

# FOP Connection

News for Members  
of the **ifopa**

Dear Member,

We often use the word milestone to describe an important event, but it also denotes a significant point in development, a moment when exceptional progress is achieved. Hence, milestone seems a particularly appropriate way to portray the outcome of the informal two-day IFOPA-hosted workshop on Strategies for the Treatment of FOP held in mid-August in Philadelphia.

Dr. Fred Kaplan, Co-Director of the FOP Research Lab stated that the focus of the event was “What is the biggest gap between what we know and what we need to know in order to achieve successful treatment and a cure for FOP? How do we get there in the short term (1-3 years) and in the long term (3-5 years)?”. Dr. Kaplan wrote that the 27 scientists attending created “a war room atmosphere as they sat face-to-face around a large conference table and sketched the outlines for a final assault on a long-term enemy – FOP itself”. The ultimate product of the workshop was a list of treatment options prioritized for further basic research and preclinical development. For a community that has waited more than 25 years for scientists to even contemplate treatment options, the workshop was clearly a milestone.

Beyond the tangible outcomes, one scientist spoke of “smelling the ozone in the room”, echoing Dr. Kaplan’s characterization of the think-tank atmosphere being “palpably exciting with a verve and tone unparalleled in the history of FOP research.” For a lay person such as myself these are heady words, especially from scientists who are customarily cautious when speaking about their work. The inescapable conclusion is that there is now a much higher level of optimism about the prospect for FOP treatments and a cure than has existed previously. Certainly, years of work remain to be done in the lab and at our family fundraisers where the critical life blood funding of the research is generated. But in the words of Ian Cali, we have gone “from hopeless to hopeful”. There is the unmistakable smell of ozone in the atmosphere!

In closing, I’m pleased to note another milestone -- the rebuilding of our IFOPA staff. On behalf of the IFOPA board and our association members, I welcome Jane Millen as Executive Director, Victoria Mandracken as Communications and Membership Manager and Denise Vietti as Accountant. Jane brings with her 25 years experience with the YMCA and similar organizations. Victoria provides an impressive range of communication and media skills for our organization. Victoria was most recently involved in public relations and

communications for the non-profit Rebuilding Together Orlando. Denise has worked for several organizations in the Orlando, Tampa and Dallas areas. She has a MS degree in Accounting and Information Management and is currently preparing to sit for the CPA exam. The board is extremely pleased to have these talented professionals join our organization. We wish them a very warm welcome.

Malcolm C. Munro, PhD  
IFOPA Board Chairman

## New IFOPA Staff

### Jane Millen, Executive Director

I graduated from Edgewood College in Madison, WI with a degree in Education. I have over 25 years of experience with the YMCA, most recently as the Executive Director of the J. Douglas Williams YMCA in Lake Mary, FL. I have risen over \$500,000 for the YMCA Youth Scholarship Campaign and am looking forward to bringing my experience and expertise to the IFOPA. I am married to Mike, who is a teacher in Seminole County, and have a one year old son, Jordan. Please feel free to contact me at [jane.millen@ifopa.org](mailto:jane.millen@ifopa.org).

### Denise Vietti, Accountant

I have a Master Degree in Accounting and Information Management. I have worked in non-profit entities for 20 plus years and I am dedicated to the success of the IFOPA. Please feel free to contact me at [denise.vietti@ifopa.org](mailto:denise.vietti@ifopa.org).

### Victoria Mandracken, Communications and Membership Manager

I have a Bachelor Degree in Fine Art and over 20 years of experience in graphic design, business communication and project management. I look forward to using my experience and skills to help the FOP community. I’m married to Daniel and we have a thirteen year old daughter. Please contact me if you would like help designing your promotional materials for fundraising events at [victoria.mandracken@ifopa.org](mailto:victoria.mandracken@ifopa.org).

## Scientific Workshop for a Cure: Strategies for the Treatment of FOP

by Frederick S. Kaplan, MD Robert J. Pignolo, MD, PhD, Eileen M. Shore, PhD



**Seated (from left to right):** Mrs. Amanda Cali, Mr. John R. Cali, Dr. Robert Pignolo, Dr. Fred Kaplan, Dr. Eileen Shore, Dr. Aris Economides, Dr. Michael Zasloff.

**Standing (from left to right):** Mr. Ian Cali, Mrs. Robin Gambaiana, Mrs. Jennifer Snow, Dr. Viet Le, Dr. Kristi Wharton, Dr. Bjorn Olsen, Dr. Jay Groppe, Dr. Vicki Rosen, Mr. Mark Gambaiana, Dr. Ernestina Schipani, Dr. Corey Hopkins, Dr. Karen Lyons, Mrs. Diane Weiss, Dr. Petra Seemann, Dr. Masahiro Iwamoto, Dr. Bettina Much-Le Ny, Mr. Robert Snow, Dr. Joseph Kitterman, Dr. Emile Mohler, Dr. Malek Kamoun, Dr. Maurizio Pacifici, Dr. Damian Medici, Dr. Lixin Kan, Dr. Ed Hsiao, Dr. Charles Hong, Mrs. Moira Liljestrom

In mid-August, 2011, 27 scientists (13 from the University of Pennsylvania and 14 from other institutions) met in Philadelphia for an informal, but intense two-day workshop on: "Strategies for the Treatment of FOP." The workshop was co-organized by Frederick S. Kaplan, MD, Robert J. Pignolo, MD, PhD, and Eileen M. Shore, PhD, with the tireless and gracious support of Mrs. Amanda Cali. The workshop was sponsored by generous contributions from Mrs. Diane Weiss, the IFOPA, the University of Pennsylvania, and an anonymous donor. The primary goal of the workshop was to establish priorities for developing effective treatments and an eventual cure for FOP. An important secondary goal of the workshop was to stimulate and strengthen basic scientific and translational collaborations that will lead to the development of a cure.

Participants were provided with an extensive reading list of the most up-to-date scientific articles in the field of FOP research a month prior to the meeting, and were encouraged to scour the details before arriving in Philadelphia. All clearly did.

Discussions ensued in a series of small workshop sessions focused on four highly plausible areas of therapeutics, all bolstered by recent advances in FOP research:

1. Down-regulating ACVR1/ALK2 signaling (from the FOP gene and its downstream targets)
2. Inhibiting neuro-inflammatory triggers of heterotopic ossification
3. Blocking responding progenitor cells
4. Altering the molecular microenvironment of the incipient FOP lesion

The meeting was interactive and vibrant, highlighting an agenda that limited formal lectures and promoted brainstorming. The discussions and collaboration-building continued seamlessly well beyond the designated sessions. Participants discussed unpublished data and novel ideas in a dynamic interdisciplinary forum that began in a conference room environment and evolved into informal gatherings.

After brief introductory greetings and scientific updates, the scientists self-assigned themselves to one of three small working groups (BMP pathways; Lesional stem cells; or the Microenvironment of early FOP lesions) for “shop talk” and a discussion of scientific and therapeutic priorities. Each workshop self-selected a group discussion leader who focused the conversation on the broad general question: “What is the biggest gap between what we know and what we need to know in order to achieve successful treatment and a cure for FOP? How do we get there in the short term (1-3 years) and in the long term (3-5 years)?”

Following the introductory workshops, the small working groups reconvened to summarize their proceedings for all in attendance. The remainder of the meeting was spent in several larger workshops where all of the scientists participated in the agenda of each of the smaller working groups.

The workshop participants represented diverse and far-ranging scientific fields relevant to the understanding and treatment of FOP including genetics, cell and molecular biology, immunology, neurology, vascular medicine, structural biology, biomechanics, animal model development, medicinal chemistry, pharmaceutical

development, micro environmental biology, and clinical and translational medicine. Manuel Robert, a 14 year-old young man with FOP from Buenos Aires, Argentina was commissioned to depict the theme of the workshop and the goal of all FOP research in a specially designed, computer-generated poster. Selected from among six renditions, the illustration joins the pantheon of work from historic FOP meetings:

STRATEGIES FOR  
THE TREATMENT  
OF FOP  
(A SCIENTIFIC WORKSHOP)



PERELMAN SCHOOL OF MEDICINE  
THE UNIVERSITY OF PENNSYLVANIA  
AUGUST 10-13, 2011

**1991: Save the FOP Children (Ashley Kurpiel)**

**1995: Accentuate the Positive (Sarah Steele)**

**2001: We are the World (Tiffany Linker)**

**2007: Together We Can Move Mountains  
(Hugo Fahlberg)**

**2011: Cure FOP (Manuel Robert)**

The illustrated theme, a mandate in two words “Cure FOP,” says all that needs to be said as the scientists moved the jigsaw pieces of the FOP puzzle into place. The meeting focused on critical pieces that still might be missing as well as currently available knowledge that could be translated most quickly into more effective treatments.

Recalling an earlier time, two decades ago (September, 1991), at the first FOP Symposium in Philadelphia when war was declared on FOP, the scientists recreated a war room atmosphere as they sat face-to-face around a large conference table and sketched the outlines for a final assault on a long-term enemy – FOP itself. The workshop culminated in an intense working session where treatment options, as presently conceived, were prioritized for further basic research and pre-clinical development.

The Workshop think tank atmosphere was palpably exciting with a verve and tone unparalleled in the history of FOP research. “The tools and enthusiasm were never more available to do so much,” said one scientist commenting on the enlightening exchange of ideas. “One could smell the ozone in the room.”

The workshop was peppered with a series of brief inspirational messages from organizing members of the core FOP Laboratory and from The Center for Research in FOP and Related Disorders as well as from the Dean of the Medical School, the Chairman of the Department of Orthopaedic Surgery, members of the IFOPA Board, and most memorably from FOP patients Patrick Doerr and Ian Cali whose messages were moving and inspirational.

The workshop, held at the Inn at Penn on the University of Pennsylvania campus, began with an informal reception at which the attendees were greeted by members of the Penn academic community and representatives of the IFOPA Board of Directors and culminated with a deep appreciation by all of the mysteries and miseries of FOP and the mandate and possibility for a cure. As Ian Cali said, we have taken the step “from hopeless to hopeful.

## Reflection of 2011

As we near the end of 2011, let’s celebrate our successes and YOU!

1. To our families who have fundraised this year: You have

done a phenomenal job. We could not reach our goals and achieve what we have done without the extraordinary work of your grassroots efforts. We love you and thank you.

2. To our donors who generously continue to give to the IFOPA each year: We are extremely grateful for your support of the mission of the IFOPA. Thank you for keeping us in your heart, for your warm thoughts and for your generous gifting.

3. To the many volunteers who give unselfishly of their time and talents at fundraising to help make each event a huge success. Our dedicated volunteer members who serve on committees and provide support on our projects and our volunteers who have worked diligently at the IFOPA office this year: We thank you and appreciate you!

4. To the FOP Community worldwide for your support to members and their families: Your knowledge, strength, inspiration and wisdom provide encouragement and hope. There is presently an amazing connection of people on Facebook sharing their lives with each other and I always look forward to reading what our friends around the globe are doing. IPC members who translate documents. You are all so incredible!

5. To Dr. Fred Kaplan, Dr. Eileen Shore, Dr. Bob Pignolo and their research team: Your extraordinary love and dedication for us will enable us to achieve the ultimate goal of a treatment and a cure for FOP. That is a blessing and a miracle. The extraordinary Strategies for the Treatment of FOP meeting held at The University of Pennsylvania earlier this year was a remarkable milestone in our quest for a cure, and has engaged and energized researchers in an outstanding way.

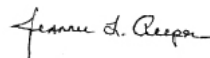
6. To the IFOPA Board of Directors who has given graciously of their time and effort to reorganize the office priorities and staffing needs to keep the organization moving forward: It has been a great labor of love: Your exceptional diligence demonstrates the wonderful leadership and unity of our organization.

7. To Linda Daugherty and Becky Kaplan for assisting the IFOPA office in our transition to new staff: Your valuable knowledge of IFOPA history has provided stability, perspective, and guidance to our new staff. Linda has created an Operational Manual for the Executive Director and Becky, along with Gail Weakland, IFOPA Treasurer, has created an Operational Manual for the IFOPA Accountant. Thank you for your commitment to the IFOPA.

8. And to our new staff....Jane, Denise and Victoria: We look forward to working with you in our journey into the future.

The excitement of the coming year.....2012.....what will it bring us? We don't know for sure, but with the recent new research developments we have HOPE that clinical trials may be a possibility in the not too distant future. We continue on our journey with each other, with love, courage and HOPE.

With Love and Gratitude,



Jeannie Peeper  
President

## IFOPA Awards

Jeannie Peeper International FOP Association (IFOPA) Awards recognize those who make exceptional contributions to the worldwide FOP community through their leadership, service, fundraising and accomplishments. This year's Awards Selection Committee—Lori Henrotay (Chairperson), Patrick Doerr, Karen Munro, Jeannie Peeper (Honorary Chairperson), and Nancy Sando—would like to thank everyone for your participation. It is very difficult to choose just four winners because all of you are deserving of an award. We hope to continue each year to recognize and highlight the extraordinary accomplishments within our community. Below are brief summaries of each winner's extraordinary contributions.

### President's Lifetime Leadership Award *Amanda Laue Cali*



Amanda Cali

Upon Ian's FOP diagnosis in 1994, Amanda embarked as a mother on a tireless journey to fund FOP research, promote awareness and assist the IFOPA in many facets. With her family she established the Ian Cali FOP Research Fund with its primary focus on supporting collaborative ventures between the FOP Lab and other centers of research excellence. She created many first time events including the FOP Parent Meeting in Cranford NJ, the Adult FOP Meeting in Parsippany NJ, Planning for Today and the Pathway to the Future IFOPA

Organizational Meeting, and the wonderful Mother's Retreats. Amanda provided outstanding service as an IFOPA director and as the first Board Chairman after Jeannie's retirement. Among her many initiatives, she provided important guidance and support in establishing the International President's Council. We are deeply grateful for her quiet and amazing generosity in providing much valued financial and organizational support on so many occasions over the years.

## Outstanding Community Involvement Award

*The Weldon Family*



Whitney, William, Bill and Hillary Weldon

In reviewing the Weldon family's many contributions and supportive activities for the IFOPA and the FOP community, we would like to recognize them for the scope

and variety of their fundraising and awareness activities. As a start, of course, there is the establishment of the Weldon FOP Research Fund with its focus on the genetic causes of FOP and the development of safe treatment options. In addition, their extraordinary efforts at organizing events such as the annual golf tournaments and luncheons, dinner dances and celebrity boxing bouts, cocktail parties and comedy shows, and Friendraisers and recruiting Boston Marathon runners (to name only some!) are truly impressive. The extraordinary outreach of the Weldon family each year to bring FOP awareness through local media coverage via television and radio is amazing and we are deeply grateful for all that they have done for the FOP Community.

## Emerging Leader Award

*Ashley Kurpiel*

Ashley is an incredible role model and an amazing spokesperson for the FOP Community and the mission of the IFOPA. Ashley's many speaking engagements have included traveling the country speaking at various FOP family fundraisers, local rotary clubs and her most recent speech at Starr's Mill High School Baccalaureate. Over the years, Ashley has been instrumental in promoting FOP awareness by the many press and media outreach she has done including; ABC News 20/20, Mystery Diagnosis, BBC The Skeleton Key, YouTube, Tyra Banks Show



Ashley Kurpiel

and others. Ashley also played an important role in representing FOP as a spokesperson at events, including Capital Hills Awareness Days. She has provided support in any way possible; assisting with the Teen/Young Adult Meeting, Symposia, hosting fundraising events, including her most recent American 5K Run/Walk event,

supporting International IFOPA Awareness Day and many other IFOPA sponsored events. Ashley, we have seen you grow up from a child to an amazing talented woman. We are very proud of you and want thank you for all that you do for the FOP Community.

## Outstanding International Leadership Award

*Roger zum Felde*



Roger zum Felde

Roger's extraordinary leadership as the FOP e.V. – CEO of FOP Germany, the first international FOP organization, and his guidance as the IFOPA International President's Council representative for Germany exemplifies the amazing community network that we all represent. His steadfast commitment to promote FOP

awareness through personal interviews with the Press and other media such as YouTube videos and presentations at service clubs, such as Rotary and Mercedes-Benz Auto, is a remarkable testimony of his pledge to make a difference. Roger's wonderful personality shines brightly and provides an inspiration to others. Roger's tremendous support in joining our team effort in fundraising for FOP research and the IFOPA brings us one step closer to our dream of a treatment and a cure for FOP.

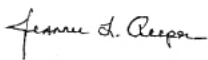
## A Special Thank You

I would like to say thank you to Malcolm Munro, grandfather of FOP member, Miranda Fritz for graciously serving as IFOPA Chairman this year. His leadership and guidance has been extraordinary. Malcolm has diligently worked on many

different projects, always being efficient and effective. We greatly appreciate your service to the IFOPA.

Also, a special thank you to FOP Member Pat Doerr for serving as a Board of Director for the past three years. During his terms, Pat has graciously served as Secretary, Vice Chairman and Executive Committee member, performing a variety of tasks to assist the IFOPA in reaching our goals. His dedication and enthusiasm is very much appreciated. Pat's kind, compassionate manner will be greatly missed.

Thanks so much Malcolm and Pat for a job well done!



Jeannie Peeper  
President

## International Meetings for FOP

### The II FOP Latin American meeting,

organized by the Fundación FOP with the support of the International FOP Association was held May 12th to the 15th in Buenos Aires, Argentina.



Latin American Meeting

The meeting was directed to FOP families, as well as doctors treating FOP patients and those interested in the pathology. A total of 21 FOP families from Brazil, Chile, Venezuela, Colombia and Argentina attended, as well as Amanda Cali

from the United States. The doctors who attended from the United States were Dr. Frederick Kaplan and Dr. Robert Pignolo from the University of Pennsylvania, Center for Research in FOP & Related Disorders. From Latin America

Dr. Carmen de Cunto, from Hospital Italiano and Dr. Patricia Delai from la Santa Casa de la Misericordia from Sao Paulo, both FOP references in their respective countries attended along with Dr. Gabriela Scagnet and her team of dental specialists in disability from the Universidad de Buenos Aires.



Special Dance

The workshops for FOP families also included child care so parents were able to increase their knowledge and exchange experiences and 10 to 15 doctors from the main Children Hospitals in Argentina attended talks about FOP Research. Clinical consultations for FOP

patients also took place during the meeting with Dr Kaplan, Pignolo, De Cunto and Delai. There were also odontological consultations with Dr Scagnet. Each family received, the Family Guide printed in Spanish; the Medical Binder; an Emergency Card; and a Catalog of tools developed by Fundación FOP. The last dinner on Saturday included a special and touching presentation that integrated dance among three couples some in wheelchairs. Thank you to everyone who made the meeting a success.

### The 5th Italian F.O.P. Conference

held in Rome on March 24-26, 2011. F.O.P.ITALIA Onlus was founded in 2006 by few families of young FOP patients, and is still managed by these families. In Italy 25 persons have now been diagnosed with FOP.

Under the guide of Mr. Enrico Cristoforetti, President of the Association, and with the medical/scientific support of the Genova University, each year an international symposium has been organized, with important participation of the major worldwide experts in research and clinical knowledge of FOP and associated disorders.

The 2011 Italian F.O.P. Conference was held in Rome with a 3 day program. The conference goal was a general update on the research results, treatment guidelines, and open discussions among doctors, experts and the audience. The conference was open to the public and useful for doctors in medicine and other medical personnel willing to improve their education score, as required by the Italian legislation on medical professions.

The topics discussed in the various sessions of the first 2 days were the following:

- Progress of research on pathogenic mechanisms of FOP
- Clinical aspects and treatment of FOP patients
- Progress of research on pathogenic mechanism of FOP
- Multipotent progenitors with osteogenic potential
- Progressive osseous heteroplasia and disorders associated to GNAS gene mutations



Italian FOP Conference

In the third day the focus was moved onto the Italian FOP Association activity performed in the last year, with a

medical final summary by the Scientific FOP Italian Committee. The Board of Directors of FOP Italia Onlus also approved the 2010 balance and discussed the main strategies for 2011.

Italian patients also had the benefit of a visit done by the pool of American, German and Italian doctors who attended the conference along with experts in clinical research.

The 3 days conference ended with a successful convivial dinner in a traditional Rome restaurant. The day after, a short tour was organized for the doctors and experts still in Rome to visit the ancient ruins in the very center of the town.

#### Doctors and experts who attended the conference:

Eileen Shore – University of Pennsylvania, School of Medicine, U.S.A., Robert J. Pignolo - University of Pennsylvania, School of Medicine, U.S.A., Rolf Morhart – Garmisch Hospital, Germany, Martine Le Merrer – University of Paris, French, Irina Stefanova – University of Lubeck, Germany, Francesc Ventura – University of Barcelona, Spain, Jim Triffitt – University of Oxford, UK, Moira Liljestrhom – President of F.O.P. Argentina Association, Roberto Ravazzolo, Renata Bocciardi, Maja di Rocco, Donato de Angelis – University of Genova, Italy, Davide Gatti – Physician, Verona Hospital, Italy, Ermanno Baldi – Pediatrician in Trento, Italy, Paolo Bianco – University of Roma, Italy, Giovanna Mantovani – University of Milano, Italy, Gianpaolo di Iulio – Physician, expert in non traditional medicine, Roma, Italy, Roberto Bufo – President of IPOHA Italian Association, Domenica Tarascio – Director of the Italian Rare

Diseases National Center (CNMR), Nicola Spinelli – Vice President of the Italian Federation for Rare Diseases Association (UNIAMO), Enrico Cristoforetti – President of FOP ITALIA Onlus, Maria Marcheselli, Francesco Moresco, Massimo Alfieri – members of the Board of FOP ITALIA Onlus

## Annual meeting of the German FOP e.V. in Valbert-Meinerzagen July 29th to July 31st 2011.

By Roger zum Felde

At the end of July, 59 members of the German FOP Group met in the middle of Germany.

As in years past we booked the beautiful Nordhelle Hotel with many facilities like bowling, swimming pool, playground etc. in the North-Sauerland - Valbert Meinerzhagen. You can visit the hotel web site <http://www.haus-nordhelle.de>

On Friday the 29th July we met in the afternoon, received a big “Hello” from the group’s CEO Petra Sommer and took care of the new members. Afterwards Petra and I reported about the different things that happened during the year like charities, TV and Newspaper appearances, the honor Petra Sommer received from the Bavarian ministry for extraordinary work, my honor from the IFOPA and so on. The rest of the night we spent together talking and catching up on what has personally happened to each other during the year.



German FOP Members

Saturday after breakfast we started our meeting with an interesting speech from Professor Petra Seeman of the Berlin-Brandenburg Center for Regenerative Therapies. Here is the web site address <http://bcrt.charite.de/index.php?id=535>. It was brilliant to hear about analyzing FOP within the chicken egg -

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an animal from the FOP-Zoo. Professor Lutz Schomburg reported about personalized medicine and a new blood-Test. In the afternoon we talked about what to do within the next year as a group and had computer lessons. The evening we spent as the night before enjoying each other's company.

On Sunday we heard news about different insurances and as in the previous two years one person with FOP has the chance to talk about his/her life. This year we listened to Meike Mrugallas share his biography from Switzerland. At the end of our meeting we heard about our financial situation from our cashier Ralf Fischer and decided what to do with the funds. In the afternoon our little Symposium ended and we had to say good bye.

## Focus on Fundraising

### Hand Crafted Jewelry



Severine Letartre and her mother Martine founded an association in 2001 to have their Jewelry Fundraising go towards helping Dr. Kaplan's FOP research team. Their efforts not only help the IFOPA but also inform people

about FOP, research and how they can give private donations. Each piece of jewelry is designed and hand crafted by Severine and her mom. Together they invite friends to come to their home in December before Christmas and May before Mother's Day to purchase the beautiful jewelry. If someone can't attend they have a blog <http://sephyr29.skyrock.com> where people can see the jewelry and phone in their request. Their friends have also organized private jewelry sales and people are happy to give money for FOP research in exchange for hand crafted jewelry. Thank you Severine and Martine for using your creativity to help the FOP community!



Severine and her assistant Virginie with Jewelry

### Morgan Lawler Spaghetti Dinner Fundraiser

After learning that the younger sibling of two students attending the Gordon W. Mitchell Middle School in East Bridgewater, MA, was suffering from FOP, Stan Piltch, the Principal decided to hold a fundraiser to benefit The Morgan Fund.



Back Row: Will Lawler, Mrs. Stephen, Kristine Lawler, Principal Piltch, Front Row: Marisa, Morgan and Matthew Lawler

The event was a Spaghetti Dinner with a silent auction and DJ for entertainment held on June 17th. In order to make the Spaghetti Dinner more eventful and attractive to community members, Principal Piltch and Mrs. Shel Stephen (a 5th grade teacher at the school) vowed to shave and cut their hair if the event was successful at reaching its goal. The goal was set high, at raising \$20,000. The community reacted very positively and the Dinner had an overwhelming attendance which contributed to the fundraiser exceeding the goal! Good news for everyone, except perhaps Principal Piltch who had his head shaved and Mrs. Stephen who had her hair cut by more than 15 inches with all their students cheering them on. The smiles on Principal Piltch and Mrs. Stephen told everyone they enjoyed getting new hair styles!



Reaching the Goal Principal Piltch Shaves His Head

Just prior to the Spaghetti Dinner an article was placed in the Boston Globe, in which hundreds of donations were sent in from all over the state of Massachusetts. On June 16th the school held a bake sale and a Hat Day, in

which 1,200 FOP awareness bracelets were sold. Morgan's brother and sister's school had a lot of fun fundraising with the community – Thank you!

## Justin Time Cure FOP Fundraiser



Justin Henke Among  
the Prizes

From July 22nd to the 24th, the “Justin time, Cure FOP” fundraiser ‘pooled’ in some cool cash for the IFOPA, in honor of Justin Henke, 11, of Middletown, DE.

Teammates of Justin’s from his winter swim team (Greater Newark Boys & Girls Club), as well as from his summer team (Delaware Aquatics Riptide), kicked it into high gear swimming loads of laps for FOP, while land-loving friends and adults took many positive steps walking for FOP. Knowing that the

greatest prize of all is a cure for FOP, youth participants were also motivated by marvelously donated prizes from ‘bone’afide businesses in the area. Stuffed among some of the prizes is one happy bird, Justin.

## Ride for Joshua’s Future of Promises



Over 100 Motorcyclists  
Participated!

The first annual Ride for Joshua’s Future of Promises was held on August 6th. It was a successful day and the heavy rain held off until the bikers completed their ride. A little over one hundred people registered for the ride. It was quite a sight to see the bikes lined up and getting ready to

depart from Indian Trail Park in Northampton.



Joshua Scoble with  
his Mom

Despite the heavy downpour people stayed for the festivities. We had a ton of food, a basket raffle and numerous drawings; one of the prizes donated was two airline tickets to anywhere in the continental United States!

Everyone had a great time and we were able to educate more people about FOP. At one point Joshua got a hold of the microphone and was thanking everyone for coming. A couple of people commented on how great it was to see Joshua and interact with

him. His presence seemed to help them better understand what FOP is and how it affects the person afflicted and their family. We hope to make future rides even more successful! A huge Thank You to both Kelly Beers and Lori Schaller for organizing this event!

## Golf for a Cure in Honor of Shane Terry



Shane Terry with Mom -  
Kim Hayes

Golf for a Cure in Honor of Shane Terry took place in Watertown, New York on July 23rd and the weather was beautiful in the mid- 80s. This was Shane’s third golf tournament and he started the festivities with his famous saying, “Send It!” A local candy store helped golfers begin the day with sweet energy by providing

goody bags for each golf cart which included not only candy but peanuts and golf tees too. 119 golfers participated in three divisions (Men, Women and Co-Ed) with first and second place winners of each division receiving a \$25.00 restaurant gift card. Shane enjoyed participating in the tournament by getting around the course in a special street golf cart to play and visit with each team. After golfing, 150 people participated in a special dinner and Chinese Auction. It was a full day of fun and \$6,000 was raised. Thank you to everyone who organized and participated in this fundraising event.

## Lincoln’s Legacy Event Generates Over \$50,000

A special fundraising event in Sioux City, Iowa held in honor of Lincoln Wheelock has added over \$50,000 to FOP research. The event, conducted on August 19, attracted over 350 people to a dinner that featured a silent auction, drawings for special items and outright contributions. Over 150 items were contributed.



Lincoln Wheelock

The event was organized by Lincoln’s grandmother, Marilyn Wheelock, and included a special appearance by Dr. Fred Kaplan from the University of Pennsylvania’s FOP research laboratory. Dr. Kaplan updated the audience on the progress of FOP research, including the recent scientific workshop. Dr. Kaplan also met with the medical staff at Mercy

Medical Center during his visit to Sioux City.

Lincoln's Legacy is an annual fundraising program designed to raise awareness and financial support for FOP. The major fundraiser is held every other year in Sioux City. Other events/activities held included a winter carnival, fun run, and a trike-a-thon. Since 2009, over \$180,000 has been raised to support FOP research in honor of Lincoln, 5, who lives in Des Moines, IA with his parents, Lee and Trisha, and a brother, Hudson.

## Erin's Day

On Friday, September 23, 2011, the Danzer family, along with supportive friends and family, held the 3rd Annual Erin's Day Golf Tournament, Dinner, Silent Auction, and Opportunity Drawing, at The Crossings Golf Resort in Carlsbad, California. There were 39 eager golfers, with eight being sponsored by Echo Pacific Construction, a wonderful and supportive company for the last three years. We are so thankful for them. The weather was perfect for a golf outing, 75 degrees, under partly cloudy skies. Also perfect weather for Erin to drive around in the golf cart with her Aunt Terri to take photos. Ken Danzer's claim to fame this evening was to say, with a chuckle, that he broke his record by only losing 17 balls.



Erin Danzer at Golf Course

After the tournament, approximately 60 more people joined in the fun, eating hors d'oeuvres and listening to 50s music and even a bit of bluegrass, all played by a band called Too Much Fun! Dinner was wonderful. MC Don Brister, from Santa Maria, who is a former IFOPA board member and has been a dedicated friend of the FOP community for many years, started off the evening by talking about his being on the IFOPA board and about the

important scientific meeting that had just recently taken place in August with Dr. Kaplan, Dr. Shore, Dr. Pignolo, and many others, in Philadelphia. Glen Eckart, father of Cassie Eckart, a member with FOP, was also in attendance and helped in all areas, including presenting the Mission of Hope video and a really sweet power point presentation of various pictures of Erin's Day events throughout the years. Denise Vietti from the IFOPA office worked tirelessly also to help make Erin's Day successful.

There were approximately 150 items donated for the auction and drawing, including an afghan donated by Mildred Riewald of Santa Maria in Honor of Stephanie Snow, and an oil painting painted by the talented Cassie Eckart. One of the highlights of

the evening was of Don Brister presenting a check to Erin for \$1,000 from Santa Maria Kiwanis for Kids. She had a big smile on her face. At the end of the evening, Erin received a standing ovation for just being Erin. That really put a smile on her face! What a great way to end the evening!

## UpComing Events

### Race to Fight FOP

November 19, 2011 - Urbandale, Iowa

In Honor of Lincoln Wheelock and Kyle McWilliams

### Bingo for A Cure

March 18, 2011

In Honor of Joshua Scoble

If you would like to host a fundraising event please contact the IFOPA at [together@ifopa.org](mailto:together@ifopa.org).

## IFOPA Receives Major Gift in Honor of FOP Member Margherita Russo



Margherita Russo

The IFOPA has received a gift valued at \$104,100 from the estate of the late Kevin R. James of South Australia.

The gift is the third largest single gift ever received in the 23-year history of the IFOPA and was made in honor of FOP member Margherita Russo. Ms. Russo is a Senior Paralegal for the Webster Lawyers law firm in Adelaide, South Australia.

"The IFOPA is deeply grateful to Mr. James for his foresight and generosity in providing for this extraordinary gift," said Mark Gambaiana, board member and fund development chair. "This estate provision provides a substantial boost to our FOP research efforts at a critical moment in our quest for treatments and a cure."

The estate gift is included in the Jeannie L. Peeper Heritage Roll of Honor, a legacy society established to recognize and honor those individuals and families who have included the IFOPA in their estate plans.

## 2011 Fundraising

The IFOPA would like to extend a special thank you to the many individuals who supported and were involved in the recent fundraising events. We appreciate the following fundraisers for their contributions:

- All American 5K: In Honor of Ashley Kurpiel
- Bingo for a Cure! in Honor of Joshua Scoble
- Charleston Marathon in Honor of Ashley Kurpiel
- Christmas Card Campaign in Honor of Yorick Blonk
- Coins for a Cure in Honor of Matthew Wadd
- Disney Princess Half Marathon in Honor of Wayne Gopshes
- Emily Collins Fundraiser at Nicholas School
- Erin's Day in Honor of Erin Danzer
- Francis Marion Dirt Dash Half Marathon & 5K in Honor of Ashley Kurpiel
- "Friends of Oliver" in Honor of Oliver Bedford-Gay
- FOP Awareness Week at Woodstock Academy in Honor of Jasmin Ariel Floyd
- Golf for a Cure in Honor of Shane Terry
- Hand Crafted Jewelry Fundraiser in Honor of Severine Letartre
- Hat Days in Honor of Morgan Lawler
- Harford Chapter No. 83, Order of the Eastern Star in Honor of Nathaniel Padilla
- Hofstra University Students Fundraiser to Fight FOP in Honor of Laura Rossano
- IFOPA Bid to a Cure
- Jeans and Green Day: In Honor of Morgan Lawler
- Justin Time - Cure FOP in Honor of Justin Henke
- Keystone Candle Fundraiser in Honor of Joshua Scoble
- Kros Trivia Night in Honor of Lucas Whitmore
- "Leap for Lincoln" Winter Carnival in Honor of Lincoln Wheelock
- Lincoln's Legacy in Honor of Lincoln Wheelock
- Luciana's Walk in Honor of Luciana Wulkan
- Racing for a Cure in Honor of Joshua Scoble
- Ride for Joshua's Future of Promises in Honor of Joshua Scoble
- Ring Toss & Hat Booth, JNES Spring Carnival in Honor of Dilyn Martin
- Scandinavian FOP Association Collection Project to Fund FOP Research
- Spaghetti Dinner & Auction in Honor of Morgan Lawler
- Strike Out FOP in Honor of Lucas Whitmore
- Tav-on-the-Ave: In Honor of Lincoln Wheelock
- Teamwork Makes the Dreamwork in Honor of Damian Fredericks
- Tenth Annual Comedy Show in Memory of BJ Giannone
- Trike-4-Lincoln: In Honor of Lincoln Wheelock
- Unmasking the Mystery of FOP II in Honor of Cody Dennings
- Valentine Card Fundraiser
- 3rd Annual Morgan's Ride in Honor of Morgan Lawler
- 5th Annual FOP Garage Sale & BBQ in Honor of Dilyn Martin

## Friendly Reminders

Look for your Voting Ballots, Membership Renewals and Annual Appeal to come by mail in November 2011.

## Recieve FOP Connection in Color via Email

Send your name and email address to [victoria.mandracken@ifopa.org](mailto:victoria.mandracken@ifopa.org) to receive the FOP Connection and other IFOPA communications in color.

## Submissions

We welcome submissions of articles, stories, photos and artwork for future FOP Connections. For consideration, please email all submissions to [victoria.mandracken@ifopa.org](mailto:victoria.mandracken@ifopa.org)  
Thank you.

## Research Updates

### The Nervous System and FOP

New findings recently published in two complementary articles have found a distinct connection between the sensory branch of the nervous system and the formation of Heterotopic Bone. A very exciting new discovery! An editorial by Dr. Fred Kaplan, Dr. Eileen Shore and Dr. Bob Pignolo of The Center for Research in FOP and Related Disorders at the University of Pennsylvania describes the significance of these findings as it relates to FOP.

The first article published by Baylor University describes the connection between the sensory nerves and the regulation of the immune system. Two researchers/authors of this article, Francis Gannon and Elizabeth Olmstead-Davis have previously worked in the FOP laboratory at the University of Pennsylvania.

The second article published from Northwestern University in a collaborative research effort with the University of Pennsylvania describes the connection between a neuro-inflammatory factor (Substance P) and FOP/Heterotopic Ossification.

These papers give new insight into the neurological connection in FOP bone formation, and potential new treatment targets. Pieces of the puzzle are coming together! To read more about Research Breakthrough - Neurological Connection to FOP go to [www.ifopa.org](http://www.ifopa.org) select Latest News under the News and Events section.

### Great Compounds

On April 3rd, 2011 an announcement was sent out regarding a new study published in the April, 2011 online edition of Nature Medicine providing great hope and insight into the direction of development of effective medications to prevent and treat heterotopic bone formation in FOP and related conditions.

Information about this study including additional FOP research news is now available in the 20th Annual Report of the FOP Collaborative Research Project and in the News & Views editorial (April, 2011 issue of nature Medicine) by Dr. Frederick Kaplan and Dr. Eileen Shore. To review these exciting reports on our web site read Exciting Update, Great Hope . . . go to [www.ifopa.org](http://www.ifopa.org) select Latest News under the News and Events section..

*Address Service Requested*

**FOP Connection**  
International FOP Association  
P.O. Box 196217  
Winter Springs, FL 32719  
[www.ifopa.org](http://www.ifopa.org)

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