Team #curefop

Planning Guide

Introduction

Are you passionate about bringing hope to those with FOP? With Team #curefop program, you can do just about anything to raise funds to #cureFOP - from baking to singing, BBQ eating to hosting a dinner party.

This toolkit was designed to help walk you step by step through your fundraising activity for the IFOPA. And, the IFOPA staff is here to help. If you don't find the answer to your question in this guide (or even if you do!), don't hesitate to reach out to us for guidance, support and brainstorming.

You can contact Sara Brown, Fundraising Events Consultant, at sara.brown@ifopa.org or 816.489.2928.

What are you waiting for? Let's get started!

Checklist: Get Started

☐ **Choose Your Fundraising Activity**

When you participate in Team #curefop, the ways you can fundraise are endless. Start by thinking about your hobbies, what interests you and your friends, and what you'd enjoy doing to raise funds. The sky is the limit!

Here are some ideas to help you brainstorm:

- Letter writing or virtual campaign
- Chili Cook Off
- Bowl-a-Thon
- Lemonade Stand
- Garage Sale
- Golf Outing
- Host a Dinner Party
- Mow lawns for donations
- Penny War
- Birthday Party
- Work Jeans Day
- Benefit Concert
- 5K or 10K
- Prize drawing or silent auction
- Home shopping party (ex: Stella & Dot or Mary Kay)
- Kick Ball Tournament
- Pub Crawl
- Neighborhood Carnival
- Holiday Gift Wrap
- Restaurant percentage of sales night
- Car Wash

Still stumped? Check out what these supporters of the IFOPA did through Team #curefop.

☐ **Register Online**

Registering online for Team #curefop is the next step. When you register online, you'll be asked to tell us a little bit about yourself and what you plan to do to raise funds. You'll also be invited to make your own gift to get your fundraiser off to a great start!

The IFOPA provides easy and convenient fundraising web pages free of charge for participants. When you register for Team #curefop, your page will be automatically created and ready for you to use right away. Here are just some of the features of your personalized fundraising page:

- Your page may be customized with a photo or video and your own text. This means that you may use your page to share your personal story, fundraiser information and more!
- You may create a customized URL for your page, allowing for easy sharing and marketing.
- Friends, family and community members may support your fundraising activity directly through your personalized page. Making a donation online is easy and secure.
- Your page features an honor roll of all your donors and a thermometer to help you track your progress.
- When donors make a gift to your page, the IFOPA will automatically send a tax acknowledgement letter to the donor.

To register online and get started with your personalized fundraising page, click here .

☐ Set your fundraising goal

When you register online for Team #curefop, you'll be asked to set your fundraising goal. Setting an attainable yet challenging fundraising goal can be one of your most critical steps as you prepare for your fundraiser. Thinking through some of these questions will help you set your goal:

- How many people do you expect to support your fundraiser?
- What is the average amount you expect friends and family to give?
- Is it an option to obtain sponsorship or other community support?
- Can you make a personal financial investment in your activity? If so, how much?

☐ Get the Word Out

The best way to get the word out about your fundraiser will depend upon what your activity entails. If you're hosting a work jeans day, you'll communicate very differently than if you are hosting a neighborhood garage sale. Regardless, here are some general rules of thumb that will help you spread the word about the good you're doing for the IFOPA:

- Share, share, share your personalized URL. This URL is perfect for Facebook and social media, emails and posters you create.
- Talk about why you're raising funds for the IFOPA through Team #curefop. Your story is your most powerful fundraising tool.
- Check out the About the IFOPA and Where Your Money Goes section of this guide for great talking points about the IFOPA and all we're doing - with your help - to #cureFOP.

When you are marketing your fundraiser, please be mindful of these promotion and brand guidelines:

- Your fundraiser should be promoted and conducted in a manner to avoid the appearance of the IFOPA endorsing any product, firm, organization, individual or service.
- All advertising and promotion must clearly state that the IFOPA is the beneficiary of the fundraiser, not the host, sponsor or endorser. For example, this language will be appropriate for use: "Join us for my fundraiser to benefit the IFOPA!"
- Your fundraiser will be considered a legitimate activity to benefit the IFOPA only after you've registered online. Before that time, we are unable to confirm your activity if an inquiry arises.
- After you're registered online, you may email sara.brown@ifopa.org to request a copy of the IFOPA's logo for use in your promotional materials.
- A copy of the IFOPA style guide will help you make sure you use the IFOPA's logo correctly. To obtain your copy, email Sara at sara.brown@ifopa.org.

☐ Achieve Your Fundraising Goal

Fundraising sounds tough, but it doesn't have to be! With these three steps, you'll reach your goal in no time.

Step 1: Make your own gift

Nothing shows your supporters how important the cause is to you like your own personal donation. You may make a gift to your fundraiser during online registration, or directly on your personalized fundraising page after you've registered. Remember, no gift is too small!

Step 2: Reach out to those closest to you
Make a list of your friends and family members, and reach out to them directly to tell them what you're doing to #cureFOP. Don't forget to include your closest co-workers, neighbors and business partners on this list! Personally call or email this group and ask them to help you spread the word and make a donation to your fundraiser.

Step 3: Make your general appeals
Once you've received support from those closest to you, it's time to tell the masses. Take to social media and tell your friends and followers about your fundraiser. Create posters or fliers and distribute them around your community. Ask your local church, school, coffee shop or radio station to help you spread the word. Be creative! You never know who will be interested in helping your cause.

Where Your Money Goes

With the money you raise as part of Team #curefop, you will help fund these critical pieces of the IFOPA’s mission. We are proud that 72 cents of every dollar goes to programs. When you choose to designate funds to the program of most need, you can rest assured that we’re using the most money for our mission critical work.

Research

- More than $500,000 is given to the Center for Research in FOP and Related Disorders at the University of Pennsylvania School of Medicine each year.
- Instrumental scientific research studies are administered on FOP patients facing additional afflictions.
- The FOP Connection Registry is a global, voluntary database that collects and reports demographics, disease and quality-of-life information directly from individuals with FOP twice a year via a secure, web-based tool.
- The Competitive Research Grant Program provides, through a competitive application process, research funding to scientists conducting research on fibrodysplasia ossificans progressiva (FOP).
- The Tooth Ferry Program at UPenn collects baby teeth as children lose them to study as a model for how FOP functions at a cellular level. Children with FOP, as well as siblings and non-family members, are welcome to participate.

Education

- Education is provided to the medical community on early signs of FOP.
- Various publications and other media about FOP, clinical trials and issues surrounding those diagnosed with FOP are distributed via the IFOPA website.
- A collection of videos highlighting various aspects of FOP are available on the IFOPA website, as well as the IFOPA.
- The IFOPA hosts regional events, such as the Midwest Family Gathering, to bring together

families with FOP and clinicians in the field for a weekend of learning and networking.

Support

- The FOP Connection is a monthly eNewsletter featuring articles and photos about FOP research, resources, fundraising, and the FOP community.
- Online support groups allow individuals living with FOP and/or parents of people with FOP to connect with one another in a safe environment.
    - IFOPA'ers: Private Facebook group to share thoughts, advice, questions and concerns (not administered by the IFOPA)
    - FOP Online: Email group to share thoughts, advice, questions and concerns
    - The Parents' of FOPers: Private Facebook group for parents of children with FOP to ask questions, seek advice and talk about things that may be concerning them whilst bringing up a child with FOP
    - Pray for FOP Healing: Diverse email group that shares inspirational quotes, prayer requests and how faith sustains them
    - Ladies of FOP: Email group for women with FOP age 13 and up to join together and discuss puberty, relationships and other issues
    - FOP Ladies: Private Facebook group for women with FOP to talk and share thoughts, ideas, ask questions and get support
- To learn more about support groups click here. To join a support group, please contact us at together@ifopa.org with your full name, email and the group(s) you would like to join.
- Quality of L.I.F.E. (Living Independently with Full Equality) Awards are granted to patients with FOP. The program is designed to promote health, welfare and independence. Examples of awards range from adaptive equipment, walkers, wheelchairs, adaptive bed, vehicle adaptation, tuition/registration for vocational training, specialized bicycles, computer hardware or assistive technology and reading aids. Click L.I.F.E. Award for guidelines and application.
- The Mentoring Program is designed to provide constituents in the FOP community the opportunity to have mentors to better guide them through the challenges of FOP.
- Periodic symposia, gatherings and meetings bring together FOP patients with health professionals who specialize in FOP research and care. These gatherings provide a wonderful opportunity for FOP patients to gather in a collaborative forum to discuss FOP research, exchange information and experiences, share coping strategies, and much more.
- Medical binders are available to help patients with FOP keep track of their health. FOP individuals can receive this by completing the FOP Patient Packet Sign-Up form
- Guidebooks written for families dealing with FOP are available online.

Advocacy

The IFOPA is an active member of:

- NORD National Organization for Rare Disorders
- EveryLife Foundation for Rare Diseases
- Global Genes
- Rare Bone Disease Alliance

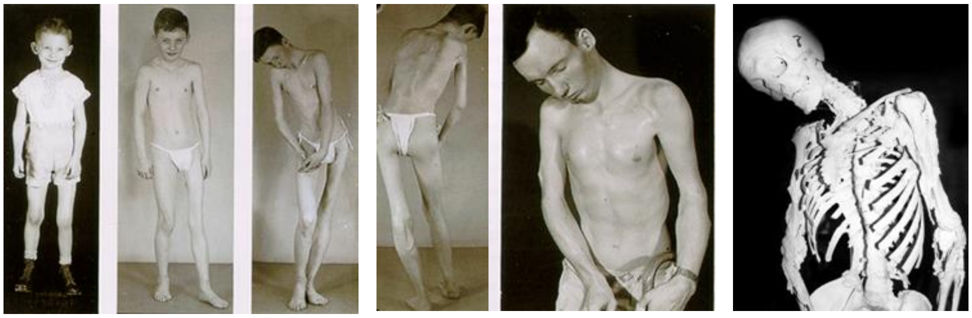
About FOP and the IFOPA

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 joints, progressively restricting movement and forming a second skeleton that imprisons the body in bone. There are no other known examples in medicine of one normal organ system turning into another. There are no effective treatments for FOP.

An example of the typical progression of FOP:

Spontaneous flare-ups of the disease arise in defined temporal and spatial patterns, resulting in ribbons and sheets of bone that fuse the joints of the axial and appendicular skeleton, entombing a patient in a skeleton of heterotopic bone. These photos show an individual with FOP through his lifetime.



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.

Demographics of FOP:

- Genetic disease affecting 1 in 2 million people
- No ethnic, racial or gender patterns
- 800 confirmed cases across the globe
- 285 known cases in the United States

Clinical Characteristics of FOP:

- Characteristic malformations of the big toe
- Surgery makes the condition worse
- Flare-ups occur spontaneously or following bodily trauma such as: childhood immunizations, falls while playing, viral illnesses
- Misdiagnosed in a majority of cases as cancer

About the IFOPA

The International FOP Association is a 501c3 nonprofit organization supporting medical research, education and communication for those afflicted by the rare genetic condition fibrodysplasia ossificans progressiva (FOP). We support members across the board through a multi-faceted approach to research, and we serve as a life support to those with FOP.

Our mission is to fund research to find a cure for FOP while supporting, connecting and advocating for individuals with FOP and their families, and raising awareness worldwide. Our vision is a cure for FOP, accessible worldwide.

Our primary sources of funding come from FOP family fundraising, public contributions, IFOPA special events, and private foundations.

Founded in 1988 by Jeannie Peeper, a woman with FOP, the IFOPA was originally established because Ms. Peeper wanted to bring people with FOP together. Today, the organization has grown to include members across the globe, supports FOP research at the University of Pennsylvania School of Medicine at a rate of approximately $500,000 annually and is a life-support to those who suffer from FOP.

FAQ's

Why Team #curefop?

Team #curefop gives YOU the flexibility to #cureFOP in the way that is most meaningful to YOU. It gives you complete control to plan a creative fundraiser from start to finish - how you want and when you want.

Is there a registration fee for Team #curefop?

No, there is no registration fee to participate. When you register, you will be invited to make an optional gift in support of your fundraiser.

How much do I have to fundraise?

Your fundraising goal is entirely up to you! Fundraising goals typically range from $250 up to a few thousand dollars.

How do I fundraise?

Fundraising is actually much easier than most people think. If you're passionate about the cause and willing to send a few emails, fundraising will likely come easily for you. Check out our checklist for step-by-step fundraising tips and tricks.

Can I use the IFOPA’s logo in my fundraiser's promotions?

Yes! the IFOPA’s logo is available for your use as you promote your fundraiser. After you've registered online, email sara.brown@ifopa.org to obtain digital copies of the logos and style guidelines. The style guidelines will ensure that your use of the IFOPA logo correctly reflects the IFOPA brand.

Will the IFOPA pay for expenses related to my fundraiser?
No. Once funds have been donated to the IFOPA, they cannot be used to pay expenses related to your fundraiser. The funds will be put to work supporting the mission of the IFOPA.

Can funds I raise be used to pay expenses of my fundraiser?
You may reserve a portion of funds raised offline (cash or check) to cover your fundraiser's expenses. A general guideline is to not allow your fundraiser's expenses to exceed 10 to 15 percent of what you raise in total. Any funds used for expenses before they are submitted to the IFOPA cannot be receipted and therefore are not tax deductible.

It is important to let your donors know that a portion of what they donate may be used to cover your expenses.

Once funds are received by the IFOPA, either online through your personalized fundraising webpage or via cash or check, they may not be used to cover your expenses.

You say the sky is the limit, but are there any restrictions on the kind of fundraising activity I can do?
The only 'restriction' is on an activity that may have a negative effect on the reputation of the IFOPA. The Association reserves the right to decline any fundraiser if it chooses. If you have a question about whether or not your activity will have a negative effect on the IFOPA's reputation, contact us at sara.brown@ifopa.org and we'll be glad to help you.

How will my friends, family, co-workers, neighbors etc. know that my fundraising activity is legitimate and supports the mission of the IFOPA?
After your fundraiser is registered online, the IFOPA is able to verify your fundraiser and its support of our mission. You'll also have access to the IFOPA's logo so that others will know that you're raising funds on behalf of the Association. Your supporters can rest assured knowing that any donation they make online through your personal fundraising webpage comes directly and securely to the IFOPA.

To obtain copies of the logos, email sara.brown@ifopa.org after you've registered.

How can the IFOPA help me as I plan and execute my fundraiser?
The IFOPA staff is here to assist you with ideas, tips, brainstorming and moral support as you fundraise. Contact Sara at sara.brown@ifopa.org for assistance.

Are there IFOPA awareness materials available for me to use at my fundraiser?
Yes! The IFOPA is happy to supply you with written materials by request and if available. You may request a supply of materials by emailing sara.brown@ifopa.org at least 15 business days prior to your fundraiser.

Can an IFOPA representative attend my fundraiser?
The IFOPA cannot guarantee that a staff or board member can attend your fundraiser, however we'll do our best to make this happen! Contact Sara at sara.brown@ifopa.org to request that a representative attends your event.

How do I send in funds I've raised?

The easiest way for your donors to support your fundraiser is by making a secure credit card gift online, directly to your fundraising page. Please note that gifts made online should be made to your personal fundraising page via your unique URL, *not* through the "donate" section on the IFOPA's main website. However, if this happens, let us know and we'll move the gift to your fundraising page.

Additionally, cash or check donations may be mailed to:

The IFOPA
Attention: Team #curefop
1520 Clay Street, Suite H-2
North Kansas City, MO 64116

In the subject line of each check, please include your name and "Team #curefop". Please allow 2-3 weeks upon receipt at the IFOPA for the gifts to appear on your personalized fundraising webpage.

Are donations to my fundraiser tax deductible?

Donations received to your online fundraising page are tax deductible to the extent permitted by law. A donor who wishes to make a gift via check must make the check payable to "the IFOPA" in order for the gift to be tax deductible.

I still have questions. Who should I contact?

Contact the IFOPA staff anytime at sara.brown@ifopa.org. We're happy to help answer your questions!