



# Melorheostosis

## ASSOCIATION

### Board of Directors

Lyn Pickel, President  
Kathleen Harper, Founder  
Alice Albin, Secretary  
Linda Hembree

[www.melorheostosis.org](http://www.melorheostosis.org)

### Scientific/Medical Advisory Panel

#### Dr. Fred Kaplan, M.D., Panel Chair

Isaac & Rose Nassau Professor of  
Orthopedic Molecular Medicine  
Chief, Division of Metabolic Bone  
Diseases & Molecular Medicine  
Department of Orthopaedic Surgery  
University of Pennsylvania

#### Dr. William P. Cooney, III, M.D.

Professor of Orthopedic Surgery and  
Professor of Hand Surgery  
Mayo Medical School and  
Mayo Graduate School

#### Dr. Francis H. Glorieux, M.D., Ph.D.

Professor of Surgery, Pediatrics &  
Human Genetics, McGill University  
Director of Research  
Shriners Hospital for Children, Montreal

#### Dr. Jill Helms, PH.D., D.D.S.

Associate Professor  
Plastic and Reconstructive Surgery  
Stanford University

#### Ms. Jeannie Peeper, President

International Fibrodysplasia Ossificans  
Progressiva Association (FOP)

#### Dr. Eileen M. Shore, Ph.D.

Associate Professor of Orthopaedic  
Surgery & Genetics  
University of Pennsylvania  
Department of Orthopaedics

#### Dr. Ethel Siris, M.D.

Director, Toni Stabile Center for the  
Prevention & Treatment of Osteoporosis  
Columbia-Presbyterian Medical Center  
Metabolic Bone Diseases Program  
College of Physicians and Surgeons  
Columbia University

#### Dr. Andrew Weiland, M.D.

Professor, Orthopaedic & Plastic Surgery  
Weill Medical College  
Cornell University

#### Dr. Michael Whyte, M.D.

Medical-Scientific Director, Center for  
Metabolic Bone Disease & Molecular Res.  
Professor, Medicine, Pediatrics & Genetics  
Division of Bone & Mineral Diseases  
Washington Univ. School of Medicine

#### Dr. Michael Zasloff, M.D., Ph.D.

Dean, Research & Translational Science  
Georgetown University Medical Center

### Announcing

## 2<sup>nd</sup> Annual Conference of the Melorheostosis Association: “Symposium Presentations and Selected Patient Case Studies with the Scientific/Medical Advisory Panel”

To be held on the campus of Michigan State University  
In East Lansing, Michigan on

August 24-26, 2004

Special accommodations and assistance for planning this meeting have been graciously offered by several departments of Michigan State University. The Melorheostosis Association gratefully acknowledges and thanks the MSU Department of Radiology for providing conference room space, the MSU Kellogg Center for offering significantly reduced hotel room rates; the MSU Department of Genetics and MSU Department of Physiology for providing speakers to address useful information on topics relevant to melorheostosis.

### Meeting Highlights

- Welcome Reception, Tuesday, August 24, 7:30 p.m., Kellogg Center
- Scientific Presentations and Medical Panel Discussions
- Case Reports from Patients and their Families
- “Educate the Doctors” Clinics with Selected Patients and the Panel
- Genetic Panel Discussion
- Audience Question & Answer Sessions Each Day
- An Opportunity to Meet other Melorheostosis Participants and Have Lots of Fun!!

**Additionally, participants will hear the panel summarize ideas, identify pressing questions/issues from a medical perspective, strategize on areas for future research and identify funding needs.**

### Who Should Attend

- Those with Melorheostosis (and their families)
- Professionals Interested in Learning More about the Disease

### Meeting Registration Fees

- \$100 Single Registration
- Add \$50 for each *attending* family member

This fee includes the cost of lunch on Wednesday and Thursday, a formal dinner on Wednesday, break refreshments each day, and offsets a portion of meeting costs.

## Travel Arrangements

**Air:** Lansing Capital City Airport (10 miles from campus)  
**OR**  
Detroit Metropolitan Airport (90 miles from campus)

**Note:** *The Kellogg Center offers complementary shuttle from Lansing's Capital City Airport. If necessary, other arrangements can be made for pick up with Alice Albin.*

**Train:** Amtrak Depot, East Lansing, MI (located 1 mile south of Kellogg Center)

**Car:** **From the East or West:**  
Take I96 to 127 North;  
exit Trowbridge Road;  
turn left at Harrison Road stoplight;  
Kellogg Center is approximately one mile on the right.  
**From the South:** Take 127 North;  
exit Trowbridge Road and follow  
above instructions.

## Lodging

### Kellogg Hotel & Conference Center

South Harrison Road  
East Lansing, MI 48824-1022  
Phone: 1-517-432-4000  
Toll Free: 1-800-875-5090  
Fax: 1-517-353-1872  
<http://www.hfs.msu.edu>

**Room Rate:** \$49/night  
**Reservation Deadline:** 7/26/2004  
**Mention:** "Melorheostosis Conference Rate"

#### Notes:

- A block of 30 rooms have been tentatively reserved for the Melorheostosis Conference at a nightly cost of \$49. [Regular room rates at Kellogg Center run between \$100-115/night.]
- The DEADLINE for confirming reservations is July 26, 2004. After this date rooms will only be available on a first-come, first-serve basis.
- **Please confirm your own reservations with Kellogg Center by phoning the toll free number listed above.**
- There is a complementary shuttle from Lansing Capital City Airport; specify your flight details when making your reservation.
- The **Welcome Reception** will be held on Tuesday evening, August 24, 7:30 p.m. at the Kellogg Center. Desserts and refreshments will be served.

\*\*\*\*\* DETACH AND MAIL \*\*\*\*\* DETACH AND MAIL \*\*\*\*\*

## MEETING REGISTRATION FORM

**Name:** \_\_\_\_\_  
**Address:** \_\_\_\_\_  
\_\_\_\_\_  
**Email:** \_\_\_\_\_

\_\_\_\_\_ **Single Registration @ \$100**  
\_\_\_\_\_ **Additional Person(s) @ \$50**  
**List others:** \_\_\_\_\_

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

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

\$\_\_\_\_\_ **Total Amount Enclosed for Meeting Registration**  
\$\_\_\_\_\_ **Optional Donation Enclosed**  
(see note about fundraising below\*)

**Questions?** Call Alice Albin at (517) 355-7673 days, (517) 521-4459 evenings or email [albin@msu.edu](mailto:albin@msu.edu)  
OR call Lyn Pickel at (314) 996-2656 or email [lynbpickel@earthlink.net](mailto:lynbpickel@earthlink.net)

**Deadline Reminders:** **Hotel Reservations** **July 26, 2004**  
**Registration Fee** **July 15, 2004\***

*NOTE: We will accept registration fees up until the day of the meeting, but it will help us tremendously with the planning of catered meals, etc., if you could let us know by the deadline listed above of your intention to attend.*

**\*Special Note about Fundraising and the Costs of this Meeting:** *The Melorheostosis Board would appreciate donations over and above the registration fee to help offset the cost of this meeting. If you can help, please send a donation with your registration. If you are interested in doing a fundraiser on behalf of this meeting, please contact Alice or Lyn for assistance in planning your event.*