FOP News

A Message from the IFOPA Board Chair Marilyn Hair

The FOP Connection Registry patient portal is now open. I hope you have seen the announcements. FOP community members of all ages and from everywhere in the world are encouraged to join the Registry.

Creating the Registry has been a huge effort by many IFOPA staff and volunteers. The launch is a notable accomplishment for the IFOPA. Dr. Kaplan has been advocating for several years to have one FOP Registry where all FOP patients worldwide can tell their story and have the stories collected in one place.

The IFOPA owns the FOP Connection Registry. This gives the FOP community authority to decide how information about FOP patients will be used. De-identified, summarized data can be provided to many researchers and pharmaceutical companies who are trying to understand FOP and how quickly it progresses, as well as demographic characteristics of the FOP population such as age range and how many people with FOP live in various countries. The FOP Registry demonstrates that the FOP patient community is well organized and able to help support clinical trials. The Registry will help pharmaceutical companies design clinical trials to test potential new treatments.

The FOP Registry was launched on July 29. In the first 24 hours, the Press Release had over 2000 views. In the first 15 minutes after it was launched, 3 people with FOP registered. By that evening, 13 had registered, and in 24 hours, 18 had registered. The FOP patients were from USA, UK, Canada, Brazil, India, Ethiopia, Denmark, Sweden, and Australia. Launch of the FOP Registry was highlighted...
Whatever your role in the IFOPA; FOP patient, family member, donor, clinician, researcher, advocate, pharmaceutical, or interested friend, thank you for the part you play. Your dedication allows us to pursue our mission to find a cure for FOP while supporting individuals and their families through education, public awareness, and advocacy.

With appreciation,

Marilyn Hair
Chair, Board of Directors

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**Registry Insights**
by Neal Mantick

It has been just over one month since the Registry’s launch. Please read the latest insights collected on August 31st by clicking on [The FOP Community Responds: The Journey Begins!](#).

**Registry Videos and More**

We have four videos to help our FOP community understand the importance of participation, step-by-step instructions on how to register, update one’s profile and tips to complete a survey.

- **Registry Introduction**
  Gives an overview and explains the significance of participation

- **How to Register**
  Step-by-step instructions.

- **Registry Dashboard**
  Details about the participant dashboard and how to update your profile.

- **How to Complete a Survey**
  Overview of features and tips on how to complete a survey

You can also download a [Questions & Answers PDF](#) for more detailed information covering a wide range of questions. If you have a question that has not been answered send an email to registry@fopconnection.org

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**On other topics:**

Family fundraisers support every aspect of the work of the IFOPA, including the FOP Registry. We are so grateful to individuals and families who hold fundraisers. This FOP Connection includes articles about recent family fundraisers Lincoln’s Legacy and the Annual Walk & Ride to Cure FOP in Canada.

The IFOPA 2014 Annual Report, which recognizes our many donors, will be out soon, and may be in your email inbox already.

IFOPA is working to make it easier to renew your membership and to cast your vote for Board of Directors nominees. These member responsibilities are part of the Annual Appeal, to be mailed in the fall. Please read our “Cast Your Ballot” article.

Three national FOP meetings took place during July and August, including the Annual German FOP meeting, the Sweden FOP meeting, and the 2nd Annual FOP meeting in Russia. Articles from the organizers are available.

The IFOPA is developing a new, improved website. Watch for it to go live in the coming months.

Last but not least, Clementia Pharmaceuticals is currently recruiting for the [Phase II Clinical Trial of palovarotene](#) and for their [Natural History Study](#). Both of these clinical trials are going well. Thanks to all of you who are participating in these trials to help find a treatment for FOP.

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in the National Organization of Rare Diseases (NORD) e-newsletter, bringing FOP and the FOP Registry to the attention of many rare disease patient organizations.

In September, the IFOPA, working with the appropriate national FOP leaders, will begin the process of translating the FOP Registry. The first translations will be into Spanish, Italian, Russian, Portuguese, and German. We are in contact with other national FOP leaders to identify additional languages for translation, beginning in January. Having the Registry available in many languages will make it possible for FOP patients from many countries to join. The more who join, the more successful the FOP Registry can be.
Interested in Participating in the Clementia Phase 2 Clinical Trial?  
Study is ongoing  
Enrolling FOP patients age 6 and above.

If you have a flare-up, or would like more information call or email:

Lisa Gardo, UPenn at 215-294-9112 or Lisa.Gardo@uphs.upenn.edu

Helene Favre, UCSF at 415-353-9087 or helene.favre@ucsf.edu

Geneviève Baujat, Necker (Paris), +33(0)171196418 or genevieve.baujat@nck.aphp.fr

**Sincerely - The Study Investigators:**
Fred Kaplan, MD, University of Pennsylvania  
Bob Pignolo, MD, University of Pennsylvania  
Ed Hsiao, MD, University of California, San Francisco  
Umesh Masharani, MD, University of California, San Francisco  
Geneviève Baujat, MD, Hôpital Necker-Enfants Malades, Paris France

Interested in Participating in the Natural History Study Sponsored by Clementia Pharmaceuticals?  
Study is ongoing and open to FOP patients ages 2 to 65 years old.

Clementia has agreed to share data from the natural history study with the global FOP Registry we are developing. This innovative agreement will allow learnings from the natural history study to extend beyond Clementia's needs, making it a vital set of data for our entire community.

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

USA, California - Helene Favre, PhD at 415-353-9087 helene.favre@ucsf.edu

USA, Pennsylvania - Lisa Gardo at 215-294-9112 lisa.gardo@uphs.upenn.edu

Argentina - Leonardo Crama at 0054944195801 leonardo.crama@gmail.com

Australia, Queensland  
Linda Bradbury +61 7 3443 7077 l.bradbury@uq.edu.au

Canada, Ontario - Not yet recruiting  
Stephanie Hedges stephanie.hedges@sickkids.ca

France  
Genevieve Baujat, MD at 00-33-7-85-98-05-46 genevieve.baujat@nck.aphp.fr

Italy - Marta Bertamino at +39-349-1033410 martabertamino@libero.it

United Kingdom - Jacqueline Vinton at 0208 909 5425 jacqueline.vinton@rnoh.nhs.uk
Our International Community

Annual German FOP-Symposium
by Roger zum Felde

From 24th to 26th of July 2015 we held the 20th annual FOP gathering in Germany. This year the meeting was organized by Ralf Fischer, the new CEO of FOP e.V. at the well-known House Nordhelle in Valbert-Meinerzhagen. More than 70 guests stayed over-night.

Meet and greet on the terrace.

After the “meet and greet” in beautiful weather on the brand new terrace of the hotel, we went inside and spent the evening with talks, laughter and fun.

After a warm welcome to all doctors, members, family and guests, Ralf started the meeting with the interesting presentations from Drs. Donna Grogan, Eileen Shore, Fred Kaplan and Olli Morhart (translator) about the news around FOP and the Clinical trial of Palovarotene.

To create a form to reduce FOP misdiagnosis, Stephanie Hoffmann from Clementia held questionnaire sessions with patients and researchers.

In the afternoon we heard the FOP research update from our friends at the Charité Berlin Drs. Petra Seemann, Lutz Schomburg and Laura Hildebrand.

Newly arrived doctors from a hospital in Cologne introduced themselves and offered to be a point of reference for FOP patients who have to be treated in the right way. After the last presentation from Dr. Heinecke on pain-therapy and an alternative way of movement, the evening entertainment began.

Surprise performance!

Roger zum Felde’s friends turned out to be a Rock and Roll dance group who surprised everyone with a couple of their dances. Because of the bad weather that evening, we had a fantastic indoor barbecue with everything you could wish for.

On Sunday our meeting ended with a report from Dr. Bob Pignolo about FOP research. The CEO Ralf Fischer and Vice Chairman Roger zum Felde made references about the ups and downs from last year. Highlighted in that report was last year’s concert “Last Night of the Proms for FOP” which was absolutely brilliant. We reached the fantastic amount of more than 10.000€.

We are looking forward to the future and will meet again in July 2016.
FOP Meeting in Eskilstuna
Sweden 28-29 July 2015
by Marie H Fahlberg IFOPA IPC representing Sweden and mom to Hugo age 17, diagnosed at 2.4 years in 2001

I could write the usual story about our successful meeting with around 70 attending families from Sweden, Norway, Finland, four doctors from Sweden plus the amazing Drs. Fred Kaplan, Bob Pignolo and Eileen Shore from the FOP lab in Philadelphia. But instead, I'd like to explain the reasons why I arrange a meeting like this and why it is important to have them every few years.

A FOP meeting is an event where Drs. Fred Kaplan, Bob Pignolo and Eileen Shore give us the latest information about FOP research and this year’s talk also included information about clinical trials. They explain the different ways it may be possible to stop FOP flare ups in the future (different kinds of medications and different targets). The families receive information from their perspective, giving us an insider’s view and hope for the future. We do not understand everything or all the strange scientific terms and new words. But that is not important. The important thing is we are all invited, together with our children, to listen. The three doctors manage to explain the complexities of FOP, so we understand how difficult the research is. They explain the problems that need to be solved to confirm the medication only “hits FOP” and does not damage any other functions in the body. In the end we understand why there is no reason to be impatient or frustrated. We realize our need to have fun in life and live life to the fullest with our children. FOP is part of our journey. We need to inspire the researchers to continue their work and be thankful that clinical trials have started. We must not forget all the hard work researchers have accomplished over the years and accept they are really working as hard and as fast as they can for us and our future. For me that has always been a source of inspiration to make the best of Hugo’s FOP and to help the researchers. But I am not a researcher so what can I do to help them? What do they need help with? What do they need that money can’t buy? What do they get out of attending a meeting in Sweden? Personal consultations with FOP patients.

Each family receives a 30 minute personal consultation. This is not only important for the families but also the researchers and doctors. I want to give all the families in Scandinavia the opportunity to meet the specialists in person by private consultation together with Scandinavian doctors. I really want both families and doctors to feel the support we have from Fred, Bob and Eileen. Specialists answers on all the families’ questions. Almost every consultation includes at least one question with the answer “we don’t know.” That might seem sad, but it is not! We get an honest answer. And it is important for us to understand there are things not even our FOP specialists can answer (yet). By having clinics we also educate both the families and the doctors from Scandinavia. We create networks around all the families so they know who to turn to in a FOP situation.

Another important aspect of the clinics is the families share their FOP stories in person with our researchers giving them a “Live Natural History Study” to help move research forward when they return to the FOP Lab. They see patterns and they see what has happened to the patient since the last time they met. They see and hear things that might not be observed without talking to the patients and having dialogues with the other doctors. At this meeting we had clinics with 14 patients from ages 1.5 years to 60 years of age. This gave the doctors in Sweden who attended those clinics a unique “FOP Specialist Education.” They got the chance to see the whole spectra of FOP: patients of different ages, at different stages, with different and similar histories. Since it is vital we educate doctors in our own countries, this is a great way to create a FOP Specialist team in Scandinavia. By arranging meetings like this we
find the doctors that are really interested in FOP and want to collaborate with Drs. Kaplan, Pignolo and others who could not attend our meeting. This networking makes it so much easier for Fred and Bob to help the patients in our Scandinavian countries.

So in the end this event is much more than just a FOP family meeting. It is part of huge puzzle with many different levels. During a meeting like this different pieces suddenly come together at the right place and time making it possible for the research work to continue at a new level. The funny thing is I never know when I arrange the meeting what the next level will be. But I do know that spending time with Fred, Eileen and Bob is the very best part of Hugo’s FOP. As a FOP mother, these are the people and reasons why I arrange FOP meetings.

2nd Annual FOP Russia International Conference and Family Meeting
by Vladislav Grachev

From July 31 to August 2, the annual international FOP conference and family meeting was held in Moscow, Russia. Funding for the conference was provided by FOP Russia patients, their parents, Clementia Pharmaceuticals, and Harald Gerth and Sabina Marx of FOP Germany.

The President of FOP Russia, Svetlana Urvanova, was the director of the event and Russia IPC Mihail Belyaev was the conference host who introduced the speakers. FOP Russia’s professional camera operator Polina Kozlova filmed all the presentations.

The event included simultaneous interpretation by professionals so all language groups could understand the presentations and reports. More than 150 people attended the conference which included scientists and doctors from USA, Germany, the Ukraine, FOP patients and their families, students and interns. Reports were presented by M.D. Frederick Kaplan, Ph.D. Eileen Shore, M.D. Rolf Morhart, M.D. Natalia Golovanova, M.D. Irina Nikishina, M.D. Margarita Dubko, genetics professor Ph.D. Vladimir A. Polyakov, Head of FOP Ukraine Natalia Musina, and Executive Director of Clementia Pharmaceutical Michael Harvey. Michael Harvey shared information about the ongoing palovarotene clinical drug trials, their plans to conduct phase 3 clinical trials in Russia and the opening of an office in Russia for this purpose.

The presentations and reports segment lasted until the evening, and right after it the first examinations of FOP patients commenced and continued during the 1st and 2nd of August. On August 2, with support of the Moscow branch of All-Russian Society of Disabled People, FOP Russia organized a sight-seeing tour around Moscow for all attendees and a special purpose bus for FOP patients. Russia IPC Vladislav Grachev was the tour guide. On August 3, FOP Russia organized another sight-seeing program in English around historic places in Moscow for American, German and Ukrainian doctors. Thanks to the Baranov’s family (FOP Russia) foreign doctors and scientists were provided with transfers from airports and railway stations.
On August 3, 2015, an interview with Eileen Shore and two FOP patients from FOP Russia was conducted by the special newspaper neinvalid.ru.

The 2nd Annual FOP Russia International Conference and Family Meeting was highly appreciated by Russian and foreign scientists and doctors. Attendees appreciated the unique format of communication between doctors, scientists, students, patients and family members. Click Photos to view more images from this meeting.

The next conference and family meeting will take place in St. Petersburg, Russia, in the summer of 2016.

Focus on Fundraising

Annual Canadian Rides & Walks to Cure FOP!

A total of four fundraising events were held this summer in Canada to raise funds for FOP research.

- 6th Annual Newmarket Ride to Cure FOP
- 4th Annual London Ride to Cure FOP
- 5th Annual Calgary Ride/Walk to Cure FOP
- 4th Annual Sault Ste Marie 5K Run/Walk for FOP

Your can read an online article about the Sault Ste Marie event at SOOTODAY. Our member Valerie Herce said, “The 6th annual Ride to Cure FOP at Newmarket was a huge success! As a team, we were able to raise over $14000! We had 16 riders and 30 walkers come out! This year the weather was great so we were able to enjoy a fun celebratory BBQ outside. Every year brings us that much closer to a cure!”

Another year, another successful Walk for FOP . . . Woo hoo!

by Karen Munro

I'm delighted to tell you that our event this year brought in over $24,000! This is an amazing number, and will probably yet climb a bit this week after some last-minute contributions which I understand are on the way. We gathered these funds for the benefit of the Canadian FOP Network, a registered charity in Canada which financially supports research into fibrodysplasia ossificans progressiva.

On the day of the event, we had amazingly good luck with the weather – it was a beautiful sunny day, but not too hot, so perfect for walking and the picnic afterward. Probably the best part though was spending time enjoying each other’s company. For instance, my daughter Miranda particularly enjoyed getting to know event co-host Kathleen’s nephew, a super sweet one year old cutie.

Many, many thanks to all who donated to our cause, and to especially all our friends and family who joined us for this incredible event. Last but certainly not least, a shout out to my friend Stephenie, who did the event in Vancouver in honour of her daughter, Alex, who has FOP. Stephenie managed to pull in a whopping $10,000 donation which very impressively swelled our total take! We are delighted to have had Stephenie and her family along for the Walk this year.

Here’s our Calgary group, in all our glory!

Lincoln’s Legacy Generates $55,000 for FOP Research

by Mark Gambaiana

Since 2009, a host of “Lincoln’s Legacy” fundraising events have provided a reliable and significant stream of revenue each year to boost FOP research. The events are staged in honor of nine-year old Lincoln Wheelock of Des Moines, IA, the son of Lee and Trisha Wheelock.
On August 21, 2015, an estimated 500 people attended another Lincoln's Legacy fundraising event in Sioux City, IA, producing $55,000 in income for FOP research. Participants enjoyed a catered dinner and had the opportunity to purchase tickets for more than 125 prizes through drawings, bid on silent auction items and make outright contributions.

Dr. Fred Kaplan is pictured with FOP members Claire Kapphahn, Kyle McWilliams, Lincoln Wheelock, Sivapiya Saravanakumaran, and Scott Whitmore, father of Lucas Whitmore at the Lincoln’s Legacy event.

Dr. Fred Kaplan, the world's leading FOP clinician from the University of Pennsylvania, gave a presentation on the exciting FOP research progress. Dr. Kaplan also provided clinical appointments to the four FOP patients in attendance – Lincoln Wheelock, Kyle McWilliams, Claire Kapphahn and Sivapiya Saravanakumaran. In addition, Scott Whitmore, father of FOP member Lucas Whitmore, also attended the event.

Marilyn and Doug Wheelock, grandparents of Lincoln, led a corps of volunteers who provided outstanding support to ensure a smooth and successful event.

The biennial event, also staged in 2009, 2011 and 2013, is part of a series of fundraisers that have now combined to generate more than $500,000 for research. Other Lincoln’s Legacy events include an annual “Run through the Mud” for Cure FOP, a direct mail campaign, support from the Sioux City Bandits indoor arena football team, a winter carnival and various other activities.

Current Fundraising Events

ZipperQ 4 BBQ Event!

ENTER TO WIN YOUR CHOICE OF
RAM 1500 | JEEP WRANGLER | DODGE CHALLENGER

Don't miss out on your opportunity to support this fundraising event by purchasing 2015 Vehicle Drawing Tickets or Event T-shirts. Those of you who can drive to Claremore, Oklahoma will have a grand day on October 3rd! Check out all the details at ZipperQ 4.

BCMS Awake for a Cure

Bethlehem Central Middle School will hold its first ever Awake for a Cure, a overnight lock-in to benefit FOP research in 2015. Students are raising funds in honor of Bethlehem 8th grader Ashley. To make a donation click BCMS Awake for a Cure.
Membership News

Membership Spotlight:
Dr. Vanessa Schaker

Recently I had the privilege of corresponding with our FOP member Dr. Vanessa Schaker who is the second person in our FOP community to become a medical doctor!

Vanessa lives in Brazil and in 2006 she started her medical career by studying dentistry. When the limitations of FOP hindered her progress in dentistry she chose to study general medicine. In August 2009 she started attending the medical school at the Lutheran University of Brazil (ULBRA) and graduated on July 24, 2015.

The IFOPA congratulates Vanessa on fulfilling her goal to become a medical doctor and hopes her accomplishment will inspire all of us. Enjoy the short interview and photos in this issue. – Victoria Mandracken

Who are your mentors and how have they inspired you?
Please note, I’m hesitant to talk about where my inspiration comes from since my sources are varied. My first source of inspiration is my parents since they never ceased to remain determined, confident and united through all of life’s challenges. Next are the many people who overcome something and win a daily challenge. When I learn about these people, I put myself in their place to learn from their experience. I know that when we have some limitations or problems we can become fixated on them, but one must learn to look at the distant goal and always see the light. Accept the opportunity to grow.

What were some highlights of attending ULBRA?
While attending medical school I made several friends and some I plan to keep forever. After graduating we lose daily contact, many returned to their hometowns and now we live far from each other. In ULBRA, I always had the help of my friends so the limitations of FOP never prevented me from trying different activities. Many things I learned to do my own way.

Attending the university was a very important experience. There we can look beyond our limitations and personal thoughts, we learn to live with different and new thoughts, and go beyond our comfort zone. This causes one to become a stronger and better person. It teaches us to be resilient.

What are your future goals?
I plan to start working on my medical specialization. I’m interested in pursuing psychiatry or radiology and diagnostic imaging. In November I will take exams to determine which one and the next institution I will attend.
Volunteer Spotlight:
An Interview with Board Member Karen Munro

1. When did you start volunteering for the IFOPA and why? I started volunteering for the IFOPA in 2011 when I joined the Jeannie Peeper Awards Committee. I did so because I thought the JP Awards sounded like a great way to recognize valuable members of our community, and it would be interesting to be involved.

2. What are your current volunteer positions for the IFOPA? I am currently an IFOPA board member and the secretary of the board, plus a member of the JP Awards Committee.

3. What are your typical duties as Secretary? As secretary, I am in charge of producing written minutes of all meetings, keeping track of board member volunteer hours, and participating in both board and executive committee meetings.

4. About how many hours does your Secretary Position take per month? The secretary position has been taking me about 4 to 5 hours per month.

5. Can you share details about any special projects/committees you are working on? The JP Awards Committee is a time-limited effort each year, running from February through May, and is a fascinating opportunity to learn about the amazing things people have done for the FOP community.

6. What are you looking forward to accomplishing as a board member? I look forward to contributing hard work to the IFOPA board, because the IFOPA is very valuable to my family. I also look forward to seeing how the board can help the IFOPA become even more amazing than it already is – for a disease as rare as FOP, we are largely unique in the world of rare diseases.

7. Are there any skills you recommend volunteers have before starting an IFOPA committee or board position? Good organizational and communication skills are particularly important and useful for committee or board members.

8. What are the challenges of serving and how have you overcome them? The challenges of serving are centred around balancing board duties with work, life, and other volunteer commitments. So far, I have overcome these challenges by trying to focus on one week at a time, and accomplishing each task as it comes without looking too far down the road. Somehow everything falls into place.

9. What are the perks of serving the FOP community? The perks of serving the FOP community are many, and include:
   a. Getting to know and form friendships with other board and committee members.
   b. Learning about breaking news and initiatives early in the day.
   c. Helping shape the direction of the IFOPA.
   d. The chance to travel once a year to participate in in-person board meetings, which are fun and interesting.
   e. Developing my own skills and knowledge of how charities and not-for-profit organizations operate.
   f. Last but not least, helping propel us toward a treatment for FOP – I feel like I’m on the forefront!

Cast Your Ballot
by Nancy Sando

As we approach the end of the year, all members have the opportunity to cast your vote for the slate of nominees that have accepted the invitation to become Board Members for the next two years (beginning January 2016). The IFOPA doesn’t run elections like you would normally see with campaigns, platforms and debates. We are all involved in the IFOPA for one reason: To cure FOP. Our mission is to fund research to find a cure for FOP while supporting individuals and their families through education, public awareness and advocacy.
With that said, our voting ballot is comprised of individuals willing to volunteer their time and talents to further our goal. They are not in competition with each other nor are there “winners” and “losers.” Because of these volunteers and the existing IFOPA board, we are all winners as we get closer to the goal we have set out before us.

You may be asking yourself, “Why vote if these people will be on the board anyway?” This is a valid question. Well, if you are an official member and have ever read our bylaws, it states that:

Section 4.4 Annual Membership Meeting. The Association shall hold an annual meeting of its membership by electronic mail and/or hardcopy mail in the fall of each year, or at such other time and date as shall be determined by the Board of Directors. The purpose of the annual meeting shall be to elect directors.

Not only is your participation mandated in our bylaws but we, as board members are encouraged by the votes we receive from the worldwide IFOPA membership that we are representing and working for. Consider your returned ballot a “stamp of approval” for our board to continue to act on behalf of our worldwide community.

So please, remember to cast your ballot when you receive your annual appeal letter at the end of October.

Special Poem and Letter

Lessons in life are given at every step. Some include happy gestures, few may provide moments of grief, yet life continues. Perhaps the most special and close to my soul is this poem written by Iuvjot Oberoi, brother of Rabjyot Singh Oberoi when he passed away on May 1st 2015.

- Surinder Oberoi

The Mighty is an amazing website that has daily posts dedicated to “finding strength, joy, and beauty in disability.” I’ve followed them for a while now and am always touched by the inspiring stories written with such grace, strength, and hope. March 2015, they have asked their readers to write a letter to a diagnosis that has affected them or their family. Here’s my letter.

- Jasmin Floyd

Friendly Reminders

September 7th is the deadline to Volunteer.
We are looking for people who want to help us achieve our goals and advance the IFOPA mission by serving on existing committees or becoming a member of the board. Committee and board members can be
• professionals
• a person with FOP
• friends and family of a person with FOP.
To learn more about these opportunities to serve as a volunteer click Committee Member and Board Member.

Have you moved? Changed your email address?
Please be sure to update your contact information with the IFOPA when it changes. We want you to receive all the latest IFOPA news and FOP research communications. Please contact a staff member by emailing us at together@ifopa.org or calling our English speaking staff at 407-365-4194.

FOP Member's Updates
All FOP members in good standing with their membership will receive a monthly email called FOP Member’s Updates. This email will include member’s birthdays for the month, names of new FOP members, condolences, and other news. Please contact Victoria Mandracken by email if you are not receiving you FOP Member Update monthly email or your birthdate is missing or incorrect on these monthly messages. Thank you!
Do you have an article, poem, photo, drawing or good news to share?

The next FOP Connection will be published December 2015. Please email or mail Victoria Mandracken creative pieces and good news you would like to share with our FOP Community by November 17, 2015. The C&PR committee looks forward to the opportunity of reviewing your work for future publications.

International FOP Association
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Casselberry, FL 32707 USA
Phone: 407-365-4194 to talk with English speaking staff
Fax: 407-365-3213 Email: together@ifopa.org

IFOPA Mission
Fund research to find a cure for FOP while supporting individuals and their families through education, public awareness and advocacy.

Our Vision
A Cure for FOP