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International Fibrodysplasia Ossificans Progressiva Association

## **FOP CONNECTION**

### **March 2011 | Issue 5**

Dear Ms. Peeper,

Everyone Needs Therapy!

If you are reading this, you almost certainly know the shock of receiving an FOP diagnosis, either for yourself, a beloved family member or a friend. For my wife and I, our shock occurred in May 2007 when we learned our granddaughter Miranda Friz had FOP. Shock quickly gave way to sadness which gave way much less quickly to feeling frustrated that we didn't see how we could help Miranda in any significant way. Had we been as wealthy as Bill Gates or as brilliant as a Nobel Prize winner for Medicine, we could donate millions to the cause or participate in the research to find a cure. But alas, we had neither great wealth nor scientific brilliance.

I did, however, have some knowledge of Internet marketing from my years as a business school academic. For several months I attempted to raise funds by establishing an online toy store. Sure, I sold some toys but I never generated sufficient profit to justify the effort. I sent a few modest donations to IFOPA but eventually let the project quietly lapse. I still felt frustrated.

Then in Fall 2008, I was asked if I would be interested in serving as a director on the IFOPA board. As I had just retired and had time available, I said yes and was elected to the board for 2009-2010. I quickly became immersed in board activities and realized that I didn't need to be either Bill Gates or a Nobel Prize winner to make a difference. I also realized that by serving on the board, I no longer felt frustrated. I was doing something to help.

But Mark Gambaiana, a board member whose grandson Lincoln has FOP, gave me further perspective at our February 11-12 board meeting. Mark, a vice president of Truman University, remarked that joining the board and mounting a very successful fundraiser (Lincoln's Legacy) were a form of therapy, a way of coping with the need to help Lincoln in some meaningful way. Jennifer Snow, a long time FOP fundraiser and board member, quickly picked up the theme and similarly described her efforts. I hadn't thought of my own board involvement and my other FOP-related activities as therapy but the shoe fit!

So if you are searching for some way to help the FOP cause, wanting to do something to help your loved one, you could not choose a better year to act than 2011! During our February board meeting, Dr. Fred Kaplan and Dr. Eileen Shore told us about promising research results. But they also pointed out that exploring these new opportunities will require additional funds and hence

their annual funding request from the IFOPA would be greater this year. For the IFOPA, nothing has higher priority than funding research -- the lab request will be met. But in order to meet this extra call for funding, IFOPA needs every family to organize some kind of fundraiser however small or large. ([See our website for some great fund raising ideas](#)) We need to be absolutely sure that the FOP lab has the funds to maintain its research momentum as it hones in on treatments for our loved ones. In short, think of your family fundraiser as a form of therapy -- and feel the satisfaction of making your personal contribution to finding a cure.

In closing, the IFOPA is also in the process of reorganizing, setting goals and priorities to move forward in a more efficient, cost effective way. As many of you know, staffing has recently changed; Wendy Cooper, Membership Manager had completed all projects and her position was no longer needed, Karen Revels, Executive Director resigned and Erin Turner, Development and Communications Manager has received another wonderful career opportunity elsewhere. We wish to thank these ladies for their fine contributions to the IFOPA and we wish them the best of success in their future endeavors. We want to ensure you that the IFOPA President, Chairman, Board of Directors and staff are working hard to meet the needs of the membership and our growing organization.



Malcolm C. Munro, PhD  
Chairman of the Board

## **Upcoming Events**

### **Thursday, March 24 - Saturday, March 26**

FOP Meeting in Italy  
Rome, Italy

### **Sunday, March 27**

Bingo for a Cure  
Allentown, Pennsylvania, USA  
[More Information](#)

### **Saturday, April 2**

Hofstra Islanders United Day Fundraiser  
Uniondale, New York, USA  
[More Information](#)

### **Thursday, April 7**

Fist Pump to Beat FOP  
Newark, Delaware, USA  
[More information](#)

### **Saturday, April 23**

International FOP Awareness Day  
All locations  
[More Information](#)

**Friday, May 13 - Sunday, May 15**

FOP Meeting in Argentina  
Argentina

**Saturday, May 28**

All American 5K in Honor of Ashley Kurpiel  
Peachtree City, Georgia, USA  
[More Information](#)

**Friday, August 19**

Lincoln's Legacy Fundraiser  
Sioux City, Iowa, USA

**Friday, September 23**

Erin's Day Fundraiser  
Carlsbad, California, USA

**Saturday, September 24**

Morgan's Ride Fundraiser  
East Bridgewater, Massachusetts, USA

## Announcements

### Publications Delivery Guidelines

The world in which we live offers technology that is ever changing and advancing. The IFOPA wants to utilize this technology to deliver as much information to our members as we can. The reason? It's two-fold: We can deliver publications to you much faster & efficiently electronically and it helps us keep our costs down. This enables us to funnel our funds to aid research and member's needs. If the IFOPA office already has your email address you will receive the FOP Connection bi-annually in your email inbox. In the event we don't currently have your email address, please send it to the IFOPA office ([together@ifopa.org](mailto:together@ifopa.org)) so we can add you to our email distribution list. Don't have an email address or access to a computer? Don't fret! We will still continue to send a printed copy to you, however, please make sure the office has your current mailing address if it ever changes.

The FOP Connection will be published two times a year, in the Spring and Fall. Along with sending you the newsletter we will also have a link to the current and past issues of The FOP Connection on the IFOPA website ([ifopa.org](http://ifopa.org)). Other publications of interest will have a link on our website as well. These include:

- The Twentieth Annual Report of the Fibrodysplasia Ossificans Progressiva (FOP) Collaborative Research Project by Drs. Kaplan, Pignolo and Shore (available beginning of April)
- IFOPA Annual Report (available this summer)

You will be able to view all publications and print them using your own printer. We will be more than happy to send you a paper copy of any publication the IFOPA has, however you will need to contact the office [+1\(407\) 365-4194](tel:+14073654194) [+1\(407\) 365-4194](tel:+14073654194) to have your request be fulfilled. If you have any questions regarding any publications, please contact the IFOPA

office.

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## **Nominations Open for Jeannie Peeper IFOPA Awards**

*Deadline for Nominations - April 8, 2011*

The IFOPA is pleased to invite you to submit nominations for the Jeannie Peeper IFOPA Awards to recognize those who make exceptional contributions to the worldwide FOP community through their leadership, service, fundraising and accomplishments. These awards honor Jeannie Peeper for her initiative, leadership, vision and courage as Founder and President of the International FOP Association.

Award categories:

- [President's Lifetime Leadership Award](#)
- [Outstanding Community Involvement Award](#)
- [Emerging Leader Award](#)
- [Outstanding International Leadership Award](#)

*\*Please be aware that the Emerging Leader Award is a revamping of the Outstanding Youth Award. The age criteria has been changed to candidates age 29 and under.*

[Please click here to view this information on our website and complete the nomination form.](#)

All completed forms should be submitted by email to [Lori Henrotay](#), Committee Chair.

Keep in mind the following deadlines and remember self-nominations are not allowed.

### **Important deadlines:**

#### **March 9**

Call for nominations

#### **April 8**

Nominations submitted to Committee Chair

#### **April 30**

Selection Committee completes selection of nominees

#### **May 15**

Board reviews and recommends approvals based on nominee slate

#### **June 8**

IFOPA founding anniversary date; Awards announced by Jeannie Peeper.

For questions regarding any aspect of the awards or selection process or to submit your nominations, please email [Lori Henrotay](#), Committee Chair, or call [+1\(314\) 550-0218](#) [+1\(314\) 550-0218](#) . Please also feel free to reach out to any of our committee members:

- [Jeannie Peeper](#)
- [Patrick Doerr](#)

- [Karen Munro](#)
- [Nancy Sando](#)

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## **Lego League Competition Team Brings Awareness to FOP**

Saahil Shah, Jeremy Fan, Kevin Fang and Nitin Prabhakar together make a team of 5th and 6th graders who recently worked on a project as part of a Lego League Competition in the Massachusetts area. As part of their project challenge, they were instructed to explore the cutting-edge world of Biomedical Engineering to discover and research innovative ways to repair injuries and overcome illnesses and disabilities.



This outstanding team of young individuals chose FOP as their topic in hopes to generate awareness of the genetic disorder. Gathering information from the internet, the IFOPA office and Dr. Frederick Kaplan himself, they were able to successful present their project in the competition and have advanced to the state level competition for the state of Massachusetts. We would like to congratulate this young team for their hard work, dedication and enthusiasm to bring awareness and useful research to FOP. Keep up the great work!



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## **IFOPA Announced Winner of Most DonorEdge Portrait Views... Again!!**

Some of you may remember that the IFOPA was the winner of the Most Viewed DonorEdge Portrait award presented by the Community Foundation of Central Florida for the month of November 2010. Well folks, we did it again!

We are very excited to tell you that the Community Foundation of Central Florida announced us AGAIN as the organization with the most visits to our DonorEdge portrait during the month of December.

Simply by viewing our DonorEdge portrait, you helped us win a total of \$2,000 for FOP!

Thank you for your help and support!

The IFOPA

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## **International FOP Awareness Day**

The IFOPA is proud to announce **April 23rd** as **International FOP Awareness Day!**

As most of you know, April 23, 2006 is the day the FOP gene was discovered. What better

day to recognize FOP and spread awareness!

To make this global effort a success, **we need your participation!**

We need members and families to speak with your employers, school systems, sports teams and community groups to see if they will allow the recognition of FOP Awareness Day on Friday, April 22 (as April 23rd falls on a Saturday this year) by implementing a dress down day/jeans day. Our goal is to have 100 people raise \$100 each for a total of \$10,000 - that's as easy as asking 10 friends for 10 dollars!

Dress down days and jeans days are easy and fun! Employees, classmates, faculty members, teammates and community members donate money to the IFOPA in support of FOP research and in return get to dress casually and comfortably that day!

[Click here for more creative ideas for how to recognize the day!](#)

For those interested, the IFOPA will provide you with an FOP awareness kit which can be customized for you. It can include such items as awareness bracelets and t-shirts to use to help raise funds.

As April 23rd is to be recognized internationally, our goal is for this to have a global impact. For those members outside the United States who wish to participate in raising awareness, we ask that you please request your IFOPA materials soon to allow plenty of time for shipping.

To join this effort, please email the [IFOPA office](#) or call (407) 365-4194 (407) 365-4194 .

Thank you for your support and commitment to making International FOP Awareness Day a success!

## Research News



Danish Nagda

### **An Unexpected Calling**

*By Erin Turner, Development & Communication Manager*

For many physicians, their careers are the result of a lifelong plan. Since the time they were children, they wanted to make people better, and so they planned their futures accordingly. For University of Pennsylvania medical student, Danish Nagda, his story is a bit different.

A graduate of Washington University in Saint Louis' Olin Business School, Danish first worked as an entrepreneur and a consultant before deciding he wanted to go back to school to study medicine. His initial interest in the medical field came from wanting to help spinal cord injury patients in Kashmir who were devastated by a 7.6 Richter earthquake. This yearning to help others is what led him to the University of Pennsylvania School of Medicine, which then led him to a Genetics lecture led by Dr. Frederick S. Kaplan.

In that Genetics lecture during Danish's first semester in medical school, Dr. Kaplan introduced the rare genetic disorder known as FOP. He also introduced a young man with the disorder to better explain the effects on FOP patients; the young man's name was Ian

Cali. "They stood up in front of class and took us all by surprise. I wasn't expecting FOP, or Ian," explains Danish, "It was like a sucker punch. [Ian's] perspective on the world shows a level of maturity and perspective that I wish we all had." From that moment, he was hooked, feeling motivated to help and eager to get involved. After the lecture, Danish spoke with Ian and Amanda, Ian's mother, about ideas he had for the researchers that he had brainstormed during the lecture.

Today, Danish is a graduate assistant in the FOP Laboratory. In addition to his work, Danish enjoys meeting with Dr. Kaplan and hypothesizing new and different approaches to a treatment and a cure. His hopes and ideas for the future include assisting and working with a future FOP clinical trial once it is introduced and continuing research in clinical medicine. Danish hopes to one day help find a cure for FOP.

## **Programs & Services**

### **Customize Your Own FOP Booklet**

Looking for a way to spread FOP awareness to your community but not sure where to begin? Look no further!

As part of a Girl Scout project, Jessica Grippaldi has created a customizable FOP Booklet to help create awareness in local communities by adding a personalized touch.

[Click here to download your FOP Booklet](#)

*Tip: Use this brochure when promoting FOP Awareness Day!*

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### **Ladies with FOP**

This group within the Member Center community on the IFOPA website is exclusively for women afflicted with FOP. As many topics discussed are personal as well as sensitive, this group is private and available only to women with FOP. This group requires approval to join.

[Click here for more information](#)

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### **Mentoring Program Available to Members**

*By Nancy Sando, Board member*

1. Mentor a : a trusted counselor or guide b : tutor, coach

The IFOPA is establishing a program to help meet the needs of our member's and their family's. We are laying the ground work so that our members can get support and guidance while they are confronted with the effects of FOP. One of our goals is to be available to new members as they become more aware of FOP and its unique characteristics. Other goals include:

- **The sharing information to our members during a flare-up to help them "re-invent" their new normal**
- **Providing understanding & compassion to our members**
- **Offering advice regarding schooling, recreational activities, relationships, college and careers**
- **Creating a safe, trustworthy and confidential relationship**

One of my personal passions is to connect people diagnosed with FOP together with others that "have been there." When I was first diagnosed with FOP in the 1960's, my family and I felt like we were stranded on a remote island with lots of questions and very few answers. Sound familiar? As the disease advanced, my family and I weathered many storms as each new challenge presented itself. During my adolescence we never found another family dealing with FOP.

Now fast forward to the mid 1980's. This is when I first became aware that there was a doctor (Dr. Michael Zasloff) at the NIH who was studying FOP. I wrote him immediately and was thrilled by his response. He led me to Jeannie Peeper and a few other gals around the country. We became fast friends. In fact when reading their letters (this was way before email!) it felt like I had just discovered family members I didn't know I had. Because of these friendships, my family & I were indeed rescued from that remote island. Working with Jeannie, the International FOP Association was born in 1987. The eleven founding members became its driving force as we embraced one another's hopes, dreams and even shed a few tears. About that same time, the FOP Laboratory was formed at the University of Pennsylvania under the direction of Drs. Fred Kaplan and Eileen Shore.

One of the eldest in our tight-knit group was Margaret Jean Jones (1936-2009) from Alabama. I received my first correspondence from her when I was 23 years of age. Beginning with her first letter in 1982 until her last email days before her death in 2009 she blessed me with her inspiration and encouragement that I still treasure today. Not only did we share a special friendship, but because of Margaret's unending enthusiasm to share her experiences with me, I was able to learn by her faith, knowledge and understanding. My relationship with Margaret was one of the catalysts that drives me to implement an IFOPA Mentoring Program that we can all benefit from.

Shortly after the IFOPA began, I was blessed with marrying Andy, who had FOP as well. We shared fourteen years together, learning, living and loving before his untimely death in 2003. Soon after our marriage in 1988 we realized we had a unique perception of FOP. I, as a woman could easily relate to the ladies and parents of FOP children, whereas Andy could counsel males without much difficulty. Not only could we share the "how to's" but also recognized the need to embrace one another with understanding and compassion. Andy & I were fairly creative in dealing with our physical losses and we eagerly shared some of our homemade adaptive tools (such as our typing sticks, eating utensils etc.) In recent years I have realized that I am in an exclusive spot where I not only cope with FOP daily but because of our marriage I have been on "the other side of the bed" tending Andy's needs much like parents do as they look after their child's needs and desires. (In many ways I believe it is much easier to have FOP than to see a beloved family member's health decline as the disease progresses.)

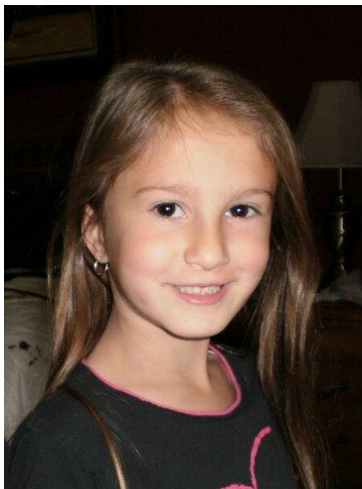
Now in 2011 I find myself back in a leadership role as an IFOPA Board Member and feel very strongly that it is now my responsibility to help mentor others within our FOP family. I am now the age that Margaret was when we first met. Her abundant compassion and

independent spirit continues to motivate me. I am hopeful that the team of Mentors we have can guide others within our FOP family like Margaret did for me during our twenty five years of kinship. My only prayer is that I can do Margaret Jean proud!

In the event you would like more information regarding how to become a Mentor or would like to participate in our program, please feel free to contact me by calling 231 (347-1833) or by emailing me at [nasando@chartermi.net](mailto:nasando@chartermi.net).

Respectfully,  
Nancy Sando

## Focus on Fundraising



7 year old FOP member,  
Morgan Lawler

### **Morgan's Ride in Honor of Morgan Lawler**

*By Kristine Lawler, Mother of FOP member, Morgan Lawler*

In 2009, the Morgan's 1st Annual Ride was established. At the first ride, we met Rick and Samantha Wood and quickly became friends. Rick and Samantha decided to organize Morgan's Ride fundraiser every year beginning in 2010. Rick and Samantha have worked tirelessly on the event in the hopes of making Morgan's Ride one of the largest organized bike rides in the State of Massachusetts.

On Saturday, September 25, 2010, Morgan's 2nd Annual Ride left Raynham, Ma at 12:00pm and ended at approximately 1:30pm at The Knights of Columbus in Whitman, Ma. One hundred and thirty riders participated making this a very successful event. The Knights of Columbus hosted the after-ride event with entertainment, food, and a silent auction.

Rick and Samantha have worked year round to promote the event and they are currently working on Morgan's 3rd Annual Ride which will take place on Saturday, September 24, 2011 departing and arriving at the same locations. If you would like more information, please email Rick and Samantha at [morgansride@verizon.net](mailto:morgansride@verizon.net)



Front row: Rick Wood, Morgan Lawler, Samantha Wood. Back row: William and Kristine Lawler

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Tables at the event were decorated to fit the masquerade theme.

## **Unmasking the Mystery of FOP II in Honor of Cody Dennings**

*By Dave Dennings, Father of FOP member, Cody Dennings*

Friends and family of 15 year old Cody Dennings (diagnosed with FOP at age eight) held their Unmasking the Mystery of FOP II benefit in Houston, Texas on February 26, 2011. Two hundred fifty people filled the League City's Johnnie Arolfo Civic Center for the fun and festivities.

The evening kicked off at 6 pm with a happy hour and opening of the silent auction containing over 50 wonderful items including: a seven night stay at a Park City, Utah ski resort, an island getaway at a Costa Rica resort, a weekend stay at a Galveston Island beach house, and a four hour Galveston Bay cruise on a 40 foot yacht.

Tamara Vogt of Mario's Pizzeria catered the evening's dinner gratis that started with Italian bruschetta in scoops and guacamole stuffed scoop with jumbo lump crab and cilantro served by a fantastic team of teen volunteers serving the hors d'oeuvres on silver platters as the guests arrived and began to mingle. A buffet style dinner was served consisting of porcini ravioli and chicken ala Mario's with

artichoke hearts, mushrooms and capers along with a wonderful spinach salad, vegetable medley and dinner rolls.

Honorary chairperson Dr. Greg Smith, Superintendent of Clear Creek Independent School District, said a few inspirational words about Cody, and then introduced Cody's parents Jen and Dave Dennings, who presented recognition plaques to some of the generous sponsors. Dr. Greg Smith, Tamaro Vogt, Scott Counts of Sysco Foods and fundraiser committee member, and Jeremy Holzbach of Bach Sound Productions were among those recognized for generously donating their products and services.



A great turnout of FOP members at the event! From left: Daunte Hernandez, Steve Eichner, Ashley Kurpiel, Cody Dennings and Nick Mahler.

Recognition was also given to the fundraising committee comprised of the Campise, Clay, Counts, Daigle, Ingenthron and Radney families, (special friends of the Dennings) for helping to make such a wonderful event a reality, and to Cody Dennings for whom the evening was in honor of.

In attendance were several of our FOP family including for a second time fellow Texans Steve Eichner and his wife Nancy, and Nick Mahler and his wife Lori. In addition, this year two new special guests were in attendance Ashley Kurpiel from Atlanta and Daunte Hernandez from Las Vegas. Everyone was so excited to have Becky Kaplan representing the IFOPA also in attendance for this year's event.

As everyone was finishing their dinner and preparing for dessert - double chocolate cake and New York cheesecake - a presentation of the IFOPA informational video "Our Mission of Hope" really grabbed their attention and clearly emphasized the purpose of the evening's festivities.



The evening's host! The Dennings Family: Cody, Jen, Cameron and Dave.

The evening came to a close with everyone having so much fun dancing and bidding up the silent auction items, which alone brought in \$15,000. In total approximately \$36,000 was raised for the IFOPA. The Dennings family would like to thank everyone who donated to this great cause, helping to make Unmasking the Mystery of FOP II a huge success.

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Spiderman, Grandpa Mark Gambaiana, Lincoln Wheelock and Batman take a break from the carnival.

**"Leap for Lincoln" Winter Carnival Nets Nearly \$12,000 for FOP Research**

*By Mark Gambaiana, IFOPA Board Member and Grandfather of FOP member, Lincoln Wheelock*

A chilly Iowa February afternoon brought many warm-hearted family, friends and well wishers indoors for the first-ever "Leap for Lincoln" winter carnival staged on February 26 in West Des Moines, IA.

The event was held in honor of four-year old Lincoln Wheelock of Des Moines, son of Lee and Trisha Wheelock, and designed to raise

awareness and financial support in central Iowa. Approximately \$12,000 was netted for FOP

research from the carnival.

Nearly 400 kids of all ages attended the event that featured carnival games, face painting, arts and crafts, a caricature artist, concessions and a silent auction. Special appearances were made by Spider-Man, Batman, Care Bears, and the Dance FX team.



Lincoln notches a strike in the bowling game!

In addition, Spencer Johnson, a Des Moines native and member of the USA Gymnastics team currently training for the 2012 Olympics, conducted a demonstration for the participants. Also performing for the kids was Dan Wardell, host of Iowa Public Television's Kids Clubhouse program.



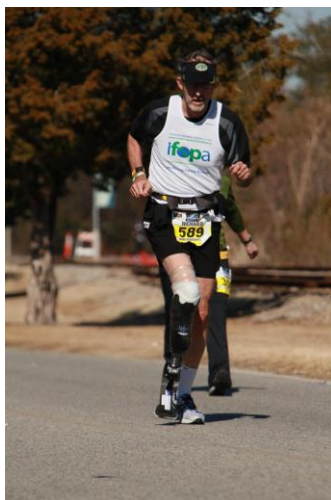
IFOPA board member Mark Gambaiana, FOP member Kyle McWilliams, Trisha Wheelock and Lincoln Wheelock pose for a photo.

The carnival was organized by Kristie Kolsrud, Lincoln's babysitter, and included over 60 volunteers.

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## **Runner Competes in Charleston Marathon in Honor of Ashley Kurpiel**

*By Erin Turner, Development & Communications Manager*



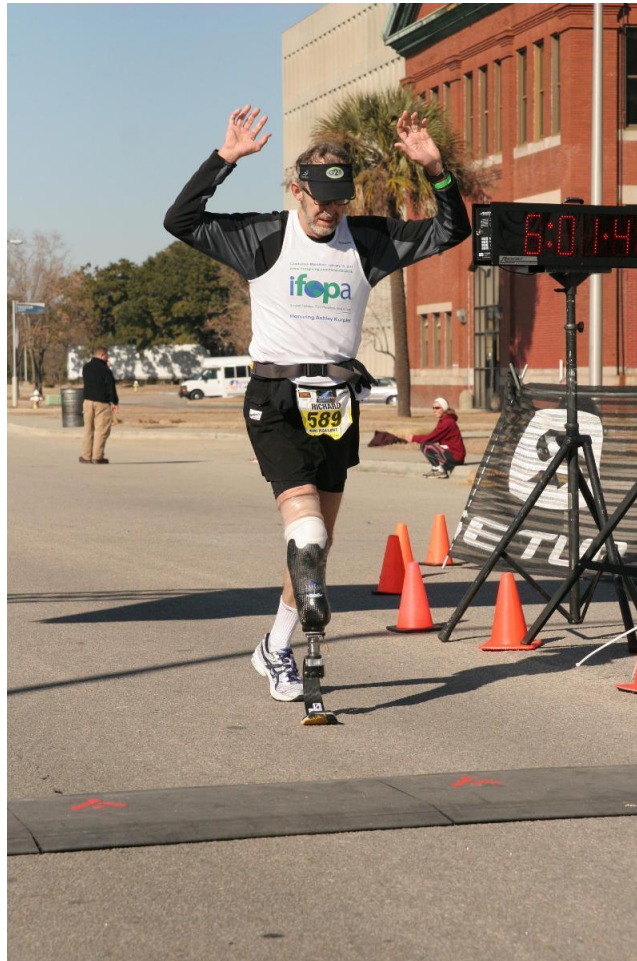
Richard Blalock runs marathon for FOP.

As many of you may recall, Richard Blalock, a remarkable person and good friend of FOP member, Ashley Kurpiel, created a blog called "My Marathon for FOP" for his run in the Charleston Marathon on January 15th of this year. Like Ashley, Richard is an amputee; Richard's leg was amputated below his knee a little over a year ago. As this was his first marathon post-amputation, we are happy to announce that Richard successfully completed the 26.2 miles sporting the customized shirt he had made to honor Ashley! The support and encouragement Richard received prior to and during the race was overwhelming. "Believe me," Richard explained, "that show of love and support helped me through many tough miles."

[Click here to read more about Richard's experience](#)

Richard already has plans to run the next Boston marathon as well as a 5K fundraiser Ashley is planning in Georgia this April.

Thank you to Richard for all you have done to spread the word of FOP. We wish you luck and support in your future marathon endeavors to raise awareness and funding for FOP!



Richard crossing the finish line!

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**High School Student Raises Funding and Awareness for FOP**

Emily Collins, niece of FOP mother Amanda Cali and cousin of FOP member Ian Cali, recently gave a presentation on FOP at her high school on January 8, 2011. In addition to explaining FOP and its characteristics, Emily sold IFOPA awareness bracelets and is proud to report that more than half of the students and teachers at her school are wearing them! Emily's outstanding efforts raised \$1,125 for FOP! Thank you to Emily for helping to spread awareness of FOP and raising much needed funds!



Emily Collins (front) and her high school supporters!

**Media News**

**FOP Member Featured in Vanderbilt Medicine Magazine**

FOP member, Sharon Kantanie, was recently featured in Vanderbilt Medicine, a magazine distributed to alumni of Vanderbilt's School of Medicine.

[Click here to view the article](#)

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**Matt Horick on Mystery Diagnosis**

FOP member, Matt Horick, was featured in an episode of Mystery Diagnosis which aired on Wednesday, January 12, 2011.

[Click here to view a clip of the episode](#)

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**Australian Newspaper Publishes Article on Young FOP Member**

A local Australian newspaper published an article on young FOP member, Zach Armstrong.

[Click here to read the article](#)

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## Article Published on FOP and Stem Cell Research

An article on FOP and stem cell research was recently published - a collaboration between the FOP laboratory at the University of Pennsylvania and Dr. Olsen's lab at Harvard University.

[Conversion of Vascular Endothelial Cells into Multipotent Stem-Like Cells](#)

[Building Bone from Blood Vessels](#)

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## Mother's Article on FOP Published in Magazine

Karen Munro, mother of FOP member Miranda Friz, wrote an article about Miranda and FOP for a Canadian magazine called "Today's Kids in Motion". The magazine is about children with disabilities and special needs, and is distributed mainly to family physicians' and pediatricians' offices.

[Click here to read the article](#)

## International Updates



FOP member Jelena Milosevic, third from the left, has been elected as the President of NORDS.

### Establishment of National Organization for Rare Diseases, Serbia (NORDS)

*By Jelena Milosevic, FOP member and IPC Representative for Serbia*

It is my pleasure to inform you that the National Organization for Rare Diseases, Serbia (NORDS) was finally established in 2010. It is the union of seven associations which gather people with different rare diseases and the members of their families. One of these is the Muscular Dystrophy Association of Serbia.

Both of us with FOP in Serbia are the members of the Muscular Dystrophy Association of Serbia.

I was elected as the President of NORDS. The main aim of NORDS is improving the quality of life of people with rare diseases and the members of their families through numerous

activities and initiative. There is a lot to be done in this field in Serbia.

Even though the idea of the establishment of the National Organization for Rare Diseases, Serbia, had already been announced in the media, this organization had its first official media appearance at the Press Conference in November 2010. We spoke about our goals and plans, how everything began, the medical, social and personal challenges people with rare diseases and their families face. It was also a great opportunity for me to speak about FOP, as one of the rarest disorders. The media coverage of this event was very good.

We all have plenty ideas and plans for 2011 and a lot of energy and ambitions to fulfill them. In addition to this, we are aware of the fact that the best way to achieve our goals is through the continuous cooperation and joint work with related national and international organizations and national and city authorities.

Together we can make a difference.

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## **New IPC Member**



**Dr. Antonio  
Morales Piga,  
Spain**

I am a Spanish rheumatologist who after more than 20 years working for the Spanish National System of Health recently moved to the Institute for Research of Rare Diseases, at Madrid (Spain). My oldest son lives in Aachen (Germany) working as a Speech scientist, and my youngest one, just graduated in Computer engineering, currently is working for a technology company specialised in "Quantitative Risk Research".

Since the beginning of my medical training I became interested on clinical research of metabolic bone diseases. As a consequence, I spent a year in Loma Linda VA hospital working with David Baylink who taught me the love for the work well done and the commitment to research. At that time I was predominantly engaged on Paget's bone disease, for whose intriguing causality and amazing clinical picture I felt deeply interested. This brought me the possibility of meeting Fred

Kaplan at the first symposium of the Paget Foundation I could attend, in Oxford, at 1998. I will never forget the conversation we had while enjoying breakfast in such a wonderful place. His fascinating personality and exceptional mind discovered me a new world: FOP. Although I knew the disease since the early 80s (in fact I co-authored the publication of the first two cases reported in my country), after this encounter with Fred I learnt its true essence. A process at the same time wonderful and very sad. Wonderful because when I see any of the patients with FOP I can recognize courage, intelligence and desire to live. And very sad because all these good qualities collide with a harsh shell that oppresses them unfairly.

And that is why I am here: to make my small contribution for help changing this unfair situation.

***Please join us in welcoming Dr. Piga to the IPC!***

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## **Dutch FOP Symposium**

By Irene Snijder, IPC Representative for The Netherlands and mother of an FOP member

The Dutch FOP symposium was held on Saturday the 27th of November at the Marriott hotel in Amsterdam. We are thankful for the care and discounts that were provided by the Marriott hotel. We like to thank our donators, because of them we get subsidy from the government that allows us to organize this FOP symposium. It was a very informative day, the lectures contained a lot of new findings. Above all, the lecture of Peter ten Dijke (Leiden University Medical Center) about the FOP ALK2 and new ideas for further research was very interesting. Unfortunately Dr. Eileen Shore and Dr. Kaplan were not able to attend but we hope that they are able to join us at the next FOP symposium.

**Dentist Elinor Bouvy Berends and mouth hygienist Annemieke van den Broek (CTB Rijnmond)** who are specialists in dental care for disabled people kept a lecture about what a particular dental center can do for FOP patients. Elinor Bouvy Berends explained us about infiltration anesthesia and about STA (single tooth anesthesia), the anesthesia can be given by a CCLAD Computer Controlled Local Anesthesia Delivery Machine, which is safe for people with FOP. Annemieke van den Broek, the mouth hygienist, told us about a product from Australia called Recaldent that prevents tooth decay. Recaldent contains natural proteins: Recaldent caseine, Casein Phosphopeptides, known as CPP, and Amorphous Calcium Phosphate known as ACP. It is available in three variants: MI paste plus, Tooth Mousse and Dry Mouth Gel. The dentist can do a saliva test and can tell you which one is most suitable for you. It is not recommended to use it when you have an allergy for milk. She told us to look on the site: <http://mun-h-center.se/sv/Mun-H-Center/> of the orofacial called the Mun -H -center in Sweden that has a bright collection of gadgets and advices.

**Peter ten Dijke, professor in molecular cell biology from the LUMC (Leiden University Medical Center)** kept his lecture about the fundamental research he is doing with pluripotent stem cells and the use of new techniques in analyzing exons. In a powerpoint-presentation he explained the research that is done at the Leiden University Medical Center in co-operation with the University of Twente which is published in " Journal Bone and Mineral Research". He explained us how the mutated FOP ALK 2 receptor works and how cells become high sensitive for BMP growth- factors. The department of human Genetics from the LUMC is successful in other rare diseases analyzing different exons as in other muscle diseases to study new therapeutic strategies.

### **Prof. medical Dr. Coen Netelenbos VUmc informed the group about all the news from the FOP laboratory.**

He gave a powerpoint-presentation and explained everything from the finding of the FOP gene till the latest research and animal developments from the FOP laboratory of Eileen Shore PhD./Medical and Dr. F.S.Kaplan

### **Nathalie Bravenboer PhD, from the Department of Endocrinology / Clinical Chemistry, VU University Medical Center kept a lecture about the histology of the bones.**

She told us that there are 1200 bone biopsies in the VUmc, from which a lot of them were taken by Dr. Coen Netelenbos and she explained the procedure from the biopsy to the microscopic slide. She chose eight of them from different people (with normal bone tissue

and abnormal bone tissue) and explained us the difference. She showed us trabecular bone, compact bone and explained us about the osteoclasts, osteoblasts and osteocytes.

**Medical Doctor Marelise Eekhoff in the Endocrinology from the VU University Medical Center** kept a lecture about heart and lung function. Dr. Kaplan published an article about deceased individuals with FOP which is published in "The Journal of Bone and Joint Surgery" 2010. Cardiorespiratory failure from thoracic insufficiency syndrome by FOP patients is a common issue and beside this article three FOP patients of the nine in the Netherlands have had a pericarditis. Marelise Eekhoff likes to pay attention on this subject and will screen heart and lung function yearly in the FOP patients which she will coordinate in VUmc.

The VUmc will start research on fibroblast tissue culture derived from FOP patients and healthy persons and she explained us all the details about this research.

**Irene Snijder kept a short speech because we were running out of time.**

She tells us about the importance of international cooperation because of the very few patients with FOP in the Netherlands and worldwide. The International FOP Association has 465 people with FOP registered. Working together is crucial for medical findings worldwide and clinical trials in the future. She honors Burçin Çolak (student molecular cell biology of the VU) for all the translations she made in Turkish. We hope that because of her efforts more people in Turkey will be diagnosed. She received an loud ovation of the audience.

**Suzanne Krete of the Dutch organization MEE held a presentation and answered questions.**

MEE is a Dutch organization for anyone with a handicap, functional disability or chronic illness. MEE is for people whose restrictions cause difficulties in their day-to-day lives and who cannot fully participate in social life. MEE gives information, advice and support.

**Hypnotherapist Dick Wernars gave a workshops about stress management and breathing techniques.**

The hypnotherapy session of Dick Wernars started in the afternoon when it was already dark outside. A good moment for everyone to relax after an intensive day after all medical information. Every exercise could be done sitting in a chair. First were hypnotic breathing techniques learned for deep relaxation, secondly a stress reduction technique; magnetic hand release, in order to let tension flow away. Thirdly, in the hypnotic trance, people were instructed to go back in time to a place or experience where they felt comfortable, secure, strong and self-confident. These thoughts and emotions were then connected to a special sign (make a ring with your right thumb and forefinger) in order to experience these processes also out of the hypnotic trance. After the sessions everybody felt very relaxed and wanted to practice the acquired skills at home.



Group photo at the Dutch FOP Symposium.