



October 2020

## ***President's Corner & Conference Announcement***

***By: Jen Gordy***

I hope everyone is having a good year in the midst of all the craziness out there and staying safe and healthy (well, as healthy as we can be). If you haven't seen it already, we have decided to postpone the Melo Conference that was going to be later this month in Bethesda. Luckily, we already have the dates for the new conference scheduled! The new conference will still be held in Bethesda, Maryland (near the NIH) at the Marriott Bethesda Suites on Friday, October 15 - Sunday, October 17, 2021.



We are sad we will not be able to see you all this year, but we hope with the extra time, we will be able to see ALL of you in Bethesda next year!! There are so many things happening with research right now, it is extremely exciting!! We can't wait to share it!

Read on for more information about what is going on around the Melo community!

ONWARD!

Jen

## ***Seattle Melo Pub Crawl Fundraiser***

***By Stephanie Papke***

The Seattle Melo peeps had another super fun and successful pub crawl in December 2019! We changed things up a bit and did a silent auction at the first stop instead of a raffle at the last stop, and it was a big success! We had a perfect

location to host the start of the crawl because they had an entire back room for us to set up in and pretty much take over! We had about 40 items from beer baskets to camping chairs to mini fridges! People loved having items to bid on after they checked in and started the drinking festivities!

We hit three more bars in the downtown Renton area where we drank, ate, and played fun games before heading out to the next location! Every place was walkable, very friendly, and accommodating! We even picked up a few tag-a-long crawlers along the way!

We lucked out on the weather considering it was December and had no rain or snow! We all wore our super soft and festive winter Melo T-shirt's and we also had lots of fun outfits again this year because our theme was winter headwear (deely bobbers). Our attendees are so fun and always up for going all out with their outfits! We raised money for a great cause and had an amazing time!

We love hosting these crawls every year and people can't wait to come back because they have so much fun! I don't think we will be able to have a crawl this year so we will make the 2021 crawl twice as good!



Stephanie Papke (left with green hat & Melo patient) & Mykel Papke (to the right with glasses - twin sister & HUGE supporter)





Lynne - 2nd from left in brown shirt & jeans



Lynne - 2nd from left in patterned shirt

## ***Melorheostosis: Patient Article*** *by Lynne Byrne*

Hey, I'm Lynne from Oregon USA. I'm a 63-year-old female with my Melorheostosis in my right tibia (shin bone). In childhood my Melo was never noticeable physically or with any symptoms. Around age 12 I was trying on the zip up style boots and my parents noticed the right boot would not zip up all the way and there was just a small firm bump on my shin. I was a City Champion short stop and basketball point guard. In high school I was on the tennis team and a cheerleader for football and basketball for four years. Pain and mobility never limited my activities. At age 18 the bump was bigger and we had it biopsied with a long vertical incision. Results came back only as "non-cancerous". No other information.

Spent the next 35 years watching it protrude more and becoming more painful. I went to multiple doctors and specialists. No answers. At age 55 I could barely walk. The head of the orthopedic department in Portland did an X-ray and finally

put a name on it. Melorheostosis! He had never seen it before in his career but remembered the telling X-ray "candle wax drip" image from a textbook in medical school. He said he could do two separate incision surgeries (one from front and one from back of knee) and help me. Did not sound right to me.

I then found the Melorheostosis Association online, since I now knew the name of this. Multiple evaluations continued and went to another orthopedic surgeon who said he could do a minor arthroscopy surgery and help me. Ok, yes, schedule it! Unfortunately, the surgery was June 2012, and the first Melorheostosis conference I knew of to attend was October 2012. A few months too late to have prevented my decision to not do that surgery. The conference was invaluable. Three months of three days a week PT followed the arthroscopy surgery and it's worse. A few years ago it began affecting my toe and ankle, just like I learned at a Melo lecture.

I have attended every conference since 2012 and learned so much every time. The friendships I have developed are special, the conferences give me comfort and support, and the Melorheostosis board members, providers, and patients are my family. A very FUN family!

I had decades of a lingering wonder and fear of what it could be, but now I found out what it is. I found patients from around the world who can relate to me and providers who know about it! It was a lonely life. It was desperate. It was painful. Yes, it still is, but I have a weekend every two years to look forward to that brings me hope, comfort, and new knowledge. It's a priority for me, mentally, physically and emotionally. My "unicorn" family reunions have changed my world. Our Facebook group is a daily comfort and wealth of knowledge to me as well. It may not be often we see each other, but when it happens, it's life changing. Every time. With every one of you.

I hope I am fortunate enough to attend the next Melorheostosis Conference in October 2021 and see you then.

Your Melo sister,

Lynne

## ***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. You can also post your Personal History with Melorheostosis on our website, [www.melorheostosis.org](http://www.melorheostosis.org).

### **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](http://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.

### **2020 Melorheostosis Association Officers and Directors**

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