Melorheostosis Association

July 2019

President's Corner

By: Jen Gordy

Hello Melo Family! I hope everyone had a very happy start to 2019, spring season and start to their summer!

We closed out last year with one of the greatest conferences on record. It was amazing the amount of information that was shared!! It is exciting to hear what the NIH has discovered so far and with still so much to learn!! We had old friends, new faces, a dance party and photo booth. Read on to find out more details around the conference. Were already planning for 2020 and we hope to see you there!!

We participated in the Rare Bone Disease Conference immediately preceding the ASBMR conference in Canada, and you can continue reading to find out more information about our part in the conference.

We are thrilled to announce the NIH has released a new article summery the study and their finding so far. You can read a copy of the article here.

As you know, we are an all-volunteer organization and could not have these fabulous conferences without the fundraising that our patients, family and friends do in their spare time. Read on to learn more about how you can get involved in fundraising!!

As always - stay positive and ONWARD!!

Jen

Conference Article

By: Katrina Wells

In October 2018, patients, doctors, and supporters gathered in Rochester, MN for the 11th annual Melorheostosis Conference! We had amazing attendees, speakers and even a DJ and photobooth to top it all off!

Dr. Michael Whyte, Melorheostosis Association Medical Panel Chair, provided patients and doctors with an informative overview of Melorheostosis. We followed it up with major research updates from Drs. Michael Whyte, Geert Mortier, Joan Marini, and Timothy Bhattacharyya. There were moments of electricity in the room as doctors collaborated and connected on patient research. We had a Skype presentation with Kr Kassim Javaid discussing what they are doing in the UK with Melo. Then we had Dr. Patrick Mantyh go through a presentation on bone pain and what drives it to help the participants understand more around that topic.

The afternoon was filled with patient-focused sessions as the doctors in attendance reviewed patient cases. Patients interacted with others through discussion, and learned some movement & stretching techniques. We wrapped up the day with dinner and a DJ dance party & photobooth. Our doctors even got in on the photobooth action!

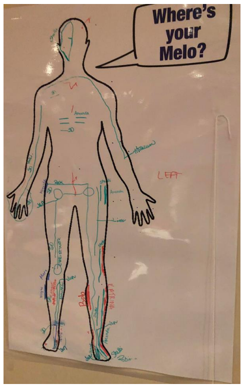
Sunday, we wrapped up with discussions on surgery with Dr. Timothy Bhattacharyya, Dr. Anupam Kotwal gave us an update on the Melo patients who have been to the Mayo Clinic, and an overview of the work Dr. Whyte is doing for young Melo patients at Shriners Hospital in St. Louis, Missouri.

We're deeply grateful to all of the doctors who spent their weekends with us, to all the patients and supporters who joined us with their questions, fears, and hopes. And, to our most faithful sponsors, the Papke sisters and the MeloFund who made it all possible through their continued fundraising and support.

The Board is beginning to plan the 2020 conference. We look forward to sharing more details with you soon and hope to see you there!


Melorheostosis
ASSOCIATION
11th International
Melorheostosis Association Conference
October 13-14, 2018
Rochester, MN USA


BALLROOM 2



ASBMR Conference

by Kathleen Harper

Melorheostosis Association Board members Katrina Wells and Kathleen Harper had the great privilege of representing the Association at a special two-day conference on Rare Skeletal Diseases, Sept 26-27, 2018, in Montreal Canada. The conference featured an inspiring presentation by Dr. Timothy Bhattacharyya about the NIH Long Term Study of Melorheostosis, and the recent, exciting discovery of a gene mutation. Also featured was a presentation by our Medical Panel Chair, Dr. Michael Whyte, on the amazing work he has done for patients suffering with another rare bone disease, hypophosphatasia, and what can be accomplished in finding treatments for rare bone disease patients. We are grateful to Dr. Bhattacharyya and Dr. Whyte for their continued work on behalf of Melorheostosis patients around the world.

The Rare Skeletal Diseases conference immediately precedes the American Society for Bone and Mineral Research (ASBMR) 2018 Conference which brings together representatives from its nearly 4,000 scientists and clinicians from 60 countries. The ASBMR Annual Meeting is a critically important place to be for bone and mineral medical professionals to connect with each other and learn about important developments in the field.

FUNDRAISING

by Amanda Shapiro

Restaurant Nights

One of the easiest ways to raise money is at a restaurant night. Talk to your local restaurants and see if they do fundraisers. Most places will donate a portion (usually 20 to 35%) of their sales to our association. You just choose a night and ask all your family, friends, and community to come eat on a chosen night. I did it at Chick-Fil-A and it was super easy! It turned out to be a fun night and at the end I was able to walk away with a check for $250 that went 100% to the association!

Cocktail Parties

We know asking for money isn't easy! So we created a fun, easy way to do so. Host a cocktail party! We have pre-made invitations, thank you notes and a short video to show. Just invite your friends and family over and be sure to have some snacks and drinks for everyone. You can even make a signature cocktail, maybe the "Melo Martini!" Once everyone is over give a short talk about how Melo has affected you, show the video and hand out the donation envelopes. Contact the Melo Board for help with this.

Bar Crawls

This is one of our largest fundraisers! Founded by Stephanie Papke and the Melofund ladies the bar crawl can raise up to $4,000 in just one day! They have an amazing model already set up and are happy to walk anyone through the steps. Please contact Jen Gordy for more info.

Facebook Birthday Fundraisers

Did you know that on your birthday Facebook will donate $1 to any charity of your choice? They will also create a template for you to post to your wall asking for donations be made in honor of your birthday. This is a quick and easy way to raise money.

Goodsearch.org

Here's an easy and painless fundraiser! Just set your default search engine to goodsearch.org and they will donate a small percent to us each time the site is used. It's self-explanatory once you log onto the site, but feel free to reach out to the Melo Board for any guidance.

Amazon Smile

Do you shop on Amazon? I'm guessing the answer is yes! Next time you buy something instead of going to amazon.com go to amazonsmile.com and choose the Melorheostosis Association as your charity of choice. A portion of everything you buy will go straight to the Melorheostosis Association. This also is an easy website to register with but if you need any help please reach out. Think of how much we can raise during the holidays!

You shop. Amazon gives.

Amazon donates 0.5% of the price of your eligible AmazonSmile purchases to the charitable organization of your choice.

AmazonSmile is the same Amazon you know. Same products, same prices, same service.

Support your charitable organization by starting your shopping at smile.amazon.com

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.

2019
Melorheostosis Association
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