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FOP News

A Message from the IFOPA Board Chair Paul Brinkman



I am pleased to announce that the IFOPA will be hosting our second Drug Development Forum (DDF) this fall in Boston on Oct. 24 and 25. This comes just about two years since the inaugural DDF, also held in Boston, in Nov. 2014.

Purpose

The DDF provides an opportunity to:

- Address questions and knowledge gaps that exist in FOP drug development
- Stimulate new ideas to help advance development of potential therapies as quickly and efficiently as possible
- Facilitate dialogue, foster collaboration and form connections among interested researchers

Simply put, the DDF is designed to move us forward in the search for a safe and effective therapy for FOP. This year's DDF comes at an especially auspicious moment, as drug trials for FOP are no longer just a dream, but a reality. There is still much to do, of course, and thus the need to bring these experts together once again.

Participants

Participation in the DDF is by invitation. The majority of individuals invited are scientists and doctors from leading universities and biopharmaceutical companies worldwide. Invitations may also be extended to relevant experts such as government experts and venture capital firms. The International President's Council members will be included, and a small number of FOP patient and parent advocates

will be asked to join and speak about their experiences with FOP.

The composition of the attendee list is intended to maximize dialogue and information exchange amongst researchers and foster as much progress and collaboration in drug development as possible. The patient voice is important too, as they provide a powerful perspective for the researchers in attendance, as we know from comments received at the 2014 DDF.

One of the unique roles of a patient organization is convening. Just as the IFOPA convenes academic research, industry and regulatory agencies we have both the ability and responsibility to convene patients as well. Our Executive Director Michelle Davis-Wingate recently attended the FOP Friends Family Conference and Gathering in Manchester, England. She witnessed the power of bringing patients together and as the IFOPA continues our strategic planning process, development of regional patient and family gatherings is among the topics of discussion.

Agenda

We are currently developing the DDF agenda under the capable leadership of Betsy Bogard, IFOPA's Global Research Development Director. She will be getting advice from academic and industry experts alike. We will likely follow the general format of the first meeting, with a number of sessions of four or five short talks focusing on topics such as clinical trial design, biomarkers for FOP, natural history studies, tools and models for FOP drug screening and, of course, therapeutic approaches to FOP, all in an effort to highlight innovative ideas and areas where discussion is needed for FOP drug development.

How You Can Help

The DDF is a critical meeting for the FOP scientific community around the world. Your support means we can bring attendees to the DDF without charging a registration fee and also provide a limited number of travel stipends for academic researchers who wouldn't be able to attend without assistance. Your gift keeps the IFOPA and FOP patients in the driver's seat facilitating collaboration to solve FOP. **Inspired by the success of the matching challenge**

for the IFOPA's 10th anniversary, another generous donor has stepped forward and will match the first \$10,000 given in support of the DDF. You can help ensure we receive these matching funds by making a donation today at donate.ifopa.org/2016DDF. Thank you for your continued generosity!

While I look forward in great anticipation to this fall's DDF, I have to admit just a bit of anxiety. Comments on the first DDF were amazingly positive. For example, from one highly regarded researcher, "*I can say honestly it was the most inspiring and informative meeting I have ever attended without question.*" In short, we have a tough act to follow. Lots of work ahead. We will keep you informed about the DDF as it takes shape, as well as the insights and directives that ultimately flow from this critical meeting of academic and industry researchers.



Paul Brinkman
Chair, Board of Directors

Registry Insights: ECRD Posters

by Neal Mantick

The FOP community was well-represented at the 8th Annual European Conference on Rare Diseases & Orphan Drugs (ECRD) in Edinburgh, Scotland, on May 26-28, 2016. Two scientific posters were on display for an international group of rare disease researchers, pharmaceutical companies, government agencies and other nonprofit patient advocacy organizations.

Clementia Pharmaceuticals and International FOP Association Partner to Advance Drug Development, from Clementia Pharmaceuticals, was authored by Donna Grogan MD, Chief Medical Officer at Clementia, and Stéphanie Hoffmann, VP General Manager Europe at Clementia, as well as Betsy Bogard and Chris Bedford-Gay from the IFOPA. It describes the collaboration between Clementia and the IFOPA in the development of a FOP disease-specific, patient-reported outcome measure – the fibrodysplasia ossificans progressiva

physical function questionnaire (FOP-PFQ). The FOP-PFQ is now being used in several Clementia-sponsored FOP clinical trials and, through an innovative data-sharing agreement, in the FOP Connection Registry. This type of industry-patient advocacy group collaboration benefits the entire FOP community, including treating physicians, researchers and individuals with FOP and their families.

[View the poster.](#)

The FOP Connection Registry: A Patient Registry Directed by the FOP Community

presented data from the first 150 participants in the FOP Connection Registry and was authored by Neal Mantick, Betsy Bogard and the IFOPA Research Committee. It displayed data on participant age and FOP type, as well as information on the frequency of medical and dental care and the effects of FOP on different body systems. Information from the Registry will give individuals with FOP and their families a better perspective on how similar or different their experiences are compared to others, which may contribute to better patient care and the growing research efforts that are focused on bringing new FOP treatments to patients.

A number of people stopped by both posters and several congratulated Clementia and the IFOPA on our pioneering efforts. They commented on the importance of establishing strong collaborations between industry and patient advocacy groups early in drug development programs and of developing research tools like the FOP-PFQ to ensure that research studies indeed collect disease information that is most relevant to individuals with FOP and their families.

[View to see poster.](#)

The FOP Connection Registry team would like to thank the current **174** Registry participants and their families from **28** countries who have contributed information to the Registry. We would also like to encourage all participants to complete the Registry surveys every six months, as well as to recruit any new participants to join your fellow FOP community members in this important registry study. Together, we can make (and **ARE** making) a difference!

Note, translated versions of the Registry are coming. If you would like to participate in the English version of the Registry go to fopconnection.org

FOP Connection Registry

**One coordinated and shared
Registry program
benefiting FOP patients,
physicians, researchers and the
biopharmaceutical industry worldwide.**

**Every person has a unique
experience with FOP.**

**Share yours at
fopconnection.org**



Next Step in Clementia's Clinical Program for FOP

On June 13, 2016 the IFOPA was pleased to share the announcement and new FAQs from Clementia Pharmaceuticals regarding the palovarotene clinical trial.

Read the announcement about the [Next Step in Clementia's Clinical Program for FOP.](#)

Read the new [Frequently Asked Questions.](#)

Without patient participation in research, medical breakthroughs can't happen and new therapies won't be approved for patient use. With such a small patient population, it is critical that everyone living with FOP consider what part they can and want to play in advancing medical research. We are thankful to all the participants, their families and everyone that is involved in this trial. Your efforts are greatly appreciated!



Interested in Participating in the Natural History Study Sponsored by Clementia Pharmaceuticals?

Study is ongoing and open to FOP patients
ages 2 to 65 years old.

If you would like more information,
call or email study locations:

U.S., California

Tea Chan at 415-316-8308

tea.chan@ucsf.edu

U.S., Pennsylvania

Katherine Toder at 215-294-9144

katherine.toder@uphs.upenn.edu

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Our International Community

FOP Friends UK Conference and Family Gathering 2016

by Chris Bedford-Gay

The weekend of May 20 to 22, 2016 saw the second FOP Friends Conference and Family Gathering held in Manchester, UK. FOP experts from around the world attended the event, presenting the latest research and information on advances made in the search for treatments for FOP. In addition, experts also provided updates on current and future clinical trials and Neal Mantick from the IFOPA presented on the importance of the FOP Connection Registry. Sessions also took place explaining the science behind 'What is FOP?' for non-scientists. Further sessions allowed families of FOP patients, and FOP patients themselves, to discuss challenges faced by themselves, from diagnosis, through early school life and into adulthood. The weekend also provided families with the chance to meet Drs. Fred Kaplan, Bob Pignolo and Richard Keen, who were able to offer clinical sessions and provide their expert advice and support.



FOP Friends UK Conference & Family Gathering 2016



A crèche (i.e. child care) was provided, allowing the adults to take part in the sessions without distraction. Not only was the crèche a place for children to meet, talk and have fun through various activities, they were given the opportunity to meet and take



Thank you FOP Friends Team!
Top to bottom and Left to Right:
Fiona White, Mari Jones, Chris
Bedford-Gay, Rachel Almedia,
Alison Acosta Bedford, Helen
Bedford-Gay, Nicky Williams

part in a presentation delivered by Dr. Gehan a consultant dentist experienced in FOP from Great Ormond Street Hospital in London. The children were shown how to look after and care for their teeth and gums. They all left with a 'goodie bag' containing toothpaste and a toothbrush, with other helpful items to ensure healthy gums and teeth.

The conference continued into Saturday evening where families gathered together for a meal and a night of entertainment from famous feet trivia to music trivia where there was much singing.

The weekend was fantastic and brought together families from the FOP Community around the world, who could provide support for each other as well as lots of fun and laughter along the way.

Australia's FOP Conference

by Julie Collins

June 3 to 5, 2016 saw the second-ever FOP conference held in Australia. This time it was held in Brisbane and it was entitled the Australasian FOP Patient Narrative Gathering. We had 10 patient families represented from Australia and New Zealand out of a total of 16 known FOP patients in these two countries.

Gathering attendees travelled many thousands of kilometers to attend from Western Australia, Victoria, South Australia, New South Wales, Nelson in New Zealand and Queensland. A total of 65 people registered to attend, including 18 physicians and allied health professionals.

Gathering presentations on day one included a very worthwhile audio link up with Drs. Fred Kaplan and Bob Pignolo on 'Best Practice in the Medical Management of FOP Patients.' Dr. McGill presented on 'The History



People with FOP attending the Australasian FOP Patient Narrative Gathering Brooke Scott, Damian Jones, Cody Wilson, Dylan Barker, Ollie Collins, Tyson Stanley, Viet Nguyen, Dominic Hanna
Missing from the photo: Jarvis Budd

of FOP.' Stephanie Hoffmann presented an 'Update on the Clementia FOP Clinical Program and the Narrative Project.' Professor Matt Brown and Linda Bradbury gave an update on the FOP Natural History Study, both globally and in Brisbane, and Oliver Collins gave a presentation on the FOP Connection Patient Registry.

The second day began with an FOP Patient/Parent/Sibling sharing session 'Our Roots and Our Wings' facilitated by Ann Harper and Glenys Smith, both highly qualified and experienced social workers. The gathering concluded with an informal FOP Australia brainstorming session.

We hope to share a copy of all the information from the gathering with those FOP patients, families and physicians unable to attend.



FOP Australia Chairperson Lara Boniface celebrating the launch with friends

With so many FOP families together, the opportunity was taken to hold the official launch party for FOP Australia, the new patient and family support organization that was formed in May 2015. Over 240 people attended the event and it was deemed a great success, with raffles, silent auctions, guest speakers, food and drinks and a band to celebrate. The night was also a successful fundraiser

and we hope that somewhere in excess of \$20,000 will have been raised when final figures are in.

Spain's FOP Meeting



The annual General Assembly of A.E.F.O.P. was held in Madrid, Spain on June 17, 2016, in the noted ISCIII (Instituto de Investigación Carlos III). During the meeting IPC leader, Patricia Marin Murciano, talked about three new cases of FOP in Spain and noted there are now 27 people in Spain who have FOP. Investigator doctors of the center and two partner-collaborators of the association, Josemi Lorente and Miguel Coronado, collected FOP information useful for their careers. Miguel Coronado, a graduate nurse, also shared his bachelor work in FOP with the group. Attendees shared a nice time together along with their hope of a new discovery to treat FOP.



Annual German FOP Meeting will be held July 29 to 31, 2016 in Valbert-Meinerzhagen

For more information email roger@fop-ev.de

Focus on Fundraising

Finding A Cure: An Evening of Fellowship and Fundraising

by Sam Maracic



Left to right: Megan and Ashley Martucci

On March 9, 2016, nearly a year of planning and organization culminated as the first ever Finding A Cure, FOP Charitable Event commenced in honor of Ashley Martucci who was diagnosed in 2015 with FOP.

Surrounded by sweeping views of the Statue of Liberty, Ellis Island and New York Harbor, guests, volunteers and distinguished speakers came together at the renowned Ritz-Carlton in Battery Park, New York, to enjoy an evening of fellowship, food and fundraising. Through the tireless effort and unwavering dedication of the Martucci, Maracic and Segal families, members of the FOP Ashley's Cure Committee, the IFOPA and friends and family, a truly remarkable evening took place.



Left to right: Rod & Judy Gilbert, Gary Segal & Donna Martucci-Segal, Anthony & Joanne Maracic

Emceeding the night's event was former New York Ranger and 1982 Hockey Hall of Fame Inductee Rod Gilbert. Monsignor Jamie Gigantiello bestowed guests with an



Dr. Fred Kaplan

opening prayer, while friend, composer, musician and songwriter, Lynn Portas, provided musical entertainment. Patrick Tully served as the program auctioneer. Through the support of the construction industry and the help of incredible sponsors including: Jay and Sharon Podolsky and

family, ADCO Electrical Corporation, Mark and Rachael First, G4 Capital Partners, Hellman Electric Corporation, Levine Builders, Nick and Andrea Patti and family, Skanska USA, David and Pamela Small, Sherwin Williams, Von Rohr Equipment Corporation, Greg and Lisa Cerchione and family, Sciame Construction, Chelsea Lighting, Electrotech, Gilston Electrical Contracting Corporation, the Greves family, L & L Painting Company, Mercury Paint - PPG, NY Electrical Contractors Association, Riverso Associates, Inc., Tishman Construction Corporation and WDF, Inc., as well as the tremendous kindness of friends and family, Finding A Cure grossed nearly \$500,000 in donations.



Left to right: Joe Martucci and Ian Cali

Martucci; FOP community mentor, advocate and fundraiser Ian Cali; and keynote speaker Dr. Fred

All proceeds from the event will benefit the IFOPA and the FOP Research Lab at the University of Pennsylvania to support critical research in finding a cure for FOP.

The evening was co-chaired by Donna and Gary Segal and Joanne and Anthony Maracic. Speakers included Ashley's father, Joseph

Kaplan. From varying perspectives, all three men bravely confronted the fearsome realities and groundbreaking developments associated with finding a cure for FOP. During each address, an overwhelming theme of hope rang true throughout the room, reminding everyone that with continued research, tenacity and drive, we each have the power to create change. Exceeding every and all expectations, the first Finding A Cure event was one to remember.

The 2017 Finding A Cure event has been scheduled for March 29.

9th Annual Bingo For A Cure



David, Stacy and Joshua Scoble

March 20, 2016 nearly 1,400 people attended Bingo For A Cure hosted by Joshua's Future of Promises at the Allentown Fairgrounds in Pennsylvania. This amazing event is possible due to the dedication of 80 volunteers, the generosity of the entire community and the family plus friends of Joshua Scoble. FOP families and the FOP Lab researchers look forward to this event and the following ten FOP people

attended: Patrick Doerr, Lindsay Ruiz, Christine Lichtenberg, Joey Hollywood, AJ Gonzales, Jeanette Bordeau, Lisa Bordeau, Bobbi Johnson, Kathy Ford and Joshua Scoble. Throughout the year Joshua's Future of Promises holds many fundraising events and close to \$115,000 was raised to benefit FOP research at the University of Pennsylvania and the IFOPA! Thank you Chrissy Flexer and the Joshua Future of Promises team for your continued support.

The 2017 Bingo For A Cure event will be held March 19.

Samson Strong 5K



Left to right: Candace, Samson, Maximus and Jason Hixson



Samson enjoyed the 5k on his birthday

On March 26, 2015 we hosted our first annual Samson Strong 5k. It was a beautiful morning in Chattanooga, at the Tennessee River Park, and also Samson's first birthday! With the

help of friends and family sharing our story, the local news station picked up interest in Samson and FOP. They did a brief interview with us prior to the 5k and when the story aired locally, thousands of people learned about FOP for the first time. The story also drew several more people to want to participate in our event. We could not have been happier with the volunteers who helped us, the help we got from Victoria and Denise at the IFOPA office and the overall turnout the morning of the event. When it was all said and done, we raised over \$11,000 to benefit the IFOPA and to fund research to find a cure for FOP. It was such an honor to be able to play a small role in the big world of research and funding. We are so hopeful that we will see a treatment for FOP in Samson's childhood, and we

look forward to hosting the 2nd Annual Samson Strong 5k next year! FOP is part of our life, but it isn't defining who we are and we learned that best from our FOP family across the globe. Thanks to all of you for showing us that we can be strong, we can fight to make a difference, and we aren't alone.

Much love,
The Hixson Family
Jason, Candace, Maximus and Samson

Mother's Day Miles & Smiles!

by Wendy Henke

On Mother's Day, friends, family and FOP researchers went the extra mile, running and volunteering at the Delaware Marathon Running Festival (DMRF). Delaware is home to 16-year-old FOP member Justin Henke. Stepping up were 8-person and 4-person relay teams, half-marathoners, full-marathoners, as well as two shifts of water-station volunteers, including FOP member Nathaniel Padilla's great-aunt and uncle, Helen and Mike Leek.



Cure FOP Team at Delaware Marathon Running Festival

Flying into action, the 'FOP Tooth Fairy' Ruth McCarrick-Walmsley recruited runners and cheerleaders from the FOP Lab and the Orthopaedic Departments at the University of Pennsylvania School of Medicine. Chief among the cheerleaders was Dr. Eileen Shore. Both Ruth and Eileen agreed that everyone enjoyed the team-building experience, the training and fun competitions in the weeks leading up to race day. Their positive and spirited dedication, inside and outside of the FOP Lab, is phenomenal.



Left to right: Dr. Eileen Shore, Justin, Wendy and Kevin Henke

Thanks to generous sponsors, our group donned 'Cure FOP' shirts, displaying photographs of FOP toes and Harry Eastlack, Jr.'s skeleton; the shirts generated conversations and certainly raised FOP awareness among thousands at the event. Raising funds for IFOPA, donations were collected online, including one from DMRF officials, in return for our volunteers manning a water-station.

The miles and smiles of Mother's Day will forever warm my heart. Hopefully someday soon, we'll receive the best Mother's Day gift yet: a treatment and cure for FOP!

Jamba Juice Fundraiser Betina Charis Ramirez



Thank you Betina Charis Ramirez for raising funds for the IFOPA

If you have a Jamba Juice in your community and would like to raise funds for the IFOPA, please call 407-365-4194 or email us at together@ifopa.org with your Jamba Juice manager's name, location address and phone number. Please note, not all Jamba Juice locations offer this fundraiser.

In Clovis, California, FOP member Charis has been raising FOP awareness and funds for the IFOPA by selling Jamba Juice Cards and giving out 'What is FOP?' awareness cards. She has sold 75 cards, raising \$375 for the IFOPA! Charis invites others to join her as a Jamba Juice fundraiser for the IFOPA.

If you have a Jamba Juice in your community and would like to raise funds for the IFOPA, please call 407-365-4194 or email us at together@ifopa.org with your Jamba Juice manager's name, location address and phone number. Please note, not all Jamba Juice locations offer this fundraiser.

2016 Griffin's Fun Run

Sunday, June 12 was the third annual Fun Run coordinated by Griffin Rizzi and his mother Shawna. Each year Griffin chooses a different charity, and this year he chose the IFOPA in honor of Maria Wray, a family friend who has FOP. Seventy-four people attended the event on a beautiful sunny day and numerous people donated online. Thank you for raising \$1,115.92!



Left to right:
Maria Wray,
Felicia Wray,
Griffin Rizzi,
Philip Wray,
Taylor Wray, and
younger Taylor Wray

Below: Griffin's Fun Run



Current Fundraising Event



2016 Midnight Sun 5K Color Run

In honor of Dilyn Martin
July 9, 2016
(meet at the city of
Kotzebue, Alaska
fairgrounds by 2:30 pm)
Help us color out FOP!
Walk or run through five

color stations! All proceeds from the race will go to the IFOPA to help find a cure for FOP.

Register at [Midnight Sun 5K Color Run](#)

Membership News

2016 Jeannie Peeper Award Winners

by Mary Lou Frank

In 2010 the IFOPA launched the Jeannie Peeper Awards in honor of Jeannie's initiative, leadership, vision and courage as Founder and President of the International FOP Association. The Peeper Awards recognize those who have made exceptional contributions to the worldwide FOP community through their leadership and service in raising FOP awareness, supporting patients and families, and raising funds to support the IFOPA's vision to cure FOP. We're pleased to announce the 2016 class of Jeannie Peeper Award Winners; they join 27 previous winners. The IFOPA will be soliciting nominations for next year's winners in spring 2017, so start thinking now of who you would like to nominate. Keep in mind that current IFOPA board members aren't eligible to be nominated. Congratulations to the 2016 Jeannie Peeper Award Winners!

Presidential Lifetime Leadership Award Marilyn Hair



Marilyn Hair

of a new patient group, the International FOP Association (IFOPA). Marilyn remembers, *"My husband and I talked to Jeannie Peeper. It was life-changing, Jeannie said, 'FOP isn't the end of the world.' We were no longer alone."*

Marilyn served on the IFOPA Board of Directors from 1994-2006 and 2011-15, at different times chairing two

committees and serving as secretary, vice chair and board chair. She conducted workshops at FOP Symposia and co-authored, with Sarah, the FOP children's book, *What is FOP? Questions and Answers for the Children*.

Marilyn is most proud of the FOP children's book and of helping establish the L.I.F.E. Committee and Quality of L.I.F.E. Award, a scholarship that provides equipment and training to improve independence for people with FOP. She is also proud of having served as board chair.

Marilyn is amazed by how much is now understood about FOP, and by how many groups are working to find a treatment. *"At the beginning of our FOP journey, we were told that FOP is so rare, nobody was interested in studying it. Now the gene has been identified and many pharmaceutical and biotech groups are involved in drug development for FOP. Seeing meaningful treatments on the horizon gives me hope."*

Thanks to the Internet, the isolation of having FOP is over. Families are quickly referred to Drs. Kaplan and Pignolo at the Center for Research in FOP and Related Disorders. Marilyn says, *"I hope that in addition to finding clinical care, families will join the IFOPA and connect to the FOP community. Meeting others with FOP was the best thing that happened to our family. We have found comfort, strength and hope in the FOP community."*

Marilyn and her husband, Rick Steele, have three grown children. Marilyn lives with Rick and Sarah in Redmond, Washington. She holds masters' degrees in divinity and public health and works as Outreach Manager in a research center that studies human health at the University of Washington.

The International FOP Association appreciates Marilyn's 25 years of involvement and service and is thrilled to have her representing the United States on the International President's Council.

Outstanding Community Involvement Award Individual: Wendy Henke



Wendy Henke

Wendy Henke was in 8th grade when on a class field trip she saw an exhibit at Philadelphia's Mütter Museum that was etched forever in her memory. *"It was a human skeleton connected without pins and wires, but standing upright . . . I read the plaque . . . Harry Eastlack's bones had fused together."*

More than two decades later, Wendy's youngest son, 6-year-old Justin, was diagnosed with FOP. Despite having been evaluated since birth for peculiar abnormalities by the chief of pediatric orthopedics at an internationally renowned medical center, Justin's condition had eluded everyone. (There were even other FOP patients at this very institution.) On April 23, 2006, Wendy serendipitously clicked on an article about a groundbreaking discovery in the so-called 'stone man disease.' She immediately suspected that Justin was a sufferer, and after contacting Dr. Fred Kaplan, the condition was confirmed.

As a former classroom teacher and marathon runner, Wendy was adept at conducting personal and community fundraising events. She began devoting more of her time and expertise to raising two things for the IFOPA: funds and awareness.

In the years since Justin's diagnosis, Wendy and her husband Kevin have conducted annual events, both large and small, in which hundreds of family members, friends and neighbors have taken part. Her favorite by far is gathering 'Cure FOP' teams to participate in the annual Delaware Marathon, which attracts thousands from near and far.

And Wendy remains a tireless advocate for raising awareness about FOP's telltale sign of symmetrically malformed big toes. She even created a captivating business card featuring a photo of the digits and a headline that

parodies a familiar children's nursery rhyme . . . *This little piggy went to the doctor.*

Wendy's efforts also secured 'CUREFOP.ORG,' an action-oriented, easy-to-remember domain name that links seamlessly to the IFOPA website.

Spurring one another on, the Henkes are grateful for all the different ways IFOPA members support one another and contribute to the mission of finding a treatment and cure for FOP. *"Together, we can move mountains!"*

The International FOP Association appreciates Wendy's tremendous efforts over the last nine years to fundraise and raise awareness of FOP.

Outstanding Community Involvement Award Group: Erin's Day

Year after year, Lori and Ken Danzer have organized numerous community fundraising events benefiting the IFOPA. Since 2009, their efforts have contributed an amazing \$230,000+!

"We started out helping the Snow and Eckart families in Santa Maria," Lori says. *"We would sell their event raffle tickets here in San Diego, then take the proceeds to add to their fundraising totals."* Eventually, with some *"amazing help from friends, colleagues and neighbors,"* the couple began organizing their own annual 'Erin's Day' golf tournament near their hometown of Oceanside, California. The first year yielded \$75,000.



Lori, Erin and Ken Danzer

The Danzers' 18-year-old daughter Erin was found to have FOP when she was 10 months old. Dr. Marilyn Jones, a geneticist at Rady Children's Hospital in San Diego, connected the dots between the baby's previous disparate diagnoses and newer symptoms to correctly identify FOP as the single cause for her increasing problems.

Ken and Lori were put in touch with Jeannie Peeper at the IFOPA and began to network with the few California families who share their plight. Over the years, Lori has helped educate neighbors and friends about FOP. She was featured on a local ABC News program and has helped getting several newspaper articles published to spread awareness of the disease.

Lori's words of wisdom for patients and families newly diagnosed? *"It's important to be able to see that even though it might feel like the end of the world, it's not. I am completely in awe of how amazing our FOP community is — they know what you're going through. They get through life with conviction and hope. Get involved online and at some functions, and know that there are caring, knowledgeable doctors who can answer your questions."*

Lori's family makes it a point every day to say, *"Today is a good day,"* so that they can appreciate each day and not dwell too much on an uncertain future. They have great hope because of the amazing advances happening in recent years, looking forward to the day when Erin and everyone with FOP will *"be free, unlocked, no longer be held hostage by their own bone."*

For the coming year, the Danzers are considering holding a Casino Night and Beer/Wine Tasting event at San Diego's Village Nurseries, where Ken is employed.

The International FOP Association is thankful for the commitment of Lori, Ken and Erin Danzer for spending the last seven years raising awareness and much-needed funds for the fight to end FOP.

Inspiring Leadership Award Jelena Milosevic



Jelena Milosevic

The year was 1988. IFOPA was founded in the U.S., and across the ocean in the Serbian capital city of Belgrade, 9-year-old Jelena Milosevic became the first person in her country known to have FOP. Four years later, Jelena met Dr. Kaplan at the University of Pennsylvania. And in 1994, the teen traveled back to Orlando for the

inaugural international FOP convention. *"That trip, and meeting IFOPA founder Jeannie Peeper, changed my life. I realized we are not alone in the world."*

Back home, Jelena began dedicating herself to advocating for disability rights and serving as a stronghold of support and communication for FOP patients in Serbia and nearby countries. She has served as the youngest vice president of Belgrade's Muscular Dystrophy Association and co-founded Serbia's National Organization for Rare Diseases. Jelena is a member of IFOPA's International President's Council and the FOP Connection Registry Patient Advisory Board.

Jelena's dedication and accomplishments continue to touch the lives of fellow patients, while raising awareness of FOP across Serbia. In 2014, Jelena organized the country's first FOP conference, with Drs. Fred Kaplan and Eileen Shore as keynote presenters. The meeting garnered national media coverage and affirmed for Jelena the importance of education and awareness building for families who feel alone in their journey.

She expresses her philosophy of living life to the fullest: *"FOP is certainly a big and important part of our lives, but it is not the only part. I believe we all need to find something we care for and love doing, and then dedicate ourselves to that, despite*

the disease. I love education, reading, writing and translating. . . that's what makes me feel free."

Jelena holds masters' degrees in both English and Political Science. She hopes one day to continue her studies abroad. She lives in Belgrade with her parents.

The International FOP Association is indebted to Jelena for her work to raise awareness and support the FOP community in Serbia and Southern Europe and actively serve on the International President's Council and Patient Advisory Board for the FOP Connection Registry.

Outstanding International Leadership Award Irene Snijder



Irene Snijder

In 2004, Irene founded the Dutch FOP Foundation. As its president, she has helped the country's nine known patient families to share information with one another. Irene has also worked tirelessly to centralize all FOP patient medical records and anatomical samples, giving the country's FOP researchers and collaborating agencies

far greater access to vital data — a truly exceptional model for every country with its own national association.

Irene remembers the day the FOP gene was identified like it was her birthday, because it was her birthday! *"April 23, 2006 — that was a bright spot, a moment of a tremendous amount of hope and happiness,"* she recalls.

In 2009, Irene became IFOPA's International President's Council (IPC) member for the Netherlands. She offers other parents crucial advice she learned by experience. *"I found one less-published trigger for flare-ups is emotional stress. I tell parents to help their children stay calm during*

school exams, and urge them to take notes about the flare-ups, treatment and outcomes."

Irene is retired from her role as President of the Dutch Foundation.

The International FOP Association is grateful to Irene for founding and leading the Dutch FOP Foundation for 12 years and appreciates her continued leadership through the IPC.

Friendly Reminders

Have you moved? Changed your email address?

Please be sure to update your contact information with the IFOPA when it changes. We want you to receive all the latest IFOPA news and FOP research communications. Please contact a staff member at together@ifopa.org or call our English speaking staff at 407-365-4194.

Do you have an article, poem, photo, drawing or good news to share?

The next FOP Connection will be published September 2016. Please email victoria.mandracken@ifopa.org or mail creative pieces and good news you would like to share with our FOP Community by August 16, 2016.

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