



# The PMD Foundation Newsletter

Striving for a World Without PMD

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Summer 2016

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## Francisco Oller — San Juan, Puerto Rico



My name is Francisco Oller, and I was born in San Juan, Puerto Rico. Although I came into this world without any complications, I developed nystagmus within two weeks. After a CT scan and MRI, I was immediately referred by my father's uncle, Dr. Jose Luis Garcia Oller, to Dr. Neil Miller, a neurophthalmologist at Wilmer Eye Institute at The Johns Hopkins Hospital. At three months, my diagnosis was thought to be either congenital motor nystagmus or spasmus nutans. Later on, I developed head nodding, which did not cease until I was nine months old.

At 15 months, I started to exhibit a delay in walking and ataxia. Despite normal cognitive and language development in my childhood I still exhibited signs of ataxia and hypotonia. As I continued to grow, I experienced a delay in my progression from crawling to walking. At a follow-up appointment at Johns Hopkins Hospital, my parents mentioned their concerns of my delay in walking to Dr. Miller. He proceeded to refer us to Kennedy Krieger Institute for Children with Disabilities, an affiliate of Johns Hopkins, where I have been treated since that time.

In 1996, after I underwent a series of tests at Kennedy Krieger and the results were sent to Indiana University's Department of Medical Genetics for further analysis, I was diagnosed with PMD/SPG2. The mutation is in the proteolipid protein gene, specifically a T494G = Val165Gly mutation. My new mutation was the subject of a paper in the *American Journal of Human Genetics* in 1999.

My childhood seemed normal to me – as if I was the same as any other child without disabilities. I walked short distances, usually with the support of one of my loving parents. Although I never learned to ride a bike or skateboard, I was undeterred from experiencing the joys of childhood. In my early years I took occupational therapy, which stopped once I entered elementary school. I have been taking physical therapy since I was a baby and continue to do so.



During my elementary school years, the school made certain accommodations for me, but some of my classmates bullied me because they thought the added support was unfair. Further exacerbating my identity crisis was the fact I was rarely invited to any sort of outing. Being treated with such prejudice early in life traumatized me for a long time. My life has shaped the person I am today and given me the greatest gift — a unique relationship with my mom.



In 2012, I moved to the United States to attend Providence College and received a high-level college education. Throughout my life I've learned a great deal about chance and faith. At Providence College, I found a caring community, from the Dominican fathers to the deans who nurture you and the professors who teach you. At Providence College I made lifelong friends, who always included me in everything. We attended concerts, went to movies, and just hung out. Whatever the destination or its accessibility, my friends and I always found a way. These relationships helped me discover the benefits of being vulnerable, and asking for help made for deeper, more genuine connections with people.

While at Providence College, I discovered my passion for public speaking. I held annual motivational speaking engagements during all four years of college for various constituencies including faculty, staff, students, and alumni. I served as a guest speaker on the subject of motivation to business classes and community outreach pro-



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## Francisco Oller (continued)

grams at Duke University and Roger Williams University. I became comfortable in addressing radio audiences through National Public Radio Rhode Island and appeared on the weekly segment *This I Believe: Coping with Challenges*. Additionally, I made television appearances on the Telemundo Television Network in Puerto Rico.

Through motivational speaking and by sharing my story of being born with PMD/SPG2, I hope to leave listeners with a more positive outlook on life. I would like listeners to realize that one can overcome fears and insecurities with an optimistic outlook, and that it is important to accept our imperfections and live life to the fullest. I stress in my speeches that people should see those with disabilities as equals. When looking at people with disabilities, people should not feel sorrow, but instead recognize the courage these souls possess. People with handicaps are constantly readapting to their environment. When referring to people such as myself the common words are disabled or handicapped. While labels like this do not personally offend me, these labels do not get it quite right. I am not a broken-down computer; in fact, if I had to fancy myself as something it would be a sleek, new state-of-the-art MacBook Pro! My mindset can best summarized by a paragraph from my senior year motivational speech called, *Rolling Through Life*: "Disabled implies that there are things you can do that I can not. That's true. But I guarantee you that if we were racing to lower campus, I would win most of the time."

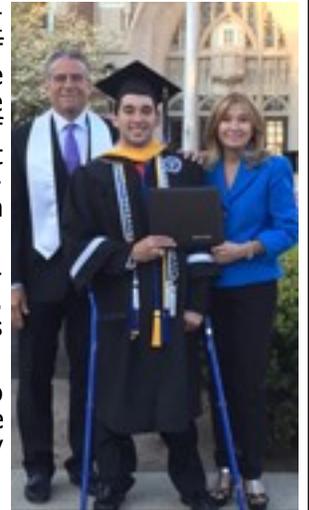


Becoming actively involved in college life and excelling academically became priorities. My education culminated in graduating *magna cum laude* and in the top 10% of my class at Providence College. I graduated with other honors, including being inducted to the International Business Honor Society, *Beta Gamma Sigma*; making the deans' list every semester and being named Student Leader of the Month. I also served as an Admissions Ambassador, Orientation Leader and Executive Vice President of the Student Congress. One of the biggest honors I received was given to me on April 25th at The Student Recognition Ceremony. I was awarded the Leaving a Legacy Award. "The Leaving a Legacy Award is given to a senior who has impacted Providence College in a way that will be remembered for years to come."

Although my handicap has impacted my life significantly, I have been able to develop a positive mindset largely because of my strong Catholic faith, my parents, and my friends. The mindset involves preparing myself for the challenges I will face. I remind myself during those challenges that no matter how much how much I accomplish each day I should be proud of myself. Given PMD, I face a world that is often challenging and taxing, but also a world that holds so much beauty. Those beautiful moments remind me of a quote by A.A Milne, the author of *Winnie the Pooh*, who once said, "You're braver than you believe, and stronger than you seem, and smarter than you think"

I do not exactly know how my medical condition will progress. It is possible I might someday be more mobile and require less assistive devices, and I continue to live with that hope. The day we lose hope is the day we inadvertently impose limits on ourselves. What matters most in life is how we shoulder our daily challenges.

I am excited to begin my first year as an MBA student at The University of Tampa and to pursue my goals and career. I believe life — the good and the bad -- is an experience to be shared with others. Sharing is the only genuine connection. I am grateful for the opportunity to raise awareness of PMD and to share my journey with The PMD Foundation.

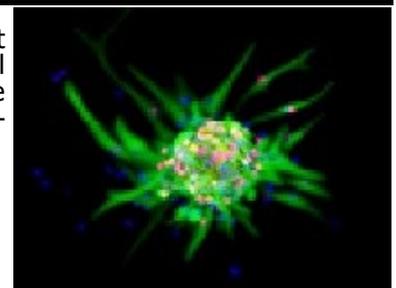


*Francisco Oller*

## Research Update

### Stem Cell Research Continues at Cambridge University

Dr. David Rowitch was the principal investigator in the StemCells Inc. patient trials at UCSF. It was discouraging when that company decided not to continue with clinical trials. It's wonderful to see that Dr. Rowitch is carrying on his research into PMD as the Head of Pediatrics at the University of Cambridge in England. If you'd like more information about his current studies, click [here](#).



# Letter from the Chair

Wow, I can't believe we are half-way through the calendar year. I am extremely honored to serve as the PMD Foundation Chair(Wo)man. Since January, we, as a board, have re-established our goals and missions. These include the following:

- *Goal 1 Develop a stronger, committed and active scientific board*
- *Goal 2 Patient Registry*
- *Goal 3 Fundraising/Research -*
- *Goal 4 Ambassador/Board Member - Cisco Oller*

We, as the board will continue to serve your family as best we can and always in the best interest of our loved ones that are affected by Pelizaeus-Merzbacher Disease. As a mom to one of our PMD Warriors, it is my pledge to you to continue the fight to find treatments and possible cures. To reach our goals, we will be reaching out to you to the community to help us. Please stay tuned to the website and email as we post updates. In addition, always feel free to reach out to me personally via email, I will respond as time permits, but would love to learn more about your PMD warrior and family needs!

Warm Regards,

*Doris Parker*  
[dorisparker97@gmail.com](mailto:dorisparker97@gmail.com)

## Fundraising - We can all contribute a little...

### 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](http://www.donationline.com)

### iGIVE

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](http://www.iGive.com)



Pelizaeus-Merzbacher Disease  
(PMD) Foundation



## Recent Events

### 2nd Annual Gabriel Luke Vandenberg Golf Outing



August 8th was the date for a repeat of this exciting event at Egypt Valley Country Club in Ada, Michigan (just outside Grand Rapids.) Last year's outing was a sell-out, and it looks like it was a repeat this year. The weather cooperated more this year and it was a glorious day. More details about the outing will follow in the next Newsletter.

If you could not attend, but would like to make a contribution, please do so via the PMD Foundation website, at <http://pmdfoundation.org/donate/>. Keep this in mind for next year, you don't want to miss out.

## Past Events

### 15th Annual PMD Golf Outing



The 15th Annual PMD Golf Outing was held on Tuesday, June 14th at the Cranbury Golf Club in West Windsor, NJ. This was the last golf outing to be hosted by Linda Katz Leonard and her crew of fantastic supporters who have been organizing this event since 2009. They went out in style, wench style that is, as the theme this year was pirates (a re-visitation of a very successful past event.)

The day included a BBQ lunch, a shotgun-start four person scramble golf outing, followed by live music, cocktails & hors d'oeuvres and ending with dinner, prizes, raffles and an auction. All this; including a golf cart, all day drink service by the merry wenches, a Hole-in-One Contest and prizes for every golfer were included in the entry fee.

Those who didn't care to participate in the actual golf event had the option of attending the cocktail hour, dinner and auction. The fun continued into the evening, and, as usual everyone had a wonderful time.

A special tribute to our PMD children was a new addition this year. Each hole had a sign honoring one of our PMD-affected fellows, including those who are still with us and those who have passed. At the end of the golfing event, the signs were gathered and placed near the dinner tent. It was a great opportunity for the attendees to learn more about the awesome kids who make all our efforts worthwhile.



# Past Events

## 27th Annual PMD Family Support Conference



Photo courtesy of Amanda Thompson and PMD Family Support

The 27th annual PMD Family Support Conference (held in Indianapolis at the Crowne Plaza Hotel from June 16th—19th) was another huge success! We had 19 families from 15 states and Canada. We had 17 PMD males and 1 PMLD girl, ranging in age from age 1 to 34. Six of these families were new to us this year, but as always, our other PMD families made them feel right at home! We also had several Grandparents with us this year. It is 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.

This year's T-shirts were pretty cool. They were individually tie-dyed, before we had them printed. Amanda and Patti spent many days banding, dying, washing, drying, and ironing. They turned out great! But it was a one time adventure!

We had several families who came in on Wednesday, so, we did a small group dinner at the Hard Rock Cafe on Thursday. Unfortunately, the only baseball game this year was on Thursday evening, so due to timing we were unable to attend. Hopefully next year their schedule will line up better with our dates.

Friday Dr. Walsh saw patients at Riley Children's Hospital, and on Saturday we had the doctors presentations at the hotel as usual. This year's speakers were: Dr. Karen Moody (Palliative Care), Dr. Larry Walsh (Genetics and Neurology), and Dr. John Stevens (Pulmonary). Dr. Joseph Croffie (GI), was called in for an emergency surgery and was unable to join us, so Dr. Walsh and Dr. Stevens attempted to answer general GI questions. We tried to live stream of the medical presentations, which wasn't very successful but we are hoping to try again next year. Jill Andrews, one of our PMD moms, recorded the presentations for us and we are making them available upon request. Thanks to Jill's friends, Keith and Sari, we had audio equipment to assure everyone could hear the presentations. Our wonderful group of volunteers (Kayleigh, Taylor, Shari, Trinity, Abby, and Abby's friend Allie) 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. The older guys also took their annual trip to Hooters, complete with pictures and T-shirts! There were small group trips to the Zoo and Children's Museum and many trips to Steak 'N Shake. As always we had many opportunities for visiting and late night chats. Because the conference dates included Father's Day this year we had a couple little special treats for the dads. Sandi Anderson, with her scrap booking talents, assisted the kids with making Father's day cards, and Amanda made candy bar bouquets in Father's day mugs for



Photo courtesy of Amanda Thompson and PMD Family Support



Photo courtesy of Amanda Thompson and PMD Family Support

all the Dad's and Grandfather's. Everyone except Anita and JR Chalupa left by Monday, due to over booking they were bumped. We don't believe that things just happen by accident, the weather took a turn for the worse and they would have likely have ended up stranded at the airport. However, George got them to the airport on Tuesday, and they made it home safe and sound.

Dr. Grace & Don were pre-celebrating their 50th Anniversary, and took some photos at the hotel, complete with Tux!



Photo courtesy of Amanda Thompson and PMD Family Support



Photo courtesy of Amanda Thompson and PMD Family Support

This year's conference was, as always, a great success. Big thanks for all the generous cash donations, as well as those made thru Amazon by our PMD families and friends! It really helped us stretch our budget. You guys are awesome! As soon as we can have our dates for next year set with the doctors and hotel we will post them, so everyone can schedule their vacation dates for 2017.

If you would like more information about PMD Family Support, or you would like to see more pictures of all of the fun we had please check out our website at

[www.PMDFamilySupport.com](http://www.PMDFamilySupport.com).

*Amanda Thompson Klinge & Patti Daviua*

# The Voice of a PMD Mom — Marcy White

## It's More Than 'Venting' When I Speak Up For My Special Needs Son



*This article was previously published in The Huffington Posts Blog in January 2016.*

I was a very private person before I became a staunch advocate for my son Jacob. I would rather have had gum surgery than talk about my feelings. Things are very different now.

Parenting, in general, is hard. Parenting medically fragile children and teenagers is fraught with unimaginable stresses, heart-crushing decisions and endless battles to ensure our kids are receiving the best care and access to the fullest lives possible. Our children's needs don't fit neatly in a box, and a cookie-cutter approach to caring for our kids creates additional problems for all involved.

As medical technology advances, kids with complex needs are living longer than in previous generations. Hospitals are discharging children with complicated care into the community in ever-increasing numbers.

Unsustainable pressures are placed on moms like me to act as doctors, nurses, speech/physio/occupational therapists and problem-solvers for our children's medical needs around the clock without a break. This goes on for years, often decades, until our children pass away or are placed in full-time group homes.

It's no secret that I have [publicly stood up to the Toronto District School Board](#) on more than one occasion to make sure that Jacob's educational needs are met.

I'm thrilled to report that it has been recognized that in addition to benefiting from the academic inclusion, Jacob has taught teachers, students and administrators some wonderful lessons about perseverance and tolerance. He has won over many skeptics and proven that he is more than simply a body in a wheelchair — a degrading position nobody should ever be in.

It is also widespread knowledge that Jake's medical needs have increased exponentially over the past year and a half. I've shared many details about the struggle I've faced with the home care system that is supposed to help me manage his medical needs at home.

Despite sufficient government funding (and not many people can say that!), home care nurses and the inherent dysfunction in the system are failing miserably, making our lives even more arduous and depleting than they need be.

A few days ago, I was surprised when a friend commented that she is used to seeing me "vent" on social media. I didn't think I regularly used online groups to unleash my frustrations (aside from the groups that are intended for such purpose, and thankfully there are a few).

*"To the doctors, nurses and social workers who hear our struggles and witness our breakdowns, please don't just listen and commiserate. Step up and gather the courage to instigate change."*

Sharing the obstacles I encounter as an advocate for my son with severe medical issues is done with the hope that people will begin to experience a bit about what I, and many others in similar situations, deal with on a regular basis. My objective is that if people know and empathize with our tribulations, change will be more likely to occur.

So I share.

Broadcasting these battles has never been for the express purpose of "venting." I share the demands of our lives in such a public way in order to assemble the strongest, safest and most comprehensive team of caregivers and opportunities for my son. The educational and home care systems in Ontario have not kept pace with the medical advances.

I am speaking up to draw attention to the deficits in my community. I am exposing some (not all!) of my challenges with the hopes that it will make a difference. I am sharing my experiences because most people are unaware of the flaws in the system. And if people don't know how the parents, caregivers and families are suffering, then changes will not happen fast enough for our generation.

I'm disseminating details about my conflicts for the slew of other exhausted, beaten-down parents who don't have the time, energy or ability to do it for their children. Just because I'm the loud mouth, pain-in-the-butt parent, don't assume that I'm the only one. There are so many of us.

To those in a position to effect change, whether you are in a government, medical or another field, please don't continue to stand by and watch us sink under the enormous pressure in which we find ourselves.

To the doctors, nurses and social workers who hear our struggles and witness our breakdowns, please don't just listen and commiserate. It might not be in your written job description and I know you are worried about alienating some of your colleagues and being viewed as trouble-makers in the eyes of your superiors, but you are the ones who see and know our desperation. Stop watching and wishing you could make things better for us. Step up and gather the courage to instigate change.

Please do your part to get the help we desperately need for our beloved children. They deserve it.

*Marcy White*

# Summer Crafts To Do With Your Kids

## "Better than Salt Dough" Clay

1/2 cup cornstarch  
1 cup baking soda  
3/4 cup water

(if you want to make colored dough, add the food coloring to the water before you mix it in.)

In a medium sized pot combine the cornstarch, baking soda, and water. Stir over medium heat. After a couple of minutes, the mixture will begin to thicken. When it looks like smooth, mashed potatoes, remove the pot from the heat. Spoon the ball of dough into a bowl and cover it with a damp cloth until it's cool. When it's cool, knead it on a smooth surface until smooth. Add more cornstarch if it feels sticky.



Roll out clay to 1/4 inch thick on a surface lightly dusted with cornstarch. Use cookie cutters to cut out shapes or form 1/2 inch thick circles for hand and footprints.

Preheat oven to 175 degrees F. Line baking sheet with parchment paper. Transfer shapes to the prepared baking sheet. You can use a straw or bamboo skewer to make a hole at the top so you can add ribbon or string later to hang it. Place them in the oven for about an hour, \*turning them over halfway through cooking.\*



You can let them air dry overnight if you prefer

not to bake them.

## Bottle Sprinkler



Start with a clean 2 liter bottle with the label removed. Poke holes all around the bottom and sides of the bottle (the more holes you poke, the quicker you'll get soaking wet.)

Attach the mouth of the bottle to a hose, using duct tape (or purchase a cheap male-to-male hose adapter at a hardware store.) If the threads on the mouth of the bottle are not the right size, you can heat it up a little with a blow dryer to shrink the bottle's mouth.

Now, just suspend your new sprinkler from a branch, fence or other tall object and turn on the water. Instant cooling fun!!

## Paper Pinwheels



Glue two equal-sized square contrasting pieces of paper, wrong sides together. Cut slits from each corner approximately 1/3 the length of the diagonal. Poke holes on the right half of the cut corners and fold (without creasing) in toward the center. Glue the corners into the center, lining up the holes. For a simple post, stick a pin with a large head through a button and then through the holes in the paper and into the eraser of a pencil, bending the pin over with a pair of pliers. For a stronger post, cut a square piece of an eraser, dig out a hole large enough to hold the end of a small dowel and push a hatpin through the holes of the pinwheel and into the eraser. Bend the point of the pin down against the eraser for safety.



## The PMD Foundation

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**Together, we can make 2016 the year that a treatment is discovered, leading to an eventual cure!**

**Please make a donation either:**

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**[CLICK HERE](#)**

**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

1 Green Tree Center  
10000 Lincoln Drive East,  
Suite 201  
Marlton, NJ 08053

***THANK YOU FOR YOUR SUPPORT!***