



Melorheostosis
ASSOCIATION

Spring 2021 Newsletter

President's Corner

Hello Melo Community –

And hello 2021!! I think I speak for most when I say I am SO happy to see the last of 2020. I hope everyone is staying healthy and safe out there.

We are still planning on having our conference this October...BUT will be modifying it to be **100% VIRTUAL!!** It will still be on **Friday, October 15th and Saturday, October 16th** with more details about the virtual agenda, registration and fun things to come!! We hope to "see" you there.

Read below to learn more about what's going on in the Melo world and our next patient spotlight. We are thrilled to hopefully see you virtually this October and can't wait to share all the fabulous things happening with Melo research right now!

ONWARD!

Jen



Melorheostosis: Patient Article

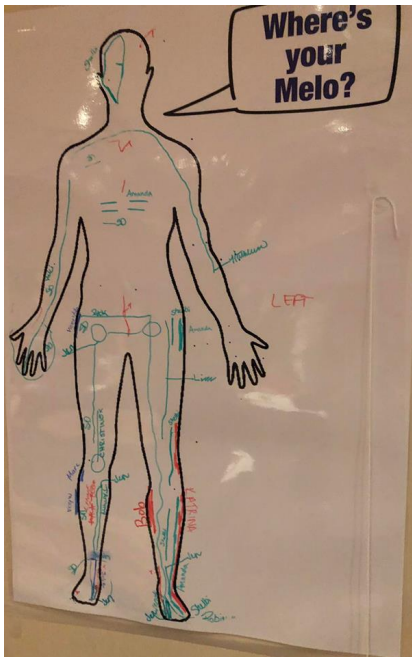
By: Katrina Wells



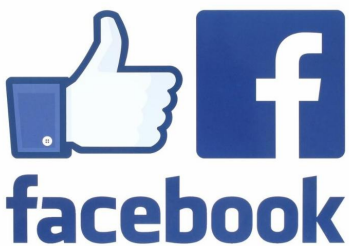
Hi Melo friends! It's Katrina Wells, Melorheostosis Association treasurer & community manager. I joined the family when I was diagnosed as a teenager. I currently have Melo in my left leg from my femur through my ankle. You can learn more about my story below, but I want to share a couple of my favorite Melo moments with you now.



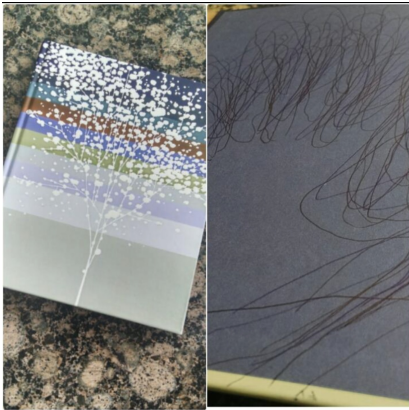
Let's start with the conference! I attended my first conference in Rochester, Minnesota, seven years ago. It was truly a life-changing experience. I had never been in the same room as someone with Melorheostosis before. That first night, I finally met people who understood one of the most painful parts of my life. I didn't need to explain the pain or spell it or sound it out. We could look into each other's eyes and just know. I could take a deep breath and know life was going to be ok. It was overwhelming to say the least. These moments continue to give me chills with each conference or meet-up I attend. We're hoping to get back to our conference plans here in 2021 - if you're on the fence or have questions about attending, I'd love to chat with you.



Next, let me take you back to the early 2000s. Imagine waiting for your dial-up internet to connect on your Compaq desktop. That was teenage me after being diagnosed with Melorheostosis in my early teens. I have vivid memories of the surreal moments from diagnosis to the car ride home to finding such a small community of others online. Those were the days of discussion boards and online personal histories where you could wait months for someone else to login and see your post. Fast forward to today, and we have an amazing private support group on Facebook for all patients, family, & friends to share their experiences - from the newly diagnosed to the seasoned Melo warriors. It makes me smile every day when I see patients and family connecting in the group to support and stand beside each other. If you aren't a member, hop over to Facebook & join [Melorheostosis Patients & Friends](#).



Finally, I'd be remiss if I didn't mention all of those who are bravely participating in the



NIH study to help identify a cause and potential treatment for Melo. One of my favorite parts of the study has nothing to do with science - it's our Melo Study Journal. Stored at the NIH Library to be checked out only by patients participating in the study. It's a way for all of us to connect - either by sharing some advice, or simply adding our hand to the outlines of so many other hands who have joined in participating in the study. Living with a chronic illness can be isolating at times. If you're in the study, grab the journal, get connected with those who came before you and share something with the next person.

All of these Melo moments aren't about the pain, sleepless nights, x-rays, or doctor visits. They're about all of us and the community we create. Someone asked me recently if I'd trade having Melo, and I realized I couldn't if it meant giving up some of the greatest humans I know. The Melo community has been a great source of strength and light in my life and I wouldn't trade that for anything. On those grey days, I encourage you to find a Melo friend to connect with. Keep sharing your stories. It's important that we hear your voice and feel your presence. We're stronger together.

I recently had the opportunity to be featured as a guest on The Patient Project podcast with Dr. Jonathan Lowery from Marian University. As a professor and director of the Bone & Muscle Research Group, he uses this platform to share stories of those living with chronic illnesses. After learning more about Melorheostosis, he's started to incorporate it into his courses and has students reaching out with additional questions about Melorheostosis and my experience. As Dr. Bhattacharyya has said, "collaboration is rocket fuel." This experience is a prime example of that - I'm looking forward to Dr. Lowery's continued support of Melo as he works to learn more about the disease and educate future doctors.

Learn more about my experience with Melorheostosis by listening to the podcast episode here: <https://www.jonlowery.com/the->

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.

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.

2021

Melorheostosis Association
Officers and Directors

Name Title Address Email

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 amandashapiro11@gmail.com

Susan Dunaway Newsletter Graham, WA dunawayrs@comcast.net

Melorheostosis Association | 410 East 50th Street, New York, NY 10022

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