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The IFOPA Board held its 2013 in-person board meeting in Orlando in February. Pictured front row, left to right: Nancy Sando, Chris Bedford-Gay, Moira Liljesthrom, Dr. Eileen Shore, Jeannie Peep; Back row, left to right: Mark Gambaiana, Gail Weakland, Gary McGuire, Eric Otto, Jennifer Snow, Malcolm Munro, Betsy Bogard, Marilyn Hair, Gretchen Emmerich.
What is Fibrodysplasia Ossificans Progressiva (FOP)?

One of the rarest, most disabling genetic conditions known to medicine, FOP causes bone to form in muscles, tendons, ligaments and other connective tissues. Bridges of extra bone develop across the joints, progressively restricting movement and creating a second skeleton that encases the body in a prison of bone.

This immobilizing and catastrophic genetic condition strikes approximately one in 2 million people. It is estimated that 2,500 people worldwide have FOP, although there are only 800 confirmed cases and some 285 cases in the United States.

FOP, known by many names throughout its history, first appeared on the medical landscape more than 250 years ago when a London physician, John Freke wrote in a letter to The Royal Society of Medicine in which he described a 14-year old boy “with many large swellings on his back…they arise from all the vertebrae of the neck and reach down to the os sacrum; they likewise arise from every rib of his body, and joining together in all parts of his back, as the ramifications of coral do, they make, as it were, a fixed bony pair of bodice.”

The disease eventually became known as myositis ossificans progressiva, which means “muscle turns progressively to bone.” The condition was officially modified to its current name in the 1970’s by Dr. Victor McKusick of Johns Hopkins University School of Medicine, to acknowledge that other soft (fibrous) tissues in addition to muscle are replaced by bone.

Symptoms of FOP almost always begin in the first two decades of life, and the majority of patients learn they are affected before the age of ten. Inflamed and painful swellings, usually in the shoulder and back areas, are the first signs of the condition. These swellings eventually clear up, but leave behind an area of mature bone.

FOP patients experience different rates of bone formation, and the exact rate of progression is unpredictable. The bone growth can occur spontaneously, or can be triggered as a result of trauma, an injury, bump or fall. The extra bones grow in the same order that they are first formed in the fetus – from the head, shoulders, arms and progressing to the hips and knees. As the condition worsens, patients eventually have joints locked in fixed positions.
The International FOP Association

The International FOP Association is a 501(c) (3) non-profit organization formed to support those afflicted by the rare genetic condition Fibrodysplasia Ossificans Progressiva. The IFOPA's mission is to fund research to find a cure for Fibrodysplasia Ossificans Progressiva while supporting individuals and their families through education, public awareness and advocacy. The vision of IFOPA is a cure for FOP.

The IFOPA was established in 1988 by Jeannie L. Peeper, a woman with FOP. The focus of the IFOPA has been, and will always be, to find a treatment and cure for FOP. Until that day, the organization strives to improve the lives of people around the world who suffer from the condition while continuing to support research.

The IFOPA's programs and services are focused in four primary categories – research, education, support and advocacy.

Since its founding in 1988, the IFOPA has directed over five million dollars to the University of Pennsylvania FOP Core Laboratory at The Center for Research in FOP and Related Disorders (FOP Lab). Nearly $500,000 is restricted each year from IFOPA operations for research.

Awareness is among the top objectives of the IFOPA. Nearly 90 percent of patients are misdiagnosed, with the correct diagnosis taking an average of four years. Potentially harmful tests, procedures and biopsies are often conducted on patients before a correct diagnosis is made. The organization provides education to the medical community on early signs of FOP and distributes information about the condition via the IFOPA website.

The Betty Ann Laue FOP Library is a central repository for FOP information that offers scientific and medical articles, interesting stories on FOP members, information materials, videos, special interest articles and copies of medical publications for families, physicians and those interested in FOP.
Support to patients and families ranks as a top programmatic objective.

Periodic symposiums bring together FOP patients with health professionals that specialize in FOP research and care. These gatherings provide a wonderful opportunity for patients to gather in a collaborative forum to discuss FOP research, exchange information and experiences, and share coping strategies.

The Traveling Resource Center (TRC) provides the global FOP community with a traveling showcase of tools and devices available for use in daily living. The TRC has had a presence in numerous FOP gatherings across the world.

The IFOPA provides L.I.F.E. Awards (Living Independently with Full Equality) to its members and is designed to promote health, welfare and independence. Examples of the awards range from equipment, walkers, wheelchairs, adaptive beds, vehicle adaptation, tuition/registration for educational purposes, specialized bicycles, computer hardware or assistive technology and reading aids.

The FOP Connection is a newsletter distributed to the FOP community and features stories about members, fundraising events, research updates, helpful suggestions and resources for living with FOP. An online member forum provides a vital medium to connect members for discussion, support and research news. Periodic web-based E-Learning events spotlight issues that are of relevance to members.

The IFOPA sponsors a mentoring program that provides members with the support they need to better manage the daily challenges of living with FOP. Additionally, new members receive a comprehensive resource package which includes the following items: What is FOP? A Guidebook for Families, a medical binder which includes a flash drive containing important medical information, a portable pill holder which holds one dose of emergency medication, and medical forms to customize with their medical information.

IFOPA’s financial support comes almost exclusively from families, friends and others who join forces by holding barbecues, golf events, auctions and other events to raise the funds to support the organization’s annual operating budget. Nearly half of the one million dollars generated each year is directed toward research efforts at the Center for Research in FOP and Related Diseases (FOP Lab).
IFOPA
Vision and Mission Statements

Our Vision: A Cure for FOP

Our Mission: Fund research to find a cure for Fibrodysplasia Ossificans Progressiva while supporting individuals and their families through education, public awareness and advocacy.

Our Vision and Mission Explained

For those affected, “A Cure for FOP” means a release from and prevention of abnormal bone growth that freezes limbs and bodies. We look forward to the day when:

• FOP is identified at birth and treated so that no harm occurs.
• FOP no longer progresses in those already affected and their mobility is improved.

To achieve our vision, our highest mission priority is to fund research to find a cure. We value accountability and in turn we:

• provide in full measure the research funds requested annually by the University of Pennsylvania FOP Core Laboratory at The Center for Research in FOP and Related Disorders (FOP Lab).
• respond to the FOP Lab’s unanticipated research opportunities, and additional financial needs that may stem from future clinical trials.
• appreciate and help advance FOP research worldwide.

Our organization is dedicated to the well-being of individuals with FOP and their families. We value open communication, equality, and compassionately respond to our multinational community with:

• counseling resources, forums, and online discussion groups
• an extensive online website, multi-language newsletter and personal representatives in six continents
• grants to those with FOP to obtain equipment, devices or services to enable independent living.

We value awareness and advocacy, and strive to:

• increase awareness of FOP among the public through use of commercial and social media.
• educate the medical community regarding this rare disease to promote immediate diagnoses.
• advocate for better conditions and support from legislators and other public officials.
• work with other rare disease organizations such as the National Organization for Rare Diseases, Bone and Joint Initiative USA, and EveryLife Foundation for Rare Diseases

Our Challenges and Advantages

Our challenges:

• FOP is rare even among rare diseases, with an incidence of 1 in 2 million.
• the public is not aware of FOP and we lack the community-wide support available to associations whose causes are common afflictions such as cancer or heart disease.
• to date, we have not attracted a high profile spokesperson to bring public awareness or a wide donor base

Our advantages:

• we have a compelling story. Because FOP is a catastrophic condition, it often receives attention when the media or funders learn about FOP.
• FOP research and fundraising are energized with the possibility that a cure for FOP may also be a key to a range of other conditions involving unwanted bone growth such as brain and spinal cord injuries, athletic injuries, burns, high impact war injuries, total joint replacement, valvular heart disease, and atherosclerosis.
• we have a close and historic partnership with the FOP Lab at the University of Pennsylvania which is dedicated to finding treatments and a cure for FOP.
• the FOP research challenge has attracted a worldwide community of researchers.
• we are actively supported by the families and friends of those with FOP who raise funds locally using a wide variety of means ranging from auctions, athletic events and barbecues to bingos, entertainment and letter writing campaigns.
• we support family fundraising efforts by providing personal guidance, advice, information, and occasionally on-site staff support for families organizing fundraisers.
• our staff exemplifies the values of dedication and excellence as they serve our community at large.
• our volunteer board of directors is actively involved in governing the association.
• we value financial responsibility: our yearly audits reflect good stewardship of our budget, historically keeping organizational costs to less than 20 percent of annual revenues.
• our organization is a grassroots effort, the lifeblood of which is our volunteer families and friends.

In 2013, IFOPA celebrates its 25th anniversary, a testament to the vision of our founder, Jeannie Peeper, and the dedication and vigor of our association members.
Our Founder
President, Jeannie L. Peeper

Jeannie Peeper’s pioneering spirit, vision and unwavering devotion to the cause of finding a treatment and cure for FOP has been a source of strength and beacon of hope to the many patients and families within the FOP community.

Founded as a pen pal group in 1988, she led the organization through a period of unprecedented growth into a world class non-profit that has emerged as the number one global resource on FOP. Today, the IFOPA serves over 800 patients and families in 52 countries through education, public awareness, program-based initiatives, networking opportunities, and support to families while instilling hope through research while searching for a cure for FOP.

A native of Ypsilanti, Michigan, Jeannie’s life began to change at an early age with the onset of FOP. Instead of allowing the condition to overwhelm her, she began a journey that allowed her to earn a college degree, and create an organization that has ended the isolation formerly associated with the disease to connect and support persons with FOP and their families.

Jeannie has served as President of the IFOPA since its founding. In 1989, she began working with Dr. Frederick Kaplan, who was established as the IFOPA medical advisor. In 1992, Dr. Kaplan and Dr. Eileen Shore founded the University of Pennsylvania FOP Core Laboratory at The Center for Research in FOP and Related Disorders (FOP Lab), and it remains the preeminent center for FOP research in the world. Since then, the IFOPA has provided more than five million dollars to the quest for treatments and a cure. A team of over 15 researchers led by Drs. Kaplan and Shore are working and progressing steadfastly to solve the mystery of FOP.

The list of IFOPA achievements under Jeannie’s leadership are multiple, and include hosting four international symposiums for families and medical researchers, establishing a website, participating in many media projects, hosting organizational/strategic planning meetings for the IFOPA, supporting many family gatherings, visiting with donors and providing valuable counsel to many FOP families.

Jeannie is the symbol of the FOP cause, emblematic of the close-knit community that is unrivaled in its linkage of patients, doctors, scientists, researchers, families and the laboratory all united in the search for treatments and a cure. She has provided the passion and the dream to help the next generation of FOP patients.
A prominent scientist once said that the International FOP Association was the “poster child” for rare disease organizations that bring together afflicted families and the research community. As President of the IFOPA, I know that any success we enjoy in this regard is the gift of people described by that wonderful word “volunteer.” So I want to close 2012 by thanking most sincerely our army of dedicated volunteers – the families and friends who rally each year to organize fundraisers, create FOP awareness, and support those afflicted with FOP and their caregivers. I want to thank and acknowledge our many donors - that special category of volunteers whose generosity move us closer to a cure and provide us all with much-needed encouragement. I want to thank our International President’s Council members and the many other families in our international community, a number of who have been extremely helpful over the past year or two by translating our documents and parts of our website into many languages. They play a vital role in bridging the international gap. And last, a special word of appreciation for our hard-working Board of Directors, all of whom are volunteers, and our office staff who routinely go well beyond the call of duty. Volunteers are the lifeblood of our cause and I am deeply grateful to you all.

Every few years, an organization needs to step back and review its goal and purpose. We did this in 2012, sharpening our focus, and clarifying our values and priorities. Overall, our association exists to find a cure for FOP, to raise funds in support of FOP research, and support families and our community with comfort, counseling, awareness and advocacy. We refer to the result of our discussions as our Vision and Mission, and I invite you to review this important statement elsewhere in this annual report.

Our highest mission priority is to support FOP research at the FOP Lab of the University of Pennsylvania led by Drs. Kaplan, Shore and Pignolo. We deeply appreciate their outstanding work, and are much encouraged by the prospect of clinical trials in the coming year or two. We were very pleased to provide our assistance and support in 2012 for the important Natural History Survey which will provide critical information in designing clinical trials. To strengthen our ties with the FOP Lab and the FOP research community generally, we have established the IFOPA Research Liaison Committee. Its goals are to provide community leadership for FOP research efforts worldwide, drive collaboration within the community with respect to research efforts worldwide, build the foundation for a united voice approach to clinical trials and develop and support a patient registry.

Let me close with a note of optimism as I feel we are now much closer to finding a treatment than we have ever been since the beginning of the IFOPA in 1988. Your support and encouragement over these many years has been outstanding, so very important in bringing us to where we are today. I’m deeply appreciative.

With Sincere Gratitude,

Jeannie Peeper
President and Founder
A Message from IFOPA Board Chair Mark Gambaiana

It is my great pleasure to present the IFOPA’s 2012 Annual Report. Our organization enjoyed an extraordinary year, punctuated by solid financial performance, continued strong support for FOP research, the global expansion of interest in FOP and the launching of several key steps as we enter a new era on the path to clinical trials.

The IFOPA charted one of its finest years in recent memory on the financial front, with revenues of $940,692 and expenses of $614,209, strengthening our net asset position by $326,483. These additional resources will be deployed in the future to offset costs associated with the planning and implementation of clinical trials. As the global economic turmoil lingers, and the challenges of operating a small non-profit organization mount, our performance was exceptional.

Thank you to the many families and friends who conducted fundraising events in 2012. The IFOPA is funded exclusively from private contributions, and each year we must begin anew with our fund development efforts. Your support is critical and appreciated.

After nearly a year in construction, an FOP Flare-Up Survey was distributed in December to 673 FOP members worldwide and in 14 languages. This Natural History Survey received a 67 percent response rate and the data collected will provide researchers with important information in the design of a successful clinical trial. Thank you to IFOPA board members Chris Bedford-Gay and Moira Liljesthrom for their countless hours and perseverance on the project, and to several IPC volunteers who assisted in translation efforts.

Early in 2012, and with clinical trials now on the horizon, a new IFOPA board committee was formed. The Research Liaison Committee is building the foundation for a united voice within the worldwide FOP community to best support and meet the needs of research and clinical trials. This dynamic committee is comprised of representatives from some of our most loyal families – Betsy Bogard, Jennifer Snow and Amanda Cali – and another from an enthusiastic new family – Eric Otto.

This vibrant committee is leading an effort to broadly engage an expanding global research environment of international labs, scientists, researchers, pharmaceuticals, biotech firms and government agencies who have demonstrated an interest in FOP. While the core and comprehensive work continues to be paced at the University of Pennsylvania, there are at least 19 venues working on components of FOP research, all with the goal of developing a more effective treatment and eventual cure.
Additionally, the committee is leading efforts to launch an FOP Patient Registry in conjunction with the NIH Global Rare Diseases Patient Registry and Data Repository (GRDR). The FOP Registry will collect data from as many FOP members globally as possible to facilitate drug and therapeutics development.

Finally, as we look ahead to 2013, we will celebrate the 25th anniversary of the IFOPA. A series of year-long activities and events are planned to commemorate and highlight our remarkable evolution from a pen pal group to the world’s leading non-profit resource on FOP. These activities will culminate with the 25th anniversary gathering set for November 7-9 in Orlando, please make plans to attend. Other priorities throughout the year will include programs and services in the areas of research, education, support to FOP members and families and advocacy.

On behalf of our founder and President, Jeannie Peeper, who inspires us all, and the IFOPA Board of Directors, I encourage your continued involvement and support.

Mark Gambaiana
IFOPA Board Chair

2012 in Review
Research Updates

Genetic Technology Breakthrough

The editorial explanation of the landmark paper published in the Thursday October 20, 2011 online edition of Gene Therapy a Nature Journal is available. You may read how Dr. Fred Kaplan, Dr. Josef Kaplan and Dr. Eileen Shore developed a new genetic approach to specifically block the damaged copy of the FOP gene in cells while leaving the normal copy untouched. Go to www.ifopa.org and under the Research tab choose Medical Articles, then click on the link Genetic Technology Breakthrough to read Dr. Fred Kaplan’s and Dr. Eileen Shore’s editorial explanation. You will also be able to click on the link Restoration of Normal BMP Signaling Levels to read the paper published in Gene Therapy a Nature Journal.

Orphanet Journal of Rare Diseases Update

An updated abstract and article regarding FOP has been posted to the website of Orphanet Journal of Rare Diseases. We greatly appreciate Dr. Pignolo, Dr. Shore and Dr. Kaplan for providing this update and we thank Malcolm Munro and Marie Hallbert for working with the OJRD and FOP Lab to make this possible. To view the abstract and article go to this web site address http://www.ojrd.com/content/6/1/80.
Dr. Eileen Shore Appointed to the Cali and Weldon Research Professorship

The IFOPA community was very pleased to learn that Dr. Eileen Shore of the FOP Lab was appointed in 2012 as the first Cali and Weldon Research Professor in FOP in the McKay Orthopaedic Research Laboratory in the Department of Orthopaedic Surgery at the Raymond & Ruth Perelman School of Medicine.

We want to extend a special thank you to John and Amanda Cali, and Bill and Hillary Weldon, for their extraordinary generosity in establishing and securing this endowed position. It is an incredible gift that will solidify this important position in FOP research.

FOP Core Laboratory Renovation

by Victoria Mandracken

After twenty years, the University of Pennsylvania FOP Core Laboratory at The Center for Research in FOP and Related Disorders has been renovated! The renovation took place within the Department of Orthopaedic Surgery in the School of Medicine. This construction project to update the lab was completely funded by the School of Medicine’s renovations budget. Dr. Eileen Shore noted that it was time to renovate since the lab’s general infrastructure (such as shelves and benches, chairs, sinks, and chemical work areas) was worn out and poorly functioning plus the room layout was no longer efficient.

Construction began in May 2011 and was completed in March of 2012. During this time the entire research team continued their work to find a cure for FOP by setting up a temporary lab in the Department of Genetics at Penn’s Perelman School of Medicine. Steve Liebhaber MD, Chair of Genetics, and the entire genetics faculty were very hospitable and supportive as the FOP lab team kept their research moving forward during the 10+ months they shared Genetics Department space. Even during the one week move to the temporary lab and the one week move back to the renovated lab, some FOP lab team members continued to do their experiments in other borrowed spaces! Everyone in the lab participated with energy and enthusiasm to organize every item in the lab and pitching in to move twice from one building to the other. Dr. Shore noted that Ruth McCarrick-Walmsley and Meiqi Xu contributed heroic efforts in organizing and coordinating the renovations and relocations, ensuring that both moves were completely successful.

The FOP Mice were never affected by the renovation process since they live in special climate controlled rooms outside the FOP Lab where they are very carefully monitored and humanely cared for by a veterinary staff.
Before the renovation, the lab was divided into multiple small rooms making it difficult for team members to interact and work efficiently together. Today many walls have been removed, allowing lab team members to work together more effectively within their newly designed and better organized space. Dr. Shore shared that the renovation has made work easier since everyone has their individual lab bench work areas close by their desks, along with the shared common space used for specific experiments. The IFOPA is very thankful to have such an excellent and dedicated team of researchers who now have the "renewed" FOP Lab that gives them the ability to work more efficiently together to find a cure.

The Tooth Ferry Program
at the FOP Lab

by Ruth McCarrick-Walmsley and Dr. Eileen M. Shore

The participation of so many patients and families who contribute blood/DNA samples to help the research in the FOP lab has been valuable and is very greatly appreciated. These samples were critical to our discovery of the gene that causes FOP and for identifying the specific DNA sequence changes that occur in classic and variant forms of FOP. And although much of our research is now done using mouse models of FOP and heterotopic ossification, it will always be important that we have patient cells and tissues in order to confirm that the information that we learn from mice holds true in FOP cells.

We have relied on blood samples from patients for many years since blood can be safely obtained without risk of triggering an FOP flareup. However, while these cells have been very useful, one important disadvantage of blood cells is that they can provide limited information about bone cell differentiation. Fortunately, recent advances have identified additional types of samples that can be important to our work. One of these cells types is “SHED cells”.

SHED stands for Stem cells from Human Exfoliated Deciduous teeth – a long name that describes the cells that are inside primary or baby teeth. When a baby tooth falls out naturally, we can recover the cells from inside the tooth. We have used baby teeth from FOP patients to show that these cells can be grown in our lab and treated in special ways to form bone cells, providing us with an informative system to examine how the FOP mutation changes the bone cell differentiation potential.

A few years ago, the FOP lab started a “Tooth Ferry” program to encourage families to send FOP baby teeth to us so that cells from these teeth could be used for FOP research. These cells have already given us useful information about the effects of the FOP mutation on bone cell formation and these cells were used in our recent RNAi studies. SHED cells continue to be very important for some of our lab experiments. Because the cells have a limited lifespan and since multiple samples from a person are very informative, we continually need additional “donations” to continue to conduct our studies with SHED cells.
Anyone with a child who is losing teeth can participate in “The Tooth Ferry Program.” When your child loses a tooth or needs to have one pulled at the dentist’s office, you can send it to us in a preassembled kit that we will provide to you. Teeth from siblings and non-family members are welcome as controls. In addition to baby teeth, we are also happy to receive wisdom and other permanent teeth from people with FOP.

Ruth McCarrick-Walmsley is heading up our effort to collect the teeth and study SHED cells. There is a short window of opportunity for receiving the teeth for best results, so we have developed specific instructions for their handling and shipping. If you decide to participate, we will send you a kit including all of the necessary return packaging (for several teeth), return FedEx labels, Ruth’s contact information, a tooth diagram to fill out and return, and a copy of these instructions. We are also providing information about the program on the IFOPA website, www.ifopa.org, however it is very important that you contact us before sending a tooth - if teeth arrive by surprise at the lab, we don’t have time to prepare to take care of them as best as possible.

The tooth ferry kit is very simple to use. This is an IFOPA supported program and there is no cost to you. The IFOPA website has details about the “Tooth Ferry Kit” and contact information for receiving one. You can find the Tooth Ferry Program by clicking on this link [http://www.ifopa.org/research/tooth-ferry-program.html](http://www.ifopa.org/research/tooth-ferry-program.html). If you have children with teeth still to lose or are being pulled, please contact Ruth by phone (610-513-4470) or email (rwalmsle@mail.med.upenn.edu) and a “Tooth Ferry Kit” will be on its way to you soon!

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**Penn Team IFOPA Meet for Global Research Update**

The Research Liaison Committee organized a meeting with the University of Pennsylvania team in December 2012 to gain insight into the current FOP research activities at the University of Pennsylvania, gain a better understanding of the broader FOP research efforts worldwide, and develop a roadmap to help guide the IFOPA’s future engagement in the FOP research arena. Meeting invitees included Drs. Fred Kaplan, Eileen Shore and Robert Pignolo from the University of Pennsylvania; the Research Liaison Committee of Betsy Bogard and Jennifer Snow; board leaders Jeannie Peeper and Mark Gambaiana; and Eric Otto and Amanda Cali. In conjunction with the meeting, Eric and Amanda were added to the research committee. The expanded committee will implement key findings and decisions from this meeting in 2013 in consultation with the board.

Worldwide interest in FOP research has mushroomed since the 2006 discovery of the FOP gene. Now an international effort, there are at least 19 venues working on components of FOP research, with the core and comprehensive work being paced at the University of Pennsylvania.
International labs, scientists, researchers, pharmaceuticals, biotech firms and government agencies around the world have demonstrated interest in FOP. All are united in the common goal to discover a much more effective treatment and a cure for FOP.

In this expanding research environment, the IFOPA is committed to serving as a clearinghouse of information for validated research progress as it becomes available for dissemination to the community. Please regularly consult the IFOPA website for updates.

Researchers presented a progress report as potential compounds continue to be refined for efficacy and possible use in clinical trials. While more pre-clinical trial work remains, we are closer to that major step.

FOP members received a comprehensive Natural History Survey of FOP Flare-ups in December 2012. All members were strongly encouraged to participate in this endeavor as completely and quickly as possible, as this information will provide researchers with critical and necessary data to design a successful clinical trial.

Research Committee Focus is Established

The IFOPA’s Research Liaison Committee was formed for the first time in February 2012 with the appointment of Betsy Bogard and Jen Snow to the committee during the annual in-person board meeting in Orlando, FL. During its inaugural year, the committee applied for and won a spot on the NIH Office of Rare Diseases project to establish the Global Rare Diseases Registry and Data Repository (GRDR). Orientation to the GRDR project and development of an FOP registry was a primary activity for the committee for the remainder of 2012. A draft registry protocol and informed consent were prepared before the end of the year. The committee is continuing registry development in early 2013 and looks forward to launching this project within the FOP community as soon as possible.

Researchers at the University of Pennsylvania’s FOP Laboratory and officials of the IFOPA held a December, 2012 meeting in Orlando to discuss advances in FOP research and gain a deeper understanding of global efforts in the ongoing quest to develop effective treatments and an eventual cure.
Jeannie Peeper Awards for 2012

Jeannie Peeper International FOP Association (IFOPA) Awards recognize those who make exceptional contributions to the worldwide FOP community through their leadership, service, fundraising and accomplishments.

The 2012 Awards committee members - Karen Munro, Jeannie Peeper, Gretchen Emmerich, Nancy Sando and Megan Pheif - were honored to select the worthy recipients in recognition of exceptional service and dedication to the FOP cause. There were many excellent people to choose from, so it wasn’t an easy task... But it definitely was a labor of love! The following are the winners for 2012.

President’s Lifetime Leadership Award
Nick Bogard

Nick Bogard is the father of FOP Member, Jud Bogard. Nick is a true pioneer of the IFOPA, as he quickly became involved in 1989 after Jud’s diagnosis. His commitment to the growth and development of the organization was paramount. In 1990, Nick established the very first IFOPA fundraising event for FOP Research, the Jud Bogard Golf Invitational, which still stands as a benchmark for our grassroots family fundraising efforts. This fundraiser was a miracle for the IFOPA, as it allowed us to give funding to Dr. Frederick Kaplan and Dr. Michael Zasloff for the very first FOP Symposium at the University of Pennsylvania. This one event spearheaded the enthusiasm and the FOP Research initiative.

Nick has also graciously volunteered many hours, serving on the IFOPA Board of Directors for eighteen years (1989-2007). He is the longest serving Board Member to date. During this time he also chaired and continues to serve on the Finance and Audit Committee. His dedication to our mission is a testimony that encourages all of the families that continue to carry the fundraising torch.

Outstanding Community Involvement Award
Christine Flexer

Christine Flexer is the aunt of Joshua Scoble, a little boy diagnosed with FOP a few years ago when he was a baby. After her nephew’s diagnosis, Christine sprang into action. In short order, she organized the “Bingo for a Cure”, which raised many thousands of dollars. Under Christine’s leadership, the Bingo for a Cure has become an annual event in Pennsylvania, and has continued to raise very significant funds for FOP research and awareness. However, Christine’s efforts didn’t stop there - she was a driving force behind the establishment of a new FOP charity, Joshua’s Future of Promises, which puts on the Bingo for a Cure, as well as a number of other fundraising events throughout the year. Christine’s efforts for FOP appear to be the equivalent of full-time employment, and yet are done on a completely volunteer basis.
Emerging Leader Award
Stephanie Snow

Stephanie has been involved in raising awareness for FOP since her diagnosis in 1995 at the age of three. She spreads awareness of her condition by being a “poster girl” for a variety of IFOPA fundraising events including the “Find-A-Cure” BBQ, “Find A Cure” Dinner/Auction/ Drawing and “Fill’er up to Find A Cure” (donations per gallon of gas sold), just to name a few. Stephanie also regularly attends two annual community FOP fundraisers in which her family is involved with a smile on her face and an attitude of “let’s have some fun!” Stephanie has been interviewed numerous times by the media to help increase awareness about FOP, most notably when she was “the face of FOP” during the exciting times of the discovery of the FOP gene. Stephanie shows leadership in her life with her involvement in local non-profit groups. Currently she is the leader of the rabbit group at her local 4-H, and she donates her time to the animal shelter as well as a veterinary office. Recently, she has been raising funds and awareness for the George Mark House (a pediatric palliative/hospice care facility). As Stephanie continues to study for her degree in Psychology, she also has become a fish breeder, supplying fish for the local pet store. She hopes with this new ‘pet project’ to work on a new way to help the IFOPA through a new idea called “Fish for FOP”.

Outstanding International Leadership Award
Marie Hallbert

Marie’s son Hugo Fahlberg, who is now a young teenager, was diagnosed with FOP at age two. When Hugo was diagnosed, Marie noted that there were no resources about FOP in their home country of Sweden, and certainly no Swedish language information. Marie set about to change that. She is the founder of “FOP Sverige”, a group which provides support and information to Swedish and other Scandinavian people with FOP and their families. Through FOP Sverige, Marie has organized three FOP conferences in Sweden over the years, and she has worked to ensure that important information about FOP is available in Swedish - including parts of the FOP Treatment Guidelines. Marie has also been interviewed about FOP numerous times by Swedish news media, and has given speeches about FOP in Swedish to medical professionals. More recently, Marie organized the FOP “Collection Project” in which cans for donations by the public are placed in stores and other public places. Marie has also designed and organized FOP Sverige’s new website, and has been writing a regular Swedish language blog on the site about her family’s life with FOP and important news concerning FOP. Throughout this time, Marie has been a source of help, strength and support for families dealing with FOP, especially in cases of new diagnoses (both in Scandinavia and elsewhere). One mother of a recently diagnosed child in Sweden calls Marie the “FOP Angel”.

The committee, on behalf of the IFOPA, gives heartfelt thanks to each of the award recipients for their extremely important work for the FOP community. The lives of people with FOP are enriched incalculably by your accomplishments.
This conference was held in Milan on March 23-24, 2012 by F.O.P. ITALIA Onlus which was founded in 2006 by a few families of young FOP patients. Today these families continue to manage the association. In Italy 26 persons have now been diagnosed with FOP. Under the guide of Mr. Enrico Cristofoletti, President of the Association and with the medical/scientific support of the Genova University, each year an international symposium is organized, with important participation of the major worldwide experts in research and clinical studies of FOP and associated disorders. A special thank you to the hospitality of the “Cà Granda Policlinico” hospital and the fantastic contribution of Doctor Giovanna Mantovani.

The topics discussed in the various sessions of the meeting, focused on “Progress of research on F.O.P. and P.O.H.” were the following:

- Understanding FOP through in vitro and in vivo models
- Prevention of heterotopic ossification by retinoid action
- ACVR1/ALK2 gene expression regulation
- Bone-fat reciprocity in progressive osseous heteroplasia
- Vascular associated progenitors and inflammation in muscle remodeling
- Consequences of FOP mutations on cell differentiation
- All Trans Retinoid rationale and experience
- Clinical phenotypes associated to GNAS gene mutations
- Reflections on FOP clinical aspects
- FOP and odontoiatria: presentation of a stomatologic questionnaire for FOP patients
- Current research on FOP in the UK
- Research on FOP in the Netherlands
- Proposal for international cooperative research in FOP

During the second day of the meeting, the main Italian Associations active on rare diseases, both Public (CNMR) and Private (UNIAMO, CndMR-Insieme, Telethon), presented their activity and projects for supporting patients, families and research. Italian patients also had the benefit of a professional visit done by the pool of American, German and Italian doctors attending the conference and experts in the clinical approach.

The two day conference was also gladdened by successful convivial dinners in traditional Milan restaurants. The day after, a short tour was organized for the foreign experts still in Milan, to visit the many historical monuments in the very center of the town.

**Doctors and experts who attended the conference:**
Eileen Shore - University of Pennsylvania, School of Medicine, U.S.A, Robert J. Pignolo - University of Pennsylvania, School of Medicine, U.S.A., Maurizio Pacifici - Children's Hospital in Philadelphia, U.S.A., Luisa de Sanctis - University of Torino, Italy, Silvia Brunelli - University of Milano, Italy, Rolf Morhart - Garmisch Hospital, Germany, Petra Seeman - University of Berlin, Germany, Jim Triffitt - University of
Scandinavian FOP meeting in Stockholm, Sweden — June 2012

by Marie Hallbert Fahlberg

At the end of June, the Scandinavian FOP organization held a FOP meeting at a hotel in central Stockholm which Dr. Shore and Dr. Pignolo attended. This was the 4th FOP meeting in Sweden. The earlier gatherings were held in 2004, 2006, and 2008. It had been four years since we last met so this was a very important event for our families. The meeting was also of great significance to our medical people in Scandinavia since Sweden had four new children diagnosed with FOP in the past two years and a few new families from Finland were diagnosed.

There were 16 FOP families and 11 doctors/medical personnel from Sweden, Norway, Denmark and Finland. All together there were almost 70 people attending the meeting.

Dr. Shore and Dr. Pignolo held lectures about FOP and the research that is being done. Although the lectures are important the main reason for the Scandinavian meetings are the clinics. The clinics give families the opportunity to get together with Dr. Pignolo and Dr. Shore for 30-45 minutes to ask all their questions. This is also a wonderful educational experience for the doctors in Scandinavia to be able to attend the clinics and listen to the family’s questions and also be able to ask their own questions of Dr. Pignolo and Dr. Shore. This is a great opportunity for the Scandinavian doctors to meet other FOPers, better understand their medical risks, the progression of the disease, different FOP issues and listen to the answers Dr. Shore and Dr. Pignolo give these patients.

The purpose of the Scandinavian meeting is to make the families feel a little bit more relaxed and calm when they go back home to their daily life with FOP. Thank you to everyone who attended and helped make this possible!

Annual meeting of the German FOP e.V. in Valbert-Meinerzagen

by Roger zum Felde

From the 27th to the 29th of July 2012 the German FOP Community met in Valbert-Meinerzhagen for their annual Symposium.

We were very proud to have Prof. Dr. Kaplan from America, Dr. Morhart, Dr. Unterboersch, Prof. Dr. Seemann, Prof. Dr. Schomburg from Germany and Dr. Grytsenko from Ukraine.
The International President’s Council (IPC) is comprised of 17 representatives from North and South America, Europe, Africa, Asia and the Pacific. The Council is a network for the exchange of ideas over international boundaries and for identifying ways IFOPA can best serve its international members.

In 2012, IPC played a very important role in expediting the Natural History Survey, an effort by Doctor Fred Kaplan and the FOP Lab to gather information critical to the design of future clinical trials. Drawing on its multilingual capabilities, IPC members translated the survey into the following languages: Dutch, French, German, Italian, Mandarin, Polish, Portuguese, Serbian, and Spanish. IPC also assisted in the process of having the survey translated into Danish, Japanese and Korean. IPC members and doctors with whom they worked also sent invitations to all known FOP cases in their countries. This very great effort to obtain as large a response as possible to the survey resulted in about 470 responses for a response rate of close to 70 percent, an extremely high percentage as compared with a more typical 20 percent or so for similar surveys. Other translation work completed by FOP members in 2012 included translation of the 20th Annual Report of the FOP Collaborative Research Project into French. Also, IFOPA’s Guidebook for Families is currently being translated into French, Mandarin, Polish and Portuguese.

When someone joins the IFOPA, they are provided with a new member package and an emergency card. To further enhance the value of the information in the package, in 2012 IPC members provided information relevant to their country, such as contact information for a local physician with FOP expertise, contact information for the IPC member, and other local information relevant to each country. The appropriate local country information is then incorporated into each new member package along with information provided by the IFOPA.

In 2012 IFOPA announced that Dr. Keqin Zhang MD PhD of the People’s Republic of China accepted our invitation to join the International President’s Council. Dr. Zhang is a clinical endocrinologist and Director of the Department of Endocrinology, Tongji Hospital, affiliated with Tongji University, Shanghai. Dr. Zhang met his first FOP patient in 2008 and was inspired to do research on FOP. He has since acquired about 83 FOP patients in China with the help of TV, newspapers and the Internet.
Have You Completed This Important Survey?

Dear Patients and Friends,

The FOP Scientific Retreat held recently in Philadelphia consolidated new frontiers in FOP research, and focused on targets for therapeutic intervention. For the first time, we have both a repertoire of potential candidates and a sound scientific foundation for testing classes of drugs for efficacy in animal models of FOP.

In order to advance the lessons learned from on-going animal studies into the design of meaningful clinical trials for FOP, it is necessary to obtain a comprehensive and contemporary understanding of the natural history of FOP and of the behavior and progression of flare-ups (new episodes of disease activity) in the context of symptomatic management. We are therefore conducting this survey to help us determine the optimal design of clinical trials. Regardless of whether or not you decide to participate in a future clinical trial, we still need to obtain accurate clinical information from all FOP patients worldwide. This information will be used to design a clinical trial that will maximize the potential to identify an effective treatment for FOP. It is therefore important that you complete this survey. We have field-tested this survey and it should take no more than 45 minutes to complete.

We ask you to please complete this survey for yourself (or for your child who may have FOP). Please read through each page completely before answering the questions on that page. All identifying information will be kept protected to the best of our ability. Only tallied, aggregate information will be published and applied to the design of clinical trials. This is a promising time in FOP research.

We need your help. We personally thank you for your time and effort in completing this survey (no deadline date). Please use this address to go to the survey: https://www.surveygizmo.com/s3/1059412/English and enter the password: stopFOP1!

With many thanks and our best personal regards,

Fred, Eileen, and Bob

Frederick S. Kaplan, MD • Eileen M. Shore, PhD • Robert J. Pignolo, MD PhD Center for Research in FOP & Related Disorders • The University of Pennsylvania.
Quality of LIFE Awards 2012

The Quality of LIFE (Living Independently with Full Equality) Award began in 2003 with one mother’s inspiration to make a difference in other people’s lives.

Marilyn Hair, mother of Sarah Steele who has FOP, experienced first-hand how having the “right tools” in a person’s life could make a profound difference. Sarah’s mom dreamed of seeing all people with FOP have an opportunity to obtain critical tools that support their independence, and so she founded the LIFE Awards Program and began fundraising to make sure the funds were available to those in need.

To date the IFOPA has provided 64 awards to help FOP members purchase tools such as computers, voice recognition software, motorized wheelchairs, power lift chairs, accessible van, service dog, vehicle repairs, van lift, memory foam mattress pads, wheelchair ramps, scooters, protective helmet, and educational tuition and books.

In 2012 the LIFE Award committee, of Christine Ford, Amanda Cali and Gretchen Emmerich, approved and processed six awards for members living in the USA, Romania and Australia. These gifts totaled close to $5,300 for the following purposes: building supplies to construct a wheelchair ramp and platform, recliner chair, removable home access ramp, hearing aids, wheelchair, and an adjustable bed frame.

For more information on eligibility, qualifying items and how to apply, please see the Member Center on the IFOPA website. Funding for LIFE awards is provided by donors and family fundraisers who direct their donations to the LIFE Award Fund.

Mentoring Program

The Mentoring Program was established to enable new families/individuals with FOP to have contact with someone who can acquaint them with the IFOPA and its resources and education. This program can also help our existing members cope with their challenges (flare-ups, school issues, care, etc.). Each of our mentors either has FOP or is a parent or caregiver of someone with FOP.

Our activities during 2012 have welcomed new members into the organization and helped them know they can depend on the IFOPA for support as they gain more knowledge about FOP. There were a few young families contacted that praised the IFOPA for “being there” otherwise they would not know where to turn. There were also a few older members that gained knowledge and comfort in sharing their surgical experiences to others going through similar surgeries.
The IFOPA office staff has been excellent in referring our members to our program if the situation seems appropriate.

We continue to seek ways in which to promote our Mentoring Program. In the event you would like more information regarding this program or know of a family that might appreciate contact with a mentor, please contact Nancy Sandoz (nasando@chartermi.net).

New Communications and Public Relations Initiative

The Communications & Public Relations Committee (C&PR) was created in 2012 for the purpose of increasing awareness and understanding of FOP by our IFOPA constituencies (IFOPA members, those with FOP and their families worldwide, and donors), the medical community, media, and the general public. Our goal is to educate clinical care providers to decrease misdiagnosis and resulting harmful interventions as well as shorten the diagnostic odyssey. Our task includes creating IFOPA printed and online materials and keeping it up to date, writing press releases, disseminating FOP awareness and IFOPA events by social media, and other communication and public relations tasks as needed.

In 2012 the C&PR Committee included Marilyn Hair and Chris Bedford-Gay. IFOPA Communications and Membership Manager Victoria Mandracken provided substantial and continuous support to our committee.

These IFOPA documents were updated this year:
- Donation Acknowledgement cards
- Facts-in-Brief Sheet
- IFOPA Brochure
- Children's Guidebook: What is FOP? Questions & Answers for the Children (illustrations & formatting in process)

Dr. Kaplan’s assistant Kay Rai, distributes an IFOPA membership brochure and IFOPA/FOP Facts-in-Brief sheet to FOP patients on their first visit to Dr. Kaplan. These materials recently were reviewed and updated to include a membership application and detailed information about the programs, services and medical research being done for our members around the globe and the entire FOP community.

Ways to increase FOP Awareness have been considered. This Committee consulted medical and technology experts along with FOP expert Dr. Joseph Kitterman (author of *Iatrogenic Harm Caused by Diagnostic Errors in FOP*, Pediatrics, Nov 2005). Continued publications in professional journals, and
Have You Checked Out IFOPA in Wikipedia Lately?

Were you aware that IFOPA has a full article on Wikipedia? Or if you were aware, have you checked it out lately? A Wikipedia article is different from those in your 26 volume hard-copy encyclopedia in that a Wikipedia article can and should be updated regularly. In our case, in 2012 we made several changes in our article to reflect events and activities of the year.

First, with the adoption of our new vision and mission statements, we accordingly updated the Infobox which appears at the beginning of the article on the right-hand side. Second, we were pleased to revise our biographical paragraph on Doctor Eileen Shore, one of our medical and scientific advisers, announcing her appointment as the Cali and Weldon Research Professor in FOP at the University of Pennsylvania where she is also Professor of Orthopaedic Surgery and Genetics and Co-director of the FOP lab. Last, we were pleased to incorporate photos and biographical information on Dr. Bob Pignolo and Dr. Michael Zasloff of the University of Pennsylvania and Georgetown University School of Medicine respectively, as new members of our team of medical and scientific advisers.

When new friends inquire about FOP or the IFOPA, or you are preparing fundraising materials, we suggest you refer to our Wikipedia article. The article provides a brief history of the IFOPA, our fundraising activities, how we employ donations, photos and information regarding our outstanding team of medical and scientific advisers, a description of our services and programs, and links to various useful resources. Our Wikipedia article is thus a concise though comprehensive summary of our association, an efficient way for new friends to learn about IFOPA. To find our article go to http://www.wikipedia.org/ and type “IFOPA” in the search window.
New Board Members
Elected in 2012 for 2013-14

Would you be interested in serving on the IFOPA Board?

The people who serve on your IFOPA board are elected each year by our members worldwide and serve for a two-year term. The board generally teleconferences 6-8 times during the year and usually has one in-person board meeting each February. Our Board Nominating Committee recruits new board members from our membership at large by a nominating process that begins in late summer and concludes when the membership is asked to approve a slate of nominees in October-November.

Though some directors serve more than a single term, and must stand for reelection each time, our limited term policy means that board opportunities are available every year for new members, thereby renewing the board with fresh perspectives and different skill sets. But this also means the departure of serving board members whose contributions will be sorely missed. In this regard, we would like to acknowledge Christine Ford as an out-going board member. Christine, who is also Jeannie Peeper’s aunt, served for several terms and as Secretary of the board in 2011. In 2012, Christine devoted considerable time to strengthening and improving the Living Independently with Full Equality (LIFE) award program. Her wisdom and dedication to the organization has been appreciated by everyone.

For the 2013-14 term, the final slate of nominees consisted of Marilyn Hair, Chris Bedford-Gay, Gary McGuire and Eric Otto, and was approved by the membership in the election. Marilyn is the mother of Sara Steele, a young adult with FOP; Chris is the father of youngster Oliver who has FOP; Gary is the father of 12-year-old Natalie who has FOP; and Eric is the father of three-year-old Sienna who has FOP. We invite you to read brief information about each of these outstanding new board members, and about the full board, by clicking on the tab About the IFOPA/Board of Directors and Officers on the IFOPA website.

Board Nominating Committee members for 2012 were Nancy Sando (chairperson), Marilyn Hair, Don Brister and Teresa Caruso. The Board Nominating Committee is comprised of two current and two past board members. The committee is always interested in hearing from anyone interested in serving on the board, and you are invited to contact Nancy directly (through the IFOPA website page indicated above).
Why Aren’t Pediatricians More Aware of FOP?

Have you ever heard this story? “When our infant son bumped his head and developed a large swelling, our family doctor referred us to a pediatrician who checked our son’s toes and promptly confirmed a diagnosis of FOP. He informed us that our son’s tumor along with his pronated toes were the primary symptoms of FOP.” Never heard that story? The far more common version is one of repeated visits to assorted medical experts, speculation, biopsies, misdiagnoses, lots of worry for mom and dad, and months or even years before FOP is finally diagnosed.

Unfortunately, a story of prompt FOP diagnosis is probably as uncommon as FOP itself is – about one in 2 million cases. Okay, to be fair, FOP is “only” misdiagnosed about 90 percent of the time. Still, this is a staggering statistic, especially when the consequences of misdiagnosis are often biopsies and surgery, sometimes with catastrophic results. It’s also a staggering statistic when you consider all that the IFOPA and our community has done to create greater awareness.

Over the past several years, FOP has gotten lots of exposure in the media. TV and radio interviews and documentaries, particularly in the USA, UK and Australia, provided valuable exposure and awareness of FOP. Other important awareness outlets have been YouTube, Facebook, Wikipedia, chat groups, and blogs about FOP. The more people become aware, the more willing they are to donate funds to support research to find a cure. In this sense, creating greater public awareness is a critical success factor for the IFOPA because it directly supports our mission to raise funds and find a cure.

Yet in spite of increased public awareness, stories of FOP misdiagnoses are still all too common. The reason is simple. The general public doesn’t make diagnoses - pediatricians do. And pediatricians aren’t watching a lot of mainstream television, browsing YouTube, reading blogs or participating in chat groups. So how do we reach pediatricians to make them more aware of FOP and help them make quicker diagnoses of FOP?

Before we go any further, let’s remember that there are apparently 7000 rare diseases. So let’s have some sympathy for both our family doctor and pediatrician. For a start, our medical partners didn’t learn about FOP in med school. There simply isn’t time in the medical education curriculum to explore rare diseases, and furthermore a large majority in the medical community will go through their entire professional career without ever seeing a single rare disease. In general, medical professionals are challenged simply to stay current with the latest research on common conditions, drug effectiveness, medical technology and surgical techniques.
Then how can we bring awareness to time-strapped pediatricians regarding FOP? Unfortunately this is a deceptively difficult task. Some of the more obvious ideas simply don’t work or are impractical. Forget the large media campaign – far too expensive for us and may not even reach our target audience. Forget the mail-out campaign. A brochure sent to a pediatrician’s mailbox will quickly find its way unread into the recycling bin – pediatricians seldom read unsolicited mail. And if they did, it’s a costly one shot deal whose effectiveness may be fleeting. Presentations at medical conferences and articles in academic journals, however important in other ways, reach only a very small audience, a drop in the bucket relative to the total population of pediatricians. Editors of medical textbooks provide only very limited space for rare diseases, and much less for extremely rare diseases such as FOP. You get the idea. This situation is like the whack-a-mole game at the county fair – any idea we can come up with can be quickly batted down with the reality hammer.

Our reality is that there is no easy answer to creating greater FOP awareness among pediatricians. This is a battle that must be fought patiently, incrementally, and on many fronts. At the same time however, we have a few significant advantages and reason to be optimistic. First, unlike many rare diseases, the symptoms of FOP are somewhat easy to recognize, and once recognized, the diagnosis is nearly always assured. The lesson here is that our challenge is more about how to expose physicians to the message rather than about communicating something complicated. Second, let’s not discount the educated and informed parent. In our Internet era, many parents search the web for medical information, and the greater our “web presence”, the more likely parents are to encounter and communicate those critical clues to their pediatrician. We are also at the dawn of the era of genetic testing. In the foreseeable future, a genetic test at birth may be available to detect a range of medical conditions, of which FOP could be one. This would be a major weapon in winning the battle for early diagnoses. In the best of all worlds, by that time we may also have an arsenal of powerful medications to stop FOP before it does its nasty business.

Malcolm Munro,
IFOPA Board Secretary
Total IFOPA Revenue Continues Upward Trend in 2012

Total revenue to the IFOPA increased by 10.5 percent in 2012 while the number of donors to the organization soared 38.3 percent, among the many financial highlights of the past year.

Revenue from all sources approached one million in 2012 – and was the seventh highest in the 24-year history.

Contributions, investment income and other revenue totaled $940,692 last year. Net income for the year was $326,483, a significant performance at a time of continued economic uncertainty. A total of 4,455 gifts were received to the IFOPA in 2012, including a remarkable 2,153 new donors.

“Thank you to the many family and friends who are working side-by-side with us to generate the revenue so crucial to fund IFOPA priorities,” said Mark Gambaiana, Board Chair. “Each year we begin our fundraising efforts anew and we are blessed to have so many families who so willingly conduct events year after year, and new families who emerge and contribute greatly to our overall success.”

Three families burst onto the IFOPA scene in 2012 and each surpassed $100,000 in family fundraisers, the first time in the organization’s history that three fundraisers netted six figures. And two of those events were held on the same day – October 6 – making that an extra special day in the history of the IFOPA.

The Zipper Q event was held in Claremore, OK, organized by Amy and Jacob Gordon and held in honor of their son, Zip. The event featured a BBQ cookoff, live music, games for the kids, silent and live auction and the drawing for a Dodge Ram truck. In addition, Sienna’s Splash, a swimathon in honor of Sienna Otto and organized by her parents, Eric and Rory Otto, was held at Princeton University in New Jersey. A few weeks later, the Otto family unveiled “Sienna’s Flower Garden” an online fundraising effort to assist with FOP research to a significant response.

A fundraiser organized by Gary and Abbie McGuire in honor of their daughter, Natalie, also generated more than $100,000 in revenue. Two annual IFOPA family fundraisers, “Bingo for a Cure” in honor of Joshua Scoble and “Lincoln’s Legacy” in honor of Lincoln Wheelock produced $75,000 and $72,000 respectively.

All events and gifts are important to the success of the IFOPA.

Throughout its 24-year history, the IFOPA is truly unique among the nation’s universe of not-for-profit organizations.
Since a modest beginning in 1988, when a total of $1,450 was generated during that inaugural year, family fundraising has become a major focus of the IFOPA’s annual operations. From 1988 through 2011, a remarkable $15,698,812 has been generated to support the IFOPA cause.

The majority of this financial support has come from the deeply devoted families who rally together and form family fundraisers to advance the quest for treatments and a cure while providing necessary services and support to FOP patients and families.

Examples of family fundraisers over the years include bake sales and suppers, barn dances and bingo, chicken barbeques and spaghetti dinners, garage sales and silent auctions, country fairs and benefit concerts, raffles and rodeos, sales of holiday cards and embroidered quilts, 5K runs and road races, ice fishing contests and winter carnivals, golf tournaments and bowling parties, and wine tasting events and lemonade stands.

Meanwhile, the IFOPA is grateful to the many families who conduct various fundraisers within their communities and circles of influence. Year after year, these special events provide the majority of revenue to propel the IFOPA mission forward.

2012 Fundraising Events

Jewelry and Objet d’art Fundraiser

On December 9, 2011 Severine Letartre and her mother Martine invited friends to their home to raise funds for the IFOPA (and donated in 2012) by purchasing Christmas gifts they created.

Since Severine had been experiencing FOP inflammation since April, Martine did not know if she would be able to create new jewelry so she decided to sell her own Objet d’art pieces.

Martine has lived on a big farm for many years which has given her the space to collect and restore vintage furniture, pictures and paintings. She donated a good amount of her Objet d’art stock for this event and fortunately Severine was able to create jewelry. Together they presented a beautiful collection and this unique event raised 9,500 Euros which is approximately $12,000 US Dollars!

Martine, Severine and all of us who are a part of the IFOPA thank their friends for purchasing Christmas gifts at this event for FOP research.
Bingo for a Cure!

Joshua’s Future of Promises! (Joshua’s F.O.P.!) hosted our 5th Annual Bingo For A Cure! event on March 18, 2012 at the Agri-Plex Hall in Allentown, PA. Joshua’s FOP! is a non-profit organization set up in honor of 5 year old Joshua Scoble who has FOP. This non-profit organization was created by Joshua’s family and has been set up in an effort to help raise funds and awareness for FOP research as well as to help support those who have been afflicted by FOP.

Bingo for a Cure! is the largest attended FOP Fundraiser in the world.

This past year, proved to be another outstanding year for Joshua’s Future of Promises! . . . with the help of all our fund raising events . . . such as Bingo for a Cure!, Ride for Joshua, Racing For A Cure!, Keystone Candle Sale and other independent fundraising events, we were able to raise over $82,000! We are thrilled to be able to invest this money in research through the IFOPA. Scientists continue to make advances in research and we are grateful to be able to play a small role in helping them reach their goal of a treatment/cure for FOP.

Chrissy Flexer

Unswerving, The Trans-Wisconsin Bicycle Ride

John Emmerich the step-father of Patrick Doerr started dreaming about this fundraising event in 2010! With the help of his wife Gretchen (the mother of Patrick) this dream became a reality that raised over $10,000 and FOP Awareness across the state of Wisconsin. Gretchen and John handed out Fact-In-Brief sheets at each stop during the journey from the Mississippi to Lake Michigan. Thank you to everyone who donated to this event after reading about it in the June FOP Connection.

John completes ride for FOP community.

Patrick and John on the shores of Lake Michigan.
**Photo Shoot and Birthday Fundraiser**

Servane Letartre is the aunt and godmother of FOP member Séverine Letartre who lives in Belgium. Aunt Servane rented her house for a magazine's photography shoot and decided to give the money to the IFOPA. She then had another wonderful fundraising idea and for her 60th birthday party Servane asked her friends to make donations to the IFOPA instead of giving her a present. Servane Letartre said, “It was the most beautiful present I have received for my birthday.” The IFOPA and its members are grateful and thanks Servane, her husband and all her friends who have been so generous in giving over $6,000!

**Erin’s Day**

On Friday, September 28th the 4th Annual Erin’s Day took place at the scenic golf course, The Crossings at Carlsbad, in Carlsbad, California. This year Erin’s parents Lori and Ken added to their venue a Golf Clinic for beginners and participants received two hours of PGA Professional Instruction. For seasoned golfers the shotgun start to the tournament was at 12 noon and 21 golfers played 18 holes. Around 5:30pm appetizers were served before the delicious dinner buffet which 65 people attended. Everyone at the dinner was impressed by the keynote speaker Dr. Edward Hsiao from the University of California, San Francisco. Dr. Hsiao spoke about the FOP research he is doing and his hope that this may also help people with osteoporosis. His PowerPoint presentation was inspiring when he noted the extended efforts by many doctors around the world who are searching for an FOP cure. There were many great items people placed bids on during the Silent Auction and there was also a drawing for 12 special items. This wonderful event raised over $20,000 for the IFOPA in honor of Erin Danzer - thank you to everyone who helped and participated!

**Sienna’s Splash: Princeton Swimathon to Cure FOP**

Sienna Otto is now a dynamic three-year old who was diagnosed with FOP (Fibrodysplasia Ossificans Progressiva) in May 2012 after several months of painful flare-ups. In June 2012 her family joined the IFOPA and they began raising funds to find a cure. Sienna loves picking flowers, playing dress-up, eating Tex-Mex food, and especially swimming.

As trauma has been shown to speed up the FOP ossification process, swimming is the only active sport recommended for FOP patients. Luckily, swimming was in Sienna’s blood as her parents Eric and Rory were both lifelong swimmers. Sienna’s friends and family combined their love for swimming with their love for Sienna to host the amazing fundraising event Sienna’s Splash. Rory was very pleased to learn The Princeton Swimming family does not end with graduation and the event
Sienna Splash Swimmers

Dr. Kaplan, Sienna, and Rory

was held at Princeton University’s DeNunzio Pool, on October 6, 2012. The Princeton Women’s Swimming Head Coach Susan Teeter donated the use of the pool and got her entire team on board to help support the cause to raise funds for FOP Research!

Rory stated, “It has taken pretty much the whole state of New Jersey and maybe half of Texas to pull off Sienna’s Splash with just three months of preparation. Who knew there was so much work involved?! Our deepest thanks go out to all of you who supported us, attended the event, swam, and donated from afar (and we mean FAR)! Sienna Splash has raised over $62,000 generated by over 254 donations from across the world, from as close as Princeton to as far away as Korea! This brings donations in honor of Sienna Otto to over $112,000 for the year! Donations and employer matches are still coming in, so the IFOPA continues to process the funds for research. Rory exclaims, “We were so excited that Dr. Kaplan was able to join us at the event, and he let us know that these funds will enable the lab at Penn to hire another post-doc fellow for two years! Thank you everyone for helping us get one step closer to the cure!”

If you would like to see more photos from the event, go to http://www.thesiennafoundation.org/2012/siennaswimathongallery/

Zipper Q

In February of 2012, Amy and Jacob Gordon along with their family and close friends formed the ZipperQ planning committee to hold a BBQ Challenge and Auction with the goal of raising $30,000 in honor of their son Zip. This team of 25 individuals met monthly and the ZipperQ fundraiser blossomed and grew to include a New Dodge Ram Truck Drawing and fun activities for all age groups. The team also grew when Amy used the FOP Member Directory online and contacted Jeremy Frame’s family who were pleased to join them in raising money for the IFOPA. The IFOPA was happy to help and we are very pleased to announce over $130,000 was raised in Claremore, Oklahoma on October 6th!!! Approximately 1,200 to 1,500 people attended ZipperQ!

Our IFOPA chairman Mark Gambaiana in a published letter to the editor of the Claremore Daily Progress wrote: On behalf of the International FOP Association and the members-families we serve, I wish to extend deep appreciation to the Claremore community for making last Saturday’s ZipperQ fundraiser a rousing success!

The Claremore Daily Progress was very gracious in helping Amy Gordon advertise the ZipperQ event and raise FOP Awareness by running at no cost a half page ad for five
weeks that contained a new story each week in the middle of the ad about Zip and FOP. The entire community learned about the difficulties of diagnosing FOP and the challenges of living with FOP. The ZipperQ team also put up a Facebook page and website www.zipperq.com that showed all the auction items and linked people to the IFOPA site so they could purchase truck drawing tickets, BBQ tasting kits, and enter the BBQ Challenge.

Lincoln’s Legacy Continues to Raise FOP Awareness, Funds

Since 2009, the family of FOP member Lincoln Wheelock of Des Moines, IA has conducted various fundraising events to generate research dollars. In 2012, activities included fundraising at the Sioux City Bandits indoor arena football games, a holiday shop, a letter drive and the annual “Run through the Mud to Cure FOP” at the Living History Farms off-road race in Des Moines.

The Mud Run continues to be a popular event within Lincoln’s Legacy as 25 runners generated pledges from family and friends as they participated in North America’s largest off road race, a seven mile run through rugged terrain, streams, embankments and Iowa farmland with 7,500 total runners.

Contributions in honor of Lincoln were more than $72,000 in 2012, and the family has generated nearly $270,000 for FOP research over the past four years.

Lincoln is six years of age and lives with his parents, Lee and Trisha, and a brother, Hudson.
2012 Fundraising

3rd Annual Francis Marion Dirt Dash
4th Annual Morgan's Ride in Honor of Morgan Lawler
9th Annual Newark Academy Student Council 5K Run for FOP in Honor of Ian Cali
Ali's Army in Honor of Ali McKean
Bingo for a Cure in Honor of Joshua Scoble
Blue Jeans Day in Honor of Lincoln Wheelock
Christmas Card Campaign in Honor of Yorick Blonk
Dancing for a Cure in Honor of Ashley Kurpiel
Dubs for a Cause in Memory of Susan Kadala
Erin's Day in Honor of Erin Danzer
Fall Silent to Raise Awareness in Honor of Emma Albee
Fish for FOP in Honor of Stephanie Snow
Golf for a Cure in Honor of Shane Terry
Hayden's Hope 9th Annual Letter Drive in Honor of Hayden Pheif
Hand Crafted Jewelry and Objet d'art Fundraiser in Honor of Severine Letartre
Holiday Fundraiser in Honor of Patrick Doerr
Jeans Day in Honor of Cody Dennings
Jeans Day in Honor of Justin Henke
Joey Hollywood Letter Drive and Bracelet Sales in Honor of Joey Hollywood
Keystone Candle Fundraiser in Honor of Joshua Scoble
Lincoln's Legacy Letter Drive in Honor of Lincoln Wheelock
Lincoln's Legacy Holiday Shop in Honor of Lincoln Wheelock
Making Spirits Bright Holiday Benefit Concert in Honor of Alexandra Rodriguez
Mary Kay Fundraiser in Honor of Joshua Scoble
Natalie McGuire Letter Drive in Honor of Natalie McGuire
Pitch In for a Cure in Honor of Joshua Scoble
Photo Shoot and Birthday Fundraiser in Honor of Severine Letartre
Polaris Elementary School 5th Grade Class Fundraiser in Honor of Laura Rossano
Rachel Dell Half Marathon in Honor of Justin Henke
Ride for Joshua's Future of Promises in Honor of Joshua Scoble
Run through the Mud to Find a Cure in Honor of Lincoln Wheelock
Sienna’s Flower Garden in Honor of Sienna Otto
Sienna Splash: Princeton Swimathon to Cure FOP in Honor of Sienna Otto
Sienna Otto
Sioux City Bandits in Honor of Lincoln Wheelock
Striking Out FOP in Honor of Carli Henrotay and Timothy Hazlett
Unswerving, The Trans-Wisconsin Bicycle Ride in Honor of Patrick Doerr
Victor Ice Fishing Benefit in Honor of Kyle McWilliams
Zipper Q Route 66 Golf Tournament in Honor of Zip Gordon
Zipper Q BBQ Challenge, Truck Drawing and Event in Honor of Zip Gordon
Zumbathon in Honor of Ashely Kurpiel
When I first started feeling unwell
And my back and shoulders started to swell
All of my thoughts were scattered
And finding out what was wrong was all that mattered
Soon we started to see
That everything matched up with FOP
My family was so sad
Because everything turned out so bad
When they finally told me
I wanted to flee
But I knew that I had to stay strong
Because home is where I belong
So I bundled up my doubts
And threw them all out
I have no fear
For I know the cure is near

NATALIE MCGUIRE
AGE 11

stay strong
The IFOPA gratefully acknowledges the generous contributions from friends, families, fundraisers and special events, corporations and foundations that make our programs possible.

The IFOPA enjoyed an exceptionally solid fiscal year in 2012 with revenues of $940,692 and expenses of $614,209, strengthening the organization’s net asset position by $326,483. As of December 31, 2012, the IFOPA’s net assets stood at $1,905,351.

In 2012, 64 percent of the organization’s revenue came from net proceeds of special fundraising events, and 32 percent from outright contributions. Revenues increased $89,693 from the previous year. On the expense side, program services accounted for 78 percent of expenditures, including 68 percent for medical research, the highest priority of the organization.

### Revenue and Public Support

<table>
<thead>
<tr>
<th>Source</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>Contributions</td>
<td>$320,238</td>
</tr>
<tr>
<td>Special Events, Net</td>
<td>$598,272</td>
</tr>
<tr>
<td>Other</td>
<td>$22,182</td>
</tr>
<tr>
<td><strong>Total Revenue and Public Support</strong></td>
<td><strong>$940,692</strong></td>
</tr>
</tbody>
</table>

### Expenses

**Program Services:**
- Medical Research: $420,248
- Public Awareness: $18,610
- Education and Support: $37,851
- **Total Program Services**: $476,709

**Support Services:**
- Management and General: $72,818
- Fundraising: $64,682
- **Total Support Services**: $137,500

**Total Expenses**: $614,209

<table>
<thead>
<tr>
<th>Source</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>Change in Net Assets</td>
<td>$326,483</td>
</tr>
<tr>
<td>Net Assets at Jan. 1, 2012</td>
<td>$1,578,868</td>
</tr>
<tr>
<td>Net Assets at Dec. 31, 2012</td>
<td>$1,905,351</td>
</tr>
</tbody>
</table>

### Revenue Composition

- **Contributions**: 34%
- **Special Events**: 64%
- **Other**: 2%

### Expenses Composition

- **Medical Research**: 68%
- **Fundraising**: 11%
- **Management & General**: 12%
- **Education & Support**: 6%
- **Public Awareness**: 3%
### 2012 IFOPA Donor Honor Roll

Thank you to the many wonderful families, individuals, organizations, corporations and foundations that supported the IFOPA with generous contributions between January 1, 2012 through December 31, 2012.

#### Diamond
$25,000 and above
- Joshua’s Future of Promise, Inc.
- Svenska FOP Foreningen
- Zipper Q

#### Platinum
$10,000-$24,999
- Bridgewater Associates, LP
- Grampian Fellowship
- Jewelry and Objet D’art Fundraiser
- Johnson & Johnson Family of Companies
- Alex & Virginia McCloskey and Betty Kelber
- Melton Sales
- Roemex Limited
- George & Pamela Rohr
- Clara M Ruspino
- The Dorothy Jane Slawson Individual Living Trust
- Kristina Sligh & Charles (Skip) Sligh, V Diane N Weiss
- George & Lydia Weiss

#### Gold
$5,000-$9,999
- Alcester Grain Company
- Mark & Robin Gambaiana
- Herman Goldman Foundation
- Servane Letartre
- Patrick Lynch
- Michael & Carol Man
- Allison & Nino Marakovic
- Charles & Wendy Otto
- Halsey & Natalie Otto
- Skelmir, LLC

#### Silver
$2,500-$4,999
- Steve Angle
- Canyon Partners
- Nipa Chowhan
- Wayne Deans
- David DuBard
- Gretchen & John Emmerich
- Fidelity Charitable Gift Fund
- FirstGiving, Inc.
- Golf for a Cure
- Claudia & Kerry Hueston
- David & Jami Jones
- Mark Myles & Craig Landon
- Lawrence A. Martin II, Attorney PC
- Michelle Maguire
- Delmar & Mabel McWilliams
- McWilliams Farm
- Mondrain Investment Partners, Inc
- Sioux City Bandits
- Howard & Sarah Solomon
- Striking Out FOP
- The Velez Law Firm
- Tower Components, Incorporated

#### Bronze
$1,000-$2,499
- Jeanne Altberger
- Aronson Johnson Ortiz, LP
- August Packaging
- Chris & Helen Bedford-Gay
- Elizabeth & Robert Blanchette
- Pete & Jenny Bulban
- John & Amanda Call
- Cherokee Spur Ranch
- Mario & Anna Chuliver
- Clear Creek Independent School District
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- Douglas & Sharon Coleman
- Compi Distributors, Inc.
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Steve Abruzzo
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