

A Fond Farewell to Jeannie Peeper

Jeannie Peeper, President of the International Fibrodysplasia Ossificans Progressiva Association (IFOPA), is stepping down as one of the founding members of the Melorheostosis Association's Scientific/Medical Advisory Panel. Since our inception, Jeannie has provided invaluable advice to the Melorheostosis Association on all kinds of organizational issues, ranging from how to best fundraise to sharing effective strategies for cultivating membership. Last fall, Jeannie graciously hosted a meeting of the Melorheostosis Association board at the IFOPA headquarters in Florida to field our many questions and concerns about creating and sustaining a viable not-for-profit organization.

Jeannie founded the IFOPA on June 8, 1988. FOP is a rare and progressive disease which, simply stated, causes muscles and other connective tissues to turn into bone, eventually causing immobility as the FOP joints fuse. Jeannie was first diagnosed with the disease at age 4. Today, all of her joints are locked except for her right wrist, and she is wheelchair-bound. At first, the organization consisted of just her and her mom. But Jeannie, who has a degree in social work, resolved to reach out to help others with the disease. With the help of Dr. Michael Zasloff, then of NIH (who is now also a member of the Melorheostosis Association Scientific/Medical Advisory panel and on the faculty of Georgetown University), she was able to secure a list of other individuals with FOP. Her first mailing, which consisted of a cover letter and a membership form, yielded 11 responses. The organization was off-and-running!

For the past 17 years, Jeannie has presided over the IFOPA and nurtured its development from a fledgling kitchen-table operation to a professional and respected not-for-profit organization, with a paid staff and a research budget exceeding a million dollars/year.

Jeannie is quick to shift credit for the organization and its progress to the visionary efforts of three research doctors: Dr. Michael Zasloff, Dr. Fred Kaplan and Dr. Eileen Shore (all of whom are members of the Melorheostosis Association Scientific/Medical Advisory Panel as well). "The IFOPA and the Melorheostosis Association are extremely fortunate to have these wonderful doctors who have devoted so much of their lives and research to our related causes," she noted.

Jeannie is formally relinquishing her role as President of the IFOPA in June but plans to retain a title of President Emeritus and spokesperson for the organization. While impressive and promising strides in the research of FOP have been made since Jeannie first started the organization so many years ago, the cause remains elusive. "Our biggest challenge," said Jeannie, "is to continue being able to generate adequate research funding to secure the answers that are needed to treat FOP more effectively, and ultimately, to find a cure. I hope to live to see the day."

In honor of Jeannie's visionary leadership and courage, and in deep gratitude for all she has done for the Melorheostosis Association, we are sending a tribute gift of \$1,000 to the IFOPA. In addition, we are setting up a scholarship fund in Jeannie's name to fund travel and related expenses for families who would otherwise not be able to attend the regular Melorheostosis Conferences.

If you would like to donate a tribute gift of your own to the IFOPA in Jeannie's name, please send it to:

IFOPA, P.O. Box 196217, Winter Springs, Florida 32719-6217

Thank you, Jeannie, and good luck in all your future endeavors!



WELCOME Dr. Anthony Stans, M.D. Dr. Stans has graciously accepted an offer to serve on our Scientific/Medical Advisory Panel. He is currently Chair of the Division of Pediatric Orthopedics at Mayo Clinic in Rochester, Minnesota. We believe Dr. Stans has much to offer, and we are excited he has agreed to help us pursue our mission.

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.

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

Sunday, July 17

7:00- 9:30p Welcome Reception, SLU Historic Cupples House

Monday, July 18

Concurrent Sessions - Watertower Inn

Scientific/Medical Advisory Panel, Guest Speakers & Panel Guests		Patients & Family Members	
8-9:00a	Breakfast and Introduction Dr. Fred Kaplan, Moderator 644 Watertower Inn	8-8:45a	Patient & Family Conference Overview Lyn Pickel, President Dr. Rob Fleming, M.D., SLU Sponsor 1501 Watertower Inn

Scientific & Medical Presentations - Allied Health Building Auditorium

- 9:20a Mrs. Lyn Pickel, President & Dr. Fred Kaplan, M.D. Conference Moderator - "Welcome & Introductions"
- 9:30 Dr. Geert Mortier, M.D. - "The Role of LEMD3 in the Pathogenesis of Melorheostosis"
- 10:20 BREAK
- 10:30 Dr. Michael Whyte, M.D. - "Deactivating Germline Mutations in LEMD3 Cause Osteopoikilosis and Buschke-Ollendorff Syndrome, But Not Melorheostosis"
- 11:15 Dr. Howard Worman, M.D. - "The Identification and Characteristics of MAN1: The Protein Mutated in Melorheostosis"
- 12:00p LUNCH - Multi-purpose Room, Allied Health Bldg.
- 1:00 Dr. Peter Klein, Ph.D. - "MAD N' SANE: Regulation of BMP/Smad Signaling in Development"
- 1:50 Dr. Jill Helms, Ph.D., D.D.S. -- To Be Announced (TBA)
- 2:40 BREAK
- 3:00 Dr. Dror Paley, M.D. - "Limb Lengthening and Deformity Correction for Melorheostosis"
- 3:50 Dr. Roger Smith, M.D. - TBA
- 7:00 DINNER - Allied Health Building Multi-Purpose Room
Keynote Speaker: Dr. Michael Zasloff, M.D. - "African Frogs to a Pine Forest Fungus: The Development of Drugs Doesn't Necessarily Make Sense"
- 9:00 Cocktails and Hospitality - A night view of the St. Louis Arch - Watertower Inn, 2nd Floor Lobby

Tuesday, July 19

Scientific & Medical Presentations - Allied Health Building Auditorium

- 9:00a Dr. Eileen Shore, Ph.D - "Dysregulation of the BMP Signaling Pathway in Two Rare Bone Disorders"
- 9:50 Dr. Laura McCabe, Ph.D. - "Mechanisms of Suppressed Bone Formation"
- 10:40 BREAK
- 11:00 Dr. Jeffrey King, M.D. - "A Comprehensive Analysis of the Melorheostosis Database"
- 12:00p LUNCH - Multi-purpose Room, Allied Health Bldg.

Concurrent Sessions

Scientific/Medical Advisory Panel, Guest Speakers & Panel Guests "Patient Case Studies"		Patients & Family Members	
1:00	TBA	2:15	TBA
1:25	TBA	2:40	TBA
1:50	TBA	3:05	Panel Discussion
1:30	Annual Association Meeting "Plans, Strategies and Dreams" Lyn Pickel, Moderator		

- 4:00 Wrapping Up
Dr. Fred Kaplan, M.D., Moderator - "The Path Forward"
- 7:30 **Riverboat Cruise**

Children's Activities

Three optional activities are tentatively planned for young people attending the conference: a trip to the St. Louis Zoo, a tour of the St. Louis Arch, and a trip to The Magic House, an interactive science museum for children, of particular interest to kids ages 2-14. Chaperones, transportation and admission fees will be provided.

Transportation to St. Louis, Missouri

Options include air, car, bus, or Amtrak. For those of you who will be traveling by air, more information will follow on transportation options between the airport and the hotel.

Meeting Registration Fees

Meeting registration is \$150 per person. This fee is based on 2004 conference expenses per person and is an estimate of actual costs for the reception, breaks, and meals thru lunch on Tuesday.

Lodging Details

A block of 40 rooms are being held at the Water Tower Inn on the campus of SLU. The discounted room rate is \$70/night. Rooms accommodate up to 4 people at no extra cost, and include a complementary breakfast. Please phone your reservation in to the:

It's not too late to register!

There are currently 56 people scheduled to attend the conference of which 17 are patients, 18 are medical professionals, and 21 are family members. If you are interested in attending the conference, please contact Alice Albin via email and submit the registration form as soon as possible. *Hope to see you there!!*

Watertower Inn

3545 Lafayette Avenue

St. Louis, MO 63104

Phone: (314) 977-7500

Mention: Group Reservation #668

[www.slu.edu/events/water tower inn.html](http://www.slu.edu/events/water_tower_inn.html)

2005 CONFERENCE REGISTRATION FORM

Name: _____

_____ Registrations @ \$150

Address: _____

Please list others and include age of children:

Email: _____

Please make checks payable to:

Melorheostosis Association

_____ Optional Riverboat Dinner (July 19, 7:30-9:30 p.m.)

No. Adults _____ @ \$35

No. Children _____ age 3-12 @ \$18

Specify Riverboat Meal Selection:

Prime Rib: #Adults _____ #Children _____

Champagne Chicken: #Adults _____ #Children _____

Fish: #Adults _____ #Children _____

Pasta: #Adults _____ #Children _____

Mail check and registration form to:

Mrs. Alice Albin
MSU-DOE Plant Research Laboratory
Michigan State University
East Lansing, MI 48824

\$_____ Amount Enclosed for Riverboat Dinner Cruise

\$_____ Amount Enclosed for Meeting Registration

\$_____ Optional Tax-Deductible Gift (*thank you!*)



6611 Clayton Road, Suite 211
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 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