

2020 FOP Family Gathering Offers a Free Virtual Experience

The IFOPA's FOP Family Gathering is going virtual for 2020 due to the many challenges the FOP community is facing as a result of the ongoing COVID-19 situation. Though the pandemic means no longer meeting in Dallas, Texas, the ability to meet online opens up new and unique opportunities November 20-22.

- » Thanks to the generous support of our sponsors, this Virtual Family Gathering will be accessible to all community participants free of charge!
- » And it's for everyone – people with FOP, family members (even extended family), caregivers, doctors, researchers, pharmaceutical teams and donors.
- » And it's available worldwide. General session presentations will have written and audio translations in up to 16 different languages.
- » It's timeless (well, for a year)! Registered attendees will be able to access the virtual platform for one year after the date of the event.

Three days of presentations will feature panelists from around the world. It's a great chance to get the latest updates and hear from FOP experts while coming together for connectivity and support.

Sessions of interest include an update on FOP research from Dr. Fred Kaplan; two FOP medical expert panels – one with doctors from the US and one with doctors from the United Kingdom, Brazil and South Africa; an Ability Toolbox panel led by individuals living with FOP; and the always popular update on clinical studies and trials.

The event will provide times for small group discussions where specific people – moms, dads, siblings, spouses and others – can connect with each other. Attendees can also enjoy fun games and evening activities.

You can learn more at ifopa.org/social_events

An online exhibit hall will share downloadable resources, pre-recorded demonstrations and allow chats with exhibit booth staff.

"The 2020 Virtual Family Gathering will be our first-ever event to provide the opportunity to learn, connect and grow to our global FOP community," said IFOPA Family Services Manager Hope Newport.

"We know the opportunity to meet in person will be greatly missed, but we are excited to be able to connect in a different way with a larger portion of the FOP community than ever before.

"We believe that with impactful session content, engaging small group discussions and family-focused extracurricular events this Family Gathering will be an inspiring event for everyone!"



"The 2020 Virtual Family Gathering will be our first-ever event to provide the opportunity to learn, connect and grow to our global FOP community."

—Hope Newport, IFOPA Family Services Manager

TURN THE PAGE
for a sneak peek at the
full preliminary itinerary.



2020 Family Gathering Itinerary

Subject to Change



We're grateful to our two Success Councils who have assisted with the planning of this first-ever Virtual Family Gathering.

INTERNATIONAL SUCCESS COUNCIL

Chris & Helen
Bedford-Gay
Anna Belyaeva
Elinor Bouvy-Berends
Nadine Großmann
Moiria Liljesthrom
Brooke Scott
Odette Schwegler

US SUCCESS COUNCIL

Danie Coyne
Lori Danzer
Eric & Johanna Klein
Nancy Sando
Joey Suchanek

Thank you to our 2020 Virtual Family Gathering Sponsors*

REGENERON
science to medicine®



**Additional sponsors to be announced.*

FRIDAY, NOVEMBER 20

9:00 to 10:00 am ET	FOP Update from Dr. Fred Kaplan
10:00 am to 11:30 am ET	Common Health Questions of FOP'ers Panel with US Treators
11:30 am to 12:00 pm ET	Comfort Break (plus Exhibit Hall and Lounge Time)
12:00 to 1:30 pm ET	FOP Clinical Trials
1:30 to 2:00 pm ET	Comfort Break (plus Exhibit Hall and Lounge Time)
2:00 to 3:30 pm ET	Small Group Discussions
3:30 to 6:30 pm ET	Exhibit Hall and Lounge Time
7:00 pm ET	Community Social Events

SATURDAY, NOVEMBER 21

4:00 to 5:30 am ET	Small Group Discussions for International Participants based on Country
6:00 to 8:00 am ET	Exhibit Hall and Lounge Time for International Participants
8:00 to 9:30 am ET	Common Health Questions of FOP'ers Panel with International Treators

Choose 1:

11:00 am to 12:30 pm ET	Pain Management Panel
11:00 am to 12:30 pm ET	Dental Care and Anesthesia Experts Panel
11:00 am to 12:00 pm ET	IFOPA Research Update

Choose 1:

12:30 to 2:00 pm ET	Living Well with FOP and the Ability Toolbox Program
12:30 to 2:00 pm ET	Complimentary Therapies Panel
12:30 to 1:30 pm ET	Staying Positive & Coping with Loss
2:00 to 2:30 pm ET	Comfort Break and Kids Contest (plus Exhibit Hall and Lounge Time)
2:30 to 4:00 pm ET	Small Group Discussions
4:00 to 7:00 pm ET	Exhibit Hall and Lounge Time
7:00 pm ET	Community Social Events

SUNDAY, NOVEMBER 22

10:00 to 11:00 am ET	Clinical Studies & Trials: Your Choice, Your Role, Your Responsibility
11:00 to 11:45 am ET	IFOPA Family Services
11:45 am to 12:15 pm ET	Comfort Break and Kids Contest (plus Exhibit Hall and Lounge Time)
12:15 to 1:00 pm ET	FOP Registry
1:00 to 1:45 pm ET	FOP Awareness & Fundraising
1:45 to 2:00 pm ET	Live Wrap-up of the 2020 Family Gathering



SIGN UP TO ATTEND THE 2020 VIRTUAL FAMILY GATHERING AT
ifopa.org/2020_virtual_fop_family_gathering

The IFOPA Launches *In Pursuit of a Cure* Campaign to Expand FOP Research

The IFOPA is excited to take the next step in FOP research with the *In Pursuit of a Cure* Campaign. *In Pursuit of a Cure* will increase research support to fund:

- » New ACT (Accelerating Cures and Treatments) for FOP research grants
- » IFOPA's first-ever targeted research grant in gene therapy

The campaign goal is to raise at least \$250,000 to expand FOP research; as of mid-September \$350,000 has been raised.

Gene therapy experts from the University of Massachusetts and FOP specialists will collaborate to discover if gene therapy can be a path to a cure for FOP. "We are committed to exploring every avenue of research toward a cure for FOP," said IFOPA Executive Director Michelle Davis.

"Gene therapy doesn't replace our research in drug development or current and future clinical trials, but if successful, gene therapy has the potential to cure FOP. It's a long road, but we must leave no stone unturned in the search for a cure."

A virtual event, *In Pursuit of a Cure – An Evening of Inspiration & Possibility*, was held in August on Facebook and YouTube. The event was both educational and touching. Viewers heard about the success of the ACT for FOP Grant Program which started in 2015, learned what gene therapy is and how it may benefit the FOP community, and met FOP families, including some very special Youth Ambassadors.

A generous donor offered a special \$50,000 gift to match the first \$50,000 in donations to *In Pursuit of a Cure*. The event not only raised much-needed funds for FOP research, but it spread the word about FOP. The two-day virtual event had a reach of more than 16,000 and received more than 3,000 reactions on Facebook & YouTube.

Thank you to the *In Pursuit of a Cure* Co-chairs and participants who helped make this special event a success:

CAMPAIGN CO-CHAIRS

Rory & Eric Otto
Rebecca Wallace & Kyle Wallace

RESEARCHERS

Marelise W. Eekhoff, MD, PhD
Guangping Gao, PhD
Ben Levi, MD
Jae Shim, PhD
Eileen Shore, PhD
Bernard Smilde, MD
Paul B. Yu, MD, PhD

Hollywood Family
Moirá Liljesthröm
Klein Family
Ng Family
Otto Family
Porter Family
Russell Family
Wallace Family
Wheelock Family
Williams Family
Wray Family

IFOPA LEADERSHIP

IFOPA Board of Directors
IFOPA Research Committee

PRODUCTION PARTNERS

Trailhead Films
JJB Creative Design
Merrigan & Co.
Dane Wutke

And thank you to everyone joining us *In Pursuit of a Cure*!



MISSED THE *IN PURSUIT OF A CURE* EVENT OR WANT TO WATCH IT AGAIN?

You can watch or share the recording at ifopa.org/curefop_live_event

WANT TO HELP THE IFOPA CONTINUE TO EXPAND LIFE-CHANGING RESEARCH?

You can still donate at ifopa.org/curefop_give

INTERESTED IN LEARNING MORE ABOUT GENE THERAPY?

- » Watch Gene Therapy Basics at ifopa.org/gene_therapy_basics
- » Watch the Intro to Gene Therapy in FOP Webinar at ifopa.org/curefop_webinar

Welcome Packet Helps Families Navigate FOP Journey

A newly designed Welcome Packet will offer support to recently diagnosed patients and patients who have had a diagnosis but never connected to resources and other people with FOP.

"We know from our experience working with families that connecting isolated or newly diagnosed individuals to the IFOPA and the FOP community is a vital step in their journey," said IFOPA Family Services Manager Hope Newport.

"This packet will allow us to meet families where they are in their FOP journey. It will give them the tools and resources to understand they're not alone and that the vast network of the IFOPA is ready to support them when they're ready."

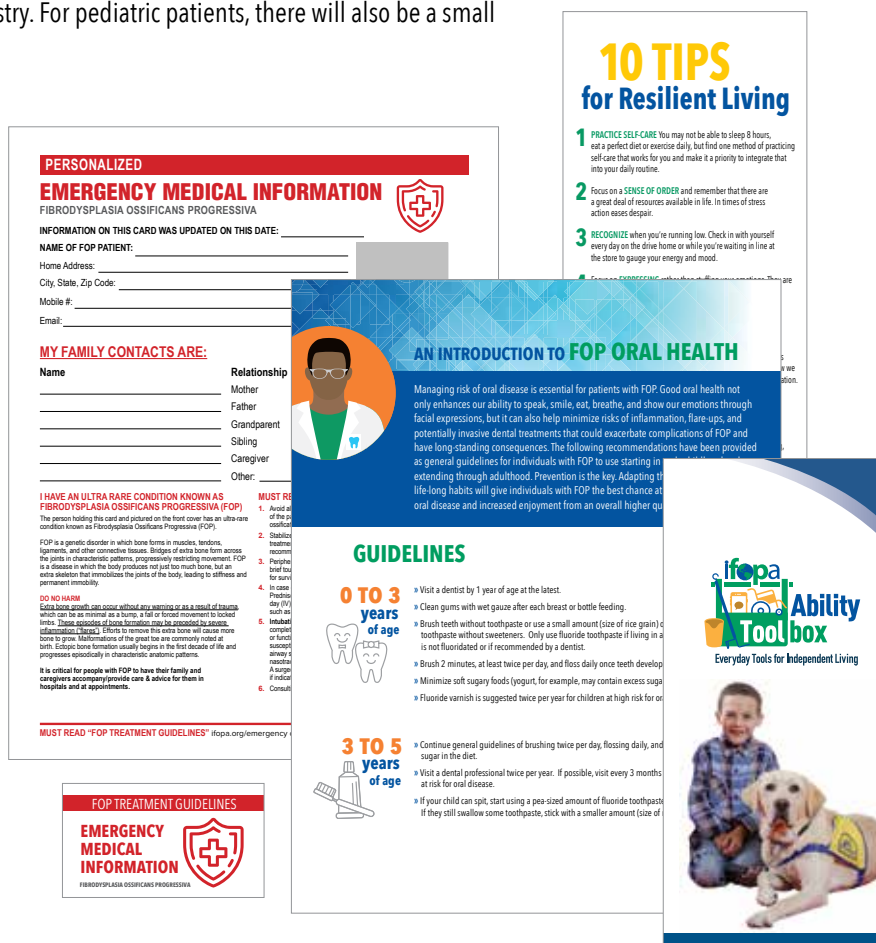
The Welcome Packet will provide overviews of the IFOPA and the education and support programs that are available, as well as ways for them to support research like the FOP Registry. For pediatric patients, there will also be a small teddy bear with an IFOPA logo shirt.

The materials in the packet will be translated in Dutch, French, German, Italian, Portuguese, Russian and Spanish. Welcome Packets will be distributed to doctors or national organization leaders in 13 countries.

No matter where someone is in the world or in their journey with FOP, the packet will let them know there are people who understand how they feel and can provide invaluable guidance and support. The hope is that it's a first step in patients and families building life-long relationships with the IFOPA and FOP community.

The new Welcome Packet will include information on:

- » 10 Tips for Resilient Living
- » Ability Toolbox
- » Clinical Trials and Drug Development
- » Dental Care Resources
- » Emergency Contact Card with FOP Doctors
- » Emergency Resources and Managing Medical Needs
- » FOP Registry
- » Harold and Elaine Kaplan Quality of L.I.F.E. Awards
- » IFOPA FOP Biobank (US only)
- » Your IFOPA



Lots of Ways for You to Still Participate

The IFOPA's Resilient Living Program provides education for strengthening the mind and spirit as every family works to overcome the challenges they face throughout their journey with FOP.

The flagship program is the Resilient Living Educational Series which provides an opportunity for members of the FOP community to come together virtually to learn about ways to incorporate habits that support their mental and physical well-being in day-to-day living. **There are 2 live webinars left this year – October 20 and November 24 – plus you can always go back and listen to the eight previous sessions.** **Get involved at ifopa.org/resilient_living_educational_series**

New Preclinical Drug Testing Program Begins

In July, the IFOPA announced the launch of a new preclinical drug testing program which will provide opportunities to assess how drug compounds work in two FOP mouse models. **This program could accelerate the discovery of new FOP treatments by lowering the costs and barriers of evaluating promising drugs in *in-vivo*, or living, models of the disease.**

"Preclinical drug testing is meant to be a mechanism by which new ideas can be rapidly evaluated in *in-vivo* FOP models without the time or expense of acquiring, expanding and maintaining mouse colonies," said Dr. Robert Pignolo of the Mayo Clinic College of Medicine and International Clinical Council on FOP founding member.

"Centralizing preclinical testing also allows for results to be standardized and compared across compounds, thereby enabling the identification of agents that have the highest likelihood of beneficial effects in patients," he continued.

"The program is unique in that it is open to stakeholders from industry to academia to lay individuals. We will be translating the best ideas into evidence for possible future first-in-human pilot and larger studies."

This exciting program is operated through a collaboration with investigators Drs. Pignolo and Haitao Wang at the Mayo Clinic where all preclinical testing will take place. The IFOPA greatly appreciates their commitment and involvement.

The IFOPA will accept preclinical drug testing proposals from academic researchers, biotech or pharmaceutical companies and FOP community members. A competitive review process will determine which proposals will be given access to this service.

"It's testing in a box. Researchers only need to provide the idea, or the drug in the case of pharmaceutical companies, and we will test it," said the IFOPA Research Development and Partnerships Director Adam Sherman.

"This could include new treatments, repurposed treatments (i.e. testing drugs approved for other diseases) or combinations of treatments. We also hope this will help companies who are interested in FOP, but need pilot data to support a decision, to move forward."



Dr. Robert Pignolo,
Mayo Clinic College of
Medicine and International
Clinical Council on
FOP founding member



LEARN MORE
at ifopa.org/preclinical_drug_testing

Prevalence Study Underway to Update Estimate on Cases of FOP



The IFOPA is conducting a prevalence study to better estimate the number of known individuals living with FOP in the United States.

The current prevalence figure for FOP of 1 in 2 million is an estimate. Very few studies have looked at FOP prevalence in a more rigorous way. Data from this new study will help focus efforts on early diagnosis, make it easier to identify countries of under-diagnosis and provide an opportunity to raise awareness about FOP.

The goal is to publish study results in a scientific journal by year end. The IFOPA is working on this project with Drs. Fred Kaplan (University of Pennsylvania), Edward Hsiao (University of California, San Francisco), Robert Pignolo (Mayo Clinic) and Genevieve Baujat (Hôpital Necker Enfants Malades, France), as well as an epidemiologist consultant.

Thank you to sponsors Blueprint Medicines, Ipsen and Regeneron Pharmaceuticals for making this study possible.



Team
#curefop

Team #cureFOP Goes on a Virtual Million Dollar Bike Ride

Team #cureFOP had 14 participants for the Penn Medicine Orphan Disease Center's (ODC) 7th Annual Million Dollar Bike Ride (MDBR) on June 13, 2020. This was the IFOPA'S third year participating and the first-ever virtual Million Dollar Bike Ride. The Ride was a huge success for rare disease research.

The IFOPA is grateful to the riders and donors who represent every part of the FOP community – individuals with FOP and their families, doctors and FOP researchers, and even people who work for Ipsen Biopharmaceuticals. We're also thankful to the ODC for providing a \$30,000 match. **Thanks to the support of everyone on Team #curefop and the ODC match, there will be two \$40,000 FOP research grants available!** The Million Dollar Bike Ride Pilot Grant Program is open to the international research community. Watch for an announcement later this year of the grant recipients.



WATCH the Million Dollar Bike Ride Welcome Video at ifopa.org/2020MDBR_welcome

You'll hear from John Emmerich, FOP'er Patrick Doerr's stepfather, at 22:08.



Participants of the #cureFOP Virtual Million Dollar Bike Ride: 1. Lisa Gillooly, New Mexico; 2. Brendan Scott, South Australia; 3. Maria Wray, New York; 4. Ed and Ian Hsiao, California; 5. Curt Mull, Georgia; 6. John Emmerich, Arizona; 7. Tara Valley, Pennsylvania; 8. Joe and Abby Burns, New Jersey; 9. Savannah Porter (left) and Saniya Porter (right), California; 10. Jake, Pam, Wyatt and Graham Reichert, Massachusetts; 11. Jeanne McGrath, Colorado; 12. Seth and Olivia Fritts, Colorado; 13. John Roys, North Dakota; Not pictured Karine Lalonde

Meet the 2020 Jeannie Peeper Award Winners

On June 8, the IFOPA's 32nd anniversary, our Founder Jeannie Peeper called the 2020 Jeannie Peeper Award Winners to share that they had been selected to receive this very special award.

The Jeannie Peeper Awards – which honor our Founder's initiative, leadership, vision and courage – recognize those who make exceptional contributions to the IFOPA through their leadership, service, fundraising, awareness-building and other accomplishments.

Since 2010, the IFOPA has recognized individuals and groups for their service to the FOP community.



You can read about this year's winners at ifopa.org/2020_winners

OUTSTANDING COMMUNITY LEADERSHIP - GROUP AWARD

Sienna Otto & Family



OUTSTANDING COMMUNITY LEADERSHIP - INDIVIDUAL AWARD

Stephen Guisepppe



OUTSTANDING INTERNATIONAL LEADERSHIP AWARD

Massimo Alfieri



INSPIRING LEADERSHIP AWARD

Steve Eichner



PRESIDENT'S LIFETIME ACHIEVE AWARD

The International Clinical Council on FOP



The ICC meeting in Baltimore, Maryland November 2018. From left to right; Upper row: Robert Diecidue, Clive Friedman, Coen Netelenbos, Rolf Morhart, Christiaan Scott, Edward Hsiao, Elisabeth Marelise Eekhoff, Carmen De Cunto, Richard Keen, Maja DiRocco, Amanda Cali; Lower row: Patricia Delai, Robert Pignolo, Frederick Kaplan, Zvi Grunwald, Genevieve Baujat, Mona Al Mukaddam; Absent: Matthew Brown, Tae-Joon Cho, Nobuhiko Haga, Michael Zasloff, Keqin Zhang

THANK YOU to the 2020 Jeannie Peeper Awards Committee, which included Jeannie Peeper, Gretty Emmerich, Nadine Grossmann, Nancy Sando and Michelle Davis.

ACT for FOP Grants Fund Crucial Research

The ACT (Accelerating Cures and Treatments) for FOP Grant program is going into its sixth year of supporting the research and development of safe, transformative therapies for FOP.

Through a competitive application process, the IFOPA has awarded more than \$1 million in crucial funding to scientists conducting promising research related to FOP. So far, this includes 18 grants at 14 different institutions around the world. Many of these grants are to projects focused on new treatments for FOP.

"Until we have a cure for FOP, we need as many 'shots on goal' as possible for treating FOP," said the IFOPA Research Development and Partnerships Director Adam Sherman.

"The ACT for FOP Grant Program provides vital grant funding to researchers who have innovative research ideas and potential treatments for FOP, but limited financial resources to continue their research."

The IFOPA is grateful to the Scientific Advisory Board who helps review the grant applications and makes funding recommendations. The Scientific Advisory Board includes:



Chair Dr. Vicki Rosen,
Harvard School of
Dental Medicine



Dr. Marie Demay,
Mass General Research
Institute



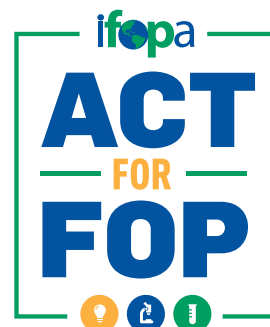
Dr. Karen Lyons,
UCLA / Orthopaedic
Hospital Department of
Orthopaedic Surgery



Dr. Michael Whyte,
Washington University
School of Medicine



Dr. Michael Zasloff,
Georgetown University
Medical Center



"Until we have a cure for FOP, we need as many 'shots on goal' as possible for treating FOP."

— Adam Sherman, IFOPA Research Development and Partnerships Director

The ACT for FOP Grant Program was launched in 2015 by friends and family of Sona Brinkman. Today others who are passionate about curing FOP have joined them in funding the ACT for FOP Grant Program with lead gifts from: Joshua's Future of Promises, Canadian FOP Network, FOP Australia, FOP Friends®, FOP Italia and friends and family of Sona Brinkman.

Many thanks go to the generous donors who give to fund this critical research. ACT for FOP grants would not be possible without your support. **Please consider making a gift to ensure the IFOPA can fund nearly \$300,000 in grants in 2020 to move important research forward. You can give at ifopa.org/curefop_give and select ACT for FOP as your designation.**



LEARN MORE about ACT for FOP Grants and past recipients at ifopa.org/funding_opportunities

14 GRANTEES 2015-2020

18 Grants Awarded



Monthly Donors Focus On Possibilities

The IFOPA currently has 81 monthly donors on our Focus On Possibilities team. Monthly giving is an easy way to lift the burden of fundraising off FOP families and help the IFOPA generate awareness, fund research and support and educate families.

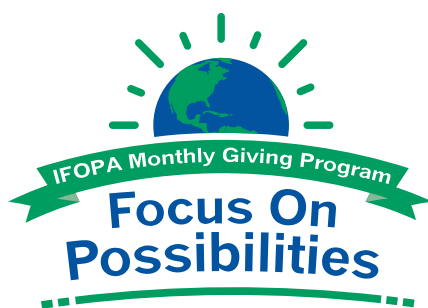
"Monthly giving is incredibly important. It ensures a reliable base of support for the FOP community. It's convenient to set up and any amount helps because it adds up every month. It's a great way to make a difference," said IFOPA Community Fundraising Manager Cathryn Roys.

Right now, Focus On Possibilities team members give from \$2.27 to \$200 each month. Several of them give through a workplace matching program, so their monthly gift is doubled.

Take advantage of the ease of monthly giving – no mailing checks, no remembering to make your gift – and join the Focus on Possibilities team today.

We're grateful for those that give to fund research, support families and raise FOP awareness each month.

**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 and Partner in Possibilities!**

THANK YOU TO:

24 anonymous donors
Bukki Adedapo
Emma Albee
Joseph Barbera
Bedford-Gay Family
Sarah Benish
Paul Brinkman
Bernard Buckley
Paula & Brian Callahan
Douglas Coleman
Jan & Wedge Crouch
Charles Curry
Michelle Davis
Pam Emery
Flexer Family
Fransen Family
Danielle Fraser
Bethany & Don Gibson
Lisa & Pat Gillooly
Gonzales Family
Amy Gordon
EMG and TLG Grimm
Marilyn Hair
and Richard Steele
Shannon Halford
Tage Hansen
Evan Harris
Sammi Kile
Karen Kirchhoff
Chang Jae Lee

Ann Lothrop
Joe Martucci
Abbie & Gary McGuire
Sondra & George McKean
Beth Miller
Katy Miller
LaVerne Miller
Molly Miller
Steven Miller
Family of Heather Niles
Megan Olsen
Natalie & Halsey Otto
Otto Family
Daniel, Kelli & Maddy Perrien
Cassandra Porter
Christina & Jamal Porter
Lindsey Quinn
Ann Rhodes
Frank & Barb Rickabaugh
Cathryn & John Roys
Nancy Sando & Family
Anne Marie Suchanek
Chris & Paul Surovich & Family
Brianna Tanner
Alicia & Josh Vera
Rebecca Wallace
Ilene Weiss
Wray Family
Nichole Yco

**As of September 15, 2020*



**Soon the leaves will be changing
and cooler temps rolling in.**

Get a #cureFOP fleece jacket, hooded sweatshirt or fleece blanket so you can stay warm and raise awareness throughout the Fall.

**Check out these items and
more at ifopa.org/store**



First Registry Medical Portal Sites Approved



The IFOPA is thrilled to announce that the first sites have been approved for the FOP Registry Medical Portal. Initial participants are Dr. Alberto Hidalgo-Bravo, at the Instituto Nacional de Rehabilitación in Mexico City, Mexico, and Dr. Carmen De-Cunto, FOP Registry Medical Advisory Board Chair, at the Sociedad Italiana de Beneficencia in Buenos Aires, Argentina.

The FOP Registry consists of a Medical Portal and a Patient Portal. The Patient Portal is open to people living with FOP, where they enter data about their FOP experiences. Participants in the FOP Patient Portal fill out surveys every 6 months and are eligible to receive a \$25 gift card for completing their surveys. The Medical Portal is for FOP clinicians to enter clinical information about their FOP patients. Although our Patient Portal has been collecting patient reported data since 2015, the addition of clinical data in the Medical Portal represents an important step to growing and augmenting the FOP Registry.

This is a special milestone, as it involves several regulatory processes for sites to become approved to participate in the Registry. In order for physicians to participate in the Medical Portal of the Registry, they must receive the approval of their local Ethics Committee. Once a physician and their site are onboarded into the Registry, they are encouraged to enter clinical data on their FOP patients twice a year.

"We're excited to receive the first two sites' Ethics Committee approval to participate in the Medical Portal of the Registry and look forward to

initiating activities with sites of Drs. Hidalgo-Bravo and De-Cunto," said FOP Registry Project Manager Sammi Kile.

"We await several additional sites around the world to participate in the Medical Portal in the near future. The IFOPA thanks Dr. Hidalgo-Bravo and Dr. De-Cunto, as well as their clinical teams, for their participation and future contributions to our FOP Registry."



Dr. Alberto Hidalgo-Bravo,
Instituto Nacional de
Rehabilitación in Mexico City,
Mexico



Dr. Carmen De-Cunto,
FOP Registry Medical Advisory Board
Chair, at the Sociedad Italiana de
Beneficencia in Buenos Aires, Argentina



VISIT ifopa.org/fopregistry to learn more about the FOP Registry or to enroll.

FOP-PROMPT The IFOPA is launching the FOP-PROMPT Development Study

This fall the IFOPA is beginning a patient-reported outcome (PRO) development study, FOP-PROMPT, to help include the patient voice in drug development.

FOP-PROMPT will serve the FOP community by helping researchers and clinical trial sponsors measure the impact of FOP on daily symptoms. Having a tool that accurately measures these symptoms will help support clinical trial sponsors in their drug development endeavors.

In order for a PRO tool to be validated and rendered fit for clinical trial use, the tool must go through a series of development phases. To accomplish this, the IFOPA is working with Adelphi Values, a leader in the field of PRO

tool validation, to work through the validation process and present the tool to regulators.

As part of this process, the IFOPA is excited to announce the launch of the FOP-PROMPT Development Study, which is a 30-day study that involves up to 50 individuals with FOP. Participants will be asked to complete a short daily questionnaire about their FOP symptoms. This phase of the validation process will be used to demonstrate the performance of the tool, and to gain an understanding of the scoring so it may be understood and used in future clinical trials.

"The validation of this tool is integral to the FOP community, as it will allow for FOP researchers and companies to use this tool

in their clinical trials which will ultimately help their drug development efforts," said FOP Registry Project Manager Sammi Kile.

"The FOP-PROMPT Study will help fulfill a key stage of the regulatory validation process. We will continue our collaboration with regulators and sponsors as we work towards making this tool available to the FOP community in the very near future."

Once a PRO tool is ready, the IFOPA will work on linguistic validation for translations in other languages. Watch for an announcement that the PRO tool has been added to the FOP Registry and Registry app, making this available to sponsors to use in clinical trials.



TO LEARN HOW YOU CAN PARTICIPATE

in the FOP-PROMPT Development Study, visit ifopa.org/other_research



We are grateful for the support of our sponsors: Blueprint Medicines, Ipsen and Regeneron Pharmaceuticals. Thank you to the Radiant Hope Foundation for the visionary funding that launched the FOP Registry.





The IFOPA is able to offer Ability Toolbox: Everyday Tools for Independent Living thanks to generous support from the Radiant Hope Foundation, as well as Regeneron Pharmaceuticals, Ipsen and Blueprint Medicines. We're pleased to share our first Ability Toolbox Annual Report.

JUNE 2019-MAY 2020 PROGRAM ACTIVITY REPORT

The Ability Toolbox: Everyday Tools for Independent Living program empowers individuals with FOP and supports their caregivers by promoting independence and a problem-solving mindset as a critical tool for coping with FOP progression.



HIRED FAMILY SERVICES COORDINATOR

KAREN KIRCHHOFF, MSPT
Family Services Coordinator

- » Manage Ability Toolbox Program
- » Administer Quality of L.I.F.E. Awards Program

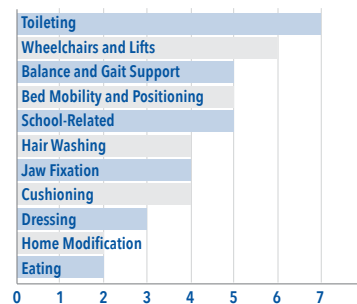
NEARLY 200 COMMUNITY CONNECTIONS ONE-ON-ONE SUPPORT TO 81 FAMILIES AND MEDICAL SUPPORT STAFF, IN 17 COUNTRIES



CONNECTING THROUGH:

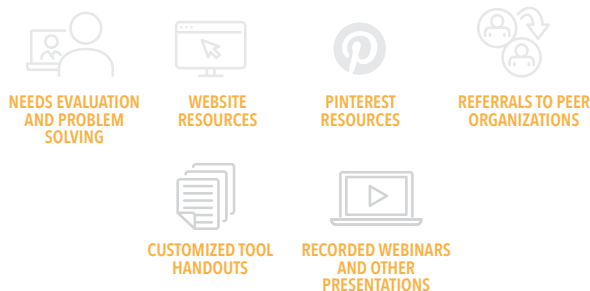


TOOL INQUIRIES:



GIFTED NEARLY 100 SPIROMETERS AND DRESSING STICKS to individuals with FOP in Germany, Russia, France, The Netherlands, United States and Italy. Spirometers are a tool to promote lung health.

CONSULTS PROVIDING:



ON THE HORIZON FOR YEAR 2:



THANKS TO OUR SPONSORS



Ability Toolbox Online Guidebook Launching This Fall

The IFOPA is launching a new Ability Toolbox Online Guidebook that will help members of the FOP community discover and share practical, useful tools for everyday needs.

The Ability Toolbox program empowers individuals with FOP by promoting independence with the use of tools and home modifications. The primary goal of the program is to foster a problem-solving mindset to help people adapt as their FOP progresses.

The Online Guidebook will feature commercially purchased tools and homemade tools that members of the FOP community have crafted. Each tool will have a page with a description, tips for use, pictures, video (if available) and purchasing information.

There will be search functions within the Online Guidebook and users will be able to leave reviews and comments. Individuals with FOP will also have a login feature giving them the ability to save favorite items for later reference.

To top it all off, the Online Guidebook will be able to be translated with the click of a button, making it a worldwide FOP community resource.

For new families just beginning to learn about tools or someone looking for ways to adjust as mobility changes, the Online Guidebook will be a fantastic resource. It will save time and effort by putting the tools many use on a daily basis in one place. It will also help save money as individuals and families share what works best for them or how to use an existing tool in a different way.

"I truly hope this will be a useful resource for the FOP community and make it easier for them to find and share tools that help make living with FOP more manageable," said the IFOPA Family Services Coordinator Karen Kirchhoff.

"Even though the Online Guidebook will be managed by the IFOPA, I want this to be the community's resource – created and expanded upon by them – so that it's a more meaningful and engaging resource."

The Online Guidebook should be available this fall with a few tools in each category. The hope is that more tools will be continuously added as time goes on and as more people participate by offering remarks, pictures, videos and new tool ideas.

New Ability Toolbox Online Guidebook will be organized by activity for quick, easy reference:

- » Toileting
- » Showering & Bathing
- » Dressing & Clothing
- » Cooking & Eating
- » Everyday Useful Tools
- » Bed Mobility & Positioning
- » School & Workplace
- » Recreation & Hobbies
- » Home Modifications
- » Wheelchairs, Lifts & Mobility Aids
- » Preventative Health & Dental



"I truly hope this will be a useful resource for the FOP community and make it easier for them to find and share tools that help make living with FOP more manageable."

— Karen Kirchhoff, IFOPA Family Services Coordinator

Designing a Better Life for People with FOP

Students Develop Practical Tools for Daily Tasks

Professors and students from Thomas Jefferson University are contributing to a new program – The WILL Project – by designing tools to ensure “We Improve Life and Living (WILL) with FOP.”

Dr. Zvi Grunwald, a founding member of the International Clinical Council on FOP, introduced the Thomas Jefferson University team to the FOP community. Through his work at the university, Dr. Grunwald connected with Eric Schneider, assistant professor of industrial design, and others focused on using design in health care and rehabilitation services.

Those discussions led to students inventing practical tools that could make life easier for people with FOP. The goal was to focus on less expensive items for daily use that would provide someone with more independence.

BIG IDEAS FOR SMALL TOOLS

The students began by participating in the IFOPA's 2019 Family Gathering to talk with attendees and discover what tools could be helpful. The conversations resulted in four interesting designs that show promise for possible use in the FOP community.

“Aaron Herl’s device for self-feeding soft foods is quite innovative in that he discovered he could pump pureed food using air pressure. Grace Choi’s wheelchair device holder is also clever and needed by anyone confined to a wheelchair with limited upper body mobility,” Schneider said.

“Nik Pathak’s modular reaching device has a number of unique features such as his proposal to use a gecko-inspired adhesive pad to grab objects. And Lauren Huggler’s showering assist system brings much needed independence to washing and bathing.”

These ideas took shape under the guidance of Schneider and Tod Corlett, director of industrial design programs at the university. Sarah McNabb and Michael Barrett, who are studying occupational therapy, were also involved.

FEEDBACK FROM THE FOP COMMUNITY

The Family Gathering, along with video chats and home visits, played a crucial role in the

designs. For Choi, who created a modular concept to customize what someone might attach to a wheelchair armrest, those interactions provided vital information.

“Meeting individuals and getting to know their personal experiences helped me connect with the intimate details in their lives that would not have been possible from just reading or researching,” said Choi. “For example, Kathy Ford’s input on the modular armrest changed the way the cup holder was mounted, and she validated the usefulness of the spring clip which I could only speculate on.”

Monica Anderson hosted a home visit and is thrilled to be a part of an initiative that will hopefully benefit the entire FOP community.

“The fact that someone came to my house to learn about FOP and my specific needs and then designed something from our conversations was a dream come true... I prayed for someone to actually do this not only for me, but for people with FOP. We want to be seen as ‘normal’ and this project is just the beginning of what we consider normal,” Anderson said.

Ian Cali agrees. He watched the students’ final presentations and offered feedback as an adult with FOP. Cali is excited by the thoughtfulness and energy of the students as well as the professors’ knowledge and ability to encourage perseverance in trying to address different problems.

“We collectively realized that the design process was far from linear and that any viable solution to the problems in discussion would take a series of efforts,” said Cali. “Overall, it was an awesome effort on all fronts, and I feel fortunate to have had the opportunity to be a part of it and meet everybody involved.”

LOOKING TO THE FUTURE

Schneider says this collaboration gets to the heart of his program. It has given students the chance to learn about universal and adaptive design, but also gain understanding and empathy. He counts it a success that his students are motivated to create practical products that will truly benefit the people who use them. The



Dr. Zvi Grunwald,
a founding member of
the International Clinical
Council on FOP

students are inspired by the courage of the FOP community and want to see designs more fully come to life.

Herl plans to turn his feeding system into his thesis project for a master’s degree and hopes to continue working in adaptive equipment manufacturing. Huggler, who designed a showerhead that could help with scrubbing the scalp and lathering shampoo, also dreams of seeing these ideas make a positive difference.

“The WILL Project has been the most rewarding and challenging collaboration I have been a part of thus far,” Huggler said. “I look forward to continuing my research in product development of assistive devices in order to provide accessible and affordable independence to those who need it most through the power of innovative design.”

SPECIAL THANKS AND ADDITIONAL RESOURCES FOR INDEPENDENT LIVING

While these products are only prototypes and aren’t commercially available for purchase, the IFOPA and Ability Toolbox program are grateful for the creative efforts of the WILL Project in 2019-2020 and are excited to see the direction it takes in the upcoming school year.

**INTERESTED IN
LEARNING MORE
ABOUT ADAPTIVE TOOLS OR NEED
HELP MODIFYING ONE TO MEET
YOUR NEEDS?**



**Learn more about the
Ability Toolbox program at
ifopa.org/ability_toolbox_program**

New Resources Promote Oral Health and Make Dental Care More Accessible

Good oral health is essential for individuals with FOP. It can help minimize risks of inflammation and flare-ups. It also helps avoid potentially invasive dental treatments that could worsen complications of FOP and have long-term consequences.

To help people with FOP and their families manage oral health, the IFOPA has put together a dental resources page on ifopa.org. It features:

- » Dentistry contacts who are familiar with the needs of the FOP community
- » Guidelines for care
- » Recorded webinar on oral health that explains helpful tips and tools

The new page is available at ifopa.org/oral_health_and_dentistry

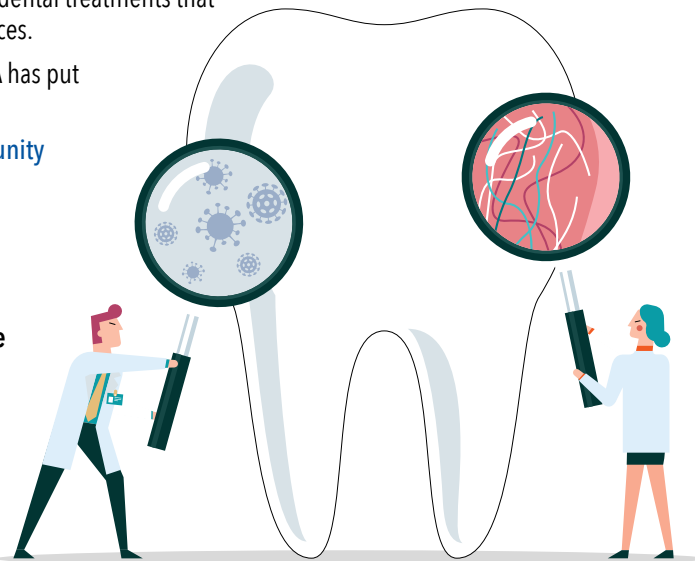
In addition, a travel stipend program for dental care is now available that can assist eligible families with transportation and lodging.

This stipend helps families who are financially burdened by traveling for dental care that can best be completed by an FOP dental expert at Jefferson University Hospitals in Philadelphia, Pennsylvania.

For more information, visit ifopa.org/dental_care_travel_stipend

"I am so delighted to see the IFOPA supporting the oral health of persons with FOP with their new dental stipend program and the dental resource page," said Clive Friedman, DDS, International Clinical Council on FOP founding member.

"Over the many Family Gatherings that I have attended, a common finding is difficulty of travel to obtain necessary care as well as easy access to all that is available to aid in obtaining excellent oral health. Remember, oral health is the gateway to the body – and what we find in the mouth is often an indicator of what is found in the rest of the body. Kudos for this initiative."



Clive Friedman, DDS,
International
Clinical Council on
FOP founding member

**#GIVING
TUESDAY**

The IFOPA is excited to build support for dental care by making the stipends program the focus of **#GivingTuesday for 2020**. Stay tuned for more details as #GivingTuesday approaches this year on **DECEMBER 1**.

Bereaved Families Connect Virtually

FOP Bereaved Families is a private group, managed by FOP community members Marilyn Hair and Nancy Sando, for family members and close friends of loved ones with FOP who have passed away.

Whether your loved one passed away months ago or years ago, you are welcome in the FOP Bereaved Families Group.

This group is an opportunity for those who have lost a family member to FOP to support each other in loss and grief. Meetings have included guest speakers, a Book Club or just meetings spent getting to know one another and sharing.



If you're interested in participating in our monthly Zoom meetings, email us at together@ifopa.org



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and 20% of your purchase will benefit

International FOP Association
October 1st & 2nd

Not combinable with other offers.

Kendra Scott

Shop for Good online at KendraScott.com on October 1 & 2. Use web code **GIVEBACK8753** and **20% of your purchase will benefit the IFOPA**. Shop for yourself, do some early holiday shopping and share the code with friends and family. The more people that shop using the code GIVEBACK8753, the more that will be donated to the IFOPA. There is lots to see in Kendra Scott's newest Fall Collection! The Shop for Good event is 100% online and 20% of all purchases come back to the IFOPA.

WATCH FOR THESE

upcoming events being held in the United States or online during Fall 2020:

Oct 1-31 // First-ever B.A.D. to the Bone Virtual Bike Ride hosted by the family of Justin Henke

October 3 // ZipperQ BBQ Throwdown: A Virtual Benefit in Claremore, Oklahoma hosted by the family of Zip Gordon

October 22 // FOP Ashley's Cure Virtual Gala hosted by the family of Ashley Martucci

October 24 // Gaming for a Cure Smash Ultimate Charity Event hosted by the family of Daniel Williams

November 20-22 // FOP Virtual Family Gathering

To sign up for the FOP Virtual Family Gathering visit ifopa.org/2020_virtual_fop_family_gathering

With these events virtual, there are lots of opportunities for you to participate no matter where you live.

More details at ifopa.org/calendar_of_events

2021 marks 15 years since the discovery of the FOP gene. Be watching in March 2021 for ways to get involved!

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