Melorheostosis News & Views

Patient Newsletter ⌘ Vol. 2, No. 1 ⌘ March, 2006

www.melorheostosis.org

The Executive Director's Corner


Lyn Pickel

Is it really possible that almost a year has gone by since our last conference in St. Louis? This year seems to have flown by so quickly, and we now find ourselves busily preparing for our 4th International Melorheostosis Conference. This year's Conference is being held at the University of Wisconsin in Madison, June 4-6, 2006. Information about the agenda, all of the exciting activities that are being planned, as well as details regarding lodging can be found in this newsletter as well as on our website.

Thanks to the fantastic efforts of Board Treasurer, Lydia Zepeda, we have been able to reserve a block of rooms at a nearby Best Western at the deeply discounted rate of $62/night for a single and $82 for a double. However, rooms are limited, and we urge you to make reservations **NOW** if you are planning to attend. To make your reservations, simply go to our website, click on the link for information on the conference, located on the homepage, and then follow the posted directions. The deadline for reduced room rate is 5/4/06.

The conference cost will be the same as last year's: $150/individual and $50 for children, ages 18 and under. This covers some—but not nearly all—of the true costs associated with holding such a conference. In not passing along all the costs to you, we are able to make the cost as affordable as possible to most of our members. Nonetheless, we understand that this fee may be out of reach for some of you. If this is the case—and you would like to attend—please contact either myself at lynbpickel@earthlink.net or Board President, Alice Albin at albin@msu.edu for information about the limited number of available scholarships. We want everyone to attend! This conference promises to be our most exciting one yet!

Melorheostosis Brochure Now Available Online

If you haven't already seen the downloadable Melorheostosis brochure on our redesigned website, make sure that you check it out.

Lyn Pickel, Executive Director, said: "Writing of the brochure has been in the works for about a year. Until very recently, though, we felt that we lacked sufficient and reliable information to produce one worthy of wide distribution. Armed with the information presented at the last two conferences as well as the growing body of credible research on melorheostosis, we now have a brochure that we think will not only be helpful to patients and their families, but also informative for treatment professionals and members of the research community."

Board President Alice Albin worked long and hard on the brochure and deserves special recognition for her diligent and creative efforts. If you need to educate someone on Melorheostosis—OR if you think your doctor(s) could benefit from possessing more definitive information on the disease, feel free to download a copy. If you need several copies or do not have the capacity to print, contact Lyn Pickel who can send them to you via snail mail.

For Detailed 2006 Conference Information — See Page 2

Dr. Vicki Rosen of Harvard to Give Lead Presentation at Upcoming Conference

Vicki Rosen, Professor and Chair of the Developmental Biology Department, Harvard, will give the lead presentation at the ***4th International Melorheostosis Conference, scheduled June 4-6, 2006, at the University of Wisconsin—Madison***. Dr. Rosen's topic will focus on the role that the BMP signaling pathways play in musculoskeletal tissues.

Dr. Rosen has a PhD in cell biology/physiology. In her first job as a scientist with Genetics Institute, she helped identify the factors present in bone that are responsible for bone formation. These factors, called bone morphogenetic proteins (BMP), were first recognized by Dr. Marshall Urist in 1965, but had remained a vaguely defined concept. As part of a research team that combined protein biochemistry, molecular cloning and cell biology, Dr. Rosen and her colleagues, in 1988, were able to isolate the first BMP genes and report their activities. This led to Dr. Rosen's interest and subsequent investigation of the physiological roles that BMP's have in the skeleton and the signaling pathways used by the BMP proteins to exert these effects. She continued to work on these questions at Genetics Institute until 2001, when she moved to her present position at Harvard School of Dental Medicine, shifting her lab from an industrial to an academic setting. Of her participation in the upcoming conference, Dr. Rosen said: "I must admit that I knew very little about melorheostosis until I heard from the Melorheostosis Association. I am delighted to attend the upcoming conference and hope that my participation and input is useful to the melorheostosis community."

Other scientific/medical participants who have confirmed their plans to participate in the conference include: Dr. Fred Kaplan, Scientific/Medical panel Chair, University of Pennsylvania; Dr. Pam Robey, National Institute of Health; Dr. Howard Worman, Columbia University; Dr. Geert Mortier, Ghent University Hospital, Belgium; Dr. Michael Whyte; Washington University; Dr. Deborah Wexler, St. Louis University; Dr. Rob Fleming; St. Louis University; Dr. Michael Zasloff; Georgetown University; Dr. Jeffrey King; Michigan State University, and Dr. Laura McCabe, Michigan State.

Tentative Agenda
4th International Melorheotosis Association Conference
June 4-6, 2006
University of Wisconsin—Madison

June 4, 2006

Welcome Reception 7-9:30 p.m.
Location to be Announced

June 5, 2006

8:00– 9:15 a.m.

Concurrent Sessions	
Scientific Medical Panel & Guest Speakers: Get Acquainted Breakfast	**Patients: Dr. Robert Fleming—**"Overview of Medical Terminology, Genetics & Melorheostosis"

9:25- 9:30 a.m.	**Mrs. Lyn Pickel, Dr. Fred Kaplan—Brief Introduction & Welcome**
9:30-10:30 a.m.	**Dr. Vickie Rosen,** "BMP and b-TGF Pathway Mechanism"
10:30-10:45 a.m.	**Break**
10:45-11:30 a.m.	**Dr. Geert Mortier**
11:30-12:15 p.m.	**Dr. Howard Worman,** "Targeting and Discerning Function in MAN1"
12:15-1:30 p.m.	Lunch
1:30-2:15 p.m.	**Dr. Pamela Robey**, "Stem Cell Aspects"
2:15-3:00 p.m.	**Dr. Michael Whyte**
3:00-5:00 p.m.	Free Time for Patients Scientific/Medical Advisory Panel & Guest Speakers will Meet to Discuss Candidate Genes and Most Commonly-Asked Questions
7:00-9:00 p.m.	Dinner, Keynote Speaker: **Dr. Michael Zasloff**

June 6, 2006

8:30-12:00 p.m.

Concurrent Sessions	
Scientific Medical Panel & Guest Speakers: **Patient Clinicals** **New Patients** **To be announced**	**Patients:** **8:30 Dr. Robert Fleming—**"Layman's Overview of Scientific Talks" 9:30 Break 10:00 Patient-relevant talks to be announced 11:00 Patient-relevant talks to be announced

12:00-1:00 p.m.	**Lunch**
1:00– 1:45 p.m.	**Dr. Jeffrey King,** "Surgical Implications"
1:45– 2:30 p.m.	**Dr. Laura McCabe**, "Bone Marrow Issues"
2:30– 3:15 p.m.	**Dr. Frances Glorieux**
3:15– 4:30 p.m.	Free Time for Patients Advisory Panel & Guests: Debriefing Session
4:30– 5:30 p.m.	A Retrospective and the Path Forward: Entire Panel
6:30– 9:30 p.m.	Informal Dinner—to be announced

2006 Conference Planning & News

4th International Melorheostosis Association Conference
June 4-6, 2006
University of Wisconsin—Madison
Conference Host: Lydia Zepeda, Director

Join the Growing Melorheostosis Community

Hotel Accommodations

Best Western Inntower—Madison
Phone: 1-608-233-8778
Fax: 1-608-233-1325
Email: info@inntower.com
Website: http:\\www.inntower.com
Group Rate: "MELO"
$62 Single
$82 Double
DEADLINE for DISCOUNT: 5/4/06

Special Day of Activities for Children and Teens

An all-day trip to
Mt. Olympus Theme and Water Park in the Wisconsin Dells
Monday, June 5
Cost: $27.75 per person in advance or $34.98 + tax at the gate
Spectator Cost (no rides, no water park): $10 + tax at the gate
Bus transportation will be provided.

NOTE: Parents are responsible for arranging their own supervision, but are welcome to coordinate with the two adults who have already agreed to accompany the group. If you think your child(ren) or teens would like to participate in this special activity, you are urged to include advance payment (non-refundable) with your registration fee.

Questions???

If you have questions about any aspect of the conference, please do not hesitate to contact:

Lyn Pickel (lynbpickel@earthlink.net) OR
Alice Albin (albin@msu.edu)

Scholarships Available

Contact:
lynbpickel@earthlink.net
Or
albin@msu.edu

2006 CONFERENCE REGISTRATION FORM

Name: ______________________________________

Address: ___________________________________
____

Email: ___________________________________

Registration Fee:
$150 Adult Meeting Attendees
$50 Non-Meeting Attendees (Meals Only) and Children

Please make checks payable to:
Melorheostosis Association

Mail check and registration form to:
Mrs. Alice Albin
MSU-DOE Plant Research Laboratory
Michigan State University
East Lansing, MI 48824

Please list others accompanying you (include age of children):

____
____
____

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Optional Activity:

June 5 Mt. Olympus Theme and Water Park in the Wisconsin Dells

⌘ ⌘ ⌘ ⌘ ⌘

Please specify amounts enclosed:
Registration Fee:

_______ **Adult Meeting Attendees**

_______ **Non-Meeting Attendees & Children**

Mt. Olympus Theme & Water Park Admission:

_______ **Adult or Children @ $27.75/person**

$_______ TOTAL ENCLOSED

Board News & Initiatives

Redesigned Website


Kathleen Harper

If you haven't had an opportunity to visit our website (www.melorheostosis.org) in a while, you'll be amazed by the changes and additions that have been made. Among others, new features include abstracts and power point presentations made by our Scientific/Medical panel members (under "Conference Papers" on the sidebar), our brochure (formatted in a downloadable form), a document discussing considerations in the surgical management of melorheostosis by panel member, Dr. Jeffrey King, and a "Put Yourself on the Map" showing the location of melorheostosis patients from across the world who have contacted the website. Hats off to Kathleen Harper who has done a phenomenal job of redesigning—as well as founding and maintaining—the website!

Quarterly Board Directors Meeting Held February 24-26 in Chicago, IL

Alice Albin, Lyn Pickel, Kathleen Harper, Donna DeLuca and Lydia Zepeda recently met to address several issues relative to financial growth and long-term viability, and to strategically plan new and/or discuss current patient initiatives for the Melorheostosis Association. Topics discussed included fundraising (past and present); communication/awareness (website updates, children's initiatives, the possibility of formalizing an Association Membership); the logistics of the upcoming conference; scientific and medical research initiatives (100 questions document, tissue repository, and ways to expand and enhance patient support services). Approximately 1 1/2 days were devoted to exploring these topics. Michelle Lundie (U.K.) was not able to attend.

Please know that ***the Board welcomes input and ideas from all patients about what YOU need*** *from this organization. Simply contact any one of the Board members with your idea or suggestion. Contact information is listed on the website.*

Kathleen Harper & Alice Albin Represent the Melorheostosis Association at a Rare Bone Disease Meeting in Washington, D.C.

On April 6, 2006, Board President Alice Albin and Board Member Kathleen Harper traveled to Washington, D.C. to participate in a meeting designed to bring rare bone diseases into the larger "bone community". According to Charlene Waldman, Executive Director of the Paget Foundation, the meeting had three purposes: 1) to introduce the rare bone disease organizations to other organizations within the larger bone community; 2) to provide an opportunity for the rare bone disease groups to meet and network; and 3) to discuss potential bone-related projects for the remaining years of the US Bone and Joint Decade. Speakers at the meeting included: Dr. Joan McGowan, Chief, Musculoskeletal Disease Branch, National Institute of Health; Dr. Stephen Groft, Director, Office of Rare Diseases, NIH; Toby King, Executive Director, US Bone and Joint Decade; Ann Elderkin, Executive Director of the American Society for Bone and Mineral Research; Christy Gilmour, Manager, Medical Research, American Academy of Orthopedic Surgeons; Judith Cranford, Executive Director of the National Osteoporosis Foundation, and Heller An Shapiro, Executive Director of the Osteogenesis Imperfecta Foundation.

Besides the Melorheostosis Association, rare disease groups represented include FOP, IFOPA,POH, Vitamin-D Resistant Rickets, and the Fibrous Dysplasia Foundation.

As a result of this meeting all of the foundations represented are considering forming a coalition under the umbrella of the Bone & Joint Decade. This coalition would foster initiatives to: 1) promote mentoring between foundations in order to further common goals in a timely manner; 2) facilitate future scientific symposia which would address each of these bone diseases and seek government funding for such a meeting; and 3) possibly determine ways to increase the governments allocation of research monies specifically for rare bone diseases. A organizational meeting of the coalition will be held in the future.

An invitation to testify on Capitol Hill in Spring 2007 was made to Alice and Kathleen by the American Academy of Orthopedic Surgeons. More information will follow on this exciting opportunity to increase awareness about melorheostosis. Kathleen and Alice felt that the invitation to testify, coupled with the opportunity to unite and network with other similar rare bone disease groups, is bound to make a difference for melorheostosis patients. This was definitely a historic meeting for all the rare bone disease groups involved.

Brochure Published into the World's Most Commonly-Spoken Languages

With the help of several international students attending the University of Wisconsin, the melorheostosis brochure currently is being translated into the world's most commonly-spoken languages, including modern and traditional Chinese, Spanish, Portuguese, French and German, among others. We are deeply indebted to Ms Jinghan Li, a student working with Lydia Zepeda, who recently translated and reformatted the brochure into the Chinese language. (For those of you fluent in Chinese, check out the brochure on the melorheostosis website!) Her translation has resulted in making the brochure easily understood by approximately 1 billion Chinese readers!


Lydia Zepeda

Scientific/Medical Advisory Panel News

Scientific Community Celebrates Passage of Budget to Support Medical Research


Dr. Laura McCabe

Dr. Laura McCabe, member of our Scientific/Medical Advisory panel and patient advocate for National Institute of Health (NIH), sends along great news concerning the passage of a $7 billion funding measure to support health and education agencies, including medical research programs. Commenting on the bill's passage, Federation of American Societies for Experimental Biology (FASEB) President, Bruce R. Bristain said: "The biomedical research community wants Congress to understand that medical research translates to real treatments and real hope for real people. NIH is a top priority for the American people, and passing this amendment shows that it is a top priority for the budget as well." A reduction in support for NIH would have resulted in fewer scientific opportunities for medical breakthroughs.

If you would like to be kept informed of Congress' activity related to scientific research funding, especially in the area of bone research, contact Lyn Pickel at lynbpickel@earthlink.net She will be happy to forward relevant news items as well as any bulletins urging citizen support for Congressional votes vital to advancing bone and rare disease research.

Most Commonly Asked Questions Project Update

With the help of input provided by members of our growing community, we have submitted a final list containing approximately 100 of the most commonly-asked questions regarding melorheostosis to Dr. Fred Kaplan, Chair of our Scientific/Medical Panel. Dr. Kaplan plans to divide this list, by area of expertise, among members of our Scientific/Medical panel. Our hope is that we will be able to compile all of the questions and the corresponding responses in a book, to be published and available for distribution to our members in the upcoming year.

A Sampling of Most Commonly-Asked Questions

Below are just a few of the questions submitted by members of our community as part of the list of "Most Commonly-Asked Questions".

1. What is melorheostosis?
2. Is it a disease, a condition, and what is the difference?
3. Is melorheostosis present at birth regardless of when it is diagnosed?
4. How does someone get melorheostosis?
5. If someone in the family has melorheostosis, should other members of that family be examined or tested?
6. How will discovering faulty gene(s) impact the treatment and progression of melorheostosis?
7. What causes limb length discrepancy? And, why do some melorheostosis patients have this, and others do not?
8. What is carpal tunnel syndrome, and is it a common complication of melorheostosis of the hands and arms?
9. Can melorheostosis "entrap" nerves in other parts of the body, causing carpal-tunnel like symptoms?
10. How is it possible for a person to have melorheostosis in one part of the body and osteoporosis in another? In such a case, how can you treat the osteoporosis without making the melorheostosis worse?

Live Conference Link with U.K. Research Team Being Explored

The U.K. Melorheostosis Association has funded a research fellow position with Oxford orthopedic doctors Paul Wadsworth and Roger Smith. The U.S. Association is exploring the possibility of establishing a live link to Drs. Wadsworth and Smith during the upcoming conference.

US Bone and Joint Decade

Did you know that the first 10 years of this millennium have been earmarked as the US Bone and Joint Decade? For more than 35 million Americans—that's 1 in 7 people—movement is restricted by a musculoskeletal disorder. As part of the US Bone and Joint Decade initiative, patient and physician healthcare organizations, government agencies, and industry have come together to improve prevention of bone and joint disease and to improve the quality of life for those affected. By 2011, the goal of the Decade is to increase awareness, resources, education, research and treatment of musculoskeletal conditions. For information on activities and to get additional material related to the US Bone and Joint Decade, go to their website: 222.usbdjd.org.

Summarized from the US Bone and Joint Decade website homepage (www.usbdjd.org)

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.

The Fundraising Page

States Where We Are Licensed to Fund Raise

California
Florida
Illinois
Kentucky
Massachusetts
Michigan
Missouri
New York
Oklahoma
Pennsyvania
Washington
Wisconsin

States Which Do NOT Require Special Licensing

Idaho
Indiana
Iowa
Montana
Nebraska
Nevada
South Dakota
Texas
Vermont
Wyoming

Let's do it for the children... PLEASE HELP!

Recent Fundraisers

- Friends of Lyn Pickel, Bill and Angie Purcell, hosted a special evening of cocktails and appetizers in St. Louis on April 1. Dubbed "A Season for Growth", the evening featured a silent auction, and a 50/50 raffle. This event brought in over $9,500!
- Donna DeLuca held a Bingo Fundraiser on April 9. The results are not in on this yet. Donna also is conducting a candle sales fundraiser which a few people from the melo website are also participating in. We are crossing our fingers that these initiatives are successful.
- Funds are still coming in on Alice Albin's holiday letter-writing campaign. Alice has raised nearly $2,000!
- Lyn wrote a conference proposal to Amgen Foundation in the amount of $20,000. This was denied, but she was encouraged to resubmit to Amgen Healthcare Institute/Medical Education. The latter was denied as well.
- Lyn wrote a conference proposal in the amount of $20,000 to Abbott Foundation. This proposal is still pending.
- Lydia Zepeda submitted a conference pre-proposal to the Gates Foundation. Through that process it was determined that Gates would not fund our conferences.

Fundraising Guidelines

The Association has recently compiled a fundraising packet containing ideas and guidelines for raising money. "Any fundraiser—no matter the size—will be acknowledged publicly in our newsletter," said Lyn. "But of course, that is small recognition compared to the great satisfaction one can take in knowing that their fundraising efforts have made a vital contribution to keeping the Melorheostosis Association organization going and growing!"

If you or somebody you know is interested in sponsoring a fundraiser, please contact Lyn at lynbpickel@earthlink.net for the fundraising packet as well as for any additional assistance you may need.

Who Would've Guessed?

The majority of contributions made to the Paget Foundation are in the $20-50 range (mostly $20), according to Paget Executive Director, Charlene Waldman. Pagets' conducts huge letter writing campaigns to previous donors annually to raise research and operational funds.

Wish List

The following items represent things that either the Association could use for patients or in the office. If you can help, we would appreciate it.

1. Registration Fee of $150 to Support the Attendance of another Patient at 4th International Melorheostosis Conference, June 4-6 (a restricted gift)
2. Frequent Flyer Miles for use by either patients to attend the conference or board members or the Executive Director to attend professional or quarterly meetings. (NOTE: To date the Board Members and Executive Director personally pay their own transportation costs due to the limited resources of the Association)
3. 37 Postage stamps
4. Gift certificates (any denomination) to Office Depot or Office Max for office supplies
5. Dell printer cartridges (black and colored for 990 Printer. Black #4640; Color: #4646)

Items may be sent to the Melorheostosis Association Office: 6611 Clayton Rd, Ste. 209, St. Louis, MO 63117. Be sure to include your name and the value of your donation so that we may acknowledge your gift as a tax-deductible charitable contribution.

Maybe You Would Like to Make A Tax-Deductible Cash Donation?

Simply send the Association a check!

Getting to Know You

.Kevin Amelio Collevechio

This is a continuation in a series of articles aimed at introducing members of our growing community to one another.

Tell us a little about yourself: your age, where you live, family, your hobbies, etc.

I am 50 years old and recently separated from my wife. I live in a little town near Jim Thorpe, the great football player, called Lansford, Pennsylvania. My hobbies include playing golf, helping out with the local high school golf team, and being a caretaker for my mother and whomever else may need me. I have beautiful twin daughters, Allison and Brittany, age 22, who are graduating from college this year. Allison majored in elementary education and plans to move to Florida to be close to her boyfriend and get a teaching job. Brittany majored in business and is looking for job opportunities. She hasn't quite decided what she wants to do yet. After working as a quality control specialist at Kraft Foods for 22 years, I retired on full disability about three years ago.

How has melorheostosis affected you?

Melorheostosis has affected every aspect of my life. I was not officially diagnosed until 1993, but my doctors believe that I probably have had it most of my life. I was injured playing football as a youngster and had to have a bony lump removed from my shin when I was 12 or 13. At the time, the doctors assumed that the growth was a result of my injury. Looking back, though, I think it was probably melorheostosis. I have melorheostosis in my left leg, left arm, my skull and lower spine. I am in constant, acute pain. The pain is not only debilitating physically, but also emotionally and spiritually. I'll be honest with the members of our community. I battle depression and have sought professional help for it. I think it's important that we understand pain can be extremely depressing. It robs you of the quality of life. There should be no stigma attached to seeking whatever help is necessary to deal with the pain and depression that accompanies it.

What are the greatest challenges you have confronted in dealing with this disease?

I think one of the greatest challenges is my appearance. That is, if you look at me, I look normal. People might think: "What's his problem? Nothing appears to be wrong with him. Why is he on disability?" I think it's very hard for people to grasp that you can be suffering terribly when there is nothing visibly wrong with you. This includes people who are closest to you. It is for this reason that I am most grateful for the love and support of the melorheostosis community. I felt so isolated before I met them.

What words of wisdom do you have for others who are coping with this disease?

To be open: to talk honestly with one another. It is only through honest, open communication that we can truly understand the impact that this disease has on us, and therefore, the approaches needed to treat it. My greatest hope in being involved with the Association is to find a cause and treatments for the children who have this disease. I pray that we will be able to find a way to prevent them from having to experience such tremendous pain and the other debilitating consequences of this disease.

Other News from Our Members

Mari Fairman-Painter (formerly Mari Robinson) wrote us with the great news that she and her son, Matthew, are all Painters now. Thomas, her husband of nine months, adopted Matthew in November. "We are all one big happy family now," enthused Mari. Mari said that she also incorporated her maiden name as a tribute to her late father who passed away last year. Congratulations to the Painter family!

Alice Albin's son, Kevin, recently signed on as Assistant Deputy Public Defender in Orange County, California! Alice was pleased to learn of this appointment, and is quoted as saying, "WOOO HOOOO!!!"

In our next issue...
An Interview with one of the
Association Founders:
"Linda Hembree"

A publication of the Melorheostosis Association
Acting Editor, Alice Albin
(albin@msu.edu: 517-355-7673)

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St. Louis, MO 63117
(314) 727-0887

> **"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."**
>
> **William Harvey, 1657**