



January 2018

President's Message

By: Jen Gordy



Melo Community!!

I am THRILLED to announce we have finalized the dates for our 2018 conference; Friday, October 12 - Sunday, October 14. It is always a pleasure for me to announce this but this year I also get to announce an exciting new venue. This year we will be at the Rochester Marriott Mayo Clinic Area in Rochester, MN USA.

For those who haven't been to a conference before it is such a special experience. There really is nothing like being able to talk with someone who is going through the same thing you are and understands what you are going through. I encourage everyone to register today! We have some great new speakers and information to share this year. It is truly going to be one of the best. Read on to find out more.

ONWARD!!

Jen

***SAVE THE DATE & SIGN
UP NOW!***

**2018 Melorheostosis Conference
October 12 - 14, 2018
Mayo Clinic, Rochester, MN**

We are very excited to announce the dates for the 11th International

Melorheostosis Conference. We will be welcoming both new and returning patients and we can't wait to see you there!



We don't want anyone to miss this opportunity to learn more about the disease as well as meet others that have Melorheostosis and the incredible doctors working on our behalf! The Conference and hotel accommodations will be at the Rochester Marriott Mayo Clinic Area in Rochester, MN USA. Your hotel rooms will be paid for by the Melorheostosis Association thanks to the generous work of Stephanie Papke and her family and friends! A HUGE thanks to them and the awesome work they do. There will also be limited scholarships for travel expenses for those with special needs to attend.

All you need to do to sign up is fill out and send in the registration form and mail in a check for the deposit, which will be returned to you when you check in at the conference.

[Click here to register today!](#)

If you have questions about the conference or scholarships, contact Jen Gordy at gordyjm282@gmail.com.

***UPDATE: Long-Term
Study of Melorheostosis at
the
National Institutes of
Health***

The team at NIH continues to be actively researching Melorheostosis along multiple lines of inquiry. Our clinical study has enrolled 30 patients, of which 15 have had bone biopsies and 8 have had skin biopsies. We continue to see new patients and follow ups. Two patients have actually returned to have surgery on their Melorheostosis with improvement.



For 2018, we hope to be able to release some of our findings. When we first proposed working on Melorheostosis we were told it was a "tough nut to crack." That has proved more than true. We are very grateful for the support of the Association we have received over the years.

Dr. Timothy Bhattacharyya,
Head, Orthopedics Research
Clinical Trials and Outcomes Branch

Note: For information on the NIH Long-Term Study of Melorheostosis and how to apply, see the homepage of our website, melorheostosis.org.

My Journey with Melo

By: Danyel Degenhardt

My story begins 21 years ago in the prairies of Canada. I was 10 years old and my pointer finger on my right hand was becoming noticeably crooked. There was no pain, just a funny looking finger. Specialists didn't know what it was or what to do with it.



When I was 13 and now living on the east coast of Canada a new round of doctors and specialists were baffled, yet positive that a contracture release would be beneficial. On X-ray my finger did not have the dripping wax look yet, it just appeared "fully grown". I was getting into basketball, and while recovering from the surgery I was getting real good at using my left hand. Even though I'm right handed, I'm much better with my left. It's a bit of a secret weapon, even when I play basketball today. I can cross someone over and take the ball in with ease. The surgery to release the contracture was unsuccessful and left quite a bit of

scar tissue. I also had some aches and pains and started to feel tightness in the hand, but nothing I considered serious.

When the growth spurts started and I grew from 5'6" to 6'2" the crooked finger started to get a bit more noticeable. The rest of my hand and wrist also became tight and limited into extension. Numbness and tingling began in my middle finger, spread to my ring finger, and parts of my thumb, pinky, and pointer fingers. It was starting to become difficult to maintain a grasp on objects, and pain and intense tingling would set in shortly after activities like biking or typing.

I started my Bachelor of Science in Human Kinetics at St. FX because my best friend in high school said "You like sports, why don't you go into Human Kinetics." He was right, I did like sports. I thought Human Kinetics had to be good for figuring out what was going on with my hand too. Over the next four years I asked every professor and classmate I could about my hand with no clear answers.

When I graduated I started a two year stint as a Sports and Fitness Instructor for the Canadian Forces. Man, was I ever fit with all the fitness classes and workouts. I was even biking 10-15 km a day, with the usual shaking of the hand about every 100m to decrease the tingling that would occur. I just developed habits to manage the symptoms and continued to learn more about how the body works. I was frustrated at times that I wasn't able to fully recover from my condition, and looking back I think that's what I felt about my job as well. I couldn't create the positive effects I knew were possible in my clients and get them to peak performance.

So I decided to learn some more and got accepted into the Master's of Physiotherapy Program at Dalhousie University. Surely one of these professors would have an idea of what's going on with my hand. I was certain that I would find all the answers to the questions I had. I would get rid of the frustrating tingling, numbness, aches and pains. Unfortunately, one by one the professors apologized because they had no clue what I had. Conditions like camptodactyly, dupuytren's, juvenile arthritis, and even cerebral palsy were thrown out there.

Another few specialists later, EMG nerve conduction tests showed I had moderate to severe carpal tunnel symptoms at the age of 25. After a 5 minute assessment a rude specialist said "I don't know what you have but I'll do a carpal tunnel release". I thought to myself, 'Yeah ok buddy. I'm not convinced you have my best interests in mind. I'll pass.'

I graduated from physiotherapy school with a lot of knowledge, but nothing that helped my hand. However, Dalhousie University gave me an even better gift. I met my classmate Ashley, who became my fiancé the day before we graduated. We started off our physiotherapy careers on the other side of Canada in a new province. It was difficult to manage the manual therapy aspect of my job at times. I was starting to feel like I would never find a way to improve. Yet, I continued to go to occupational therapists, physical therapists, chiropractors, massage therapists, and reiki therapists. Basically anyone that said "Sure, I may be able to help." Finally at the age of 28 a young, new specialist gave me the diagnosis of Melorheostosis. It was actually the x-ray technician and the specialist said "I'm not sure, but we can both look into this and see if it fits." At this stage EMG studies showed my carpal tunnel symptoms had progressed to severe.

That's when I found the Melorheostosis Association. I read most of the information on the site and joined the Facebook Support Group. I finally had a diagnosis! I posted my story in the group and asked if I should get the carpal tunnel release surgery. I was directed to one of the amazing Doctors on the medical panel and he suggested it was a safe surgery that could help. The surgery was a moderate success with improved sensation, less tingling and not as much sharp pain with activity.

I moved to New Zealand with my wife, and tried my hand working at a private practice with a heavy manual therapy focus. It wasn't for me. My symptoms had improved from the surgery, but not enough to handle that much force. I shifted to a hospital position with a focus on using exercise and education to help my patients. With the knowledge I have gained over the years, and my growing passion for pain education I started the Rethink Pain Workshop.

In the Rethink Pain Workshop I teach what pain is and a tool that I developed to better manage it. Before starting the workshop I made a conscious decision to see the Melorheostosis in my hand as a gift. Without the undiagnosed Melorheostosis I would not have had the drive to find out more about the human body and go to school for Human Kinetics and Physiotherapy. I would not have met my amazing and supportive wife, and we would not have moved across the world to New Zealand. I would not have the opportunity to pass on valuable pain education to my patients, friends and family on a daily basis. If I can overcome a rare condition that a primary symptom is pain, and do it with grace, hopefully I can inspire others to do the same.

An interesting thing happened after I made this decision to see Melo as a gift. My hand started to feel better. I still have the symptoms, but they don't bother or stress me out as much. For

the first time in my life I feel confident that I'll be ready for whatever the future has in store. I don't have all the answers. What I do have is hope. With 7.6 billion people living on earth there will always be another treatment or therapy that someone has used or developed that can help me. In a recent activity from a book called "The Upside of Stress" I found out the two values that drive my life are personal growth and happiness. All I need to do is keep growing as a person and have a great time doing it! There is also a potential 7,600 people in this world that have Melo. Even more promising is the recent Mayo Clinic study on Melo reporting that 14% of us don't even feel pain! That means at least 1064 people who have bones as hard as a diamond, are living their life in comfort.

So what's next? I've already told you what I plan on doing. How can you take my story and start making positive changes in your life? I want our community not only supporting each other in desperate times, but celebrating the parts of our life that make our hearts sing. Whether it's just a visit with an old friend that makes you feel happy, or achieving that goal you've been working towards. Let us know! I believe if we work together there can be more of us joining that 14% who have Melo and don't feel pain.

Read these 7 points everyday for the next 30 days, and see how your life changes

1. It's your attitude at the beginning of a task more than anything else that will determine your success or failure.
2. It is your attitude towards life which will determine life's attitude towards you – Life plays no favourites.
3. You control your attitude. If you are negative it is because you have decided to be negative –not because of other people or circumstances.
4. Treat everybody as the most important person in the world.
5. Develop the attitude that there are more reasons why you should succeed than reasons why you should fail.
6. When you are faced with a problem, adopt the attitude that you can and will control your life.
7. We become what we think about. Control your thoughts and you will control your life.

About the Melorheostosis Association

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!



Share your story!

We have an active community of patients and friends on Facebook. [Click here](#) to request access to the private group. Posts within the group are private and will not be seen by your Facebook friends.

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 for Melorheostosis. Our focus is 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.

**2018
Melorheostosis Association
Officers and Directors**

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