



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.

FOP CONNECTION

December 2010 | Issue 4

Dear Members,

As my term comes to a close, I would like to thank you, the IFOPA community, for giving me the opportunity to serve you as a board member over the past five years, and as chairman for the last two. I have learned so much from you, the IFOPA staff and from my fellow board members!

Before I leave, I would like to particularly thank a few board members whose terms are also ending this year:

Amanda Cali, whose steady hand has helped me and the IFOPA have a clear view to the future, and whose efforts brought our community the Traveling Resource Center and the Medical Binders among many, many other highly impactful programs. It is hard to overstate Amanda's impact on this organization and our quest to find a cure for FOP.

Joe Kitterman, whose medical insights allowed the IFOPA to interpret the maladies of a few of our members into a global neurological research study that will help further our research efforts toward a cure. Joe has also initiated our first broad-based effort to educate the neo-natal nursing community - a critical step toward eliminating misdiagnosis.

Mike Man, whose financial guidance and long-term support of the IFOPA through the Spencer Man drawing have helped the IFOPA year after year reach our financial goals, enabling us to support our members.

And of course I would also like to thank our outstanding staff: Karen for her leadership, Erin for her fantastic marketing and communications, Wendy for coming quickly up to speed and making programs like the Medical Binder a reality, and to Becky for supporting our fundraising families and keeping our financial house in order.

I know the IFOPA will continue to support research, education, and our members in new and meaningful ways. I look forward to seeing the progress that Malcolm and Karen, as well as the rest of the board and staff, bring to you in the coming years!

Warm regards,

Sara Olsen
Chairman of the Board

• Upcoming Events

December 24, 2010
IFOPA Office Closed
Oviedo, Florida

February 11-12, 2011
In-Person Board Meeting
Orlando, Florida

March 24-26, 2011
Italy FOP Meeting
Italy

December 31, 2010
IFOPA Office Closed
Oviedo, Florida

February 26, 2011
Unmasking the Mystery of FOP II
League City, Texas

March 27, 2011
Bingo for a Cure
Emmaus, Pennsylvania

January 15, 2010
Richard Blalock to run Charleston Marathon
Charleston, South Carolina

March 12, 2011
10th Annual Comedy Show to
Benefit FOP Research & the IFOPA
Mountainside, New Jersey

Announcements

Jeannie Peeper Receives Lifetime Leadership Award

On Friday, November 12th, Jeannie Peeper was recognized as the 2010 recipient of the Association of Fundraising Professionals (AFP) Lifetime Achievement Award at the National Philanthropy Day Awards ceremony, held this year at the prestigious Ritz-Carlton Orlando Grande Lakes.

All in attendance of the awards ceremony were truly at "the Academy Awards of the non-profit world"! Each award recipient was introduced in an Oscar-like fashion by a lead sponsor, had a countdown clock for their acceptance speeches, and was exited off stage to music by a live orchestra; it was a delightful morning to say the least!

Of all the awards given that morning, Jeannie received the most prestigious. She was also one of only two recipients to have a pre-recorded video of them shown before presenting their award. The audience sat speechless as Jeannie's story was told. As the video concluded, members of the audience had eyes full of tears; Jeannie received a standing ovation.

Jeannie graciously accepted her award and all guests of the IFOPA joined the stage for a group photo to remember the morning by. It was indeed a wonderful morning full of pride for our very own Jeannie Peeper.



The evening before the awards ceremony, Jeannie was presented with a keepsake full of your letters and notes that we had previously requested. She was truly touched by the kind words and thoughts everyone shared with her. Jeannie would like to thank everyone who participated; she is truly blessed to have you all in her life.

The IFOPA would again like to extend our sincere congratulations to Jeannie, a true hero in our community who is incredibly deserving of this award.

Introducing the IFOPA Wikipedia Page

By Malcolm Munro

I'm pleased to announce the publication of IFOPA's Wikipedia article.

You may ask why a Wikipedia article might be of value to our organization. Certainly, there is an awareness factor. Wikipedia daily attracts an enormous amount of traffic, and for many people desiring quick information about a charity, a Wikipedia article can be very helpful. I can imagine prospective donors wishing to get a quick "read" of the IFOPA story visiting Wikipedia for the purpose. In our case, our article also provides links to our website and to a number of other relevant websites.

I feel that a good Wikipedia entry also enhances our credibility as a solid and substantial "player" in the nonprofit community. Aside from hopefully creating a positive overall impression, our article discusses our rating as a charity, enumerates our many publications, and establishes our solid link with the FOP lab through our highly esteemed medical advisors, Fred and Eileen. My sense is that this kind of information communicates our solid accomplishments and, if you will, our ability to "punch over our weight" as a charity - which we have done now for many years!

You may access the article by going to the Wikipedia homepage and keying "IFOPA" in their search window. Or you may go directly to the article by visiting <http://en.wikipedia.org/wiki/IFOPA>.

Help Win \$1,000 for FOP...AGAIN!

With your help, ***we did it!***

The Community Foundation of Central Florida announced today that we were the organization with the most visits to our DonorEdge portrait during the month of November. Simply by viewing our DonorEdge portrait, you helped us win \$1,000 for FOP by over 500 views!

Best of all, we are still eligible to win again for the month of December! Please continue to view our portrait!

Just a reminder, the visits to our portrait must come from the links on either the IFOPA website or the IFOPA Facebook page.

Visit the IFOPA home page (www.ifopa.org) or IFOPA Facebook page at www.facebook.com to vote!

With your help, we can do it again! All you have to do is click and view! Please tell everyone you know and have them click and view too!

Thank you for your support!

Research News

Article Published in Nature Medicine on FOP and Stem-Cell Research

Nature Medicine is one of the most prestigious medical journals in the world.

An article on FOP and stem cell research was recently published in Nature Medicine was a collaboration between the FOP laboratory at the University of Pennsylvania and the lab at Harvard University.

Visit the IFOPA website at www.ifopa.org to see the full article.

Neurological Survey for Research

Please return your Neurological Survey by December, 31st! Our goal is to have 100% participation.

If you have already completed the Neurological Survey for Research, we would like to thank you for your assistance in this matter; it is greatly appreciated!

Dear members of the FOP community,

Recently, Dr. Kitterman sent out an important survey on neurological symptoms in FOP patients.

An enormous amount of work and preparation went into developing his survey based on the desire of the FOP community to learn more about possible association of neurological symptoms with FOP. To date, I understand that very few completed surveys have been returned. In order to help us help you and others with FOP, please take the time to complete this survey (if you have not already done so) whether or not you have neurological symptoms. If you need assistance with filling it out, Wendy Cooper at the IFOPA office will be happy to complete it for you over the phone.

The more people who complete this survey, the more accurate the information will be. I personally appreciate the time and effort

you take to do this.

Sincerely,

Fred

Frederick S. Kaplan, M.D.
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IFOPA website: www.ifopa.org
POHA website: www.pohdisease.org

To Complete the Survey, please visit the IFOPA website at www.ifopa.org

If you have already completed the Survey, we would like to thank you for your assistance in this matter; it is greatly appreciated!

Programs and Services

Merlin's Magic Wand

Much like Give Kids the World, there is another company that provides similar experiences for children. **Merlin's Magic Wand** is a worldwide charity for children, aiming to provide magical experiences for those who are seriously ill, disabled or disadvantaged. To learn more visit <http://www.merlinsmagicwand.org>

Member Center on IFOPA Website

A friendly reminder that the new Member Center on the IFOPA website is up and ready for use! When logging in, you will notice that the Login screen has a different look to it. We encourage all members to explore this new Member Center and all that it has to offer!

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 be able to create a personal profile, add friends, upload photos, join specific Member Groups, discuss topics amongst these Member Groups, locate past discussion topics to review previous advice given and control their privacy settings. In addition, this new system will allow easier access to the Membership Directory and an interactive map showing nearby IFOPA members in a specified location or zip code.

It is our plan to eventually transfer our current message group, FOPonline, from Yahoo! Health Groups to our IFOPA website. As Yahoo! owns and maintains the program currently, when problems arise the IFOPA is unable to resolve or manage any issues. We will be transferring FOPonline to one of the discussion groups in the new Member Center on the IFOPA website; FOPonline will remain as it is currently, viewable to IFOPA members only. To ease this transfer process, we will not remove FOPonline from the Yahoo! Health Groups until the end of this year.

If you have any questions or concerns regarding this new Member Center or any of its functions, please contact Erin Turner, Development & Communications Manager at erin.turner@ifopa.org

Launch of Mentor Program

You don't have to know all the answers.

Has there ever been a time during your journey with FOP that you would have liked to have someone to talk to? Someone who

might be going through or have gone through the same hurdle you are facing? You are not alone. The Mentor Program was created for just this purpose. Sometimes all you need is a shoulder to lean on and a sympathetic ear to listen and other times you might me looking for some real answers to some tough questions. We have some fabulous Mentors in place already but are always looking for others who feel like their life experiences could benefit others. Also if you are interested in having a one on one connection to someone in our Mentor community, we would love to hear from you!

Contact Wendy Cooper, Programs and Membership Manager at wendy.cooper@ifopa.org or call her at +1-407-365-4194 today.

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 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 or (407) 365-4194.

Focus on Fundraising

5th Annual Spencer Man Memorial Benefit Drawing Raised Over \$14,000 With Your Help!

It is our pleasure to announce the winners of the 5th Annual Spencer Man Memorial Benefit Drawing!!

- **Apple iPad - Winner: David Wadd**
- **Nintendo Wii Console - Winner: David Forshtay**
- **Flip Ultra Camcorder - Winner: Ashley Kurpiel**
- **Dooney & Bourke Handbag - Winner: Lydia Anderson**

Carl from our neighboring business, Southeast Audit Services, Inc., was kind enough to draw our winners!



Congratulations to our winners!

Thank you to everyone who participated in this fundraiser and made the drawing a success!

HAYDEN'S HOPE BENEFIT – NOVEMBER 13TH

By Megan Pheif, Mother of FOP Member Hayden Pheif

To Picture: *verb:* to imagine; to foresee; to envision.

I imagine on a daily basis what a cure would mean for Hayden. I envision a community of FOP patients able to move again. I foresee that the FOP lab will find a therapy that will help make all of this come true.

In that spirit, we held the 8th Hayden's Hope Fundraiser for FOP. The theme of the evening was "Picture a Cure". To help celebrate the theme, we had a photo booth with lots of funny props so people could take fabulous and funny pictures that we could remember the evening by.

The event was held on Saturday November 13th. The silent and live auction items were displayed on wonderfully decorated tables throughout the venue.



We were lucky to have some of our wonderful IFOPA board members attending including Sara Olsen, Joe Kitterman and Mark Gambaiana. Also from the IFOPA, Becky Kaplan and her boyfriend Kurt turned their west coast vacation into a labor of love by handling all of the check in and check out processes that are needed with a group as large as we had in attendance. She and Kurt were amazing and I don't know what we would have done without them there. Thank you!!



Megan Pheif with sister and IFOPA Chairman, Sara Olsen.



Guests were encouraged to take funny pictures to remember the evening by!

We also were blessed to have Dr. Kaplan as our guest speaker. With record attendance of almost 250 people, Fred gave a wonderful and inspiring speech on where the state of a therapy/cure is for FOP. What I love most about these fundraisers is that our supporters get to hear first hand what their donations are doing to make a difference in the search for a cure. It's not often that a donor knows exactly how his/her donation will be spent to help a cause.

I love putting on these events. It takes a lot of hard work, but with the help of the IFOPA, friends and family it is the way that we can help to keep the IFOPA funded for community outreach, resources and research. The fundraiser is also very rewarding work. If any of you are interested in putting on a fundraiser, have never done one before and/or are daunted at the thought of the task, please feel free to call me as I am happy to help you, as is the IFOPA.



Hayden & his Self Portrait, which was a silent auction item.



Lincoln's Legacy "Runs through the Mud" in Search of FOP Cure

By Mark Gambaiana, Grandfather of FOP member Lincoln Wheelock

A group of 13 energetic cross country runners braved brisk temperatures and a challenging course to raise funds for FOP research in honor of Lincoln Wheelock. The runners participated in the 32nd annual Living History Farms Race held on November 20th, 2010 in Urbandale, IA.

The Living History Farms Race is the largest cross country race in North America featuring 7,500 participants and a seven mile off road race that winds through Iowa farmland, creeks, streams and wooded areas. Temperatures were in the 20's at race time with windy conditions adding to the test.



Lincoln's Legacy 2010

Runners were responsible to generate pledges for the 2010 Lincoln's Legacy fundraising campaign. Approximately \$12,000 was generated from the race, and combined with other fundraising activity, nearly \$38,000 has been raised for FOP research through Lincoln's Legacy in 2010.

Lincoln Wheelock was diagnosed with FOP in

March of 2009. He is four and a half years old and

Lincoln's parents, Lee and Trisha!

lives in Des Moines, IA with his parents, Lee and Trisha, and a brother Hudson, 2. Lincoln attends pre-school and enjoys Buzz Lightyear, Lightning McQueen, fishing, riding on the 4-wheeler and Ranger, and being on the golf course.

Lincoln's parents, Lee and Trisha, both competed in the race, as did his uncle Adam, aunt Cindy, and other family and friends.



A terrific turnout!

5K Fundraiser for FOP

By Erin Turner, IFOPA Staff Member

On Thanksgiving morning I participated in the annual Turkey Trot 5K in downtown Orlando to help raise funding and awareness for FOP.

A little over a month prior to the 5K, I created a simple FirstGiving page to help collect donations. Hoping to increase the amount of donations, I added a little twist. No matter what, I would run the 5K for FOP; however, if my fundraising goal was met, I agreed to run it dressed up as a banana. You heard right, I would run the 5K dressed in a banana costume!

I am so thankful to family and friends because as luck would have it, I met my fundraising goal within just a few hours (apparently everyone wanted to see me humiliate myself)! Therefore, I increased my fundraising goal with another added incentive (see my FirstGiving page – details below) for more information).



Posing with an inflatable turkey!



My parents came out to support me!

To spread awareness of FOP (and so people knew I wasn't just some crazy person in a banana costume), I created a sign in the shape of a banana sticker that read "Cure FOP". I can't count how many people approached me asking, "What's FOP?" And I told them. When I was busy explaining FOP to someone, my mom and dad would pitch in and answer other 5K participants questions about FOP. It was truly a joint effort and I am so thankful my parents were with me that day.

A few friends and family joined me bright and early for the 5K, both to show their support as well as to pick fun at me; I didn't mind, it was for a good cause!

All in all, it was a great morning! Money was raised, awareness was spread and I was able to enjoy a guilt-free Thanksgiving dinner!

Visit www.firstgiving.com/erinturnerbananasuit to view my FirstGiving page for more details and pictures!



Crossing the finish line!

Runner will Participate in Charleston Marathon in Honor of FOP Member

Richard Blalock, a remarkable person and good friend of FOP member, Ashley Kurpiel, will be running the Charleston Marathon on January 15, 2011 in honor of Ashley. Like Ashley, Richard is an amputee; Richard's leg was amputated below his knee a little over a year ago. This will be his first marathon post-amputation. To help raise funding and awareness, Richard has created a blog called "My Marathon for FOP" which is linked to his FirstGiving page. All proceeds raised will be donated to the IFOPA.

Please join us in supporting Richard in his efforts to raise awareness and funding for FOP!

Calling All Families **WE NEED YOU!!**

The IFOPA only exists because of families that help fundraise. Please consider doing a fundraiser this year in support of the IFOPA. No matter how large or small, every bit counts.

To get you started, here are some simple ideas that make a *world* of difference:

Letter Drive

WE NEED 40 FAMILIES!!!! "Easy as 1, 2, 3!" A letter drive is simply sending a letter of request for support to everyone you know that explains why raising money for FOP is so important to you. All you have to do is provide a list of names and addresses to the IFOPA and we will take care of the rest! We will create a letter (that you approve of course!), print, stuff and send to your list of contacts! This is a VERY effective way to reach out to everyone you know. We could raise \$20,000 with just 40 participants agreeing to send out letters, and if each letter had 50 responses of friends and family donating just \$10! Won't you join us in finding a cure for FOP??? Think of the impact we can have if we all do a little!

Contact Your Local Restaurant

Helpful and delicious! Many local restaurants (Boston Market, Friendly's and Uno's Pizzeria are some examples) offer Fundraising Nights where they will donate a percentage of all sales made that night to your cause. Once you set a date with the restaurant, it is up to you to advertise the fundraiser and get people to come out to the restaurant that night. Word-of-mouth, fliers and Facebook events work well for inviting local residents of the community.

Fundraising extra: *At the event, hold a small drawing for prizes (that you have had donated – also ask the restaurant if they will donate gift certificates or coupons). Also consider selling IFOPA Awareness bracelets at the event!*

Create a FirstGiving Page

Very similar to a Letter Drive, but virtual! Visit <http://www.firstgiving.com/ifopa>, click the Get Started button under "Want to raise money?", choose your Event Type/Reason for Fundraising, and follow the steps from there. Once your page is created, you can send a personalized e-mail to your friends, family, neighbors and coworkers including a link to your FirstGiving page! If you would like help creating your FirstGiving page, please contact the IFOPA at together@ifopa.org or +1(407) 365-4194 for assistance! To see an example FirstGiving page, please [click here!](#)

Dress-Down Days

These are fun and simple! Speak with your work supervisor or school principle/administrator to see about getting permission to host a "dress-down" day for FOP. For work, this could mean employees who donate (usually a set amount between \$1 - \$10) in return get to wear jeans to work instead of their usual business attire. For schools, dress-down privileges would work in the same manner, however would depend on the school's existing dress code. Who doesn't love casual days?!

To get started, to learn more simple fundraising ideas, or to inquire about more advanced fundraisers, please contact [Erin Turner](#), Development & Communications Manager.

Whichever you choose, the IFOPA will be by your side every step of the way. We are here to help in any and every way that we can!

Media News

FOP Mother Interviewed for Article

Karen Munro, mother of FOP member Miranda, was recently interviewed in support of a fundraiser for a local rare disease organization. Please visit the IFOPA website at www.ifopa.org to view the article.

Thank you to Karen for continuing to spread awareness of FOP!

International Updates

The IFOPA Welcomes a New IPC Representative



Dr. Christian Scott - South Africa

I am a Pediatric Rheumatologist from Cape Town, South Africa. I work in the Red Cross War Memorial Children's Hospital. I first diagnosed a beautiful little girl with FOP in 2009. The disease was completely new to me and it has been an unsettling journey of discovery. Unfortunately for this young girl the diagnosis was delayed and she had biopsies at 4 different sites before she came to my attention. I was very saddened by this course of events as these biopsies resulted in additional tissue injury which should have been avoided. It became clear to me that the best way for me to help would be by creating awareness around FOP to prevent this from happening to patients in the future.

I made contact with colleagues in the Genetics department and discovered that Professor Peter Beighton had diagnosed six children with FOP in 1982. We managed to track down two of these patients, who had developed severe disability and complications. Through presentations and papers aimed at orthopaedic surgeons, rheumatologists, paediatricians and radiologists I have been able to identify a further 5 patients, mostly young children. All but one of these patients are from Cape Town, so there is clearly still a lot of work to do in the rest of South Africa. There is an urgent need for these patients to get connected to the broader FOP community. I am passionate about child health advocacy and about the plight of children in the developing world with rheumatic and musculoskeletal diseases, as these diseases have been neglected historically.

Please join us in welcoming Dr. Scott to the IPC!

IPC Page on IFOPA Website

Just a reminder the International President's Council (IPC) now has an official page on the IFOPA website! This page includes biographies and contact information for each of our IPC Representatives, links to each country's website, and resourceful IFOPA information that has been translated. Please visit the IFOPA website at www.ifopa.org for more information.

Traveling Newspaper

The Traveling Newspaper has just visited California, U.S., North Wales, U.K. and Amsterdam, Holland , Europe! Visit <http://www.fopsverige.se/gallery.asp?page=472> to see all of the places the Traveling Newspaper has been! *Please use Google Translate if needed as this website is in Swedish.*

If you wish to be an added stop on the Traveling Newspaper's worldwide trip, please contact Marie Hallbert at



At Erin's Day 2010 in California!

marie.hallbert@telia.com!



With Rachel and husband, Paul in U.K.!



At the Dutch FOP Symposium in Amsterdam!

Membership

Members with Talent

The following poem is written by one of our very own members!

Mommy

By FOP member, Laura Rossano

Rollercoaster.
Cotton candy.
Hotdogs.
Anything is possible
when you're a kid at Coney Island.
The Cyclone inches towards its zenith,
before its frightening freefall.
The little girl, who'll one day be my mother,
invincible.
How I become as I conquer my rollercoaster ride:
Hofstra's Unispan.
Toe to toe I go,
(not heel to toe.)
One,
two,

three,
Come on, Laura, only ten more steps
she chants as we slowly reach the summit.
I am on top of the world.
We are on top of the world.
The Span is my Cyclone.
It is a grueling climb.
Each step takes time and precision
as I slowly step on the balls of my feet
trying to maintain balance.
I am on my own,
with no hand to hold.
It is all me taking the slow and steady strides,
as the sweat glistens on my forehead.
You can do it. You can do it, Sweetie
After reaching the bottom I beam.
Mommy shines.
I did it.
We did it.
I rode my rollercoaster.
She never gives up on me.
She never lets me down.
Her Sweetie,
invincible
Just like that little girl
at Coney Island.

Joining the IFOPA

To join the IFOPA, please visit our website at www.ifopa.org or contact us at together@ifopa.org or (407) 365-4194. Thank you!

Support Families, Fund Research, Find a Cure

