

1988 to 2013 Twentyfive years of funding FOP research and supporting families around the world

2013

ANNUAL REPORT

Commemorative Edition

International Fibrodysplasia Ossificans Progressiva Association



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Front Cover Image: Eleven Founding Members of the IFOPA

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25th Anniversary DVD

The IFOPA is pleased to provide you with the 2013 Commemorative Annual Report and DVD as an expression of our gratitude for your continued support of our mission: to fund research to find a cure for FOP while supporting individuals and their families through education, public awareness and advocacy.

What is Fibrodysplasia Ossificans Progressiva (FOP)?



Young boy with 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 1 in 2 million people. It is estimated that 3,500 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.” In the 1970’s, the condition was officially modified to Fibrodysplasia Ossificans

Progressiva to acknowledge that other soft (fibrous) tissues in addition to muscle (for example tendons and ligaments) are replaced by bone. The late Dr. Victor McKusick, of Johns Hopkins University School of Medicine, who is considered the father of Medical Genetics, is responsible for the name Fibrodysplasia Ossificans Progressiva.

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.



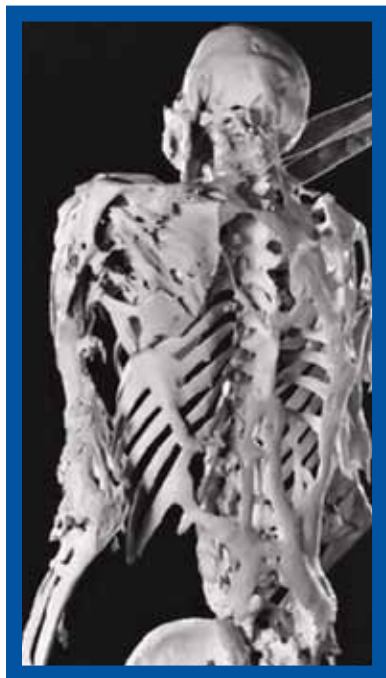
2009 IFOPA group photo of teen and young adults with FOP - also shown is Drs. Kaplan and Kitterman, San Diego, CA

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.

Unlocking the Mystery of FOP – The Skeleton of Harry Eastlack

The skeleton of Harry R. Eastlack (1933-1973), a man who lived with FOP, is on display at The Mutter Museum of The College of Physicians in

Philadelphia, PA. Late in his life, Harry Eastlack made a decision to bequeath his body so that physicians and scientists in future generations could study FOP. The Mutter Museum houses a collection of human specimens and models depicting many diseases in various stages of development.



Harry Eastlack skeleton at The Mutter Museum, The College of Physicians in Philadelphia, PA

One of the few existing skeletons in the world, it has become a window into the medical mysteries and scientific challenges of FOP. It illustrates the harsh reality of FOP more than any chart, or slide of clinical description could accomplish.

Harry Eastlack's skeleton is nearly fused into one piece. Sheets of bone cover his back, and ribbons, sheets and plates of bone lock his spine to his skull and his skull to his jaw. Additional ribbons and cordons of bone span from the spine to the limbs and immobilize the

shoulders, elbows, hips and knees.

This FOP skeleton, which stands as Harry Eastlack stood in life, is a continuous reminder of how far scientists have come in the research of FOP, and how much work remains.

This remarkable bequest continues to educate and inspire scientists, physicians, students, and patients alike.

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 fund research to find a cure for FOP while supporting individuals and their families through education, public awareness and advocacy. The vision of the 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.

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

Since its founding, the IFOPA has directed over six million dollars to the Center for FOP Research & Related Disorders at the University of Pennsylvania School of Medicine. Over \$500,000 is provided 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. www.ifopa.org

The Betty Anne Laue -IFOPA Resource Center is based in the IFOPA office and is not an online resource. The Resource Center offers



scientific and medical articles, interesting stories on FOP members, unique FOP-related resource materials and much more. Support to patients and families ranks as another top programmatic objective.

Periodic symposiums bring together FOP patients with health professionals who 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 LIFE Awards (Living Independently with Full Equality) to its FOP members. The program is designed to promote health, welfare and independence. Examples of the awards range from equipment, walkers, wheelchairs, adaptive bed, vehicle adaptation, tuition/registration for vocational training, specialized bicycles, computer hardware or assistive technology and reading aids.

The FOP Connection newsletter is regularly distributed to the FOP community and features stories about members, fundraising events, research updates, helpful suggestions and resources for living with FOP.



Jack Sholund received an award to purchase an Apple computer for communicating and creating digital art.

FOP Online member email group forum is a vital medium to connect members for discussion, support and research news.

The IFOPA sponsors a mentoring program designed to provide members with the support they need to better manage the daily challenges of living with FOP.

New members receive the comprehensive resource book, **What is FOP? A Guidebook for Families**, along with a medical binder, which includes a flash drive containing important medical information, and a portable pill holder, which holds one dose of emergency medication. Additionally, the new member will receive medical forms to customize with their personal medical information.

The IFOPA works with National Organization for Rare Disorders (NORD), the National Institutes of Health (NIH), Rare Bone Disease Network under the US Bone and Joint Initiative as well as EveryLife Foundation for Rare Diseases.

IFOPA's financial support from families, friends and others who join forces to meet the organization's annual operating budget are the backbone of the organization. Nearly half of the one million dollars generated each year is directed toward research efforts at the Center for Research in FOP & Related Disorders (FOP Research Lab) at the University of Pennsylvania. The primary source of support is raised by FOP families at barbecues, golf outings, fun runs and other special events.



Jasmin Floyd points to one of the IFOPA fundraising events held in her honor. The poster timeline was displayed at the 25th Anniversary Celebration.



Fund Research, Find A Cure, Support Families.

The Quest for Treatments and a Cure

The Center for Research in FOP & Related Disorders (FOP research Lab), created in 1992, is located at one of the most prestigious medical and research institutions in the country – the University of Pennsylvania School Of Medicine.

Led by Frederick Kaplan, M.D., and Eileen Shore, Ph.D., the FOP Research Laboratory's dedicated research team includes three principal investigators supplemented by many post-doctoral fellows, scientists, students and staff. This core team collaborates with physicians and scientists worldwide to develop treatments and – someday – a cure for FOP.

In a monumental award-winning article entitled, "The Mystery of the Second Skeleton," which appeared in the June 2013 edition of the **Atlantic Monthly**, Carl Zimmer wrote: "A tiny percentage of the world's population suffers from fibrodysplasia ossificans progressiva which locks its victims in cages of superfluous bone. For centuries, these patients were dismissed as a lost cause. But recent genetic and technical advances have propelled researchers towards an understanding of this disease that may transform the lives not just of people who suffer from it, but of those afflicted by much more common ailments. Rare diseases, it turns out, are more relevant than we ever imagined."¹

Worldwide interest in FOP research has blossomed since the gene discovery in 2006. New technologies are being developed at a rapid pace, and new ideas forged daily. FOP research is now an international enterprise. At least 30 distinct venues perform research on FOP, with the core activity at the Center for Research in FOP & Related Disorders at the University of Pennsylvania.²

Scientists and physicians at university laboratories, researchers at corporations, pharmaceutical companies, biotechnology firms, and international government agencies have expressed keen interest in FOP and are engaged in a worldwide effort to create better treatments and a cure.³

Recent activities at the FOP research laboratory include the collaboration with international pharmaceutical companies to develop promising compounds for clinical trials, conducted a global survey of FOP flare-ups that will be used to design clinical trials, completed the first –year of a comprehensive pre-clinical drug-testing and biomarker discovery program using FOP mouse models for testing possible treatment for FOP, among others.



Joey Hollywood of Bridgewater, New Jersey proudly sporting his new "direction-finder" (GPS device) with journalist Carl Zimmer and Dr. Kaplan

There is no treatment available for FOP today, but research has led to several possibilities currently under investigation at multiple institutions. The theme of 2013 was how you, the FOP patients and families worldwide, have laid the foundation for clinical trials by your participation in

FOP research – from your global contribution to defining the natural history of FOP flare-ups, through your participation in new biomarker studies, to your contributions to patient reported outcome studies in FOP, to your generous donations of blood, teeth, urine and tissue specimens for ongoing research, and to your fundraising and educational efforts in the broader community worldwide. You make all of this possible. This work will continue and expand into 2014 and beyond.⁴

1, 2, 3, 4 reprinted from 23rd FOP Collaborative Research Project Annual Report pages 7 - 9 "The Journey" from Frederick S. Kaplan, MD; Robert J. Pignolo, MD, PhD, Eileen M. Shore, PhD

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 Center for Research in FOP & Related Diseases (FOP Lab) at the University of Pennsylvania.
- 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 (NORD), the Bone and Joint Initiative USA, and the EveryLife Foundation for Rare Diseases, and the National Institutes of Health (NIH).



Inside Edition Crew with Nick Mahler’s family at the IFOPA 25th Anniversary Celebration and FOP Family Gathering

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, the IFOPA celebrated its 25th anniversary, a testament to the vision of our founder, Jeannie Peeper, and the dedication and vigor of our association members.

Reflections on 2013 and 25 Years



Jeannie L. Peeper

As I prepared to write my page for the Commemorative 2013 IFOPA Annual Report, I embarked on a wonderful journey down memory lane reminiscing about the many things we have all accomplished together over the years. I hope my love for you and the many that make our global association so special, will shine through when you see

our slideshow on the enclosed DVD. Our community's strength, courage and determination is extraordinary! We are strong in spirit and determined to reach our goal of a treatment and a cure for FOP.

I believe FOP doesn't control us, but it does impact the person that we become. I still remember coming home from that fateful trip with a list of names Dr. Zasloff had given me. I first met him, at the National Institutes of Health, in September 1987. Although my personal hope for a hip replacement was shattered, I was mesmerized by Dr. Zasloff's every word as he explained his research and the FOP patients he had seen throughout the years. How could it be that he knew 20 people with FOP? Since my parents were given very little hope for my future, when I was diagnosed in 1962, at the age of four, I had never even contemplated that there were others in the world like me. After Dr. Zasloff got me in touch with Monica Anderson, we talked on the phone for a long time about everything under the sun and for the first time in my life, I didn't feel so lonely.

Thus my mission began, I wrote to every FOP person Dr. Zasloff had given me (note this was before HIPAA laws), because I had a million questions! I wanted to know about each FOP person - their childhood experiences, if they were affected the same way I was, did they know anyone else with FOP? I received ten responses and you can read about each of these individuals and their families in this report. These ten people inspired me.

Friendships developed, the isolation of the past was finally over. I created the FOP Connection newsletter to share the information I was gathering from everyone with FOP. This connection of people with FOP, sharing a common goal - sparked the need to incorporate a non-profit organization to raise funds for research. On June 8th, 1988, the International FOP Association was born, and I have been honored to serve as President of this organization since its inception. Due to you and your families countless fundraising and awareness efforts, our eleven member pen pal group has transformed and grown into the leading international FOP association, with 12 sister FOP organizations in 18 countries.



Dr. Zasloff, Jeannie Peeper and Dr. Kaplan at the 1st International FOP Symposium held in 1991 at University of Pennsylvania with 28 physicians and scientists and 21 FOP families

programs through the grass-root efforts of FOP families. Today our family fundraising continues to propel us on our journey toward a treatment and cure. Within this report you can read about our associations' early highlights on the enclosed timeline, review the list of 2013 fundraising events and the names of our generous donors.

Our first donation to research, made in April 1990 was \$1,200. It was a small beginning, but a strong one. Nick Bogard, the father of a young son with FOP, organized the first large fundraiser for the IFOPA and FOP research. The Jud Bogard Golf Tournament started our unique tradition of raising research dollars and support for IFOPA



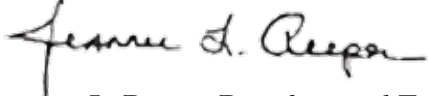
1994 FOP Family Meeting at Walt Disney World

I'm thankful for our shared blessing of having many friendships across the globe. I still vividly remember the first time I had a personal meeting with FOP friends Sandi Lee, Andy and Nancy Sando. On that warm day in 1989, I wondered what would it be like, at the age of 29, to finally meet, in-person, someone with FOP? Would our bodies look the same? Being together surprised me, as a new comfort washed over me. I finally knew that I was no longer alone in my struggle with FOP. This was a relief, that I was not really expecting, but graciously accepted and hoped to share with others by holding FOP family meetings. The first "official" FOP family meeting was held in Orlando, Florida in May 1991. Eight families attended, along with Dr. Kaplan, a soft-spoken man with a giant heart who has made FOP research his life's work. To date, the IFOPA has held six FOP family meetings in Orlando. November of 2013 was another amazing FOP family meeting and IFOPA 25th Anniversary Celebration with 59 FOP individuals, their families, physicians, researchers, and for the first time pharmaceutical companies in Orlando! The number 59 becomes huge when we contemplate how unique we are – only 1 in 2 million people have FOP. Each FOP person represents a special family and different region of our world. I truly can't imagine my life without you, my beloved friends who are resilient. Together we are strong, as we work for a cause that we believe will one day bring a treatment and cure. Rising to the top of all my cherished memories of our past 25 years together, is the phone call I received in April 2006 from Dr. Fred Kaplan – the FOP gene was discovered. It was a moment in time, that I will never forget and the greatest gift in my lifetime. I am grateful to Dr. Michael Zasloff for directing my path. I'm thankful to Dr. Fred Kaplan and

Dr. Eileen Shore for their leadership at the University of Pennsylvania, their lab team and all the doctors, researchers, universities and pharmaceutical companies who have joined our global fight to realize our vision, A Cure for FOP. Our hope for a clinical trial to treat FOP flare-ups will begin in 2014. We have all worked long and hard for this opportunity and we are very excited that our FOP community can participate in upcoming clinical trials.

I'm honored that the FOP patient registry will be named FOP Connection since it will benefit each of us, as we share what we know about FOP with researchers, industry and each other. By providing a central resource for patient information, there is no doubt that the registry and our participation in it, as a united community, will impact the discovery of a drug to treat FOP. Our mission, to raise funds for FOP research while supporting individuals and their families through education, awareness and advocacy continues as we move forward with excitement and anticipation as we journey together! Thank you for your continued support and team effort globally to make our dream a reality.

With Love and Gratitude



Jeannie L. Peeper, President and Founder

Our Founder and 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 more than 450 patients and families in over 50 countries through education, public awareness, program-based initiatives, networking opportunities, and

support to families while funding research to find a cure for FOP.



Jeannie Peeper and Robert Anderson visit the Panasiwicz family from Poland. Left to right: Katarzyna, Karina, Robert, Jeannie, Pawel and Alicja

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 Center for Research in FOP & Related Disorders (FOP Lab) at the University of Pennsylvania, and it remains the preeminent center for FOP research in the world. Since then, the IFOPA has provided more than six 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 extensive, 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 cornerstone 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 Message from 2013 IFOPA Board Chair Mark Gambaiana

What a year it was! As I look back on 2013 – and ahead to the future – we may well remember our 25th anniversary year as the catalyst to a new phase in our relentless pursuit of an effective treatment and eventual cure for FOP.

A festive 25th anniversary celebration, a record-breaking year for revenues, strengthening of the bottom line for future investments, strong support for FOP research, blossoming international interest in FOP and the continuation of several key pre-clinical trial steps all capped a magnificent year.

Our 25th anniversary celebration staged in Orlando, Florida, November 7-9 attracted 279 participants, including 59 FOP members and attendees from 12 countries and three continents. The combination family gathering and research-drug development update was a fitting time to reflect and say thank you to our community for the FOP journey that has taken us to the doorstep of clinical trials.

The IFOPA achieved its finest financial year in history with record revenues of \$1,478,676. This figure included the two largest single gifts in IFOPA history, a \$320,000 grant from the Jesse David Hendley Foundation in memory of the late FOP member Craig Hendley, and an anonymous \$250,000 gift made in honor of FOP member Natalie McGuire.

Thank you to the many families and friends that conducted fundraising events in 2013. The IFOPA relies heavily on private contributions, and each year we begin

again with our fund development efforts. Every gift is needed and appreciated, and we received 4,064 total gifts last year.

Our audited financial statements reveal that we added

a remarkable \$640,783 to the balance sheet in 2013 – growing our net asset position to an all-time high of \$2,546,134. In two years, we have expanded our assets by nearly one million dollars.

The IFOPA Board of Directors is making strategic investments with these additional resources. Examples include the appointment of Betsy Bogard to a 12-month position as Global Research Development Director, the launching of an IFOPA Patient Registry, and the planning of a 2014 drug development forum in Boston, all activities designed to accelerate a soon to be announced clinical trial.

Finally, the 2013 year also marked the end of an era – the retirement of our founder Jeannie Peeper from day-to-day activities of the IFOPA. Jeannie won't completely disappear and will remain as President but will now focus the majority of her time on her health, relaxation and other pursuits.

Because of Jeannie's vision, steadfastness and ability to unite our community, we are now poised to take that next step on the road to treatment and a cure. Your continued gifts of time, expertise and financial resources are needed to complete the journey.

With Deep Appreciation,



Mark Gambaiana, IFOPA Board Chair



Robin and Mark Gambaiana at the IFOPA 25th Anniversary Celebration and FOP Family Gathering

Eleven Founding Members

Jack Sholund by Nancy Sando

Jack, now 56 years old lives in Grand Rapids Minnesota. In 1966, at age 9, he was diagnosed with FOP at Minnesota's Mayo Clinic in Rochester. He attended schools in Hibbing, Minnesota where he graduated from Hibbing High School in 1975.

Jack became interested in artistry as a young man. With the encouragement from long time family friend and fellow artist, Marian Wirtanen, Jack excelled in learning the patient process of working with watercolors. He works on a variety of mediums from canvas, wooden objects (boxes, vases, ornaments, bookends) and snow globes. His watercolor paintings are detailed and even contain hidden critters on the larger formats. Jack can be found displaying his artwork at local art exhibits which he enjoys doing since he likes having people view his art. Jack also shows the people at exhibits how he paints even with his disability by switching hands to accomplish his specific artistic task. His artwork is displayed in his own small gallery in the home where he lives. Jack also does commissioned pieces of art that customer's request. This has resulted in several one-of-a-kind paintings by Jack of cabins, lakes shores, wildlife and pets. His work has been accepted into the Sister Kenny Art Show every year since 1976 and his various pieces have been selected by THASC and Courage Center for the mass production of greeting cards.

In Jack's non-painting hours he takes pleasure in spending time meeting people and hanging out with his family on the lake where he grew up. Some of his hobbies include coin collecting, photography, reading, computers and listening to a wide range of music.

During Jack's younger years, he recalls taking many trips by car (without a personal DVD or CD player!) He and his family explored the US from the Midwest to the West Coast as well as Florida and Arizona. Jack and his parents attended the first FOP Symposium held in Philadelphia. Here Jack personally connected with many

friends he had only written to previously. He now finds it enjoyable to catch up with his friends through email or on Facebook. Jack is an easy going FOP veteran of the IFOPA. He likes simple foods like spaghetti and lemonade. He has a liking towards crime/ drama / TV shows like CSI or Person of Interest. He was quick to volunteer his favorite movies are Harry Potter and The Lord of The Rings. Jack liked Harry Potter so much he named his dog, Hermione after one of its characters.



Detail from one of Jack Sholund's butterfly paintings.

When asked what dreams or goals Jack wanted to accomplish in his life, he paused, then said, "When I was in my early 40's I always wanted to reach 55." Jack has now passed that age so he is now working on his new wish list! Jack's ultimate goal in art is to complete 3000

paintings and he currently is at 2950. He considers himself to be very lucky to have such wonderful parents that encouraged him with his artwork and taught him to always treat others as you would want to be treated. His extended family is also a big influence in his life and Jack continues to strive to improve in his art by exploring new subjects. Jack hopes his artwork puts a smile on people's faces.



Hermione and Jack hanging out.

Jack recalls being a pen-pal of Jeannie Peeper's before the IFOPA began. He will be forever indebted to Jeannie for her dedication throughout the last twenty-five years. Jack has gained many long lasting friendships from being a member of the IFOPA as well as continuing to increase his

health knowledge from communicating with its members and medical team. Jack will always treasure the friendships he has made through the IFOPA.

Nancy (Whitmore) Sando

by Gretchen Emmerich

Nancy was born on May 29th, 1959 in Detroit, Michigan. A few years later, she and her family moved to Fairfield, Connecticut where her father took a job as an Electrical Engineer. At age 5, Nancy was initially misdiagnosed with cancer when FOP began flaring in her back muscles. Lucky for her, Dr. Pack, the Oncologist from NYC who examined her noticed her toes and correctly diagnosed Nancy with FOP. From that point, Nancy was followed by the Pediatric Child Disability Clinic at Yale where she recalls that she felt like a human guinea pig. At one point, her health care team attempted to “elongate tendons” on her right arm with surgery. Unfortunately for Nancy, this was before the knowledge that trauma would induce FOP flare-ups. In 1976 Nancy’s family moved to Petoskey, Michigan.

Nancy recalls her grade school years (back in the mid 1960’s) how children with disabilities were placed in separate classrooms from the “regular” kids. Nancy’s mother however, would have none of that, and advocated for her to be able to remain in a regular classroom. It worked. Gym classes were off limits for Nancy due to the physical liability yet Nancy was able to do office work during that period, or was chosen to be the score keeper during more rigorous physical activities.

The middle school years were tough for Nancy, but High School was a turning point. Academically, Nancy excelled and one teacher in particular saw Nancy’s potential asking her to be the proprietor of the greenhouse on the school property. Nancy’s self-worth soared with the responsibility given to her, and to this day she still loves plants. At one point, Nancy had over 130 plants in her bedroom! In Nancy’s early life, another self-esteem builder centered on children. She became the “go to” babysitter in her neighborhood throughout her high school years and was usually booked out for several weeks in advance! Nancy today enjoys the Kid’s Ministry at her Church.

When asked who her greatest support was during times of sickness and flare-ups Nancy quickly responded with this list of special people:

Her sister, Sharon- who is two years older than Nancy, used to rub her back as a child. The two sisters used to make names for the different lumps and bumps on her back calling one Mt. Rushmore and another Mt. Washington. Nancy laughs that as they studied US geography they used her back as the topography diagram!



Nancy Whitmore Sando

Nancy’s Father, John - He would always help Nancy find new ways to do the things that were no longer possible for her to do.

Helen Keller - Helen made a huge impact on Nancy, especially how Helen overcame different obstacles. Her story inspired Nancy.

Margaret Jean Jones - Another key player and support for Nancy was a fellow FOPer named Mary Jean who Nancy met in her 20’s. Although they never met face to face, the two women were pen pals. Nancy was always inspired by Margaret Jean’s positive outlook on life even though she was bedridden for most of it.

Nancy’s faith in God has also sustained her through the tough times. In Nancy’s words, she knows that she was given a unique life and chooses to live it according to God’s plan not her own. She feels blessed and has always been provided with everything she needs.

Nancy feels privileged to be one of the founding members of the IFOPA. It was while Nancy was in Junior college in 1982, that she and Margaret Jean began writing each other. Shortly after that Nancy was contacted by Jeannie Peeper through the mail. Nancy recalls “It was the greatest thing to know that Jeannie had the vision and desire to contact us. We instantly had a very special bond. It felt like I was coming home. Kind of like how an adopted person must feel when they meet their biological parents.”

Eleven Founding Members

In 1988 Nancy met Andy Sando who also had FOP. Nancy laughs as she recalled that he was a city boy and she was a country girl. "We fell in love and were married in 1988," says Nancy. It was a match made in heaven. They shared their love of family, their faith, and being positive influences in the world around them. There never seemed to be "no" in their vocabulary. Andy passed away in 2003, and although she misses him terribly, Nancy's memory banks are filled to the brim of 14 joy filled years with Andy.



Mr. & Mrs. Sando

Nancy is quite well known in Petoskey, Michigan. She walks her 2 dogs every day, and is an avid award winning knitter. Nancy lectures at the North Central Michigan College twice a year, has been featured in numerous newspaper articles, and is very involved in her church serving in children's ministry, publishing the newsletter, maintaining their website, coordinator of the e-prayer chain and leads small groups where she has numerous friends. Nancy employs three full time attendants, Jessica, Elke and Sheryl, and four part time aides, Jennifer, Pat, Kathy & Heather, who are more like family to her than care givers.

Nancy has served the IFOPA as a Board member for several terms and her tenure exceeds 12 years. Nancy loves heading the Mentoring program sharing hope with newly diagnosed families. Nancy also heads the Board Development committee and the Nominating Committee. Nancy has attended several of the IFOPA Symposiums. Articles by herself and Andy have been published in the Ladies Home Journal, The Atlantic Monthly, Max Lucado's Book entitled "John 3:16,"

Inside Edition and numerous news segments and many professional medical publications.

As for the goals of the IFOPA, Nancy is hopeful the IFOPA will remain strong in supporting its members and its FOP research now and for future generations.

Monica Anderson by Nancy Sando

Monica Anderson, 44, was diagnosed at the age of three years at John Hopkins Hospital by Dr. Victor McKusick. She has lived in the Washington DC – Maryland area her whole life and has enjoyed vacationing with her family in Niagara Falls, Bahamas, Williamsburg and Busch Gardens to name a few places.

After her 1987 high school graduation, Monica continued her education by attending the American University in Washington DC. In 1991 she received her Bachelor's degree in Russian Studies and her Master's degree in Russian and International Studies in 1994. With her two college degrees under her belt, she worked for Tax Analysts, a tax publication company, in the translation department then moved to the finance department a year later. She held that position for thirteen years until the company downsized and she was let go.



Monica Anderson working as a translator.

In Monica's free time she enjoys a good mystery, going to the movies – she likes any type - comedy, drama, and action. When at home she can be found watching CSI,

Criminal Minds or similar shows. Her most coveted time is with family and friends or going to a live theater performance. Monica enjoys a good Italian meal or a feast of crab cakes.

Monica feels that her college years and thirteen years of work experience are among her top accomplishments. She would still love to work and finds being involved in church activities helps fill this void. Monica believes she is a good listener and helps those that need encouragement by her naturally gentle way.

Monica has been inspired by her parents and third grade teacher, Dr. LaUanah King-Cassell. Dr. King-Cassell was warm, caring and she made her students strive for the best. She was a teacher that went way beyond the call of duty.

As a long time patient and friend of Dr. Zasloff, who formerly worked at the NIH (National Institute of Health), Monica learned about the IFOPA right away. Dr. Zasloff was instrumental in FOP research before the University of Pennsylvania team was formed. Monica learned about our newborn organization through Dr. Zasloff's office when Jeannie Peeper received Monica's address among others which started Jeannie's letter writing campaign to form friendships with other FOPers and begin funding FOP research.

In the 1980s, Monica was excited to meet people like herself through the IFOPA. She volunteered as a IFOPA Board Member for one term and served on the LIFE Committee.

Monica is grateful to have such a wonderful family and has met some great people along the way.



**Monica and
her parents**

Sharon Fitts **by Nancy Sando**

Sharon Fitts was born in 1956 in Henderson, North Carolina. She has lived in Louisburg, NC her entire 57 years. She graduated from high school and shortly thereafter married Henry. They just recently celebrated their thirty-second anniversary!



**Sharon and Henry Fitts'
25th Anniversary Portrait**

During her adult life, Sharon devotes much of her time to being a loving wife and successful homemaker. Her favorite times are baking many different recipes that include chocolate, chocolate and more chocolate. Among her other leisure activities are crocheting, candlewicking (a form of embroidery), bird watching and what women tend to do best . . . shop til we drop!

Sharon enjoys her home and has not travelled too far from it. She has taken a few trips to the East Coast and into the mountains but is very content where she is planted.

In asking Sharon about her accomplishments and goals in life she states that she has done so much more than she ever dreamed possible. Sharon believes she has been able to achieve so much in life because of the love and support her mother gave her. Now that her mother has passed away she feels blessed to have a husband that is so devoted and sweet. Sharon also acknowledges that her daily positive outlook on life has made her a winner.

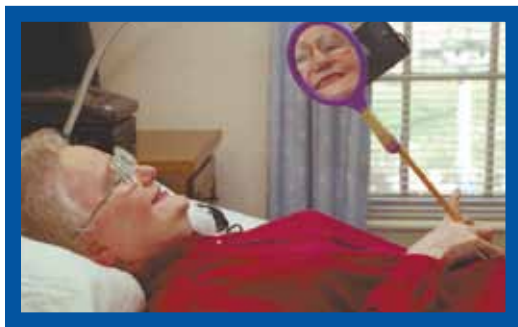
For entertainment, Sharon enjoys a wide variety of shows. She likes sitcoms such as Everybody Loves Raymond as well as suspense and thriller type movies. The scarier the better!

Sharon is so grateful she had the opportunity to be one of the founding members of the IFOPA. She remembers being invited to join through the encouragement of myself, Nancy Sando. Today Sharon marvels at how far we have come and how our IFOPA organization has reached so many people around the world.

Margaret Jean Jones by Nancy Sando

Margaret Jean Jones was our oldest founding member who joined the IFOPA at 53 years of age. Born March 27, 1936 in Baileyton, Alabama, Margaret Jean was a prolific and accomplished writer and encourager. She became “bedfast” (a term she created) shortly after her high school graduation, due to the severity of F.O.P. limitations. Although Margaret was bedfast, F.O.P. did not stop her from participating in the world around her. By using her hand mirror to look out her bedroom window, the ingenious and warm-hearted young lady brought the world to her. Today we are fortunate Margaret Jean learned to use a typewriter and home computers once they became available to connect with our world.

She was a newspaper columnist, magazine writer, and author of three published books, including *Combing Cullman County*, *Cullman County Across The Years*, and her autobiography, *The World In My Mirror*. Margaret Jean was the recipient of two awards from the Freedoms Foundation for published essays, one of which was published in the Congressional Record.



Margaret Jean Jones

Several historical awards were given to her from various civic organizations for outstanding contributions toward the preservation of local history. She

was a charter member of the Board of Directors of Ideal Industries and served as president of the new facility from 1973-75. In a surprise move, the charter board members of the sheltered-workshop type facility for the mentally and physically challenged clients, was re-named the Margaret Jean Jones Adult Activities Center in her honor at the grand opening in 1975. She never had a part in the daily staff operation of the facility but, by staff request, she wrote an inspirational and motivational-type

article called “Musings” for the monthly newsletter from the facility’s beginning.

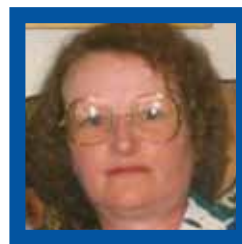
In a 1998 interview with her local paper, Margaret Jean was quoted as saying, “There are probably things I would have done differently, but all in all I’ve had a blessed and fulfilling life. I can’t look back and be bitter. I have made a conscious effort not to be bitter, but to concentrate on the things I have done that I’ve enjoyed.”

Margaret Jean was a Christian who very much believed that Christ was the best model to follow. She stated in a previous interview that she always tried to live her life by what Paul wrote in the book of Philippians, chapter 4, verse 19. The verse reads, “And my God shall supply all your needs according to His riches in glory in Christ Jesus.”

On March 16, 2009, Margaret Jean passed away. She was challenged not only with F.O.P. but with a very rare and deadly type of skin cancer diagnosed in 2008 as merkel cell carcinoma. Because of all the lives Margaret Jean touched by her kind and expressive words, she will truly live on in each one of us – far beyond her 72 years of life.

Sharon Van Slyke by Nancy Sando

Sharon Van Slyke, of Austin, Texas, was one of the members in my pen-pal circle which was established prior to the International F.O.P. Association. She was married for over twenty years to Tom who worked for the State of Texas. They were truly devoted to one another as they had little family contact for support.



Sharon Van Slyke

Sharon enjoyed doing crafts, reading, writing her friends and being a wife. She didn’t leave her house often and travel from home was usually to visit the doctor when necessary. Tom was a good man and provided for her care and companionship.

She was quick at sharing advice and ideas to make adjustments in life as F.O.P. reared its ugly head. In the

mid 1980's, Sharon was instrumental in helping me when my jaws became affected by the progression of FOP in my body. She always seemed happy and positive.

Unfortunately, her world crumbled when her beloved Tom took his own life. Sharon struggled with her broken heart and a hidden addiction to prescription drugs. This proved to be too great for her to rise above and she passed away just three months after Tom died.

I think about Sharon from time to time. Her story is sad but true. A life lesson that must be told so other couples or families can be saved from such tragedy.

If you know someone who is struggling with the reality of living with FOP or caring for a loved one who has FOP, please contact me, (Nancy Sando) or the IFOPA office (ph. 407-365-4194). Our association has a Mentor Program for all IFOPA members. You can read more about this program on page 34. Thank you.

Sarah Cameron **by Victoria Mandracken**

Sarah Cameron was born July 25th, 1947 in England and passed away on Christmas Day, 1997. As I researched the life of this IFOPA founding member by reading her letter in our scrapbook, interviewing Jeannie Peeper and asking questions of Dr. Kaplan, I discovered a fun, active lady whose actions continue to help FOP research today.



Sarah Cameron

Our president and founder, Jeannie Peeper said, "I gave our non-profit the name 'International Fibrodysplasia Ossificans Progressiva Association' after Sarah wrote back to me from the United Kingdom and included the name of her FOP friend Valda Pinder who lived in Australia." Fondly

known as "Val", this amazing lady who taught French also became Jeannie's friend, and joined the IFOPA, cementing our association's name and premise to bring our global community together.

Jeannie enjoyed being pen-pals with both Sarah and Val for many years and Jeannie had the joy of meeting them at the Second International FOP Symposium in October, 1995. During this Symposium Sarah was greatly inspired by the valuable gift Harry Eastlack gave to the Mutter Museum – his complete FOP skeleton. During this event, Sarah told Dr. Kaplan she wanted to donate her body to medical research when she passed away to increase awareness of the disabling effects of FOP to clinical professionals and laymen alike. Upon her return to the UK Sarah discussed at length the possibilities with Professor James Triffitt and activated the practical and legal necessities required for such a donation. Sarah wrote Dr. Kaplan, Jeannie and Val letters until she passed away. At that time, Professor Triffitt, from The University of Oxford and a long time friend of Sarah's, orchestrated a valiant effort to assure that Sarah's last wishes were fulfilled.



**Back of Sarah Cameron's
Skeleton - detail of skull and torso.
Acknowledgement: Images of Sarah
Cameron's skeleton demonstrating
fibrodysplasia ossificans progressiva
© Museums at the Royal College of
Surgeons.**

In 2002, a small portion of Sarah Cameron's skeleton was exhibited during a commemorative event and

international FOP medical and scientific conference organized by Professor James Triffitt of The University of Oxford at the Hunterian Museum at the Royal College of Surgeons in the United Kingdom. Dr. Kaplan attended the presentation of Sarah's final gift which continues to help FOP researches today. "The Sarah Cameron Fund" also continues to monetarily support the FOP research work being done at the University of Pennsylvania and at The University of Oxford.

Although both of Jeannie's first two international friends, Sarah and Val are now FOP angels, their lives continue to inspire us. Thank you for reading this small summary of our founding member Sarah Cameron's life.

Louis (Lou) Cantwell by Gretchen Emmerich

"I've always kept that letter. I know right where it is."

Yes, 25 years later, Jacqueline Cantwell, mother of Louis Cantwell remembers the day that Jeannie Peeper's pen pal letter arrived in their mailbox in Sidney Mines, Nova Scotia, Canada.

Louis was 23 years old the day that letter arrived in 1988. Jacqueline and Louis felt a special bond to this stranger who reached out to them, and have always been grateful to Jeannie for doing so.



Louis Cantwell - 1970
at the age of five

Louis was born on November 2nd in 1965. At birth he had the usual crooked toes that all FOP'ers have. It wasn't until he was five years old that he developed a bump on his head. Jacqueline drove the four hours over to Halifax, Nova Scotia, where a friend of hers, a Pathologist, accurately gave the diagnosis as FOP. Unfortunately the next four to five years were not quite so smooth. Jacqueline recalls traveling the difficult road of going from specialist to specialist. They travelled many

miles, far from their remote town in the upper part of Nova Scotia. Luckily, a local Orthopaedic doctor referred them to Johns Hopkins in Baltimore, Maryland, USA. At this medical facility in 1975, Louis was examined by Dr. Victor McKusick and Dr. Michael Zasloff. Louis was 10 years old at that time when his diagnosis was definitely confirmed. If it hadn't been for that meeting with the doctors, Jeannie would not have received information about Louis from Dr. Zasloff.

Louis is a middle child, born to Jacqueline and Louis Cantwell. He has an older brother, Fred who lives in the same town, and an older sister Alisa who lives nearby in Sydney, Nova Scotia. His younger sister Lynn lives in Hamilton, Ontario. Louis' father died of cancer, at the age of 56, the same year that Jeannie's letter arrived at the Cantwell home. It is fortunate that Louis' mom had a medical career as an operating room Registered Nurse for 35 years, for it served her well since she was his main caregiver up until last year. Presently, Louis has a team of aides that come and help him with his care.

Jacqueline wanted Louis to have as normal a childhood as possible and he was very active. Louis did just about everything, and was quite mobile and able to walk. As a young boy, Louis loved playing hockey. He was so happy to get his driver's license at the age 16! Louis loved driving his car and it wasn't until a rear end collision that his FOP flared to the point that he could no longer drive.

Today, Louis enjoys visits from his friends and listening to a range of music from Rock to Country. He also loves playing games on his computer.

Spencer Man By: Nancy Sando after Interviewing Michael Man

Spencer Man had an infectious smile. Adults were so taken by his tenacious spirit that they named their own children after him. Spencer, in his short life of fourteen years, left a legacy we can learn from that takes most people decades to accomplish.

Spencer was born in Oklahoma City, OK in 1976 into the Man family where he was raised with two older brothers, Chris and Derek Man. At birth, it was noted

that Spencer had malformed great toes but it didn't prepare the family to what was ahead. As is common in childhood, Spencer received immunizations in his early years, but this led to mysterious swellings or lesions, which then led to a diagnosis of FOP. His parents, Michael and Carol, travelled to visit Dr. Michael Zasloff at the National Institutes of Health, the predecessor to Dr. Fred Kaplan and the University of Pennsylvania research team to learn more about FOP. Dr. Zasloff introduced the Man family to the newly formed IFOPA. They readily jumped on board and became active members by attending events and organizing fundraisers. During this time, Spencer grew to admire and cherish his friendship with Dr. Fred (Kaplan). They spent many hours on the phone sharing stories, laughs and genuine affection.



Spencer Man

In spite of Spencer's physical limitations appearing at such an early age, he forged ahead enjoying life to its fullest. He excelled in almost anything he put his mind to. This included swimming and high diving (much to his dad's surprise!) and other sports that he found rewarding. Some of Spencer's pastimes included watching TV and movies, particularly the

Indiana Jones series starring Harrison Ford. There were many times the Mans would go on fishing trips where Spencer was driven to catch as many fish as possible... not necessarily the biggest but quantity prevailed! Spencer marveled at the super heroes of his time, the likes of Hulk Hogan – to name one. Relaxing for Spencer meant challenging his granddad to a friendly game of cards or singing a song that he liked. He had an incredible memory and only needed to hear the song lyrics once or twice before he knew it by heart.

Spencer passed away in 1991, at the age of fourteen, but his spirit and legacy lives on in everyone he met. A tribute to Spencer's quest in life was his belief that achieving success was possible in any situation. He made lifelong impressions on everyone he encountered and was able to overcome several obstacles with the support of his

family, the grace of his God and the enduring love that surrounded him.

The Spencer Man Foundation (1994-2012) was created in his memory to further FOP research and education. His family remains active in contributing time, resources and knowledge so that other families find hope and encouragement. Especially close to the Man's family heart are those that are new to the IFOPA and new to fundraising for FOP. The IFOPA is grateful to the Man family for their shared legacy of Spencer, their fundraising and general support of the IFOPA's vision, a cure for FOP. This is a testimony to the legacy that Spencer left behind.

Shay Williams **Interview by Gretchen Emmerich**

When did you join the IFOPA? January 1, 1988

How did you find out about the IFOPA? My mom, Susan Williams, told me about it.

What do you remember about the IFOPA when it started? When I was 14 we went to NIH and met Dr. Zasloff. So at that point I knew there were others with the condition. Five years later the IFOPA was formed. It was nice to know there was an organization out there supporting this very rare condition.

Please share your experiences since then . . . including any hobbies, pets, favorite foods, etc. Well since joining the IFOPA I graduated from UC Berkeley with a B.S. in Business Administration and graduated from California State East Bay with a Masters in Public Administration. I have been living on my own all that time. I have personal care attendants that help with daily tasks. I work for the Educational Testing Service scoring the California High School Exit Exam (CAHSEE), Early Assessment Program (EAP), and English Placement Test (EPT). The scoring is done all online. I watch a lot of sports on television and play video games. I have attended Cal football home games for 27 years. I went to a lot of concerts when I was younger. Now I seem to go to a lot of comedy shows.

Please share a bit of your childhood memories and any information about when you were diagnosed. I had heart surgery when I was three and half years old to fix what was called a coarctation of the aorta. They were going to wait until I was older but a doctor heard a heart murmur and decided it needed to be done sooner than later. After the surgery my back, shoulders, and neck froze shortly thereafter and I had bumps on my head that they thought were neurofibromatosis so they cut them off. Luckily they never grew back. Eventually they figured out because of my big toes that it was myositis ossificans progressiva which later became known as FOP. I was diagnosed in 1973. When I was young I did just about everything other kids did. Yes, I had limitations, but I still was able to ride bikes, run around, and play sports with my friends. I would fall down and get back up. As my FOP progressed more and more of my body was affected- but I would do things until I couldn't do them anymore. I am glad I got to experience being a kid that way I didn't feel like I missed out. Sure my mom was scared every time I went out to play but she realized that being a kid was an important part of life. The condition keeps progressing but I had a great childhood and experienced many things including climbing the steps of a waterfall in Yosemite.



Mackinzie Castillo, Susan Williams, and Shay Williams.

What is your hope for the IFOPA's future?

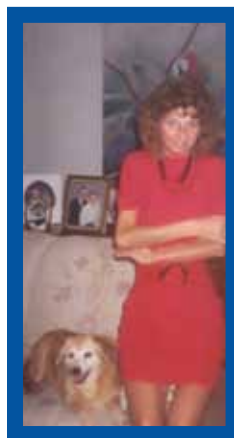
My hope for the IFOPA is that they continue to do research but also focus some on the people that are living with it (FOP) and the difficulties involved. Research is important because a cure would be great.

Part of the funding should be put towards helping people and families live with the everyday difficulties of FOP.

Where have you lived since becoming part of the IFOPA Family? I have lived in Berkeley since joining the IFOPA. I moved here for school and decided I liked the city because it is very accessible. I have lived in Berkeley ever since.

What do you want us to know about your family? My mom, Susan Williams, was a big part of my life and was involved in the IFOPA. She was a board member and helped many within the FOP community with her knowledge of all the things she learned advocating for me. She helped set up the LIFE committee. Unfortunately she died a few years ago. I have a girlfriend, Kish Castillo, who has a son, Mackinzie. I have helped raise him and Mackinzie is presently in college.

Jeannie Peeper by Gretchen Emmerich



**Jeannie Peeper
with her canine
friend Muffin in
1988**

Then and Now . . .

Remember 1988, the year the IFOPA was founded?

- Gas was 91 cents per gallon in the US
- Interest rates in the UK for the Bank of England stood at 12.88%
- The Hubble Space Telescope was just being put into operation
- Women imitated Princess Diana's hair style with the "feathered-look"

Somehow we managed life back then without our Smartphone, Facebook and Twitter. We read newspapers and watched the evening news. If you said the word "Google" in 1988 it would probably be interpreted as "google-eyed," an adjective meaning bulging eyes or wide-open eyes. And FOP? Not even on our radar screen. Back then, people would have thought

you meant the “Fraternal Order of Police”. Plus, the only place you’d find Jeannie Peeper’s name was in the local phone book from Winter Springs, Florida. That was the world we lived in the year that Jeannie Peeper founded the IFOPA.

Now, fast forward 25 years to 2013, the anniversary year of the IFOPA.

- Gasoline is \$3.44 per gallon in the US
- The UK interest rate is 3.4%
- Google Sky Map now brings the universe into the palm of our hands
- The “flat iron look” is the latest craze among women’s hair styles

Today, I’ll bet many of you are reading this article on your Smartphone, iPad or other electronic device. And “Google?” The website has become an institution and our highway to information. And what about “FOP?” If you Google FOP, you get 2,810,000 hits in 0.36 seconds. Google Jeannie Peeper’s name and you get 39,400 hits in 0.27 seconds! Jeannie has come a long way since her exclusive listing in the local Winter Springs phone book!

The Challenge

Jeannie Peeper has been quoted, photographed, tweeted and videotaped. Songs and poetry have been written about her. Jeannie is listed in Wikipedia. She can be found all over YouTube. And, not once, but twice, she has been featured in the exclusive magazine “The Atlantic Monthly”. As a mother of a son with FOP, I have had the pleasure of knowing Jeannie Peeper for 25 years. While Jeannie continues to successfully conquer challenges aplenty, my challenge is to share Jeannie’s epic tale from a unique vantage point.

It’s Never Been About Jeannie

Jeannie Peeper is so darn humble! She doesn’t like to be center stage, preferring to stay in the recesses where she meticulously attends to the needs of the organization that she founded.

“If it weren’t for Dr. Michael Zasloff and Dr. Fred Kaplan my life would be so different.” ~ Jeannie Peeper

I contacted Dr. Michael Zasloff and Dr. Fred Kaplan to gather their memories of Jeannie Peeper from 25 years ago. They both recall being astounded by her selflessness and simple desire to get to know someone else with this rare disease.

Pen Pals

Back in 1987, Dr. Michael Zasloff was working at the NIH when he met Jeannie. At that time he was caring for 18 individuals who had FOP. Dr. Zasloff recalls “I was more than happy to fulfill her request of having the names of other individuals with FOP.” Of course, this was prior to HIPAA rules of patient privacy. Dr. Zasloff continued, “I recall Jeannie’s joy in knowing that she was not the only one in the world with this disease. The pen pal group she began in 1988 eventually evolved into collaboration with the University of Pennsylvania to facilitate fundraising for research.” And he added, “When I first met Jeannie, it struck me as amazing that her own health and cure of FOP was not the impetus that propelled her in forming this organization.”

Jeannie knew she was not alone when she received 10 responses from Dr. Zasloff’s list of FOP patients. Friendships developed and the connection to other fop’ers in the world had begun.

Amazing Grace

Dr. Fred Kaplan first met a child with FOP in 1989. From that moment on he has dedicated his life work to the cure of FOP, and to the families who live with it. Dr. Kaplan recalled his first meeting with Jeannie and reminisced “Jeannie astounds me! She is the paragon of equanimity and grace. It is amazing that someone with FOP did not start this organization to find a cure for herself!”

And the beat goes on . . .

Since the beginning, Jeannie is a “connector” to families who are newly diagnosed. She has spoken to dozens of families over the years, most of whom can tell you verbatim what she said in that initial conversation. Jeannie’s motivation to simply connect with others who have FOP created a culture of care that was felt in every niche of our organization. Jeannie holds a Bachelor of

Arts Degree in Social Work which provided her with important tools that she used to launch the IFOPA.

Funny Fundraiser Story

How does an 11 member pen pal group transform into a foundation of research for FOP? Why, through BBQ fundraisers, of course! And golf tournaments, 5-K runs, country fairs, ice-fishing contests, opera events, horse-plowing competitions, banquets, bingo and much more.

Yes, grassroots fundraising are the backbone of our FOP research. While research happens in Petri dishes... fundraising happens while dishing beans, hitting golf balls, catching fish and running a race.

Jeannie recalls, "During a BBQ fundraiser hosted by the Snow family in Santa Maria, California (near Vandenberg Air Force Base), Dr. Fred Kaplan was standing on a stool, decked out in an apron and baseball cap serving baked beans. The volunteer next to him began to suggest a better way to scoop out the beans, to which Fred said 'It's not rocket science.' To Fred's surprise the volunteer replied, 'I AM a rocket scientist!'"



2006 Gene Discovery Photo: from left to right Jeannie Peeper, Stephanie Snow, Dr. Eileen Shore and Dr. Fred Kaplan at the podium

Shock and Awe

"Why should I fly to Philadelphia?" Jeannie inquired on the phone with Dr. Kaplan that spring morning of 2006. He replied, "Jeannie, I want you to be present when we publicly announce at the press conference that we have discovered the FOP gene, ACVR1." Tears filled Jeannie's

eyes and she was stunned. She told Dr. Kaplan, "This is the best gift I have received in my life. Of course I will come!"

The vision to find a cure for FOP catapulted from earth's orbit that day and has continued to gain exciting momentum ever since. In fact, the mission, to fund research to find a cure for Fibrodysplasia Ossificans Progressiva while supporting individuals and their families through education, public awareness and advocacy, is about a community coming together, working together for everyone's benefit - not just one. We are better together!

Sharing Hope

I asked Jeannie what message she would give to a young family whose two-year-old was just diagnosed with FOP. "Naturally, I would first share the hope that we hold as we embark on clinical trials in the near future. Secondly, I would desire to convey that their child will inspire them and show them great courage and determination." Jeannie paused while giving my question further thought, "Each child with FOP is a teacher. This special two-year-old will share lessons with his/her parents that are not found in textbooks. Their child will grow the parents into a deeper maturity that only comes through rich valleys of experience. Lastly, I would tell the family that they have an amazing, loving FOP family all around the world ready to help them with each step of their journey."

Glowing Push Pins

My next question to Jeannie was, "What is your message to the community who fundraises and advocates for a cure of FOP?" Jeannie began by sharing, "We would not be where we are today without these special individuals who fundraise and advocate. I am continually humbled by the hard work of our fundraisers and advocates of the IFOPA. I wish to give my heartfelt thanks to each and every one of you for your dedication!"

After this, our conversation morphed into laughter as our imaginations kicked in. Jeannie and I began picturing individuals all over the globe who, at that very moment, were doing something to support the cure of FOP. We naturally started with Dr. Fred Kaplan and Dr. Eileen Shore whose dedication to FOP research at

The Center for Research in FOP & Related Disorders at the University of Pennsylvania has been going on since 1992. Next we considered the dozens of individual research labs found around the globe who are also joining in the mission to find a cure of FOP. Further, we considered our staff, Denise, Victoria and Sue, who work more than full time for the IFOPA passionately fulfilling their important roles year round. Joining them we logically included the IFOPA Board and Committee members who tirelessly volunteer their time in pursuit of our mission. Jeannie and I continued by mentioning Betsy Bogard, the IFOPA's Global Research Development Director and the hard working team of the IFOPA Research Committee. We then moved on to the nearly 800 known FOP individuals and their families whose vested interest in seeing their loved ones cured spurs them to creative fundraising. Onward we marched, imagining friends of ours who carry the torch for FOP to their friends, workplaces, doctors and anyone who will listen. The morphing grew as we imagined the hundreds of posts and tweets on social media happening at that moment.

Whew!

We had to stop! We laughed out loud as we pictured a neon push pin for each individual who was fundraising or advocating for the IFOPA together. Our smiles widened as we pictured thousands of glowing push pins all around the globe - a bright glow of neon unity in the cure of FOP!

Now and Then . . .

My last question for Jeannie was, "What message do you have for the next generation as they begin to step into leadership roles in the IFOPA?"

She replied, "In 1988, I had no idea where the IFOPA would be in 25 years. What I did know was that the strength of an organization is evident in the dedication and hard work of each individual. Leading the IFOPA into the future will require a commitment and the desire to embrace the mission that we were founded on and to care for those in our community as we continue together toward our goal, a cure."

This will be an exciting new season! The next generation will need to take the organization forward in their unique way. Communication styles are vastly different today. The Internet has made us closer. Our physicians can look at FOP lesions over Skype. Donations can happen with the click of a cell phone button. We can share documents in the cloud and edit in real time.

The advent of upcoming clinical trials marks the new frontier of our organization. Yes, the road is untraveled, but it does not need to be lonely as:

- We have each other to walk with
- A common purpose to guide us
- And a history of stories to encourage us.



Jeannie Peeper and Dr. Fred Kaplan at the IFOPA's 25th Anniversary Celebration and FOP Family Gathering, November 2013

Jeannie Peeper is proof that one person truly can make a difference in this world. It has been a privilege to witness Jeannie as she follows her dream, see her make a difference in many lives and know this will continue to be her legacy.

IFOPA Revenue Sets Record in 2013!

Buoyed by the two largest single gifts in its 25-year history, the IFOPA notched a record-high \$1,478,676 in revenues during a memorable 2013 year. Outright contributions and revenue from special fundraising events generated 98 percent of the organization's revenue.

The year was punctuated with two remarkable gifts that propelled IFOPA revenues to new heights and added substantially to the organization's net asset position – allowing for strategic investments in new activities designed to accelerate treatments and eventual cure.

In October, the IFOPA received a \$320,000 grant from the Jesse David Hendley Foundation of Atlanta, GA, the largest single gift in history. The gift was made in memory of FOP member Craig Hendley, who passed away in 2004.

The IFOPA also received a \$250,000 contribution from an anonymous donor that was made in honor of FOP member Natalie McGuire of Midland, MI, daughter of Gary and Abbie McGuire. The gift was part of the McGuire's fundraising campaign that generated \$400,953 in 2013.

Increase in net assets for 2013 was \$640,783 which increased the IFOPA's net assets as of December 31, 2013 to an all-time high of \$2,546,134.



Mason & Connor hold a birthday party fundraiser in honor of Bobby Johnson

“Thank you to the many families and friends who are working side-by-side with us to produce the revenue so crucial to fund IFOPA priorities,” said Mark Gambaiana, Board Chair. “Each year

will begin our fundraising efforts anew and we are blessed to have so many families who willingly conduct

events year after year, and new families who emerge and contribute greatly to our overall success.”

Several other major events contributed to the strong bottom line. The ZipperQ2 was held in Claremore, OK, organized again by Amy and Jacob Gordon and held in honor of their son, Zip. The BBQ cook-off and jeep drawing produced nearly \$125,000 in revenue.

Two annual fundraisers, Lincoln's Legacy and Bingo for a Cure, generated \$116,187 and \$100,000 respectively. Lincoln's Legacy is in honor of Lincoln Wheelock and includes a series of special events. The Bingo for a Cure is held each year in Allentown, PA and drew over 1,100 attendees. The event is held in honor of Joshua Scoble.

Unveiled in the fall of 2012, “Sienna's Flower Garden” continued its popularity and received 616 gifts. The online fundraiser is conducted in honor of Sienna Otto, daughter of Eric and Rory Otto. Sienna's Flower Garden raised \$49,750 in 2013.

All events and gifts are important to the success of the IFOPA. In 2013, a total of 4,064 gifts were received from 2,852 individuals.

Throughout its 25-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 2013, a remarkable \$17,364,387 has been generated to support the IFOPA cause.

2013 Financial Statements/ Revenues and Expenses

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

In 2013, the IFOPA enjoyed one of its strongest years ever in terms of financial operations with revenues of \$1,478,676 and expenses of \$837,893, strengthening the organization's net asset position by \$640,783. This exceptional performance boosted the IFOPA's net assets to \$2,546,134 as of December 31, 2013.

Revenues increased by \$537,984 from the previous year. In 2013, 54 percent of income came from special events, and 44 percent from contributions. On the expense side, program services accounted for 80 percent of expenditures, including 58 percent for medical research, the highest priority of the IFOPA.

Revenue and Public Support

Contributions	\$653,988
Special Events, Net	\$803,779
Other	\$20,909

**Total Revenue and
Public Support \$1,478,676**

Expenses

Program Services:

Medical Research	\$484,802
Public Awareness	\$19,980
Education and Support	\$169,061
Total Program Services	\$673,843

Support Services

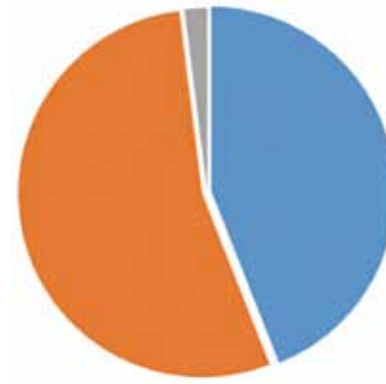
Management and General	\$99,099
Fundraising	\$64,951
Total Support Services	\$164,050

Total Expenses \$837,893

Change in Net Assets	\$640,783
Net Assets at Jan. 1, 2013	\$1,905,351
Net Assets at Dec. 31, 2013	\$2,546,134

Revenue

Revenue Sources 2013



Special Events	54%
Contributions	44%
Other	2%

Expenses

Functional Expenses 2013



Program Services	80%
Management and General	12%
Fundraising	8%

IFOPA Celebrates its 25th Anniversary in High Style!

To commemorate the wonderful growth, multiple achievements and progress toward a treatment and cure, the IFOPA celebrated its 25th anniversary with a family gathering from November 7-9, 2013 at the Gaylord Palms Resort and Conference Center in Kissimmee, FL.



Saturday night's celebration included dinner, gifts & dancing

More than 279 people enjoyed the three-day festivities, including 59 FOP members. Attendees represented a dozen international countries and six continents.

The 2013 year marked a special milestone in the history of the IFOPA – our 25th year of operation! Founded by Jeannie Peeper as a means to end the isolation of those afflicted with FOP, our organization began in 1988 as a pen pal group. Now, we are the world's leading advocate and resource on FOP whose programs and services are focused on research, education, support and advocacy.



Family friendly activities included a magician

An opening reception, series of family-oriented activities, research updates, clinical appointments, special presentations on dental and anesthesia workshops and a celebration banquet all highlighted the weekend. The banquet included remarks by Richard Simcox, one of the world's leading FOP philanthropists, Dr. Fred Kaplan, the world's leading FOP clinician, a special presentation by Saskia Blonk of The Netherlands to the FOP researchers, and a tribute to our founder and president, Jeannie Peeper.

The anniversary year was a time to reflect and say thank you to the many families and friends who have made investments of time and resources to advance our cause. Because of you, we have funded research and provided programmatic support to improve the lives of people around the globe who suffer from this condition.

Thank you to our scientists and researchers who are working daily to solve the mysteries of FOP and keep the march moving forward toward a treatment and a cure.



Left to right: Drs. Iwamoto, Friedman, Hsiao, Pignolo, Pacifici Shore, Zasloff, Kaplan and Hong. Front: Jeannie Peeper





Group Photo of members and doctors who attended the IFOPA 25th Anniversary Celebration & FOP Family Gathering November 9, 2014
Enclosed DVD includes more family portraits from our 25th Anniversary event.



The Wheelock Family: Trisha, Lincoln, Hudson, and Lee from Iowa.



Suzanne and Erin McCloskey from Washington with grandma Retha McCloskey

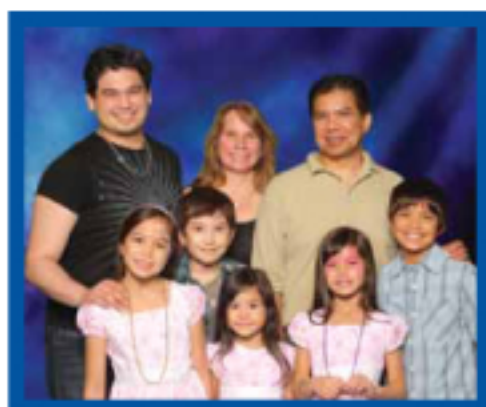


Martin Carlsson, Augusta Carlsson Josefsson, Annalena Josefsson, Kurt Carlsson Josefsson from Sweden



Fund Research, Find a Cure, Support Families

International Fibrodysplasia Ossificans Progressiva Association



Ryan Chong-Kee, Debbie and Joventino Dizon, Jessica, James, Jenna, Julie and Joseph Dizon from Canada



Connie Timmerman, Shane Terry, and Kim Hayes from New York



Kennedy Miller, Tamera Watts, Edward Braden, Mya Watts and Janashia Bedford from Georgia



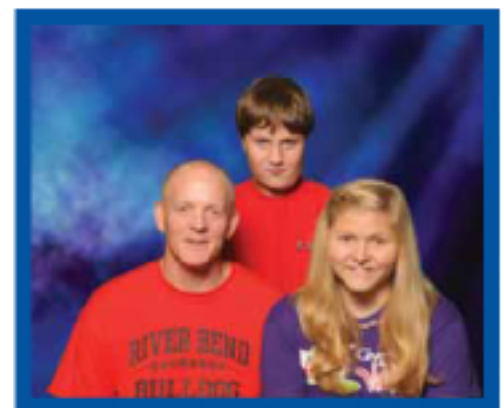
Note: The Dental and Anesthesia Workshops presented November 9th, 2013 during the IFOPA's 25th Anniversary Celebration and FOP Family Gathering are available for viewing on YouTube channel FOP News.



Charles and Tammara Darnell with
Amie and Matthew Specht from Texas



Edixon Rojas Gauncha and
Gloria Marina Gauncha from Venezuela



Scott, Lucas and Madison Whitmore from
Illinois

25th Anniversary Celebration and FOP Family Gathering

During the 25th Celebration everyone had an opportunity to write a message to the future and draw something for the IFOPA's time capsule. Members from around the globe also sent photos and other items.



A special memorial dedicated to our friends was created by Alice and Shane Flournoy, Sharon Smith and Kimberly Shields.



Shane, Alice and Jason Flournoy and Sharon Smith with the FOP Angel Memorial at the IFOPA's Family Gathering Room Friday, November 8th - Gaylord Palms, Orlando.



25th Anniversary signature poster holds hope filled messages.



Ellen Brodock helps Karen Munro find her family's gift bag containing a special 25th Anniversary Commemorative silver photo framed with her family's photograph.



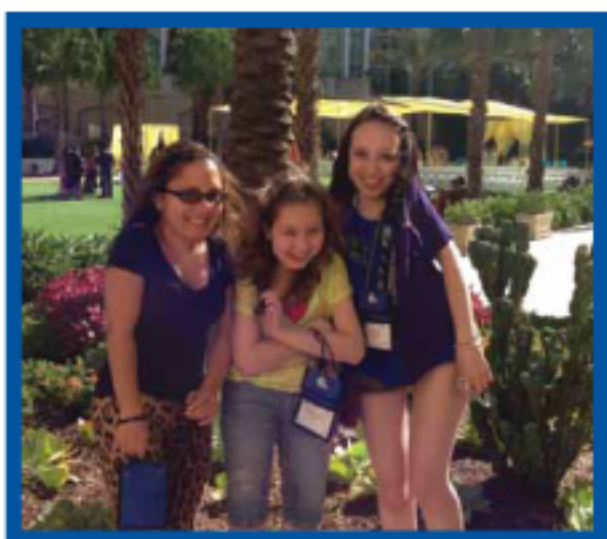
Kimberly Shields at the FOP Angel table.



Each star has the name of an FOP member we remember. The large angel was created in memory of Tiffany Linker.



Each family and individual received commemorative coloring books, crayons and an opportunity to win a prize after dinner. Left to right: Grace, Dr. Susan Law Pignolo, Nicholas, and Dr. Robert Pignolo



Lindsay Ruiz, Alexandra Rodriguez, and Jasmin Floyd enjoyed spending time together between activities at the Gaylord Palms Resort.



IFOPA Fundraising Poster Timeline paid tribute to 25 years of family fundraising events. Our posters spanned the entire wall of our convention center room!



Members from England, Florida and Iowa enjoyed dinner together. George & Isabel Scott, Margie & Donna McWilliams, Vinny & Paula Zamudio, and Nathan Thomas.



The Blonk family from the Netherlands brought the beautiful folded crane art with the hope of our community and the people of their country - A Cure for FOP. Left to right: standing - Saskia, sitting - Rianna, Yorick and Erling.



Drs. Shore and Kaplan with the folded crane gift the researchers received at the 25th Anniversary Celebration.



Annica Larsson, Katarina Mansson, Ann-Sofi & Eva Klint



Leckenby sisters: McKinsey and Whitney



Hazlett Family: Debbie, Timothy and Kevin

Thursday night families enjoyed face painting, henna art, clowns, balloon art, a photo booth and received beads. Families were also invited to participate in two studies to launch FOP drug development activities.



The McAlister family is from Oklahoma, USA. Back row from left to right: Chris and Billie, with grandmother Gail Henslick. Front row from left to right Ellaina, Kelsie, and Logan



Nancy Sando with special flowers her family sent for everyone to enjoy during the IFOPA 25th Anniversary Celebration and FOP Family Gathering.

Friday families enjoyed viewing 25 years of memories. On display were items from FOP organizations around the globe, scrap books, photos, newsletters and annual reports



Walter Fernandez, Andrea Silvia Gomez and daughter Nicole Candela Fernandez from Argentina write and draw messages for our time capsule.



Tamera Watts looking at IFOPA scrapbooks Jeannie Peeper created.

A Report on Drug Development Activities at the IFOPA 25th Anniversary Celebration

by Betsy Bogard



Betsy Bogard

This past November, the IFOPA hosted a 25th Anniversary Celebration in Orlando, Florida. It was an amazing event attended by approximately 279 people, including 59 individuals living with FOP, their families, and researchers.

Among the participants were representatives from two pharmaceutical companies,

Clementia Pharmaceuticals and Novartis Institutes for Biomedical Research (NIBR). Both companies were in attendance not only to get to know the FOP community better, but because they are each developing tools to help advance FOP drug development efforts.

Donna Grogan, MD, Chief Medical Officer at Clementia, and Ursula Schramm, PhD, Translational Medicine Expert at NIBR, gave presentations on their respective projects at the welcome reception.

Here is some information about each of those two projects.

Clementia Pharmaceuticals Inc. is developing a new tool to measure the impact of FOP on physical functioning. The tool will be called the FOP Physical Function Questionnaire (FOP-PFQ) and will be a custom-designed questionnaire to capture the unique and very challenging ways that FOP affects physical function and activities of daily living. These types of tools are used commonly to document the status of physical function and general well-being in many diseases. This knowledge is important for understanding the degree of limitations imposed by a disease, which makes it very useful in the drug development process.

Developing this tool requires input from individuals living with FOP. Clementia requested help from the IFOPA in obtaining this input, beginning with one-on-one interviews at the 25th Anniversary Celebration. Twenty adults participated in these interviews at the meeting and two others participated by phone afterwards. A second round of interviews is expected to begin in a different group of approximately ten adults beginning in March. The first round of interviews was designed to elicit concepts relevant to FOP physical functioning while the second round is intended to assess cognitive understanding of these concepts and refine the draft questionnaire. Each round is conducted in a different group of individuals. In the next few months a similar process will be used to develop a questionnaire for the pediatric population.

When the questionnaire is ready for both adults and pediatrics, Clementia will use it in clinical studies to support the evaluation of palovarotene as a potential therapy for FOP, and also to evaluate the natural history of FOP in a physician-directed, non-interventional longitudinal study. Clementia plans to make the final questionnaire available to the IFOPA and to publish the questionnaire for use in other FOP research.

Clementia's project is being conducted by a team of specialists from Evidera who have expertise in designing these types of patient-reported outcome measures.

Novartis Institutes for Biomedical Research is sponsoring a biomarkers study to evaluate whether certain changes in urine may be indicative of an FOP flare-up. Drs. Fred Kaplan and Robert Pignolo at the University of Pennsylvania are the investigators for the study. Approximately 25 patients have enrolled in the study, for which recruitment began at the 25th Anniversary Celebration. The study requires each participant to collect and ship urine samples on a regular basis for approximately three months for analysis by Novartis.

Once the three-month period of sample collection has been completed for all participants, Novartis will start analyzing urine samples. Together with Drs. Kaplan and Pignolo, the data will then be reviewed and analyzed

and key findings will be published. If any biomarkers are identified as predictors of an FOP flare-up, these will be published and will be useful for any future efforts to develop a therapy for FOP.

IFOPA 2013 Research Committee Report

**By Betsy Bogard
2013 Research Committee Chair**

Formed in 2012, the IFOPA's Research Committee has the overarching goals to gain insight into 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. Led by chair Betsy Bogard, other committee members in 2013 included Amanda Cali, Eric Otto and Jen Snow.

The Research Committee (RC) focused on several major areas of work in 2013: developing a patient registry, collaborating with Clementia Pharmaceuticals on their efforts to develop palovarotene, providing research guidance and leadership at the IFOPA 25th anniversary celebration, engaging the IFOPA's scientific and medical advisors at the University of Pennsylvania, establishing and expanding dialogue with other FOP researchers and potential drug developers, and hiring a research consultant.

Registry Development

The RC continued development of a patient registry under the NIH Office of Rare Diseases grant to establish the Global Rare Diseases Registry and Data Repository (GRDR). In 2013, the RC finalized the registry protocol and informed consent, developed the questionnaire that comprises the core data collection tool in the registry, developed the registry website, and obtained IRB approval for the project. The first two years of the NIH grant for the project expired in September, and although the NIH has expressed an intention to renew the grant, they have not yet done so and have not released the registry to go live. In the meantime, Clementia

Pharmaceuticals engaged the IFOPA in dialogue about registry development. In the absence of NIH project funding, without clarity on the NIH project direction, and given Clementia Pharmaceutical's presence and needs, the RC is exploring alternative vendors and data collection platforms for registry implementation.

Throughout the year, members of the RC presented registry development plans at international forums, including FOP Italia in March, the Canadian FOP meeting in May, and the IFOPA 25th anniversary celebration in November.

Collaboration with Clementia Pharmaceuticals

The RC provided support to Clementia Pharmaceuticals in their efforts to develop palovarotene as a therapeutic intervention for FOP. The RC facilitated development of a Clementia-sponsored patient reported outcomes (PRO) tool by reviewing and providing feedback on the study plans and helping Clementia implement patient interviews at the 25th anniversary celebration. The RC met with Clementia in-person in December 2013 to review and provide feedback on Clementia's clinical trial plans, a natural history protocol, and their interests in registry development.



Betsy Bogard (center) with Drs. Kaplan and Zasloff at the IFOPA 25th Anniversary event

Providing research guidance at IFOPA 25th Anniversary

The RC and IFOPA staff dedicated substantial time to guiding research

activities at the 25th anniversary celebration, including preparation and coordination of presentations by Clementia Pharmaceuticals and Novartis, assistance implementing the Clementia PRO project, assistance implementing the Novartis biomarkers study, and overall coordination of the research sessions at the meeting.

Engaging IFOPA Advisors at UPenn

The IFOPA maintained regular dialogue with our advisors at UPenn, including an in-person meeting in Philadelphia on April 19, planned teleconferences in September and December, and via phone and email as needed throughout the year.

Establishing and Expanding Dialogue with Other Entities

The RC engaged in dialogue with various academic and industry entities in 2013, including Novartis, the NIH TRND team, Charles Hong, Ed Hsiao, and Paul Yu, as well as individuals in attendance at NCATS R&D day on September 12, 2013, which included representatives from Genzyme and Alexion.

Hiring a research consultant

The rapid expansion of FOP research and drug development activities has placed a demand on the RC that exceeds volunteer capacity. The RC developed an RFP for research consultant, received board approval for the position in December, and identified a candidate, Betsy Bogard, who accepted the position and initiated consulting work on January 24, 2014.

Looking forward to 2014, the committee has identified several goals. They include:

- Make a go/no-go decision about implementation of the Patient Crossroads registry software;
- If decision is made to redirect registry efforts to a new technology (i.e., one that would be more suitable for later integration with physician-reported data), identify new vendor to develop the registry on a new platform (Q2 2014) and define budget, timeline, and plans for development & launch (Q3 2014);
- Establish a registry advisory board to guide long-term registry development needs (Q3 2014);
- Promote collaboration and information exchange in research and drug development by hosting a two-day research-oriented forum on FOP
- Engage the international community in dialogue about registry development and other RC initiatives by sending a delegate to international FOP meetings,

including FOP Italia (April 2014), FOP Action UK (May 2014), and other forums, to be confirmed;

- Expand and strengthen dialogue and collaboration with relevant industry and academic entities (ongoing/continuous);
- Develop a strategic research plan for the IFOPA

LIFE Awards

The Quality of LIFE (Living Independently with Full Equality) Award began in 2003 with one mother's inspiration to make a difference in FOP members' lives. Marilyn Hair, mother of Sarah Steele, experienced first-hand how having the right tools can make a profound difference to support the independence of FOP members.



Stephanie Snow received a Quality of LIFE Award toward the purchase of her service dog.

Over the past ten years, the IFOPA has provided 69 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, wheelchair ramps, scooters, protective helmet and educational tuition and books.

The LIFE Award is designed to assist members living

with FOP to live more independently by providing awards that will improve our members' health, welfare and independence. In 2013, a total of five awards were presented. Funding for LIFE awards in recent years has been provided by a \$5,000 annual grant from the Herman Goldman Foundation.

Mentoring Program

The purpose of the mentoring program is to enable new families and individuals with FOP to interact with volunteers who are suited to help them get acquainted with the IFOPA and its availability of resources and education. The program also benefits established members to encourage and assist them through their difficult times such as flare-ups, school issues and day-to-day care.

Several activities are highlighted in the 2013 year, including responses to multiple inquiries by members through social media. These issues included new diagnosis, flare-ups, adaptive equipment, housing, care or general health concerns. Other activities include extending birthday wishes for members, announcing the passing of FOP members on social media, and assisting with inquiries from high school or college students that have chosen to do class projects on FOP.

“The IFOPA office has continued to connect our members with this program. I greatly appreciate their help in making sure our members get contacted in a timely fashion so we may establish a relationship with them in their times of need,” said Nancy Sando, mentoring chair.

Jeannie Peeper Awards Presented in 2013

Jeannie Peeper International FOP Association Awards were established in 2010 to recognize those who make exceptional contributions to the worldwide FOP community through their leadership, service, fundraising and achievements. These awards honor Jeannie Peeper as Founder and President of the International FOP Association. The 2013 awards committee was composed of Karen Munro, Jeannie Peeper, Denise Vietti, Nancy Sando, Gretchen Emmerich and Steven Eichner. Once again, the selection process was challenging, given the number of candidates who have demonstrated exceptional service to the IFOPA. The following individuals were cited in 2013:

President's Lifetime Leadership Award



Diane Weiss

Diane Nassau Weiss is among the world's leading philanthropists to the FOP cause. After being introduced to Dr. Fred Kaplan many years ago, the two began a special relationship in which she has faithfully and significantly supported Dr. Kaplan's work to find a cure.

In 1997, Weiss established The Issac & Rose Nassau Professor of Orthopaedic Molecular Medicine at the University of Pennsylvania School of Medicine, the first endowed chair in the nation for orthopaedic molecular medicine. The gift was made in memory of Diane's parents and has enabled Dr. Kaplan to advance the pursuit of treatments and eventual cure.

As a result of this endowment, Dr. Kaplan has held consultations with virtually all known FOP diagnosed patients across the globe, has participated in multiple FOP conferences and symposiums and attended many family fundraisers to raise awareness and promote private support. Dr. Kaplan noted in a speech, “Diane created this endowment with a name and a purpose that continues to link the memory and the history of her own past to a brighter future for children whose lives desperately depend on it.”

It is impossible to overstate the value of this contribution to the FOP community.

In addition to her extremely important contribution to FOP research, Diane Weiss has also supported numerous special events, symposiums and family gatherings.

Outstanding Community Involvement Award – Individual



Lori Henrotay

Since becoming a member of the International FOP Association in 2001, Lori Henrotay has played an active and impactful role in the organization's growth. Her daughter, Carli Henrotay is an FOP member.

While serving on the Marketing Committee of the IFOPA, she helped to update an IFOPA brochure, the website, and letterhead. Lori also created the FOP Facts & Insight series video in which she interviewed scientists at the University of Pennsylvania and talked about various issues of importance to the FOP community. She was also twice the chair of the Jeannie Peeper Awards committee, and was an IFOPA board member from 2005 through 2008. Lori begins her second term as a board member in 2014.

Lori has also organized a number of fundraising events, including fashion shows, golf tournaments, and in April of 2012, a bocce ball tournament called "Striking out FOP."

Outstanding Community Involvement Award – Group

The Outstanding Community Involvement Award was presented to the Dennings Family (David, Jennifer, and sons Cody and Cam) of Seabrook, TX. The Dennings family has a long history of conducting major fundraising events and helping to raise FOP awareness.

For two years, the Dennings family conducted a fundraiser entitled "Unmasking the Mystery of FOP," an FOP dinner mystery event that attracted many families, friends, community members and other FOP families. Cody and Jennifer have also been featured in periodical articles which have raised awareness of FOP in their area of Texas.



The Dennings Family

Intermediate School raising FOP awareness and funds when he attended. Cam followed in his brother's footsteps and held the same event successfully on his own. Both brothers have had great success selling "Cure FOP" bracelets at these events and Cody has also used the bracelets to befriend some special athletes.

In recognition of their efforts, the city council of Seabrook, TX, decided to recognize April 22, 2013 as "Cody Dennings' Day" during International FOP Awareness week.

The spirit of raising FOP Awareness and funds has been passed from David and Jennifer to their sons. Cody established a "Jeans Day" at Seabrook

Emerging Leader Award



Vincent Whelan

medical doctor by graduating from the University of California-Irvine medical school.

Now as a resident physician in pediatric medicine at UCSF-Fresno, Dr. Whelan's career path was inspired

Vincent Whelan is the 2013 Emerging Leader Award recipient. Vincent made history in 2012 by becoming the first FOP member to become a

by two individuals long associated with FOP, Dr. Fred Kaplan and Dr. Joe Kitterman.

At the age of ten, Vincent had a life-changing experience when he met Dr. Kaplan. He was so amazed by Dr. Kaplan's compassion and dedication to helping people with FOP world-wide, Vincent decided to become a doctor. As soon as Vincent entered high school he started taking as many science courses as possible. During the graduation ceremony on June 2, 2012, Vincent had the honor of receiving his doctorate hood from his mentor Dr. Kitterman, who is also well known in the FOP community for his studies with neurologic problems common to persons with FOP.

Like his mentors, Dr. Whelan is also very interested in contributing to the dynamic field of FOP research, and as such brings a unique and valuable perspective to this important work. Dr. Vincent Whelan's current hope is to someday work with children affected by rare disorders.

Outstanding International Leadership Award



Richard Simcox

Richard Simcox is one of the world's leading philanthropists to FOP. A resident of Aberdeen, Scotland, Mr. Simcox is the founder and managing director of Roemex Chemicals, LTD, a firm that supplies completion and production chemicals to the oil and gas industries in the North Sea and worldwide.

Richard first learned about FOP when his wife, Gail, taught a child with the condition at a local preschool. Since then, he has been a major donor to the IFOPA and the research efforts at the Center for Research in FOP & Related Disorders (FOP Laboratory) at the University of Pennsylvania. Additionally, he provided major funding to FOP research at the University of Oxford, including two postdoctoral research positions. He currently is the

President of FOP ACTION, the United Kingdom's largest FOP advocacy and fundraising group, and provides funding so families can participate in the group's symposiums and gatherings.

Richard contributed time and effort to the filming of *The Human Mannequin*, a UK documentary featuring aspiring fashion designer Louise Wedderburn who has FOP.

Hendley Foundation Gifts Honor Son; Spark FOP Research Initiatives



Craig Hendley is pictured with his constant companions, Sammie and Pepper.

The IFOPA has received two recent distributions that total \$640,000 from the Jesse David Hendley Foundation of Atlanta, GA.

Each distribution of \$320,000 represents the largest single gift ever received in the 25-year history of the IFOPA and provides significant additional resources to invest in priorities designed to accelerate research for

a treatment and eventual cure.

The magnificent gifts are made in loving memory of FOP member Craig Hendley of Stone Mountain, GA, who passed away in 2004 at the age of 36. Craig enjoyed following the Atlanta Braves baseball team and loved his constant companions, poodles Sammie and Pepper. He enjoyed science fiction and fantasy, and collecting pocket knives, buttons and Star Trek pins. Craig loved to laugh, was a kind and caring person and had a positive attitude.

The Hendley Foundation was established after the passing of Craig's father, Jesse David Hendley in 2011. He started the firm JD Hendley and Associates, an

industrial sales and supply company based in the Atlanta, GA area. They are survived by Craig's mother, Jorie, and sister, Terri.

The Hendley family was among the early FOP pioneers and made visits to several medical institutions seeking care for Craig prior to the formation of the Center for FOP Research & Related Disorders at the University of Pennsylvania.

Funds from these wonderful grants will be used to undergird the IFOPA's long-standing financial support of the FOP Laboratory at the University of Pennsylvania and allow investment in the IFOPA's top two priorities for 2014 – the creation of an FOP Patient Registry and the hosting of an FOP Drug Development Forum.

International Presidents Council Activities in 2013



Moira Liljestrom

By Moira Liljestrom IPC Chair

The International President's Council (IPC) was established in 2007 with the objective of developing an international FOP community voice and to assist the IFOPA to better serve their international members. The IPC is a network of country representatives

from around the world whose mission is to create a communication system to exchange ideas, share activities across boundaries and to improve, facilitate and accelerate research to find a cure.

Given FOP's extreme rarity, the small number of patients, the lack of treatment, and the scarcity of information for the public and health professionals, an international approach is required to improve the life of people living with FOP and their families.

The following highlights were achieved in 2013:

Expansion of the IPC through the inclusion of new countries and representatives

One of the objectives of the committee is to expand the Council to add the representation from new countries and/or regions which may facilitate building a FOP community — one voice in pursuit of a treatment for FOP. Our criterion is to invite those people who have previously shown their initiative and ability to perform some of the activities required to be an IPC member. Regarding this item, in 2013, the committee included the following countries and IPC representatives:

- Russia, with Vladislav Grachev, who is the father of a child with FOP and developed a website regarding FOP. He is also doing a search of FOP patients and at this time has discovered more than 30 from Russia;
- The inclusion of a second IPC representative in some countries already incorporated, like Spain, Poland and South Africa. The incorporation of a second representative in Poland was in response to the IPC's representative request;
- In the UK, Julie Hopwood retired and Chris Bedford-Gay is now the IPC representative. In France, Beatrice Bertrand retired and Antoine Lagoutte is now the IPC representative.

Exploration of the existence of FOP groups in selected Asian countries

With future expansion of the IPC in mind, the committee made contact with IFOPA members localized in Asian countries like Bangladesh, Pakistan and Japan to explore the existence of any FOP association or group working together. The result of this search was that neither Pakistan nor Bangladesh has any FOP group according to those contacted. In Japan a FOP organization named J-FOP exists with about 30 FOP patients. The president is a mother named Natsue Tsuruta and with whom we were able to start a communication however, language is a barrier.

Search and make contact with health professionals reporting FOP cases

With the purpose of expanding the FOP community and including those FOP patients that may remain isolated, the committee tried to find them through those health professionals reporting FOP cases. The committee searched papers reporting FOP cases and contacted their authors. Some of them answered in a positive way and others did not respond. A total of nine countries reporting FOP cases whose authors were contacted during last November, and a new search revealed five more FOP cases reported in India. That information will be sent to the IPC representative in that country if he agrees in trying to establish a contact.

Submission of an abstract poster to the Eurordis congress

With the purpose of bringing more visibility of the international FOP community into the European rare diseases platform we submitted a poster abstract for the next Eurordis Congress that is held in Berlin in May. In case it is accepted, Roger Zum Felde our IPC representative from Germany will present it.

Translations

In 2013, the Family Guide Book was translated into Polish, French, Russian and Hindi. At present, the Hindi and Russian versions are under revision. In addition, the Chinese and Portuguese versions are still in progress.

FOP Italia 2013: Bringing Leaders in the FOP Community Together

As global efforts to treat and cure FOP advance, the IFOPA continues to both monitor developments and serve as an advocate for the FOP community. With this in mind, Betsy Bogard (IFOPA Board Member and Chair of the IFOPA Research Committee) and Moira Liljeström (IFOPA Board Member, President of Fundación FOP Argentina and President of the IFOPA International President's Council) attended the FOP Italia annual meeting in Parma, Italy on March 22-23.



FOP Italia 2013 was well attended

The meeting was extremely productive and was characterized by a strong spirit of collaboration and community. In addition to connecting the FOP community in Italy, FOP Italia brought together some of the most brilliant FOP minds in the world to share information about efforts to develop a treatment and a cure. We recognize and thank FOP Italia for their great success in this global effort.

Speakers at the meeting represented leading global academic institutions focused on finding a treatment and cure, including the University of Pennsylvania, the University of Oxford, Harvard University, Leiden University Medical Center, VU Medical Center (Amsterdam), the University of Berlin and the University of Genova.

While there were numerous highlights from the meeting, we want to share one development in particular: Dr. Maurizio Pacifici from the Children's Hospital of Philadelphia announced that Clementia Pharmaceuticals (Montreal) has licensed palovarotene from Roche Pharmaceuticals, culminating months of collaboration, including input from Dr. Fred Kaplan and Dr. Eileen Shore from the University of Pennsylvania. Clarissa Desjardins, Ph.D. and CEO of Clementia Pharmaceuticals, was in attendance at the meeting. Palovarotene is a nuclear retinoic acid receptor γ agonist, which are potent inhibitors of heterotopic ossification in mice. While much work remains to be done, this is an important step forward.

In addition, Betsy Bogard discussed the FOP registry that the IFOPA is developing in conjunction with the NIH Global Rare Diseases Patient Registry and Data Repository (GRDR). The goal of the GRDR is to establish a rare disease data repository by the patients, for the patients. The FOP registry will collect data from as many FOP members globally as possible, in order to

facilitate drug and therapeutics development. The FOP registry will help support clinical trial planning and enrollment, and other research activities. Put differently, establishing a robust patient registry is a critical item on the path to developing a treatment and cure for FOP.

Canadian FOP Network Hosts 2013 Conference

**By Carrie Connell
President CFOPN**

On May 31 - June 1, 2013 the Canadian FOP Network (CFOPN) hosted the 2nd Canadian National FOP Conference at Thames Valley Children's Centre in London, Ontario.

The conference started on Friday morning with early registration and patient education clinic appointments with Drs. Fred Kaplan, Bob Pignolo, Zvi Grunwald and Dr. Clive Friedman. While patient clinics were running, Dr. Eileen Shore attended and presented at a Skeletal Biology Symposium at the University of Western Ontario sharing her research with local researchers. Later that evening CFOPN hosted a "Meet & Greet" reception for the families at the Best Western Lamplighter Inn and Conference Centre which was the conference hotel for those needing accommodations.



Canadian National FOP Conference in London, Ontario

Saturday was the main event, with presentations by the doctors throughout the day. Kids enjoyed a variety of activities onsite, including face painting, tattoos, soft play, arts & crafts with volunteers while their parents attended the presentations. Everyone came together

for lunch which was followed by a very well received family panel discussion and the continuation of patient medical clinics.

Panel presenters Ian Brodie and Maren Wallace, young adults with FOP, Amanda Cali and Karen Munro, parents of a young child and young adult with FOP, shared their personal stories and hosted questions and discussion related to living successfully with FOP, their challenges, accomplishments and outlooks. Individuals with FOP and their families shared pictures, artwork, newspaper clips, etc. through "All About Me" displays boards they had prepared. The "All About Me" displays provided an opportunity for the families to learn more about each other, their likes, their pets, and what makes them proud.



Kathleen Degenhart,
Amanda Cali and Bri
Lachance

The conference finished off with a presentation about the global patient registry by Amanda Cali and a brief meeting with the doctors and Clarissa Desjardins Chief Executive Officer of Clementia Pharmaceuticals, who had attending the afternoon portion of the event to hear the parent panel. A conference dinner back at the Best Western Lamplighter Inn and

Conference Centre was the finale of the weekend allowing families to network with new and old friends and pose for group pictures.



Drs. Grunwald, Pignolo
and Kaplan at the
Canadian FOP Family
Meeting in London,
Ontario with Karen Munro
and Miranda Friz.

2013 Fundraising

- A Day of Fitness in Honor of Sienna Otto
- Bad to the Bone Cure FOP Henke's Delaware Marathon Relay Team in Honor of Justin Henke



Wendy, Jared, Justin, Jenna and Kevin Henke,

- Bingo for a Cure! In Honor of Joshua Scoble
- Boston Marathon in Honor of Ashley Kurpiel
- Cody's Jean Day in Honor of Cody Dennings
- Dinner for FOP in Honor of Erin McCloskey
- Focus on FOP in Honor of Cody Dennings
- Harry Bruno Salon Holiday Fundraiser in Honor of Maria Wray
- Ice Cream for a Cause in Honor of Maria Wray
- Lil Southern Belle Online Beauty Pageant in Honor of Patrick Doerr



Maya and Ashley wearing their crowns

- Lincoln's Legacy in Honor of Lincoln Wheelock
- Lincoln's Legacy Mud Run in Honor of Lincoln Wheelock
- March for a Cure for FOP in Honor of Nathan Thomas
- Mason & Connor's Birthday Party in Honor of Bobby Johnson

- Menchie's Fundraiser in Honor of Sienna Otto
- Natalie Campaign in Honor of Natalie McGuire
- Roll IRA Lifestyle and Retirement Dreams Expo in Honor of Justin Henke
- Sienna's Flower Garden in Honor of Sienna Otto
- The Morgan Fund Fundraiser in Honor of Morgan Lawler



Kristine and Morgan Lawler with fundraiser Rick Wood

- Victor Ice Fishing in Honor of Kyle McWilliams
- ZipperQ 2 in Honor of Zip Gordon

McGuire Family Fundraising Sets New Pace in 2013

Bolstered by the second-largest single gift in IFOPA history, a letter drive in honor of FOP member Natalie McGuire of Midland, MI, generated a remarkable \$400,953 for research during 2013.



Gary, Natalie and Abbie McGuire

An anonymous \$250,000 contribution in honor of Natalie paved the way for a fundraising effort that included a total of 166 gifts. Several other substantial gifts were received from family, friends and business associates.

Natalie is the daughter of Gary and Abbie McGuire and Gary is a member of the IFOPA Board of Directors.

Bingo for a Cure Attracts More than 1,100 Participants!

The sixth annual Bingo for a Cure event was held March 17, 2013 at the Allentown (PA) Fairgrounds Agri-Plex Hall.

More than 1,100 persons attended the event held in honor of seven-year old Joshua Scoble of Emmaus, PA, the son of Dave and Stacy Scoble. The event featured bingo, basket drawings, door prizes, a bake sale and a visit from Star Wars characters.



Lindsay Ruiz, Ashley Kurpiel, Joey Hollywood, Dr. Fred Kaplan, and Joshua Scoble at Bingo for a Cure.



People supporting Bingo for a Cure which benefits the IFOPA.

Joshua's aunt, Chrissy Flexer, organized this event and several others throughout the year. Joshua's FOP! Is a non-profit organization established in Joshua's honor, and the various events generated \$100,000 to benefit the IFOPA in 2013.

Lincoln's Legacy Raises 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 2013, activities included a Lincoln's Legacy event in Sioux City, IA, the annual "Run through the Mud to Cure FOP" at the Living History Farms off-road race in Des Moines, IA, and a letter drive.



A total of \$116,187 was raised over the course of 2013, the highest ever for Lincoln's Legacy.

Also included in those totals was a \$10,000 grant from the Jimmie Johnson Foundation Blue Bunny Helmet of Hope. The IFOPA was among ten charities selected from more than 3,000 applications to receive the grant from NASCAR driver Jimmie Johnson's Foundation. The application was written by Lincoln's aunt, Kristina Sligh.

A total of 637 gifts were received from various Lincoln's Legacy activities in 2013.



Robin Gambaiana with grandson Lincoln Wheelock holding the official Blue Bunny Helmet of Hope at the IFOPA 25th Anniversary Celebration

ZipperQ 2 a Huge Success!

For the second straight year, the Claremore, OK area came out in huge numbers to support the Jacob and Amy Gordon family in their efforts to raise funds for FOP research.



The ZipperQ 2 attracted more than 1,500 people to "The Nut House" on historic Route 66 outside Claremore for a BBQ Throwdown Competition, live music, silent and live auctions, BBQ tasting, games for the kids, and a drawing for a 2013 Red Jeep Wrangler.

Nearly \$125,000 was raised for the IFOPA during the event, plus several thousand dollars of donated items for the silent and live auction. Zip Gordon is the seven year old son of Jacob and Amy Gordon.



Leia Hassell receives the key from Zip and Amy Gordon in exchange for the winning ticket.

Sienna's Flower Garden Flourishes!

Fundraising efforts in honor of four-year old Sienna Otto are continuing and making a significant impact on the IFOPA.



Sienna Otto

In 2013, a total of \$90,501 was generated in honor of Sienna, including outright contributions, a letter drive and contributions to Sienna's Flower Garden. There were 616 gifts received for the Sienna's Flower Garden that launched in the fall of 2012, the flower garden has generated \$87,990 through 2013 in contributions toward FOP research.

Sienna is the daughter of Eric and Rory Otto of Rye, NY.

IFOPA Timeline

FOP Community & IFOPA's First 25 Years

The following pages briefly cover highlights from our 25 years of working together to find a cure for FOP.

A complete timeline containing more fundraising and research details is available on our website.

We are grateful for your grass root efforts that brings hope to our FOP community.

1988

- June 8, IFOPA incorporated as a 501(c)3 non-profit organization with 11 FOP members
- FOP Connection newsletter first published by Jeannie Peeper

1989

- IFOPA joined the National Organization of Rare Diseases (NORD)
- FOP Collaborative Research Project established at the University of Pennsylvania School of Medicine by Drs. Frederick Kaplan and Michael Zasloff

1990



- 1st Annual Jud Bogard Golf Tournament raises \$30,000 to fund the 1991 FOP Symposium

- 1st FOP Natural History Study conducted by Drs. Kaplan and Zasloff

1991

- 1st FOP Family Meeting held at Disney World with 8 FOP families
- 1st International FOP Symposium held at University of Pennsylvania with 28 physicians and scientists and 21 FOP families
- Dr. Eileen Shore joins the University of Pennsylvania FOP research group

1992

- IFOPA membership reaches 100
- FOP Molecular Biology Laboratory established at the University of Pennsylvania

1993

- FOP Family Meeting held in Nashville, Tennessee
- Natural History of Heterotopic Ossification in Patients with FOP, A Study of 44 Patients published by Drs. Kaplan and Zasloff

1994

- FOP Family Meeting at Disney World
- Dr. Kaplan awarded Johnson & Johnson Orthopaedics Research Grant for "Molecular Pathogenesis of Heterotopic Ossifications in FOP and in a Transgenic Animal Model"
- National Institutes of Health (NIH) Research Grant provides \$200,000 annually for 3 years for FOP research.
- 1st Annual Find-A-Cure Dinner & Auction, Santa Maria CA, by Snow Family, the longest running IFOPA fundraiser (16 years)

1995

- IFOPA contributes \$25,000 to the FOP Research Lab
- "What is FOP? A Guidebook for Families" and "What is FOP? Questions and Answers for the Children" published



- 2nd International FOP Symposium held in Philadelphia with 75 physicians and scientists and 42 FOP families
- John and Amanda Cali establish the Ian L Cali FOP Research Fund at the University of Pennsylvania

1996

- Milestones - Contributor newsletter first published
- IFOPA Annual Fund Drive established
- IFOPA contributes \$130,000 to the FOP Research Lab

1997

- FOP website created by Sharon Kantanie
- FOP Family Meeting at Disney World with 37 FOP families

1997 continued

- Instructions for collecting tissue samples distributed to FOP community
- IFOPA contributes \$300,000 to the FOP Research Lab
- IFOPA membership reaches 173
- Dr. Kaplan awarded the Isaac and Rose Nassau Professorship of Orthopaedic Molecular Medicine at the University of Pennsylvania School of Medicine, established by Diane Weiss in memory of her parents
- NIH Research Grant renewed for 4 years
- FOP Research Lab collaborates with scientists from University of California-Berkeley, Oxford University and Association Francaise Contre Les Myopathies.
- 1st FOP Family Meeting in Germany

1998

- Patient Emergency Cards produced and distributed to FOP community
- IFOPA hires first 2 staff members
- FOPA distributes and publishes FOP Flare-Up Survey
- A Few Hundred People Turned to Bone, by Thomas Maeder published by The Atlantic Monthly
- IFOPA Patient Needs Life Award Project begins

1999

- IFOPA Distinguished Research Associate Scientist Award given to FOP research scientist Meiqi Xu
- BBC's Horizon aired "Skeleton Key" documentary on the history of FOP research
- ABC's 20/20 aired feature story about FOP, "The Bone People"
- FOP-e.v. (Germany) holds their first meeting

2000



- 3rd International FOP Symposium held in Philadelphia, with 150 physicians and scientists, 84 FOP families, and 9 POH families

- "In Search of a Cure" 20 min FOP informational video

- Human Genome Project completed

2001

- IFOPA membership reaches 262
- IFOPA first rents office space
- Flu Survey conducted by FOP Research Lab & IFOPA
- IFOPA website adds content in Spanish, German, French and Portuguese
- FOP Treatment Guidelines published

2002

- Betty Anne Laue IFOPA Resource Center established
- Exceptional Parent Magazine Organizational Spotlight features IFOPA
- 1st FOP Family Meeting in United Kingdom
- Phase I Clinical Trial for safety & efficacy of Squalamine, sponsored by Magainin Pharmaceuticals. Protocol was complex and no patients enrolled
- Dr David Glaser joins the University of Pennsylvania FOP Research Group

2003

- FOP Family Gathering at Disney World
- US Bone & Joint Decade established, IFOPA represented
- IFOPA's Multigenerational FOP Families International Search to find the FOP gene funded by the Weldon Family
- Quality of LIFE Awards program established
- Traveling Resource Center established
- 1st Latin American FOP meeting in Brazil

2004

- IFOPA membership reaches 363 persons with FOP in 50 countries. Growth attributed to Internet

- IFOPA contributes \$600,000 to the FOP Lab
- South American FOP meeting, “Latin American Experience” hosted by Dr. Patricia Delai
- 1st Scandinavian FOP meeting held in Sweden
- FOP Mothers Retreats in Colorado and New Jersey, hosted by Amanda Cali and Hillary Weldon
- Whitney Weldon FOP Research Fund at University of Pennsylvania established by Bill and Hillary Weldon

2005

- Jeannie Peeper retires from daily responsibility at IFOPA. Planning the Future Board Meeting in Orlando. Linda Daugherty is named Executive Director, Amanda Cali named Chair of the Board
- IFOPA has 4 staff members
- IFOPA hosts “Friendraiser” on Capitol Hill, spreading FOP awareness to legislators
- South American FOP Symposium, San Paulo, Brazil
- Discovery Health Medical Incredible episode about FOP

2006

- IFOPA signs intellectual property agreement with University of Pennsylvania
- FOP gene mutation identified by the FOP Research Lab at University of Pennsylvania. A recurrent mutation in the BMP type I receptor ACVR1 causes inherited and sporadic FOP published in Nature Genetics
- Articles about the FOP gene discovery in The New York Times, Philadelphia Inquirer, LA Times, Daily Record-Scotland, Sydney Morning Herald and The Times-London. Television coverage on CNN’s Paula Zahn Now and ABC News Inside Edition
- Primetime Medical Mysteries segment about FOP, “When the Body Turns to Bone”

- A video about FOP is shown at a NY Giants football game at Meadowlands Sports Arena
- Dr. Kaplan is 1 of 15 winners of Newsweek Magazine’s Giving Back Award
- Finding Magic Mountain by Carol Whelan, the story of Vincent Whelan and FOP, is published

2007



- 4th International FOP Symposium, held in Orlando, with 80 FOP families from 23 countries including a group of clinicians, researchers and scientists.

- International Presidents’ Council (IPC) founded. 1st IPC meeting held at 4th International FOP Symposium
- FOP Patient Manual for Tools & Gadgets published
- FOP Research goals: Understand how FOP gene mutations change the function of the ACVR1 protein; Develop animal models with the FOP mutation; Test potential treatments
- FOP Italia established, sponsors 1st FOP Family Meeting

2008

- FOP Facts & Insights Video Series created by Lori Henrotay,
- National Geographic Investigates: Medical Mysteries published with a chapter about FOP.
- FOP Mothers Retreat in Colorado
- FOP Research Symposium held in Sweden

2009

- IFOPA Teen & Young Adult meeting, San Diego, CA, USA
- Canadian FOP Network sponsors 1st Canadian FOP Family Meeting

2009 continued

- Dr. Robert Pignolo joins the University of Pennsylvania FOP Research group
- Dr. Kaplan elected to the Institute of Medicine
- Both Canada and the Netherlands sponsor 1st FOP Family Meetings

2010

- Jeannie Peeper Awards established
- FOP Connection newsletter distributed by email
- IFOPA Wikipedia article online
- IFOPA distributes the Medical Binder system to all members
- Survey of neurological symptoms in FOP conducted by Dr. Joseph Kitterman
- Jeannie Peeper is awarded the Lifetime Leadership award from the Central Florida Chapter of Association of Fundraising Professionals

2011

- Scientific Workshop for a Cure: Strategies for the Treatment of FOP held in Philadelphia with 27 scientists from various institutions
- 2nd Latin American FOP meeting held in Argentina
- FOP Meeting in Italy, Rome
- Dutch FOP Symposium
- German FOP Meeting in Valbert Meinerzager

2012

- International President's Council increases to 17 members
- IFOPA has contributed a total \$8.4 million to support the Center for Research in FOP & Related Disorders at the University of Pennsylvania School of Medicine
- FOP accepted into NIH Rare Disease Registry

- IFOPA Research Committee created to assist research efforts worldwide
- IFOPA Italian Conference
- Netherlands FOP Symposium
- University of Pennsylvania FOP Natural History Survey conducted to understand the natural progression of FOP
- Neurological Symptoms in Individuals with FOP by Dr. Joseph Kitterman and others published in the Journal of Neurology
- Dr. Eileen Shore awarded the Cali & Weldon FOP Research Professorship at the department of orthopedic surgery at the University of Pennsylvania School of Medicine, established by John and Amanda Cali and Bill and Hillary Weldon in honor of their children Ian Cali and Whitney Weldon
- South Africa holds its first FOP Family Meeting

2013

- 25th anniversary of the IFOPA
- The Mystery of the Second Skeleton, by Carl Zimmer published by The Atlantic Monthly
- The Promise In Unraveling The Mysteries Of Rare Diseases, National Public Radio, Talk of the Nation hosted by Neal Conan
- FOP Research is international with 25 venues that study FOP. Primary work is located at the University of Pennsylvania Center for Research & Related Disorders in FOP.
- FOP Italia meeting brings leaders in the FOP community together
- Canadian FOP Network hosts 2013 conference
- IFOPA hosts 25th Anniversary Celebration & FOP Family Gathering where FOP Drug Development Tools were launched

2013 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, 2013 through December 31, 2013.

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\$25,000 and above

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 Cody's Jeans Day
 Jerome & Sherry Cohen
 Community Foundation of New Jersey
 Callie & Andrew Courtright
 David Craig & Gaile Moe
 Cross-Bo Construction
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 Marjorie Forshtay
 Mark J Freitas
 Gregory & Ana Freiwald
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