Melorheostosis News & Views

Patient Newsletter ⌘ Fall 2012 ⌘

The President's Corner

by Jen Gordy

Hello all –

The 8th International Melorheostosis Association Conference in Rochester, MN on November 1st-3rd is fast approaching and we have some exciting news!! I am bursting at the seams to announce that this year we will be covering the registration fees and hotel rooms (up to 25 rooms). We are going to move to every 2 years for the conference starting next year so now is your chance to take advantage of this fabulous offer – read on to find out how! This is thanks to the generous fundraising efforts of the Melofund so THANK YOU MELOFUND!!

If you have ever thought about scheduling an appointment at the Mayo Clinic—this year's conference would be a perfect opportunity to either come early or stay late to for an appointment. The best way to schedule an appointment is to have your primary doctor refer you to them. I scheduled an appointment before our last conference and found it invaluable. You can learn more about my experiences at the Mayo Clinic in my article in the December 2011 newsletter.

It is with heavy hearts we announce that Susan Hendricks has resigned her position as board director and fundraising chair of the Melorheostosis Association. She will be missed and I would personally like to thank her for her service. She has been an asset to the organization and we are very sad to see her go.

As always, try to stay positive and remember – we are here for you and you are not alone!!

ONWARD! Jen

Melorheostosis Conference

Whether you are a family member or a patient you probably remember when you heard the word "melorheostosis" for the first time. If you were like me, you may have felt an initial feeling of relief and thought, "Now we know what it is! Now the doctors will know what to do for my son!" That feeling of relief didn't last long because the next thing the doctor said was, "It is very rare and we don't know much about it." Wow, was that an understatement! The sum total of what the doctor knew was how to spell the disease, that it affected bones and soft tissue, no one knew what caused it, and that there was no known treatment.

That was twelve years ago, before the Melorheostosis Association, before the conference, before the website and before the National Organization of Rare Diseases even had melorheostosis on its list of rare diseases. No one knew much about the disease and I was told my son was the first case ever seen in the state. I looked for research papers in the library, I searched the web, I looked for experts, and I looked for other patients to talk to. At the time, there were only a few papers published and an "expert" was a doctor who had seen one case before. I contacted several rare disease networks and finally was able to find someone with melo. It was such a joy to hear his voice over the phone, to hear the story of a man in his 60s who had melo all his life; it was then that I knew that we were not alone and that my son was going to be ok.

A few months later, a miracle happened. Kathleen Harper, in her search for other patients, set up the melorheostosis.com website and I happened to be the first person who found it. Since then, thousands of people have found that website: patients, family members, doctors, and researchers. Later Lyn Pickel began the Melorheostosis Association and held the very first conference in her kitchen with three other participants. The conference has grown since then into a unique gathering of patients, family members, physicians, health professionals, and researchers dedicated to finding the cause, treatment, and cure for melo. We all get to hear

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Conference Hotel and Registration Fees Covered!

I am absolutely thrilled to announce that due to the fantastic fundraising efforts of the Melofund (www.melofund.com), the Melorheostosis Association will be covering the registration fees (a $200 value) and hotel rooms (Thursday and Friday nights - a $224 value) for up to 25 hotel rooms. This means to come to this year's conference, you only have to find a way there! Your meals at the conference and sleeping rooms will be covered.

Here's how it works:

To reserve your spot, send in the registration form along with a deposit check made out to the Melorheostosis Association in the amount of $150 per person. We will hold this check and give this check back to you when you arrive at the registration desk at the conference. If you do not attend without cancelling by October 5th, we will cash the check.

Once we receive your check, we will make your hotel reservation in your name paid for by the Melorheostosis Association. You will be required to present a credit card for incidentals when you check in to the hotel. We will waive your registration fee and your meals at the conference will be covered.

That's it! It is just that easy! We're not sure if we will be able to do this again so we hope you will take advantage of this outstanding offer!!

To find your way there – we are offering scholarships for flights (contact Jen Gordy gordyjm@yahoo.com for a copy of the Scholarship form) or you can always try to get your flight donated through your local church group or http://angelflight.org/.

That's right – you could attend this year's conference at absolutely no cost to you! Space is limited so send in your deposit check today! We are committed to making this year's conference the biggest and best conference to date!! We hope to see you there!

We Need Your Help!

The Melorheostosis Association is an all-volunteer organization; we have no paid employees. Your board volunteers their time to organize an annual conference for patients, physicians and researchers, maintains the most comprehensive and most visited website about melorheostosis, publishes a newsletter, fundraises, seeks and funds research on melorheostosis, cultivates a network of physicians, health professionals and researchers interested in melorheostosis, and answers questions from patients around the world. We also fill out a lot of state and federal paperwork to comply with the regulations to be a 501c3 charity! All of your board members have a full-time job and/or a family, so our work for the Melorheostosis Association is done in our "spare time." We need your help!

We are looking for people interested in helping with the newsletter, website, conference, fundraising, and we are also looking for new board members. If you want to help, have a few hours a month, and have experience writing, putting together a newsletter, web design, fundraising, accounting, or can translate materials for patients in other countries, WE NEED YOU! Please contact one of the board members and let us know how you would like to help!

Melorheostosis Conference 2012

International Melorheostosis Association Conference 2012—Draft Agenda

November 1st – 3rd, 2012

Thursday, November 1, 2012

7:30 pm	Registration
8:00 pm – 10:00 pm	Welcome Reception (light hors d'oeuvres included)

Friday, November 2, 2012

8:00 am – 5:00 pm (Breakfast and Lunch at the conference included)

All day sessions including topics such as:

General Melo Session

Melo Research Update

Future Research Opportunities

Interactive Patient and Patient Supporter Discussions

Living with a Chronic Pain Disease

Feedback and Melorheostosis Association

Patient Case Studies will be in the afternoon for those who wish to participate

6:00 pm – 10:00 pm

Dinner and "Fireside" Chat

Saturday, November 3, 2012

8:00 am - 12:00 pm (Breakfast and Box Lunch at the conference included)

Half day sessions including topics such as:

Patent Case Study Review

Surgery and Melo

Fundraising

Times and topics on this agenda are subject to change at any time

(**Melorheostosis Conference**; continued from Page 1)
about the latest research, surgical techniques, and recommendations for drugs and physical therapy. Patients get to meet other patients. In addition, the patients provide doctors with the unique opportunity to see the largest gathering of melorheostosis patients. Other doctors might see one or two cases in their lifetime; here they can see 20 patients in an afternoon. They learn about all the different ways the disease can present and what patients have learned about things that aggravate and alleviate the symptoms.
We are so delighted that we have found a "home" for the conference at the Mayo Clinic in Rochester, Minnesota. For many years we wandered from city to city. Being at the Mayo Clinic means that we can build closer ties to foster expertise in the disease; a place where patients can be referred to and where researchers and doctors can look for collaboration.

Each year, we see many new faces at the conference; for many it is their first opportunity to meet someone with the disease. We also see old friends who are already part of the melo family. It is always a joy for me to see our dedicated doctors and researchers; we are truly blessed to have such talented, intelligent, and caring individuals! And this year, because of the generosity and hard work of Stephanie, Carlye and Mykel of the Melofund, the costs of the conference are covered for all patients. We hope to see you at the conference this November 1-3!

Melorheostosis Conference 2012

Melorheostosis Association Conference 2012
November 1 – 3, 2012 Doubletree Rochester, MN
Registration Form

Send in your check today to ensure your FREE spot at the conference! Fill out this form and mail it with a refundable deposit check or money order for $150 per person to:

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

Please make checks payable to: **Melorheostosis Association**

Name: ________________________________

Address: ________________________________
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Email: ________________________________

Phone: ________________________________

Do you wish to be included on our quarterly e-newsletter and receive information about future conferences?

______ Yes ______ No

Deposit and Registration Fee*:

All registration fees are waived this year due to the generous donations by the MeloFund! Please send in a deposit of $150 per person that will be returned to you when you check in at the conference. This deposit secures your free registration* and hotel room for Thursday and Friday night. Failure to attend without canceling by October 5, 2012 will mean a forfeit of the pre-paid deposit.

*Registration includes hors d'oeuvre at the welcome reception; i.e. hors d’oeuvres at the welcome reception, two breakfasts, two lunches, a dinner at the conference and meeting rooms

Please list others accompanying you: ____

____ ____

Do you or anyone in your group have special dietary needs, if so, please list here? ____

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________ **I am interested in participating in the Patient Case Studies**

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Please indicate the number of people attending:

_______ Number of Adult Attendees ($150 deposit per adult)

_______ Number of Child Attendees ($150 deposit per child)

Deposit Amount:

$______ TOTAL ENCLOSED

Willing to help?

Feel free to contact us if you are interested in helping out or being a part of our board of directors. Since we are an all volunteer organization, we always need help with planning conferences, fundraising, putting together newsletters, etc. We welcome anyone willing and able to help!

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 Welcome

Please send donations to
Melorheostosis Association
2602 Stevens St.
Madison, WI 53705

Association Mission…

The Melorheostosis Association is a 501 (c)(3) 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.

2012
Melorheostosis Association
Officers & Directors

Name	Title	Address	Email
Jennifer Gordy	**President**	Parker, CO	gordyjm@yahoo.com
Kathleen Harper	**Chairman**	New York, NY	kathleen@harpervision.com
Lydia Zepeda	**Treasurer**	Madison WI	lzepeda@wisc.edu
Amanda Shapiro	**Secretary**	Reisterstown, MD	amandaherling@yahoo.com

cause treatment cure
Melorheostosis
ASSOCIATION

> **"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 then to give our minds to the discovery of the unusual law of nature, by the careful investigation of cases of rarer forms of disease."**
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> **William Harvey, 1657**