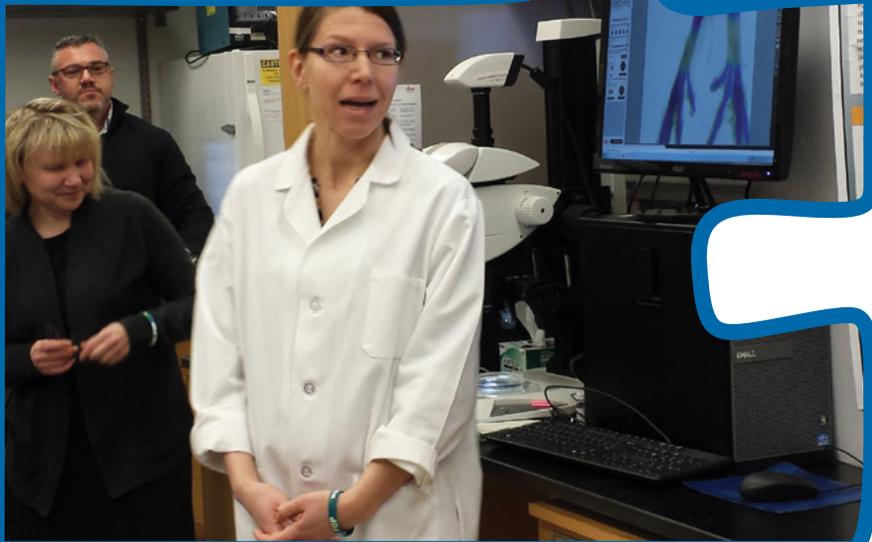


Together,
we can make
a difference!



ifopa

2015 Annual Report

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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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. There are no other known examples in medicine of one normal organ system turning into another. There is no treatment for FOP.

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.

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

How would understanding the cause of bone formation in FOP help others?

The information obtained from studying this disease will have far-reaching implications for the treatment of common disorders such as fractures, osteoporosis, hip replacement surgery and other forms of heterotopic ossification that occur in trauma and burn victims.

A Message

from 2015 IFOPA Board Chair
Marilyn Hair



The IFOPA has its eye on the prize of finding treatments for FOP. We are proud of the events and achievements of 2015 that are bringing us ever closer to our goal. New research discoveries along with current and anticipated clinical trials raise our hopes that effective treatments will be available before long that will make a real difference for people with FOP.

IFOPA activities and projects in 2015 included:

- Launching the FOP Connection Registry
- Strategic planning by the Board of Directors that led to the search for an Executive Director
- Adults and children with FOP enrolling in Clementia Pharmaceutical's Natural History Study and Phase II Clinical Trial of palovarotene
- Awarding the first three FOP Competitive Research Grants
- 3,915 individual gifts, 15 family fundraisers and total donations of \$901,500
- Nearly \$3.9 million in net assets

The FOP Connection Registry patient portal was launched in July 2015. One hundred thirty-nine (139) persons with FOP from 28 countries joined the Registry by December 31. The FOP Registry is an invaluable repository of population-wide information that will help FOP researchers, clinicians and pharmaceutical companies better understand FOP. Everyone with FOP can contribute to finding treatments by joining the FOP Registry to tell your story.

As of February 2016, Clementia Pharmaceutical's Phase II Clinical Trial of palovarotene was fully

enrolled. Many clinical trials to test new drugs fail simply because they don't enroll enough participants. Considering that FOP is extremely rare and that patients are spread across the world, this is a true milestone and an accomplishment we can all be proud of.

FOP research continues on an active and promising pathway. There are growing indications, at least in mouse models of FOP, that the disease can be treated in different ways and at different points in the disease pathway.

The IFOPA International President's Council (IPC) comprises 22 leaders of 18 national FOP organizations from across the world. Current efforts of the IPC focus on mobilizing FOP patients worldwide to help develop treatments for FOP. In April, the IPC met in person during the FOP Italia meeting in Rome. National FOP meetings were held in 2015 in Germany, Italy, Russia, Sweden and Spain.

Many thanks to the volunteer Board of Directors who guides the IFOPA. As a nonprofit organization, the IFOPA relies on contributions; we are ever grateful to the many families and friends who conducted fundraising events in 2015.

We are forever guided by the vision of Jeannie Peeper who started a pen-pal group to end the isolation of having FOP. She capably led the organization's growth to achievements even she never imagined.

Thank you for the part you play in the IFOPA. Whether you're a family member, fundraiser, donor, doctor, researcher, staff member, supporter, or have FOP, we need and appreciate you. Your dedication lets us pursue our mission to fund research to find a cure for FOP while supporting individuals and their families through education, public awareness and advocacy.

With hope,

A handwritten signature in cursive script that reads "Marilyn Hair". The ink is dark and the signature is fluid and personal.

Marilyn Hair
Chair, IFOPA Board of Directors 2014-15

Our Founder

Jeannie Peeper



The IFOPA was founded by Jeannie Peeper, a young woman with FOP, who had never met anyone else with the disease. While at the National Institutes of Health (NIH) in 1987, before the days of the Health

Insurance Portability and Accountability Act (HIPAA), Jeannie was given the names of 17 other people who had FOP. Jeannie wrote to each of them, and 10 wrote back, forming a pen pal group which became the International FOP Association in 1988.

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 by connecting and supporting persons with FOP and their families.

In 1989, Jeannie collaborated with Drs. Michael Zasloff and Fred Kaplan at the University of

2015 Board of Directors



Pennsylvania to initiate the FOP Collaborative Research Project. Since our founding in 1988, and thanks to the generosity of fundraisers and donors, the IFOPA has funded over \$9.1 million dollars in FOP research to find treatments and a cure!

The list of IFOPA achievements under Jeannie's leadership are multiple, and include hosting international symposiums and gatherings for families, clinicians and researchers; establishing a website; participating in many media projects; hosting strategic planning meetings; visiting with donors; and providing valuable counsel to FOP families. Jeannie served as President of the IFOPA from 1988 until she retired in 2013 with the title Founder and President Emeritus.

Isolation was typical before the IFOPA was formed, and Jeannie's goal was to bring people with FOP together. Today, the IFOPA is the umbrella organization for people with FOP worldwide and the place to come for education and support. The IFOPA gives support to 1,000 individuals representing over 50 countries. Over 450 of these individuals have FOP; over 280 of them are from outside the United States.

Jeannie's vision and commitment were at work back in 1988 and are still alive today as she provides support and encouragement to those living with FOP and their families. Her life's work are an inspiration to clinicians and researchers working to cure FOP worldwide.

Back row left to right:

Moira Liljeström, Chris Bedford-Gay, Rory Otto, Gary McGuire, Amy Gordon, Gail Weakland

Front row left to right:

Paul Brinkman, Karen Munro, Marilyn Hair, Nancy Sando

Not pictured:

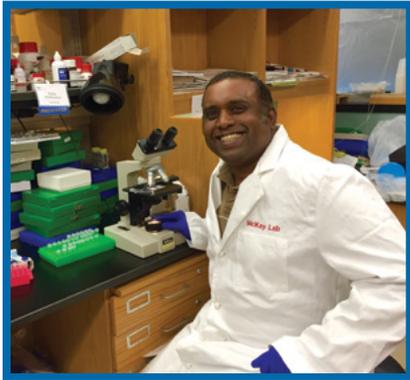
Brian Harwell

The Quest

for Treatments and a Cure

Funding basic research to grow knowledge of FOP and translational research to develop treatments and, one day, a cure for the disease are at the core of the IFOPA's mission.

The University of Pennsylvania's Center for Research in FOP & Related Disorders



Dr. Salin Chakkalakal at The Center for Research in FOP & Related Disorders

The Center for Research in FOP & Related Disorders was established in 1997 by Drs. Fred Kaplan and Eileen Shore, with the generous support of The Cali Family, at one of the most prestigious medical and research institutions in the

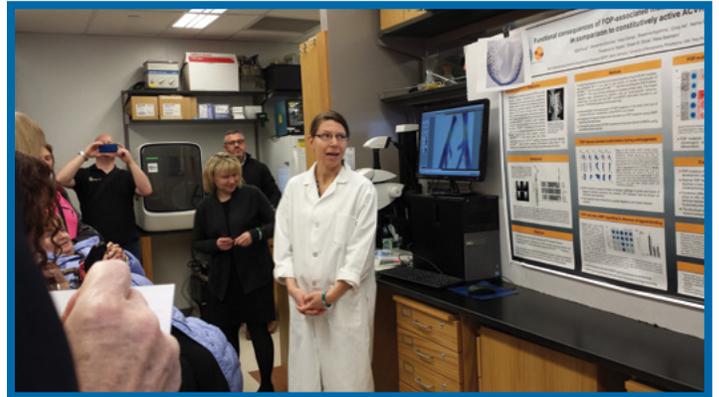
country – The University of Pennsylvania School of Medicine in Philadelphia.



IFOPA Board visits the FOP Lab at the University of Pennsylvania

In April 2006, 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.



Julia Haupt explains FOP research being done at the University of Pennsylvania to IFOPA Board members.

In 2015, the IFOPA funded nearly \$500,000 for nine research projects at The University of Pennsylvania. Fundraisers held throughout the year by families of FOP individuals are the primary source of this funding

Competitive Research Grants (CRG) Program



Sona Brinkman

In 2015, the IFOPA, through a fundraising campaign led by the family of Sona Brinkman, launched the Competitive Research Grants Program; grants focused on discovery and advancement of new therapeutic approaches to FOP

with a disposition toward approaches likely to have near-term clinical or translational relevance.

Applications were reviewed by a voluntary board with relevant and appropriate expertise related to FOP to evaluate proposals, and that was free of conflict of interest.

CRG Scientific Advisory Board

- Vicki Rosen, PhD, Chair
Department of Developmental Biology
Harvard School of Dental Medicine
- Karen Lyons, PhD
Department of Molecular, Cell and Developmental Biology
UCLA/ Orthopaedic Hospital Department of Orthopaedic Surgery
- Ernestina Schipani, MD, PhD
Department of Orthopaedic Surgery
University of Michigan
- Michael Whyte, MD
Division of Bone & Mineral Diseases
Washington University School of Medicine
- Michael Zasloff, MD, PhD
Department of Surgery
Georgetown University Medical Center

In 2015, nearly \$125,000 in grants were awarded to three institutions.

1. Assessment of small agents in FOP primary fibroblast cultures to explore new therapeutic targets

Principal Investigators: Gerard Pals, PhD and Marelise Eekhoff, MD, PhD

Institution: VU University Medical Center, The Netherlands

Award Amount: \$55,000



Gerard Pals



Marelise Eekhoff

2. The role of exercise in the progression of FOP

Principal Investigators: Paul B. Yu, MD, PhD and Yue Shen, MBBS

Institution: Brigham and Women's Hospital and Harvard Medical School, United States

Award Amount: \$28,000



Paul B. Yu



Yue Shen

3. Validation of novel diagnostic and targeted prophylaxis for FOP related heterotopic ossification

Principal Investigators: Yuji Mishina, PhD and Benjamin Levi, MD

Institution: University of Michigan, United States

Award Amount: \$41,800



Yuji Mishina



Benjamin Levi

FOP Connection Patient Registry

The FOP Connection Registry is an observational research study spearheaded by the IFOPA that collects and reports specific medical information on individuals living with FOP. The Registry will ultimately have two portals – a patient portal and a medical portal. As the name suggests, the patient portal includes data submitted by a person living with FOP, or a family member or other caregiver with their input. When available, the medical portal will include data submitted by the clinician caring for an individual with FOP. It completes the story of an individual's disease progression to have both types of data.

The FOP Registry meets the needs of all stakeholders involved in the drug development process: patients, doctors, and academic and pharmaceutical researchers. A unified, global and coordinated approach through a single registry provides the most comprehensive data on FOP, ultimately enabling better and faster development of therapies. Because of the generosity of the FOP community, the IFOPA was able to take the lead and develop a single worldwide registry for all FOP individuals. In 2015, the IFOPA invested more

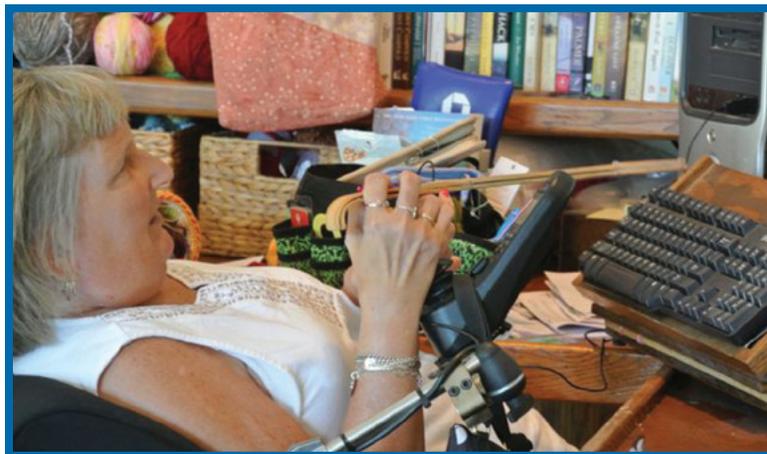
than \$230,000 to complete the design and build of the patient registry.

The FOP Registry:

- Organizes the entire FOP community for potential clinical trials and studies
- Empowers FOP patients and the community as a whole
- Collects data to better understand FOP and its impact on the body and physical function, as well as the emotional impact of the disease
- Advances the understanding of FOP treatment outcomes when they become available

The FOP Registry was launched on July 29, 2015 in English; other translations will be available at a later date. After the launch in July, the FOP Connection Registry was represented at the November 2015 FOP Stichting Nederland patient meeting in Amsterdam, The Netherlands.

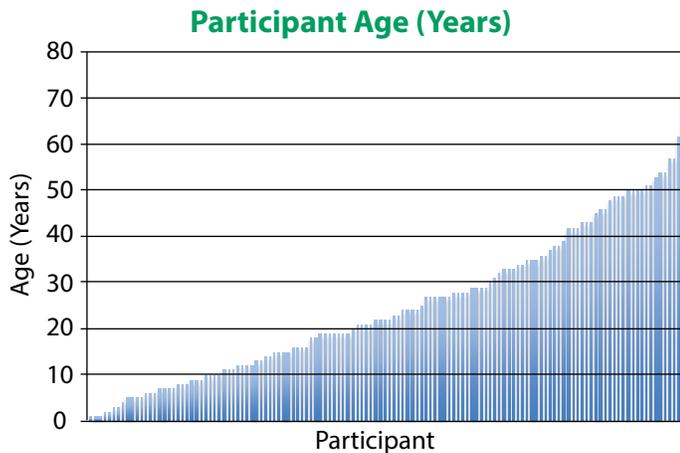
The Registry is governed, in part, by a Medical Advisory Board (MAB). The MAB is a group of clinicians with experience in FOP who, among other tasks, will design the Registry's medical portal. They also convened their first meeting at The Netherlands meeting.



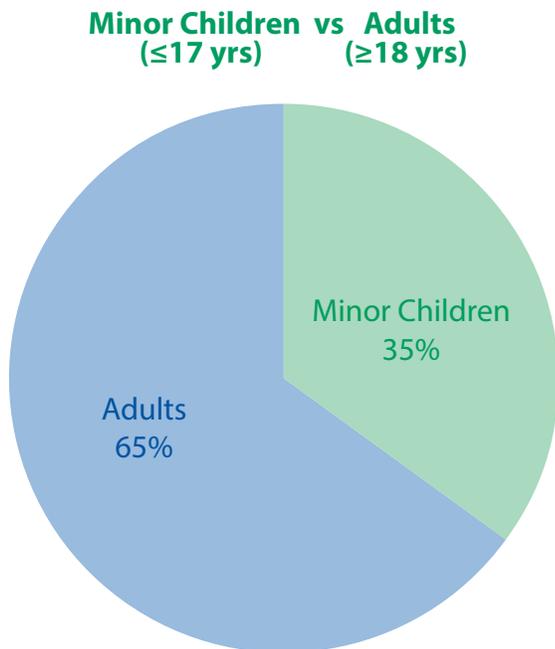
"Knowing I have personally contributed information that will help researchers and drug developers better understand FOP and eventually find multiple treatments . . . that's what it's all about, I can make a difference." Nancy Sando, First FOP Registry Enrollee

Registry Data Highlights as of December 31, 2015

- 139 registered participants from 26 countries on six continents; reflecting a truly global FOP community
- Average age of participants is 24.9 years, with a range of 1 year to 75 years (see chart)

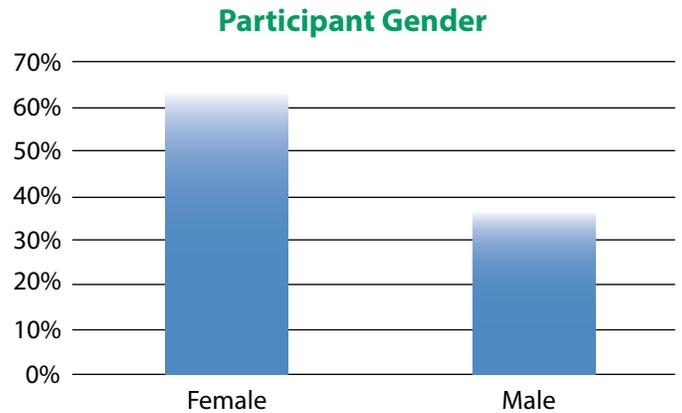


- Among the 139 participants, 35% are minor children; 65% are adult participants (see chart)



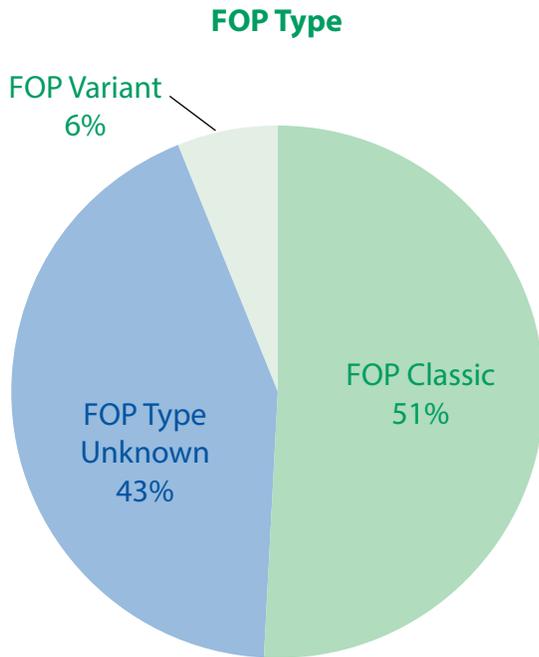
- Among the minor children, 46% are females and 54% are males; almost an even split between the genders

- 63% of participants are female; 37% are male (see chart). There is no known relationship between FOP disease and gender, so the data suggests that males overall are under-represented in the Registry.



- Of the female participants, 25% are minor children (age 17 years or younger)
- Of the male participants, 51% are minor children; a disproportionately higher percentage of minor male children compared to minor female children, suggesting that adult males are under-represented in the Registry

- 86 participants provided information about their FOP type with 51% (44/86) having reported FOP Classic, 43% (37/86) having reported FOP Type Unknown, and 6% (5/86) having reported FOP Variant



FOP Connection Registry Medical Advisory Board

Academic Medical Advisors

Genevieve Baujat, MD
Hôpital Necker-Enfants Malades
France

Matt Brown
University of Queensland
Australia

Carmen de Cunto, MD
Hospital Italiano de Buenos Aires
Argentina

Patricia Delai, MD
São Paulo School of Medicine
Brazil

Marelise Eekhoff, MD, PhD
VU Medical Center, Amsterdam
The Netherlands

Nobuhiko Haga, MD
University of Tokyo
Japan

Edward Hsiao, MD, PhD
UCSF School of Medicine
United States

Frederick Kaplan, MD
University of Pennsylvania
United States

Richard Keen, MB, BS, BSc, PhD, MRCP
Royal National Orthopaedic Hospital
United Kingdom

Rolf Morhart, MD
Klinikum Garmisch-Partenkirchen
Germany

Robert Pignolo, MD, PhD
University of Pennsylvania
United States

Maja di Rocco, MD
Gaslini Institute
Italy

Christiaan Scott, MBChB, FCPaed
Red Cross Children's Hospital
South Africa

Keqin Zhang, MD, PhD
Shanghai Tongji University
China

Pharmaceutical Industry Advisors

Eric Bachman, MD, PhD
Alexion Pharmaceuticals, Inc.

Donna Grogan, MD
Clementia Pharmaceuticals, Inc.

Xiaobing Qian, MD, PhD
Regeneron Pharmaceuticals, Inc.

Family Services

Through the generosity of donors, the IFOPA is able to provide support for individuals living with FOP and their families through a number of programs and services at no cost.

Available resources and services include:

Guidebooks

- *What is FOP? A Guidebook for Families* provides a comprehensive look at FOP answering many questions commonly asked by families and medical professionals
- *What is FOP? Questions and Answers for the Children* explains FOP in easy-to-follow language for children ages 8 to 12 and is recommended for younger children with adult supervision

Medical Binder

- Stores important personalized information all in one place
- Valuable for communication with doctors
- Easy reference to emergency contact numbers, past flare-up and medical history, and current and past prescriptions

Just a note to say thank you very much for the medical information on your website that enabled me to safely anaesthetize a middle-aged patient with advanced FOP at short notice. I found the information very helpful in my anesthetic management and advising critical care on his post-operative medical management.
Yours sincerely, Dr. Ruth S. Newton,
Consultant Anesthetist, U.K.

Emergency Tools

- Individuals living with FOP can request items to help others understand FOP in a medical emergency situation
1. Emergency card – Wallet-sized and laminated, contains key treatment information
 2. USB flash drive – Contains pre-loaded personal medical information forms
 3. Portable pill holder – Recommended waterproof container for an emergency dose of Prednisone (pill holder is not childproof)

You talked to my sister-in-law before we were diagnosed (she lives in Florida). You provided Kay's contact information and from that I was able to get ahold of the lab that tested Caleb for the classic mutation. From there, we learned that they had not tested Caleb for all possible variations. New DNA was provided and Dr. Kaplan called me to confirm he had a variation in June. Thank you so very much for your help!
Take care, Stephanie

Online Support Groups

Support groups allow individuals living with FOP and/or their parents to connect with one another in a safe environment. These groups are used to ask questions and get advice, share concerns, provide practical suggestions for everyday life and situations that may arise, and simply be connected to others with FOP.

These groups are generally administered by FOP individuals or, in the case of Parents with FOPers, by a parent of a child with FOP. To join one of these groups, send an email to together@ifopa.org and we will forward the request to the page or email group administrator.

Facebook Groups

1. IFOPAers – Group for individuals living with FOP and/or their parents
2. Parents of FOPers – Group for parents raising a child with FOP
3. FOP Ladies – Group for women with FOP where no topic is off limits

Email Groups

1. FOP Online – Group for individuals living with FOP and/or their parents.
2. Pray for FOP Healing – Diverse group that comes together in the Judeo-Christian tradition of prayer, encouragement and friendship sharing inspirational quotes and prayer requests and celebrating members' milestones; any denomination is welcome
3. Ladies of FOP – Group of women age 13 and up who discuss issues pertinent to ladies with FOP, including puberty, relationships and other issues

Mentoring Program

- Provides a family-to-family connection
- Volunteer mentors may be a patient, parent, sibling or caregiver
- Mentors listen and share their experiences
- Mentors provide open communication for families
- Mentors are familiar with IFOPA programs and services

Quality of L.I.F.E. Award (Living Independently with Full Equality)

- Monetary award designed to assist individuals with FOP to live more independently
- Award can be used for items that improve a patient's health, welfare and/or independence
- Award is a lifetime maximum grant of \$1,500

- Each application is reviewed by the L.I.F.E. Award Committee

e-Newsletter, Website and Social Media

- FOP Connection is our monthly e-Newsletter with information about living with FOP and includes research news and updates and ways you can connect, advocate and support the IFOPA. It is available to anyone who cares about our vision to #cureFOP.
- FOP Community Updates is our monthly e-Newsletter for individuals living with FOP and includes birthdays, condolences, celebrations and other community event announcements and reminders
- Thousands of people visit our website and social media pages to learn more about FOP, IFOPA events and to support our work to cure FOP each year.



ifopa.org



twitter.com/ifopa



facebook.com/IFOPA

Advocacy and Awareness

Rare Disease Day 2015

- The IFOPA and Dr. Kaplan were pleased to work with writer Christin Melton who wrote “Fibrodysplasia Ossificans Progressiva: Before You Biopsy, Look at the Toes” for Rare Disease Report to raise awareness of FOP among healthcare professionals.



- The “Role of the FOP Patient Community” webcast hosted by Clementia Pharmaceuticals paid tribute to the FOP community in recognition of Rare Disease Day. The IFOPA, FOP individuals, leading researchers and physicians shared how the patient community enhanced their knowledge of the intricacies of FOP and furthered efforts to find treatments and a cure.



We're very grateful for the work you're doing. Without the IFOPA and your help, I might not have found Dr. Hsaio's contact info and we might still be without a confirmed diagnosis (for our 13-year-old daughter). Joyce and I have set up IFOPA as our AmazonSmile charity and have been telling friends and family about it so they can do the same.

Thanks, John

International FOP Awareness Day 2015

In celebration of the announcement of the FOP gene discovery nine years ago on April 23, the IFOPA launched the FOP Competitive Research Grant Program to provide funding to scientists studying FOP for the discovery and advancement of new therapeutic approaches. See article on page 6 to learn more.



International Highlights

The IFOPA embraces the worldwide FOP community in many ways – one of which is through the International President’s Council (IPC). The IPC is an IFOPA committee made up of 22 leaders of 18 FOP national organizations around the world. In May 2015, FOP Australia was established and joined the IPC.

Current efforts of the IPC focus on mobilizing FOP patients worldwide to help develop treatments for FOP. The IPC meets in person each year at the FOP Italia annual meeting. The support of generous donors allowed the IFOPA to fund travel expenses for nine of the 14 FOP national organization leaders who attended this important meeting.

2015 highlights of the FOP national organizations include:

- Annual German FOP Meeting
- Annual Family Meeting in Spain
- 2nd Annual FOP Russia Meeting
- FOP Sverige Summer Family Meeting



Moscow excursion during FOP Russia Meeting: (left to right) Anastasia Vorobiova (interpreter), Igor Zahvatov (Heads Baltic countries for FOP Russia), Nadezda Zahvatova (Igor’s mom), Dmytriy Medvedev (volunteer), Olesya Radushko, Vladislav Grachev, Rada Borzova (Heads Siberian branch for FOP Russia), Nadezhda Borzova (Rada’s mom), Vladimir Borzov (Rada’s dad)

FOP Italia 9th Annual Meeting Held in Rome, Italy

Nearly 100 people were in attendance, March 20 to 21, including physicians and researchers from Italy, United Kingdom, The Netherlands, Germany, Japan, and the United States, as well as representatives from two pharmaceutical companies – Clementia and Regeneron. In addition, representatives from the IFOPA and International President’s Council participated in the global event that focused on research and patient issues.

Presentations on various research approaches and tools to find treatments for FOP were given and Betsy Bogard, IFOPA Global Research Development Director, updated attendees about the FOP Registry that would be launched in summer 2015.

At the conclusion of the scientific meeting, a FOP clinic for Italian patients was held and the International President’s Council convened its annual in-person meeting. The fourteen IPC leaders who attended from Argentina, Australia, Canada, France, Italy, Poland, Russia, The Netherlands, South Africa, Sweden, United Kingdom and the United States gave updates about the work they are doing in their countries. Leaders discussed how the IFOPA and IPC should coordinate working with pharmaceutical companies, the importance of translating the FOP Registry into many languages, and collecting biological samples in one or more bio banks.



IFOPA International President’s Council meeting in Rome, Back left to right: Enrico Cristoforetti, Marilyn Hair, Carrie Connell, Marie Hallbert Falhberg, Irene Snijder, Massimo Alfieri, Julie Collins and Mihail Belyaev. Front left to right: Moira Liljesthröm, Chris Bedford-Gay, Katarzyna Ziaja, Marie-Emmeline Lagoutte and Chris Scott

#FOP23April – FOP Meeting in Eskilstuna, Sweden

Marie Hallbert Fahlberg, leader of the FOP national organization in Sweden, held a special meeting on International FOP Awareness Day, April 23, to inform patients, families, doctors and the media about the palovarotene clinical trial for FOP which came to Europe in 2015.

A short feature on Swedish TV about FOP, the clinical trial, FOP Awareness Day and interviews with Marie and her son Hugo Fahlberg who has FOP, aired several times during the day and ended with a longer report in the evening news.



Hugo Fahlberg with his grandfather Per Hallbert in Eskilstuna, Sweden



Annual German FOP Symposium



Annual Family Meeting in Spain

2015

Jeannie L. Peeper Award Winners

We are grateful to each award recipient 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.

Lifetime Leadership Award

Jennifer Snow



Jennifer (Jen) Snow is one of the leading pioneers of the IFOPA. She has worked tirelessly for the past 21 years to help the FOP community and has actively supported the

IFOPA's mission. Along with her family, they have held many amazing grassroots fundraising events, including the Find a Cure BBQ. This 17-year event holds the record for the longest running fundraising event in IFOPA history, raising more than a million dollars for the IFOPA. Since her daughter Stephanie's FOP diagnosis in 1994, Jen has shared the FOP story publicly in both local and national media and at events. She has served on the IFOPA Board of Directors in many capacities over the years, including Vice Chair in 2011. Our Founder and President Emeritus Jeannie Peeper notes, "Jen, you have played a key role in so many IFOPA projects, wearing many different hats; it's hard for me to name them all." She served on and led many IFOPA committees, including those that supported past special events such as the 3rd & 4th International Symposiums, and more recently

helped design the patient panel at the first-ever FOP Drug Development Forum. Jen has played a key role in research approaches from the beginning and helped form the current IFOPA research and drug development vision as past Co-chair of the Research Committee. Jen always advocates for FOP patients everywhere. Her passion for the FOP community and her dedication to the patient voice being heard is reflected in all that she has accomplished. Thank you Jen for your dedication, love and generosity.

Outstanding Community Involvement Award

Individual – Michael Man



Michael (Mike) Man has been a pioneer in the IFOPA's fundraising efforts. His commitment to the IFOPA's mission began when his son Spencer was diagnosed with FOP, and Mike's generosity continued long after Spencer's death in 1991 at the age of 14. Prior

to Spencer's death and continuing well after, Mike's endeavors in supporting the IFOPA are historic. The IFOPA has been able to expand its research and member services because Mike was consistently committed for so many years. The IFOPA benefited from the Spencer B. Man Memorial Foundation which Mike created in honor of his son in 1994, and the IFOPA received funding from the Foundation until its closure in 2012. Mike personally donated up to a \$4,000 match for each Spencer Man Memorial Drawing event that the IFOPA held. Mike's fundraising efforts also included his memorable donation of a classic car that the IFOPA auctioned off and IFOPA member, Sharon Fitts, and her husband, Henry, won. Mike also provided consulting to the IFOPA on fundraising as the association was growing and he served as a Board Member from April 2009 through Dec. 2010. Mike's dedication and extraordinary passion are remarkable.

Group – Lincoln's Legacy: Doug & Marilyn Wheelock Mark & Robin Gambaiana



Marilyn and Doug Wheelock with grandsons Hudson and Lincoln



Robin and Mark Gambaiana

The Lincoln's Legacy events started in 2009, in honor of their grandson Lincoln Wheelock, shortly after his diagnosis at age three. Both sets of grandparents and their families immediately became involved in the IFOPA and held a dinner plus silent auction, inviting friends and family to learn about FOP and raise funds for FOP research. They have continued to host biennial dinners and auctions, with each event becoming larger. During the years they don't host the dinner and auction event, Lincoln's Legacy does a very large letter writing campaign to raise FOP awareness and funds to support FOP research. In addition to these larger-scale events, the families have created a variety of other smaller-scale activities including "Leap for Lincoln," a Trike-a-thon, holiday shop, Sioux City Bandit (indoor football team) game volunteers, and Living History Farms "Mud Runs." The "Mud Run" in November 2014, had a total of 29 runners participating in honor of Lincoln and collectively generated \$32,500 for FOP

research. Each family has had birthday parties or Boss's Day events where donations were made to the IFOPA in lieu of presents. To date, Lincoln's Legacy events have raised more than \$500,000 and we are thankful for their continued support to find a cure for FOP.

Inspiring Leadership Award Patrick Doerr



Patrick (Pat) Doerr is an IFOPA community member who has FOP. Since he became a member in 1996, Pat has demonstrated exceptional commitment to improving the quality of life of individuals in the FOP community and his personal achievements in the face of adversity are outstanding. He has served on the IFOPA Board of Directors as Secretary and Vice Chair. Presently, Pat is actively serving on two IFOPA committees, the IFOPA Website Redesign Committee (co-chair) and the IT Committee (co-chair). He has also given a hand to the Mentoring Committee from time to time. Professionally, Pat works as an accountant and his co-workers honor him annually by raising money for the IFOPA. He has encouraged others to donate to the IFOPA through online beauty pageants, local businesses, are regular donors, and his family orchestrated a bicycle event – Unswerving, The Trans-Wisconsin Bicycle Ride to honor him. Pat is faithful in representing the FOP community and the IFOPA. He has worked with Gary Whyte to further FOP and rare disease efforts in the legislative arena, and has attended annual fundraising events for many years including the Comedy Show and Bingo For A Cure! Pat's support includes attending FOP symposiums, speaking at the Scientific Workshop: Strategies for the Treatment of FOP, participating in the IFOPA's Teen and Adult Meeting, and 25th Anniversary Celebration. Leading by example, living independently with determination, exhibiting a positive attitude and a zest for experiencing life to the fullest, Pat is an inspiring role model to our FOP community.

Outstanding International Leadership Award

Carrie Connell



Carrie Connell lives in London, Ontario, Canada. After her daughter Brooke was diagnosed with FOP in 2007 at age six, Carrie joined the IFOPA, and was disappointed to learn that there was no national FOP group in Canada. She decided, therefore, to form one herself, and in 2009 she became the founder of the Canadian FOP Network (CFOPN). Carrie has served as President since the group's inception, and has been the driving force behind the organization's activities. Under

her leadership, the CFOPN became a not-for-profit corporation and obtained charity status, the latter of which enables Canadians who donate to support FOP research charitable tax receipts, allowing deductions for income tax purposes. Carrie has spearheaded and organized CFOPN family conferences in 2009 and 2013, both of which were deemed a great success by attendees. These events included opportunities for FOP patients to be assessed by FOP medical specialists Drs. Kaplan and Pignolo and by FOP dental experts Drs. Nussbaum and Friedman. Carrie has provided logistical assistance through the CFOPN to families wishing to run charitable fundraising events, including helping organize online donation websites. While leading CFOPN, Carrie has also participated in annual conferences run by the Canadian Organization for Rare Diseases (CORD), as well as recently attending the IFOPA's 2015 International President's Council meeting in Rome, hosted by FOP Italia. Her role as the IFOPA's International President's Council Canadian representative is vital to helping the IFOPA successfully implement our education, awareness and advocacy programs to support our Canadian FOP members and their families.

2015

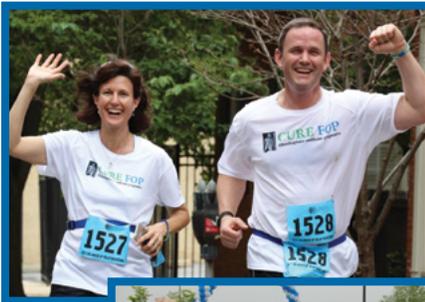
Fundraising

Each year individuals embrace their passion and creativity by hosting unique fundraising events and doing various fundraising activities to support the IFOPA's mission. We could not be more grateful to the family fundraisers and their networks of friends and colleagues who supported them so generously. Thank you!

Events that raised \$5,000 or more in 2015

All for One, One for All – Delaware Marathon

In honor of Justin Henke
Wilmington Riverfront, Delaware
\$9,716



Left: Justin's parents Wendy and Kevin Henke



Middle: Pre-race cheer by UPenn FOP Lab staff



All for One, One for All group with Justin Henke in the front row center

Awake for a Cure
In honor of Ashley Martucci
Delmar, New York
\$38,094



Dusk to dawn fun for middle school students playing carnival games at Awake for a Cure

Bingo for a Cure!

In honor of Joshua Scoble
Allentown Fairgrounds, Pennsylvania
\$92,000 grant from Joshua's Future of Promises,
501c3



Dr. Fred Kaplan speaks to the large crowd at Bingo for a Cure!



Bingo for a Cure! event brings together FOP friends and families

Back row left to right: Jeannette Bordeau, Lisa Bordeau, Christine Lichtenberg, Lindsay Ruiz, Ashley Kurpiel, Patrick Doerr, Kathy Ford

Front row left to right: Karina Chaikhoutdinov (seated), Joey Hollywood, Dr. Fred Kaplan, A.J. Gonzales, Bobby Johnson, Joshua Scoble

Charity Ride for FOP

In honor of Ashley Martucci
Staten Island, New York
\$5,259

Lincoln's Legacy Dinner, Drawing & Silent Auction

In honor of Lincoln Wheelock
Sioux City, Iowa
\$56,427



Lincoln's Legacy Dinner Event
Back row left to right: Marilyn & Doug Wheelock, Dr. Fred Kaplan, Trish Wheelock, Robin & Mark Gambiana
Front row left to right: Lee, Hudson and Lincoln Wheelock

Lincoln's Legacy Mud Run
In honor of Lincoln Wheelock
Urbandale, Iowa
\$16,450



6th Annual Lincoln's Legacy Mud Run was a snow run!

Midnight Sun Color Run
In honor of Dilyn Martin
Kotzebue, Alaska
\$5,000



Color toss at Midnight Sun Color Run in Kotzebue, Alaska



Dilyn's family with fundraisers
Back row left to right: Ann Sieh of OTZ Telephone, Jade's sister, Derek Martin (Dilyn's Dad)
Front row left to right: Maija Lukin, Lucy McConnell, Jade Hill (Dilyn's Mom) and Dilyn Martin

ZipperQ4 BBQ, Auction & Jeep Drawing

In honor of Zip Gordon

Claremore Fairground, Oklahoma

\$120,344



Amy and Zip Gordon give BBQ awards at ZipperQ4

Other Family Fundraising Activities that raised \$5,000 or more

In honor of Sona Brinkman

Letter campaign donations to support the
Competitive Research Grant Program

\$153,347

In honor of Ashley Martucci

Letter campaign donations

\$13,700

In honor of Natalie McGuire

Letter campaign donations

\$391,665

In honor of Sienna Otto

Sienna's Flower Garden donations

\$36,792

In honor of Maria Wray

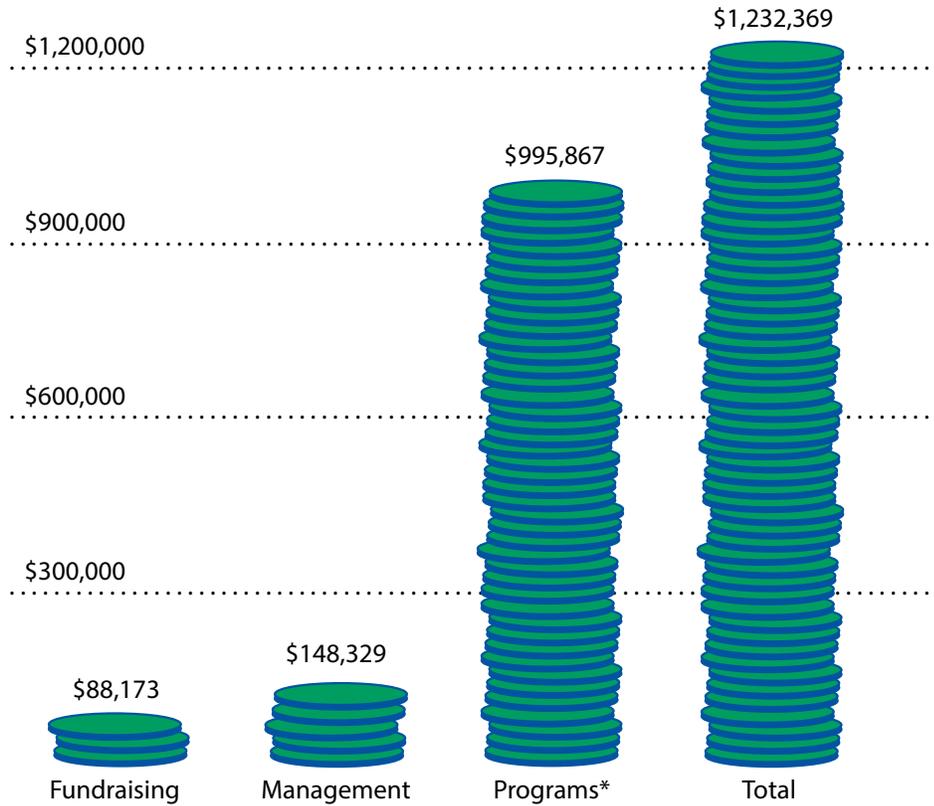
Various fundraising activities

\$11,857

Our Financials

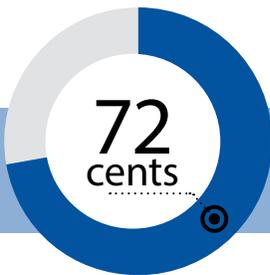
Where Your Money Went

Fiscal Year 2015



*Programs

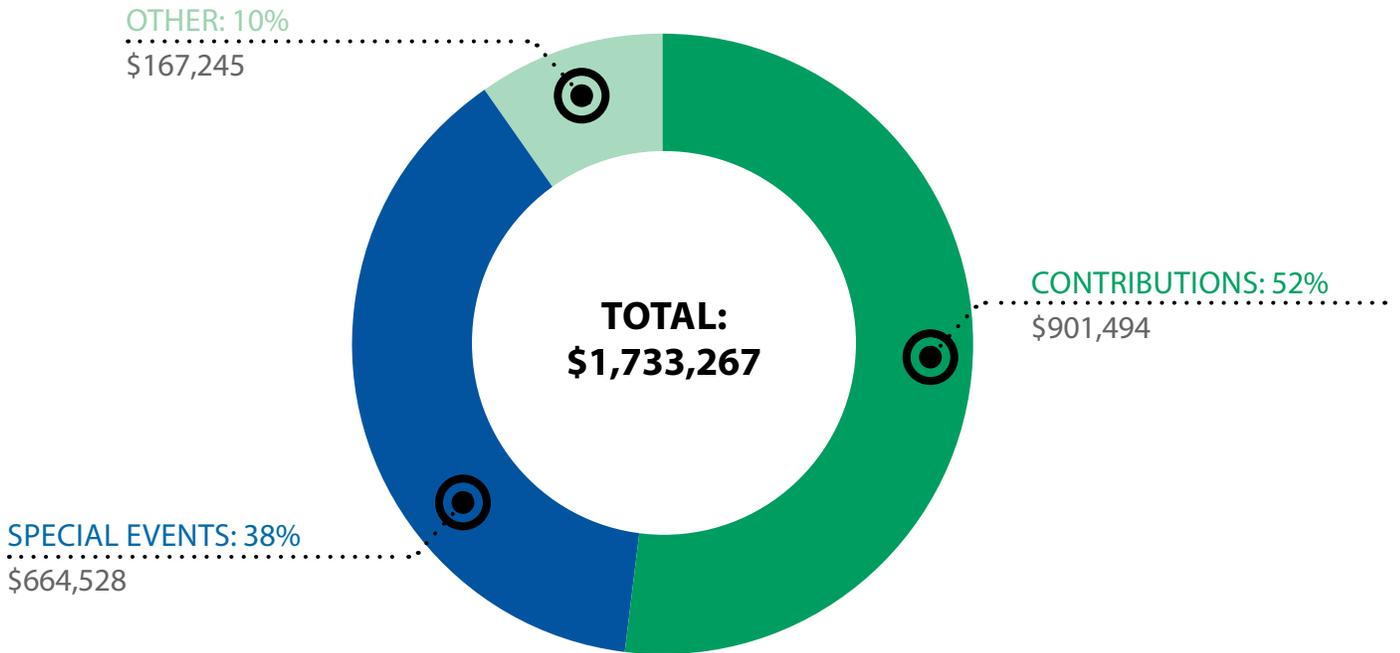
Medical Research: \$900,938 Education & Support: \$56,008 Public Awareness: \$38,921



of every dollar goes to medical research.

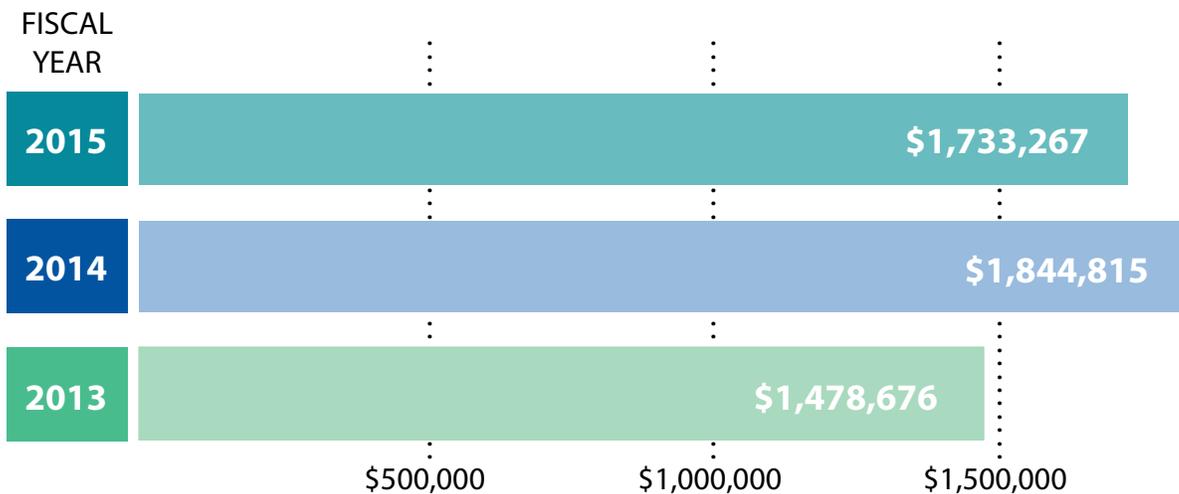
	Fiscal Year 2014	Fiscal Year 2015
Medical Research	\$757,962	\$900,938
Education & Support	\$41,116	\$56,008
Public Awareness	\$38,037	\$38,921
Fundraising	\$60,975	\$88,173
Management	\$94,259	\$148,329

Where Our Money Came From



Annual Revenues and Financial Position

Annual Revenues



Financial Position: December 31, 2015

ASSETS		LIABILITIES		NET ASSETS
\$4,200,660	–	\$312,827	=	\$3,887,833

2015 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 through December 31, 2015.

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\$25,000 and above

Anonymous
Clementia Pharmaceuticals, Inc
Jesse David Hendley Foundation
Joshua's Future of Promise, Inc.
Donna Martucci-Segal & Gary Segal
Vanguard Charitable

Jefferson County School District
Patrick Lynch
Allison & Nino Marakovic
Angela & Peter Martucci
Halsey & Natalie Otto
Societe Generale
United Way of Delaware
Doug & Marilyn Wheelock
Wheelock & Bursick Dentistry
Cecil & Gilda Wray

Brady Walker
Ed & Gail Weakland
William Blair & Company Foundation
Melinda & Taylor Wray

Platinum

\$10,000 - \$24,999

Bridgewater Associates, LP
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Fidelity Charitable Gift Fund
FOP e.V.
FOP France
Goldman Sachs Gives
Goldman, Sachs & Co.
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Resat & Tugce Korkmaz
Atul Madan
Mildred & Joseph Martucci
Phoebe Snow Foundation
Powell Broadcasting
Prestige Brands
George & Pamela Rohr
Svenska FOP Foreningen

Silver

\$2,500 - \$4,999

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BNSF Railway Company
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Central States Crane & Hoist LLC
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Robby & Erin Sawyer
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Bronze

\$1,000 - \$2,499

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\$5,000 - \$9,999

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W.K. Kellogg Foundation
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Mohamed Hafez Zaher

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\$500 - \$999

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Vinni Bhandari
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