



# Fabulous Friends Fundraising Pack

There are so many ways in which you can support FOP Friends and the people who are affected by FOP. Find all the information you'll need in our fundraising kit.



Registered with  
FUNDRAISING  
REGULATOR





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 fundraise 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 following the guidance from the Institute of Fundraising to ensure all our activities are in line with best practice.





## 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 1.4 million people, making it an ultra-rare disease.

FOP causes the muscles and ligaments to 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.

Many children with FOP cannot ride a bike, run, play football or climb trees for risk of hurting themselves and triggering a flare-up. FOP is quite simply stealing their childhood.

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 personnel who develop heterotopic ossification following blast injuries.





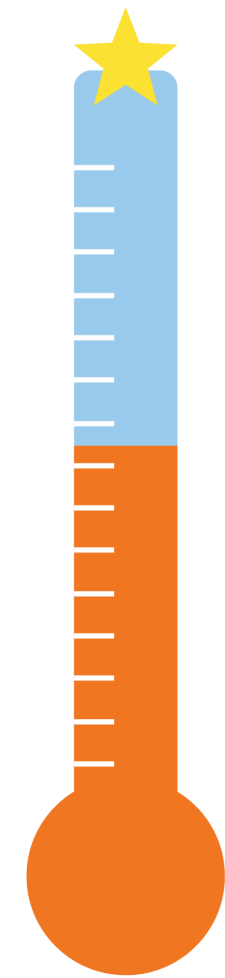
# Our annual target...

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 six 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 six 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 such as getting dressed, eating, or 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 loves school and can be found keenly taking part in

most activities. She has a Learning Support Assistant to help her throughout the day. Her favourite lessons are music and dance, and she simply loves to write!

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

We know that schools, uniformed groups, and community groups are under increasing pressure to fund-raise for their own funds and projects, as well as supporting the larger more well-known national charitable campaigns.

As a small charity, we are thankful for each and every fundraiser held for FOP Friends. Every £ we receive truly makes a difference in our quest to reach our annual target of £120,000 which is needed to support the excellent research team at the University of Oxford as well as supporting smaller projects that have the potential to expedite the research to find an effective treatment for FOP.

We are proud to declare that over **95%** of fund-raised money goes directly to supporting our mission: to find a treatment and a cure for FOP.

## Charity of the Year

Choose FOP Friends to be your Charity of the Year.

Launch your campaign by sharing our video, which is narrated by Stephen Fry, that explains FOP.

[www.bit.ly/WhatIsFOP](http://www.bit.ly/WhatIsFOP)

Keep a running total of the proceeds from small events throughout the year, and then share the Grand Total in summer.



## School council

Can the school council think of a fun way to raise money and awareness for FOP Friends across the school?



# More ways to get involved

## Hold an assembly, raise awareness

Have an assembly on genetic conditions and what makes us the same and different. There are freely available resources available online that explain genetic conditions.

FOP is an ultra-rare disease, affecting around 1 in 1.5 million people, that's as rare as a blue lobster!



Because many children with FOP can't ride a bike or play football or go to play centres, it can be a great starting point for discussions into what children take for granted: when they run around the yard at playtime, do they ever consider themselves to be lucky? A child with FOP can't do that. It is good to remind children to be thankful for the little things in life.

FOP Friends is happy to help schools or pupils develop content for an assembly or presentation, tailored to the age of the young people.

## 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. Ask if any of the parents/guardians work for a company that can help you to boost your total through fund-matching or other support.

## Earn a badge

Young people can choose FOP Friends as the focus for one of their Community Impact or Charity badges.

Information and ideas in this guide can be used by the young person to complete their charities badge, or disability awareness.







# FOP Awareness Day

23rd April is International FOP Awareness Day



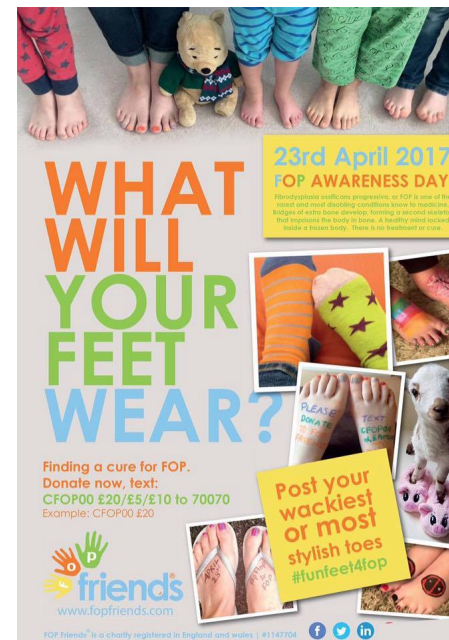
In recognition of the day the gene responsible for FOP was discovered, FOP Friends launched the #FunFeet4FOP Awareness campaign.

Why not help FOP Friends raise 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

Here are just few ideas to get you started....

## Hold a Bake Sale

Everyone likes a tasty cake! Ask the children to organise a bake sale after school or a club and donate the proceeds.

## Non-uniform day

Invite the children and staff to wear their own clothes for the day in lieu of a donation. Perhaps challenge them to wear orange or FOP Friends' colours.

## Sponsored...

A sponsored... is a time-honoured way of raising funds for a good cause. Choose something that's easy to organise and fun for the kids to do. Get in touch with FOP Friends for printable sponsorship forms.

## Name the bear

FOP Friends would be happy to donate one of their bears for naming and adoption.

## Small change challenge

Invite each class to bring in their small change. Then, each class makes a line of coins through the school hall. You can have two winners: a prize for the most money brought in; and a prize for the longest line. Pro tip: use the coin machines in your bank to count the coins!

## Toy sale

Give kids the chance to clear out their cupboards, sell their old toys and make a difference at the same time.





# 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 about FOP and our charity. There are also printable colouring sheets at the back of this guide for you to use.

We also have three quizzes: 'Famous Feet', 'Famous Friends', and 'Famous Hands', just get in touch and we'll send them to you.

If you would like to run a pop-up shop in aid of FOP Friends we would be happy to send you some merchandise to sell.

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  
[hello@fopfriends.com](mailto:hello@fopfriends.com)  
and we'll be happy help.



# Meet our Friends



## Meet Alanna

"My name is Alanna and I'm 3 years old. 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; my arms and shoulders have locked which means I can't pull myself up when I'm sitting on the floor. I have a trike which means I can get out and about and join in with my friends at the park. I'm an independent and determined little girl and my confidence is growing by the day! I continue to surprise my family and make them so proud. I won't let FOP stop me having fun and living life to the fullest!"



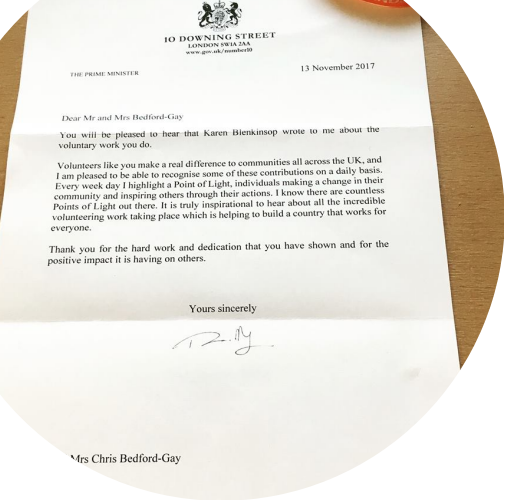
## Meet Ellis

"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 sabar 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 Millie

"Hi, I'm Millie! My family and friends are very important to me, as are my FOP doctors and nurses: they're awesome! People like that I am funny and silly! I am kind and caring. People think I'm brave coping with my illness - I only moan about it when I am in pain. I hope the future brings a cure for FOP but I do rather like riding in a wheelchair! When I move to high school, I hope people understand about me. Sports are difficult, but I don't mind because I don't like them! Sometimes I need help to put my shirt on. I can't 'do' my hair or walk too far. If people have a question about FOP I like them to just ask me!"



Mrs Chris Bedford-Gay

# 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 raises fund to support the FOP research team at the University of Oxford. Without the financial support of FOP Friends, the team - led by Professor Alex Bullock - would not be able to carry out its work. To acknowledge the charity's support, FOP Friends is annually invited to the Vice-Chancellor's Circle Dinner.

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.

In 2019, Helen and Chris received the Jeanne Peeper International Leadership Award from the IFOPA in recognition of the work they do for the FOP community, both here and around the world. Nicky was nominated for BBC Sussex and Surrey "Community Heroes of the Year" for Team Isla's fundraising efforts.

The charity published their first book: "Supporting a Child with FOP: a practical guide to their learning journey".



# Thank you

We are grateful for each and every one of our friends who chooses 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:

FOP Friends

1 Cumberland Road

Sale

Cheshire

M33 3FR

UK

Tel: +44 (0)161 282 0441

Email: [hello@fopfriends.com](mailto:hello@fopfriends.com)

[www.fopfriends.com](http://www.fopfriends.com)

You can follow us on..



# Payment details

We are thankful for any amount raised, big or small. Please visit the Institute of Fundraising website for guidance on best practice when handling money.

<https://www.institute-of-fundraising.org.uk/>

Money should not be left unattended at an event. All money should be counted and banked as soon as possible, ideally with two people in attendance.

If people would like to make a personal donation to the charity at your event, please ask them to complete a gift aid form which allows the charity to reclaim an extra 25% back from the Government at no cost to the donor.



Cheques should be made payable to: FOP Friends.

Money can be paid in via Bank transfer:

HSBC FOP Friends

a/c 31540947 Sort: 40-31-17

Or a donation can be made through our Virgin Money Giving platform:

<http://bit.ly/VirginMoneyGivingFOPFriends>

All monies received by FOP Friends are formally acknowledged by letter and certificate of thanks.





[www.fopfriends.com](http://www.fopfriends.com)





# What is FOP?

Fibrodysplasia ossificans progressiva, or FOP, is one of the rarest diseases known to medicine. It affects around 1 in 1.5 million people. It is a painful and debilitating condition. There is no treatment or cure.

Sufferers appear normal at birth except for the tell-tale turned-in big toes.

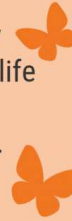
These, combined with unexplained swellings across the body, can be a key indicator of FOP.



Most cases of FOP are new. FOP is caused by a fault in the ACVR1 gene. This gene mutation happens at conception: it is an accident of nature.



FOP can significantly shorten the life expectancy of sufferers.



FOP causes the body to develop extra bone to form in muscles, ligaments and soft tissue. This creates painful swellings called flare-ups. Where this occurs across joints it progressively restricts the sufferer's movements.



FOP does not affect a sufferer's intelligence.



Many people with FOP struggle with mental well-being, anxiety, and loneliness.



Tip of the iceberg... Research into FOP has far-reaching benefits and implications for more common illnesses such as osteoporosis, childhood brain cancer, heart disease, heterotopic ossification following military injury, and burns. Research into rare diseases benefits everyone.



When people with FOP lose movement, it can mean they are unable to carry out simple every-day tasks such as washing, feeding, and dressing independently.



Children with FOP can find that they lose movement in their shoulders, neck and arms, at a young age, making playing like their friends very difficult. Children with FOP often don't get the chance to ride a bike or a scooter in case they fall off. Also, children with FOP can't take part in sports such as football as the risk of being injured, thus triggering a flare-up, is simply too great.



It is not possible to remove the extra bone growth as the surgery will prompt further flare-ups.



A knock, bump or fall can trigger a flare-up which can result in new bone growth, and loss of movement.

Whilst a flare-up can be caused by an impact, they can also occur spontaneously. A child can go to bed one night, then wake up the next morning having lost movement in an arm. Forever.



**WE HAVE HOPE!** There are three clinical trials for FOP treatments underway, and another one is due to start later this year.



