

The President's Corner



Hello everyone! My name is Jen Gordy and I am the new President of the Melorheostosis Association. I have been on the Board of Directors since 2006 and am so excited to have been elected by the Board at our in-person Board meeting in Denver, CO back in May. In my time as President I hope to focus on the patients and continue to move the organization forward with the fabulous work that has been done by past presidents. We are working toward raising enough money to continue the research work that is currently being done and need your help! As always we need your assistance with fund raising and bone and tissue samples from patients who are having surgery. So please contact us if you can offer any assistance. We also have another conference coming up next year so read on to learn more about the exciting work that is being done by the association.

I would like to welcome Amanda Shapiro to the board as our new secretary. We were first introduced to Amanda when she contacted us from her honeymoon. We also had the pleasure of meeting Amanda and her family in person at the last conference in Washington DC (only a month after giving birth to her first child). She is eager and excited to help and we are extremely lucky to have her as part of the association. You can learn more about Amanda in our new featured patient section of the newsletter below. Please join me in giving her a heart filled welcome to the association! Have you ever wanted to get involved but didn't know how? There is so much you can do on many levels of time and commitment. From being a member on a committee to fund raising and becoming a board member. To learn more about how you can assist the association, feel free to contact myself or any other member of the board.

I am really looking forward to my time as President. Together we can find the cause, treatment and cure for Melorheostosis.

Onward!
Jen

Melorheostosis Association Research Grant

Thanks to generous donations from melorheostosis patients and their families and friends, 2009 marked the funding of our first Melorheostosis Association Research Grant.

Because of your donations, we are currently supporting the important work being done by Dr. Jan Hellemans of Ghent University. Utilizing the latest technologies in genomic sequencing, Dr. Hellemans is sequencing the genes in melorheostosis samples working toward identifying the genetic defect responsible for this disease. We wish him, and his colleagues, God speed in his work on behalf of melorheostosis patients everywhere. Dr. Hellemans will be report on his work in 2010.

We are deeply grateful to everyone who donated to make this research possible. We hope you, and all melorheostosis patients and those who care about them, will continue to support the Melorheostosis Association in its mission to find the cause, treatments and a cure. See page 5 in this newsletter, or our website homepage www.melorheostosis.org, for information on how you can make a difference.

PLANNING SURGERY?

Please remember that tissue samples are critically important to our melorheostosis researchers. If you are considering surgery, please let us know right away. There is no cost to you and you will be making an invaluable contribution to melorheostosis research.

Association Mission...

The Melorheostosis Association is a not-for-profit organization dedicated to finding the cause, treatments and cure of melorheostosis. Our focus will be 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.

Mayo Clinic and Melorheostosis Association Medical Panel Members Available to See Melorheostosis Patients



Among the many challenges facing every melorheostosis patient, or parent of a melorheostosis patient, is finding a doctor to consult. The disease is so rare, it is not uncommon to hear from patients that they have spoken to a doctor who has never even heard of the disease.

It is with great pleasure, therefore, that we announce that the Mayo Clinic, located in Rochester, MN, has agreed to become more involved in the care of patients with melorheostosis and is available for consultation. In addition, several members of our Medical Advisory Panel have authorized the listing of their names and contact information as available to see melorheostosis patients.

The Association owes a debt of gratitude to the following individuals for making this initiative a reality. We are extremely grateful to all for their care and dedication and for sharing their expertise in working toward a better understanding of melorheostosis and better care for melorheostosis patients.

Dr. Daniel J. Berry, Chairman of the Department of Orthopedics, The Mayo Clinic
Dr. Bart L. Clarke, Endocrinology Department, Osteoporosis – Calcium Disorders Service Group, The Mayo Clinic
Dr. John C. Morris, Chairman, Endocrinology Department, The Mayo Clinic
Dr. Frederick S. Kaplan, Chair, Melorheostosis Association Scientific Medical Advisory Panel
Dr. Jeffrey C. King, Melorheostosis Association Scientific Medical Advisory Panel

Mayo Clinic

For more information about the Mayo Clinic, please see: www.mayoclinic.org/rochester.

To make an appointment, please call: 507 266-5800.

To have your referring physician make an appointment, which may expedite the process, please call: 1 800 533-1564.

To contact a member of the Melorheostosis Association Medical Panel for consultation, please contact:

Dr. Jeffrey C. King Specialty: Orthopaedics, Hand
601 John Street, Suite M-230
Kalamazoo, MI 49007
Contact for appointments: (269) 349-8601

Dr. Andrew J. Weiland Specialty: Orthopaedics
525 East 71st Street
New York, NY 10021
Contact for appointments: Olga (212) 606-1575

Dr. Michael P. Whyte Specialty: Metabolic Bone Disease
2001 South Lindbergh Blvd.
St. Louis, MO 63131
Contact for appointments: Tami Bowler, RN (314) 872-8306

Questions? Please contact Kathleen Harper, Kathleen@harpervision.com

Important note to patients: All of the above information is offered as a resource for patients seeking care. It is, of course, the responsibility of patients and parents of patients to verify whether a particular provider meets their needs. Only by asking questions and seeking information can you determine if a particular place is a good fit for you.

2010 Conference Planning Underway

Planning for the 2010 Melorheostosis Association Conference is well underway. Dates for the conference have not been finalized, but we are aiming for July or August. The location of choice is Rochester, MN at the Mayo Clinic.

Agenda topics include: 1) an update on the current research that is being done, 2) hot topics for patients such as pain management and 3) a patient clinic where physicians can see the different ways Melorheostosis presents. If there are topics you would like addressed, please make a suggestion. Suggestions from the melo community, along with your thoughts and ideas are always welcome. Please email suggestions to gordyjm@yahoo.com. As details are finalized, they will be shared.



2008 Conference Attendees

For those of you who have never been to a conference, they are a wonderful opportunity to meet other patients, meet doctors on our medical panel, to share stories and successes, and to broaden our wonderful melo community! For me personally, the past conferences have been a great way to meet new friends who share in dealing with this difficult disease. It is a great way to learn that you are not alone. Financial assistance may be available for those who cannot afford to come out on your own. Please let us know if you are interested. We hope to see you there!

A special note about funding conferences: Conferences are funded 100% by the Association. Examples of conference expenses include: Meeting rooms, computer or audio/visual equipment, meal catering, travel reimbursement for medical panel and some patients, and patient transportation to events. We need your help to make this upcoming conference a success. We understand times are tough for everyone right now but every little bit helps. We appreciate donations of all sizes, so please make a donation or encourage your friends and family to donate today.

- Jen Gordy

***Donations
May be mailed to:***

***Lydia Zepeda, Treasurer
Melorheostosis Association
2602 Stevens Street
Madison, WI 53705***

As always, THANK YOU, for your continuing support!!

Feature Article

Each newsletter we would like to publish a personal history featuring a patient's journey with Melorheostosis. We would love for you to be the star of the next newsletter! If you are interested please email your story to Amanda at: amandaherling@yahoo.com and look for your story in the next publication!



My Life With Melo

My name is Amanda and I have had Melorheostosis for about 15 years. I'm affected in my left foot, ankle, leg, hip and lower back. My story starts (from what I remember) when I played lacrosse in high school. I was a big athlete and I was playing for the championship in our game. I sprained my ankle and kept playing in the game even though my ankle was swelling in my shoe. I visited doctor after doctor because once they x-rayed my foot they realized my bones were white and looked like "dripping candle wax." I wasn't officially diagnosed until I was 23, 5 years after my sprain.

After being diagnosed I started to feel some minimal pain and noticed it was harder for me to wear heels when I went out in college and to play sports. I kept visiting a few doctors and of course no one knew

what to tell me except don't wear heels and I always got a few braces and medicines when I went.

Once I started my career in teaching I realized the pain was getting too much to bear. I finally started a radical treatment that was suggested by an oncologist. He had me do zometa treatments by IV once a month. I hated doing this, I was sitting with chemo patients and didn't like sitting for an hour with an IV (I hate needles!) Needless to say I did this for 7 months and they think it gave me reversed effects and made it worse. This was never confirmed but I never saw any benefit.

Currently I am 29 and have a one year old baby boy, Riley. Sometimes during my pregnancy, I felt my Melo up my leg and in my back. I got new x-rays done after he was born. It is definitely progressing and fast. Sometimes it scares me to think about it, but I am finding new ways everyday to handle and cope with it.

I have strayed away from all the doctors and treatments for now. I currently take painkillers at night for extreme pain, and Tylenol daily. I have noticed that heat and putting my foot up helps.

My days of heels are over and I am comfortable with knowing I can't be on my feet for long periods of time. Living with Melo has been a battle for me but I'm willing to fight. I have found a positive side to the condition. I have become involved with the Melorheostosis Association and am very proud to be the new Secretary for the board! My passion now isn't focused on the pain, my passion is to educate, support and work to cure all people living with Melorheostosis.

Fundraising

All of our fundraising money has been raised by a small group of patients and their families. We really need your help! If everyone was able to raise a small amount, it would add up. Email me if you need ideas.

Where do your fundraising dollars go?

Research: We funded our first research grant in 2009. It's just the first step to finding a treatment and cure. We need new funds coming in to be able to continue the progress past the end of this year.

Conferences: We have held five patient conferences. Many of the patients shed tears of happiness upon meeting another Melorheostosis patient for the first time. They finally found others who could relate to their trials. Conference costs include food, speaker fees and the hotels

charge us to use the space. Let me know if you have a connection that could provide a lower cost for any of those items.

Expenses

We have expenses for insurance, non-profit licensing, etc.

Publicity

The association can now be found on Twitter. Just do a search for Melorheostosis. Increasing the name recognition of Melorheostosis helps with fundraising. It gives us credibility and keeps us in their thoughts. One patient's mom periodically tweets that her daughter has the disease. She gives the Melorheostosis website address.

Submitted by Susan Hendricks
Fundraising/Publicity chair
shendricks@hartins.com

2009

Melorheostosis Association Officers & Directors

<u>Name</u>	<u>Title</u>	<u>Email</u>
Jennifer Gordy	President	gordyjm@yahoo.com
Lydia Zepeda	Treasurer	lzepeda@wisc.edu
Kathleen Harper	Chairman	kathleen@harpervision.com
Susan Hendricks	Fundraising/Publicity Chair	shendricks@hartins.com
Amanda Shapiro	Secretary	amandaherling@yahoo.com

“Nature is nowhere accustomed more openly to display her secret mysteries than in cases where she shows traces of her workings apart from the beaten path; nor is there any better way to advance the proper practice of medicine than to give our minds to the discovery of the unusual law of nature, by the careful investigation of cases of rarer forms of disease.”

William Harvey, 1657