



2014

ANNUAL REPORT

ifopa



INTERNATIONAL FIBRODYSPLASIA OSSIFICANS PROGRESSIVA ASSOCIATION



INTERNATIONAL FIBRODYSPLASIA OSSIFICANS PROGRESSIVA ASSOCIATION

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.*

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2014

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The IFOPA Board of Directors held its annual in-person meeting in Orlando in February. Pictured front row, left to right: Nancy Sando, Brian Harwell; back row, left to right: Gail Weakland, Moira Liljesthrom, Mark Gambaiana, Chris Bedford-Gay, Lori Henrotay, Jennifer Snow, Marilyn Hair and Betsy Bogard, Global Research Development Director. Not pictured, Paul Brinkman, Gary McGuire, and Eric Otto.

What is Fibrodysplasia Ossificans Progressiva (FOP)?

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

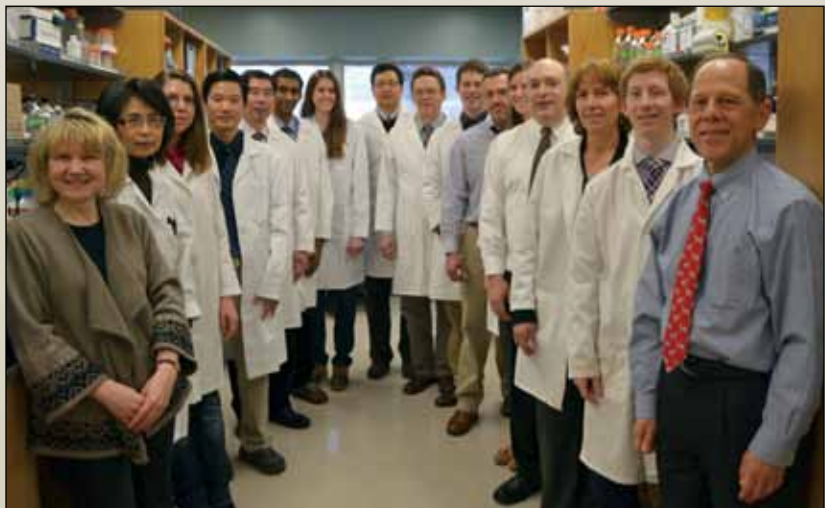
This immobilizing and catastrophic genetic condition strikes approximately one in 2 million people. It is estimated that 3,500 people worldwide have FOP, although there are only 800 confirmed cases and some 285 cases in the United States.

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.” The condition was officially modified to its current name in the 1970’s by Dr. Victor McKusick of Johns Hopkins University School of Medicine, to acknowledge that other soft (fibrous) tissues in addition to muscle are replaced by bone.

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

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



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.

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 on 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 Quest for Treatments and a Cure

The Center for Research in FOP & Related Disorders, 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 in Philadelphia.

Led by Frederick Kaplan, M.D., and Eileen Shore, Ph.D., the FOP Research Laboratory's dedicated research team includes four 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 April of 2006, after 15 years of painstaking work, the research team pinpointed a single gene mutation – one letter out of six billion in the human genome – that causes the runaway bone growth of FOP. This was a watershed event in the 300-plus year history of FOP. The discovery immediately opened the floodgates of research as the primary cause and ultimate target of the disease were instantly revealed.

There is no treatment available for FOP today, but research has led to several possibilities currently under investigation at multiple institutions.

Worldwide interest in FOP research has expanded since the gene discovery. New tools are being developed at a rapid pace, and new ideas forged daily as FOP research is now an international enterprise. At least 40 distinct venues work on components of FOP research, with the core activity centered at the University of Pennsylvania.

International laboratories, scientists, researchers, corporations, pharmaceutical companies, biotechnology firms and government agencies worldwide have expressed interest in FOP and are engaged in an effort to find better treatments and a cure.

Our Founder Jeannie Peeper



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

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

A native of Ypsilanti, Michigan, Jeannie's life began to change at an early age with the onset of FOP. Instead of allowing the condition to overwhelm her, she began a journey that allowed her to earn a college degree, and create an organization that has ended the isolation formerly associated with the disease and 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 FOP research program 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 five million dollars to the quest for treatments and a cure. A team of over 15 researchers led by Drs. Kaplan and Shore are working and progressing steadfastly to solve the mystery of FOP.

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

Jeannie is the symbol of the FOP cause, emblematic of the close-knit community that is unrivaled in its linkage of patients, doctors, scientists, researchers, families and the laboratory all united in the search for treatments and a cure. She has provided the passion and the dream to help the next generation of FOP patients.

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 to find 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 at the University of Pennsylvania School of Medicine. Nearly \$500,000 is restricted each year from IFOPA operations for research.

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

The Betty Ann Laue FOP Library is a central repository for FOP information that offers scientific and medical articles, medical binder kits, emergency cards, informational materials, videos, CD's, special interest articles and copies of medical publications for families and physicians dealing with FOP.

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 participate 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 members 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. An online member forum is a vital medium to connect members for discussion, support and research news, and periodic web-based E-Learning events spotlight issues that are of relevance to members.

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. Additionally, new members receive the comprehensive resource package which includes *What is FOP? A Guidebook for Families* as well as an ongoing mentor program for newly diagnosed members.

IFOPA's financial support comes exclusively from families, friends and others who join forces to meet the organization's annual operating budget. Nearly half of the one million dollars generated each year is directed toward research efforts at the 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.



A Message from the 2014 IFOPA Board Chair

2014 was another exceptional year for the IFOPA. Much effort has been invested to support growing research and pharmaceutical interest in finding treatments for FOP, and at the same time supporting FOP patients and families, and raising the funds needed to support our mission.

Thanks to the work of FOP researchers at the University of Pennsylvania and around the world, more and more is understood about the mechanisms that lead to bone formation in FOP. This new knowledge helps researchers identify drug targets to block the pathway, with the goal of preventing heterotopic FOP bone. Potential drugs are being identified and several are being tested in mice. One drug, palovarotene, is being tested in humans.

A major event of 2014 occurred July 14th when Clementia Pharmaceuticals launched a Phase II Clinical Trial to test whether palovarotene prevents the formation of heterotopic bone during an FOP flare-up. The first cohort of eight patients is complete, and the timing and dose of the drug has been evaluated. As I write in early 2015, the second cohort of sixteen patients is being enrolled.

Recruiting patients to participate in clinical trials is always a challenge, and particularly for FOP because there are relatively few people with FOP and we are spread across countries, languages, and far distances. The IFOPA is working thoughtfully with the International Presidents' Council, the leaders of FOP groups in 20 countries across the world, to strengthen national FOP organizations, coordinate translations, share information, and inform patients about present and future clinical trials.



The FOP Drug Development Forum took place in November in Boston. 128 researchers, pharmaceutical representatives, IFOPA leaders and representative FOP patients and families attended. The forum began with a presentation by an FOP patient and ended with a presentation by a parent. The program included 12-minute FOP research presentations and a patient panel. A major theme was the importance of collaborating to find effective treatments. A number of the researchers reported it was the best conference they ever attended.

FOP parent Chris Bedford-Gay from Manchester, England, summed up the FOP research atmosphere: "You feel like you can almost reach out and touch something coming, something that will be a game changer for everybody."

The FOP Patient Registry is on target to launch in the first half of 2015. This database of FOP patients and their health information will be owned by the IFOPA to share for research and drug development. We have every hope that the Registry will be a valuable resource the IFOPA can provide to researchers and pharmaceutical companies as they investigate treatments for FOP.

The IFOPA's work to support research has been greatly assisted by our consultant, Global Research Development Director Betsy Bogard. Betsy's family has been involved in the IFOPA since its inception in 1988; Betsy's brother, Jud Bogard, has FOP. Betsy's interest, energy and experience have contributed substantially to IFOPA research progress during 2014.

More information about FOP research can be found in the 24th Annual Report of the FOP Collaborative Research Project from the University of Pennsylvania Center for Research in FOP and Related Disorders, on the IFOPA website.

Whatever your role in the IFOPA: FOP patient, family member, supporter, donor, clinician, researcher, or interested friend, thank you for the part you play. Your dedication allows us to pursue our mission to find a cure for FOP while supporting individuals and their families through education, public awareness and advocacy.

With appreciation,

Marilyn Hair
Marilyn Hair, IFOPA Board Chair

Clementia Launches Historic Phase II Clinical Trial

Clementia Pharmaceuticals, Inc. announced in July the initiation of a Phase II clinical trial of palovarotene in FOP patients age 15 and above. The trial is the first study in Clementia's comprehensive drug development program that will support the potential use of palovarotene as a treatment of FOP.

"The FOP community has anticipated this day since the FOP gene discovery in 2006," said Jeannie Peeper, IFOPA Founder and President. "We celebrate this monumental occasion which will bring us one step closer to our dream of a treatment and cure for FOP."

Palovarotene, a RAR-gamma agonist previously tested for use in emphysema, has been shown to prevent heterotopic bone formation in mouse models of FOP. The trial has been designed to determine whether this compound will have the same effects in patients with FOP.

The double-blind, placebo-controlled trial is evaluating the safety and efficacy of different doses of palovarotene during and after an FOP flare-up. The study calls for up to 32 patients to enroll and treatment will be initiated within seven days from flare-up onset and continues for six weeks with an additional six weeks of follow-up. A number of clinical endpoints will evaluate the safety and efficacy of the drug, including imaging endpoints for new bone formation and clinical assessments of physical function and patient-reported outcomes.

"Ever since we first identified the mutation responsible for FOP, work has expanded throughout the world to find molecules that could block this target and one day lead to clinical trials," said the trial principal investigator, Frederick Kaplan, M.D., at the University of Pennsylvania. Three clinical trial sites have been established, including one at the University of Pennsylvania School of Medicine led by principal investigators Drs. Frederick Kaplan and Robert Pignolo, one at the University of California at San Francisco led by principal investigator Dr. Edward Hsiao and one at the Hopital Necker Enfants Malades in Paris, France, led by Dr. Genevieve Baujet.

"We were privileged to announce the initiation of our first clinical trial in FOP. We could have not arrived at this point without the support and collaboration of countless members of the FOP community including scientists, physicians, and most importantly patients and their families, who inspire our work every day," stated Clarissa Desjardins, Ph.D., Chief Executive Officer of Clementia. "We are committed to doing everything we can to support the clinical development of palovarotene in FOP. As such, we will continue to invest our resources toward the ultimate goal of providing a potential new treatment to people living with FOP."

In addition to the interventional trials, Clementia has also initiated a three-year Natural History Study of FOP. Annual assessments will be performed in 50 patients between the ages of two and 65. "The global FOP community is eager to gain new prospective data and insight that may lead to the improved understanding and treatment of this extremely rare, debilitating and difficult-to-study disease," said Betsy Bogard, Global Research Development Director for the IFOPA. Data from this study will be provided to the IFOPA for use in the global FOP Registry.

"This is an incredibly important time for our community, an era of clinical trials," said Marilyn Hair, IFOPA Chairperson. "It is an era in which the active voice and presence of the patient community is as important as ever. It is also an era of substantial hurdles and continued uncertainty. The IFOPA will work with Clementia and any other interested biopharmaceutical company to overcome those hurdles and realize our vision of a safe, transformative therapy for FOP."

IFOPA Moves Forward on Global FOP Registry

The IFOPA continues to make substantial progress on one of its key objectives – the formation of a global FOP registry. In 2014, a partnership was formed with Digital Infuzion, a healthcare technology firm, to build the registry.

The global effort will be entitled “The FOP Connection Registry” and is being designed to help organize the community for clinical studies, empower patients and the patient community, and improve the collective understanding of FOP and its treatment.

“We believe this registry will provide valuable insights into the prevalence, diagnosis, symptoms, impact and treatment of FOP.”

– BETSY BOGARD

“Registries play a critical role in the development of therapies for rare disease,” said Betsy Bogard, Global Research Development Director for the IFOPA. “One of the greatest challenges in rare diseases is limited patient and disease data. Building a global registry helps us overcome that challenge and take an important step toward therapeutic development. Over time, with the participation of the entire FOP community, we believe this registry will provide valuable insights into the prevalence, diagnosis, symptoms, impact and treatment of FOP.”

In simple terms, the FOP Connection Registry is a research study that will collect and report selected medical information on individuals living with FOP. The registry will have two portals – a patient portal planned for launch in early 2015, and a medical portal to be designed in 2015. The IFOPA is prepared to launch the first phase of the FOP Connection Registry, the patient portal, in 2015. A second phase, a medical portal for FOP physicians, is also planned for development.

The Registry’s patient portal is comprised of a series of surveys provided to Registry participants in six-month intervals that will focus on several categories of key information, including:

- The individual’s path to their FOP diagnosis, understanding the beginning of FOP symptoms and the challenges of receiving a correct diagnosis;
- Extra bone growth and episodic symptoms of flare-ups;
- Possible FOP symptoms in other parts of the body such as the stomach, lungs, heart, etc.;
- Quality of life, including physical functioning, pain and the psychological and emotion impact of FOP on individuals and their families;
- Medical care such as the use of health care services, caregivers and other aides and devices.

The Registry is intended to meet the needs of all stakeholders in the drug development process: patients, doctors and researchers. The IFOPA believes that a unified, global and coordinated approach to a registry will allow for the most comprehensive data on the disease, ultimately enabling better and faster development of therapies.

"The international FOP community is small but mighty and speaks with one voice in one language understandable to all: we want a cure and we need one international FOP patient registry, owned and operated by FOP patients, to help make that happen. It's one critical goal we can accomplish together and one critical way we can change our world," said Fred Kaplan, MD, University of Pennsylvania.

The registry will be available online at a dedicated website and accessible to FOP patients and once the medical portal is available, their doctors. Individual identifying information will be kept private, but summary data will be available to the community and researchers. The patient portal will be developed and tested in English first, and with the support of the International President's Council, translated into other languages.

In addition to our technology partners at Digital Infuzion, the IFOPA is pleased to be working with a registry expert, Neal Mantick, on the development of the FOP Connection Registry. Mantick brings over 20 years of registry experience and has particular expertise in rare diseases. "Rare disease registries are particularly exciting studies in which to participate," said Mantick. "Over time, the FOP Connection Registry may not only provide answers to the current medical questions that will improve the collective understanding of FOP, but it may also uncover new, previously unknown disease trends that may aid researchers in finding innovative treatments. Together, we can make a difference."

The IFOPA is convening medical and patient advisory groups to help oversee the registry and provide expert guidance. An inaugural meeting of medical advisors to the registry was held at the Drug Development Forum in Boston.



Pioneering FOP Drug Development Forum Held in 2014!

More than a year's worth of planning and preparation culminated in November as the IFOPA hosted the first-ever FOP Drug Development Forum in Boston. The forum was an innovative event that brought together researchers from universities and biopharmaceutical companies from around the world to discuss the important questions and challenges of developing an effective treatment for FOP.

"One of the top priorities of a patient organization is to bring people together," said Betsy Bogard, Global Research Development Director at the IFOPA. "The FOP Drug Development Forum convened some of the best and brightest minds under one roof to share the latest thinking about FOP therapeutic development."

It is an exciting, dynamic time in the FOP community. Incredible progress is being achieved in many directions that could lead to a treatment for FOP, ranging from Clementia's development of palovarotene, to Novartis' biomarkers study, to the many ideas and possibilities for potential therapies being evaluated in laboratories and biopharmaceutical companies around the world.



The two-day meeting was designed to support the IFOPA's vision for a safe and transformative therapy. The goals of the meeting were to address questions and knowledge gaps that exist in FOP drug development; stimulate new ideas to help advance development of potential therapies as quickly and efficiently as possible; and facilitate dialogue, foster collaboration, and form connections among interested researchers.

The patient voice is critical in the drug development process and was a key component of the meeting, with a select number of patient representatives playing an active role in the event.

"The Forum was a long-awaited dream of many community members where industry and academia came together in the spirit of collaboration, focused on identifying gaps in knowledge and forging relationships that will secure future treatments for FOP," said Amanda Cali, IFOPA Research Committee Co-Chair and Forum Coordinator.

A total of 128 individuals attended the meeting from 16 different countries around the world. The composition of the group included:

- Twelve FOP clinicians from 11 countries;
- Thirty-seven university representatives from 22 institutions worldwide;
- Thirty-five representatives from nine biopharmaceutical companies and three investment firms;
- Five participants who currently or previously worked in the US or European governments;
- Five individuals living with FOP;
- Nine IFOPA Board and Research Committee members;
- Four International President's Council members;
- Twenty-one family members, volunteers, professionals or guests

The meeting agenda covered four general topics in FOP drug development – clinical trial design and biomarkers for FOP; natural history of FOP; tools and models for FOP drug screening and development; and therapeutic approaches to FOP. In addition, presentations were made by speakers with experience on subjects of government approval and commercialization of therapies.

Two patient representatives, Ian Cali and Rory Otto, gave the opening and closing presentations of the Forum respectively. A one hour patient panel, facilitated by Julie Collins, IPC representative from Australia, was also held. All five patient representatives provided powerful perspective to the research community.

The IFOPA wanted to ensure that practical outcomes from this amazing gathering were obtained. Participants divided into focus groups to address the following questions and compiled the respective answers:

Question: What gaps in knowledge or data do we need to address to enable development of a safe and transformative therapy:

- Identification of biomarkers
- Better understanding the variable phenotype of FOP
- Advancing the understanding of FOP history
- Better understanding the systemic nature of FOP pathology

Question: What is the one thing that the community can do collaboratively to enable FOP therapeutic development?

- Share animal models, patient samples, reagents and data
- Encourage trial participation
- Hold the Forum annually
- Develop the Registry
- Fund collaborative grants with an open process

Betsy Bogard, Amanda Cali and Lori Henrotay led preparations for the Forum, with direction and approval from the IFOPA Board of Directors. Special thanks is extended to Drs. Kaplan, Shore and Pigrolo from the FOP Research Lab.



Feedback from Participants



"The Drug Development Forum was an exceptional milestone in the amazing history of the FOP community...it was an absolutely magnificent, first class event. I was proud to be there. You should all be very proud of what you accomplished."

— FREDERICK KAPLAN, MD, University of Pennsylvania

"I would like to extend my sincerest thanks for what you put together for the FOP community. I attend and participate in many conferences, big and small, and the 2014 FOP Forum was one of the best that I have ever attended. No words can match what I'd really like to say – the Forum you put together was simply exceptional."

— ARIS ECONOMIDES, Ph.D. Regeneron Pharmaceuticals



"The symposium was one of the best I've ever attended in every possible way: everything was so smooth; the wonderful mix of people, right from the patients, families, regulatory, clinicians, academicians, and industry... brilliant job! I'm back in the lab, continuing FOP research with a stronger drive, motivation and inspiration."

— DAVAVEENA DEY, Ph.D., Brigham and Women's Hospital

"Everyone present was moved by the need to urgently find a therapeutic agent that will at least ameliorate the symptoms of FOP that result in progressive immobility. We all return to our laboratories inspired to focus our efforts and work even harder to achieve this goal."

— JAMES TRIFFIT, Ph.D., University of Oxford

International FOP Association Appoints Global Research Development Director

New position underscores longstanding commitment to finding treatments for Fibrodysplasia Ossificans Progressiva

The International FOP Association (IFOPA) announced in January, 2014 that it has appointed Betsy Bogard as the IFOPA's Global Research Development Director.

Ms. Bogard has nearly 20 years of experience in managing drug development activities. She will lead the IFOPA's engagement with academic researchers and the pharmaceutical industry as the IFOPA works to foster drug development to treat Fibrodysplasia Ossificans Progressiva (FOP), an extremely rare and severely disabling genetic condition for which there is currently no effective treatment.



Worldwide interest in FOP research has expanded since the identification of the gene that causes the disorder in 2006. Currently more than 25 groups around the world are actively involved in research into the causes and potential therapies for FOP. Much of the progress to date has been supported by or conducted in consultation with the IFOPA. The IFOPA has a longstanding relationship with the Center for Research in FOP and Related Disorders at the University of Pennsylvania School of Medicine, the pioneering group in FOP research.

"Research and drug development in FOP is rapidly evolving, making this an exciting and demanding time for the IFOPA. We welcome the experience in biotechnology and rare disease drug development that Ms. Bogard brings to the IFOPA. She will be indispensable in helping us effectively partner with research groups who share our commitment to developing therapeutic approaches to FOP," said Marilyn Hair, Chair of the IFOPA Board of Directors.

"With their 25-year history of leadership in the FOP community, the IFOPA is in a unique position to promote collaboration and catalyze progress in FOP drug development," said Ms. Bogard. "I look forward to working with the community towards our collective vision for a safe and transformative therapy for FOP."

Ms. Bogard comes to the IFOPA from her position as Director, Program Management for Genzyme, a Sanofi company, where she led early-stage orphan disease drug development activities. She also brings experience developing and managing disease registries, including three years managing the International Collaborative Gaucher Group's Gaucher Registry, one of the largest and oldest registries for a rare disease. Ms. Bogard received her M.S. in Health Policy and Management from the Harvard School of Public Health.

The Bogard family has a long and deep connection to the IFOPA. Ms. Bogard's brother, Jud Bogard, has FOP and the family conducted the organization's first fundraiser in 1991. Ms. Bogard was a board member of the IFOPA from 2012-2013.

2014 Jeannie Peeper IFOPA Award Winners Announced

By Karen Munro, Jeannie Peeper, Denise Vietti, Gretchen Emmerich,
Nancy Sando and Steven Eichner

We are greatly honored and excited to announce the 2014 winners of the Jeannie Peeper Awards! Five award winners were selected by the Jeannie Peeper Awards Committee and then approved by the IFOPA Board of Directors. The committee, comprised of Karen Munro, Jeannie Peeper, Denise Vietti, Gretchen Emmerich, Nancy Sando and Steven Eichner, considered a number of nominees with wide-ranging and impressive accomplishments. As always, it was difficult to make the final decision, but the five award winners are truly outstanding in their commitment to the FOP community. The following are the award winners for 2014:

PRESIDENT'S LIFETIME ACHIEVEMENT AWARD

Sharon Kantanie



Jeannie Peeper notes, "I have chosen Sharon Kantanie for this year's award. Sharon has been a member of the IFOPA since 1990 and a pioneer who has spearheaded many projects, especially in the formative years of the organization." Sharon served as a member on the IFOPA Board of Directors from 1991 through 2000 in which she held executive committee leadership positions including Treasurer and Vice President. She was instrumental in editing the FOP Connection newsletter; producing a number of IFOPA brochures; hosting, along with her family, an FOP family meeting in Nashville, TN; establishing the first FOP Resource Center Library; co-organizing the 1995 FOP symposium; implementing the "Flat Stanley" project at the 2000 FOP symposium; helping design the first IFOPA website; and initiating and moderating the FOP online private e-mail chat group. In addition to the above, Sharon committed many hours to editing and writing multiple editions of "What is FOP? Fibrodysplasia Ossificans Progressiva: A Guidebook for Families." Sharon continues to promote FOP awareness – she was recently featured in an article about FOP research carried out by Vanderbilt University's Dr. Charles Hong. Sharon's contributions to the FOP community truly are extensive and exceptionally valuable.

OUTSTANDING COMMUNITY INVOLVEMENT AWARD

Individual – Gary Whyte



Gary Whyte is an individual who, though he has no family members with FOP, has made it his mission to promote awareness of FOP and raise funds for research. Gary is perhaps best known for performing in his very successful annual comedy show fundraiser and in 2014 he hosted the 13th Annual Comedy Show. Over the years he has generously raised funds for FOP research. Gary's commitment to finding a cure for FOP has not stopped there; he has tirelessly devoted many hours to raising awareness, including making presentations about FOP to numerous clubs and organizations, even to mayors, congressmen, senators, state assembly members and others. Recently, we learned Gary has successfully convinced 390 mayors of towns and cities out of the 566 in New Jersey, to issue proclamations to raise awareness of FOP. This was a family affair for Gary, involving his three sons in helping with presentations and other events. Gary is an extraordinary friend to the FOP community and dedicated supporter of our IFOPA mission.

Group – Hayden's Hope



Hayden's Hope was inspired by its namesake, Hayden Pheif, an adorable young boy who is now an amazing teen with FOP. Hayden's Hope was started by Hayden's mother and father, who led fundraising efforts in Northern California with the help of many relatives and friends. Year after year, Hayden's Hope provided significant revenue, which is now close to one million dollars in total donations. These donations propelled the IFOPA mission forward. All their efforts have helped bring FOP awareness to the forefront and these funds have significantly advanced FOP research. Today, Hayden's Hope continues its efforts on-line with a website and blog, while still raising awareness and funds for research and other IFOPA programs.

EMERGING LEADER AWARD

Ian Cali



Ian Cali is an adult with FOP. Over the past twenty years, he has taken part in numerous fundraising campaigns for the IFOPA and for the Ian Cali FOP Research Fund at the University of Pennsylvania (UPenn). Ian was a participant in the announcement of the FOP discovery in 2006, and for a number of years he put on presentations about FOP at UPenn for second-year medical students. In his teen years, Ian and Newark Academy started fundraising for FOP research together. Celebrating their tenth year, fundraising efforts at Newark Academy have continued even though Ian has since graduated. As a young adult he even participated in Capitol Hill Days to raise FOP Awareness among the United States political leaders. Ian has also been a guest speaker about FOP at scientific workshops and conferences, and has been featured in film documentaries about FOP that give insight into living with a rare disease. Ian organized "Fist Pump To Beat FOP," a fundraising concert series at the University of Delaware and in Philadelphia. These experiences led him to develop Contagious Atmosphere LLC, a company which supports building FOP awareness and funding research.

OUTSTANDING INTERNATIONAL LEADERSHIP AWARD

Enrico Cristoforetti



Enrico Cristoforetti lives in Italy, and is the founder and president of FOP Italia. He established FOP Italia in 2006 after his young daughter was diagnosed with FOP. Over the years, FOP Italia has organized and held annual conferences which have been attended by respected FOP researchers and many individuals with FOP and their families. Attendees have traveled from many countries outside of Italy including Holland, Austria, Russia, South Africa, Australia, Sweden, the UK, France and Argentina. With the driving force of Enrico's leadership efforts behind it, the Italian FOP organization has been active in raising funds for FOP research, and successfully obtaining tax funds available for non-governmental organizations in Italy. Incredibly, FOP Italia has even established and presently fund a small FOP research group at Genova, Italy. Enrico's extraordinary leadership skills bring together a global effort for FOP awareness and funding for research to find a treatment and cure for FOP.

The Jeannie Peeper Awards committee thanks each and every one of this year's award recipients for their continued loyalty to help the FOP community. We appreciate your passion and dedication to assist the IFOPA in its mission to fund research to find a cure for FOP while supporting individuals and their families through education, public awareness and advocacy.

2014 in Review

INTERNATIONAL PRESIDENT'S COUNCIL AND TRANSLATION COMMITTEE

The International President's Council (IPC) and Translation Committee is a network of country representatives from across the globe with a multi-dimensional mission. This mission includes the creation of a communication system to exchange ideas, share activities from an international approach and across boundaries, improve, facilitate and accelerate the shared objectives to fund research to find a cure for FOP.

Since its founding in 2007, the IPC has grown to include 18 representatives based in 15 countries and ten FOP organizations that encompass more than 500 FOP patients.

In 2014, the committee's work focused on several key areas and provided support to the IFOPA's primary activities – the Patient Registry, the Drug Development Forum and the launch of a Phase II clinical trial by the Montreal-based biopharmaceutical firm Clementia. Various activities included:

- Communication and translation of the clinical trial announcement to IPC members;
- Participation at the Registry Scientific Board during the Drug Development Forum;
- Redesign of the IFOPA website featuring a multi-language support;
- Holding a meeting at the FOP Italia in Genoa, Italy;
- Providing support to a new Switzerland FOP family to organize an FOP association in that country.

LIFE AWARDS

The Quality of LIFE (Living Independently with Full Equality) Award was established 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 profound differences to support the independence of FOP members.

Over the past 11 years, the IFOPA has provided 74 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 member's health, welfare and independence. In 2014, 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

Led by long-time FOP member and IFOPA Board of Directors member Nancy Sando, the mentoring committee provides support and counsel to families and individuals who are new to the FOP community.

In her role, Nancy contacts families to acquaint them with the IFOPA and its availability of resources and education. She also reaches out to established members of the community for encouragement as they experience the ups and downs of coping with the condition.

IFOPA INVESTMENT PORTFOLIO

At its 2013 fall board meeting, the IFOPA Board of Directors approved a new investment policy that took effect during the 2014 year. Under the direction of board member Gary McGuire, the chief investment officer at Dow Chemical and father of FOP member Natalie McGuire, the IFOPA reserves are now being strategically invested.

The portfolio is divided into two components – the liquidity portfolio using very short-term liquid investments with little or no risk and used to meet current expenses and/or contingencies – and the investment portfolio using a combination of equities, fixed income and commodity indexes and not required to meet current obligations of the IFOPA and expected to be available for a period of five or more years.

The new investment strategy replaces the former ultra conservative approach of laddering certificates of deposit that has yielded very small returns over the past several years.

FOP Italia Meeting Held in Genova, Italy

Each year, a number of significant international FOP meetings are held across globe. One of the largest gatherings is typically held in Italy, and the 2014 FOP Italia forum was no exception.

The 8th international forum brought together researchers from the University of Pennsylvania, Harvard, Oxford, Children's Hospital of Philadelphia, Saitama Medical University, Gaslini Institute, and Leiden University, along with other medical personnel, FOP families and representatives from the biopharmaceutical firm Clementia.



In addition, representatives from the IFOPA and International President's Council participated in the global event that focused on research and patient issues.

General sessions featured basic science, observational research, clinical trials, drug development and the FOP registry. Other activities included clinical appointments for FOP members, a business meeting and IPC meeting.

"This was an incredibly exciting forum with representation from around the world on both the research and patient fronts," said Betsy Bogard, IFOPA Global Research Development Director. Bogard gave a presentation on the importance of one, global patient registry.

Dr. Donna Grogan, Chief Medical Officer of Clementia, presented remarks on the development of palovarotene as a possible treatment for FOP and the initiation of a Phase II clinical trial. She also discussed plans for a natural history study involving about 50 FOP patients.

2014 UK FOP Conference and Family Meeting Staged in Manchester



The first FOP meeting held in the United Kingdom in more than 12 years was a great success! Organized and led by Christopher Bedford-Gay, board member of FOP Action and the IFOPA, the 2014 conference and family gathering featured international researchers, medical personnel, biopharmaceutical firms and nearly 30 FOP families.

The event was held on May 17 in Manchester, United Kingdom.

Research presentations were given by James Triffitt, University of Oxford, Fred Kaplan, University of Pennsylvania, Alex Bullock, University of Oxford, and Eileen Shore, University of Pennsylvania.

Robert Pignolo of the University of Pennsylvania gave a presentation on the natural history of FOP; Betsy Bogard, Global Research Development Director for the IFOPA presented remarks on the international FOP registry and Donna Grogan, Chief Medical Officer of Clementia Pharmaceuticals spoke about the development of palovarotene as a possible treatment for FOP.

FOP families from the United Kingdom, Sweden, the Netherlands, Australia, South Africa, Poland, Greece and Malta were all represented at the event and participated in clinical appointments with medical staff.

Richard Simcox, long-time benefactor for the IFOPA and FOP Action organizations, also attended the event.



IFOPA Revenue Continues Upward Climb in 2014!

Throughout its 26-year history, the IFOPA has been blessed with donors who care deeply and give generously to support the cause. The 2014 year was no exception – in fact, it was another extraordinary, record-breaking year.

Buoyed once again by the two largest single gifts in its history, the IFOPA notched a record-high \$1,844,815 in revenues during a memorable 2014 year.

The year was punctuated with two amazing 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 an eventual cure.

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

And, remarkably, the IFOPA also received another \$250,000 contribution from an anonymous donor in honor of FOP member Natalie McGuire of Midland, MI, daughter of Gary and Abbie McGuire. The gift was part of the McGuires' fundraising campaign that generated \$384,455 in 2014. Another substantial gift of \$150,000 was received from the Radiant Hope Foundation and designated for the Registry.

"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, fund development committee member. "Each year we 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 Zipper Q3 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 automobile drawing produced more than \$160,000 in revenue.

Two annual fundraisers, Bingo for a Cure and Lincoln's Legacy generated \$100,000 and \$43,863 respectively. The Bingo for a Cure is held each year in Allentown, PA and typically attracts more than 1,100 attendees. The event is held in honor of Joshua Scoble. Lincoln's Legacy is conducted in honor of Lincoln Wheelock and includes a series of special fundraising events.

Unveiled in the fall of 2012, "Sienna's Flower Garden" continued its popularity and received 193 gifts. The online fundraiser is conducted in honor of Sienna Otto, daughter of Eric and Rory Otto. A total of \$57,380 was raised in 2014 in honor of Sienna. Fund drives in honor of FOP members Sona Brinkman and Maria Wray generated \$31,706 and \$15,280 respectively.

All events and gifts are important to the success of the IFOPA. In 2014, a total of 3,108 gifts were received from 2,395 individuals and businesses.

Throughout its 26-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 2014, a remarkable \$17,258,494 has been generated to support the IFOPA cause.

Hendley Family Honored During Lab Tour, Plaque Ceremony



Terri Hendley of Marietta, GA, was a special guest during a fall, 2014 tour of The Center for Research in FOP and Related Disorders at the University of Pennsylvania. Terri was joined by Mark and Robin Gambaiana of Kirksville, MO.

The tour was hosted by Dr. Fred Kaplan and Dr. Eileen Shore and included sessions at various stations throughout the lab as comprehensive research continues on the quest toward an effective treatment and cure. The group had an opportunity to meet and interact with many of the scientists, post-doctoral students, graduate students and other staffers who work daily to support FOP research.

Terri Hendley is a trustee for the Jesse David Hendley Foundation, which has contributed \$640,000 to support FOP research. Her brother, FOP member Craig Hendley, passed away in 2004 at the age of 36.

A special ceremony was held to commemorate the Hendley Foundation's wonderful gifts and unveil a plaque with Craig's photograph. The plaque will be permanently displayed with other recognition items at the FOP Lab.

Mark and Robin Gambaiana have been active in FOP fundraising and advocacy since 2009. Mark is a former chair of the IFOPA Board. They are grandparents of eight-year old Lincoln Wheelock, FOP member from Des Moines, IA.



IFOPA Fundraising Events



Lincoln's Legacy Mud Run



Zipper Q3



Bingo For A Cure



Girls With Grit

2014 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 2014, the IFOPA set an all-time record in terms of financial operations with revenues of \$1,844,815 and expenses of \$992,349 strengthening the organization's net asset position by \$852,466. This exceptional performance boosted the IFOPA's net assets to \$3,398,600 as of December 31, 2014.

Revenues increased by \$370,194 from the previous year, an increase of nearly 25 percent. In 2014, 56 percent of income came from contributions and 39 percent from special events. On the expense side, program services accounted for 84 percent of expenditures, including 76 percent for medical research, the highest priority of the IFOPA.

Revenue and Public Support

Contributions	\$1,032,373
Special Events, Net	\$713,528
Other	\$98,914

Total Revenue and Public Support **\$1,844,815**

Expenses

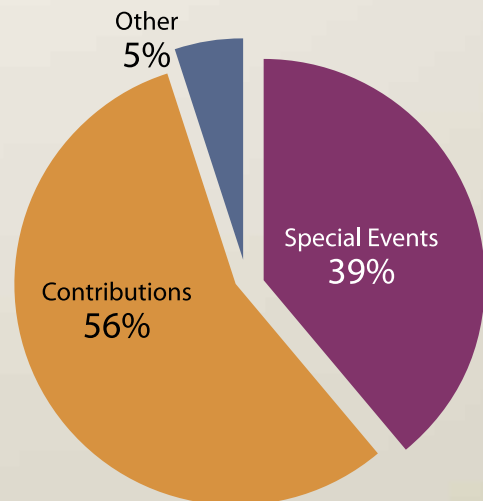
Program Services:	
Medical Research	\$757,962
Public Awareness	\$38,037
Education and Support	\$41,116
Total Program Services	\$837,115

Support Services	
Management and General	\$94,259
Fundraising	\$60,975
Total Support Services	\$155,234

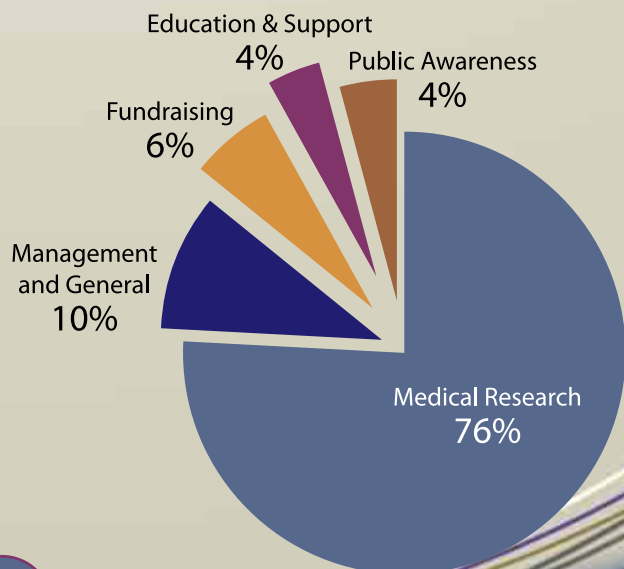
Total Expenses **\$992,349**

Change in Net Assets	\$852,466
Net Assets at Jan. 1, 2013	\$2,546,134
Net Assets at Dec. 31, 2013	\$3,398,600

REVENUE



EXPENSES



2014 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, 2014 through December 31, 2014.

Diamond

\$25,000 and above

Anonymous
Daniel D'Aniello
F.O.P. Italia Onlus
James & Beatrice Salah Charitable Trust-Salah Fdn
Jesse David Hendley Foundation
Joshua's Future of Promise, Inc.
National Christian Foundation
Radiant Hope Foundation
Roemex Limited

Platinum

\$10,000-\$24,999

Allison Weiss Brady and Chip Brady
Bridgewater Associates, LP
Chhabra Family Charitable Foundation
Clementia Pharmaceuticals, Inc
Fidelity Charitable Gift Fund
FOP e.V.
Goldman Sachs Gives
Goldman, Sachs & Co.
Greater Horizons
Harmon Foundation Inc.
Susan & Roger Hayes
Claudia & Kerry Hueston
Merck Partnership for Giving
George & Pamela Rohr
Sawaya Segalas and Co, LLC
Svenska FOP Foreningen

Gold

\$5,000-\$9,999

AQR Capital Management, LLC
Paul & Maureen Brinkman
The Cole Foundation
Constellation Energy Group Employee Fund
Crossroads of Michigan Golf Outing Account
Deans Knight Capital Management, Ltd.
FOP France
Mark & Robin Gambaiana
Investment Professionals for Charity Inc
Shashi & Bal Kalra
Patrick Lynch
Larry & Peggy Nilson
Halsey & Natalie Otto
Pelco Structural, LLC
Perella Weinberg Partners
Phoebe Snow Foundation
United Way of Midland County
Dr. Laura Willhoite, DDS
Katherine Wray & Michael Korns

Silver

\$2,500-\$4,999

BNSF Railway Company
John & Amanda Cali
California Community Foundation
Canyon Partners
Douglas & Sharon Coleman
Crim School Parent Teach Organization

Genzyme Corporation
Scott D Gordon
Dason Gwartney
Terri Hendley
Joseph Hollywood, Sr. & Suzanne Hollywood
Hooters
Michelle Maguire
Michael & Carol Man
Allison & Nino Marakovic
Delmar & Mabel McWilliams
Robert & Sandra Melton
Patti & Brady Miller
Precision Polishing Inc
Skelmir, LLC
Sons of the American Legion-Squadron 135
Peter Tauriello
United Way of Delaware
Vanguard Charitable
Brady Walker
Ed & Gail Weakland
John & Susan Wynne

Bronze

\$1,000-\$2,499

Ally Financial
Jeanne Altberger
Paul Balfour
Bennett's Route 66 Pharmacy
BKK Sports LLC
Elizabeth & Robert Blanchette
Cari & Justin Bohannon
Anita Bonanni
Rob & Priscilla Brinkman
The CarMax Foundation
Gordon Ray Carriger

Jimmy Chowdhury
 Concord Village Lions Club
 Services Foundation Inc
 Vinod & Vimal Dhawan
 Mary Drechsler
 David DuBard
 Christie Fishing
 Brent Foster
 Froman Welding & Fabrication Inc
 GE Foundation
 Charles Geoly & Stephanie Webb
 Minor & Jane Gordon
 Lisa & Michael Gagnani
 W Constance (Connie) Green
 David & Carolyn Greene
 Salvatore Guerra
 Marilyn Hair & Richard Steele
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 Sharon Holm
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 HSBC Philanthropic Programs
 Kiersten Hutchins
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 Italia-America Bocce Club, Inc.
 J9NY, Inc
 Kelly Johnson
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 Kathryn Kennedy
 Bert Kerstetter
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 Schoen Family Charitable Trust
 Schwab Charitable Fund
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 Anderson
 Sioux City Bandits
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 Deon & Mindy Smith
 Laurene Sperling
 St. Nicholas Roman Catholic
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 TexasCarDirect.com, LTD
 David Thomas
 Robert & Terri Thomas
 Thomson Reuters
 Tulsa Community Foundation
 Tom Van
 James & Beverly Wharton
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 William Blair & Company
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 Kyong Yi

Copper

\$500-\$999

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 Dori Arnold
 Vasudha Arora
 BancFirst
 Arthur George Baumann
 Marvin L Bellin, M.D.
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 James & Jeanne Anne Bonanni

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 Cardinal Health Foundation, Inc
 Cars.com
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 Foundation
 Warren & Gloria Chapman
 Dean Charpentier
 Mario & Anna Chuliver
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 Ciccone
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 Richard Colasuonno
 William Roland Cole
 Cole Roofing Co, Inc
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 Brian Deam
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 Marjorie Forshtay
 Sarah Fox
 John & Helen Franklin
 Mark J Freitas
 Gregory & Ana Freiwald
 Paul & Dixie Gambaiana
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 Corporation
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 Pete & Lori Henrotay
 Cory L Hicks
 Robert C Howard
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 James Elam Fishing, LLC
 JANA Partners, LLC

JD Beaven's Martial Arts
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 Wagner, Kuntz & Grabouski, PC

David Willis
 Julie Wingerter & Seth Lieberman
 Zazove Associates, LLC

Associates

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 Active Network, LLC
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 Julie Adams-Simmons
 Adventure Signs
 Raud Alamin & Stephanie
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 Curt & Lycia Anderson
 Tom & Kathy Andrews
 Ann's Cleaners
 Ansa McAl Trading Inc
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 Elizabeth Anzelmo
 Aon Foundation
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 Fred Duchin
 Don Dugger
 Michael Dumke
 Kelly Durm
 Jason & Celesta Easton
 Sharon Eckart
 Eleni Economidou
 Dale & Marla Edwards
 Elisabeth Eekhoff
 Teresa & Steven Egleston
 Edgar & Barbara Einhorn
 Joshua & Gwen Elliott
 Shawn & Scoti Ellison
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 Elizabeth Emery
 Pam Emery
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 William & Judy Engstrom
 Eric Epstein
 Reuben Epstein & Joanne Siegle
 Robert & Sarah Erwin
 Barbara & Craig Espe
 Brunilde Evangelista
 Michael & Tracy Evans
 Eventbrite
 Ashley Everett
 Tania Fago
 Paul Fahey
 Raouf & Mona Farid
 Fastenal
 Fred Feldman
 Bryan Fick
 Andy & Sarah Fiegenger
 James Fiesel

Brady Finton
 Brian Fisher
 Ryan Fitzpatrick
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 Susan Flicek
 Michael & Patrice Flock
 Janine Flood
 Matthew T Flood
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 Steven & Julie Forney
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 Fried Pie
 Phillip & Amy Friedrich
 Bernard Galiley
 Jeanne Galla
 Kathleen Gallagher
 June & Matt Gambaiana
 Jason Gans
 Dr. Vijay K Garg
 Stephen Gattanella
 Derek Gaudet
 Nadia Gaukova
 Heather Gaynor
 Jeffrey & Shay Gebauer
 Mona & Nolan Georgesen
 Lori & Joseph Geraty
 Kathy Geyer
 Andrea Gherini & Brad Gallant
 Alessandra Ghini & Peter Nies
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 Sharon S Hamann
 Greg & Ivy Hamerly
 Kristine Hansen
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 Harlan T Harper
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