



Frederick S. Kaplan, M.D., Elected to Institute of Medicine

On October 12, 2009, Frederick S. Kaplan, M.D., was elected to the Institute of Medicine (IOM). The IOM was established in 1970 by the National Academy of Sciences to honor professional achievement in the health sciences and to serve as a national resource for independent analysis and recommendations on issues related to medicine, biomedical sciences, and health. Currently, the IOM has 1,778 elected members.

"Election to the IOM is considered one of the highest honors in the fields of health and medicine and recognizes individuals who have demonstrated outstanding professional achievement and commitment to service," said IOM President Harvey V. Fineberg in the IOM's press release.

As most in the FOP community know, Frederick S. Kaplan, M.D. is The Isaac and Rose Nassau Professor of Orthopaedic Molecular Medicine and Chief of the Division of Molecular Orthopaedic Medicine. He studies the molecular genetics of FOP and POH, rare bone disorders in which the body forms a second skeleton of heterotopic bone. This collaborative work, conducted with his colleague Eileen Shore Ph.D., led to the discovery of the gene for POH in 2002 and for FOP in 2006.

Kaplan co-directs the only center in the world devoted entirely to this work. He has organized the medical and scientific communities worldwide on FOP and POH and is recognized as the world's leading expert on genetic disorders of heterotopic ossification and skeletal metamorphosis.

In 1997, Kaplan was awarded the first endowed chair in the nation for orthopaedic molecular medicine. In 2006, *Newsweek* magazine cited him as one of the "15 People Who Make America Great." In its story, *Newsweek* noted FOP "was so rare, nobody wanted to deal with it until he came along." The IFOPA congratulates Dr. Kaplan on this esteemed honor.

Editor's note: The information above has been provided, with written permission, by the University of Pennsylvania Department of Communications and has been edited to fit the format of this publication. For more information on this release or to view related images and information, please visit: http://www.uphs.upenn.edu/news/News_Releases/2009/10/institute-of-medicine/



Important Note on Upcoming IFOPA Publications

The newly revised *FOP Connection* newsletter and Dr. Kaplan's Annual Report on FOP Research will be sent to all IFOPA members via e-mail in 2010. We will be e-mailing the *FOP Connection* in February and October and Dr. Kaplan's Annual Report in May, as well as launching monthly communication e-blasts about research, programs, services and fundraising events.

This change is due in part to the economic climate we are all facing and to do our part to be environmentally conscious. Currently to mail the *FOP Connection* to our membership costs the organization more than \$6,000. We remain committed to our members and our mission, and moving in this direction we will be able to use those funds for new programs, such as e-Learning events, medical education on early detection of FOP, and regional meetings, as well as providing more communication to you, our membership.

This is only possible with your help! We need your e-mail address so we can effectively communicate the progress, programs and updates of the IFOPA. Please take a moment to e-mail or call us so that we can ensure you don't miss our first e-communications. As always, our FOP membership may request a printed copy of these materials if you don't have computer access. We appreciate your understanding and hope you will join us as we "Go Green" and do our part in saving donor dollars and the environment. Please send your e-mail address to together@ifopa.org or call us at (407) 365-4194.



International
Fibrodysplasia
Ossificans
Progressiva
Association

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The International Fibrodysplasia Ossificans Progressiva Association (IFOPA) is a 501(c)(3) charitable organization whose mission is Instilling HOPE through Research, Education and Support while Searching for a CURE for FOP.

The IFOPA was founded by Jeannie Peeper in 1988 and the FOP Connection is its quarterly publication. To help those with FOP and their families, we print information and ideas from our readers on methods of management and care for FOP and its consequences. As an organization, however, we do not support or endorse any particular treatment or therapy. We urge everyone to always contact his or her physician for final approval of any treatment choice.

Open invitation to our readers - The Connection always seeks to improve the content and quality of our newsletter. We encourage our readers to provide us with feedback and comments on the newsletter as well as suggestions for future issues. We also invite anyone interested in providing material such as story ideas, articles, poems and artwork to the editor. Anyone interested in contributing to the Connection is invited to contact Eyal Goldshmid at Eyal.Goldshmid@ifopa.org.

Editor: Eyal Goldshmid

Contributors: Linda Daugherty, Patrick Doerr, Eyal Goldshmid, Wendy Henke, Matt Horick, Becky Kaplan, Frederick S. Kaplan, M.D., Ashley Kurpiel, Ryan McWilliams, Sara Olsen, Robert J. Pignolo, M.D., Ph.D., Holly Pullano, Karen Revels, Jennifer Snow, and Erin Turner.

Printed Copies of *Guidebook for Families* Now Available

The third edition of *What is FOP? A Guidebook for Families* is now available in hard copy.

This third edition, edited by IFOPA member Sharon Kantanie and Drs. Kaplan, Shore and Delai, is a comprehensive look at FOP, answering many questions commonly asked of families and medical professionals. The Guidebook contains information by Dr. Fred Kaplan and others regarding research and treatment options, as well as articles by parents of afflicted children and adults with FOP offering insights into the condition.

To request a copy be sent to you, please contact the IFOPA office. The Guidebook is also available in electronic copy on the IFOPA website. Click on the "Living With FOP" tab, then on "Support Guidebooks" to download the document in PDF format.

Reminder: The IFOPA website homepage has links to the following:

- Treatment guidelines
- Emergency medical information
- Information for health professionals, caregivers and more
- Recent press releases and FOP-related news stores
- Upcoming events

The website is a wonderful source for updated, timely information regarding FOP.

Table of Contents

News and Features

Frederick S. Kaplan, M.D., Elected to IOM	1
Important Note on Upcoming IFOPA Publications	1
Printed Copies of Guidebook Now Available	2
The Flu Season Is Upon Us	3
2009 Teen & Young Adult Meeting	4-5
IFOPA's New e-Learning Events	6-7

Focus on Fundraising

Create a Personal Fundraising Page.....	8-9
Upcoming IFOPA Fundraisers	9
Shop for the Holidays, Help the IFOPA	10-11
2009 Fundraising Thermometer	11
Annual Find-A-Cure Event Bids Farewell	12
Hayden's Hope	13
Cure FOP 5K Dash & Cash	14
Race for the Cure - Chicago Marathon	14-15
Spencer Man Memorial Benefit Drawing	15

Membership Information

Birthdays	16
Contributions	17-19
Member Changes	19
New Members	19
Happy Holidays	20

The Flu Season Is Upon Us

Drs. Kaplan and Pignolo Offer Some Helpful Advice

Dear Members of the FOP Community,

The Flu season is upon us, and in addition to the usual concerns, there is additional concern this year with the SWINE FLU.

Many questions have already arisen about the swine flu and FOP.

It is important to keep in mind that influenza and influenza-like illnesses are caused by viruses and can trigger flare-ups of FOP.

We do not know exactly why they do this. Possibilities include direct attack by the viruses on the muscle tissue, release of chemicals from the viruses that attack the muscles, and quite possibly over activity of the muscles from chronic coughing that is associated with the flu and other flu-like illnesses.

The flu and flu-like illnesses are dangerous in anyone; especially so in individuals with FOP, not only because they can trigger flare-ups, but also because FOP patients have limited movement of the chest wall. This is true in nearly all individuals with FOP and due not only to extra bone formation in the back and chest wall, but due to malformations of the joints that are involved in the formation of the rib cage. We now recognize that these are common features of FOP and can limit how much the chest can expand. Add to that the flu and the risk of pneumonia increases.

As before, it is important to take the usual precautions, as one would in any flu season. These are well-outlined in the FOP Treatment Guidelines (available at the IFOPA website, under the "Living with FOP" tab). You will find the section on INFLUENZA & FOP on pages 30-32. Also, a common sense approach to keeping healthy is important, such as avoiding crowds, washing the hands frequently, and avoid touching rubbing the eyes and touching the nose and face.

In addition to the regular flu (as in any season), there are concerns about the swine flu. We think that having the protection for FOP patients of all ages is important. We do not know the safest way to give it at the moment, but if it can be given safely subcutaneously (under the skin), that would be our preference. No immunization or shot should ever be given in the muscle (intramuscularly, or IM) in an FOP patient.

We're concerned about any vaccine that is given as a nasal spray as it is a live virus and could more easily cause a flare-up. We would go with the subcutaneous route, using a very small needle (25 gauge or less) and maybe a smaller dose of the vaccine. An ice pack should be applied to the area immediately and intermittently for 24 hours, as tolerated. If someone decides not to do the vaccination, then they should consider having the anti-viral medication prescribed by their local doctor in case the flu does occur. And, importantly, never give any vaccinations while the person is having a flare-up of FOP.

Another recommendation is that any household contact of FOP patients should definitely consider getting vaccinated for the regular flu as well as the swine flu.

While we do not yet have all the information, we have a lot of knowledge that can help keep us healthy. Let's all do what we can, stay tuned to updates from The Center for Disease Control (CDC) and other health officials, and hope for the best.

Sincerely,

Fred and Bob

Frederick S. Kaplan, M.D.
Isaac & Rose Nassau Professor
of Orthopaedic Molecular Medicine
The University of Pennsylvania



Robert J. Pignolo, M.D., Ph.D.
Ian Cali Clinical and Research Scholar
The Center for Research in FOP & Related Disorders
The University of Pennsylvania

2009 Teen & Young Adult Meeting

California was the Hot Spot!

By Patrick Doerr, Matt Horick, Ashley Kurpiel and Holly Pullano

Attendance was high and the city was beautiful at the first-ever Teen & Young Adult Meeting, held in San Diego, California from Friday to Sunday, August 7-9, 2009.

Most of the attendees arrived to the hotel on the evening of August 6; it was great to see some familiar faces while meeting new ones -- even while checking in to the hotel!

Arriving early also provided a great opportunity for us to explore the Gaslamp District of San Diego, which surrounded the hotel, or to visit the really cool bar and restaurant on the roof of the hotel, which looked out over the bay and the PETCO Park baseball stadium, where the San Diego Padres play.

During the day on August 7, attendees had many options for entertainment: When not meeting for appointments with Dr. Kaplan or Dr. Nussbaum, some went to the San Diego Zoo, some went to a Padres game, some went to the fish market, and some chose to relax at the hotel.

The official meeting festivities began on the evening of August 7, with a reception at the hotel. It was a great opportunity to get the weekend started and was highlighted by an informative Research Update by Dr. Kaplan.

The following workshops were held the next day, before and after lunch:

- **FOP Members**
- **Parents of FOP Members**
- **Siblings of FOP Members**
- **Hair & Makeup**

At the **FOP Member** workshop (facilitated by FOP members Patrick Doerr, Matt Horick, Ashley Kurpiel and Holly Pullano), we got to know each other better, discussed various topics of importance, and shared stories on how we deal with every day life. This group was originally split into two for



Attendees of the 2009 Teen/Young Adult Meeting.

the morning session, to cover the age ranges present, but the two combined for the afternoon session. The results were great! Some shared, some listened, but all benefited.

Many parents attended the **Parents of FOP Members** workshop (facilitated by FOP mother, Carol Kurpiel), which covered several issues that the FOP parents who attended were concerned with. They shared information and experiences, and each parent seemed to learn something new.

The **Siblings of FOP Members** workshop was facilitated by Emily Henrich (sister of FOP member, Ashley Kurpiel), Mollie Steele (sister of FOP member, Sarah Steele), and Sean Doerr (brother of FOP member, Patrick Doerr). This workshop gave time for siblings to discuss FOP with other people of similar ages and share coping mechanisms, frustrations, and advice.

The **Hair & Makeup** workshop included a beauty makeover session for the girls; some even got their hair cut and styled! Definitely a girly time

that was enjoyed by all! Thank you to everyone who donated their time and skills for this workshop, especially Emily Henrich, Carol Kurpiel, and Missy Rozsa (Ashley Kurpiel's friend from San Diego)!

Clinical visits with Dr. Kaplan and Dr. Nussbaum took place on Friday and Saturday. In addition, we had the opportunity to sit casually and chat with them during breaks, meals and throughout the meeting.

Though some went their separate ways on the last day of the meeting, many of us chose to visit the world famous San Diego Zoo! It was a nice and relaxing way to complete a wonderful weekend together!

The most difficult part of the weekend was that we had to say good-bye to each other. We made new friends, re-kindled old friendships, and decided we needed to be in touch more often. We all agreed we need to get together again very soon!

Making Memories

Here's what some of IFOPA members who attended the 2009 Teen & Young Adult Meeting said of their experience:

"I really treasure being surrounded by peers who not only care what I've been through, am going through and will be going through, but also understand, unfortunately, from personal experience. The intangible support and lack of criticism I received in those three days is more than I can say for a year's worth at home."

– Karina Chaikhoutdinov

"I thoroughly enjoyed the Teen & Young Adult Meeting that took place in San Diego. It was a lot of fun, and I got the chance to see a lot of people I met at the Philadelphia FOP Symposium in 2000, as well as meeting new people, some from different countries. It was planned well, and everything we did was so much fun, from the dinners to the San Diego Zoo trip; it was all thoroughly enjoyed by all. It was nice to meet with the teens and young adults who have FOP, getting to know them, sharing ideas, etc, and it was nice to be able to see all of the adaptive equipment available as well. Getting a chance to meet with Dr. Kaplan and Dr. Nussbaum was nice also, especially since I have upcoming dental work soon. The hair/make-up workshop put on by the Kurpiel family and friends, was a lot of fun as well. Overall, it was a very fun weekend and I had a blast!"

-- Cassie Eckart

"Being able to hang out with old friends and meet new people with FOP is great! I think the workshops really helped accomplish that for most people as well."

-- Whitney Leckenby

"My favorite experience was going out to eat with other fellow FOPers. It was a time when we could talk and hang out. It was nice to focus on FOP during the day and then forget about it at night and just hang out."

-- Emma Albee

"It was great seeing people that I haven't seen in a long time, and I really enjoyed listening to Dr. Kaplan's talk about research progress."

-- Vincent Whelan

"I loved meeting all the other FOPers and their families, and finally met my FOP best friend I had been corresponding with on Facebook!"

-- Jasmin Floyd

"It was awesome to be with everyone and meet new people with FOP. I liked the workshops, especially the ones dealing with FOP and daily life. It was a pleasure to see my old friends again."

-- Ariana Romero Valecillos



Left to right: Sarah Steele, Stephanie Snow, Stephanie's service dog Elliot, Lindsay Ruiz, Alexandra Rodriguez, and Betina Charis Ramirez at the 2009 Teen & Young Adult Meeting.

IFOPA's New e-Learning Events

Webinars Will Help Members Stay Connected and Learn About New Resources and Tools for Living with FOP

The IFOPA is pleased to introduce a new service to its members: e-Learning Webinars, web-based live educational presentations covering a variety of topics.

A webinar is an online presentation that incorporates computers and/or phone lines to connect people in different locations to a presentation and allow full participation between audience member and presenter. As such, presenters can show pictures, images, and text to all meeting attendees, and attendees can ask questions either by typing them via a chat interface or speaking them over the phone (if a phone is used).

The IFOPA will be using this technology to help members stay connected and learn about new resources and tools for living with FOP.

There is no registration fee for participating in any IFOPA webinar. Participants will be responsible for their phone charges as regular phone rates apply.

Scheduled e-Learning Events

FOP Guidebook for Families

December 8, 2009 at 8:30 p.m. Eastern Time

Presenters: Sharon Kantanie, Steve Eichner and Karen Munro

The webinar will introduce families, particularly families who are new to the world of FOP, to resources about FOP, including the newly revised *What Is FOP? A Guidebook for Families*, FOPonline, and the IFOPA website. The workshop will also feature a question and answer session.

About the Presenters:



Sharon Kantanie

Sharon Kantanie is 40 years old and was diagnosed with FOP at age six. She lives with her family in Brentwood, TN. She has a Master of Arts in Teaching from Vanderbilt University and uses her desire to teach to help people learn more about FOP. She is editor of *What is FOP? A Guidebook for Families*. She also started the FOP Resource Center and FOPonline, an email discussion group about FOP (for which she is still an active participant), and she designed the original IFOPA website.

Steve Eichner, a long-time member of the IFOPA, was diagnosed with FOP when he was two. He will be 40 in November 2009. After 10 years of living with Nancy, his spouse, in Washington, DC, where he worked for technology organizations, museums, and as a government consultant, he and Nancy moved to Austin, TX, Nancy's hometown, where he now works for the State of Texas. Steve and Nancy live an active life, travel regularly and are well-minded by Spirit, their Pembroke Welsh Corgi.



Steve Eichner



Karen Munro

Karen Munro lives with her family in Burnaby, a suburb of Vancouver, Canada. Karen is the mother of Miranda Friz, who has FOP. Miranda is now almost five years old and was diagnosed with FOP when she was just over two years old. In addition to Miranda, Karen's family includes her husband, Peter, and son, Owen (who is almost eight years old). Karen's secondary occupation, after being a mother, is as a lawyer representing people injured in accidents. Karen is also the Vice-President and a Board Member of the Canadian FOP Network, a new Canadian charitable organization.

Food & Nutrition & More

December 15, 2009 at 8:30 p.m. Eastern Time

Presenter: Nancy Sando

The webinar provides suggestions and ideas to those members who need insight on making foods "do-able" when there are jaw limitations. There will be a short lesson on nutrition and how to better balance your meals, along with some practical tips to help the food preparer and the person who has FOP and a brief discussion on oral hygiene. At the end of the webinar, participants will be encouraged to ask questions.

About the Presenter:

Nancy Sando, a founding member of the IFOPA, was diagnosed with FOP at age five and lives in Petoskey, MI. She and her late husband, Andy, owned and operated a variety

of small businesses. She has a background in computer programming and has dedicated her life to helping people find ways to enrich their lives and the community in which they live. Nancy's own jaw locked more than 20 years ago and she has learned many ways in which to enhance her eating techniques. She is able to make *any* food possible to eat.

FOP and IEPs (Individualized Education Program): What the FOP Community Should Know

Mid-January 2010, date/time TBD

Presenters: Carol Fischer, Windy Eichner, and
others from the FOP community

The webinar provides an overview of the development and implementation of an Individualized Education Plan (IEP), including how to begin to work with a school in order to identify needs and resources for students with FOP. It will also address other school-related resources that can serve the needs of individuals with FOP.

About the Presenters:

Carol Fischer recently retired from the Broward County School System in South Florida, where she had a career as a teacher and an Exceptional Student Education (ESE) specialist. **Windy Eichner** is a retired teacher from Broward County Schools with 30 years of experience working with students with IEPs. Both are highly aware of FOP. Windy is the mother of Steve Eichner, who has FOP (see above); she has taught with Carol for 30 years.

In addition the the webinars discussed in this article, the IFOPA is also developing other topics for discussion, including *FOP and the Workplace*, *FOP and Car Adaptation*, and *Caregiving*.

If you have an idea you'd like to share, would like to head a webinar, or have any questions regarding the e-Learning Events, please contact Linda Daugherty by phone at (407) 365-4194 or by e-mail linda.daugherty@ifopa.org.

How To Participate

To participate in a webinar, you will need access to a computer and phone line.

The IFOPA will provide local toll-based call-in numbers for participants (country numbers will be provided for Australia, Austria, Belgium, Canada, Denmark, Finland, France, Germany, Ireland, Italy, Netherlands, New Zealand, Norway, Spain, Sweden, Switzerland, United Kingdom, and the United States). Please note: The phone numbers



**Nancy Sando (center) with her dogs Oreo (left)
and Rascals.**

provided may still require you to make a long distance call (although it won't be at international rates). Thus, these webinars may provide good opportunities for you to use your extra cell minutes or flat-rate calling.

Participants can also use Voice over IP (VoIP) to connect to the audio portions of our webinars. However, if doing so, you will need a fast Internet connection, a microphone and speakers (a USB headset is recommended) to participate successfully.

Technical Requirements:

Your PC must have:

- Internet Explorer® 6.0 or newer, Mozilla® Firefox® 2.0 or newer (JavaScript™ and Java™ enabled);
- Windows® 2000, XP, 2003 Server; Windows 7; or Vista;
- Cable modem, DSL, or better Internet connection;
- Minimum of Pentium® class 1GHz CPU with 512 MB of RAM (recommended) (2 GB of RAM for Windows® Vista)

Your Macintosh must have:

- Safari™ 3.0 or newer, Firefox® 2.0 or newer (JavaScript™ and Java™ enabled);
- Mac OS® X 10.4 (Tiger®) or newer;
- PowerPC G4/G5 or Intel processor (512 MB of RAM or better recommended);
- Cable modem, DSL, or better Internet connection

TO REGISTER

Reserve your space in
our webinars today!

Visit <http://elearning.ifopa.org>

— FOCUS ON FUNDRAISING —

Create a Personal Fundraising Page

The IFOPA has launched a web-based fundraising initiative in partnership with FirstGiving.org to help YOU raise funds for the IFOPA which support research, programs and services.

FirstGiving is a social networking site that specializes in creating pages for fundraisers of all kinds. Visitors make their own fundraising page on FirstGiving to raise money for a nonprofit organization of their choice.

Through it, you can create a page in honor or memory of someone, for a fundraising event you are planning, or simply as a campaign to raise funds and awareness. It is similar to a letter drive, only it is online!

How It Works

Just follow these few easy steps and you can personalize your own page complete with photos, text and more! All of the funds raised online come seamlessly and directly to the IFOPA.

1. Simply go to: www.firstgiving.com/ifopa
2. Click the orange box titled "Get Started"
3. Then either choose an event to support or select how you are going to raise money in the drop down box at the bottom of the page
4. Indicate how long you wish to raise money for (6 months, 12 months or 24 months)
5. Create an account
6. Begin personalizing your page
7. E-mail the unique website address to everyone you know and post to your social networking sites
8. Continue to promote the page and your fundraising efforts

Tips for Success

Here are some tips for getting started with your own PERSONAL FUNDRAISING PAGE and how to make it a success:

1. The most **successful fundraisers** personalize their page with photos and compelling personal stories of why they're fundraising. Not sure how to start? Try answering these questions in your personal message on your fundraising page: Why are you fundraising? Why is this cause important to you? What impact will each donation make? (To help find a cure!)

Screenshot of the IFOPA's FirstGiving page.
Get started here!

2. **Tell your contacts.** Share your fundraising page with family, friends, colleagues, parishioners, or anyone in your community. FirstGiving provides e-mail templates you can use in your account.
3. **Spread the word.** Add your fundraising web address to your website, blogs, and e-mail signature and your social network sites, such as Facebook and MySpace.
4. **Encourage your supporters** to set up fundraising pages. E-mail everyone you can and make personal calls to key supporters to get the ball rolling.
5. **Make the most of social media.** Ask your **supporters** to promote your fundraising in their online communities, such as on blogs, LinkedIn, Facebook, Twitter, MySpace, and more.
6. **Set a fundraising goal.** Donors want to see their friend succeed. In fact, some will donate again if they know their friend is close to their goal.
 - Set a fundraising target when editing your fundraising page
 - Give updates on the status of your fundraising goal
 - Raise your goal once you reach it, then update your donors again

— FOCUS ON FUNDRAISING —

7. **Thank your donors.** FirstGiving automatically emails a “thank you” message to your donors. When editing your fundraising page, personalize it. Tell donors what it means to you or how their donation is helping your nonprofit
8. **Keep sharing.** Send updates on your fundraising, life, or training. Sharing your stories about challenges and achieving milestones makes donors feel a part of your fundraising efforts. FirstGiving provides an e-mail template you can use in your account. Who knows – you may inspire some donors to join or advocate for your efforts.

You can also try some of these other fundraising ideas.

Talk about your fundraising efforts on your blog, Facebook, MySpace or Twitter pages.

This is a great place to update donors on your progress and a subtle way to tell blog visitor's that you are accepting donations for a great cause. Be sure to add a widget or link to your fundraising page.

Celebrate your birthday.

Ask friends to make a donation to your fundraising page in lieu of gifts.

Offer your services.

Remember, a fundraising page does not have to revolve around an event. It can be about anything! In exchange for a donation to your fundraising page, you could:

- Babysit
- Drive a friend to the airport
- Rake leaves, shovel snow or cut the grass.

Throw a party.

Get your family and friends in on it and divvy up the tasks.

- Set a date.
- Ask your favorite restaurant, bar, or coffee shop to donate some space.
- Have guests RSVP via making a donation to your FirstGiving page — this way you don't have to collect donations at the door and you will have an attendance list.
- Host a prize drawing. Ask local business to donate products, services or gift certificates that you can auction or give away off at your party. Use your fundraising page as a way to collect money for tickets.

The screenshot shows a fundraising page for 'Luciana's Walk' on the FirstGiving website. At the top, the 'firstgiving' logo is on the left, and navigation links 'Home', 'About us', 'Your account', and 'Help' are on the right. Below that is the 'ifopa' logo and the text 'International Fibrodysplasia Ossificans Progressive Association' and 'Support Families, Fund Research, Find a Cure'. The main content area has a header 'Luciana's Walk' and 'Page Creator: Nicola Morris', 'Page Closes: Oct 27, 2010'. A fundraising progress bar shows a target of \$1,630 and a total raised of \$110.00. A 'Give now >' button is prominent. Below the bar are links for 'Share this page' and 'I want to raise money too'. A 'My personal message' section contains a photo of a dog and text: 'Okay so you have made the first step by visiting this page! Now let me help you to help me... In 2009 I Nicola Morris from Blackburn Lancashire, and my father Keith Morris from Blackpool, Lancashire, will both be walking the highest free standing mountain in the world, Mount Kilimanjaro, standing at breathtaking 19'340 ft (5895 metres). By doing this we aim to raise as much money as possible to fund further research into a rare genetic condition known as Fibrodysplasia Ossificans Progressive (FOP). Why? At the beginning of 2008 I came to meet a young girl called Lucian Wulkan, Luciana lives with her family in Lancashire and suffers from FOP. From the day I met Luciana I wanted to do something to help. Luciana is a cheeky and ambitious 10 year old and in my eyes a strong and courageous child. You see FOP is a condition that causes muscle and connective tissue to turn to bone, therefore Luciana is unable to carry out day to day tasks that we take for granted, let alone running around and having the fun that any 10 year old child should be having.' There is also a 'Show More >>' link.

Screenshot of Luciana's Walk fundraising page for the IFOPA on FirstGiving.org.

Thank you for supporting the IFOPA. Please call the IFOPA office if you have any questions or need assistance setting up your personal fundraising page.

Upcoming IFOPA Fundraisers

Luciana's Walk

In March 2010, Nicola Morris from Blackburn, Lancashire, England, and her father Keith Morris from Blackpool, Lancashire, England, will walk to the highest free standing mountain in the world, Mount Kilimanjaro. By doing this they hope to raise money for FOP research and awareness. The walk is in honor of Luciana Wulkan, who has FOP and lives in Lancashire, England. For more information, please visit www.lucianaswalk.com.

Bingo for a Cure 2010

This annual fundraiser takes place on March 28, 2010 at the Allentown Fairgrounds, in Allentown, PA. At the event, guests will enjoy games with cash prizes of \$200, with a guaranteed \$4,000 payout and a \$1,000 Grand Prize, as well as an auction and bake sale. All proceeds benefit the IFOPA in honor of Joshua Scoble. For more information, visit www.bingoforacure.com.

— FOCUS ON FUNDRAISING —

Shop for the Holidays, Help the IFOPA

Everyone loves shopping for friends and family during the holiday season. But this year, you can also help the IFOPA while you shop.

Thanks to some great retail partnerships, the IFOPA has made it possible for members and supporters to donate to the organization by shopping for unique and meaningful gifts at some of your favorite stores.

**So far, we have raised more than \$6350
using these partnerships!**

**We know this holiday season
we can double that with your help!**

If you have any questions about any of the partnerships or programs listed in this article, please contact the IFOPA office by phone at (407) 365-4194 or by e-mail at together@ifopa.org.

amazon.com

Help the IFOPA by purchasing books, music, videos, toys, and consumer electronics through this mammoth online department store. As part of the **Amazon Associate Program**, the IFOPA earns referral fees when visitors purchase products through the link found on the IFOPA website. (Note: You must access **amazon.com** through this link, otherwise the IFOPA will not benefit from the program.)

To access:

- Visit www.ifopa.org.
- Click on "How to Help" then "Amazon & iGive."
- Click on amazon.com links at the top of that page and start shopping.

iGive.com

iGive.com is an internet shopping mall where merchants give a percentage of their proceeds from items purchased to charitable organizations. Merchants include Land's End, Amazon.com, Barnes and Noble, Outpost.com, Microwarehouse, Sharper Image, Toys R Us, and others.

iGive.com also offers a special "Six Degrees of Donation" program, which donates \$1 to the IFOPA for each friend you get to register with the shopping service. (Sign up is free.)

To get started:

- Visit www.ifopa.org.
- Click on "How to Help," then "Amazon & iGive."
- Click on the iGive link at the bottom of the page.



GoodSearch.com and GoodShop.com

What if the IFOPA earned a penny every time you searched the Internet? Well, now we can!

GoodSearch.com is a search engine that donates half its revenue, about one U.S. penny per search, to the charities its users designate. Use it just as you would any other search engine, and it's powered by Yahoo!, so you get great results.

To get started:

- Visit www.goodsearch.com.
- Enter the "International FOP Association" as the charity you want to support.
- Start searching the web.

**Just 500 people searching four times
a day will raise about \$7300 in a year
without anyone spending a dime!
Be sure to spread the word!**

GoodShop.com is GoodSearch's shopping extension. Essentially, it lets you shop for items at many popular online stores (like amazon.com, eBay, Gap and more) and the retailer, in turn, donates a percentage of your sale to the IFOPA! **According to the site, a recent \$432 purchase at online shoe store Zappos.com earned a specific charity \$26 -- you could do the same for the IFOPA!**

To use:

- Visit www.goodshop.com
- Select the IFOPA as your charity of choice
- Click on the online shop links found on that page to access the sites.
- Buy products as you normally would. The donation will be made automatically after the sale. It's that easy.

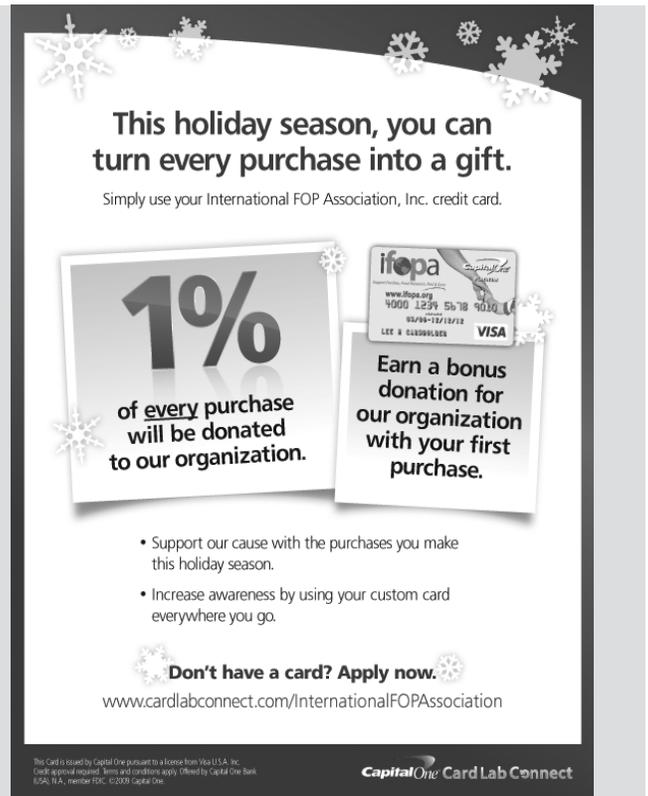
Apply for an IFOPA Credit Card

You can give more to the IFOPA without spending more by turning your everyday spending into meaningful donations with the **IFOPA Capital One Credit Card**. Share your passion and donate to the IFOPA with your everyday purchases.

Thanks to a recently formed partnership with Capital One Credit Cards' "Card Connect" program, you can now sign up for an official IFOPA/Capital One Visa Platinum credit card. Account holders will have 1 percent of every purchase they make donated to our organization. In addition, Capital One will donate \$25 to the IFOPA after each new account holder makes his or her first purchase with the card.

To help show your support, the IFOPA has designed three original cards for you, each bearing the organization's logo. Choose the one you like best, create a card of your own through the website's design tools, or upload an image of your own choosing to use.

For more information, or to apply for a card (U.S. residents only at the moment), visit the IFOPA website at www.ifopa.org.



This holiday season, you can turn every purchase into a gift.

Simply use your International FOP Association, Inc. credit card.

1%

of every purchase will be donated to our organization.

Earn a bonus donation for our organization with your first purchase.

- Support our cause with the purchases you make this holiday season.
- Increase awareness by using your custom card everywhere you go.

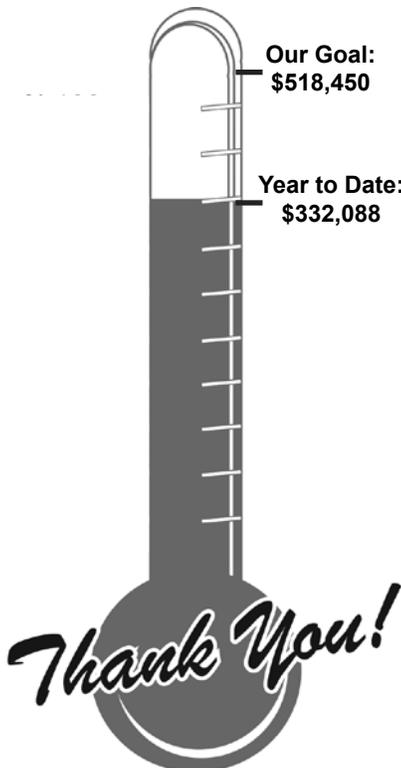
Don't have a card? Apply now.

www.cardlabconnect.com/InternationalFOPAssociation

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Capital One Card Lab Connect

2009 Fundraising Thermometer



This is our 2009 Fundraiser Thermometer. It reflects funds raised for the IFOPA from events and programs that our members organized and planned. This does not reflect funds from donations or dues. From July 1, 2009 – September 30, 2009, the fundraisers below have collectively raised \$167,556. The IFOPA would like to extend a special thank you to the many individuals who supported and were involved in these fundraising events.

- amazon.com
- Coins for a Cure
- Cure FOP 5K Dash and Cash in Honor of Justin Henke
- Cure FOP Swim-a-thon in Honor of Justin Henke
- Hayden's Hope Benefit for FOP Research in Honor of Hayden Pheif
- Erin's Day Charity Golf Tournament & Haircut-a-thon in Honor of Erin Danzer
- Golf for a Cure in Honor of Shane Terry
- Harry Hoag School Fundraiser in Honor of Matthew Wadd
- IFOPA Awareness Merchandise
- iGive
- Lincoln's Legacy in Honor of Lincoln Wheelock
- Lincoln's Legacy Bake Sale in Honor of Lincoln Wheelock
- Race for a Cure in Honor of Kyle McWilliams
- Wadd, Rizzo, Nelli, & Vollmer Garage Sale in Honor of Matthew Wadd
- Walk in the Woods to Cure FOP in Honor of Whitney Weldon

Reminder:

The IFOPA office can assist you in planning your fundraiser.

— FOCUS ON FUNDRAISING —

Annual Find-A-Cure Event Bids Farewell After 16 Years of Fundraising

By Jennifer Snow

August 2, 2009 marked the last of an annual fundraising effort which began 16 years ago in Santa Maria, CA, when our daughter, Stephanie Snow, was diagnosed with FOP at the age of three.

The Find-A-Cure Dinner/Auction/Raffle began as a small fundraising dinner for family and friends to learn about FOP and to help support the IFOPA's mission to find a cure. Due to the positive response, this became an annual event, where it grew very quickly. As others became diagnosed with FOP in California, this event also became a way for FOP members to see Dr. Kaplan, as well as FOP families to support the cause together.

In its fourth year, it was apparent that this event no longer could be put together by family and friends. We needed more HELP! The Santa Maria Valley Noontime Kiwanis Club, with the help of other local Kiwanis clubs, answered the call for help and continued to make the event a great success in the years that followed.

We would like to take this opportunity to share our sincerest gratitude to the Central Coast community, who has shown its commitment to the IFOPA year after year after year. The volunteers, businesses and individual supporters of this event have truly become heroes in the mission to find a cure for FOP.

We would also like to recognize two individuals who have given an enormous amount to the IFOPA: Jill Parry and Don Brister. Jill Parry took over the Find-A-Cure Dinner as Kiwanis Chairperson. Her leadership and dedication has enabled this event to continue all of these years. Our appreciation also goes out to Don Brister, who began as master of ceremonies for this event and then extended his commitment to the IFOPA by being elected to the IFOPA Board of Directors and serving as the IFOPA's second Chairman of the Board.

Fundraising for the IFOPA has certainly been an adventure for our family. Little did we know that sharing our story about FOP so many years ago would not only become our way of turning the helplessness of FOP into HOPE for a cure, but that the entire FOP community would have the love and support of so many who believe in this mission as well. This has truly been a humbling and rewarding experience that has forever shaped our lives and the way Stephanie and our family copes with FOP.

This adventure is not over however....

Join the Snow, Eckart and Danzer families, along with other west coast FOP families, for the 14th Find-A-Cure Chicken BBQ! (Please note: Though this event has a similar name to the one listed above, it's an entirely different and unrelated fundraiser.) It will take place, Saturday and Sunday, April 9-10, 2010, in Santa Maria, CA. We hope to see you there!



Left to right: Erin Danzer, Cassie Eckart, Matt Horick, Stephanie Snow, Elliott (Stephanie's service dog) and Dr. Kaplan.

The IFOPA would like to give special thanks to the Snow family, the Santa Maria Valley Noontime Kiwanis Club, Jill Parry and Don Brister for their continued efforts and commitment to this wonderful event – the funds you have raised have done so much to further the mission of the IFOPA.

— FOCUS ON FUNDRAISING —

New Approach for Hayden's Hope A Success

by Sara Olsen
IFOPA Chairman of the Board

Hayden's Hope 2009 was a new format for us, and wound up being a lot of fun. It also brought in significant donations.

We held the event at an old theater called the Throckmorton in Mill Valley, CA. The Throckmorton is famous for having local celebrities like Robin Williams show up to perform stand-up comedy. On September 19, 2009, the local celebrity was my nephew, Hayden Pheif!

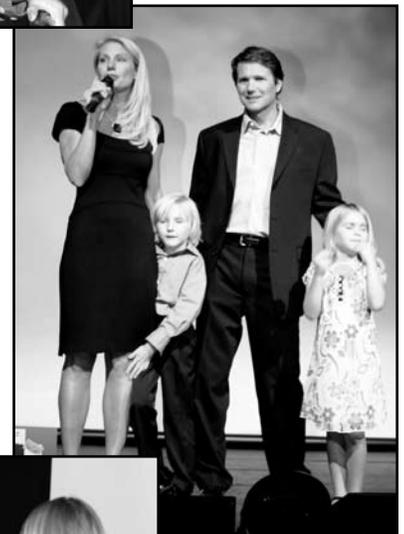
More than 200 friends attended our event, which carried a more casual spirit this year, to reflect our understanding of the economic challenges everyone is facing this year and to try to maximize our donation dollars. Instead of having our tried-and-true, large-format Silent and Live Auctions, we had a very limited set of items (five) that we sold drawing tickets for, and we focused on funding a much needed Research Fellow for the FOP Lab.

As usual, the Pheifs -- Megan, John, Hayden and Elsa Lilli -- gave a heartwarming and inspiring welcome. Fellow IFOPA Board Member and friend of the Pheifs, Warren Dowd, read a moving thank you and call for donations from Dr. Kaplan (who couldn't attend this year because our event was on his birthday).

Dr. Kaplan's message beautifully set up the main event, a "Raise-the-Paddle" effort that functionally acted like an auction, with donors pledging dollars toward a goal rather than toward winning an auction item. We geared this effort to fund a Research Fellow for the FOP Lab. I had the honor of trying out my nascent skills at running the "Raise-the-Paddle" portion of the evening -- a challenging but fun role, especially amongst friends. And best news of all, we met our fundraising goal!

Hayden's Hope is almost always largely a group of extended family and friends. I have to say that every year I am moved by how generous all of our friends and extended community are. The Old Mill School community, where both Hayden and Elsa Lilli are students, has been particularly generous to our cause -- from parents attending, to Hayden's friends, and other students working the evening as volunteers. We are humbled by the support our entire community consistently provides, and we are hopeful that their contributions will make a significant difference in getting us ALL to the goal of a cure.

If anyone reading this has any interest in putting on a similar event, please let us know. We'll be happy to share any of our tips and tricks (e-mail Megan at megan@haydenshope.com or me at sara@haydenshope.com), and of course the office staff will help make sure your event turns out successfully. It is easier than you think, and friends rally around you because they WANT to help and need a vehicle and way to assist in our cause. Everyone wins!



TOP (left to right): Hayden, his cousins Anika and Zachary Kaplan, and his sister Elsa Lilli.

SECOND: The Pheifs welcome their guests.

THIRD: Hayden and Elsa Lilli pick drawing winners.

BOTTOM: Sara and Hayden before the event.

— FOCUS ON FUNDRAISING —

Cure FOP 5K Dash & Cash

By Wendy Henke

The weather cleared, and we cleared some cash for the IFOPA at the Cure FOP 5K Dash & Cash, held on Sunday, September 27, 2009, in Newark, DE.

Attended by the Gopshes, Henke, Padilla and Cali families, 80-plus volunteers and approximately 300 participants, including an entourage from the FOP Lab, the event offered a competitive 5K race, a casual family fun-loop, a pitch-in picnic, an FOP and IFOPA information table, and a “bone”-us cash drawing.

The race coursed through the 300-acre Glasgow Park, on both paved and wooded trails, and finished just past a tremendous playground, where children played and spectators cheered the returning champions of FOP.

The pitch-in picnic began the moment the first runner crossed the finish line, so the cheers were extra enthusiastic!

For the pitch-in picnic, everyone brought a dish to share. What they brought exactly was decided by their last names: If their last names began with letters between A and J, for example, then those participants were told to bring a fruit or vegetable dish. In addition to this, a fabulous feast (supplemented by generous corporate donations) of fried chicken, drinks, cotton candy, snow-cones, and popcorn was also provided.

Individual donors to the Cure FOP 5K Dash & Cash also had the option to enter into drawings for cash prizes,



Justin Henke (front) is joined by staff members of the FOP Lab at the Cure FOP 5K Dash & Dash event.

sponsored by local businesses.

In the end, considerable awareness and resources for FOP were raised.

We look forward to next year’s Cure FOP festivities. Two valuable lessons we learned include: Scheduling a time for a photograph of all the FOP families and Lab staff together (we couldn’t get Dr. Shore off the playground!); and printing different colored “Cure FOP” T-shirts for those of us associated with FOP, to better stand out in the crowd.

Each year gets better and one ‘step’ closer to a cure and treatment for FOP. Let us not grow weary in running this good race.

Race for the Cure - Chicago Marathon

By Ryan McWilliams

On Sunday October 11, 2009, my girlfriend, Danielle, and I ran the Chicago Marathon in honor of my 15-year-old brother, Kyle, who was diagnosed with FOP at the age of three.

Danielle had set a goal that at some point in her life she would like to run a marathon, and she approached me about the idea in early February that we could run the marathon and raise money for the IFOPA. I thought it was a great idea.

We began training in early June for this marathon, running each day and increasing the mileage each week. Things went fairly well with training until Danielle got tendinitis in her left knee about two weeks before the marathon, but this did not stop her.

On the morning of the marathon, it was about 30 degrees Fahrenheit, and the amount of people at the starting



Ryan and Danielle at the big race.

Race for the Cure - Continued on Page 15

— FOCUS ON FUNDRAISING —

Spencer Man Memorial Benefit Drawing Raises More Than \$18,000

by Erin Turner

On November 6, 2009, the IFOPA held its 4th Annual Spencer Man Memorial Benefit Drawing. More than 3700 tickets were sold for the drawing, with participants vying for a chance to win some wonderful prizes -- and to help support the IFOPA and its mission.

As in the past, The Spencer Barnett Man Foundation of Oklahoma City, OK, matched (doubled) every dollar donated to the IFOPA from the drawing up to \$4,000. This meant that a \$25.00 contribution became a donation of \$50.00! Thanks to Mike Man, president of The Spencer Barnett Man Foundation and IFOPA Board Member, for his continued support.

**Combined, the drawing raised
more than \$18,000 for the IFOPA!**

In a twist from years past, this year's winners were given the opportunity to choose their prizes in accordance to the order their names were drawn. Stephanie Burns of AllState Insurance in Oviedo, FL picked the winners from our selection box.

The winners and their selected prizes are as follows:

- **Edwina Eichner** -- Two Round Trip Tickets Compliments of AirTran Airways
- **Jo Holzer** -- Ladies Brighton Wallet and \$200
- **Magusta Isom** -- Flip Ultra HD Video
- **Joan Nelson** -- Dooney and Bourke Handbag
- **Patrick Doerr** -- iPod Touch w/ Universal Docking Station



**Stephanie Burns of AllState Insurance in Oviedo, FL
picks the winners.**

Congratulations to all our winners! Thanks also to all that participated. You made this an extremely successful fundraiser -- we could not have done this without you! This fundraiser proved to be a great way for people to learn about FOP, get introduced to the IFOPA, and win terrific prizes!

Race for the Cure - Continued from Page 14

line was extremely overwhelming but also extremely motivating.

The race started, and things progressed well. We were motivated, there was music, cheering, and the environment itself made us want to go all the way until the end.

About half way through the race however, Danielle's knee started acting up. She continued to push through the pain and fought back tears as we approached the 20 mile mark. But at about mile 23, Danielle had said she didn't know if she could finish. I encouraged her and reminded her how far we had come.

With that spirit, she pushed through the pain and tears, and at mile 25, adrenaline took over and we picked

up our pace and kept moving forward. We both realized that our work was going to pay off.

At mile 26, we rounded a corner and saw the finish line. Danielle and I grabbed each others hands and ran the last one hundred yards together.

At the finish line as we received our medals. The feeling was incredible as we both were in tears as to how happy we were that we finished.

We were very proud, and more importantly we raised much-needed funds for for FOP research, which was a constant reminder of why we were doing the race, and why we were able to finish.

Distinguished Contributors and Fundraisers

Thanks to the individuals and businesses listed on these next few pages for their generous contributions to the IFOPA, which will help us fund FOP research. Contributions from July 1, 2009 – September 30, 2009 are listed. All contributions collected after September 30, 2009 will be listed cumulatively in the 2009 Annual Report, which will be made available electronically in May 2010 to all donors, members and friends of the IFOPA.



DIAMOND

*Donations of
\$25,000 or more*

Contributors

In Honor of Erin Danzer
Echo Pacific Construction, Inc.

Fundraisers

**Erin's Day Charity Golf Tournament
& Haircut-a-thon**

In Honor of Erin Danzer

**Hayden's Hope Benefit for FOP
Research**

In Honor of Hayden Pheif

Lincoln's Legacy

In Honor of Lincoln Wheelock



PLATINUM

*Donations of
\$10,000 or more*

Fundraisers

Cure FOP 5K Dash and Cash

In Honor of Justin Henke

Cure FOP Swim-a-thon

In Honor of Justin Henke



GOLD

*Donations of
\$5,000 or more*

Contributors

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Warren & Caroline Dowd
Chris Skarakis

In Honor of Lincoln Wheelock

John & Amanda Cali
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Fundraisers

Golf for a Cure

In Honor of Shane Terry



SILVER

*Donations of
\$1,000 or more*

Contributors

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Sonic
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In Memory of Jill Halsey

Joanne Halsey

In Memory of Spencer Man

John Kirkpatrick

Others:

Heather Wiley Starankovic

Fundraisers

Lincoln's Legacy Bake Sale

In Honor of Lincoln Wheelock

Race for a Cure

In Honor of Kyle McWilliams

Walk in the Woods to Cure FOP

In Honor of Whitney Weldon

Continued on Next Page



BRONZE
*Donations of
 \$500 or more*

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Erling & Saskia Blonk

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Fundraisers

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Garage Sale

In Honor of Matthew Wadd

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In Honor of Jordyn Bugarin

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