

The President's Corner



Welcome to another edition of the Melorheostosis Association newsletter. First of all, I would like to welcome all of the new patients to our little community. It is unfortunate that we need to meet under these circumstances but together we can make a difference in each others lives by providing support and hopefully finding a cure for this rare disease.

I am thrilled about the upcoming conference in August. Read on to find out all the details and how you can sign up. The agenda covers a broad variety of topics and is sure to be of interest to patients and doctors alike. This conference is funded entirely by registration fees and fundraising efforts, a little bit goes a long way so please let us know if you are interested in fundraising and we can help you get started.

Do you have a skill that could potentially assist the association? We are always looking for additional board and committee members. Feel free to contact me if you are interested in helping out!

As always, thank you for being a part of our community. Let us know if there is something specific you would like to hear about in our next issue. Until then...

ONWARD!!

Jen

6th International Melorheostosis Association Conference August 5-7, 2010 Rochester, MN USA

The Melorheostosis Association Board is pleased to announce the 6th International Conference will be held August 5—7th in Rochester, MN near the Mayo Clinic.

The conference will begin with a reception on the evening of the 5th. August 6th will be a full day of patient sessions as well as, for those patients who are interested in participating, patient case studies to give doctors the chance to review many different patient case studies at once. August 7th we will continue with more sessions and patient case studies as well as a tour of the impressive Mayo Clinic for those patients who are interested.

Topics of the sessions will tentatively include:

- Update on melo research
- Surgery and melo
- Managing pain with melo
- Endocrinology discussion

We hope that all our old friends and many new ones are able to attend. Make this a historic event, the largest gathering of melo folks ever! See page 3 for registration and logistic information. Hope to see you there!!!

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.

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 name is Donna, and I am in my 42nd year of my journey with melo. When I was 21, I was standing at the counter of a fast food restaurant when a car crashed through the plate glass window. I vaulted over the counter and injured my left foot. It was several months before I went to a doctor who diagnosed his first case of melo – I remember he seemed very excited about the whole thing!

During my 20's, my foot gradually began pronating, and I walked with a noticeable limp. I was a runner and continued to do that in spite of the increasing pain. Then I was told in my early 30's that, within five years, my foot would have totally collapse inward; that running was the worst thing I could do; and that I should stay off my foot as much as possible. I was devastated at the prospect of giving up my physical activity. Then a wonderful thing happened: I went to a wise doctor! He told me that no one could predict what was going to happen with this disease and that the important thing was to have whatever quality of life I could. I never ran

again but took up walking instead. And that doctor was right – no one *could* predict what would happen because my foot stopped collapsing as it totally fused. Once that occurred, the pain lessened. I still limp, have to wear flats and be careful not to step on uneven surfaces, but it's very manageable.

It was when I had to give up running that I started taking Tae Kwon Do. I loved it, but, because I couldn't kick with my left foot, I always used the right one – which meant, of course, that I was always pivoting on my left hip. And sure enough, it began hurting more and more until I finally went to a doctor and received my second diagnosis of melo. No more martial arts for me! – but I continued to walk and be active and manage the pain with Advil.

In the past couple of years, the pain in my hip became more aggravating and was keeping me awake at night. I found I couldn't walk as far, as fast or as often without paying the price. My x-rays showed increasing arthritis along with the bone disease in the left hip. My orthopedic surgeon's recommendation was a total hip replacement. I was very apprehensive about having this done because I was told years ago never to let anyone cut on this disease because no one knew what it would do. I struggled with the decision for many months and finally had the hip replacement in December.

The surgery took almost twice as long as expected because the affected bone was so hard and dense. My doctor says it was like trying to chisel marble. He had to adjust both his technique and the type of prosthesis he used to avoid shattering the bone. He has shared his findings with Dr. Jeffrey King, who is on the Melorheostosis Medical Panel. The Panel is putting together a data base on the disease and this appears to be the first total joint replacement on a hip with melo.

Melorheostosis Conference 2010

DoubleTree Hotel - Mayo Clinic Area

Rochester, MN USA

Tentative Agenda

Thursday, August 5, 2010

5:00 pm Arrivals and Registration
8:00 pm - 10:00 pm Welcome Reception – *All attendees*

Friday, August 6, 2010

8:00 - 9:00 am Breakfast
9:00 - 10:30 am Update on Melo Research
10:30 - 10:45 am Break
10:45 - 12:00 pm Surgery and Melo
12:00 - 1:00 pm Lunch
1:00 - 3:00 pm Pain Discussion
Ways to Relieve Melo Pain
Clinics: Patient Case Studies
3:30 - 3:45 pm Break
3:45 - 5:00 pm Way to Relieve Melo Pain (con't)
Melorheostosis Association Session
Clinics: Patient Case Studies
6:00 pm Dinner

Saturday, August 7, 2010

8:00 - 9:00 am Breakfast
9:00 - 10:15 am Endocrinology Session
Clinics: Patient Case Studies
10:15 - 10:30 am Break
10:30 - 12:00 pm Patent Activity – Mayo Clinic Tour
Physician Meeting to Discuss Clinics
12:00 - 1:00 pm Box Lunch and Departures

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

2010 Conference Logistics

Local Airports

Rochester Municipal Airport

Distance from hotel: 8 mi. **Drive time:** 20 min.

Directions: Exit onto Hwy 63 north from Airport Drive. Hwy 63 becomes Broadway in town. Hotel is located at the intersection of Broadway and Second St SE

Transportation to and from the Airport:

- **Bus Service** \$11.50 USD
- **Courtesy Bus** None Available
- **Limousine** \$40.00 USD
- **Rental Car** Hertz, Avis, National Car
- **Subway/Rail** None Available
- **Taxi** \$25.00 USD

Minneapolis-St. Paul International Airport

Distance from hotel: 80 mi. **Drive time:** 90 min.

Directions: Drive South from Airport on Hwy 55. This merges with Hwy 52 south about 10 miles south of the MSP Airport Stay on Hwy 52 for 75 miles and take the 2nd Street SW Exit. Follow about 1 mile to Broadway. Left at light. Hotel is on the Right.

Transportation to and from the Airport:

- **Bus Service** \$29.00 USD
- **Courtesy Bus** None Available
- **Limousine** \$100.00 USD
- **Rental Car** Various car rentals
- **Subway/Rail** None Available
- **Taxi** \$150.00 USD

When scheduling your flights, please remember:

- The conference will kick off with a welcome reception at 8:00 pm on Thursday, August 5th
- The conference will end in the afternoon on Saturday, August 7th

Conference Hotel

Doubletree Hotel Rochester - Mayo Clinic Area

150 South Broadway,
Rochester, Minnesota, 55904
United States
Tel: 1-507-281 8000

Reservations may be made by calling the Doubletree Rochester direct at **507-281-8000**, and mentioning the Melorheostosis Association Conference. You will receive a group rate of \$109/night. This room block will be held until **July 15, 2010** please make your reservation by this date as after that, the special rate will not be given.

Check-In: 3:00 PM - Check-Out: 12:00 PM

Parking (rate per day):
Self Parking: \$12.00 USD
Valet Parking: \$15.00 USD

Directions to the Doubletree Rochester:

From 1-90 West: Take Hwy 52 exit to Rochester. Take Hwy 63 North (Broadway) exit into Downtown Rochester. Hotel is located at the intersection of South Broadway and 2nd Street . Right turn on to 2nd St SE. Parking ramp located behind the hotel

From Hwy 52 South: Take the Civic Center Drive Exit. Travel approximately 2 miles to North Broadway. Right turn on Broadway to 2nd St intersection. Take a left turn on 2nd St SE. Parking ramp located behind the hotel.

Meal Information

Your registration fee will include the following food during the conference:

Light appetizers Thursday evening
Breakfast and lunch Friday and Saturday
Dinner on Friday Night

Registration Information

Take advantage of early registration!! Register today to get the special registration rate!!

Early Registration Fee (before July 03, 2010):
\$200 per adult, \$100 per child (ages 5 – 12)

Registration Fee (after July 04, 2010):
\$225 per person, \$125 per child (ages 5 –12)

Children 5 and under are free

To register for this event, please fill out the attached registration form and send it via mail along with a check or money order made out to the "Melorheostosis Association" for the total registration fee to:

Jen Gordy
17389 Nature Walk Trail 9-102
Parker, CO 80134

2010 Conference Registration Form

Name: _____

Address: _____

Email: _____

Phone: _____

Registration Fee:

Early Registration Fee (before July 03, 2010): \$200 per adult, \$100 per child (ages 5 – 12)

Regular Registration Fee (after July 04, 2010): \$225 per person, \$125 per child (ages 5 – 12)

Children 5 and under are free

Please make checks payable to:

Melorheostosis Association

Mail check and registration form to:

**Jen Gordy, President
Melorheostosis Association
17389 Nature Walk Trail 9-102
Parker, Colorado 80134**

Please list others accompanying you:

⌘ ⌘ ⌘ ⌘ ⌘

____ I am interested in participating in the Patient Case Studies

⌘ ⌘ ⌘ ⌘ ⌘

Please specify amounts enclosed:

Registration Fee:

_____ Adult Meeting Attendees

_____ Child Meeting Attendees

_____ Optional Donation to Assist Patients and Families (tax deductible)

\$ _____ TOTAL ENCLOSED

Fundraising



at my local Chick-fil-a restaurant and raised over \$700. It was easy and fun! All I did was send out a mass email to my family and friends asking them to eat at Chick-fil-a on a specific night. The restaurant gave me from 5-8 PM and I received 20% all the sales I brought in. I had a huge turnout and everyone had a great time. I am a new mom so the playroom was great for all the little kids and I asked for the “cow” to make an appearance which was a hit. I handed out information and talked about Melo to get the word out and had a large donation box where people could put extra money in if they wanted. After the event many people asked if I was going to do it again next year since they had so much fun!

An Easy Way to Help.....

As a new member on the Melorheostosis Board, I knew I wanted to host a fundraiser to help with our annual conference this year. In the past I have done a cocktail party and it was a hit! I raised a lot of money and it was easy to do especially because of all the pre-made materials the Board supplied me with! But this year I knew times were hard, so I didn't feel comfortable asking everyone for checks again.

After some research I decided to host a “Spirit Night”

I also learned that many restaurants hold nights like this and some give a larger percentage of the sales. If you are interested ask around your neighborhood to see who participates. And of course if you need any help or advice please contact me, amandaherling@yahoo.com.

I am realizing now more than ever that our association is so small but we are also so passionate. We need fundraising to maintain our conferences as well as our association so what are you waiting for, host your own Spirit Night!

We want to know.....

What doctor or doctors have you seen for your Melorheostosis? We know how hard it is to find a doctor with the knowledge and willingness to work with patients with Melo. After discussing with the board we realized many of us see different types of doctors from General Practice doctors to Oncologists. Share with us what type of doctor you see and we will report the results in an upcoming newsletter!

2010 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