

International Fibrodysplasia Ossificans Progressiva Association

FOP CONNECTION

June 2010 | Issue 2

Dear Friends,

It has been a busy and fulfilling 6 months serving as your Executive Director. I am pleased with the progress we have been making at the IFOPA in regard to our programs to better serve you! We have had many successful e-learning events; I hope you have been able to join us for some of them! We are excited about the upcoming launch of our new medical binder, newly designed materials and the recent launch of the Jeannie Peeper Awards! The IFOPA annual report and the highly anticipated Nineteenth Annual Report of the Fibrodysplasia Ossificans Progressiva (FOP) Collaborative Research Report written by Drs. Kaplan, Shore and Pignolo will be mailed to all members in the next few weeks.

I would also like to take this time to announce some changes that have been made here at the IFOPA office:

As many of you already know, Wendy Cooper is the IFOPA's new Programs & Membership Manager. Wendy joined our team on Thursday, March 25th and has much experience with non-profit organizations. As many of you who have spoken with her know, she is extremely enthusiastic to be working on membership programs and getting to know all of our members! She is incredibly pleasant and indeed a wonderful addition to our IFOPA family.

Also, Erin Turner, our previous Membership & Communications Coordinator, has recently been promoted to the IFOPA's Development & Communications Manager. Erin is looking forward to working with FOP fundraising families and researching grants in addition to managing IFOPA publications and maintaining the IFOPA website. She enjoys the challenge of new responsibilities and is very excited about her new position!

The IFOPA has a new administrative assistant! Andrienne Smith joins us from Workforce Central Florida on a grant that provides free administrative assistance for 3 months. Andrienne is an extremely pleasant woman and we could not be happier to have her with us!

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The IFOPA Mission

is to eliminate FOP as a health concern through education, advocacy, research and support.

The IFOPA Vision

is to search for a cure while instilling HOPE worldwide.

I hope you have a wonderful summer and we look forward to serving you the best we can!



Karen Revels
Executive Director

• Upcoming Events

June 20, 2010

A Special Benefit Concert for FOP featuring Sam Adams
Morristown, New Jersey
7:00pm ET

June 26, 2010

Benefit for FOP
East Bridgewater, Massachusetts
7:00pm ET

July 23 and 25, 2010

Cure FOP Swim-Along
Middletown, Delaware

July 24, 2010

Golf for a Cure
Watertown, New York
8:00am ET

September 19 and 26, 2010

Erin's Day 2010
Carlsbad, California

• Announcements

19th Annual Report Now Available

The Nineteenth Annual Report of the Fibrodysplasia Ossificans Progressiva (FOP) Collaborative Research Project written by Drs. Frederick S. Kaplan, Eileen M. Shore and Robert J. Pignolo is now available on the IFOPA website at www.ifopa.org!

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### **IFOPA Annual Report**

We are pleased to announce the IFOPA will be publishing an annual report for the organization

for the first time! This report will be available later this summer on our website.

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Jeannie Peeper IFOPA Award Winners Announced

It is our great pleasure to announce the 2010 recipients of the Jeannie Peeper IFOPA Awards:

President's Lifetime Leadership Award

2010 Recipient: Marie Peeper

Outstanding Community Involvement Award

2010 Recipient: The Noontime Kiwanis Club of Santa Maria, California

Outstanding Youth Award

2010 Recipient: Oliver "Ollie" Collins

Outstanding International Leadership Award

2010 Recipient: Dr. Patricia Delai

We would like to thank the Jeannie Peeper IFOPA Awards Committee which includes Patrick Doerr, Lori Henrotay, Carol Kurpiel and Jeannie Peeper for the many hours they spent reviewing each nomination. It was indeed a joint effort and we greatly appreciate their dedication.

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## **Become a Leader of the IFOPA!**

Each year the IFOPA looks to its membership, family and friends for potential candidates to serve on the IFOPA Board of Directors. But who is the IFOPA Board of Directors, and what do they do?

The IFOPA Board of Directors consists of a minimum of nine (9) Directors, with a maximum number of fifteen (15). In order to best meet the needs of the organization, the Board is represented by one-third professional members, one-third FOP family members and one-third people with FOP. Each Board member serves a two-year term which begins in January and ends on December 31st of the second year. Among these directors, there is an Executive Committee which consists of a Chairman of the Board, Vice Chair and Secretary. This committee meets via phone conference, where they keep up-to-date on the work conducted by the IFOPA office and insure that the goals of the organization are on track.

The IFOPA Board of Directors is designed not only to govern the functions of the IFOPA, but also to work on and with committees for projects that are important to the FOP community. Each IFOPA Board member is a volunteer and they are asked to spend 10 hours per month working on projects such as symposium/FOP gatherings, International Presidents Council and the newly established Jeannie Peeper awards. Another vital function of the IFOPA Board of Directors is to assist in securing funding for the IFOPA and FOP research. The entire Board of Directors meet via phone conference once every other month. There is one in-person Board meeting each year where much of the work takes place in defining the direction and budgetary needs of the organization.

This is YOUR organization and **WE NEED YOU!** As you review the new IFOPA Annual Report

and learn about the exciting things happening in our community, we ask that you consider yourself, a family member, or professional in your community to become part of this IFOPA leadership. After all, it takes all of us working together to educate, support families and Find A Cure for FOP!

If you are interested in obtaining more information or would like a nomination form, please contact Jennifer Snow at (805) 937-1420.

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New Membership Center on IFOPA Website

In the next coming weeks, the Membership Center on the IFOPA website will undergo changes. As part of Phase II of the website redesign, we are implementing a more interactive, social networking system for IFOPA families and friends. Members will have the opportunity of creating a personal profile, adding friends, uploading photos, joining specific Member Groups, discussing topics amongst these Member Groups, locating past discussion topics to review previous advice given and controlling their privacy settings. In addition, this new system will allow easier access to the Membership Directory and an interactive map showing nearby IFOPA contacts of a specified location or zip code.

Please look for future emails regarding an e-learning event for this New Membership Center! We want every member to have the opportunity to learn each of these new functions so that they may easily be connected with other IFOPA families. *Any questions or concerns regarding this new system will be addressed on this e-learning event, so be sure not to miss it!*

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## **IFOPA Proclaimed "Four Star Charity" by Charity Navigator**

In its recently published Annual Report, Charity Navigator lists its rankings for non-profit organizations. The IFOPA is mentioned as one of the "Four Star Charity" organizations!

## **● Research News**

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### **FOP Lab Researchers Volunteer to Translate**

*By Amanda Cali, Malcolm Munro, and Daniela Becker, IFOPA Directors*

Everyone in the FOP community greatly appreciates the wonderful work of the researchers at the FOP lab. But now we have something else to appreciate them for! It all started when Dr. Bob Pignolo was recently told about the IFOPA's major project to make important documents and the IFOPA website more broadly accessible to our international community by having materials translated into several major languages. He went right to work to find answers to the troubling cost of professional translators and the challenge of recruiting volunteers. Within only days, Dr Pignolo took action and reported that several FOP lab researchers whose first language is other than English volunteered to help with translating. In particular, lab volunteers have agreed to focus on translating the very important Treatment Guidelines when a revised version is available later this spring. The lab researchers' language skills will enable IFOPA documents to be translated into German, Russian, Chinese and Indian (Hindi) in addition to other languages for which volunteers will be sought. We also have had strong volunteers such

as Dr. Patricia Delai, Moira Lilljeström and several others who continue to help with translation - an exceptionally valuable service to the FOP community worldwide.

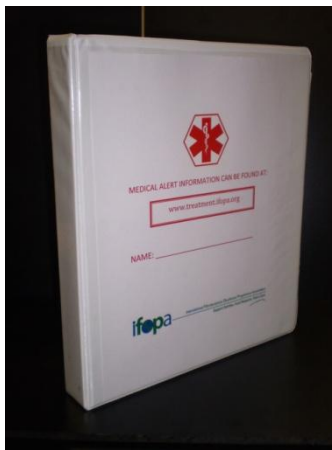
Many thanks go out to the FOP researchers and others who show how much they care by providing such a valuable service to us all! The IFOPA's translation project is headed by Daniela Becker, IFOPA Director. If you would like to volunteer to help with translating, please contact Daniela Becker at [dbecker@rollins.edu](mailto:dbecker@rollins.edu).

## • Programs and Services

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### **Medical Binders Soon Available**

*New Medical Binders will soon be sent to every FOP member free of charge!*



Medical issues are difficult enough with FOP. Having personalized medical information at your fingertips helps to reduce the stress and in some cases will provide the opportunity for you to get better care.

Medical Binders store all the important information you will need in one place. The Binder is an organization system for medical documents that will prove invaluable in communicating with your medical team about a rare condition like FOP.

Your medical binder can house:

- emergency contact numbers
- current and past prescriptions
- medical history
- history of flare-ups
- medications and supplements

Take the Medical Binder to all doctor appointments and all hospital stays for easy reference for your physicians. Your doctors will appreciate having this medical data readily available during your appointment or hospitalization.

Along with your medical Binder you will receive one USB drive and one water proof pill container; both can attached to your key chain or backpack. The USB drive comes with preloaded forms for you to fill out and can be personalized with information specific to you. In a medical emergency, things happen fast. Emergency responders need a simple way to get more

information. The emergency staff can simply plug the USB into any computer and your medical history is instantly available!

The IFOPA will provide you with one Medical Binder, USB drive and waterproof pill container free of charge; they will be automatically mailed to you by mid-August, 2010. You will have the opportunity to purchase more at an additional cost from the IFOPA.org online store. You can purchase them as a set or each item individually. Pre-order additional copies now by contacting Wendy Cooper at [wendy.cooper@ifopa.org](mailto:wendy.cooper@ifopa.org)

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Emergency Information Now Readily Available on IFOPA Website

Emergency Medical Treatment Information is now just a click away on the IFOPA website!

When visiting www.ifopa.org, you will notice a red symbol at the top right-hand corner of the page next to the wording "Emergency Medical Treatment Information". This is a symbol for a medical emergency.

If ever there is an emergency, this link will immediately provide you with contact information for Dr. Kaplan and Dr. Pignolo as well as a direct download to the Current Treatment Considerations document.

Though we sincerely hope no one ever has to use this, we want everyone to be aware of its availability and location if ever it is needed.

If you have any questions or concerns, please do not hesitate to contact the IFOPA office at (407) 365-4194 or together@ifopa.org

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## **New Membership Packet**

When members join the IFOPA, they receive a New Membership Packet that welcomes them to the community and provides them important information, medical contacts and resources. We have noticed that throughout the years the material in this packet has become outdated and slightly cluttered. Therefore, we have revised these items to provide up-to-date information in a clear, more specific way.

These New Membership Packets will be sent to all IFOPA members this summer! If you have any questions, please contact Wendy Cooper at [wendy.cooper@ifopa.org](mailto:wendy.cooper@ifopa.org)

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Launch of Website for People with Disabilities

A friend of FOP member, Louis Cantwell, has recently launched a social networking website for people with disabilities. The website is called Our Town Earth and is created by and for people with disabilities. Please visit www.OurTownEarth.com for more information!

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## **Mentoring**

When individuals and families affected by FOP contact the IFOPA, they often want to speak to another family dealing with FOP. To facilitate this process, the IFOPA has created a Mentoring Program, which is designed to provide a family-to-family connection in addition to staff support. Volunteer representatives in the Mentoring Program will be called Mentors; they will either be affected by FOP or be the parent/sibling/caregiver of a person with FOP.

Mentors in this program will serve families in the following ways:

- Listen and share their own experiences with FOP
- Provide a route of communication for families in their region
- Be familiar with IFOPA programs and provide useful information and guidance based on that knowledge

If you would like to be a mentor, be matched with a mentor or simply would like more information, please contact Wendy Cooper at [wendy.cooper@ifopa.org](mailto:wendy.cooper@ifopa.org)

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Request for e-Learning Event Topics

The IFOPA e-learning events have been very successful thus far thanks to our wonderful presenters and fantastic, interactive audiences. To continue these events, we need your help! Please tell us topics you would either like to present information on, discuss, or learn more about. This will help us better prepare e-learning events to meet the needs of our members! Please send your requests to Wendy Cooper, Programs & Membership Manager, at wendy.cooper@ifopa.org

● Focus on Fundraising

A Simple Way To Help

Add the GoodSearch toolbar to your Internet Explorer or Firefox, and each time you shop at one of the more than 1,300 participating stores, a percentage of what you spend will be donated to the IFOPA at no extra cost to you! *You could even save money as the toolbar provides coupons and deals.*

In addition, the toolbar also has a search box and each time you search the Internet, a penny is donated to the IFOPA! No registration is required. Please visit www.goodsearch.com for more information.

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### **IFOPA Staff Participates in 5K to Promote FOP Awareness**

On Thursday, April 15, the IFOPA staff participated in a Corporate 5K through beautiful downtown Orlando, Florida. Eager to promote awareness and funding for FOP, the staff encouraged friends and family to join the "IFOPA Team" and walk together sporting IFOPA t-shirts. In addition to raising \$250 in donations for the IFOPA, they created an opportunity to promote FOP awareness to the community.



**The IFOPA Team at the Corporate 5k in Orlando, Florida!**  
**Back Row: Randy Turner, David Rosenthal, Kurt Wenrich**  
**Front Row: Karen Revels, Becky Kaplan, Erin Turner**



**IFOPA staff members Becky Kaplan, Karen Revels and Erin Turner at the Corporate 5K in Orlando, Florida!**

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IFOPA Wins \$500 Cadillac Grant

Thanks to wonderful efforts from the IFOPA community, the IFOPA was recently announced the winner of the Massey Cadillac "Cadillac of Test Drives" contest and received a check for \$500! With a grand total of 1,238 votes we beat the runner up by an incredulous 702 votes! Thank you to everyone who voted!



IFOPA staff members Erin Turner, Karen Revels and Wendy Cooper at the "Cadillac of Test Drives" check presentation held at Saks Fifth Avenue in Orlando, Florida.

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## **Like Father, Like Son – A Tradition of Philanthropy**

*By Erin Turner*

It began 9 years ago with an invitation. A piece of paper that would forever change Gary Whyte, a resident of Mountainside, New Jersey. This invitation, sent by Hillary Weldon, mother of FOP member Whitney Weldon, now 18, welcomed Gary to attend a seminar on FOP awareness. It was upon leaving the seminar that Gary said to himself, "I have to do something". He felt a great need to get involved, to help; and that's just what he has been doing for nearly a decade.

Gary first met Hillary at the Children's Specialized Hospital where he served on the board of trustees. As the director of northeast operations for Ecuadorian Line, a banana distribution company for Bonita, Gary would deliver two cases of bananas to the Children's Specialized Hospital each Thursday. It was during this routine that he and Hillary met and became fast friends. Whitney and Gary's son Eric soon became friends as well, being only one year apart in age.

Not long after, Gary began hosting fundraising events to bring awareness of FOP to the community. One day in 2002, he sat down with his three sons and asked if any of them had an interest in helping. Eric, 9 years old at the time, did not hesitate for a second. He immediately accepted the opportunity and soon became very involved in the process; a truly awe-inspiring, admirable action by such a young person. Eric has been by Gary's side throughout each fundraising endeavor ever since.

In addition, Eric has also been raising funds for FOP on his own. Since the 8th grade, Eric has been Student Government Class President for his school, and this past year was elected Executive President of the entire school. During his time in these positions, he has coordinated school events such as a "Movies in the Park" fundraiser and several Penny War fundraisers; each event raising over \$1,000. Because of his titles of Class and Executive President, Eric is given the privilege to designate the charity of his choice to receive the proceeds. Each time, Eric has chosen the IFOPA.

In addition to these fundraising events, Gary and Eric host an annual comedy show fundraiser that has grown immensely throughout the years. As a bring-your-own-food-and-drink event, this event has become quite the local cook-off! Each year attendees compete amongst each other to see who has the best dish in town. Each event begins with an introduction and explanation of FOP for those who are not familiar with the rare disorder. What follows is a fun night of laughter, good food and great friends who come together to support Gary and Eric in their efforts to raise funding and awareness for FOP.

The IFOPA would like to thank Gary, Eric and all of their supporters and volunteers for making this such a wonderful event year after year. Thank you for bringing us closer to finding a treatment and a cure for FOP, one laugh at a time.

*\* We would also like to congratulate Eric Whyte for recently being announced the newest Eagle Scout of Boy Scout Troop 368 of Berkeley Heights, New Jersey! Eagle Scout is the highest rank attainable in the Boy Scouting program of the Boy Scouts of America (BSA). Eric's official Eagle Scout Court of Honor ceremony will be held in September of this year. Congratulations to Eric on this prestigious achievement!*

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9th Annual Comedy Show Fundraiser - Remembering Kimberly Messink

By Patrick Doerr

The evening started with an hour and a half drive to northern New Jersey. Accompanying me to the event were my brother and two friends, Caitlin and Scott. We were all excited for an evening filled with food, drink, friends and comedy; we got much more than that. After we arrived, I met Gary and he introduced me to his wonderful family and several other attendees to the event including various state assembly representatives. I was extremely touched by the overwhelming sense of community that was present in the room. Not being from the area, the closeness of the community and friendliness of the people there immediately put me at ease, and I was honored to be a part of the event on behalf of the IFOPA. The comedy show was preceded by an awards ceremony, during which the myriad volunteers and state representatives, many of whom have been part of the event for years, were recognized and thanked for their service. What followed was the most poignant moment of the evening, a PowerPoint tribute to Kimberly Messink, whom the annual event is in honor of. I was moved to tears, and judging by the people seated around me, I was not alone. It was a memorial deserving of the wonderful person Kim was and the indomitable spirit that she exemplified in the face of adversity. I was so touched that I wasn't sure I would be able to appreciate the comedy show still to come. I was wrong. Three very talented comedians took the stage and in no time, my sides were aching from laughter. And the night was still not over! A friend of one of Gary's sons is a DJ, and he, with the help of some of the other volunteers, played songs for the crowd, who sang and danced into the early morning hours. I was in awe, but it was getting late, and, though several people offered us a bed or a couch for the night, we had to get back. The ride home was spent rehashing the night's events and revisiting the broad spectrum of emotion that we had just experienced and even playing the CD of one of the comedians we had just seen. What a wonderful night and what a wonderful community! I'm already looking

forward to next year, and I invite everyone who can to join me!



Comedian Adam Kerr performs at the 9th Annual Comedy Show Fundraiser



Comedian Renee DeLorenzo performs

at the 9th Annual Comedy Show Fundraiser



Comedian Jeff Norris performs at the 9th Annual Comedy Show Fundraiser

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### **Student FOP Member Raises Funds through "Jean Day" at School**

Cody Dennings, a 14 year-old FOP member of Seabrook, Texas, recently organized a "jeans day" at his middle school and raised \$1,376 for the IFOPA!! On this day, students at Seabrook Intermediate School were allowed to wear jeans if they made a donation to the IFOPA. The week leading up to this "jean day" included a daily message about FOP and concluded with a video taped interview of Cody by another student on how he lives with FOP. This video was played for students during their lunch period. The IFOPA would like to thank Cody for his honorable efforts to raise funding and bring awareness of FOP to his peers and the faculty and staff of his middle school. Wonderful job, Cody!

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Bingo For A Cure 2010

By Christine Cogle, close friend of the Scoble and Flexer families and event volunteer

The smell of bingo dabbers, the sound of ripping auction tickets and the excited chatter of both novice and avid bingo players fill the air. For those of you who do not know, it is March 28, 2010, at the Agri-plex Hall in the Allentown Fairgrounds and the start of our 3rd annual Bingo for a Cure! in Honor of Joshua Scoble. Around 790 people, volunteers and players, are ready to go. But wait, I am getting ahead of myself.

When Joshua was three months old he was diagnosed with FOP, his family and friends realized that we could not just sit around and do nothing. All of us felt there was something we could do, but what? It was at this time, that Joshua's aunt, Chrissy Flexer started Bingo for a Cure! Chrissy is the mastermind and driving force behind the bingo and also the reason it runs like clockwork. Volunteer and bingo player, Shelly Zgura says, "The Bingo for a Cure! is an amazing event. To see hundreds of people come together to raise money for Joshua and others who suffer with FOP is incredible. The event is so smoothly run thanks to all the

volunteers that will do whatever it takes to help Joshua. It is a very fun and emotional day, but everyone looks forward to it year after year. When everyone works together many things get accomplished!" Once the ball started rolling on our bingo fundraiser it would not be stopped! Year after year the response we receive from the community is heartwarming. Stacy Scoble, Joshua's mom, says both she and Dave, Joshua's dad, continue to be overwhelmed and humbled by the support from contributors, volunteers and bingo players alike.

The work that goes into successfully pulling off a fundraiser like our Bingo for a Cure! is astounding. It is a year round task, but entirely worth it. Our goal is to raise as much money as possible while making sure everyone is having a good time, even if they don't win big money! In addition to being able to win bingo, we have huge Basket and Grand Basket Auctions. This year we had around 90 baskets that were auctioned. All the baskets and everything they contained are donated. Jill Matlack, a first-time attendee gives her opinion, "The 2010 Bingo for a Cure! was a fantastic event. It was a really fun day with lots of great prizes. The selection of baskets in the Basket Raffle was amazing, (even though I didn't win one!). I really enjoyed seeing Josh at the event. It was a real "feel good" event to see so many people giving so generously of their time and money to help find a cure for Josh. I will definitely attend next year, and spread the word to others!" We also have a bake sale that anyone can contribute to ... everything is always delicious! There were also a wide variety of table prizes, ranging from a \$10 retail gift card to cold hard cash in candy! Every prize that was given out from winning bingo, a basket or a table prize was ALL donated! It still amazes me and I have been involved since day one.

We always start Bingo for a Cure! with a slide show and small presentation. Not everyone who attends understands or knows exactly why they are helping to raise money to find a cure for FOP or what it is they are supporting. Joshua is also in attendance and I feel this helps everyone physically see what we are dealing with--I think he secretly likes to be there to see everyone, even though he is only going to be four-years-old and doesn't completely understand that this is all for him. It is also wonderful to see other FOP families in attendance--we are helping to raise money for them too!

We love when people come to us to offer suggestions on how to better our bingo or just tell us what fun they are having. Feedback is always appreciated. Mona Vreeland states: "Obviously, something is being done correctly in the preparation of this event, to have such a huge turn out every year and with each bingo brings in more money than the previous year! It's as if Joshua has a huge extended family helping him find a cure for FOP, even with the way the economy is today. And with this many people helping to find a cure, FOP can't lose!!!" This is what we like to hear, that Joshua has somehow reached out to all these people who feel as though they are his extended family. Even if they do not know him personally we are getting his story out to the public.

Lisa-Jon Trinidad was kind enough to give me her take on our bingo and as Joshua's adopted aunt it made me happy to realize we are really educating people. Here is Lisa-Jon's account: "About 3 years ago a friend asked if I had wanted to purchase a Bingo for a Cure! ticket. She just described it as some fundraiser for this little kid with some disease neither she nor I could pronounce. I was always looking for a day away from the house and the prizes for the bingo seemed to sweeten the deal; so I bought a ticket. The day came for the event and I was so eager for a chance to win that day. We got there, got our seats and our extra games for an even better chance to win. That's when it happened for me, the mother of this little boy who was so cute and she was just so young. They showed a slide show about Joshua; prior to that moment I hadn't really thought about it much. It was at that moment, that very second when I realized that the ticket I complained about spending \$30 for was the best money I ever spent! As I watched the presentation with tears streaming down my face I thought how awesome this event really was and prayed for Joshua and his family to give them the strength they needed to get through this challenge they are faced with. Now, each year since then I look forward to the

Bingo for a Cure! event and to find out how Joshua is doing and how far the research for this disease has come. This year's event was outstanding; intensely organized and seemingly more people than I remember in past years. I hope to see this event get bigger and better each year and I can't wait for 2011 to attend next year's event."

Joshua's family and friends realize that money is an important component to finding a cure/treatment for FOP, but we also know awareness is the key to raising that money! We will continue our Bingo for a Cure! and other fundraisers until a cure/treatment are found. All the money we have raised thus far has gone to the IFOPA for member programs, research and development a cure/treatment. As you well know, time is of the essence! The more money we can raise means a cure/treatment can be expedited faster. The money we have raised is sent directly to the IFOPA and it makes us extremely happy to be helping.

To see upcoming fundraisers or to check up on how Joshua is doing, please visit our website: bingoforcure.com. Joshua's family is also in the process of starting a nonprofit organization called Joshua's Future of Promises. The website should be up and running soon. As Chrissy always says, Joshua was unfortunate to be born with such a rare disorder as FOP, but how lucky was Joshua to be born into the circle of friends and family that he was! If you have any questions you can email us at info@bingoforcure.com.

We continue to hope and pray for all those who have FOP and we will not stop educating, raising awareness and money. We hope for continued success in our Bingo for a Cure! as well as all of our fundraising projects.

● Media News

FOP Member Featured on National Geographic

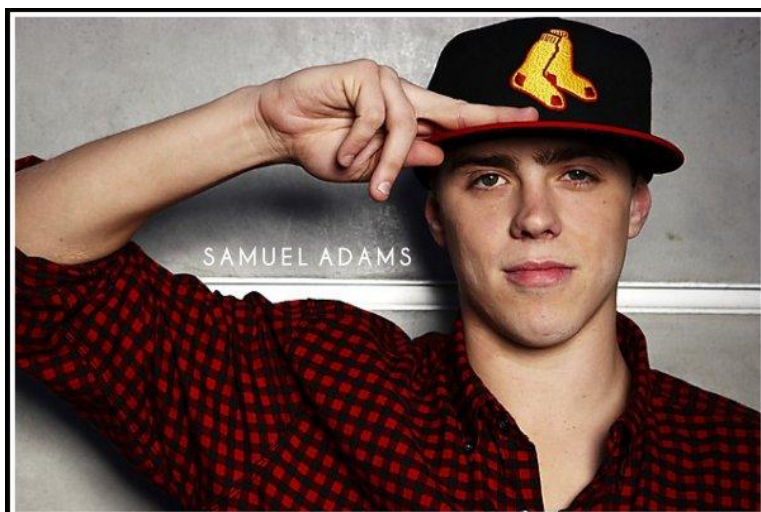
On Monday, March 22, 2010, FOP member Holly Pullano of New Haven, Connecticut, was featured on an episode entitled "Bones" of a National Geographic series entitled *Rare Anatomy!* Thank you to Holly for sharing her story and bringing awareness to FOP!

In addition to being featured on National Geographic, Holly was also recently featured in an article of the New Haven Register, a local newspaper of the New Haven, Connecticut area.

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### **FOP Fundraiser Making Headlines**

On Tuesday, June 15, 2010, the Daily Record of Morristown, New Jersey, published an article on the upcoming Weldon fundraising concert event on June 20, 2010 that will feature up and coming rapper, Sam Adams!



**Boston-native rapper, Sam Adams, will perform at FOP fundraising concert on June 20**

## • Members with Talent

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### **FOP Member Shares Her Voice**

FOP member, Nadezda Damevska of Macedonia, shares her gift of song with her rendition of "I Hate Myself For Loving You" by Joan Jett & The Blackhearts! Please visit [www.youtube.com](http://www.youtube.com) to see her video.

## • International Updates

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### **Sister of FOP Member Raises More and More Funds**

Vanessa Herce from Toronto Canada is the younger sister of FOP member, Valerie Herce. As Vanessa tells it, "I'm tired of seeing this disease affect my sister and so I have decided to do something about it. On June 17th, 2010, I am going to bike ride from Niagara Falls to Toronto in order to raise money to fund research for FOP. I will be starting out from the falls and riding 130 kilometres to Queen's Park in Toronto. I hope along the way not only to raise significant funds for important research on FOP, but also to raise awareness about what FOP is and what people who have it go through on a daily basis."

Vanessa told Board member Malcolm Munro that she hoped to raise a few hundred dollars, maybe a thousand and perhaps increase FOP awareness along the way. She set her "target" at \$1500. But as the donations started to come in, she quickly realized her target was too modest and increased it to \$5000. This target was also quickly met and after a couple of further increases, her current target is \$20,000. As of this date, she now has over \$18,500 in donations! I guess we won't be surprised if her current target needs to be changed once again! Contributions supporting Vanessa and her "crew" of bike riders are donated to the Canadian FOP Network which in turn donates directly to the FOP Lab at the University of Pennsylvania.

Vanessa has learned a valuable lesson for all of us. She says "This has really taught me that you need to set the highest goals because we are always capable of surprising ourselves." We wish Vanessa continued success and our heartfelt thanks for this wonderful effort!

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FOP Lab Established in UK

Thanks to a very generous donation from Richard Simcox, Oxford University is able to establish a UK research group dedicated to the research of FOP! Visit www.ifopa.org for more information!

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## **Interview with FOP Member from Serbia**

FOP member, Jelena Milosevic, was recently interviewed by the European Network on Independent Living (ENIL).

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Australian FOP Awareness Program

Oliver Collins, a 16 year old Australian high school student with FOP, is working with the Australian Broadcasting Corporation to produce a national radio program titled "Encounter". The program examines disability and spirituality and how families cope with such exceptional challenges. "Ollie" and his mom, Julie, will both be part of the program. The program follows Ollie on a typical day at school and home as he engages in activities such as singing in the Chapel choir and feeding the homeless as part of a street retreat program with Ollie's schoolmates and teachers. The producers also interviewed Ollie and Julie at their home during which the focus was on learning more about FOP and dealing with its effects on a daily basis. This is an outstanding event in raising awareness about FOP in Australia, and Ollie and his mom are to be congratulated!

Ollie's interview was aired on ABC Radio National last Sunday. The program is called Encounter and this particular one is called 'Every Day'.

For further information about Ollie and his remarkable public speaking ability, please see Ollie's presentation entitled "FOP and Me -- the Impact on Schooling" delivered at a teachers' conference last year.

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## **The IFOPA Welcomes Two New IPC Representatives!**

### **Jelena Milosevic - Serbia**

Jelena, diagnosed at age 9, now 31, joined the IFOPA in 1992. From the start, she says it changed her and her parents' life completely. She lives in Belgrade, the capital of Serbia, and graduated from the University of Belgrade in 2002. Since then she has worked at home as a freelance translator, meaning that she works from time to time when a person or a company is in need of my translation services. Unemployment, especially the unemployment of persons with disabilities, is a big issue in Serbia.

In addition to this work, Jelena is the Vice-President of the Muscular Dystrophy Association of Belgrade and is very active in disability movement. Through various campaigns and activities they mostly deal with disability legislation, inclusive education, employment and transportation. Jelena always finds a way to talk about FOP and numerous challenges those affected face every day. For instance, last year was the first organized press conference about Rare Disease Day - a great opportunity to promote FOP. Jelena also promoted FOP at this year's lecture for the faculty students of Medicine and Pharmacology. Most of them had never even heard of FOP.

Jelena enjoys writing and her articles have been published in the FOP Connection as well as several disability magazines. Last year her autobiographical story was published in a book called "(Not) So Ordinary Stories".

Also a member of a small group of people working on the establishment of the National Association for Rare Diseases of Serbia, Jelena will continue to keep us informed of any and all progress related to this effort.

Please join us in welcoming Jelena to the IPC!

### **Thomas Przybysz- Poland**

Thomas, 37, lives in a small village in Poland. He joined the IFOPA in 2000 and is the founder of the Polish mailing list "Foplista", which currently serves 10 patients with FOP. Through his website, he is educating his community of FOP, as well as FOP members with advice, things to avoid and how to lead a normal life with the disorder. He is very happy to be joining the IPC, and hopes to be a worthwhile representative of Poland.

Please join us in welcoming Thomas to the IPC!

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Dutch FOP Symposium Amsterdam Marriott Hotel, November 14 and 15, 2009

By Irene Snijder

Because of the generous offer from the Marriott Hotel we were able to have this symposium in this nice location in central Amsterdam. We are a small organization due to the few patients known in Holland, so we are very pleased to receive the discounts from the Marriott Hotel.

The attendance was international; besides Marelise Eekhoff, M.D., Coen Netelenbos, M.D., and dentist Elinor Bouvy Berends, also Petra Seeman, Ph.D., from Berlin and Eileen Shore, Ph.D., and Frederick S. Kaplan M.D., from Philadelphia were present. Besides the Dutch families, there was a Belgium family and a German FOP patient who is also the German ambassador. All the families were happy with the translation that doctor Coen Netelenbos gave to make the issues more understandable.

After the welcome, Eileen Shore, Ph.D., in Cell and Molecular Biology, who is the director of the research laboratory in Philadelphia, told us about some of the new research results. She explained how the protein that is changed by the FOP mutation (a receptor called ACVR1/ALK2, which is a BMP receptor) works in cells. She also described that FOP patients have a small point mutation in one copy of the ACVR1 gene to make the mutant protein that causes extra cartilage and bone. There are many projects in the laboratory that are studying

many aspects of how the FOP mutation leads to bone formation. She told us about the lab's work to develop a mouse that has FOP. These mice have all of the features of FOP - including short great toes and extra bone formation. These mice will be important for understanding how FOP develops in people and for developing and testing treatments for FOP.

Petra Seemann, Ph.D of the Brandenburg Center for Regenerative Therapies (BCRT) of the Charité, in Berlin told us about the scientifically progression made so far.

After the lunch there was a lecture of medical doctor Frederick S. Kaplan who discussed research perspectives and treatment strategies for FOP and the development of signal transduction inhibitors that can be studied in animal models of FOP.

With the cooperation of John Otten, our ambassador, and his wife, we viewed an documentary movie about gadgets and FOP which was very interesting for all of us.

Dentist Elinor Bouvy Berends of the CTB Rijnmond te Rotterdam who is a specialist in dental care for people with a handicap. She kept a lecture about "aspects of dental care for people with FOP" this is important because of the fact that in 73 % of the FOP patients at the age of 30 can't open their mouth well because of extra bone forming. Two mouth hygienists, Annemiek van de Broek and Agnes Vermeulen, gave an excellent complimentary on the mouth hygiene and they showed different gadgets which are useful for a limited mouth opening to clean the teeth. This is very important because it is impossible to fill the cavities in the teeth. Dentist Elinor Bouvy-Berends shall make a special plan for every FOP patient.

After this exciting day, we had dinner together so everyone was able to talk over a glass of wine.

Doctor Kaplan conducted medical consultations on Sunday at the Marriott, and of course, Eileen Shore and Petra Seemann as well as our Dutch doctors, Marelise Eekhoff and Coen Netelenbos and dentist Elinor Bouvy-Berends were also present.

Personally we would like to thank everyone who made this day such a huge success - all the families, doctors and the Marriott hotel in Amsterdam.

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## **Traveling Newspaper**

After its recent stop in Germany, the Traveling Newspaper is now on its way to Argentina, the United States, and France!

If you wish to to be an added stop on the Traveling Newspaper's worldwide trip, please contact Marie Hallbert at [marie.hallbert@telia.com](mailto:marie.hallbert@telia.com)!

## **● Membership**

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To join the IFOPA, please contact us at [together@ifopa.org](mailto:together@ifopa.org) or call (407) 365-4194.

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Submissions

We welcome submissions of articles, stories, photos and artwork for future FOP Connections. For consideration, please e-mail all submissions to Erin Turner, Development & Communications Manager, at erin.turner@ifopa.org. Thank you!

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