

## The President's Corner

by Jen Gordy

Hello all –

We are gearing up for the 8<sup>th</sup> International Melo Conference in Rochester, MN in November. Read on to learn more in our “save the date.”



We also have some exciting fundraisers coming up this year thanks to MeloFund ([www.melofund.com](http://www.melofund.com)). Also thanks to the MeloFund, I was able to put together a very fun, easy and successful fundraiser in October of last year; read on to hear all about the Denver MeloFund Pub Crawl. (page 3)

In each newsletter, we have a “Getting to Know You” article where you can share your story with the melo community. If you would like to contribute an article for one of our future newsletters, please contact Amanda at [amandaherling@yahoo.com](mailto:amandaherling@yahoo.com).

As always, try to stay positive and remember – you are not alone!!

ONWARD!

Jen

## SAVE THE DATE

2012 8th International  
Melorheostosis Conference

November 1-3, 2012  
DoubleTree Rochester  
Rochester, MN

We are pleased to announce the 8th annual Melorheostosis Conference! We are planning on making this the largest conference to date. If you have ever considered coming to a conference, THIS IS THE ONE!

We are welcoming new patients, as well as returning patients who have attended in the past years.

Scholarships will be available upon request thanks to Stephanie Papke, the creator of Melofund. To apply for a scholarship, please fill out the scholarship application in the email with this newsletter.

Registration information will be available with our next newsletter.

Make plans to join us today!!



## One family's Conference Success Story

By Lydia Zepeda (Exciting Update, by Susan Hendricks)

In our last newsletter, Lydia reported that Carlos and Valeria, parents of Jonathan, came to the Melo conference in August 2011 in Rochester, MN believing that Jonathan's symptoms of trouble walking and running and pain in both legs were due to Melorheostosis.

It was clear to the physicians is that rather than Melo, Jonathan may have had Camurati Engelman disease. Shortly after the conference, the family moved to Brazil and had more testing done in collaboration with Dr. Mortier. Dr. Mortier now reports that it was genetically proven that Jonathan has Cumarit Engelman disease and not Melo. Cumarati Engelman, while rare, has a known treatment and a known gene. The Melorheostosis Association will remain part of their family, their friends, and their church.

The conference was a life-changing experience for the entire family!

### The First Annual MELOFUND Golf Tournament and Auction

By Stephanie Papke

The first annual MELOFUND golf tournament and auction was held in May of 2010 at Foster golf links in Tukwila, Washington and was a huge success. The idea for a golf tournament was conjured up at a Christmas party by a few friends of mine. An acquaintance at the time, but now a close friend, Dee Dee Goodspeed, spearheaded the idea. She wanted to help and is a very kind-hearted person, so she got the fundraising ball rolling. Before we knew it, my sister had formed a non-profit organization called MELOFUND (created solely to fund the efforts of the Melorheostosis Association) and we were well on our way to pulling off a \$10,000 fundraiser!

The MELOFUND group consists of Dee Dee, my sister Mykel, my mom Linda, and my best friend Carlye. The group met regularly between January and May to plan and organize the fundraiser. Dee Dee and Carlye had helped do some fundraising in the past and the rest of us had been to an auction or golf tournament, but beyond that, we were kind of just figuring it out as we went along! We planned to do the golf tournament only in the beginning so that we didn't get in over our heads. We reserved a golf course, ordered lunch for 75, made fliers, and hoped our friends and family would come through. Between Dee Dee's friends and Carlye's family, we were fully booked almost immediately! What a relief knowing we had golfers to cover the cost of the golf and the food! Having enough golfers signed up allowed us to move quickly into the planning of the actual tournament day. It also allowed us to expand our fundraiser into a golf tournament and auction.

Adding the auction to fundraiser added quite a bit of work, but it created almost all of the profit! It's amazing what people are willing to give if you just ask them. My mom Linda was a road warrior in this department and asked just about every business she drove by if they wanted to donate. Almost everyone gladly donated goods or services, gift cards, or cash. We all pitched in and asked friends, family, and businesses to donate and we quickly had a 60+ item silent auction and 10 great live auction items. We had no idea how much this effort would benefit us in the end and are so glad we added it to the fundraiser. Our golfers had a great time bidding on the items during lunch, and we doubled my original fundraising goal because of it!

In addition to asking for donations for the auction, we asked for monetary donations from corporate sponsors. Several generous companies donated cash to help ensure the fundraiser would be a success. We also obtained 18 hole sponsors, some of which donated cash, and some of which brought fun goods to their particular hole. Topping

the list was Barefoot Winery, which brought mini wine bottles to their hole. You had to earn the wine when you arrived at the hole though...by teeing off BAREFOOT! The golfers had so much fun with this and our volunteer photographer captured many fun moments at that hole!

There were even more donations from a catering company that brought breakfast burritos, a bakery that brought scones, an espresso company that served lattes, and a sign company that graciously donated all of our banners and hole sponsor signs. Many friends and family that didn't golf donated their time as volunteers to help the day run smoothly. We had no idea what to expect and just hoped and prayed that it would go well, and with everyone's hard work and support, it was spectacular!

I had so much fun spending the day with friends and family that care about me and support my cause. My favorite moment was getting a chance to speak openly about my disease to a very attentive audience at the auction. I was humbled to look out into the audience and see friends and family hanging on my every word. Many of them didn't even know what the disease was and how it affected my life until I told them my story that day. A few tears were shed and a lot of eyes were opened about the disease. They were proud to be a part of the first golf tournament and auction in the country to support Melo.

It took a lot of work and planning to run our very first golf tournament and auction, but in the end it was all worth it! We were able to donate the money to the association and fund the 2010 Melorheostosis conference at the Mayo clinic. Plans are already in the works for an even bigger golf tournament, auction, and dinner in August of 2011. MELOFUND also plans to do several other fundraisers every year to continue funding the efforts of the Melorheostosis Association. It's amazing what people will donate if you ask, and you never know what you can accomplish until you try. I look forward to people across the world joining in our fundraising efforts and sharing their own success stories soon!





## Fun Ways to Support Melo

### Denver MeloFund Pub Crawl

by Jen Gordy

On October 8<sup>th</sup>, 2011 the streets of Denver, Colorado were stormed by Melo supporters participating in a Pub Crawl Fund-raiser. The idea came to me from the fabulous ladies of Melo-Fund who put together a very successful Pub Crawl in Seattle last year. It was so much fun and so easy, I wanted to share it with all of you.

The first step was finding the right bars. I contacted several bars that I was familiar with in the Lower Downtown Denver area all



within walking distance of each other. I told them what we were planning to do and asked if they would be willing to either donate one drink to each person participating in the crawl or allow us to pay a deeply discounted rate for one drink. Some bars were more willing than others. In the end, we found five fabulous bars that were willing to participate. We provided the drink tickets – one per person, per bar and the bars kept track of how many were turned in. Most bars gave us a discount of \$0.50-\$1.00 per drink and the last bar (The Ginn Mill) even donated 100% of the drink tickets. As we left each bar, we paid for each drink ticket that was used.

We set a schedule based on where the bars were located and what they had going on and told them approximately how many people we anticipated, letting them know we would confirm this amount as the event drew nearer.

Once we had the bars on board, we sent out invitations. We had people pay \$35 to participate which included one drink ticket per bar and a t-shirt. We also included a “Crawl From Home” option where participants who could not attend could pay \$25 and still receive a t-shirt.

Next we started coming up with other ways we could raise money while on the crawl. We put together a raffle at the last bar and sold raffle tickets. We allowed participants to play “poker” and purchase playing cards they could collect along the way to put together the best poker hand at the end. We even had some onlookers who liked the t-shirts so much, they bought one for themselves.

Not only did we have a great time, we were able to raise over \$3000 for Melo through this fundraiser!! If you are interested in putting something like this together in your town, feel free to contact me directly for help ([gordyjm@yahoo.com](mailto:gordyjm@yahoo.com)) or contact

MeloFund ([www.melofund.com](http://www.melofund.com)).



## Willing to help?

Feel free to contact us if you are interested in helping out or being a part of our board of directors. Since we are an all volunteer organization, we always need help with planning conferences, fundraising, putting together newsletters, etc. We welcome anyone willing and able to help!

## Tell us what you think!

We always welcome your feedback. Please let us know if you would like to hear about a specific topic in the next issue or if you would like to participate in the “Getting to Know You” section of the next newsletter.

## Donations Welcome

Please send donations to  
Melorheostosis Association  
2602 Stevens St.  
Madison, WI 53705

### ***Association Mission...***

*The Melorheostosis Association is a 501 (c)(3) not-for-profit organization dedicated to finding the cause, treatments and cure of melorheostosis. Our focus will be on promoting greater awareness and understanding of this progressive disease and its manifestations through education, research, communication and advocacy efforts on behalf of those affected by it as well as those dedicated to alleviating it.*

### **2012 Melorheostosis Association Officers & Directors**

<b><u>Name</u></b>	<b><u>Title</u></b>	<b><u>Address</u></b>	<b><u>Email</u></b>
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“Nature is nowhere accustomed more openly to display her secret mysteries than in cases where she shows traces of her workings apart from the beaten path; nor is there any better way to advance the proper practice of medicine than to give our minds to the discovery of the unusual law of nature, by the careful investigation of cases of rarer forms of disease.”

William Harvey, 1657