

## The President's Corner

By Jen Gordy

It is time once again for us to share with you all the wonderful things that are happening around Melo.

First off, I would like to share some very exciting news with you all. We have recently appointed Dr. Geert Mortier as the Chairman of our Medical Panel. Dr. Mortier has been a huge supporter of the Melorheostosis Association throughout our journey. He has been using our research grant along with Dr. Jan Hellemans to try to discover the gene that is thought to cause Melo. He comes over to the US all the way from Belgium to attend our conferences and participate in the patient case studies. He goes out of his way to help us when we need him.

Please join me in congratulating him on being appointed the Chair of our Medical Panel.

I would also like to personally thank Dr. Fred Kaplan for being the Chairman of our Medical Panel for the past 8 years. He has been an invaluable asset to this organization and will continue on and serve as Chair Emeritus of our medical panel. I would like to recognize that we would not be where we are today as an organization without him. He is a wonderful man and we thank him for all that he has done for us!

We just completed our 8<sup>th</sup> International Melorheostosis

Conference in Rochester, Minnesota. It was the largest conference to date and we had 14 patients and 32 total people attend which was truly amazing. Read on to find out more about this extremely successful event.

Our next conference will be in Rochester, Minnesota, again on October 23-25, 2014. Mark your calendars - we hope to see you there!

As always – we hope that you find these newsletters informative and that you know you are not alone out there. We are here to help and bring our community closer.

Stay positive and keep moving...ONWARD!

- Jen

"Character cannot be developed in ease and quiet. Only through experience of trial and suffering can the soul be strengthened, ambition inspired, and success achieved."

*Helen Keller*

## SCIENTIFIC AND MEDICAL ADVISORY PANEL

### MELORHEOSTOSIS ASSOCIATION



Dr. Geert Mortier

We are happy to announce Dr. Geert Mortier, M.D., Ph.D., will

serve as Chair of the Melorheostosis Association Scientific and Medical Advisory Panel. Dr. Mortier is Director of the Department of Medical Genetics at Antwerp University Hospital, as well as Professor of Medical Genetics at the University of Antwerp and Ghent University, and has been an esteemed member of our Medical Panel since 2004.

We are happy to announce Dr. Frederick S. Kaplan, M.D. will serve as Chair Emeritus of the Melorheostosis Association Scientific and Medical Advisory Panel. We are grateful to Dr. Kaplan for

invaluable guidance and leadership during his service as Chair since 2003.



Dr. Fred Kaplan

# 2012 Melorheostosis Conference

By Amanda Shapiro



Amanda and Quincy Jade

I am proud to say this year was a historic conference! We had 14 patients, the largest number of Melorheostosis (Melo) patients ever to be in one place!

It is always such a pleasure to see old faces from our Melo family and new ones too. One of the highlights of our conference this year was assigning our new panel chair of doctors, Dr. Geert Mortier. We are anticipating great success within our community having Dr. Mortier lead the way!

We started the conference off on Thursday evening with introductions and a short welcome reception. I think I speak for everyone when I say there was a great connection met by all. The feeling of meeting another patient and knowing you are not alone in this disease is amazing. I can only hope the next conference is even larger so more Melorheostosis patients can experience the same feeling.

Friday was an informative day starting off with a presentation by Dr. Whyte. He gave a great overview of the disease. This was followed by patient and patient supporter sessions. In the patient session, we discussed what it feels like to live with Melo. We talked

about how our pain feels, what helps, what doctors we see and even came up with a few positive things that have happened in our lives from living with Melo. While we were talking in our group, Lydia Zepeda (our treasurer), and a mom of a patient led the support group. This was for parents, spouses, and siblings etc to get together and talk about what it's like to support us.

After a quick break, we all enjoyed a nice dinner where we surprised and presented Stephanie Papke, one of our beloved patients and head of Melofund with our first ever plaque on behalf of the community. We wanted to recognize her hard work along with Mykel Papke and Carly Hupp. Without all their hard work the conference couldn't have been as historic and we thank them for that!

Another highlight of the conference was the fireside chat. There was no fire but we, as a large group, sat in a circle of patients and doctors and discussed the future of the Melorheostosis Association. Dr. Mortier believes that it is very important to create a successful storage system for samples. We also talked about ways to further our research. We are currently

talking with the Mayo Clinic about ways to make the process easier for us.

Finally, we discussed ways that the Melo community could stay in contact in between conferences. Katrina Wells offered to start up a Facebook group so that we could stay in touch and keep our community close.

Throughout all of these sessions' patients had the privilege to meet with our panel of doctors. These patient case studies were extremely helpful for new patients trying to confirm their diagnosis as well as furthering our research for the doctors to document our disease.

After a delicious breakfast on Saturday, Dr. Geert Mortier (our new panel chair!) gave us an exciting Melorheostosis research update. Following Dr. Mortier's inspiring presentation was an amazing research panel discussion. The topic "Future Research/Research Grants-Working with the Mayo Clinic" was discussed in depth by, Dr. Michael Whyte, Dr. Geert Mortier along with Dr. Bart Clarke and Dr. Salman Kimani of the Mayo Clinic.

We closed the conference with Stephanie Papke presenting on her hard work with fundraising and Melofund.

These amazing conferences couldn't happen without patients like you. Thank you to everyone for helping create such a wonderful and caring environment while we try to make the best of living with Melo. Onward!



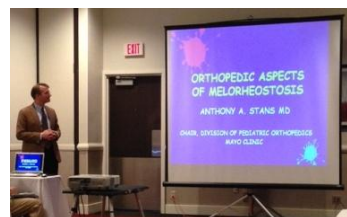
Dr. Michael Whyte  
Melo Medical Panel



Theresa, Stephanie,  
Tanda and Joanne



Group Activity –  
Bowling!



Dr. Anthony Stans  
Mayo Clinic



---

## An Eye Opener, With Them Closed

By Joanne Chapman



*Checked into the Mayo Clinic realizing I may have Melo (Melorheostosis), but it does not have ME. As I “Move Thru Melo”, holding tight to the affirmation that “I am not this body”, I know I have already succeeded!*

*As I finished my yoga this morning it was clear to me that to search for an answer may lead to disappointment and discouragement — instead I will experience the journey and know I am blessed! Feeling so fortunate that I can afford the time and cost of being at the Mayo Clinic and healthy enough to be a candidate for experimental procedures and tests. My hope is not so much for myself as it is for the Melorheostosis group/family as a whole.*

*Grateful for the last 12 years of yoga and the space, strength, and serenity it has brought to not only the body, but most importantly to the MIND! So thankful to my tenacious commitment — which has truly become a love of devotion. Had a powerful realization this week that yoga for me is expressing true love through movement and stillness. With complete compassion of those with a “have-to” whether it be driven by pain or disability.....My message from the heart is; don’t wait for a “have-to” to find your love of movement!*

---

"Have patience with all things, but chiefly have patience with yourself. Do not lose courage in considering your own imperfections but instantly set about remedying them -- every day begin the task anew."

*Saint Francis de Sales*

---

"A pearl is a beautiful thing that is produced by an injured life. It is the tear [that results] from the injury of the oyster. The treasure of our being in this world is also produced by an injured life. If we had not been wounded, if we had not been injured, then we will not produce the pearl."

*Stephan Hoeller*



---

---

## My Story

By Joanne Chapman

# MELO

Move  
Each  
Limb  
Often



I am honored to share my “experience” of Melorheostosis in hopes of creating a greater awareness that perhaps leads to a treatment or cure.

The Melo is apparent in my right lower extremity, from the big toe to the groin. I was a very active child and began to notice the pain and swelling of my right knee around the age of 8. At the time, the doctors believed it was calcium deposits on the knee.

I would be on crutches for about a week or two and then it would subside. The doctors tried using a needle to “drain” the fluid — but that didn’t work. Every year about 3-6 months apart, the right knee would swell. It was debilitating — I couldn’t walk on it or even move it. The only way to move the right leg was to use my left leg underneath it or my two arms to physically move my right leg. While my right leg/knee was in that state, it was more comfortable to keep the leg slightly bent, not allowing the muscle or knee to be in a “locked-out” position. (THAT WOULD BE EXCRUCIATING) As the years past, I noticed that I could not bend my right knee fully. I saw many doctors and came up with no real answers. The first orthopedic surgeon labeled it as Osteiopoikilosis.

Tried going to a **chiropractor** a couple of times during high school and college when the right knee would swell. A few times, I entered the chiropractor’s office on crutches and left the office walking! He would literally take my right leg across his knee and “slam” it down. The pain took my breath away and I thought at the time was the worst possible pain ever! (Little did I know how bad the pain would get)

Around age 22, I noticed the right leg was getting much larger!

Around age 27, my right big toe seemed to be doubled in size and my right foot seemed longer and more “thick”.

I have tried **massage therapy**, cranial sacral, healing touch and deep tissue. None worked — in fact too much rubbing left the leg and knee worse.

- ✓ I have tried **light lasers**—no lasting result.
- ✓ I have tried **acupuncture** in that leg—no results.
- ✓ I have seen **homeopathic doctors** and taken recommended supplements — no result.
- ✓ I have been **over weight** and I am now **slim** and neither have had an effect.
- ✓ I have gone thru 3 **pregnancies** which have seemed to alter/accelerate the condition. Ironically, being on my menstrual cycle is always more painful.

To describe the pain, it is like being electrocuted!

Without notice it ZAPS quickly and then repeats 2-3 zaps per minute—at its worst! Mostly happens at night or prolonged periods of **non-movement**.

The basic strategy I use at age 46 is to keep moving!

I do **yoga** everyday for 90 minutes in a heated room. A **HOT** bath at night helps to relax the condition and some pain pills or sleeping pills have finally helped me to sleep for at least 5-6 straight hours. (Sleep still evolves turning 2-3 times an hour)

I am so grateful to have found the Melorheostosis Association! The connection with members and the incredible panel of doctors has brought out a confidence in me that I did not realize I was suppressing!

Peace, Understanding, & Light (LUV)

Joanne Chapman

## 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 send donations to  
Melorheostosis Association  
410 East 50th Street  
New York, NY 10022  
Or donate via the web [www.melorheostosis.org](http://www.melorheostosis.org)

## Visit us on the web!

[www.melorheostosis.org](http://www.melorheostosis.org)  
[www.facebook.com/pages/Melorheostosis-Association/21343158576](https://www.facebook.com/pages/Melorheostosis-Association/21343158576)

## 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.

2013

### Melorheostosis Association Officer and Directors

<u>Name</u>	<u>Title</u>	<u>Address</u>	<u>Email</u>
Jennifer Gordy	President	Parker, Colorado	<a href="mailto:gordyjm@yahoo.com">gordyjm@yahoo.com</a>
Kathleen Harper	Chairman	New York, New York	<a href="mailto:kathleen@harpervision.com">kathleen@harpervision.com</a>
Lydia Zepeda	Treasurer	Madison, Wisconsin	<a href="mailto:lzepeda@wisc.edu">lzepeda@wisc.edu</a>
Amanda Shapiro	Secretary	Reisterstown, Maryland	<a href="mailto:amandaherling@yahoo.com">amandaherling@yahoo.com</a>
Joanne Chapman	Director	Dallas, Texas	<a href="mailto:joanne@chapmanrealty.com">joanne@chapmanrealty.com</a>



"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 usual law of nature, by careful investigation of cases of rarer forms of disease." William Harvey 1692