

The President's Corner

Hello again melo community - time for another melorheostosis newsletter. Read on to learn more about the success of the 2010 conference, hear details about our upcoming 2011 and to get to know more of our melo community.



We need your help!! We are currently raising money to fund our second research grant. We need to raise \$30,000 by December 31, 2011 and every little bit helps. If everyone on this newsletter donated \$20 we would already be a 10th of the way there!

I am thrilled to announce our next Melo Conference this August 25 – 27, 2011 near the Mayo Clinic in Rochester, MN. We will be discussing different treatment options and will be conducting patient case studies once again. Stay tuned for more information on this conference – we hope to see you there!

I would like to recognize and extend a special thank you to all of our 2010 Melo Association contributors:

Abramowitz Family Foundation
Robin Andrews
Brad D. & Courtney E. Bondroff
Sharon Cannistraci
Chick-fil-A at Owings Mills Square FSU
Mr. & Mrs. James Clinkenbeard
Scott W. & Rebecca J. Clow
David B. & Megan G. Ginsberg
Michael A. & Cristina A. Ginsberg
Shirley Gregory
Eric Heidinger
Larry & Constance Jennings
Larry Kuster
Hunter C. & Rita J. Piel
Marc A. & Nicole B. Samuel
Amanda Shapiro
Robert Shapiro
Lydia Zepeda

Thank you for your support! We would not exist without you.

I would also like to personally thank Stephanie Papke and all of the volunteers of Melofund (www.melofund.com) for their hard work and efforts to support the Melorheostosis Association. Without their contributions last year's conference would not have been possible and the board appreciates all that you do!

ONWARD!!
Jen

7th International Melorheostosis Conference **August 25-27, 2011**

Ever been told by a doctor that there's nothing they can do?
Ever have pain that you can't explain?
Are you a parent of a patient and don't know how to help or what to do?
Feel like you're all alone?
Well you're not!!

We understand what you're going through because we're just like you! The Melorheostosis Association is made up of all patients or family of patients and we know what you're going through. We want to make sure that you know you are not alone! That's why we put together the Melorheostosis Association Conferences. These conferences are designed to help patients and families meet other people in situations similar to your own. Read on to learn more about last year's conference.

Join us near the Mayo Clinic in Rochester, MN on August 25th – 27th for our 7th International Melorheostosis Conference. Come learn about the latest research efforts and alternative treatment options or share your case with doctors who are interested in learning more. You can meet other patients, share stories or just listen and learn more about our disease and hopefully ways to improve your situation. We hope to see you there!!

Feature Article

Patient Story

By
Mari Fairman-Painter



My name is Mari Fairman-Painter, I am 47 years old, a wife and mother of two and this is my story of living with Melorheostosis:

My first recollection that I may have something wrong was when I was in the third grade. As I sat cross-legged on the gym floor, I felt an uncomfortable aching deep in the back of my knee. I also noticed that it felt stiff when I began to straighten it out, but soon it felt normal again. Alarmed my mother spoke to my pediatrician about it and he dismissed it as "growing pains". I had no other outward abnormalities and it moved normally so there was no concern then, but I knew even then something was not right.

Things got interesting when I was 16! My pediatrician referred us to our family doctor. Our family doctor discovered that the pediatrician noted several discussions over the years about leg pain. He spoke with my parents and felt there maybe cause for concern and he referred us to an orthopedic doctor. A series of X-Rays and a CAT Scan was done on that leg. He showed us the X-Rays and told us he thought it was a rare bone disease called Melorheostosis and pointed out how it looked very much like candle wax flowing down the bone. It started slightly above the knee and ran all the way down until the end of the X-Ray. He sent my worried parents and me to the Mayo Clinic to see the orthopedic specialists there and they agreed that it was Melorheostosis. They informed us that little was known and they couldn't predict anything but to be hopeful that it would get better as I aged. My parents were so relieved that it wasn't something life threatening that we celebrated that night and went out for dinner. We all quietly hoped that it

would get better or at least not get worse. It did not; it slowly and steadily got worse.

In my mid-twenties I was still functioning normally but had more pain, especially behind the knee. The local orthopedic doctor preformed a surgery to the side of knee and removed an area of growth that protruded out as he was convinced it was the spot that was causing the pain. It was a big surgery and unfortunately, it was not the source of the main problem, so it continued to get worse. A couple of years after the surgery there was a turn of events. I noticed pain and difficulty bending my foot and asked the doctor if anyone ever looked to see if the disease had traveled into my ankle or foot. They had not! All the X-Rays taken prior stopped at the ankle and because I had not complained about that until now it was overlooked. The X-Rays of the foot and ankle showed the signs of the "flowing wax" down through the ankle and surrounding all the small bones of the foot and giving them almost a popcorn-like appearance. My problems with my foot and ankle continued to get worse and later a surgery was preformed to remove extra bone growth that was congesting the ankle. It was a success but again, just a couple years later I had more problems with the foot. The disease had progressed and now it had fused the joints in my foot until it was locked in a "heel-up" position. Believe it or not in order to walk some what normally I had to wear hi-heeled shoes! I could only walk on the ball of that foot when I was barefoot. At 28 a third and very successful surgery was done to correct it. The melorheostotic bone around my foot and ankle was cleaned out so they could move freely again. It was a big success and soon after I began to walk more normally again, however my knee pain was getting worse. It was hurting more often and I was minimizing bending it more and more. The appointments with the orthopedic doctors were becoming fruitless and over the years the pain intensified in the back of the knee and eventually I couldn't bend it enough to get it under a table and if it was bumped back even slightly, I would actually black out and drop to my knees in pain.

In my thirties the local orthopedic doctors said there was nothing more they could do. The melo had almost fused in the back of the knee and they said surgery was too risky because the location of the major artery and nerves. I made an attempt to see a Doctor at Mayo Clinic again but was notified that they knew of no treatments or surgical intervention and my trip would be wasted. That left me with nothing to do but be treated for the pain that was getting unbearable.

By 40 I was unable to work and walked with a cane. My knee was completely stiff and I dragged the leg about. I had to keep it straight and prop it up on a stool or another chair. Sitting at a table or desk became impossible as well as so many other things, including getting in
Continued on page 3

Patient Story, Continued from page 2

and out of a car. I was forced to give up my career because of the pain and physical limitations and I was feeling terribly frustrated I had run out of options. That year we attended our first Melorheostosis Association Conference and for the first time met others with the condition. What an amazing experience it was. I finally felt I wasn't alone and could reach out to others who could understand what I going through.

The next seven years were the hardest of my life. It was a time of a sharp contrast between having so many wonderful blessings to live for and relentless pain that interfered and darkened every aspect. Not wanting to give up, I fought a downward spiral and came to a decision. If I had to get rid of the leg to get rid of the pain I would. I felt that with rehab and a good prosthetic limb I eventually would be more mobile and most importantly without pain. I contacted Kathleen Harper with the Melorheostosis Association and explained my plight. I felt that if we didn't look for a "cure" for melo but an intervention on the specific area of pain behind the knee perhaps a surgeon could help. Within days Melorheostosis Association Medical Panel members Dr. Fred Kaplan and Dr. Jeffery King had talked to an Orthopedic Surgeon at Mayo Clinic and I was asked to send my tests to him. I was then called back by a Dr. Peter Rose who specializes in surgeries in the back of the knee and I heard these wonderful words, "I think I can help you!" A major surgery followed that removed all the melo from the knee area and freed the major affected nerve and artery. Pathology was conducted and tissue samples sent off to NMA, and Drs. Geert Mortier and Jan Hellemans in Belgium for research. I'll never forget the feeling I had when I got up to take a step and the knee freely bent, and there was no stabbing pain! It's been 6 months and I am walking better than I have for many years. I am sitting normally and able to bend it. I still have pain related to melo and likely will have more problems in other areas down the line but it is bearable now and I have them all to thank.

I have learned that those of us with melo must be our own advocates. We need to learn as much as we can about the disease to help our doctors manage our care. It is very important to ensure your family is educated as well, because they go through this with you. In my case melo caused me to lose mobility in my joints and surgery was helpful but as we all know no two cases are the same. Surgery may not be an option for you. Supporting the Melorheostosis Association will help get all of our information to the doctors and researchers and that will help in the treatment and hopefully one day they can stop the progression or even cure this disease.

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6th International Melorheostosis Association Conference August 5th-7th 2010

August 5th, 2010 marked the 6th International Melorheostosis Association Conference in Rochester MN. There were 30 total attendees; 11 patients, 11 friends and family of patients and 8 speakers and doctors who participated.

The conference kicked off Thursday evening with a reception at the DoubleTree Rochester. It was a nice chance for the conference attendees to meet and mingle.

We began Friday with a session from Jan Hellemans and Geert Mortier discussing last year's research grant and the fabulous work being done on melo research. We continued the day with sessions discussing various topics from surgery, ways to relieve pain and the Mayo clinic. We also had several patients participate in case study sessions where the doctors who attended could discuss the individual cases with the patients and learn more about this rare disease.

Friday evening we had a dinner with presentations on some very successful fundraising events from Stephanie Papke and Amanda Shapiro followed by a bowling night. I would like to extend a special thank you to Stephanie for all of her fundraising efforts through Melofund (www.melofund.com). Saturday we continued the discussion with topics such as endocrinology and pain management and then wrapped up the day with lunch.

I would like to personally thank all the patients and doctors who participated to make the conference such a success as well as the families and friends of the patients for their continued love and support.

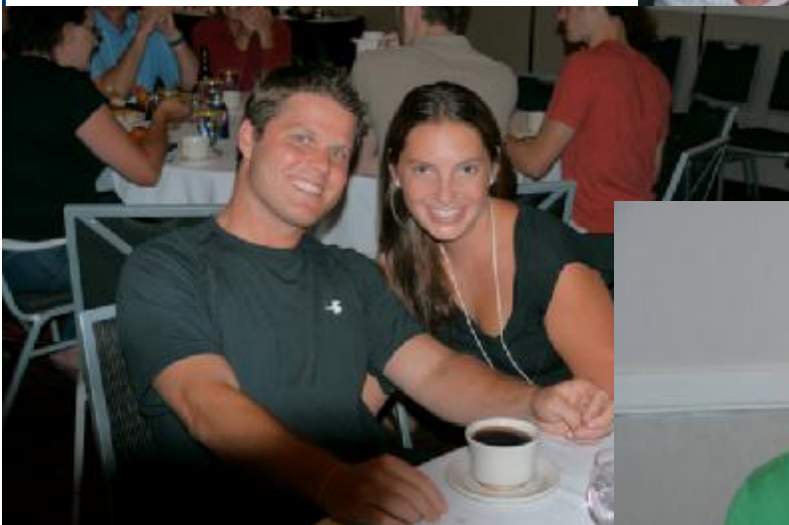
The registration fees only cover a small portion of what it takes to put on a conference. The more money we can raise ahead of time, the less it will cost for everyone to attend. In these hard economic times, it is difficult to spare funding but every amount is helpful for a small organization like ours.

These conferences are a great way to get doctors and patients together and for patients to meet other people with this rare and confusing disease. As a fellow patient, I find it helpful to meet other patients and discuss the challenges of living with melo. It is important to note that these conferences are funded 100% through fundraising efforts from you and the melo community and they are not cheap.

Thank you to everyone who assists in putting on these conferences and bringing our community closer. We hope to see you at this year's conference August 25-27 2011 !! - Jen

2010 Melo conference in Rochester, MN

Geneticists from Belgium: Dr. Mortier and Dr. Hellemans of our Medical panel with Kathleen Harper, Chairman of The Melorheostosis Association.→



Amanda Shapiro, Secretary of The Melorheostosis Association and her husband



Stephanie Papke and Carlye Hupp

Jen Gordy, President of The Melorheostosis Association and her husband



Patients, family and friends

Medical Presentations



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 and 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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Jennifer Gordy	President	Parker, CO	gordyjm@yahoo.com
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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