



# PROGRESS *Report*

FEBRUARY 2020

## FDA Holds a Listening Session on FOP

Members of the FOP Community Share Experiences and Hopes

The IFOPA and members of the FOP community participated in a one-hour listening session with representatives from the U.S. Food and Drug Administration (FDA) in May 2019. The goal of the informal session was to provide FDA officials from a number of divisions and departments with the perspectives, needs and treatment priorities of people living with FOP.

Individuals with FOP shared their experiences on a wide range of topics, including the often long journey to diagnosis, issues caused by misdiagnosis and ways FOP impacts daily life functions as it progresses. They also discussed the physical pain they endure and limitations FOP places on career options and other life choices which can create intense mental and emotional struggles. Family members in attendance told of the sacrifices required to try and meet needs, such as giving up jobs and the hardship caused by medical expenses, making homes accessible and other necessities.

By giving FDA representatives a look into what life with FOP is like, everyone who spoke served to impress on them the importance and urgency of finding treatments and a cure. Members of the FOP community made it clear that safe and effective treatments are desperately needed so that they and others can lead independent and fulfilling lives.

There was also time during the session for the IFOPA to present an overview of the FOP Registry, the largest and most in-depth database of clinical and medical information about FOP and those who are living with the disease. The FOP Registry was developed by the IFOPA and launched in July 2015 and now offers both patient and medical portals. The IFOPA offered to share sample case report forms from the FOP Registry, as well as reports of de-identified data with the FDA.



**Many thanks to the following FOP community participants at the FDA Listening Session who contributed valuable information:**

- » **Joshua Scoble**, person with FOP
- » **Stacy Scoble**, mother of Joshua
- » **Chrissy Flexer**, Joshua's aunt
- » **AJ Gonzales**, person with FOP
- » **Kristi Gonzales**, mother of AJ
- » **Alexis Gonzales**, sister of AJ
- » **Natalie McGuire**, person with FOP
- » **Keegan McGuire**, Natalie's brother
- » **Danie Coyne**, person with FOP
- » **Samantha Coyne**, Danie's sister-in-law
- » **Brian Harwell**, person with FOP
- » **Barbara Harwell**, mother of Brian
- » **Adam Sherman**, Research Director, IFOPA
- » **Michelle Davis**, Executive Director, IFOPA



**To read more about the listening session and the FOP community testimony, visit [ifopa.org/fda\\_listening\\_session](https://ifopa.org/fda_listening_session)**

**To learn more about the FOP Registry visit [ifopa.org/fopregistry](https://ifopa.org/fopregistry)**

# Quality of L.I.F.E. Awards Help 77 People with FOP

## Program Renamed in Honor of Transformational Gift

**T**he IFOPA's Quality of L.I.F.E. (Living Independently with Full Equality) Awards Program makes daily life easier for people with FOP. The program provides individuals with FOP of all ages, from around the world a \$1,500 USD grant for items, services or education and training that improves their health, welfare and independence.

Since 2005, the IFOPA has awarded grants to 77 people living with FOP totaling more than \$85,000. Patients with FOP have received practical, tangible assistance to obtain items that help them live more independently – home comfort aids; home and vehicle modifications; school, workplace and communication aids; mobility aids; and even financial support to acquire a service dog.

In February 2019, Dr. Fred Kaplan generously donated the monetary prize he received when he was awarded The Grand Hamdan International Award in Medicine to the L.I.F.E. Awards program. This incredible gift was made in memory of his parents, Harold and Elaine Kaplan, who admired the FOP community and supported their son's work.

As Co-Director of the Center for Research in FOP and Related Disorders at the University of Pennsylvania, Dr. Kaplan is well-known and loved for his tireless efforts to make life better for people with FOP. His donation is transformational for the L.I.F.E. Awards and bestows much-needed funding to ensure grants for those living with FOP continue for many years to come. With deep appreciation and in honor of Dr. Kaplan's parents, the program was renamed as The Harold and Elaine Kaplan Quality of L.I.F.E. Awards.

"The IFOPA is grateful to have such amazing support from Dr. Kaplan which allows us to assist those with FOP in getting needed, but often costly, items that make a huge difference in day-to-day life," shared Executive Director Michelle Davis.



*Elaine & Harold Kaplan*



*Fred Kaplan, MD and  
Tina Bales Kaplan, MD*



**"I am so grateful for the Quality of L.I.F.E. Award. It helped me get the kitchen renovated so I could get my independence back. Before I wasn't able to reach the cooker or sit at the table. Now I have an oven that I can access easily and a breakfast bar to sit at to eat! I have easy access to food in the cupboards and a fridge I can reach into without any help at all. It has been life-changing. Thanks so much!"**

—Rachel Hopwood Winnard, United Kingdom



To learn more about the Elaine & Harold Kaplan Quality of L.I.F.E. Awards, visit [ifopa.org/quality\\_of\\_life\\_award](https://ifopa.org/quality_of_life_award)

# ACT for FOP Grant Pushes Research Forward



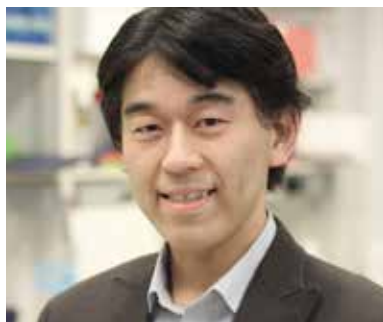
Exciting FOP research developments are advancing thanks in part to programs like the IFOPA ACT (Accelerating Cures and Treatments) for FOP Grant Program. This grant program uses a competitive application process to provide funding for promising research focused on the development of safe and transformative therapies for FOP.

The IFOPA, in partnership with the Canadian FOP Network, awarded funding in 2016 to Dr. Toshifumi Yokota, Professor at the Department of Medical Genetics, University of Alberta, Canada, and his lab. In 2012, Dr. Yokota's group was focused on therapeutics for muscular dystrophy using DNA-like molecules called antisense oligonucleotides.

After hearing Dr. Takenobu Katagiri of Saitama Medical University discuss FOP and the IFOPA at a conference, Dr. Yokota's lab saw the potential to treat FOP and they have pursued that research for the past five years.

"These molecules target mutated products of the gene ACVR1. Compared to other drugs currently under development, this technology is very unique and advantageous because we can target the mutated gene products while preserving the normal gene copy and function. We have already demonstrated the effects in cells and mice with the FOP mutation," said Dr. Yokota.

Dr. Yokota believes the ACT for FOP Grant Program plays a vital role in supporting academic researchers, who are making significant contributions to the development and success of new drugs and therapies. He's very grateful for the financial support and the opportunity to connect with the FOP community. Dr. Yokota also believes the IFOPA's FOP Drug Development Forum is important to his lab's work as it provides a unique opportunity for collaboration with researchers from around the world. He feels optimistic for the future.



**"Our goal is for our research to eventually result in the practical use of antisense drugs as a form of treatment for FOP. We would like to contribute to a better tomorrow for the FOP community," Dr. Yokota said. "To that end, we are currently searching for an industry partner to further develop antisense therapy for FOP."**

The 2019 ACT (Accelerating Cures and Treatments) for FOP Grant Program awarded four grants totaling \$275,000. This year's grantees include a first-time IFOPA grant recipient at the University of Barcelona in Spain.

The ACT for FOP Grant Program provides vital funding for research projects to accelerate the development of new drugs for FOP. Since the program's inception in 2015, 18 FOP research grants have been funded in five countries – Canada, Spain, The Netherlands, United Kingdom and the United States.



Meet the 2019 ACT for FOP Grantees [ifopa.org/act\\_for\\_fop\\_grants\\_2019](https://ifopa.org/act_for_fop_grants_2019)

# Learn Habits to Support Mental & Physical Well-Being in Day-to-Day Living

The IFOPA's Resilient Living Program launched in February 2019 thanks to a RARE Patient Impact Grant from Global Genes. Based on Turning Point's\* facets of resiliency, this new program offers people with FOP, families and caregivers the tools to improve emotional health and coping skills and reduce anxiety and depression as they face the challenges of this disease.

During 2019, FOP Connect peer mentors participated in a virtual web-based training and nearly 25 community members learned these important skills during a pre-conference workshop at the FOP Family Gathering.



<<< (left) Rebecca Wallace, mom to Eli who lives with FOP shared, "There are so many useful tools offered in the resiliency training that are fairly easy to implement and yet can make a significant impact on one's overall well-being. I appreciated the wide variety of topics which allowed me to pick and choose what to focus on in my own life. Even a few small changes can make a big difference."

>>> (right) Nancy Sando, IFOPA Board Member and person with FOP said, "Since dealing with FOP since 1965 as a five year old, I've had a lot of experiences that the disease has challenged me with. In participating in the Resilient Living program I have been reminded of the many of the areas I have excelled in and those that continue to be tweaked. I hope that I can be an example to younger people with FOP to encourage them in our unique journey we've come to know so well."



## RESILIENT LIVING INTERACTIVE WEBINAR SERIES

Each training is one hour – 30 minutes in a lecture-style presentation followed by 30 minutes of discussion. You can attend one, several or all of the trainings.

### **SESSION 1: What does Resiliency Mean to You?** **Tuesday, February 18**

We'll start this series off by looking at some of the important aspects of implementing resilient habits and learning why resilience is important for our mind and body.

### **SESSION 2: Emotional Expressiveness** **Tuesday, March 24**

Emotional expressiveness is the awareness of basic emotions as they occur and the ability to process them appropriately.

### **SESSION 3: Ability to Self-Calm** **Tuesday, April 21**

The ability to self-calm is using self-awareness to practice relaxation techniques and self-regulation skills to align our intellect, emotions, actions and words.

### **SESSION 4: Hardiness** **Tuesday, May 19**

Hardiness is our ability to place ourselves at the center of the controls and realize that challenges create opportunities for potential learning, growth and personal betterment.

### **SESSION 5: Self-care** **Tuesday, June 16**

Self-care is choosing healthy behaviors that balance the effects of emotional and physical stressors.

### **SESSION 6: Ability to Self-replenish** **Tuesday, July 21**

The ability to self-replenish is recognizing when our inner stores of energy and positive experience are becoming depleted and doing what it takes to fill ourselves up again.

### **SESSION 7: Non-judgement/Self-Supporting Talk** **Tuesday, August 18**

Self-supporting talk is challenging unproductive thoughts and replacing critical thoughts with more productive ones.

### **SESSION 8: Hope and Optimism** **Tuesday, September 15**

Optimism is remembering that our perception creates reality and that we must have hope to define our goals and make a plan to achieve them.

### **SESSION 9: Sense of Coherence** **Tuesday, October 20**

Sense of coherence is focusing on a sense of order and remembering that there are a great deal of resources available in life. During times of distress action eases despair.

### **SESSION 10: Social Support** **Tuesday, November 24**

Social support is about turning to the people who support you when you need them and remembering that reciprocating that support is key to a healthy relationship.



To register, visit [ifopa.org/resilient\\_living\\_educational\\_series](https://ifopa.org/resilient_living_educational_series)

\* Turning Point is a nonprofit organization based in Kansas City, Missouri that empowers and transforms the body, mind and spirit of individuals living with a serious or chronic physical illness and their loved ones.



# 4th Annual FOP Drug Development Forum

The IFOPA's FOP Drug Development Forum (DDF) is the only meeting solely dedicated to FOP research & drug development in the world. The 2019 DDF keynote speaker was Dr. Emil Kakkis, President and CEO of the pharmaceutical company Ultragenyx, and President of The EveryLife Foundation for Rare Diseases. Dr. Kakkis highlighted his experience developing 10 treatments for rare diseases. Dr. Jacqueline Karp, FDA Division of Bone, Reproductive and Urologic Products, participated in the 2019 DDF and addressed some of the key regulatory challenges in developing rare diseases treatments. Dr. Karp also participated in a moderated panel session. Throughout the DDF, there was plenty of discussion during the moderated Q&A sessions that sparked new ideas and also challenged our current understanding of FOP. It was remarkable to see how much progress has occurred since our last DDF meeting in 2017.

**PURPOSE OF MEETING** Discuss latest research, Solve drug development challenges, Strengthen research collaborations

**154**  
attendees



Researchers, clinicians, biotech and pharmaceutical company representatives, regulators, advocates and people living with FOP

**35**  
FOP Talks  
in six sessions



**19**  
countries  
represented



**2** Drug Development  
panel discussions  
plus opening and closing talks  
by FOP community members




Read the FOP Talk summaries at [ifopa.org/2019\\_DDF\\_recap](http://ifopa.org/2019_DDF_recap)  
See the 2019 DDF Wrap-up Video at [ifopa.org/2019\\_FOPDDF](http://ifopa.org/2019_FOPDDF)

## Annual FOP Family Gathering

**PURPOSE OF MEETING** Learn from FOP experts and one another, Reconnect with old friends, Develop new relationships

**207**  
attendees



49 FOP families plus clinicians, biotech and pharmaceutical company representatives, and researchers

**21** people  
took part in the  
Resilient Living Pre-Conference



**12** General Sessions

**12** Small Group Discussions



**14** kids took part in  
the FOP Fun Zone



**2** FOP research studies  
conducted onsite



**35** Ask a Doctor  
meetings



**32** Ask a Dentist  
meetings



**2** new FOP treaters  
from Mexico and South Africa



For **51%** of families it was their first time attending a Family Gathering



Take a peek inside the  
2019 FOP Family Gathering at  
[ifopa.org/2019\\_FOPFamilyGathering](http://ifopa.org/2019_FOPFamilyGathering)

Thank you to our biotech and pharmaceutical partners for supporting both of these critical FOP meetings.

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FAMILY GATHERING SUPPORTER

Keros Therapeutics

# Connections Make the Family Gathering a Highlight of the Year



**"But most importantly, you get to meet a fantastic group of people—FOP'ers and their families and the dedicated individuals working for the IFOPA. We are so grateful for this incredible community."**

The annual Family Gathering represents the heart of what the IFOPA is about – bringing the FOP community together and sharing resources and information. IFOPA supporters who help make this event possible are providing invaluable support for individuals with FOP and their families.

The Hamilton/Theoret Family from Ottawa, Ontario, has participated in events with the Canadian FOP Network and attended the IFOPA Family Gathering for the first time in 2018 in Baltimore, Maryland. For parents Lara and Steven, and their sons Aiden and Jaxon Hamilton (Jaxon was diagnosed with FOP at age 2), it was a special time to learn and bond with the FOP community.

"We have fantastic online communities for those living with FOP and their family members, but nothing beats the experience of face-to-face interaction. The discussions are richer and more tips, tools and ideas arise when engaged in dialogue," said Lara. "Life with a rare disease can be isolating. It's so fulfilling to be with those who get it. It was incredible to meet friends I've known online for years and feel that connection in person. It has strengthened our relationships."

The family is thankful the FOP Family Gathering has something for everyone. The boys enjoyed the Fun Zone with activities and new friends that kept their attention each day. Steven and Lara appreciated the chance to leave their sons in the care of people who understand the needs of kids with FOP. The Fun Zone allowed them to remain engaged as parents and concentrate on the presentations and discussions to get the most out of the sessions.

During a medical advocacy breakout, Lara was asked to share Jaxon's Special Point Of Care document that has transformed his care at a local hospital. She enjoyed getting to contribute to the conversations as families exchanged ideas for helping their kids. It was one more way the Family Gathering proved to be exactly what their family needed.

"The presentations share all the latest research, the breakout discussion groups are a treasure trove of ideas and resources, there is a fantastic display on tools to aid in independence and mobility challenges, and the kids can have fun all day at the Fun Zone. Plus, appointments are available with the world's leading experts in FOP care, both doctors and dentists, that can offer personalized insights into well-being and care," Lara said.



## SAVE THE DATE!

**The 2020 FOP Family Gathering will be held November 19-22 in Dallas, Texas. Visit [ifopa.org/family\\_gathering](https://ifopa.org/family_gathering) for updates.**



# Building Hope and Community Around the World



Top to bottom: Attendees of the FOP Russia meeting get a hands-on opportunity to learn about the IFOPA's Ability Toolbox Program; Those living with FOP gather for a photo at the FOP France meeting; German FOP community members Nadine and Sarah collect their dressing sticks and spirometers - gifts of the IFOPA's Ability Toolbox Program



**T**he IFOPA is truly an international organization. We're upholding our commitment to the global FOP community and expanding the resources offered worldwide.

In 2019, the IFOPA's Executive Director Michelle Davis attended family meetings in Germany, Russia, The Netherlands and France sharing about the FOP Registry, including the new Registry Rewards Program; Ability Toolbox: Everyday Tools for Independent Living; and the Harold & Elaine Kaplan Quality of L.I.F.E. Awards.

A video presentation was sent to the meeting in Italy along with translated materials and a spirometer and dressing stick for those living with FOP - gifts from the Ability Toolbox program.

There has been an increase in people outside the United States seeking Quality of L.I.F.E. Awards, enrolling in the FOP Registry, hosting fundraisers and donating to the IFOPA.

A lot of interaction happens online via email and social media—and while the website can be translated, it's important to spend time with people face-to-face.

"Nothing compares to sitting and sharing a conversation, a meal or a workshop with someone in person. When you can interact directly and ask one other questions (even with the assistance of an interpreter), you each gain new knowledge," said Michelle Davis. "Connection grows when you're together."

"When we go to these meetings, we learn what different organizations are developing for their countries. We're always excited to partner with them to bring some of these programs or services back to the United States," Davis said.

Attending international meetings also strengthens relationships with physicians around the world. They're learning more about the IFOPA and becoming ambassadors, sharing our information when they meet with families.

"We're excited that in 2020 we will be developing IFOPA Welcome Packets for doctors so they can give families something to take home. These Welcome Packets will be translated into multiple languages," said Davis.

"FOP is an ultra-rare disease. We have to stick together," Davis said. "Participating in international meetings allows us to be more than just an online community, develop relationships and increase the relevance and value of our programs and services worldwide."



The IFOPA is grateful to the Radiant Hope Foundation for their leadership support of Ability Toolbox, as well as additional sponsor support from Ipsen, Regeneron and Blueprint Medicines.





# FOP Registry Insights Shared at the RARE Drug Development Symposium

Winning Top Poster Highlights the Importance of our FOP Registry



The IFOPA won Top Poster at the 2019 Global Genes RARE Drug Development Symposium in June. Each year Global Genes hosts this event which focuses on the latest topics covering rare disease research and drug development. The IFOPA's Director of Research Development and Partnerships Adam Sherman presented a poster at the symposium highlighting our FOP Registry.

Contributing authors to the poster also included Dr. Fred Kaplan; Dr. Robert Pignolo; Kin Cheung, FOP Registry statistician; and Mary Anne Fitzpatrick, then-FOP Registry project director. The poster demonstrated the importance

of the FOP Registry and shared insights gained so far from the data available thanks to the individuals with FOP who have contributed information. The FOP Registry is off to a tremendous start with over 40 percent of all known people with FOP participating.

Also in attendance at the Symposium was Kyle Wallace who serves on the IFOPA's Research Committee and is the father of Eli who has FOP. He attended the September 2019 Global Genes RARE Patient Summit and exhibited the poster.



If you have FOP and want to make an immediate and lasting impact on research, visit [fopregistry.org](https://fopregistry.org) to enroll.

## Help Us Connect and Serve Siblings

When an individual is diagnosed with FOP the whole family experiences the impact of the diagnosis. The IFOPA aims to provide programming to support the entire family unit. As our Family Services program grows we will be recognizing the sibling relationship and providing resources geared towards supporting our siblings of all ages.

In order to do this, we need to create a database of siblings in the FOP community. Please email [Hope Newport, Family Services Manager](mailto:HopeNewport@ifopa.org), at [hope.newport@ifopa.org](mailto:hope.newport@ifopa.org) with the sibling's name, whether they are an adult or 17 & under, mailing address and an email (email for adults only).

Thank you for helping us connect to and serve siblings!



The Gonzales siblings, Hamilton siblings and Sherrod siblings.

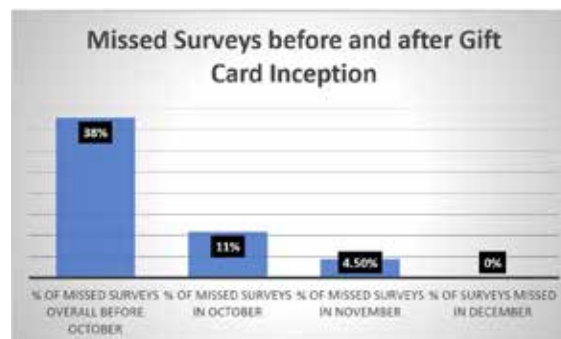


# FOP Registry Participation on the Rise

The FOP Registry is the largest and most in-depth database of clinical and medical information about FOP and those who are living with the disease; it is owned and operated by the IFOPA. The Registry accelerates FOP research, enables clinical trials and improves our understanding of the disease. Last Fall the IFOPA launched two important initiatives to increase participation in the FOP Registry.



Prior to October 1 when the Registry Rewards program began, 38% of Follow-up Surveys weren't completed. After we implemented Registry Rewards, that number dropped to 11% in October, 4.5% in November, and in December every single person completed their Follow-up Survey.



## FOP Registry Mobile App

We know that more than half of the IFOPA's website visitors use a mobile device, and that for many living with FOP it's easier to use a mobile device than a personal computer. In November the IFOPA launched the FOP Registry Mobile App to provide Registry participants with the flexibility to complete their Enrollment or Follow-Up Surveys on their mobile device. The app improves the participants' experience while completing their surveys, and provides an option that may better accommodate their lifestyle.

The app is currently available for iPhone users, but an Android app will be launched later this year. Translations of the Registry app in French, German, Italian, Portuguese, Russian and Spanish are also in development.

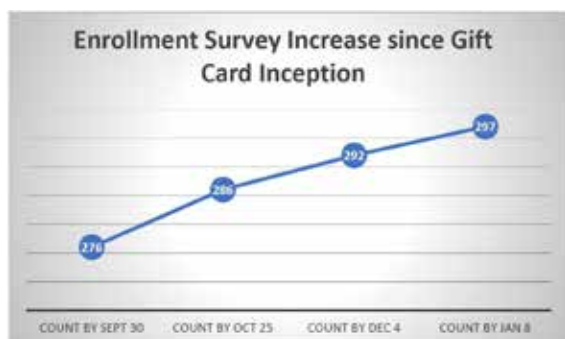
We are grateful to each person with FOP who has fully enrolled in the Registry and is completing their Follow-up Surveys. You are making important contributions to FOP research!

*The IFOPA oversees the FOP Registry on behalf of the FOP community thanks to generous support from Blueprint Medicines, Ipsen and Regeneron Pharmaceuticals. Thank you to the Radiant Hope Foundation for the visionary funding that launched the FOP Registry.*

## FOP Registry Rewards Program

In October, the IFOPA launched the FOP Registry Rewards Program. This program rewards new and existing FOP Registry participants with a \$25 Visa gift card when they submit their completed Enrollment and Follow-up Surveys. The goals of this program are not only to thank Registry participants for the time and effort they put into completing their Registry surveys, but also to increase the number of surveys in the Registry, which will ultimately help researchers better understand FOP.

Since the inception of the Registry Rewards program in October, the number of Enrollment surveys submitted increased from 276 in October to 297 in December. Enrollment surveys provide important information about a patient's FOP diagnosis and FOP history, which is essential to understanding the FOP patient's journey.



Once an Enrollment survey is submitted, the Registry participant will receive follow-up surveys by email every 6 months. These surveys help researchers understand how FOP progresses over time. The value of the FOP Registry is in its longitudinal design. In longitudinal studies, repeated observations of the same variables are captured over time. FOP Registry participants are reminded of their upcoming and open surveys through email, and they have 30 days to complete it before it closes.



To learn more about the FOP Registry and access frequently asked questions, visit [ifopa.org/fopregistry](https://ifopa.org/fopregistry)

# New IFOPA Videos Raise Awareness and Teach About Drug Development and Clinical Trials

The IFOPA uses a variety of tools to connect, educate and support the FOP community. In 2019, three new video resources were released for the FOP community.



**Raising awareness** is a key part of the IFOPA's mission. *The Same But Different: A Look at Life With FOP* helps kids and teens educate classmates, friends in clubs or at church or synagogue, neighbors or anyone they are interacting with about life with FOP. The support of our many donors and fundraisers made this video a reality. Our children and teens and their parents thank you.



**Clinical trials** are the only way drugs for FOP will ever be approved, so it's important for FOP community members to really understand the drug development process and clinical trials. *The Drug Development Journey for FOP: How Medicines Become Treatments* and *Exploring Clinical Trials for FOP* use quick draw animation to educate. These videos will soon be translated into multiple languages.

Thanks to Regeneron Pharmaceuticals, Ipsen and Blueprint Medicines for underwriting these important educational tools.



You can find these new video resources on the IFOPA's YouTube channel at [youtube.com/ifopa](https://youtube.com/ifopa).

## Are You Ready to Raise FOP Awareness?

**April 23, International FOP Awareness Day,**

will be here before we know it! You'll want to get your #cureFOP gear now so you can raise awareness all month long. From t-shirts and hoodies to hats, license plate covers and PopSockets - there are lots of ways to raise FOP awareness.

**Get your FOP awareness gear at [ifopa.org/store](https://ifopa.org/store)**

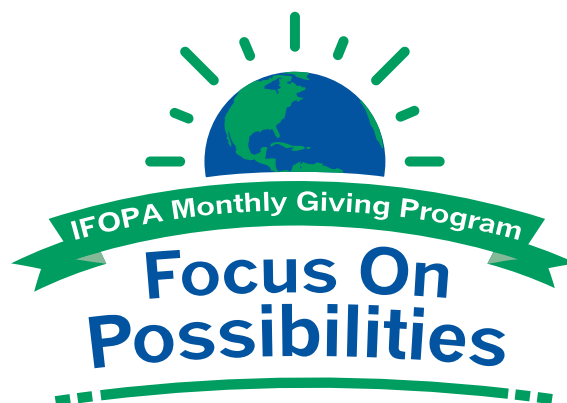


# Monthly Donors Focus On Possibilities

Monthly Giving Adds Up and Makes a Big Impact

The IFOPA's 61 monthly donors\* Focus On Possibilities to ensure research and support for individuals with FOP and their families. We're able to fund more research, offer more education and raise more awareness because monthly partners make a convenient, automatic gift that provides reliable funding for important programs.

In February 2019, the IFOPA met a challenge to get 20 new monthly donors and earned an extra \$5,000 gift from a generous friend in honor of Rare Disease Day. We're grateful to those 20 donors, as well as the other 41 wonderful partners, who give monthly gifts ranging from \$2 to \$500. Gifts of any size help us #cureFOP.



## THANK YOU TO:

### Anonymous Donors (17)

Bukki Adedapo  
Emma Albee  
Joseph Barbera  
The Bedford-Gay Family  
Sarah Benish  
Bernard Buckley  
Paula & Brian Callahan  
Douglas Coleman  
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Surovich & Family  
Brianna Tanner  
Alicia & Josh Vera  
Ilene Weiss  
The Wray Family  
Nichole Yco

*\*As of January 31, 2020*

**No matter the amount you pledge, your monthly contribution has a real impact for the FOP community.**



**OF EVERY DOLLAR YOU GIVE  
FUNDS PROGRAMS AND SERVICES**

**Together, we work to #cureFOP. Together, we are committed to hope. Together, we Focus On Possibilities.**



**If you're not a monthly donor, sign up today at [ifopa.org/monthly\\_giving](https://ifopa.org/monthly_giving) and Partner in Possibilities!**



# 2019 a Million Dollar Year for the IFOPA



The IFOPA is grateful for the incredible support received in 2019, including an extremely generous \$1 million anonymous gift. On behalf of the FOP community, the IFOPA Board of Directors and staff express our most heartfelt thanks. Strategic thought and planning is being put into making the most effective use of this funding for the benefit of the FOP community now and in the years to come.

"This remarkable gift presents us with huge opportunities for 2020 and beyond," said IFOPA Executive Director Michelle Davis.

"It will allow us to address the needs of patients, families and FOP research at a new level. We are so grateful for this gift, and are excited to make sure it helps the FOP family in powerful ways."

2019 also saw two large fundraisers – ZipperQ and Bingo for a Cure! – cross the \$1 million mark for the total amount raised since the events began. Both Bingo for a Cure! and ZipperQ have been popular for years and continue to draw fantastic support.

It's wonderful to see these fundraisers each reach this major milestone in the same year. The families and friends who have faithfully worked to make these events successful are sincerely appreciated.

With these great contributions, and the efforts of all who support the FOP community, the IFOPA is building on our strong foundation to get closer to treatments and a cure for FOP.

## IFOPA STAFF

**Michelle Davis**  
Executive Director

**Adam Sherman**  
Director of Research  
Development & Partnerships

**Hope Newport**  
Family Services Manager

**Cathryn Roys**  
Community Fundraising Manager

**Sammi Kile**  
FOP Registry Project Manager

**Karen Kirchhoff**  
Family Services Coordinator

**Brianna Tanner**  
Donor Relations & Digital  
Coordinator

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## WATCH FOR THESE

Events Being Held in the United States in 2020

**February 16** // A Transatlantic Burns Supper in Ft. Lauderdale, Florida hosted by Gail & Richard Simcox

**February 29** // Rare Disease Day

**March 22** // Joshua's Future of Promises (FOP) Bingo for a Cure! in Allentown, Pennsylvania hosted by the family of Joshua Scoble

**April 23** // FOP Awareness Day

**April 30** // FOP Ashley's Cure Finding a Cure Gala in New York, New York hosted by the family of Ashley Martucci

**May 9** // B.A.D. (Bolt Across Delaware) to the Bone Bike Ride hosted by the family of Justin Henke

**June 13** // Million Dollar Bike Ride in Philadelphia, Pennsylvania

**July 2020** // Midnight Sun Color Run in Kotzebue, Alaska hosted by the family of Dilyn Martin

**October 3** // ZipperQ in Claremore, Oklahoma hosted by the family of Zip Gordon

**November 19-22** // FOP Family Gathering in Dallas, Texas

To make sure you get details on these events sign up for the FOP Connection eNewsletter at [ifopa.org/connect](https://ifopa.org/connect) or visit [ifopa.org/calendar\\_of\\_events](https://ifopa.org/calendar_of_events)

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