



March 2017

President's Message

By Jen Gordy

Hello Melo Community!!

Hope you all had a fabulous holiday and very Happy New Year! 2016 was a wonderful year for the melo community. The NIH study is in full swing and we had our 10th international conference in Rochester Minnesota in October. I am thrilled to announce the success of this conference with the most patients we have ever had in once place. We were looking to make it the biggest and best conference ever and I hope all the attendees agree that we did just that! Read on to find out more information about this wonderful event. We hope you will join us in 2018 for our next conference!

I am thrilled to announce that Dr. Michael Whyte as agreed to become our Medical Panel Chair moving forward. We are excited for all that we can accomplish together! We also give a heart filled thank you to Dr. Geert Mortier who as served as our Medical Panel Chair for the past 8 years. He has done so much for us and we would not be where we are today without him. You can read on to find out more about my own personal journey with melo. We have also included a clinical analysis of 24 patients that you may find interesting.

We hope this newsletter finds you well and look forward to giving you more great news as the year goes on. Have a wonderful 2017 and we'll talk again soon.

ONWARD!!

Jen



10th International Conference

October 14 - 16, 2016

Rochester, MN USA

by Amanda Shapiro

The 10th annual Melorheostosis Conference did not disappoint this year! We had amazing attendees, speakers and even a surprise DJ and photo booth to top it all off! This was our largest conference ever with 32 Melo patients and 56 attendees with families, friends and medical community!

We started this year with an extra session on Friday night before we had our introductory cocktail party to get to know everyone. As an association, this worried us since it was out of our normal routine, but we didn't want to miss out on everyone hearing Dr. Stans speak about surgery and Melo. We were so thrilled with the response. Our Melo family was excited to hear what he had to say. We wrapped up his session with a small welcome reception and got to hug old friends and greet new ones this year!

Saturday morning, everyone was wide-eyed and ready for our big day filled with speakers, case studies and interactive sessions! We started the day off by hearing the wonderful Dr. Mike Whyte give an overview of what Melorheostosis is followed by a report of a patient he treated at Shriners this year.

We were thrilled to announce at the conference that Dr. Whyte has accepted the position of the new Chair of our Medical Panel. He has been a member of our medical panel since the beginning and been worked tirelessly with us over the years. He will be replacing Dr. Geert Mortier who has served as our Chair for the past 8 years and we can't thank him enough. He has gone above and beyond for our community and is excited for the future for Melo patients.



Next we heard from Dr. Bhattacharyya from NIH report on the Melorheostosis study that is going on at NIH. He provided great detail about the study and presented their findings so far with 21 patients and 14 bone samples that they have seen thus far. With our extremely rare condition we can all agree that this is an amazing amount of participation and we can't thank the community enough! To thank all of those warriors that participated in the NIH study, we acknowledged them all with a special ceremony and an acknowledgement pin. It was great to see everyone proudly wear their pins for the rest of the conference. Pins were also given to Dr. Whyte, Dr. Bhattacharyya and Eileen Lange to thank them for their work and pins will be sent to any participant in the studies who was not at the Conference. A big Thank You to Melo patient Sajjad Hossain Tuhin for designing and donating the pins to the Association.

The rest of Saturday was wonderful. We heard Dr. Matthew Pingree from the Mayo Clinic present on pain management, something we all can benefit from hearing. After that we broke out into mini sessions for patients, supporters and even a kids session. Something for everyone. While this was going on, the individual patient sessions started. This was each patient's one-on-one 15 minutes with a panel of doctors. Everyone came prepared with their X-rays and it proved to be a huge benefit for all the patients as well as the doctors to have more research and documentation completed on our mystery disease.

After a short break, the association gave a short presentation to talk about what we do, what we need done, and how you can help. On behalf of the Melo fund, Susan Dunaway gave a wonderful presentation on what they do. The Melo fund is the reason this conference was able to happen. It's a group of 3 beautiful women that started fundraising with the goal of welcoming very patient to the conference without concern for the cost of attendance. I

will never forget when Stephanie Papke told us this in one of our meetings, she said "I don't want anyone to ever have to be deprived of coming to one of these life changing conferences because of money". I thought she was crazy, but guess what - this is the 2nd conference MeloFund has completely paid for all the hospitality for our patients!

We are so grateful for all the MeloFund has done for us but we cannot expect them to do it alone. We need as many people as we can out there helping us fundraise for future conferences and research. Every little bit counts and we would love to be able to keep helping to fund the conferences to allow more patients to come. Please think about having a dinner, bar crawl, restaurant night or any new idea. The association is prepared to help you every step of the way!

After a great dinner and a fireside chat where the patients and doctors debriefed about the long information-filled day, we had a surprise to celebrate our 10th conference - a DJ and photo booth to dance the night (and the pain) away! It did not disappoint! The pictures were a blast and we loved seeing everyone up and moving!

Sunday everyone woke up (a little tired) but still ready for our annual photo in our new t-shirts of course (thanks again to Sajjad!!). Then we wrapped up with Dr. Bhattacharyya and Eileen Lang with an interactive session about what to expect when participating in the NIH study. After, we heard Dr. Whyte present about the amazing opportunity for children to be seen at Shriners.

As an association, we are extremely proud of all the work we have done. One of our goals has been to be able to direct patients where to go and we can confidently now point adults to NIH and children to Shriners. This makes us complete!

At the end of the conference, we did something new this year - we all closed our eyes and listened to a motivational guided meditation. We got some great feedback about this and hope we introduced something new to our Melo family that works for them. I know I loved it!

So if you missed it this year, hopefully after reading this, you're thinking about making it next time! Our next conference will be in 2018; dates and place to be coming soon. If you were there, I hope it was great to reminisce on the incredible few days we got to spend together.

To all my Melo family out there - we are in this together and we are fighting it together. I'm so grateful to have met each and every one of you!

ONWARD!





Our Melo Warriors
Those who have been to NIH

Jen Gordy's Melo Story



Hello Melo Community. I would like to take this time to talk to you about my journey with Melo. I was diagnosed when I was two years old. I had sprained my ankle and my parents took me into the dr. office to get it checked out. While my X-ray was up, a doctor noticed the telltale dripping candle wax and diagnosed me. At the time, my parents had noticed that I walked on the toe of my left foot and never put my heel down when I walked. When asked, the doctors didn't attribute this to the Melo at the time but thought it was a tight heel cord - completely separate of the Melo diagnosis.

To correct this, I had my first surgery at two. A few months after my surgery, the heel cord started to tighten back up again. We went through a series of testing to try to figure out why but nothing stood out. At six, they decided to try again and I went through another heel cord lengthening surgery. Again, just months after the surgery, it started to come back. It was then that they decided to link it to the Melo. We waited until I had stopped growing to try to correct it again and in the meantime, I wore a brace on my left leg to try to slow the progression as well as serial casting to try to increase my range of motion.

When I was fifteen, I had my next surgery. This time, the doctors were concerned about the high arch on my right foot so in addition to the heel cord lengthening on my left foot, they also performed an osteotomy on my right foot to lower the arch and corrected the four toes I also had affected with Melo - two on my left foot (3rd and 4th) and two on my right 1st and 2nd). These toes were contracted due to the Melo and the idea at the time was to straighten them out so I would have increased functionality. The problem was, and I'm not sure they realized it at the time; I also had Melo in my right foot beyond the two toes affected and this caused complication in the routine osteotomy and toe corrections. Only days after the surgery, my toes started to contract again and I lost circulation in them. When the nurses tried to pull the pins out holding the toes in place (which should be rather easy on normal bone - like pulling out a hair or so they told me), the Melorheostosis bone held on to the pins not allowing them to be pulled out. This was just a bit unpleasant (to say the least). They had to end up taking me back into surgery to remove the four pins in my toes and two in my right foot due to the osteotomy.

While I am not a doctor and would not advise anyone on their individual treatment, I would caution anyone looking to have this corrective surgery. If I could go back, I would NOT choose to do this. My toes are now much more sensitive and my pain on the right side where the osteotomy was performed has increased significantly since the surgery. After I got out of the hospital, I had casts on both feet and was in a wheelchair all summer. To this day, I still have a great appreciation for the fact that I can still use both my legs.

Two years later, all four of my toes had contracted back and my heel cord contracted again despite the fact that I was done growing and the doctors were stumped as to how to proceed. They noticed that I had a limb length discrepancy due to the Melo so they decided to focus on correcting that. When I was 17 they took 2 inches of bone out of my left leg to even my legs out. In a happy accident, this also loosened up my heel cord so I could put my heel down and have (mostly) full range of motion. It has been 20 years since my last surgery and while my heel is tight, I can still walk, run and function normally (for the most part).

Moving has been key to keeping my mobility up. While I will never be one to run a marathon or do an Ironman, I really believe that moving is the key to making sure I can stay active moving forward. The pain has definitely gotten worse over time. I manage it by taking Tramadol which helps but I worry about becoming too dependent on it moving forward. Heat also helps (LOVE my hot tub and hot packs) and massage (to a point) helps as well.

Even through the surgeries, casting, braces and serial castings, I was determined not to let my Melo get me down. I played sports (soccer for one season when I was younger and basketball and lacrosse in high school) and still to this day enjoy playing softball, volleyball and broomball (if you don't know what broomball is, look it up - so much fun!).

Some of you may wonder about how I got involved in the Melorheostosis Association. Back in 1999 I did a web search on Melo only to discover there was not much more information than I had found in high school while doing a research paper on it (a paragraph of info explaining what Melo is). In 2006, while watching a show on rare diseases, I thought to Google it again. This time, I found the Association and was thrilled to discover that there was a conference coming up just a few months after that in Madison, Wisconsin. I went by myself the first time and had no idea what to expect. I can't even describe to you the feeling of meeting other patients. All my life, I had never met another person (and very few doctors) who knew what Melo was or anything about it. To walk into a place and talk to other patients and doctors who had seen actual patients was the most amazing experience ever. For the first time, I felt like I wasn't alone. While my family and husband are extremely supportive, it isn't the same as talking to someone who goes through the same pain as you do every day. Also it was amazing not having to explain to a doctor what Melo is before discussing symptoms. It was liberating. So from that day forward I was involved in any way I could be with the Association. I have been the President now for the past six (6) years and it has been a phenomenal journey. While I don't wish this disease on anyone, I have never met a more positive, wonderful and caring bunch of people as my Melo family. And that is just it, WE ARE FAMILY.

Hang in there Melo sufferers. We are all in this together, and hopefully within our lifetime, we will find the cause, treatment, and cure for Melo!



Melorheostosis: A Retrospective Clinical Analysis of 24 Patients at an Academic Medical Center

The Mayo Clinic published a clinical analysis on 24 of the patients they have seen and we thought you might be interested in reading it. We have attached it here if you are.

[Mayo Clinic Publication on Melorheostosis](#)



Willing to help?

Please contact us if you are interested in helping or being a part of our board of directors. Since we are an all volunteer



organization, we always appreciate help with planning conferences, fundraising, putting together newsletters, etc. We welcome anyone willing and able to serve in this manner!

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 Always Welcome~

Please mail donations to:

Melorheostosis Association

410 East 50th Street

New York, NY 10022

or

Donate on our website www.melorheostosis.org

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.

2017 Melorheostosis Association Officers and Directors

<u>Name</u>	<u>Title</u>	<u>Address</u>	<u>Email</u>
Jennifer Gordy	President	Denver, CO	gordyjm282@gmail.com
Kathleen Harper	Chairman	New York, NY	kathleen@harpervision.com
Katrina Wells	Treasurer	Manheim, PA	katrina.n.wells@gmail.com
Amanda Shapiro	Secretary	Reisterstown, MD	amandaherling@yahoo.com
Susan Dunaway	Newsletter Editor	Graham, WA	dunawayrs@comcast.net

Contact: Kathleen D. Harper, Melorheostosis Association
410 East 50th Street
New York, NY 10022
Or email kathleen@melorheostosis.org

