

## The President's Corner



Hello all –

We just finished up a very successful 7<sup>th</sup> International Melo conference in Rochester, MN. We were able to get patients and doctors together to discuss their cases, talk about surgery and the benefits and downfalls for melo patients, discuss alternative methods of pain management such as Physical Therapy and Tai Chi and discussed recent developments in research.

We also had time for patients to get to know each other and talk about what helps them and what doesn't. Read on below for an interview on one couple's experience at the conference and conference photos.

Thank you to the patients, families and friends who attended and the doctors and speakers who participated and helped to make this event a success.

And a special thanks to the MeloFund ([www.melofund.com](http://www.melofund.com)) whose fundraising efforts not only helped to cover the costs for this conference but will also cover the costs of next year's conference. They were also able to cover sponsorships for two couples to attend the conference all expenses paid.

I would like to personally give a special thanks to the Higgins Family for our largest donation ever by an individual. This is truly amazing to an all-volunteer organization where every penny counts. Thank you for making it easier for us to help the patients and families affected by melo.

Stay tuned for the next newsletter edition where you will hear more about a very successful and fun fundraising experience!!

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

ONWARD!

Jen

## My Experiences at the Mayo Clinic by Jen Gordy

I wanted to take some time to share with you my recent experiences at the Mayo Clinic. I was able to make an appointment with the Mayo Clinic prior to attending the Melo conference in Rochester. I have to say, I was impressed!! The facility is amazing and beautiful. Everything is in one place and it is run like a well-oiled machine.

To make an appointment, I had my primary care physician (who knows only what I have told him of melo) refer me to the Mayo Clinic. It was very easy, my doctor made the call and then a week later, the Mayo Clinic contacted me with my appointment time. Since I wanted to coordinate my appointment with the conference, I needed to reschedule my original appointment. They allowed me to reschedule six weeks in advance and I was able to get the perfect time in the afternoon the day the conference began.

They were very helpful, sending information on the area and facility; maps, directions, hotels, etc. ahead of time. They sent me several sets of paperwork to fill out prior to my arrival; some to send back ahead of time and some to bring with me. It was all extremely organized.

When I arrived, I was able to speak with the receptionist right away. I gave them the rest of my paperwork and they gave me a pager. Within 15 minutes, the pager went off and I was whisked away off to take vitals and record basic information about my history and the reason I was there. Once that was complete, the doctor came in. She spoke with me about melo and we spoke about my case and history specifically. She examined me and we discussed getting x-rays of my lower body. Before I left to get the x-rays she had already made a follow up appointment the next day at lunch to review the x-rays they were about to take with us before we headed back to Colorado.

As I checked out, they handed me an itinerary with my appointment with the radiologist (immediately following my check out) and my follow-up appointment with the doctor the next day. The sheet told me where to be, when I needed to be there and all I needed to do was hand the receptionist in each area my itinerary and they told me where to go. It was all so easy. The experience with the radiologist was even better! They took approximately 26 films in about 15 minutes. They were friendly and efficient and it was a fabulous experience.

I met with the doctor again on Friday during lunch and we were able to compare my new x-rays with the older x-rays I brought in. I discovered that I had melo in places I never knew I had it. It was really eye opening and I'm glad I was able to get my specific case into the Mayo Clinic database for research purposes.

I would highly recommend the Mayo clinic. They were fabulous to work with and it was a great experience. Feel free to contact me with any questions that you may have – I am happy to share any information that I can to assist my fellow patients ([gordyjm@yahoo.com](mailto:gordyjm@yahoo.com)).

## Feature Article - Patient Story

By William



My name is William and I am 18 years old. I was diagnosed with melo in my right leg and foot in 2006. I am a twin but my brother does not have melorheostosis.

I was 13 years old when a girl in my band class pointed out an oddly shaped bulge in my right shin. I didn't bother mentioning this to anyone until a year later when another person mentioned its irregularity. I told my mother who was concerned and took me to see my doctor who immediately did an x-ray of my right leg and an MRI.

The radiologist who read the initial x-ray films suggested it might be melorheostosis. I saw a specialist shortly thereafter at UNC-Chapel Hill who confirmed the diagnosis with an additional full body x-ray. With the full body scan, he found the melo in my right toes.

I secured a local orthopedic physician to follow my case. He initially suggested I get an x-ray every year but has since changed the recommendation to every three years. I've seen him a total of three times.

The first year I was diagnosed, I also attended a Melorheostosis Conference (2006). At the conference, my family and I learned a little more about the bone disorder. The comforting thing about going to the conference was the opportunity to meet with a group of doctors who have been studying melorheo-

stosis in depth. They were able to give me several good pieces of advice.

I began taking precautions to prevent injuring my leg. I was advised not to ski for fear of breaking my bone in the ski boot. I stopped skiing. I was told not to participate in sports that put too much stress on my leg. I stopped wrestling and running as often. The only sport I wasn't afraid of damaging my leg in was swimming. Luckily I had been competitively swimming since I was 7 and it is my favorite sport!

I don't know if it's because of my cautious pampering or the fact that my melo isn't located in any joints but the melo hasn't caused any significant pain. Recently I've starting branching out and pushing the limits of my leg comfort. Recently however, when I jog and put pressure on my right leg it has become more sensitive, but not painful.

I will continue trying to test my capabilities and try not to let melo keep me from being active.



# One Family's Conference Story

by Lydia Zepeda

When Jonathan was four years old, Carlos and Valeria took him to the doctor to be evaluated. They were concerned about his gait; he was a healthy, active boy but was having trouble walking and running and complained of pains in both legs. His x-rays showed thickened cortical bone. The physician suspected melorheostosis and had more x-rays taken and reviewed by radiologists at three sites. Jonathan is seven now and his diagnosis is still “presumed melorheostosis.”

Like most parents and patients, they searched for information about melo. It didn't take Carlos and Valeria very long to find the Melorheostosis Association website. They knew about the conference for three years, but this year they finally decided to go because they are moving to Brazil next summer and before they move, they wanted to make sure they had as much information as possible about melo to give to their son's physicians in Brazil. They are very concerned because Jonathan's gait was getting worse and he complained of pain in both legs. Many mornings they would get up and find seven-year-old Jonathan soaking himself in a warm bath to deal with the pain.

Thanks to fundraising by Stephanie and Mykel Papke, Carlye Hupp, and their families and friends, the Melofund was able to help them come to the conference. Carlos and Valeria brought Jonathan's x-rays and medical reports. They talked to other patients who confirmed that heat helped them deal with the pain, but were surprised to hear that pain was not a common symptom for children. Valeria said, “Every melo patient should come to the conference, here they have the freedom to talk about it, to get encouragement from others, to find out what works. Each case is different. It helps the family to see through the eyes of the patient.”

Valeria and Carlos were very excited to participate in the patient clinic case studies because our physicians have seen more cases of melorheostosis than any physicians on earth. Conference clinics are not medical appointments; they are a way for both physicians and patients to learn about the disease together. What was clear to the physicians is that rather than melorheostosis, Jonathan may have Camurati Engelman disease, a treatable disease.

For three years Carlos and Valeria had thought Jonathan had melo, now they were shock and felt like they were back at ground zero, but with a difference. This time the disease, while rare, has a known treatment and a known gene. One of the first things they will do when they return home is ask for a geneticist to verify whether Jonathan has Camurati Engelman disease. They thought about what would have happened had they not come to the conference, had they moved to Brazil without knowing.

Carlos and Valeria made many friends during the conference; they are part of the melo family now, even though it looks like Jonathan doesn't have melo. And the Melorheostosis Association is part of their family, their friends, and their church. This story is not rare; at almost every conference someone finds out that what they thought might be melo is not. Is shouldn't be surprising, most physicians have never seen a case before and most scientific literature only reports a single or a few cases.

The physicians at our conference have seen dozens of cases, mostly through our conference case studies. They have learned that melo can present on both sides of the body, they understand that it isn't just a bone disease, but affects soft tissue, and patients' and their families' lives. Sharing and learning together we can help find the cause, treatment and cure for melo.



## 2011 Melo Conference Photos



A generous donation from MeloFund being presented to the Melorheostosis Association board by Carlye, Stephanie, and Mykel



The 2011 conference attendees at the DoubleTree Rochester MN

## *Fun Ways to Support Melo*

There are several fun and exciting way that you, your family and friends can help support the Melorheostosis Association. Here are just a few ideas on how to help.

**Restaurant Night for Melo** – local restaurants in your area may be willing to give a percentage of their night's sale to melo. You can invite your family and friends to the restaurant and help melo by simply going out to eat. Check with your local restaurants to see if they offer this fun fundraising option.

**Pub Crawl** – Invite your friends out for a night on the town – have each participant or team pay a set fee as a donation and see if you can work out drink specials at your local bars and restaurants. You can even add a theme such as everyone dressing up in 70's clothes or as their favorite superhero.

**Poker Tournament/Bunko Night** – Have some friends over to play some cards. Everyone pitches in a set amount at the beginning and the winnings go to melo.

**Sports Tournament (golf, softball, basketball, bowling)** – Work out a deal with your local park, golf course or bowling alley to help sponsor a sports tournament. Have each team pay a registration fee with the proceeds going to melo and then raise money doing something you love.

**Cocktail Party** – Invite your friends over for some cocktails. Most local liquor and grocery stores will offer discounts or donations on food and drinks and you can educate your friends on melo. The association has materials and presentations you can share.

**Silent Auction** – Several business are willing to offer a small donation or service to participate in a silent auction. This is an easy way to raise money and can be a lot of fun! Some ideas for donations are grocery, fast food or restaurant gift certificates, candles and lotions from the local gift shop, movie tickets, etc.

**Goodsearch/Goodshop** – if you search the internet or shop online – try using [www.goodsearch.com](http://www.goodsearch.com) and [www.goodshop.com](http://www.goodshop.com) choose the Melorheostosis Association as your charity and a portion of your searches and sales will go to helping melo!

**Donate your time and become a board member.** Do you have a special skill and would like to help out? We are always looking for good people to be a part of a committee or a board member. Let us know if you are interested.

All cash/check donations are welcome as well - every little bit counts!

Feel free to contact us if you are interested in helping out or being a part of our board of directors.

Let us know if you would like us to focus on anything special in the next issue or if you would like to participate in the "Getting to Know You" section of the next newsletter.

Donations may be sent to  
**Melorheostosis Association**  
**2602 Stevens St.**  
**Madison, WI 53705**

***Association Mission...***

*The Melorheostosis Association is a 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.*

**2011  
Melorheostosis Association  
Officers & Directors**

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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 then 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**