagnosis and the progress and future of Translational Research, especially gene therapy for **Leukodystrophies**. A record capacity of 350 attended the seminar to hear from members of all three of the above organizations. The CNS/NDC conference was a dramatic triumph for all Leukodystrophies.

I managed an information booth in the Convention's Exhibit Hall to reinforce the mission of the three organizations and the content of the NDC seminar. I was joined by: Bob Rauner, President of both the United Leukodystrophy Foundation (**ULF**) and the World Leukodystrophy Alliance (WLA); Dave McIntyre, President of Bethany's Hope; Dr. Grace Hobson preeminent PMD scientist and researcher; and (when not busy elsewhere at the conference), Dr. Adeline Vandever convener of the GLIA (see picture below.).

I will once again be managing a PMD information booth at The American Society of Human Genetics (**ASHG**) meeting in Orlando. Further, Dave Manley, Dr. Grace Hobson and I will be PMD advocates at the annual GLIA meeting at the Children's Hospital of Philadelphia (**CHOP**).

LEUKODYSTROPHY Care Network

WORLD Leukodystrophy ALLIANCE

GLOBAL LEUKODYSTROPHY INITIATIVE



AUTUMN

AUTUMN

Past Events

Riley PMD Family Support Conference — Indianapolis July 6-9

Our 28th annual PMD Family Support Conference was another wonderful success! We had 20 families from 13 states and Canada. We had 19 PMD males, 1 PMLD girl, and 1 SPG male ranging in age from six months to 37 years old. We had five new families attending for their first time this year, but as always, our other PMD families made them feel right at home! We also had several Grandparents with us again this year. It is always great when the extended families members can join us, it encourages them to see the other families and children. As rare as it is for the PMD parents to meet others facing the same challenges they are, it is even more unique for Grandparents, Aunts, and Uncles to meet others like themselves, trying to support their family members who are caring for PMD children.

We had several families who came in on Wednesday and Thursday, so, we did a "small" group dinner at Steak 'N Shake on Thursday.

Friday some families saw doctors at Riley Children's Hospital, while other families chose to visit the Indianapolis Children's Museum. On Friday evening we had pizza for dinner and a Physical Therapy presentation by Dr. Carolyn Sobieski.

Saturday we had the doctors presentations at the hotel. As usual the doctors from Indiana University and Riley Children's Hospitals in Indianapolis were kind enough to volunteer their time and talents for our families. We were able to live stream the medical presentations this year, which we feel is a nice addition for those unable to join us. Jill Andrews, one of our PMD moms, also recorded the presentations for us and we are planning to make them available in the near future. Our wonderful group of volunteers provided child care during the medical presentations. For lunch we had Subway sandwiches and Saturday evening we did our traditional group dinner to Buca di Beppo both of which was provided by donations. The older guys also took their annual trip to Hooters, complete with pictures and T-shirts! There was a small group trip to the Zoo on Sunday. As always we had many opportunities for visiting and late night chats.

This year's conference was, as always, a great success. We cannot say thanks enough for all the generous cash donations, gift cards, Amazon purchases, time, talents, etc.! It really helped us stretch our budget.

As soon as we have our dates for next year set, we will post them on our website, so everyone can schedule their vacation dates for 2018.

If you would like more information about PMD Family Support, the annual conference, or to make a tax deductible donation towards our annual PMD Family Support Conference please visit us at www.PMDFamilySupport.com.

Amanda Thompson Klinge







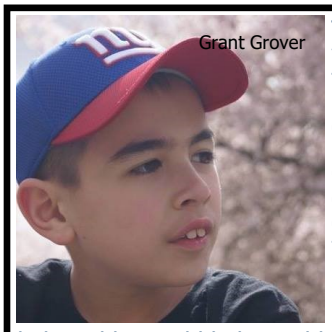




Bottom row of pictures compliments of Melissa Meade.

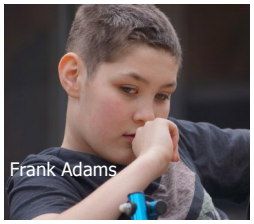
Past Events (continued)

Grant Grover's Yard Sale


Grant Grover

There is a young man in Monmouth, Oregon who sets a wonderful example for us all. For the past 4 years, Grant Grover has held a yard sale (along with his Mom, Jen Grover) to raise money by selling toys and things he's outgrown. What sets him apart is that the money he makes is not spent to buy new toys, but rather donated to a charity of his choice (ie. The Ronald McDonald House.) This year, he chose The PMD Foundation.

Grant has a relative with PMD/SPG2 (Frank Adams, who is his mother's cousin's son) and he wanted to do something to help find a cure. So he went above and beyond to make his sale this spring a big success. Monmouth is a small, close-knit town, so Grant advertised and collected additional toys and items from others to add to his sale. When all was said and done, Grant raised almost $540 (he also talked his Mom into adding her yard sale proceeds). That money was recently sent to The PMD Foundation.


Frank Adams

Many of us think there is little we can do to aid in the causes we support. Grant believed he could help, and he did. Not only that, but he had posters and hand-outs at the yard sale and his Mom created a Facebook page to advertise the yard sale and educate those in his town about PMD. What's even more amazing about Grant is that he's only 8 years old. He is a 3rd grader at Monmouth Elementary School. He loves playing the drums and plays both football and basketball. His favorite thing to do with his "cousin" Frank is play on the Nintendo switch.

Grant plans to hold future sales to raise more funds for the Foundation. The PMD Foundation wants to thank Grant and Jen for their thoughtful, big-hearted generosity.

3rd Annual Gabe VandenBerg Golf Outing





The family and friends of Gabriel Luke VandenBerg recently raised over $75,000 for the PMD Foundation on August 14, 2017. J.B. and Melissa VandenBerg hosted their third annual golf outing for the Foundation in honor of their son, Gabe. They dedicated hundreds of hours along with many volunteers to make the event a large success. Before the golf outing, the VandenBergs had a personal goal of raising around $50,000 and were blown away by the amount raised and given to the Foundation for research. The outing grew so much over the past year that both golf courses at Egypt Valley were full of golfers.



After the 18 holes, the golfers attended a meal, silent auction and other events during the evening. One event was a 50/50 raffle where the winner donated his winnings back to the Foundation. I was able to attend the outing on behalf of the PMD Foundation and spend time with the VandenBergs before and after the event. I learned more about Gabe and his big sister, Savannah. Fun facts about them; Gabe likes yellow cars and Savanah likes horses and LOL toys (where there is a surprise baby in a plastic ball.) Melissa is a pharmacist who works part-time and has an organized schedule of taking Gabe to therapy and Savanah to horse camp. J.B. is an anesthesiologist who works in a local hospital setting. The VandenBergs live in a beautiful subdivision and spend a lot of time with their friends next door and across the street. We spent time in their backyard making s'mores after hanging out at the local pool and watching Gabe in the Firefly Splashy.



On behalf of the PMD Foundation, we want to thank the VandenBerg's for their dedication to raising awareness and money for our PMD Warriors. To learn more about Gabe's story, his mom has a Facebook page called, "Hope for Gabe." Let's grow the numbers of followers for Gabe!

Easy-Peasy Halloween Treats

If you're having a hectic Fall and the thought of making homemade treats is enough to make you want to SCREAM, take a look at these "almost homemade" treats. They're cute, festive, and so easy to make from plain store-bought goodies.



Nutter Butter (or similarly shaped) cookies, dipped in melted white chocolate with two miniature chocolate chips for eyes, become "ghost cookies". The multi-talented Oreo can also be dipped in white chocolate and adding a face with black cake decorating gel will make a ghoulish "skeleton cookie" (impaling it on a stick makes it a cookie pop.) Or split that Oreo in half and add green/blue/red decorating gel and a brown M&M to make scary "eyeball cookies." Cut that extra chocolate cookie in half and attach the halves to a Reese's Peanut Butter Cup with a little extra gel, then add edible eyeballs to create cute "mini-bat bites."



If marshmallows are more to your liking, dip them in melted green chocolate bits, add some dark chocolate hair, a few of those edible eyeballs and broken pretzel stick "bolts". Voila, Frankenstein treats. Or use some of the melted white chocolate to drizzle back and forth across a plain marshmallow, add a couple of edible eyes and you have Mummy Marshmallows.

Now, that wasn't so bad… Halloween treats without breaking a sweat (not even turning on the oven.)











Mini-donut Spiders



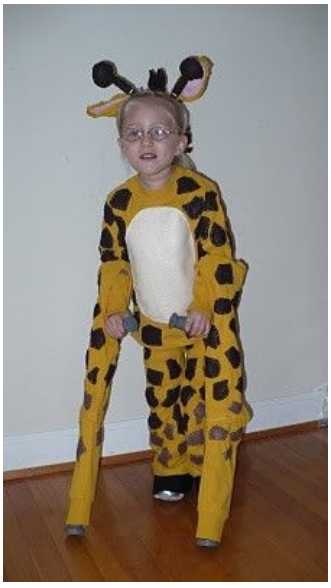
Frankenguac & Chips



Ghost Mini-pizzas

Inventive Halloween Costume Ideas

For wheelchairs and walkers



































Fun Fall Projects

Nebula or Galaxy Jar



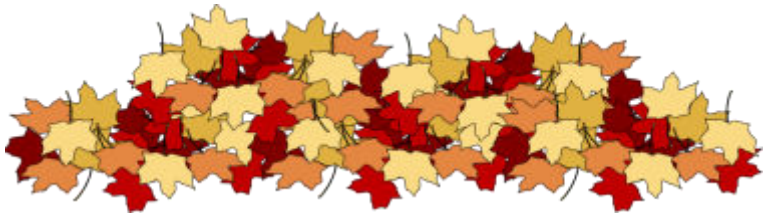




To create a Nebula jar, you are going to need a jar with a lid, water, glitter, tempera paint (2-3colors) and lots of cotton balls.

Instructions:

1) Fill the jar 1/3 with water.
2) Add several drops of a single color paint to the water, put the lid on and shake to mix the paint and water.
3) Add some glitter.
4) Stretch cotton balls and add them to the water until the bottom is filled with cotton, pressing them down into the water with a stick or butter knife.
5) Fill another 1/3 of the jar with water and add several drops of a different color paint and repeat steps 2-4.
6) Fill the final 1/3 of the jar with water and repeat steps 2-4.



Colored Foam



A great sensory experience can be achieved by playing in foam. Its unique texture creates a tactile learning experience. It can become a visual color mixing lesson by swirling together different colors. Possibilities are endless.

To make a small batch of super puffy, fluffy soap foam, you will need:

- 2 Tbsp of dish soap (preferably Dawn because it bubbles best)
- 1/4 cup water (please note if your water is especially hard or soft, you should substitute bottled water so that your foam will bubble well)
- a mixer
- food coloring or liquid watercolors (optional because it can stain surfaces, clothes, etc., but it makes the experience a visual treat)
- plastic container, plastic tub, or table for play (a non-staining surface is best for colored foam)

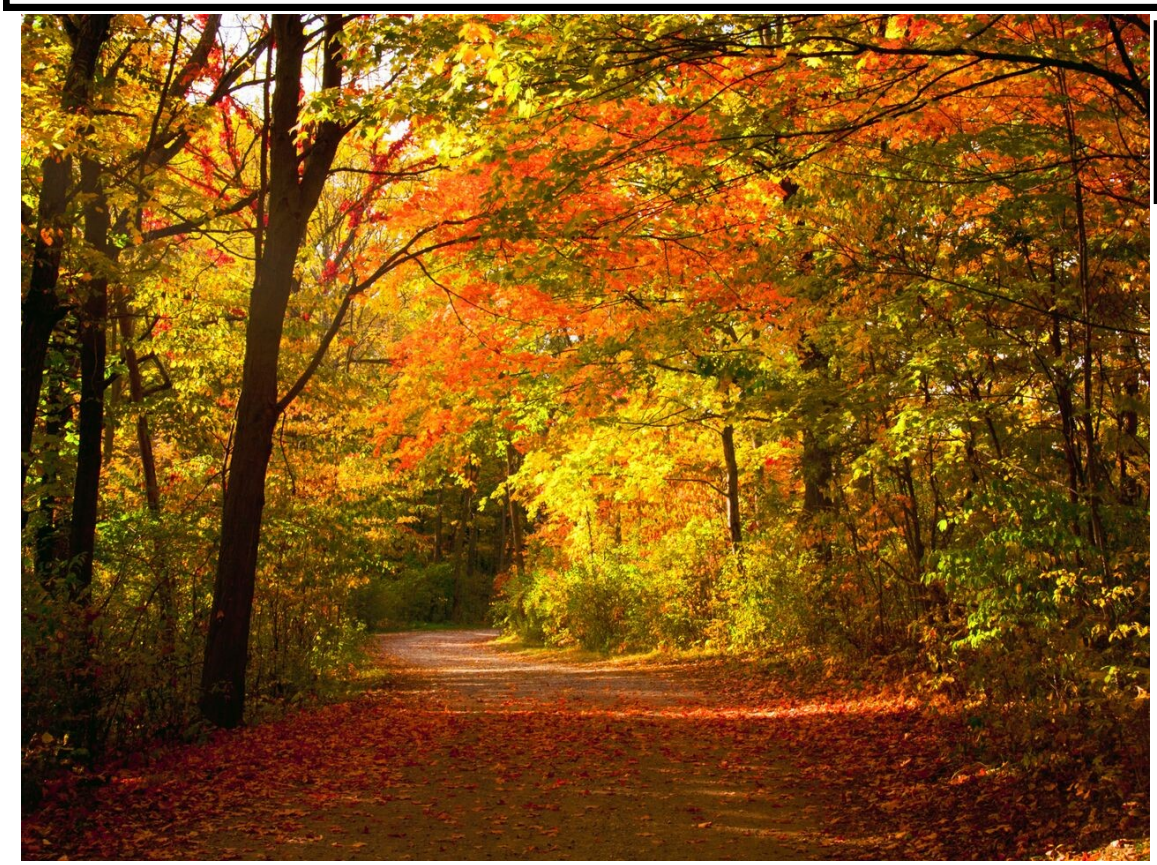
In a bowl, combine dish soap and water. Add coloring to the mix if desired. Use mixer to mix on the highest possible setting for 1-2 minutes. Your foam should be able to form stiff peaks that hold their shape. Scoop it out into a container and repeat as necessary until you have the desired amount of foam!

If your child has sensitive skin, you can substitute 3 Tbsp sensitive skin baby wash for the dish soap in the recipe above (though it may not make as "stiff" a foam consistency.

This is not recommended for very young children who may put the soap in their mouths or eyes. The foam is not meant to be ingested and may sting if rubbed into eyes.

The Beauty of Autumn (in Michigan)

by Stephen J. Foster, a Michigan Photographer



Maybury State Park,
Northville,
Michigan
2016



River Hawk Annex
Proud Lake State Recreation Area
Commerce Township, Michigan
2016

Fundraising

Monthly Giving — the easy way to show you care

Coffee Club

Do you enjoy a hot cup of coffee - or other beverage - in your home, on your way to the office or before starting your day? Could you forgo one cup a week for the benefit of PMD Research? Please consider making an ongoing donation. For as little as $3.50 a week, or $14 a month, you can Join our Coffee Club and be part of the caring community of people who are helping fund research projects for our warriors!!

Tall $14 Grande $24 Venti $36



The PMD Foundation is a family driven foundation that proactively serves those affected by Pelizaeus-Merzbacher Disease (the PMD community) by supporting programs of education, research, service, and advocacy. The Foundation is launching the first of many clubs that you can join. We are introducing the "Coffee Club" as a way of donating what you would normally spend on coffee (once-per-week) to the Foundation for research. We will launch this on our Facebook page on August 1st!!! Be sure to search **@pmdfoundation** to like our page and participate.

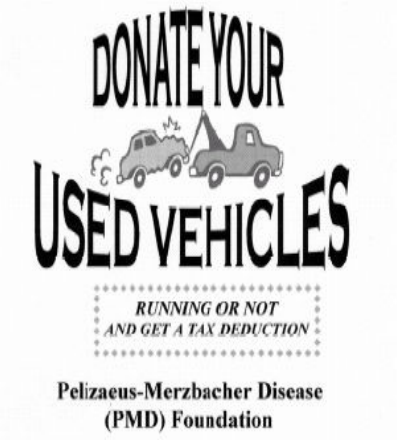
You are helping make a difference in our PMD families' lives, one cup at a time!

SUPPORT THE CAUSE — IT'S EASY TO DONATE

The Foundation is a non-profit 501(c)3 organization. Your contributions are tax deductible to the extent allowable by law. Operating costs and research funding are expenses we face to keep the Foundation viable. **We need your financial support,** it's that simple. Click **here** to make your contribution by credit card or PayPal. If sending a check, please use the address on the last page of the newsletter.

AMAZON SMILE SUCCESS!!!

Yay! We're already seeing some success with Amazon Smile fundraising. Now we just need to get **all** you online shoppers onboard. Most of you use *Amazon.com* when you do your online shopping anyway. Amazon has excelled at making shopping effortless and they have most everything you would need. But did you know that they help charities on a daily basis? All you have to do is log on to http://smile.amazon.com and enter the PMD Foundation as your charity of choice. Then use the same address when doing your Amazon shopping and .5% of eligible purchases will be donated to the Foundation. If you forget the *smile* part the next time you log on to Amazon with that computer, they will remind you and link you to the donation site. It is the same company, same prices, same website. There isn't an easier way to help raise funds by doing something you already do. Make your shopping even more meaningful and get your friends/family involved too! So the next time you need to do some online shopping, just remember to Smile.





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

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

The PMD Foundation

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Together, we can make 2018 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

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Or

By clipping the following coupon and mailing it with your check

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 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 $_____.

I would like these funds designated for _____

Name: _____

Address: _____

City: _____ State: _____ Zip: _____

Please detach and mail with your contribution to :

The PMD Foundation

PO Box 898
Salado, TX 76571

THANK YOU FOR YOUR SUPPORT!