

Corporate Fundraising Pack

There are many ways in which you can support FOP Friends.
Find all the information you'll need in our fundraising kit.



friends[®]

finding a cure for fibrodysplasia ossificans progressiva



FOP Friends exists to help people and families who are affected by the rare genetic condition fibrodysplasia ossificans progressiva, or FOP.

We offer friendship and advice, as well as signposting to other professionals and organisations. We raise awareness of FOP to reduce misdiagnosis.

We fund raise to support the FOP research team at the University of Oxford, as well as other projects that have the potential to speed up the discovery of a treatment and a cure for FOP.

We have been registered as a charity in England and Wales since 2012, and in Scotland since 2016. All our past Annual Reports and accounts are available for download, both on our website and the Charity Commission website.

We are registered with the Fundraising Regulator and follow the guidance from the Institute of Fundraising to ensure all our activities are in line with best practice.



Registered with
**FUNDRAISING
REGULATOR**



What is FOP?

Fibrodysplasia ossificans progressiva, or FOP, is one of the cruellest and most disabling genetic conditions known to medicine. It is a painful illness for which there is no treatment or cure.

It affects around 1 in 1.5 million people, making it an ultra-rare disease.

FOP causes the muscles and ligaments turn to bone, restricting the sufferer's movement. It is a progressive and variable disease, affecting different people at different stages of their life. Sometimes FOP can be aggravated after a bump or fall, other times it can cruelly flare up with no warning, taking away a person's movement overnight.

Over time, FOP progressively imprisons their body in bone: a healthy mind locked inside a frozen body.

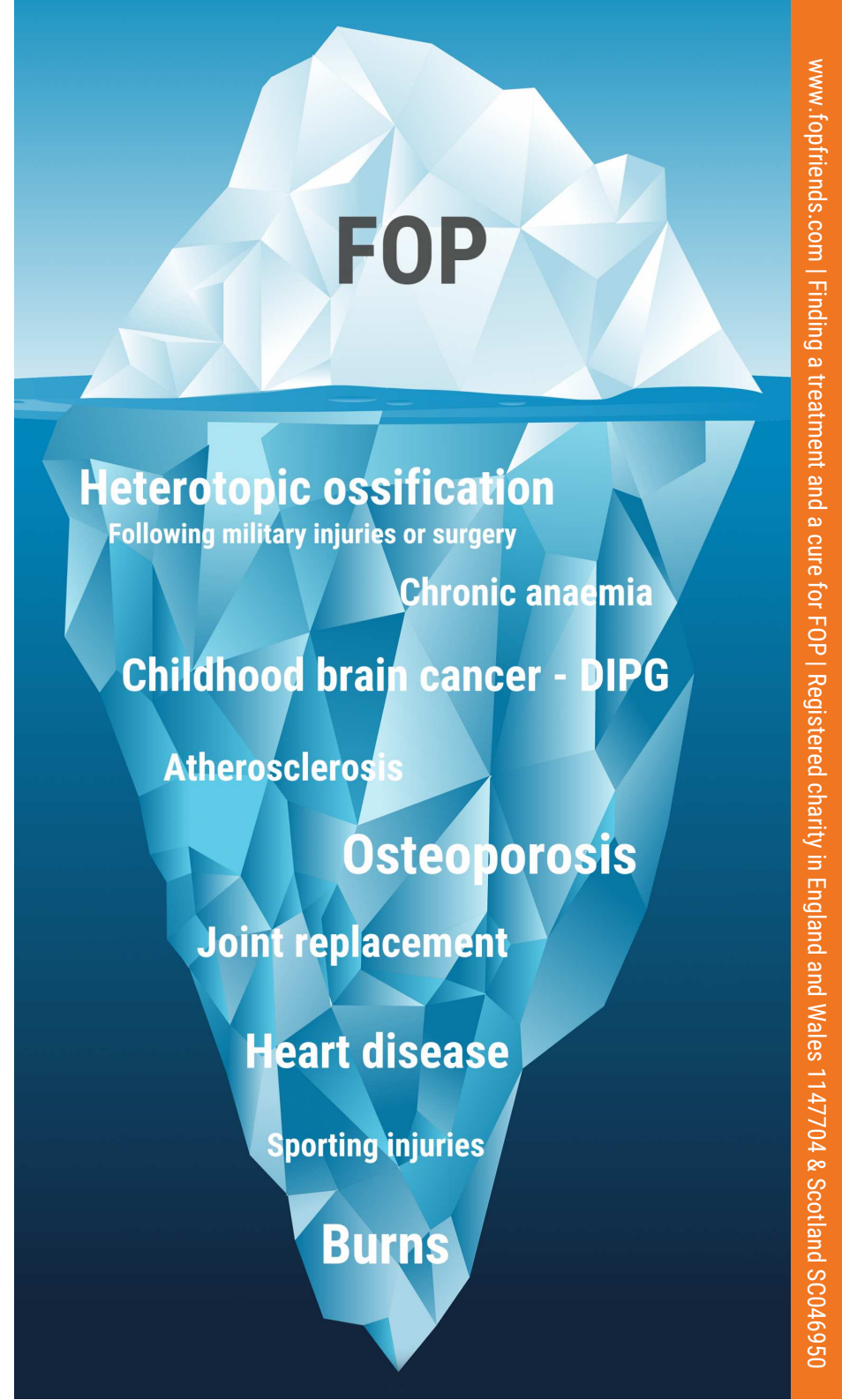


A cure for FOP...

...is just the tip of the iceberg.

Whilst FOP only affects a relatively small number of people in the UK and worldwide, research into rare diseases such as FOP helps scientists understand more common medical conditions.

Such research has the potential to advance the treatment for other more common diseases such as osteoporosis, heart disease and the rare childhood brain cancer DIPG, as well as treating injured military personal who develop heterotopic ossification following blast injuries.





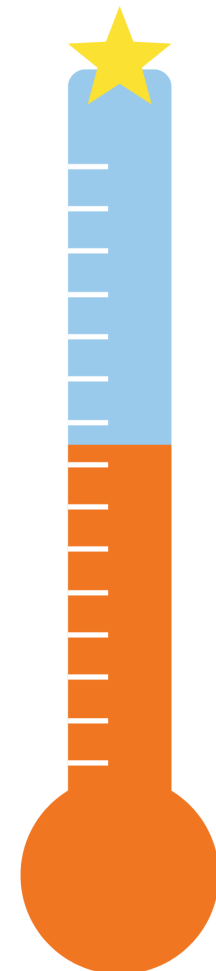
Our target...

As a charity, we receive no government or NHS funding to support our work.

Every year, we aim to raise £120,000 for the University of Oxford's FOP Research team. Without our funding, the team would not be able to commit to its research into FOP.

We also endeavour to support other smaller projects, such as the 'ACT (Accelerating Cures and Treatments) for FOP' grant program, which helps to support investigators who are interested in researching and accelerating the development of safe and transformative therapies for FOP.

Please help us to reach our target, so we can help those affected by this painful and cruel disease.



UNIVERSITY OF
OXFORD



A message from Isla's family

Isla is a bright, happy five year old with a smile that can light up any room! Isla loves flamingos, handbags, watching Gym Stars, playing with her siblings and going to the park to ride her adapted trike. She enjoys playing on the beach and splashing around in the pool. Anyone who knows her, loves her determination, her courage and her spirit.

Isla was diagnosed with FOP at just a few months old, after we searched online about her 'funny' big toes. Since then, Isla has lost independence rather than gaining it, suffering significant FOP progression starting with head flares and then onto neck, back and arms. At five years old, she has no movement in her neck or shoulders, her arms are locked bent at the elbow and most recently developed severe scoliosis which is believed to be due to the additional FOP bone. Because FOP is made worse by the trauma of surgery, any operations are currently out of the question.

Although Isla cannot complete the simplest of tasks e.g. getting dressed, eating, going to the toilet she is hugely determined and resilient. Her friends know about her "special bones" and realise that she needs to be careful and take care not to hurt herself.

Isla is helped by a Learning Support Assistant at school.

She loves schools and can be found keenly taking part in most activities. She especially loves writing, music and dance.

Just like her mummy, Isla adores horses! Each week, Isla goes riding with the RDA and has recently won South East Participant of the year for her continued enthusiasm and growth in confidence.

We are so proud of everything our little girl has achieved.

A successful treatment and cure is constantly on our minds.

Our dream is getting closer, we are hugely thankful for any support: large or small.



Ways to get involved

Charity of the Year Partnerships

We have partnered with well-known companies to be their charity of the year. We can help your company achieve its Corporate Social Responsibility goals whilst supporting a small charity with a big vision.

Introduce FOP and the charity to your workplace by sharing the video, 'What is FOP?' narrated by Stephen Fry, available on YouTube or here:

<https://www.youtube.com/watch?v=jrISA9llvsg>



Events Sponsorship

We hold a conference every two years, as well as a family respite weekend for children with FOP and their families. We would be delighted to work with you as a sponsor for one of these events.



Volunteering

Does your company have skills they can share with us? We are a small charity, run primarily by volunteers, so we can always use an extra pair of hands. If your company can offer skills that would benefit FOP Friends, please get in touch.



More ways to get involved

Payroll Giving

Some companies offer employees the option of making a regular donation to a charity of their choice through Payroll Giving.

Payroll Giving allows people to donate directly from their salary, before the tax is deducted.

This means that for someone on basic rate tax, if they donate £10 a month to FOP Friends it will only cost them £8 from their net pay. For those on the higher rate of tax, a donation of £10 a month would only cost them £6 of their net pay.



Match funding

Match funding is a highly effective way for fundraisers to reach their target.

Many employers offer to match the donations their employees raise from taking on a personal challenge, such as a race, growing a moustache, or walking the Appalachian Trail...





FOP Awareness Day

23rd April is International FOP Awareness Day



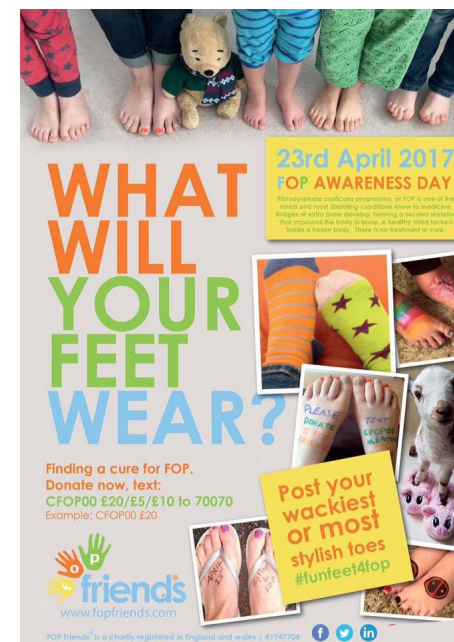
In recognition of the day the gene responsible for FOP was discovered, FOP Friends launched the #FunFeet4FOP Awareness campaign.

Why not help FOP Friends raises awareness of this cruel disease by holding a #FunFeet event in the workplace.

This could be as simple as getting people to wear wacky shoes and socks for the day for a small donation.

If you're feeling more adventurous, why not hold a sponsored Legowalk?

And don't forget to share photos of your toes on social media!





Fundraising ideas

Fundraising in the workplace can be a great way to add fun to the week, as well as raising much needed fund for FOP Friends.

Hold an office Bake-Off

Challenge everyone to bring in their signature bake for a friendly office competition. After the winner has been decided, sell the cakes and donate the proceeds.



Dress-down day

Many offices already hold a dress-down Friday for a small donation. Choose FOP Friends as the charity for the month or year.

Walk to Work

Ask staff to get sponsors for walking part or all of the way to work. It's great for the environment, great for your health, and great for us!

Swap 4 FOP

Bring in your unwanted clothes from the back of the wardrobe, then everyone makes a suggested donation, maybe £10, then everyone gets to swap their clothes for a brand new look. Lots of fun and environmentally responsible too.



Small change challenge

Grab a large glass jar, and see how long it takes the office to fill it with a coin of your choice: 50p, £1 or even £2 coins! Have a departmental competition to see which team can fill their jar the quickest!



How we can help you

If you are thinking of holding a fundraiser or event for FOP Friends, please get in touch.

We can help to make your event a success by providing you with information and promotional items. We're happy to send leaflets, pencils, bugs, wristbands, balloons... to help increase awareness and add some Friends colour to the day.

We also have two quizzes: 'Famous Feet' and 'Famous Friends' we would be delighted to send you.

For people taking part in a sporting event, we will provide them with a t-shirt, personalised with a Friends of... logo.

Drop us an email corporatesupport@fopfriends.com and we'll be happy help.



Meet our Friends



Meet Alanna

"My name is Alanna and I'm 3 years old. I was diagnosed with FOP last year. I love to play with my toys and play with my brother and my cousins. I am happiest when I am playing in my sandpit in the sunshine. FOP has already restricted some of my movement and has made it harder for me to learn to walk, but I have a walker and I am becoming stronger and more every day. My arms and shoulders have locked which means I can't pull myself up when I'm sitting on the floor. But I'm an independent and determined little girl and I won't let FOP get in the way of me having fun and living life to the fullest!"



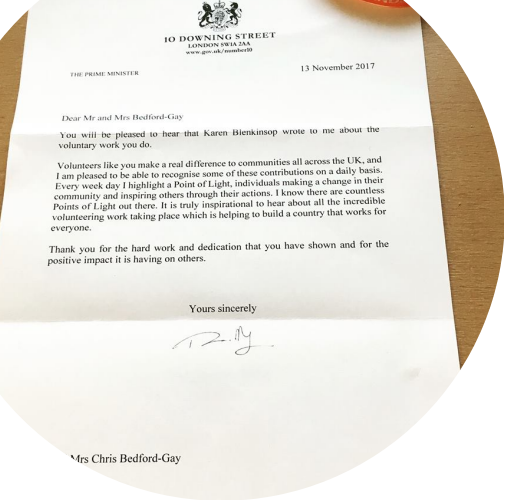
Meet Ellis

"My name is Ellis and I am 10 years old. I am cheeky with an amazing sense of humour and a smile that means I get away with most things! I like love reenacting my favourite movie Star Wars by having light sabre fights with my Dad - I am always Luke Skywalker though! I also love going horse riding and my favourite horse to ride is called Toto, because he reminds me of Bullseye from Toy Story. FOP has changed some of the things I do but it will never stop me having fun. Mum and Dad tell me there are some amazing doctors all over the world working really hard to make my bones better."



Meet Rachel

"Hi, I'm Rachel, I'm married to Paul. I love travelling, socialising with my friends, and watching bands. I used to love dancing too, but that is becoming near-impossible. I have always lived my life to the fullest, despite FOP but recently, the FOP has been more aggressive and is taking away what little movement I had left. I depend on round the clock support from my husband. I need a specially adapted wheelchair and am now unable to get up the stairs on my own. But I will keep on smiling and fighting: my spirit is one thing FOP can't take away from me."



Our achievements

FOP Friends was founded by Chris and Helen who, when their little boy was diagnosed with FOP aged just 13 months, had no support, no information and nowhere to turn. Along with the support of their family, friends and other FOP families, they built FOP Friends into a nationally and internationally respected charity.



FOP Friends works alongside the excellent FOP team at the Royal National Orthopaedic Hospital, the FOP Research team at the University of Oxford; and other international FOP patient organisations.

FOP Friends are invited to the Vice-Chancellor's Circle Dinner annually, in recognition of their continued contribution to the FOP research fund at the University.

In 2017, FOP Friends were runners up in the Altrincham Chamber of Business Small Charity Awards. In 2018, Helen and Chris were recognised by 10 Downing Street as Points of Light for their volunteering efforts for FOP Friends.



The IFOPA also recognised Helen and Chris' contributions to the international FOP Community.

In 2019, the charity published their first book: "Supporting a Child with FOP: a practical guide to their learning journey".



Thank you

We are thankful for each and every one of our friends who choose to support our small but very special charity.

Every pound you raise for FOP Friends truly makes a difference. We are proud to declare that over 95% of fundraised money goes directly to accelerating the quest to find a treatment and a cure for FOP.



Keep in touch...

If you would like to find out more about getting involved, please contact us:

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