



Connection

International Fibrodysplasia Ossificans Progressiva Association, Inc. (IFOPA)

Volume 23, NO. 1 - February 2008

MEET THE NEW IFOPA BOARD OF DIRECTORS AND OFFICERS

Jeannie Peeper
President and Founder
Board Member
Winter Springs, Florida

Relationship to FOP:

I am a 49-year-old adult with FOP.

Background:

I graduated from the University of Central Florida in 1985 with a B.A. in Social Work. My journey with the IFOPA began when I met Dr. Michael Zasloff at the National Institutes of Health and learned that he had other patients with FOP. Contacting some of those patients gave me the incentive to start the International FOP Association, Inc. in 1988, first as a pen pal group and a means to raise funding for FOP research. I met another person with FOP for the first time at age 31 — what an extraordinary difference that made to my life! The first *FOP Connection* newsletter was published in January 1989 to connect the 11 founding IFOPA members, and today this same newsletter has grown into an amazing 20-page publication. In June 2005, on the IFOPA's seventeenth anniversary, I retired from my full-time involvement in the day-to-day activities of the organization. I continue to serve as President, and as a spokesperson and Board Member.

Goals for the IFOPA in 2008:

I have always believed in the IFOPA as an organization and the many people that make it possible. I consider the years and hours of personal contact I have had with families as a gift, making my personal journey with FOP all the more fulfilling. 2008 is sure to be another successful year for the IFOPA. My vision and dream has always been to one day find a treatment and cure for FOP.



Don Brister
Chairman of the Board
Meridian, Idaho

Relationship to FOP:

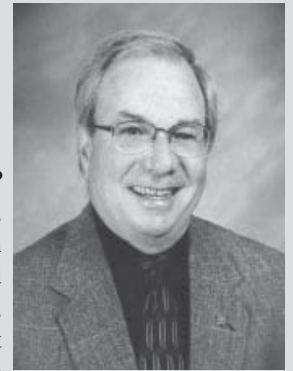
I became involved with the FOP community in 1995 in Santa Maria, California when I agreed to help with the "Find a Cure" fundraisers started by the Snow family, whose daughter, Stephanie, was diagnosed with FOP at the age of three. I eventually joined the leadership team and agreed to act as emcee for the dinner auction, which I have done for the past 12 years.

Background:

Since graduating from Texas A&M University, most of my adult life has been in the area of marketing, public relations, human resources and grant writing. I have also managed to combine a passion for sports by doing play-by-play of high school sports on the radio since 1968. After moving to Idaho in 2004, I was asked to join the Board of Directors of the IFOPA and have served in that capacity ever since. In 2006, I was the Chairman of the Grant Writing Committee and also served on the Symposium Planning Committee. Being the Chairman during the year of the largest Symposium ever held by the IFOPA was a tremendous experience; it was rewarding and thrilling to see so many people come together for a common cause.

Goals for the IFOPA in 2008:

My goal as Chairman is to increase awareness of FOP and establish partnerships with foundations and corporations that will allow for continued fundraising. We need to build on the enthusiasm generated during the Symposium and assist those members of our community who reside outside the United States. The formation of the International President's Council is a good beginning to that goal. We also need to provide the necessary funds to our research partners while taking the burden off FOP families.





International
Fibrodysplasia
Ossificans
Progressiva
Association

International FOP Association (IFOPA)
P.O. Box 196217
Winter Springs, FL 32719-6217
Phone 407-365-4194
Fax 407-365-3213
E-mail: together@ifopa.org

Website: www.ifopa.org

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 FOPnews@bellsouth.net.

Editor: Eyal Goldshmid

Contributors: Monica Latina Anderson, Don Brister, Chris Cougle, Robin Davis, Linda Daugherty, Warren Dowd, Steve Eichner, Chrissy Flexer, Eyal Goldshmid, Jeannie Peeper, Wendy Henke, Lori Henrotay, Jeri Licht, Sara Olsen, Holly Pullano, TBA Global Detroit and Heather Wiley Starankovic.

Mark Your Calendar

The following is a list of upcoming IFOPA fundraisers set to occur in 2008. Note: All dates are subject to change.

March 30, 2008

Bingo for a Cure! in Honor of Joshua Scoble
To be held at 1:00 p.m. at the Allentown Fairgrounds Agri-Plex Hall in Allentown, PA. Contact Chrissy Flexer at 610-349-8479 or cflexer20@aol.com for more information.

April 12-13, 2008

The 15th Annual Find-A-Cure Chicken BBQ in Honor of Stephanie Snow, Cassie Eckart and Erin Danzer
To be held at the Long's Drug Store Parking Lot on S. Broadway in Santa Maria, CA. Contact Jennifer Snow at 805-937-1420 or jsnow_fop@yahoo.com for more information.

May 10, 2008

Stride to Cure FOP in Honor of Justin Henke
The Healthy Delaware Foundation, in conjunction with the Delaware Center for Health Promotion, will hold its first "Walk Across Delaware" along the Chesapeake and Delaware Canal. Contact Wendy Henke at wendyhenke@yahoo.com for more information, or visit www.ifopa.org/stride08.html.

May 18, 2008

Walk in the Woods to Cure FOP
To be held at the Loantaka Brook Reservation in Morristown, NJ. Contact Holly Gehrie at 973-615-3166 or hgehrie@optonline.net for more information.

June 2, 2008

Whitney Weldon Golf Invitational in Honor of Whitney Weldon
To be held at the Plainfield County Club in Plainfield, NJ. Contact Hillary Weldon at hilly319@aol.com for more information.

August 10, 2008

The 15th Annual Find-A-Cure Dinner Hosted by the Kiwanis Club in Honor of Stephanie Snow and Cassie Eckart
To be held at the Santa Maria Elks Lodge in Santa Maria, CA. Contact Jill Parry at 805-937-9691 for more information.

September 20, 2008

Find-A-Cure Fundraiser in Honor of Kyle McWilliams
To be held at the Brooklyn-Victor Country Club in Victor, IA. Contact Ryan McWilliams at rmcwilliams@fouroaks.org for more information.

November 2008

Hayden's Hope Benefit for FOP in Honor of Hayden Pheif
Contact Megan Pheif at 415-384-0463 or megan@haydenshope.com for more information.

TABLE OF CONTENTS

New Board of Directors and Officers	1, 3-5
Mark Your Calendar	2
A Note from Jeri Licht	5
Stride to Cure FOP	6
Bingo for a Cure	6-7
Fundraising Thermometer	7
TBA Global Detroit Adopts FOP Family	8
IFOPA Store	9-11
Using the Web as a Resource	12-13
Birthdays	14-15
Member Changes	15
Contributors	16-19
Remembering Margie McConnon	20

MEET THE NEW IFOPA BOARD OF DIRECTORS AND OFFICERS

Lori Henrotay
Vice-Chairman of the Board
St. Louis, Missouri



Relationship to FOP:

Carli, my daughter, was diagnosed with FOP in September 2001, when she was in kindergarten.

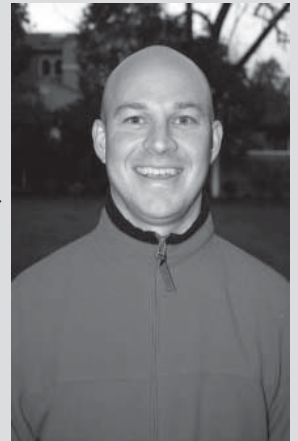
Background:

I graduated from Maryville University with a major in Business Administration and a minor in MIS. I attended college part-time and taught for the American Institute of Banking while working full-time. I am a Marketing Director with Unisys in Global Financial Services. I previously spent 15 years with IBM in Financial Services and have experience in marketing, project management, sales and consulting.

Goals for the IFOPA in 2008:

My family and I have been involved in fundraising for many years, but since Carli's diagnosis, our focus has been on fundraising and raising awareness for FOP. I enjoy serving the FOP community and look forward to continuing to learn from my FOP family.

Warren Dowd
Treasurer
San Anselmo, California



Relationship to FOP:

My first true experience with the condition came at Halloween of 2004, when I met Hayden Pheif, son of Megan Pheif, for the first time. I have subsequently seen Hayden in all manner of activities, from swimming to skiing, and Hayden's bravery and ongoing joy in the face of adversity inspired me to accept the invitation to seek election to the IFOPA Board.

Background:

I am currently employed at Deutsche Bank Securities as a Managing Director, running DB's Equity Sales and Trading operations for the Western Region.

Goals for the IFOPA in 2008:

I hope to work diligently with other IFOPA Board Members and the IFOPA membership to help secure a future without FOP. I hope to accomplish this by evangelizing the FOP cause, educating the public on the FOP and raising precious funding to support research for treatments and eventually a cure.

Monica Latina Anderson
Secretary
Upper Marlboro, Maryland



Relationship to FOP:

I was diagnosed with FOP at age three and have been a member of the IFOPA since 1988.

Background:

I have worked for the past 11 years as an Accounts Receivable Clerk for Tax Analyst in Falls Church, VA. I also work part-time as a Sales Consultant for the Avon Corporation. Prior to 1996, I was self-employed as a Lady Remington Jewelry Consultant for one year and was responsible for maintenance of my own inventory and financial records. I have a Masters Degree in Russian Studies with a Minor in International Business, and a Bachelor's Degree in Russian Studies with a Minor in Spanish and French from American University in Washington, DC. I have been a member of the Alumni Chapter of the Alpha Kappa Alpha Sorority in Prince George's County, MD since 1991.

Goals for the IFOPA in 2008:

I plan to enhance the outreach program and organize a grassroots campaign to lobby each Member of Congress for research funding. Since Congress is preparing to override the President's veto of legislation on the State Children's Health Insurance Program, the IFOPA cannot afford to miss this window of opportunity to bring FOP awareness to the forefront. I will be an asset to the Board because of my experience and knowledge of FOP. I can give the parents of young adults insight into coping with the disease. I know what the needs are and can promote living independently. I will be an inspiration to others living with FOP. I believe you can attend college and have a career with the support of family and friends.

— Continued on Next Page —

MEET THE NEW IFOPA BOARD OF DIRECTORS AND OFFICERS

Sara Olsen
Executive Committee
Member-At-Large
San Francisco, California



Relationship to FOP:

My nephew, Hayden Pheif, was diagnosed with FOP four years ago.

Background:

I have more than 13 years of operational experience in a series of industries, including real estate development, interior design and high technology. For the past five years, I have focused on real estate development, most recently completing an \$11 million conversion of a vacant hospital building on Central Park North in Manhattan. In 1999, I started HauteDecor, a web-based portal for Interior Designers and Architects, and raised more than \$12 million in venture financing for the company. I spent seven years in high technology, primarily with Macromedia, where I was responsible for a \$35 million P&L — more than 30 percent of the company's revenue. I hold a B.A. from the University of California, Berkeley, and an M.B.A. from Harvard University.

Goals for the IFOPA in 2008:

Since Hayden was diagnosed with FOP, I have been actively involved with the Hayden's Hope fundraiser spearheaded by my sister, Megan Pheif. I am looking forward to being more actively involved in the IFOPA as a whole.

Robin Davis
Board Member
Cincinnati, Ohio



Relationship to FOP:

My niece and goddaughter, Carli Henrotay, is an FOP member.

Background:

I work for The E.W. Scripps Company, where I am the head of finance and administration for the newspaper division. I am a CPA and received my bachelor's degree in accounting from Saint Louis University. I am also very active in industry organizations and sit on the board of the Inland Press Association.

Goals for the IFOPA in 2008:

I am honored to have been elected to sit on the Board and look forward to working with all of the wonderful people who have already offered so much time and talent to the IFOPA. I would like to increase awareness of FOP for the purposes of education and fundraising.

Jeri Licht
Board Member
Scarsdale, New York



Relationship to FOP:

My son Daniel, who is now 13, was diagnosed with FOP on his third birthday.

Background:

Once the shock of the FOP diagnosis began to lessen, my husband Peter and I decided that the best way to help Daniel was to help everyone with FOP by fundraising and volunteering for the IFOPA. In 1998, I was elected to the Board of Directors, and since then I have worked with many wonderful people on a variety of projects, such as: chairing the Membership and Fundraising Committees; helping create Overcoming Obstacles (the database of FOP-specific resources on the IFOPA's web site); chairing the Symposium Resource Center Committee (which organized a collection of adaptive equipment, tools, resources and ideas for the

Fourth International Symposium on FOP); sitting on the IFOPA Executive Committee from 2000 through Dec. 2007; and serving as IFOPA Secretary (from 2002 to 2006) and Vice Chair in 2007. I am grateful for the opportunities the IFOPA has given me to help those with FOP. Doing so has been personally and professionally satisfying, helped me feel less helpless in front of FOP, and strengthened me for the future.

Goals for the IFOPA in 2008:

In the upcoming year, I would like to work toward the following goals for the IFOPA: (1) Update and enlarge the Overcoming Obstacles database so it includes new information from the 2007 Symposium Resource Center and other relevant web sites/catalogues etc. and is more user-friendly; (2) Establish a continuing system for seeking and securing grant money for the IFOPA's various projects and programs; and (3) Monitor and revise IFOPA documents as needed or requested.

Thank you for allowing me to serve as a Board Member. I promise to live up to the trust, faith and confidence the membership and Board of Directors have shown in me.

MEET THE NEW IFOPA BOARD OF DIRECTORS AND OFFICERS

Holly Pullano
Board Member
Cheshire, Connecticut



Relationship to FOP:

I was diagnosed with FOP at 16 years of age. I am now 27. Although at first I was reluctant to become actively involved with the IFOPA, I now have embraced it as being my life's purpose. It is my belief that everything happens for a reason – and the reason I have FOP is so that I can use my passion to make a difference in the lives of those with FOP and their families.

Background:

I hold a B.A. in Journalism and Communications with a minor in Sociology from Quinnipiac University. I currently work full-time in the marketing and public relations department of a construction company.

Goals for the IFOPA in 2008:

It was a pleasure and a privilege to be involved in the planning of the Symposium last year. My dedication to the IFOPA remains strong, and in 2008 I am looking forward to taking on new projects that will help further our mission. This will include remaining active in fundraising and making our cause known to the media and political world. I am an outspoken FOP advocate and am dedicated to increasing awareness and furthering medical research in the coming year and beyond.

Heather Wiley Starankovic
Board Member
Philadelphia, Pennsylvania

Relationship to FOP:

It is through my position at the University of Pennsylvania that I encountered my first individual with FOP, and as the relationships have grown over the years, so has my desire to learn and contribute more to the fight for a cure and treatment for FOP.

Background:

I work at the University of Pennsylvania, fundraising for several departments in the health system and managing the endowment and generous contributions made to UPENN by the families and friends of those living with FOP. I have been a fundraising professional for a decade and have never met such a kind, cohesive and inspirational group of individuals as the FOP community, which always exhibits such contagious enthusiasm for positive change. My education experience includes two Bachelor of Arts with honors from Kent State University, one in Art History and one in Anthropology, and I hold a Master of Arts, Public Culture, from UPENN. I also have earned Certificates in Fundraising and Nonprofit Management, respectively. Presently, I am on the Board of the University City Arts League and a Youth Group Leader for Holy Trinity Lutheran Church.

Goals for the IFOPA in 2008:

I hope to raise awareness of FOP through a grass roots fundraising initiative that aims to generate funds to support the care of those living with FOP and towards discovering a cure.

A Note from Jeri Licht.....

When FOP entered my life in 1997, I thought my life changed forever. For awhile, I was barely able to function — not as a wife or mother, and certainly not as a negligence and malpractice attorney, a job which suddenly seemed less important than it used to. When the shock lessened, however, Peter and I began fundraising and volunteering for the IFOPA, and it turned out to be the key to our survival.

For ten years, I have enjoyed the camaraderie and comfort of this wonderful extended IFOPA family, sharing flare-ups, personal and professional successes and disappointments, research discoveries, illness and pain (both FOP and other), and so much more. With great pride, I worked long hours on diverse projects with my IFOPA coworkers, Board colleagues and fellow families, learning from them all. It came almost as a surprise to notice one day that, despite FOP and its unpredictability, my life had returned. Even with FOP in it, I could clearly distinguish most of the characteristics I saw before the FOP diagnosis. FOP is just one part of life, and hopefully a peripheral one at that. To keep it on the outskirts, I need to help Daniel and our family not only survive FOP, but exceed it, living gloriously well despite it. That is my primary personal goal for 2008, as Daniel gets ready for his first year of high school. In order to do so with a relatively clear calendar, I decided to reduce my responsibilities with the IFOPA. I will still be on the Board, looking toward the IFOPA's future, and on FOPOnline, enjoying the give and take of love and comfort found there. Thank you for everything.

— Jeri Licht

Stride to Cure FOP

**Saturday, May 10, 2008 - Justin's 8th birthday
Chesapeake and Delaware Canal**

By Wendy Henke

As part of a fitness initiative, the state of Delaware will hold its first (hopefully, annual) "Walk Across Delaware" along the Chesapeake and Delaware Canal on Saturday, May 10, 2008. The daylong event, which, coincidentally, will be held on my son Justin's eighth birthday, will offer participants a chance to perform a three-mile walk, a six-mile walk, or a 15-mile walk, the latter of which spans the width of the state. (Yes, Delaware is that small).

Seizing the opportunity, we sought and received permission to utilize the event as a means to raise awareness and funds for FOP. Though there can be no appearance of endorsement from the state, officials have said they are excited to have additional walkers attend.

It's an ideal scenario for us, as we expect the event to attract thousands of people, and the logistics of such a day (course preparations, transportation, water, portable restrooms, etc.) will be taken care of by others!

With the help of local businesses, who have sponsored us and covered the costs of our T-shirts, we'll definitely stand out in the crowd, sporting our light-blue "Stride to Cure FOP" T-shirts (see Justin's photo from last year, right).

For our part, we hope to form a sizeable team of walkers, who will collect pledges and walk one of the three distances for FOP. My goal is to have one walker per FOP member in the world. (If any FOP member is interested in having someone walk in his or her honor, or if you wish

to obtain a pledge sheet to help raise more funds for a particular walker, contact the IFOPA office at (407) 365-4194 or together@ifopa.org so we can take the appropriate steps to arrange this.)

Last year, we held a similar "Stride to Cure FOP" event at the annual Chesapeake Bay Bridge Walk in Maryland (and we'll continue that tradition again in 2010, when the bridge — currently undergoing repairs — becomes available again; the event usually draws 50,000 walkers). Despite high winds, which ultimately cancelled the walk at the last moment, we still experienced quite a windfall, raising significant money and awareness for FOP. When the local news media caught



our story, they felt compelled to cover it, too!

But the most memorable and meaningful aspect of that day was the time spent with family, other FOP families, friends, friends of friends, and coworkers — all of whom wanted nothing more than to support the FOP community.

We're looking forward to taking the next step this year. We'd love to have you join us. Also, if you would like to pursue a "Stride to Cure FOP" endeavor in your area at a local walk or race, please contact the IFOPA office — they have the resources to help you!

Focus on Fundraising



BINGO for a Cure!

**Hosted by Emmaus 4th Alarmers
March 30, 2008
Allentown, Pennsylvania Fairgrounds
Agri-Plex Hall
1:00pm**

By Chrissy Flexer and Chris Cogle

Hello! If you are receiving this newsletter, FOP has somehow touched your life. Well, FOP touched our family in 2006, when my then three-month-old nephew, Joshua Scoble, was diagnosed. When Joshua was born, he showed what we now know as the classic telltale signs: He had bumps on the outside of his big toes and hearing loss, and a few weeks later he developed a lump on his back. The unknown flare up at the time led to exploratory back surgery just days before his actual diagnosis.

Although Allentown, PA is only about an hour away from Philadelphia and Dr. Kaplan, the leading FOP doctor, no one could give Joshua's parents any type of explanation for his symptoms. After being completely floored by his diagnosis, our family and friends wanted — almost needed — to try to make sense of the situation. Which leads me to why I am writing. We have decided to

hold a "Bingo for a Cure!" fundraiser on March 30, 2008. What better way to fight this condition is there than by raising money and awareness!

Almost two years old now, Joshua is a very happy and precocious little boy. He has started walking — very nerve-racking — and loves to play with all his cousins. As I am sure many of you know, we need to find a way of making a cure a reality. In order to do this, funding is a very crucial component. Our family, friends and communities have already stepped up to provide support and contributions in honor of Joshua — but we still have a long way to go!

Now onto our "Bingo for a Cure!" event: It carries a guaranteed payout of \$4,000 dollars, and all games have a cash prize of at least \$200 dollars.

Other prizes include a two-night stay in Atlantic City and a "Grand Prize" of a three-night stay in Las Vegas, airfare included!

There will also be lots of exciting door prizes, raffles and drawings. Plus, everything listed has been donated!

Our bingo night will be held on March 30, 2008, at 1:00 p.m., at the Allentown Fairgrounds Agri-Plex Hall. Tickets are \$30 in advance or \$35 at the door. All proceeds benefit IFOPA in honor of Joshua Scoble.

If you have any other questions about our bingo night or would like to purchase tickets, please feel free to contact Chrissy Flexer at cflexer20@aol.com or call (610) 349-8479. Our goal is to sell 500 tickets. By the middle of January we have already sold 400! So get your tickets soon if you want to play "Bingo for a Cure!" Thank you for your time.

With the help of funding, a cure is within reach!!!

ifopa B i n g o

For a Cure!
March 30, 2008

At the Allentown Fairgrounds, Agri-Plex Hall at 1:00 p.m.

Admission Ticket—\$30 in advance or \$35 @ the door.
Tickets are limited, so buy them early!!

All games have a CASH prize of at least \$200. Guaranteed \$4,000 pay out. Other prizes include a two-night stay in Atlantic City and a Grand Prize of 3 Nights w/airfare to Las Vegas! As well as a lot of exciting door prizes, raffles and drawings.

Refreshments will be available for purchase.
This is a Non Smoking Event.

All Proceeds Benefit IFOPA in honor of Joshua Scoble.

Joshua Scoble of Allentown is a 1½ year old boy who was born with FOP. FOP is a rare genetic disease that causes his muscles to turn to bone, prohibiting him to bend at his joints. Joshua was recently on 69 news. If you would like to learn more about his story you can visit their website at www.wfmz.com, go to stories and type the keyword FOP.

WITH THE HELP OF FUNDING,
A CURE IS WITHIN REACH!!!

Tickets can be purchase at
Buss Paint & Wallpaper in Emmaus or you can send a self addressed stamped envelope to:
Buss Paint
327 Main Street, Emmaus, PA 18049
Make checks payable to the Emmaus 4th Alarms

If you have any other questions please email
Chrissy Flexer at cflexer20@aol.com or call 610-349-8479

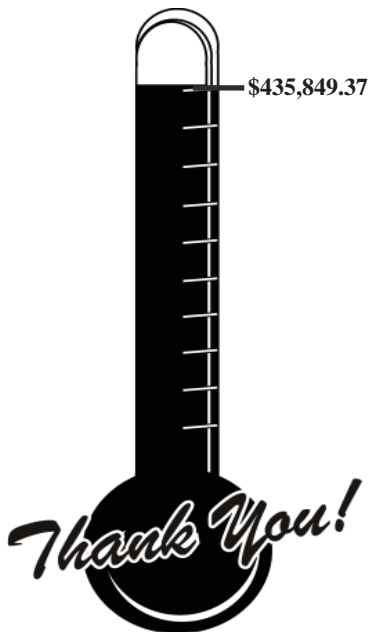
Focus on Fundraising

2007 Fundraising Thermometer

This is our 2007 Fundraiser Thermometer. It reflects funds raised for the IFOPA from events and programs that our members sponsor. This does not reflect funds from donations or dues.

In the 4th quarter (October 1 - December 31, 2007), our fundraisers raised \$92,523.42. The IFOPA would like to extend a special thank you to the many individuals who supported and were involved in our recent fundraising events. We appreciate the following recent fundraisers for attributing to the current amount raised:

- amazon.com
- Coins for a Cure
- Flexer Birthday Party Fundraiser in Honor of Joshua Scoble
- Floyd Letter Drive in Honor of Jasmin Floyd
- FOP Awareness Bracelets
- FOP Benefit Drawing in Honor of Cassie Eckart and Stephanie Snow
- GoodSearch.com
- Hayden's Hope Letter Drive in Honor of Hayden Pheif
- Hyundai Charity of the Month in Honor of Stephanie Snow
- iGive.com
- Old Oaks Country Club Charity Day in Honor of Daniel Licht
- Ruiz Letter Drive in Honor of Lindsay Ruiz
- Smith Barney Casual for a Cause Day in Honor of Alyssa Whitaker
- Svenska FOP Foreningen Ekenalliansens Squaredans Klubbar - Square Dance Fundraiser in Honor of Pontus Calmefelt
- Svenska FOP Foreningen Lumbdyskolans Christmas Bazaar in Honor of Hugo Fahlberg and All FOP Children in the World
- World's Largest Dinner Party
- Your Purse Connection Fundraiser in Honor of Joshua Scoble
- Zion United Methodist Chili Supper in Honor of Jasmin Floyd



TBA GLOBAL DETROIT ADOPTS FOP FAMILY FOR THE HOLIDAYS



By TBA Global Detroit



Cindy Bell, Vice President of Meeting Services for TBA Global, who initially worked with the IFOPA in the early planning stages of the Symposium, agreed with these sentiments.

“The entire process of working with the IFOPA, from the search for an appropriate hotel and destination down to planning activities and menus, was wonderful,” said Bell.

“Never have I worked with or seen such a dedicated organization. And once we were in Orlando and operating the program, it was clear that this was a cause we would happily embrace. The decision to ‘adopt’ an

Every holiday season, the Meeting Services Department at TBA Global makes a point to give back to the community, either by adopting a family in need or donating money to a local charity. After working with the IFOPA on its Fourth International Symposium on FOP in Orlando in August 2007, the decision was made to “adopt” an FOP family in need.

As the meeting planner who worked most closely with the IFOPA on the planning and operation of the Symposium, Melissa Clark said the experience was personally rewarding and life-changing.

“Never in my 15-year career have I ever worked with a client where I personally felt like I was doing something that actually made a difference in the world,” she said.

“The FOP families I met were amazing — strong, loving, welcoming, joyful and genuinely appreciative of everything that was done for them while they were in Orlando. My staff and I were often moved to tears, and we fell in love with each and everyone we met. By the time the Symposium came to a close, we felt like a part of the global FOP family. When I returned to Detroit, I was eager to impress upon my co-workers the need for us to do our part in supporting the families who are fighting this terrible disease.”

FOP family for the holidays was unanimous, and we hope to do this every year.”

To make the “adoption” happen, Melissa Clark contacted the IFOPA and asked the organization to recommend an FOP family who could benefit from TBA’s support. It was very hard for them to select just one family from the information supplied to them, but after much thought TBA decided to “adopt” the Woodard family of Alaska, an FOP family of six with four children between the ages of three and 13.

In early November, a letter with photos and a wish list from each child was provided to TBA. Packages containing gift-wrapped clothing, shoes and toys, along with gifts for both parents, arrived at the family’s home in time for the holidays.

As for the folks at TBA, they feel like they’ve been given a gift — the gift of having the chance to work with the IFOPA and meeting amazing families whose love and dedication to each other shines brightly in spite of the everyday challenges of dealing with FOP.





store

The IFOPA now offers organization-based merchandise and other goods for sale to the public.

On the following pages, you'll find many of the products we are showcasing, including several unique IFOPA-branded items.

For more information on the merchandise listed, or to purchase any item or combination of items featured on the following pages, as well as the other educational videos and books we offer, please contact the IFOPA office at (407) 365-4194 or together@ifopa.org.

You can also view these items online at www.ifopa.org/ifopastore.html.

Note: Prices do not include shipping or tax (7% sales tax will apply to products shipped to a Florida residence).



IFOPA Awareness Merchandise

Show off your FOP advocacy with official IFOPA merchandise



Men's Polo

Adult Sizes: Small, Medium, Large, X-Large

Price:
\$22 each



Women's Polo

Adult Sizes: Small, Medium, Large, X-Large

Price:
\$22 each



Sports Bottle

Price:
\$3



T-shirt

Youth Sizes: Medium, Large
Adult Sizes: Small, Medium, Large, X-Large, XX-Large

Price:
\$8 for youth
\$10 for adult (Sm - X-Large)
\$12 for adult XX-Large



Tote Bag

Price:
\$10



License Plate Frame

Price:
\$3



IFOPA Awareness Bracelet

Embossed with "FOP AWARENESS
WWW.IFOPA.ORG"

Sizes: Youth and Adult

Price:
\$2 each



Pen

Price:
\$1

Other IFOPA Items

ifopa
store



Special Occasion Scrolls

Honor guests of your next wedding, bar mitzvah or other special event by giving them their own IFOPA scroll.

By making a donation, the IFOPA will create and send scrolls (similar to the one pictured above) to you. An elegant white ribbon will be tied around each scroll.

The scrolls can be placed on reception tables or other locations of your choosing. Each will thank your guest for sharing this special day with you, as well as recognize the donation you made in lieu of a traditional gift.

Price: \$2 - \$5 donation per scroll



Symposium Notecards

These specially made blank greeting cards bare the themes from all four International Symposiums on FOP.

Price:

\$3 for pack of 4

\$5 for pack of 8



Earrings

IFOPA friends Lane Maloney and Lindsay Goldberg created these custom-designed earrings for FOP awareness and fundraising. They feature an omega clasp and intricate metalwork design, highlighted by two beads, the larger resembling a pearl and the smaller resembling an emerald.

Price: \$10

Coming soon: IFOPA Lapel Pins!

www.ifopa.org/ifopastore.html

Using the Web as a Resource

by Jeri Licht and Steve Eichner
Symposium Resource Center Committee

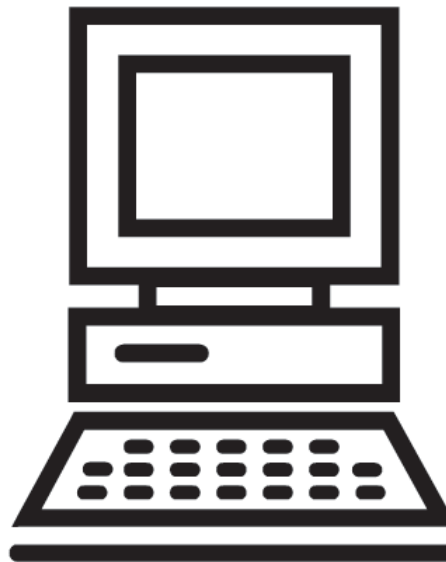
As soon as something is printed, it is obsolete. A phone number changes, a better item is invented. Progress is constantly moving, but a printed list is like a still picture of what existed at one particular moment.

How to keep a catalogue current is a problem that has been around awhile, but now the Internet has changed all that. Websites are like constantly updated catalogues, and every day people can jump on the always moving cutting edge of progress just by surfing the web!

This article, available in the IFOPA's *Resource Center Booklet*, which also contains additional information on helping FOP members gain personal independence and comfort, is a starting place for anyone looking to locate resources to help manage the consequences of FOP. It is also a living resource that can be updated regularly with your help. To ensure it stays current, please submit new items you discover to the IFOPA office at (407) 365-4194 or together@ifopa.org.

To help you research or purchase items online, we offer the following suggestions, taken from the *Resource Center Booklet*:

1. **Shop through organizations that donate to your charity with every purchase.** You can donate a portion of your purchase to the IFOPA without raising the price you are paying for the product by buying items via www.iGive.com and amazon.com. iGive is a charity shopping mall — a doorway to hundreds of major stores and web sites, and using it gives the IFOPA a percentage of your purchases. Amazon.com similarly donates to the IFOPA if you go to their site from a link on the IFOPA website. For more information about these easy ways to help the IFOPA when you shop, please go to <http://www.ifopa.org/special.html>.
2. **Check out the vendor.** Use tools like www.epinions.com, which is a website that allows the general public to submit reviews of products and retailers, and the Better Business Bureau, which focuses on individual companies at www.BBBOnline.org.
3. **Vendors differ.** When making a purchase, it is a good idea to deal only with companies that provide a physical address and telephone number. Companies of all sizes are on the web, and customer service may vary widely.
4. **Determine your willingness to accept risk.** You may not feel comfortable spending three hours researching a \$10 purchase, but you might feel very differently about a \$500 purchase, or one that involves an important item for your comfort, such as a mattress.
5. **Protect your information.** Do not send your credit card or banking information through regular email or on unencrypted web forms. If you do, it is pretty easy for someone to intercept it. You should only submit this



information on the web through a form that is using the "https://" protocol (the "s" means secure).

6. **Social security numbers.** There is no reason why a company selling merchandise needs this information, although they sometimes will ask for it. You can refuse on the grounds that it will put you at risk for identity thieves, and ask that another method of identification be used, such as your mother's maiden name, etc. Banks often require a SS number for credit cards and establishing accounts, but otherwise your SS number should never be provided.
7. **Return policies.** Some companies don't allow returns, but most do within 30 days (or similar period of time) of purchase. They usually do not refund shipping and handling costs. Return policies usually have other conditions, such as the item must not have been used, return must be in the original packaging, etc. Hygiene or personal care items may not be returnable at all, but that is often stated on the item's description page. The return instructions will be on the back of the invoice you receive with your purchase, and you should read and follow them carefully. Some stores have "restocking fees" to cover their costs in returning the item back to its location in the warehouse. Some companies that have both websites and physical stores don't let you return a purchase to the "other" store. though some do. For example, if you buy something from homedepot.com. you cannot return it to your local Home Depot. Costco, on the other hand, has a very liberal return policy and will gladly accept online purchases at any of its warehouses. Of course, always save your receipts.
8. **Shipping costs.** These costs can vary wildly. In the U.S., amazon.com offers free (slow) shipping for many items, with a minimum purchase of \$25. It can take a couple of weeks to get a product this way, but it can save you a lot in shipping, sometimes enough to cover the cost of the extra book or CD you buy to bring you to the \$25 minimum. Other sites may have shipping specials, too — Sears, Buy.

com, Overstock.com and others frequently offer reduced shipping rate specials.

9. **Feel free to shop around for better prices.** The following sites compare prices for items from vendors around the web, generally from major retailers: www.froogle.google.com, www.mysimon.com, or www.shopping.com.
10. **Availability of items.** Most companies say whether they think the item is in stock and ready to ship, but some sites are better than others in keeping inventory up-to-date. For this reason, the preferred method is that most reputable companies do not bill the customer until a product is actually shipped.
11. **Actual experience.** Sometimes, pictures and words don't do a product justice. While companies may work hard on product descriptions or pictures, it might be better to see and touch certain items, such as mattresses and pads. For that reason, depending on the product, you may want to try to find a product locally, even at a more expensive place, just so you can touch and try it before purchasing it more economically through the web.
12. **Sales tax.** If a company does not have a physical location in your state (U.S.), you will likely not be charged sales tax. There may, however, be other fees, such as a "use tax," and you might want to check your own state's law on the subject.
13. **International purchases.** The majority of vendors do not yet ship internationally, and those that do can be expensive. Search the site for shipping information or call each vendor to see if they provide that service. Also, please note that there may be some credit card charge exchange rate fees that are not listed on the vendor's website and they can add up to 5 percent (or more) onto your transaction costs.
14. **Medical insurance.** Depending on your healthcare policy, you might be able to get insurance to pay for certain medical support items (canes, bed rails, special seating, etc.). You will probably need a good doctor's note explaining the medical necessity for the item and how it relates to your medical condition, i.e. FOP. You might also be able to use Flexible Spending Account funds, if available. It is always wise to become familiar with the rules of your insurance provider.
15. **Warranties.** Check with your credit card company for extended warranty information. Many platinum and higher-level credit cards include extended warranty coverage for purchases. Please remember to save your receipts.

As we said at the beginning, this article is a living resource. Please help it stay current by submitting new items you discover as you "surf the web" to the IFOPA office at (407) 365-4194 or together@ifopa.org. Thank you.

Catalogues and Websites

Catalogues and websites offer a wide variety of items and information for people with disabilities, going far beyond the items mentioned in the Resource Center Booklet. They also contain articles on every disability related subject. Here are some recommended resources:

- **ABLEDATA:** a searchable database of available equipment to help meet your needs; 1-800-227-0216, www.abledata.com
- **Active Forever:** a website with a thorough collection of adaptive equipment at good prices; 1-800-377-8033, www.activeforever.com
- **Alimed:** the consumer catalogue has excellent items that are relevant to your needs; their professional rehabilitation catalogue is extremely complete, having many orthopedic and hospital items; 1-800-225-2610 and www.easierliving.com
- **Allegro Medical:** a consumer website filled with healthcare and support items; 1-800-861-3211, www.AllegroMedical.com
- **Carol Wright Gifts:** a varied line of home healthcare products and other products at low prices; 1-402-464-6116, www.carolwrightgifts.com
- **Dr. Leonard's:** a large assortment of healthcare and other products at low prices; 1-800-785-0880; www.DrLeonards.com
- **Dynamic Living:** a collection of very helpful tools not found everywhere else, plus articles and other useful items; 1-888-940-0605, www.dynamic-living.com
- **Ergo Mart:** a collection of ergonomic and adaptive office equipment, supplies and accessories; 1-888-420-3200, www.ergomart.com
- **Functional Solutions:** a terrific "best of" collection from North Coast Medical Inc., a company that also has a bigger catalogue listed below; 1-800-235-7054, www.beabledoto.com
- **Make Life Easier:** a collection of interesting products for the home, bath, personal care, etc.; 1-800-522-0227
- **MaxiAids:** "Products for Independent Living" — economical elder and disability support items; 1-800-522-6294, www.maxiaids.com
- **MOMS: Mail Order Medical Supply:** has a varied line of consumer home healthcare products; 1-800-232-7443, www.momsup.com
- **North Coast Medical:** complete catalogue of adaptive products and tools; 1-800-821-9319, www.ncmedical.com
- **Sammons Preston:** huge collection of adaptive, therapeutic, and medical aids: includes the *Enrichments* catalogue; 1-800-323-5547
- **Sportime Abilitations:** a huge assortment of pediatric adaptive and therapeutic equipment; 1-800-850-8602, www.abilitations.com
- **Taylor Gifts:** a collection of inexpensive products for the home and personal care; 1-800-829-1133, www.taylorgifts.com
- **ThermaKool Ice Packs:** flexible, soft and convenient ice packs of varied sizes in their own Velcro closing "comfort wraps" to keep them on the trauma; 1-631-501-1451; www.nortechmedical.com
- **Walter Drake:** a collection of home and personal care goods at reasonable prices; 1-800-525-9291; www.wdrake.com
- **Wrightstuff:** a thorough website of items focused on items to assist people with arthritis, which makes it good for people with FOP; 1-877-750-0376; www.wrightstuff.biz

To get a copy of the Resource Center Booklet, which contains more useful information like this, as well as a comprehensive list of resources and suppliers, please contact the IFOPA office at (407) 365-4194 or together@ifopa.org.

Remembering Margie McConnon.....

It is with a very sad heart that we must inform you that Margie McConnon, the IFOPA's Administrative Assistant, passed away on the evening of December 10, 2007.

Margie started with the IFOPA on July 27, 2006 and quickly became an integral part of the FOP community. During her tenure, she touched many lives both inside and outside the office, and she proved instrumental in planning and designing the Fourth International Symposium on FOP. On a personal level, she also provided us with support whenever problems arose, and her quick wit always appeared when someone in the office needed a lift.

As you can imagine, her family, friends and the IFOPA are shocked and saddened by this loss, and the IFOPA extends its full support to her family. She is survived by her two children, Makalia (17) and Colton (18), and her husband, Michael. (Michael drew caricatures of many IFOPA members at the Symposium and also created the majestic mountain painting given to Dr. Kaplan during the event.)

We will miss her kindness, warm heart and generous spirit immensely.

-- The IFOPA Office



Margie poses for a caricature (drawn by her husband, Michael) at the Fourth International Symposium on FOP.

International FOP Association

P.O. Box 196217
Winter Springs, FL 32719-6217

Address Service Requested

**Non Profit Org.
U.S. Postage
Paid
Mid-Florida, FL
Permit #8164**