

The President's Corner

There is so much good news to report!



The fundraising efforts of numerous melorheostosis patients, and parents of patients, for over a year resulted in the achievement of our goal of raising \$30,000 to fund the first ever Melorheostosis Association Research Grant. All applications have been received and are currently under consideration by the Review Committee of our Medical Panel. This marks a true milestone for our organization and we are deeply grateful to everyone who worked so hard to make this dream a reality.

Mark your calendars! The Fifth International Melorheostosis Association Conference will be held near Washington D.C., October 21 – 22, 2008. While the conference will include presentations from members of our Medical Panel, it will be very patient-oriented, rather than highly scientific. Please see pages 1 and 3 for details about this unique opportunity to gather together with fellow patients!

The Melorheostosis Association, as a member of the Rare Bone Disease Patient Network, will be participating in the historic *1st Advances in Rare Bone Diseases Conference* at the NIH, October 22-24, 2008.

Melorheostosis patients have a new way to communicate with each other. Jen Gordy has set up a Melorheostosis Facebook page to allow discussion and sharing. Check out Jen's article and give it a try!

Please contact any one of us on the board for information or if you would like to become more involved. Our main focus right now is to raise funds for the 2008 Conference. Our nominal registration fee covers only a fraction of the cost of the conference and the rest comes from donations and grassroots fundraising. We are an all volunteer charity and so every dollar you donate or raise will go directly to the expense of the conference.

5th International Melorheostosis Association Conference October 21-23, 2008 Rockville, MD

The Melorheostosis Association Board is pleased to announce the 5th International Conference will be held October 21-23, 2008 in Rockville, Maryland (just outside Washington DC). In response to patient requests, this conference will be more patient focused. 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!

The conference will begin with a reception on the evening of the 21st. October 22nd will be a full day of workshops and presentations which tentatively include:

- Patient survey results
- Physical therapy to maintain an active lifestyle
- Individual pain management & relaxation techniques
- Latest melorheostosis research
- Discussion with Medical Panel on patient concerns

On October 23rd there will be an outing in DC for patients. The evening of the 23rd we will join the Medical Panel in a fireside chat to follow up on patient concerns and future research. [NOTE: Our conference coincides with the 1st Advances in Rare Bone Diseases Conference. Drs. Kaplan, Mortier, Whyte, Bone, Helms, Glorieux, and Shore are presenting and/or attending the 1st Advances conference.]

See page 3 for registration and logistic information. Hope to see you there!!!

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.

Hey, let's chat...

In an effort to bring our melorheostosis community closer together, we have created a Melo Association Facebook page on the internet. This is a discussion board where we can chat about all things related to Melo and catch up with our Melo friends and family. Pictures can be posted to share and we can use this site learn about upcoming events for you and/or the Association (for instance, a planned surgery or Conferences). Visit the website today: www.facebook.com. Simply create an id and password, and search for Melorheostosis. The search will bring you to the Melorheostosis Association site where you can become a 'fan' of the site. Contact Jen Gordy if you have any questions about setting up your account (gordyjim@yahoo.com). Hope to hear from you soon!!!

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.

In the News...

“Surprise Package” from Bangladesh!

Imagine our surprise when the only known melorheostosis patient in Bangladesh – Sajjad Hossain -- contacted us with the news that he had designed and produced special baseball-style caps featuring the Melorheostosis Association logo! These magnificent caps are Sajjad’s kind gift to the Association to be sold to raise funds and to help the continued development of our sense of community. The caps come in navy, black or brown and one size fits all. If you would like to purchase a cap, please visit our Web-store or contact Jen Gordy, gordyjm@yahoo.com. Because the caps are donated, every penny of the \$ 25. purchase price goes directly to the Association and allows us to continue to serve melorheostosis patients around the world.



WAIT, there’s more -- Sajjad is now producing Melorheostosis Association T-shirts! The T-shirts will feature the Association logo along with the phrase “One in a Million” which, as you may know, is the estimated incidence of melorheostosis. [It also signifies how very special all melorheostosis patients are!] Look for these exciting new T-shirts in the Web-store in the coming months.



Spotlight on ‘Melo’

As many of you know, the Melorheostosis Association is a member of the Rare Bone Disease Patient Network, which is

under the auspices of the US Bone and Joint Decade. The Network brings together rare bone disease patient organizations to pursue common initiatives and offer mutual support. One of the initiatives is to distribute organization materials of network members at important medical conferences. One of these conferences is the annual Orthopaedic Research Society (ORS) meeting, which attracts 3,000 researchers worldwide. At this year’s conference, held in March in San Francisco, several network member groups manned a table with literature about bone diseases. This photo depicts individuals who kindly presented our poster and passed out literature on behalf of our organization. If you look closely, you can see our logo was prominently displayed!

Many Thanks to Donna DeLuca!

Donna DeLuca, who recently retired from the Board of Directors, has made many contributions to the Association over the past 4+ years. Her fundraising ideas, her personal initiatives, her creative ideas for reaching out to patients will be sorely missed by the Board. We were sorry to lose you off the Board, but want to graciously thank you, Donna, for all the contributions you have made over the years. You will be missed!

Melo Web Store: New Items for Sale

Have you visited our web store lately? Come see all the new and exciting products available to purchase all for the benefit of Melo! You can purchase polo t-shirts, bracelets, jewelry (designed by Abby Keough’s Custom

Creations), embroidered hats (designed and provided by our generous and fabulous fellow melo patient, Sajjad Hossain), and soon we will have custom “One in a Million” t-shirts available (by Sajjad)! If you know anyone who produces items that could be sold on our Web Store with some of the proceeds benefiting our organization, please contact Jen Gordy (gordyjm@yahoo.com). Come check it out and buy something today!

Pain Survey Initiative

One very important issue for people living with Melo is pain. In an effort to expand our knowledge of Melo, we will be conducting a pain survey that every Melo patient can participate in. All answers will be kept confidential but the results will help to drive a very important pain discussion between Melo patients and doctors at the upcoming October conference. Dr. Jeffrey King will lead this discussion. We will be sending the survey out via email and encourage everyone to participate. Knowledge is power – hopefully together we can all help each other feel better!

Board Positions Open

There are several open Board positions available for individuals who are interested in helping move this organization forward. Duties include: identifying thrust areas and/or initiatives to facilitate the mission of the organization both in the short-term and long-term; spend 10-12 hours/month working on initiatives; entrust the Association is utilizing its resources properly and ethically within the guidelines of the bylaws and mission; fundraise; and attend monthly telephone meetings and an annual face-to-face board meeting. Please contact Alice, Kathleen or Lydia if you would like to be considered as serving as Director on the Board.

Home Addresses

The Board is building a database of melorheostosis patients, and would like to obtain home addresses in order that we can send information or newsletters out via the U.S. Postal Service. If you would like to share your home address, please send it to Jen Gordy.

2008 Conference Agenda, Logistics & Registration

5th International Melorheostosis Association Conference October 21-23, 2008 Rockville, MD

October 21

7:30pm-10pm Welcome Reception & Icebreaker
Light hors d'oeuvres

October 22

a.m. Dr. Jeffrey King will speak on the results of the Patient Survey and Dr. Ryan Winters will give a presentation on the Benefits of Physical Therapy
p.m. Drs. Geert Mortier and Michael Whyte will discuss current research followed by a roundtable question and answer session led by Dr. Fred Kaplan

October 23

9:30 a.m.-4:00 p.m. Patient activity in Washington, D.C. to be arranged (possibly White House)
6:00 p.m.-9:00 p.m. Dinner at 1st Advances in Rare Bone Disease Conference followed by fireside chat with our Medical Panel

Logistics

Reagan/National DCA is the closest airport.

From DCA can take the metro or a limousine service.

For the metro take the yellow line to Gallery Place and transfer to the red line Shady Grove direction, get off at the Rockville station. It is about an hour and costs \$4.50. At the Rockville Station call the hotel shuttle to pick you up. (301) 424-4940

Dulles Airport, there is no metro, you will need to take a taxi or shuttle service to the hotel. 1-800- Blue-Van or rent a car.

Baltimore Airport BWI – This airport often has the cheapest flights, but is 40 miles away. You need to take a shuttle or rent a car.

Maryland shuttle operates a shuttle service for a fee between all three airports and can take you to the hotel: 1-800-230-0000 You need to call in advance and tell them how many people and what time their flight number and arrival time, as well as give them the hotel address: Rockville Best Western, 1251 W. Montgomery Ave. Phone: (301) 424-4940

Hotel: Rockville Best Western (see above contact information). Mention "melo" for the discounted room rate. There is free parking at the hotel and free wireless internet.

Questions: Contact Alice or Jen, Conference Co-Chairs

Name: _____

Address: _____

Email: _____

Please list others accompanying you:

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Registration Fee:
\$150 Adult Meeting Attendees

Optional Activity:
To be Arranged

Please make checks payable to:
Melorheostosis Association

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Mail check and registration form to:
Ms. Alice Martin, Treasurer
Melorheostosis Association
1754 Briggsville Road
Fowlerville, Michigan

Please specify amounts enclosed:
Registration Fee:
_____ Adult Meeting Attendees
\$ _____ TOTAL ENCLOSED

Feature Article

Living an Active and Healthy Lifestyle with Melorheostosis

By
Dr. Ryan Winters PT, DPT, CSCS
Rocky Mountain Spine and Sport

Many research articles have been published about the incidence, symptoms, radiology, and treatment of melorheostosis. They all seem to have the same conclusions: there isn't enough evidence, more research needs to be done, and here are some options that may or may not work. There have been advancements in the role of the LEMD3 gene and the cause of melorheostosis, but not much has been published about how to live an active life while being burdened by the disease.

The seven top symptoms or complications seen in melorheostosis are:

- Restricted joint mobility
- Skeletal anomalies
- Upper limb asymmetry
- Lower limb asymmetry/hemihypertrophy
- Thick skin
- Haemangioma-capillary
- Amyotrophy/muscle agenesis

This translates into altered joint mechanics and inability to perform every day tasks pain free. Although drugs and surgeries have been shown to have varying effects they should still be considered as treatment options. One thing is still possible—living an active lifestyle. Since the majority of symptoms lie in the altered mechanics, altered bone growth, and altered soft tissue realm, there may be existing physical therapy techniques that might

prove helpful. There is plenty of research on how to treat joint deformities, muscle shortening, and skeletal asymmetries with other diseases. We may be able to extrapolate this research into treating melorheostosis.

Because the disease process is on the genetic level there doesn't seem to be any correlation between exercise, stretching, and activity with increasing the progression of the disease. Joint deformities and skeletal asymmetries can be treated by joint mobilization by a certified professional (i.e. Physical Therapist). Muscle shortening and weakening can be treated by static stretching and strengthening.

These conservative (non-surgical) treatment options allow the affected individual the ability to make changes to their bodies and allow them to live a more pain free lifestyle. A daily stretching routine concentrated to the affected muscles, strengthening through resistance training, and cardiovascular training to maintain an adequate level of fitness are all safe and viable options to improve quality of life in an individual with melorheostosis.

Melorheostosis presents differently in every individual so a professional medical provider should be consulted prior to any exercise program. The utmost importance must be placed on starting slowly and progressing gradually. There need not be any fear of living your life with melorheostosis. One must accept the disease and be an active individual in their own treatment to allow for the greatest chance for success. This is only a start; further research must be done to find the specifics of the disease so that more specific treatment options may be developed.

“Life is a series of obstacles, we may either choose to stop and admit defeat or choose to break through life's obstacles and live free.”

I just can't resist...

A Commentary
By Alice Martin

With all the trouble you and I have had over the years as melo patients finding THE DOCTOR:

- The doctor who cares,
- The doctor who knows something about melo,
- The doctor who wants to know something about melo,
- The doctor who takes the time to listen,
- The doctor who dares give advice in the face of a disease that so little is known about in terms of successful treatments, and
- The doctor who wants you or your child to come back!

After reading the above article, aren't we blessed? Every now and then one of us gets lucky and stumbles upon a doctor like Dr. Ryan Winters! Dr. Winters is the physician of one of our fellow patients. He had never heard of melo. Not only did he take the time—for one patient—to read everything he could find about it, but he decided he would take it upon himself to share with us what he learned. Also, he has agreed to come, speak and meet other melo patients at the upcoming conference. What an inspiration it is when we find a doctor like Dr. Winters. Yes, we are blessed—more than we realize sometimes. Thank you, Dr. Winters. You truly make us feel special!

Fundraising

Fundraising means...

- **Stepping out of your norm**
- **Taking a risk at something new**
- **Reaching out,**
- **Being vulnerable to family and friends**
- **Being humble**
- **Believing in a cause**

Fundraising can be...

- **Heart-warming**
- **Rewarding**
- **Satisfying**
- **All it takes to “make a difference”**

It is amazing how far this organization has come in our fundraising endeavors. In 2003 we started with nothing. In 2004, 2005, 2006 and again this year we have managed to raise the money to plan patient conferences. We raised over \$30,000 to fund our first competitive research project. It has not been easy. Every feeling listed above has been felt by anyone who has sponsored a fundraising event. Of course,

the best feeling is knowing somehow you will make a difference. Little by little, every penny counts towards achieving our goal of someday finding the cause, treatments and cure for melorheostosis.

If you would like to help, we would love to hear from you. We have lots of work and initiatives that require financial support. It mostly takes courage and perseverance to succeed at fundraising—two qualities all melorheostosis patients and family members already possess.

If you would rather support our cause by making a personal donation, those are always welcome as well. Tax-deductible donations may be sent to:

Alice Martin, Treasurer,
1754 Briggsville Road
Fowlerville, MI 48836

You too can make a difference!

***Our Continuing Debt of Gratitude
Need Not Go Without Saying:
Our Scientific-Medical Advisory Panel
Is the Best Ever!***

***Every Melo Patient Holds You
In the Highest of Regards
Thank You
for Everything You Do!!!***

2008 Melorheostosis Association Officers & Directors

<u>Name</u>	<u>Title</u>	<u>Address</u>	<u>Email</u>
Kathleen Harper	President	New York, NY	kathleen@harpervision.com
Lydia Zepeda	Secretary	Madison WI	lzepeda@wisc.edu
Alice J. Martin	Treasurer	Fowlerville, MI	alicejo@msu.edu
Lyn Pickel	Director	St. Louis, MO	lynbpickel@healthcareforkids.org
Jennifer Gordy	Director	Parker, CO	gordyjm@yahoo.com
Michelle Lundie	Director	UK	michelle.lunde@hants.gov.uk



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“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