

The President's Corner

Happy New Year to all!

We are very happy to announce that Susan Hendricks has joined our Board of Directors. Susan will be focusing on fundraising to support the work of the association. Please give Susan all your support as she takes on this important task on behalf of melorheostosis patients everywhere. Welcome, Susan!



2009 is an especially important year for melorheostosis patients. The genetic research, funded in part by the first Melorheostosis Association research grant, is already underway. To insure success of this research, **bone and tissue samples from melorheostosis patients are urgently needed**. If you are planning – or even considering – surgery, please notify us immediately for information.

We are grateful for all the blessings of 2008. The 5th International Melorheostosis Association Conference, October 21 – 22, 2008, was a huge success, as was our participation in the historic *1st Advances in Rare Bone Diseases Conference* at the National Institutes of Health. Greater visibility for our disease and melorheostosis patients came through an extensive article in USA TODAY and a piece on INSIDE EDITION (see website homepage). And, as I mentioned above, the association awarded its first ever research grant. With the help and support of melorheostosis patients and their families and friends, we look forward to continued progress in 2009!

Please contact any one of us on the board for information, or if you would like to become more involved in this wonderful organization. There are opportunities large and small and much to do. If you can, please consider a donation, of any size, to continue our work.

Peace, joy and health to you and your families in 2009.

Onward,
Kathleen Harper

Melorheostosis Research Funded

Dr. Jan Helleman

Ghent University

Awarded \$30,000 to Study

“The identification of the genetic defect in sporadic melorheostosis by means of whole exome sequencing”

The Melorheostosis Association is pleased to fund Dr. Helleman's research. An abstract in layman's terms explains the work Dr. Helleman intends to do:

“The identification of the genetic defect responsible for melorheostosis would give us important insights in the cause of this disorder and in this way allow us to design new therapeutic measures for treatment of this disease. Because of the non-familial occurrence of sporadic melorheostosis, classical genetic approaches have failed to pinpoint the causal defect. In addition, sequencing of candidate genes has not yet revealed any mutations so far. The advent of high-performance, next-generation sequencers makes the sequencing of massive stretches of DNA possible. With this new technology all human genes can now be screened in a short time for the presence of mutations. Apart from the causal mutation, this approach will also reveal a long list of non-relevant variants (so-called polymorphisms) in the human genome. We plan to identify the causal genetic defect by comparing sequences from affected and unaffected tissue by screening a series of melorheostosis patients, and by eliminating the irrelevant variants that can be detected in normal individuals. By using the latest technologies in genomic sequencing, we believe that sequencing of all genes in melorheostosis samples now becomes feasible. This new strategy significantly increases the likelihood of identifying the causal genetic defect responsible for this rare disease.”

In this issue:

- *Plea for Melorheostosis Tissue Samples*
- *First Advances Conference*
- *5th International Melorheostosis Conference*
- *Feature Article: Our Growing Melorheostosis Community*
- *Fundraising Ideas*



Dr. Fred Kaplan, Head of the Melorheostosis Scientific-Medical Advisory Panel enjoying dinner and the keynote address at the First Advances Conference in Washington, D.C. last October.

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.

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

Nine melorheostosis patients, 11 family members, 2 Advisory Panel Members, and 4 scientific medical doctors convened at the opening reception to get acquainted and socialize. There was an opportunity for everyone to sit and introduce themselves, and share experiences.

Wednesday, October 22nd started off with an overview presentation by Dr. Lacey Rao and Dr. Jeff King on melorheostosis and the results of the pain survey. A guest presenter, Dr. Ryan Winters, gave a talk on his study of melorheostosis cases in the medical literature as well as tips on living an active life style with melorheostosis. After the morning sessions, the attendees were transported over to the Hyatt Regency in Bethesda, Maryland to convene with the 1st Advances Conference where Drs. Michael Whyte, Gert Mortier and Yun Zhang discussed the latest advances in melorheostosis research. Led by Dr. Fred Kaplan, an in depth roundtable discussion ensued to answer patient and family questions. After the sessions we attended a dinner at the Hyatt Regency with the attendees of the First Advances conference.

Thursday, October 23rd was a fun day in Washington, D.C. for patients and families alike. Attendees were bused into D.C. to attend a self-guided tour of the White House, lunch at the American Indian History Museum and a guided tour of the Capitol Building. Later, everyone again convened for dinner at 1st Advances conference followed by a “Fireside” chat with the melorheostosis medical panel and patients to determine short and long term goals for researching melorheostosis.



Stephanie Papke,
Griffin O'Neal,
Dr. Lacey Rao, Dr. Jeffrey King



Dr. Gert Mortier
(center)



Alice Martin,
Linda Hembree,
Nancy Dallas

Right: Dr. Deborah Wenkert (left) and , Dr. Michael Whyte (right)



Below: Dr. Roger Smith, Susan Hendrick



Right:
Kathleen Harper;
Sajjad Tuhin

Dr. Ryan Winter, Lindsay Winter, Stephanie Papke, Caryle Sessler



Melorheostosis Association Participates in Historic 1st Advances in Rare Bone Diseases Conference

The Melorheostosis Association has been an active participant in the Rare Bone Disease Patient Network since its inception in 2006 and was one of its founding members. A dream of the Network from the beginning was to bring together leading experts in rare bone disease for an unprecedented exchange of ideas and information. That dream became a reality at the 1st Advances in Rare Bone Diseases Conference, which was held at the National Institutes of Health in Bethesda, MD, October 22-24, 2008. The meeting was jointly organized by the Rare Bone Disease Patient Network and the U.S. Bone and Joint Decade.

Nine melorheostosis patients attended the conference dinners, and heard presentations from conference co-chairs, Drs. Michael J. Econs and Craig B. Langman and others. They also participated in the melorheostosis “Fireside Chat,,” which brought together 30 doctors, researchers and patients who brainstormed together on how to make progress toward finding the cause, treatments and cure for melorheostosis.

The 1st Advances Conference featured two excellent and comprehensive presentations on melorheostosis. The Association offers its sincere gratitude to Dr. Geert Mortier and Dr. Deborah Wenkert for their excellent work in presenting melorheostosis facts, research and analysis at this historic conference. The presentations of Drs. Mortier and Wenkert are available on our website, www.melorheostosis.org, in the section “2008 Conference Papers.”

Melorheostosis Tissue Samples Needed for Research

If you are planning surgery, the bone or tissue sample from your surgery could be the one that leads to answers for melorheostosis patients. Important research is now underway but tissue samples from melorheostosis patients are urgently needed to continue this important work. Because melorheostosis is so rare, tissue samples are equally rare, and they are absolutely essential if research is to be successful. Please notify us immediately if you are even considering surgery.

The donation process is simple and we will be happy to guide you every step of the way. Here are the 5 easy steps:

1. Notify The Melorheostosis Association as soon as you can that you are planning surgery. There will be no expense to you or your doctor.
2. Tell your surgeon as soon as possible you want to donate tissue from your surgery for melorheostosis research. All collection and shipping materials will be provided. Let us know if there are any questions.
3. Notify us as soon as possible of the surgeon's full name, phone number and the address where the collection materials, instructions and patient consent form should be sent.
4. Verify the materials have been received by the surgeon and sign the consent form.
5. Remind the surgeon and staff on the day of surgery that samples are to be sent.

We will be happy to speak with you, or your doctor, and to answer any questions you may have. kathleen@melorheostosis.org.

Our Growing Melorheostosis Family

Have you checked out your own personal “dot”? On the homepage of the website (www.melorheostosis.org) are maps which show a visual representation of the members of our growing “melorheostosis family” around the world. The geographic location of each patient on the maps is positioned as carefully and precisely as possible.

The reason for the precision in placement of the dots reflects the keen awareness that each “dot” represents a living, breathing person who matters deeply to the rest of us and who is coping daily with the effects of melorheostosis. When a patient looks at his/her dot on the map, our hope is that there will be other dots clustered nearby so they will know they are not alone. And further, that they may even be near enough to reach out to another person on the map and meet face to face – possibly to look into their eyes of a fellow patient for the very first time. Possibly to speak with someone for the very first time who truly knows what they are going through because they are living with melorheostosis too.

I have recently finished the first updating of the maps in 2009. Like every posting, it brings its own insights and rewards. In this update, I am happy to add new patients across the US, literally from Maine to California. And I am overwhelmed to “meet” patients from around the world, including our first ever patient in India. Welcome, Rakhi. And welcome, too, Erika from Sweden, and Taewan from Korea, and Suzanne from Australia, and Eva-Marie from Germany, and young Brandon and his mom Tammy from Canada. We also welcome a patient in Denmark who prefers not to post his history but wants us – and the doctors and researchers working on our behalf – to know he is there (indicted by a blue dot on the map).

How blessed are we to live in an age when the wonders of the Internet can bring us all together? How wonderful is it to have each other searching for answers together and rooting for each other’s progress and success. It is a privilege to be part of this wonderful family, and working together we *will* find answers.

-- Kathleen Harper, President

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 (gordjim@yahoo.com). Come check it out and buy something today!

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.

Fundraising

Fundraising – Show your strength!

The Melorheostosis Association needs your help fundraising. Proceeds go toward patient conferences and research to find a treatment and eventually a cure.

Why should you, employers, friends, or family help? There are only about 400 people who have been identified with Melorheostosis, but the research for Melorheostosis could help millions of people with other bone or related diseases.

Because Melorheostosis sometimes isn't visible, others may not know how painful or debilitating a disease it can be. Many patients don't mention it to those around them for fear of alienating them or appearing weak. What better way to show your strength than to help find a treatment and cure?

If we show that we are united in helping ourselves, larger organizations will be more likely to donate or fund our organization

Here are some ideas to help you find what works for your schedule and abilities.

Goodsearch/Goodshop.com

- Earn 1 cent per search by using goodsearch.com as your search engine. This adds up!!!
- By using Goodshop.com, you may purchase from over 700 stores, and at the same time delegate a percentage of your purchases to go to the Melorheostosis Association. [Please use adware and antivirus on your computer as a general precaution.]

Greeting Cards designed by patients or family members

- Cards can be sold on the Melo website, at conferences, or at other events such as cocktail parties

We are looking for a parent or patient to organize this idea!

Legacy Planning

- Patients, families, or friends donate a percentage of their

estate, investments or life insurance policies to the Association. Check with your life insurance agent or attorney for the wording.

Fundraising Ideas Gathered from other Organizations

- **Letter drive** – send letters asking for donations
- **Change the World** – collect your family and friends' coins for a period of time and see how fast it adds up
- **Garage, Bake, or Book sales**
- **Birthday or cocktail party**– ask for donations instead of gifts
- **Walk-a-thon, Bowl, Swim, Skate**
- **Ask for donations** from church or service organization such as Rotary, Lions and Elks clubs
- **Service Work** – perform childcare, housecleaning, etc. for a donation
- **Lead** or get someone to lead a nature walk, an architectural tour, a historic tour, a sailing trip, a rafting trip, or a horseback ride.
- **Wrap presents for donations.** An idea from Autism Speaks suggests asking a local store such as Borders Books to donate the space, gift wrap, and tape
- **Golf Tournament** – charge a fee for golfers and ask businesses to sponsor a hole

Why should you help? There are only about 400 Melorheostosis patients who have been identified in the world. Because Melorheostosis isn't usually visible, people don't know you and others sufferer from it. It is up to us to get the word out. For some Melo patients, it is difficult to talk about it. They don't want to complain. What better way to show your strength than by raising funds for yourself and others for a treatment and eventually a cure?

Why should others help? The research for Melorheostosis could help millions of people affected by other bone and joint diseases. These are tough economic times, but there are still many individuals, service organizations and business which have budgets for helping others.

Call for Fundraising Committee members

Did you know that The Melorheostosis Association has a Fundraising Committee? It is chaired by me, board member, Susan Hendricks. There have been so many good ideas that I'm looking for committee members for help.

You don't necessarily need to actually fundraise although it would certainly be welcomed! Mainly what is needed is help with researching websites or making phone calls to the representatives of different organizations and reporting the results to me. I will give you ideas that anyone has given me and you choose which of them you'd like to help with.

If you don't have time to join the committee, but you have ideas, email me and the committee will check them out. We are looking for all types of ideas—available grants that we can apply for, fundraising ideas that you have seen work in your community, etc.

Susan Hendricks
shendricks@hartins.com

**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
Susan Hendricks	Director	Federal Way, WA	shendricks@hartins.com



1754 Briggsville Road
Fowlerville, MI 48836

(517) 521-4459

“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