



The PMD Foundation

Newsletter

Striving for a World Without PMD

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Valentin Bal – The Netherlands

Valentin Josef Bal, was born in June 2011 in the Netherlands. He was a heavy, healthy and happy baby. Everything seemed perfect. In December 2015 he was diagnosed with Pelizaeus-Merzbacher disease. Valentin is half Dutch, half Austrian, and therefore raised bilingual. He understands both languages and speaks primarily Dutch as we live in the Netherlands.



Valentin loves cars (especially Lightning McQueen and Mater), trains and everything that is a little technical and has wheels. He is a fan of Mickey Mouse Clubhouse and he adores his sister, Selina. He loves goofing around, eating spaghetti and exploring the world.

During the process of getting the diagnosis we were always sent to the most specialized doctor in a certain area. In the Netherlands all 20 PMD patients see Dr. Wolf, a neurologist at a hospital in Amsterdam. They have a department specializing in white matter diseases and therefore have different MRI techniques that really measure the progress of the white matter.

Not a lot changed for us in terms of daily care for Valentin after receiving the diagnosis. He was already going to a "day care" at the rehabilitation center, where he was getting physio, occupational and speech therapy and after the diagnosis we increased OT and physiotherapy.

However, for me everything changed. As I wanted to understand this disease and his mutation in every way, I deep-dived into genetics and bio-chemistry. I called various researchers and doctors and got in touch with other PMD families. Since I work in a bio-pharma company, I also started talking to many directors and executives from various departments. I even sent mail to our CEO. What I do may not bring a cure or a treatment, but I want to do the best I can to support getting there. For that reason, I was very excited and grateful to have been nominated to serve as a Board Member for the PMD Foundation.



In regards to care and schools in the Netherlands, the 'day care' at the rehabilitation center is only for

2.5 hours 3 times a week. So as working parents, this requires quite some time and logistics planning. I used to work 3 full days but cut down to 2 full days working at the office and half day from home as otherwise it wouldn't have been possible. My husband's mother is taking care of the kids when we are at work but she does not have a car which adds additional logistical problems. Right now, we are trying to get Valentin into a 'regular' playgroup twice a week, but even there they don't dare to take Valentin without an additional caregiver, although the groups are small and he doesn't require medical aid. So we have to get together with some institutions now to see if we can get this arranged.



At 4 years old, children start school (pre-school) in the Netherlands. Unfortunately, the regular schools are not very advanced with integration or inclusion yet. As I am from Vienna, I always compare how things are done in Austria vs the Netherlands. In Austria, integration and inclusion are very common at all daycares and schools. So, we have another half year to figure out if we would want to try regular school with assistance (although they might not be able to fully deliver best care and integration) or send Valentin to a special school. The advantage would be that it would be next to the rehabilitation center where he would get all his therapies during school time. Whereas, in the regular school we would have to take care of all therapies ourselves and maybe plan them even outside school time. I do understand that this would be hard for Valentin, especially in the first year, but I see now what he is learning from Selina or his cousins in Austria and I wonder if those things aren't more important.



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NEWSLETTER
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Marianne Bal
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Doris Parker

Valentin Bal (continued)

Here in the Netherlands, we receive aids like wheelchairs, high-low-beds, standing tables, walking aids etc. They have been financially covered so far and requesting them was fairly easy with the help of the people in the rehabilitation center. Things that will be more difficult to request are the additional care during school e.g. This process involves a lot of paperwork and you need to defend your position in front of a committee.

Furthermore, we need to move since we currently live in a house where the bathroom is on the second floor and as we want to give Valentin the opportunity to do things as independently as possible, we would need a house or apartment where everything is on the same floor. I feel that life with PMD will limit his world to a certain extent, and therefore we would want to give him as much independence as possible at home.

We are looking to get a van to be able to take Valentin's wheelchair and walker with us wherever we go and we travel a lot to see my family in Austria. We also travel around to see many other places. Just recently we had the opportunity to get together with other PMD families in England and meeting those amazing boys and their families filled my heart with so much love and strength. I truly believe that they are brave and strong warriors with a special power - their smile. With that smile, PMD warriors will conquer the world.

Marianne Bal



The Voice of a PMD Dad — Carlos Labrada

The 20 Minutes I Spent Lying on the Floor With My Son With Pelizaeus Merzbacher Disease

I love my child and am constantly searching for ways to help him. But sometimes I fall into a daily habit and routine while time passes by. It was early morning and my son, Leo, had finished breakfast. Leo is 2 years old, nearing 3. He does not walk, does not sit unassisted and struggles to belly crawl. He has a leukodystrophy, Pelizaeus Merzbacher disease (PMD). We must make sure he is burped and stays upright for some time before we lay him on the floor to play with his toys. This minimizes the chances of a choking or puking accident.

This morning he looked at me as if saying, "That's it? You are just going to leave me here?" I put away my phone and decided to be late for work. This time I laid on the floor along with him. I mimicked his movements. I intended to see what he saw — a world so vast and so different than my own. It was Alice in Wonderland in my bedroom. The small became big. Forgotten toys became his friends and accomplices. Sandals was not an exclusive beach resort, but a pair of his dad's Crocs on the far reaches of his Earth.

While on my belly, I reached the toys near my grasp, no further than an arm's length. Leo tried to move an inch to get a hold of a shopkin that was left on the floor by his older sister. There were some pieces of litter, a half-empty eight-ounce bottle of water, a coin and a string dangling from his mother's pink robe that hangs from the southeast corner of the bed. He tried to kick it with his feet. Four out of five times, he was unsuccessful. The times he realized his actions create an equal and opposite reaction, he would marvel at what his perseverance accomplished. He would look at me proudly, and I would cheer him on.

This morning I was extra silly with him and played without haste. This morning we crossed the boundary of dad and son to playmates. And it was wickedly fantastic.

My morning drive to the office and back in the evening throughout the years seems repetitive, an homage to "Office Space" and "Groundhog Day." I enjoy the challenges and adventures that keep me hooked on cutting-edge technology, yet since having a child with special needs, that world seems inconsequential in comparison. This morning, in a modest bedroom, I saw my child's world brighten by 20 minutes with his dad on the floor. He allowed me in, and I made the best of it. Time is priceless, mighty and impactful. It is the most precious bounty I can offer him while pressing for a cure.

I kissed his neck and smelled his hair for the last two minutes of our playdate. He chuckled and babbled: "Amo." The most transparent "love you" I have received. The one word that keeps me fully charged to battle on his behalf.

I believe in time it will be the unbreakable bond between parent and child that will at long last find the Holy Grail. I believe love will ultimately be the one that wins the fight against these diseases. It will be the parent and child who venture together to unknown worlds and risk their lives in the process so science can get it right, and that will save many lives. And for the many yet to be born, they will be their unnamed legends and heroes.

This article was previously published on the website The Mighty in January 2016.

Carlos Labrada



Letter from the Chair



Friends,

Many may already know this, but for those of you who don't, Logan, is the Texas Ambassador for Children's Miracle Network Hospitals for 2016-17. Each children's hospital nominates a child from their hospital to represent their state. The CMN Hospital staff chooses one child based on character, individual's story and community involvement.

In June of this past year, we traveled to Washington, D.C. and met the other ambassadors from all over our nation. During this trip, we met with legislators, Miss America and a tremendous number of CMN Hospital staff. We are sharing our extraordinary story with everyone that will listen. Also during our year, we have and will continue to attend various fundraisers across Texas. In March, we will have a ceremony at Disney called Momentum. At this time, we will share a lapel pin that was specially made for Logan. Recently, we were told that new ambassadors would not be chosen next year and we will extend our service to two years.



We will continue to share our story with everyone that we meet. Our story is your story! My family is honored to represent our PMD community to spread awareness.

Hugs,

Doris Parker

PMD Foundation News

Those of you who read the Summer issue of the Foundation Newsletter were introduced to Francisco Oller, a young man who is making great strides in his life in spite of his diagnosis of SPG2. He is currently working on his Master's degree at the University of Tampa. We are proud to announce that "Cisco" has joined the PMD Foundation Board, and has stepped up to the position of Secretary. Keep an eye out for updates on this young man, he is definitely going places.

Even though we have many "family members" from around the world, the PMD Foundation has truly become international with the appointment of Marianne Bal as a new Board member. Marianne is from Austria and currently lives in the Netherlands (and is also fluent in English.) Her son Valentin is this month's cover story. Marianne will provide insight into how PMD is handled outside the U.S and keep us informed on what is happening with related groups, like the European Leukodystrophy Association (ELA).

We hope you will welcome both of them into our PMD Foundation Family.

GoBabyGo

Many of you may have seen the article that was featured on the PMD Foundation Facebook page about Dr. Cole Galloway and Go Baby Go collaborating with Mattel to make mobility toys for children with physical disabilities. You might not know that Dr. Galloway's group has started a movement that has driven the many institutions to hold workshops across the country to help others learn how to adapt these toys and make them available to many more children. A \$100 mechanical toy, modified with \$100 of additional parts can become a way for young children to gain some independent mobility before they are eligible for powered wheelchairs (at a much greater cost.)

If you'd like to learn more about this program, click on the links below.

<http://www.cnbc.com/2016/10/04/how-a-doctor-who-tinkers-with-toys-got-mattels-attention.html>

<https://www.youtube.com/watch?v=U-NE7BORTdA>

<http://tedmed.com/talks/show?id=292991>

<http://sites.udel.edu/gobabygo/>

<http://sites.udel.edu/gobabygo/contact/>



If you are mechanically inclined, you can attempt to build your own adapted vehicle by following the pdf available at the following link: <http://www1.udel.edu/PT/About%20Us/People/Galloway/GoBabyGoManualMcQueenStepByStep.pdf>



Give Thanks by Giving Back



Fundraising - We can all contribute a little...



TRICK OR TREAT FOR PMD



Some of you may remember a time when you carried a little orange box around on Halloween and collected change for UNICEF. The little bit of money you collected did not seem like much, but when you brought it to school and it was all added together, it often became a significant amount. Well, we'd like to apply that same principle to the upcoming holiday. We have many PMD families and friends in our group, and if everyone collected just a little, it could end up being quite a lot. It's also amazing how much can be raised in your workplace by setting a box on your desk. Not only that, but if people ask what you're collecting for, it gives an opportunity to spread awareness about this disease that affects our sons, brothers, cousins, uncles and friends. If you click on this [link](#), you will find a pdf you can print out to cover a small coffee can (or tissue box) showing that your efforts are supported by the PMD Foundation with the hope of spending these funds to further our research programs. You can then either make your donation online via our [website](#) or mail in a check to the address on the back page of this newsletter. This is a fundraiser everyone can do with very little effort. All contributions are appreciated!! Every little bit helps!!

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. ALL participants of The PMD Foundation serve as **VOLUNTEERS**, however, 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

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RUNNING OR NOT
AND GET A TAX DEDUCTION

Pelizaeus-Merzbacher Disease
(PMD) Foundation



Yummy Fall Treats

Scary Screaming Pretzels



Ingredients:

Mini twist pretzels
Dark chocolate candy melts
Candy eyeballs

Directions:

1. Melt the chocolate candy melts according to the directions on the package, adding a small amount of vegetable oil to the mixture for easy dipping.
2. Dip the pretzels into the candy melts, coating both sides. Place the pretzel on waxed paper making sure the bottom section of the pretzel (the "mouth") is not filled with chocolate.
3. Insert melted chocolate into the top two sections of the pretzel. Place a candy eyeball into the top two sections. Allow to set until firm.

Dracula's Dentures

- 2 dozen chocolate chip cookies (homemade or store bought, but they must be soft enough to easily cut in half)
- ½ cup red tinted frosting
- 1¾ cups miniature marshmallows
- 48 slivered almonds

DRACULA'S DENTURES



Cut each cookie in half for a total of 48 halves.
Frost the bottoms of all cookie halves with frosting.
Place 6 marshmallow teeth around curved perimeter of 24 halves.
For additional support, an additional marshmallow can be placed behind the teeth.
Top with remaining 24 frosted cookie halves.
Insert two almond slivers in between teeth for fangs. If fangs do not adhere, dip tips into frosting.

Easy Fall Acorns

Donut holes
Nutella, peanut butter or chocolate frosting
Chocolate sprinkles or chopped nuts
Pretzel sticks

1. Dip or spread half the donut hole with Nutella.
2. Cover the Nutella with chocolate sprinkles.
3. Place about 1/3 of a pretzel stick into the donut hole for a stem.
4. Voila! Easy peasy.



Cornucopia Snacks



4 cups "Bugles" (original flavor)
2 cups "Trix" or other small round multi-color treat (M&Ms)
16 oz white (or yellow-tinted) frosting

Over-fill bugles with frosting so there is extra extending outside the hole.
Place Trix or M&Ms in the frosting, leaving very little frosting showing.
Let them set so frosting will harden a bit to hold the "fruit and vegetables".
Make a lot of them, they're a great bite-size treat and so easy to make!

Fall Fun

Birdseed Cakes - From House of Hawthornes

Supplies:

- 3 cups wild bird food
- 1/2 cup boiling water
- 3 tablespoons Karo syrup
- 1 packet unflavored gelatin (Knox or a generic version)
- 3/4 cup flour
- Non-stick cooking spray
- a mold of some sort – jello mold, bundt pan, etc
- string, twine or yarn
- a straw if your mold doesn't have a hole for easy hanging

- 1) Spray your mold with cooking spray
- 2) Mix the gelatin packet into the boiled water until it is dissolved.
- 3) Add flour and syrup until it is mixed well. It's going to look like a thick cake batter.
- 4) Add birdseed into the mixture and mix well.
- 5) Spoon 1/2 the mixture into your mold.
- 6) Push straw through the seed mixture to the bottom of the mold.
- 7) Add a bit of string (this is going to act like a piece of rebar in cement and add extra stability).
- 8) Spoon remaining seed mixture into the mold and compress it down as much as humanly possible.
- 9) Put mold into the fridge or freezer overnight to harden up and allow the gelatin to set.
- 10) Remove from the mold. If your seed cake doesn't slide out of the mold easily when you turn it upside down, sit the bottom of the mold in a shallow pan of warm water for a few minutes and the cake should pop out.
- 11) Gently remove straw and thread a piece of string through the hole for hanging.
- 12) The birds can steal the "rebar" string to make their nests with when they're done eating through the cake.



Marble Run — From frugalfun4boys.com



Start with cardboard sheets cut from a very large cardboard box.

You will also need:

- craft sticks
- Scissors
- hot glue
- paper cups
- duct tape
- marbles

1. Tape strips of cardboard to the sides of the sheet to keep the marbles from rolling off. Cut the rims off the cups before gluing them to the cardboard so that the marbles roll smoothly into the cups.
2. Glue craft sticks to the cardboard with hot glue to form a maze. You can do sections with little short sticks to make it sort of like the Plink-O game. It works great! You can experiment with how much of an incline will work for your marble run, but leaning it against the couch may work perfectly.
3. If some marbles roll between the cups, you can block the holes with tin foil or cotton balls.





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

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Enclosed is my tax-deductible donation of \$_____.

I would like these funds designated for _____

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