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## *Spring 2022 Newsletter*

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### *President's Corner*

Hello Melo Community –

Wow – where does the time go? I can't believe we are already well into 2022!! I hope everyone enjoyed your holidays and have been starting the new year off with a bang!

This newsletter is packed with great information about our first ever virtual conference last October as well as a year end wrap up from the National Institutes of Health (NIH)! It was sure good to see old friends and welcome new faces at our conference, and I hope we can get together again very soon! We are discussing options for this year so stay tuned for more great info to come!!

I hope everyone is staying healthy and for those with Melo – I hope your pain is manageable. We are here for you if you need us - you are not alone!

ONWARD!

Jen



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## **THE 12th International Melorheostosis Conference**



October 15-16, 2021  
By: Amanda Shapiro

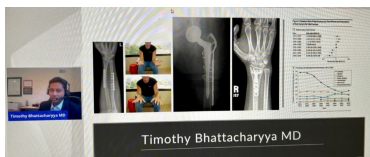
The Melorheostosis Association gratefully acknowledges the speakers who so generously shared their time and expertise with us at the 2021 Melorheostosis Conference.

**A heartfelt thank you to:**

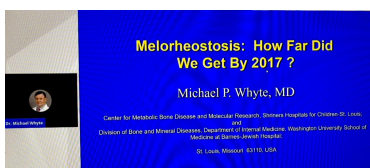
Dr. Timothy Bhattacharyya  
Dr. Leslie Biesecker  
Dr. John Fowlkes  
Dr. Joan Marini  
Dr. Geert Mortier  
Dr. Michael Whyte



Special thanks to Dr. Michael Whyte, Medical Panel Chair, for his expertise and guidance.

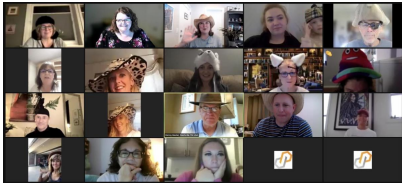
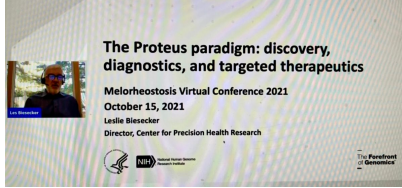


The annual Melorheostosis Conference looked and felt a bit different this year due to COVID but it didn't disappoint! After much contemplation, the board decided to cancel our in person conference that would have been held in Bethesda, Maryland, and create an online conference. I know most of us had dealt with many online experiences this year from online school to online birthday parties. We were extremely excited to find Momentum Event Company that helped us create an efficient and entertaining way to present to everyone all the newest information this year at the conference.



Our first day opened on Friday with amazing and informative medical presentations. Some of the exciting updates announced this year were, the TWO genes discovered from the bone samples that the NIH has collected. We also heard from Dr. Fowlkes who has created our first animal (mouse) model to study our disease! We ended Friday night with a happy hour to start some introductions and introduce our board to everyone we haven't met before. We met so many new faces this year and can't wait to meet in person at our next conference. Of course it is always a pleasure to see our old friends and faces that we haven't seen in awhile.

Saturday continued on as a wonderful day of learning new information about Melo and getting to know each other. There was a Medical Panel Q+A and some breakout sessions. We also had each



patient fill out a questionnaire and spent some time going over the results. We were surprised but excited to hear the doctors were very interested in our answers and it helped them in their own research. As patients and supporters we spent some time deep diving into the questions and talking about our personal experiences. This is always a special and meaningful session for me. We ended the long day with a fun social activity called Crazy Hat Trivia! It was great to unwind and laugh with everyone after the exciting few days. We even got to see a few kids on the screen helping with the Melo trivia! ( My son Lincoln included )

A number of wonderful presentations were recorded and are posted on our website [melorheostosis.org](https://melorheostosis.org) if you would like to view them.



## Melorheostosis Association Scientific & Medical Advisory Panel Update

We are excited to announce **Dr. John Fowlkes, MD** has joined the **Melorheostosis Association Scientific and Medical Advisory Panel**. Dr. Fowlkes is Professor of Pediatrics, Medicine and Pharmacology, and Nutritional Sciences as well as Director of the Barnstable Brown Diabetes Center at the University of Kentucky.

Dr. Fowlkes is author of **Constitutive activation of MEK1 in osteoprogenitors increases strength of bone despite impairing mineralization** and he presented important information about his research at the **2021 Melorheostosis Conference**. Welcome, Dr. Fowlkes!

## Melorheostosis Patient Article

By: Alma Milijovic

## This is my Melo Story -



Ever since I could remember, I had pains and aches in my left leg. My parents used to tell me it was just growing pains. They never thought much of it until my left foot started to swell a little bit. Needless to say, we went to many doctors and hospitals before I got diagnosed with Melorheostosis in Croatia when I was 13 years old. After many X-rays, I was told I had a very rare bone condition and it was affecting my left foot and femur.

The years went by and I was okay. However, when I was 24, I got pregnant and that is when my pain increased along with the deformity in my foot. I am not sure if the pregnancy itself was what caused this. At that time my husband and I immigrated from Bosnia. Again, I had to search for a doctor who could help me. I was fortunate enough to find Dr. Myerson at Mercy Hospital in Baltimore. After giving birth to my daughter, my foot was very swollen, painful, and deformed. I could hardly walk on it. Dr. Myerson performed a triple arthrodesis surgery in 1998. After that surgery I was fine for about five (5) years until the Melo in my foot progressed rapidly. I had six (6) surgeries to remove extra bones from the left foot. I am so happy with the outcome. The bones did not grow back from the areas they were removed. I can walk without limping and there is almost no pain in my foot.



Now my Melo is spreading to my knee, fibula, and hip. I do have Melo on my femur as well, but that is not giving me any trouble for the time being. Anti Inflammatory medicine helps with the pain, and applying heat also helps. I learned to live with Melorheostosis, and I will not let this ugly disease control my life. It is not easy as you all know, but I keep active all the time because the stiffness is worse than the pain itself. I participated in the Melo research study at NIH, and although the doctors do not recommend surgery, I personally believe surgery changed my life. Without the surgeries, I would most likely be in a wheelchair by now.





To all my Melo friends, I would recommend seriously thinking about operating on your affected areas. This may change your life for the better, as it did mine.

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## **Wonderful News!**

### **NIH Long-term Study of Melorheostosis Renewed for Three (3) More Years**

We are happy to share with you the 2021 year-end summary from NIH, including the exciting news of the renewal of the study for three (3) more years.

We are beyond grateful to the many talented and brilliant people who are contributing to the quest for the cause, treatment, and cure for Melorheostosis. Here are photos of Dr. Timothy Bhattacharyya and Dr. Joan Marini so we can all remember what true heroes look like!



### **Melorheostosis 2021 Year-End Summary**

**Timothy Bhattacharyya MD**

Despite difficulties with COVID19, I'm happy to report we continue to make progress towards our research goals. We have resumed seeing patients here in Bethesda, which has rejuvenated the research team. The two surgeries we performed this year helped both the patients and provided valuable samples for basic science research.

In 2021 we had to say goodbye to Amelia Hurley-Novotny after two (2) years in the lab. Our loss is the U of Iowa medical school's gain. We welcomed a new postdoctoral researcher Jyoti Maity who will focus on creating a model of Melorheostosis. When we have a model that replicates Melorheostosis, the next step will be searching for compounds that could modify the disease, but that is a long way (and many gray hairs) away. Nancy Spencer RN continues to provide frontline services for the clinical protocol.

At NIH, each research program is subjected to a rigorous review every three (3) years. The goal of this triennial raking-over-the-coals is to ensure taxpayer money is being well spent. The Melo team was privileged to experience this process last summer, and we were indeed renewed with a little additional support. So you can expect three (3) more years of letters from Bethesda.



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## ***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 are most welcome and greatly appreciated!

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.

## Melorheostosis Association Officers and Directors

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