fop friends® Together

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FOP Friends exists to **help find a treatment and a cure** for the rare genetic condition fibrodysplasia ossificans progressiva (FOP), and to **support the families** affected by it

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Terrific Trio!

The events over the past three months have proved challenging for all of us: some people have been on the front line as key workers; others have been working from home; some have been shielding; for many people with FOP and who are house-bound, nothing much has changed; and some have simply been trying to adjust to the new 'normal' that was so suddenly thrust upon us.

However, three of our youngest supporters decided to use some of their lockdown energy to raise money and awareness for FOP Friends.

We are so proud of Ben (6) who ran 26.2 miles over the month of May in honour of his cousin Oliver, raising an impressive £860.50. Brother and sister duo Zachary and Annalise were inspired by their mum's training efforts for the London Marathon so set themselves challenges of their own, in honour of their friend Isla. Zachary (9) ran 26.2 miles over six days, totalling 4 hours and 9 minutes; and Annalise (6) did a virtual "climb" of Scafell Pike, reaching the dizzying height of 1000m. She achieved this by climbing up and down the ladder on her climbing frame in her garden, over a period of two weeks, often wearing a princess dress! Together they raised an incredible £656.25. You all made your families and your friends proud.

A word from Fiona

Welcome to yet another fabulous issue of 'FOP Friends Together'. I am delighted to be writing a short word, yet find myself distracted by the strange times we have found ourselves in.

In May, we should have been preparing to attend yet another wonderful FOP Friends Conference in Manchester. Unfortunately, due to circumstances beyond our control, this event had to be cancelled. However, as always, FOP Friends took on its renowned optimism and organised a virtual quiz with many families joining in the event: children had the opportunity to take part in a fun scavenger hunt around their homes. It was fabulous to see the smiling faces of many families and get to mark the occasion in a positive way. In addition to this, clinicians, pharmaceutical bodies, children and trustees came together in a film to relay a lovely message: although far apart we are in this together and there for each other. We can now look forward to our 2022 conference where we will be able to celebrate 10 amazing years as a charity.

Do not worry, things are not on hold until then! FOP Friends is hosting a STOPFOP Webinar in July. This will explain the plans underway to recommence the STOPFOP clinical trials in Europe. We will of course keep you updated: there are exciting times ahead.

Having been a trustee for a number of years, I feel a real sense of pride as I continue to watch the work of FOP Friends. Even in these times, FOP Friends has continued to offer support and advice where it can. The support and opportunities it provides are invaluable; it makes a big difference to so many people. Your support is crucial in ensuring we raise awareness of FOP, ensuring the fight to cure FOP continues.

Fiona
FOP Friends Trustee

STOPFOP trial making preparations to restart

Covid-19 has impacted us all in different ways. One of the consequences for the FOP community was the challenge it created for clinical trials.

Just after going to print in our February newsletter, the STOPFOP trial, which has been part funded by FOP Friends, was put on hold. We are now delighted to announce that tentative plans are being made to restart the trials, with Amsterdam hoping to resume in July, and the UK trial site in London a few months after that. The trial will be open to adult FOP patients living in Europe, and who are not enrolled on any other trials. For more information, visit **www.stopfop.com**

Happy Birthday Ava!

Many of you will recognise Ava as the studious pupil on the cover of our schoolbook.

Ava and her family have long been supporters of the charity, and Ava decided that for her 9th birthday this year, she didn't want presents, and instead requested donations to FOP Friends for Oliver. What an incredible gesture from a kind young girl and thanks to the incredible generosity of her friends, she raised £501! We hope you had a fabulous birthday!

Regular Donors

Did you know you can become a regular donor for FOP Friends? Life can seem so busy and hectic (even in lockdown when we have nowhere to go!) and sometimes we just can't find the time to support the causes closest to our hearts. We are so lucky to have lots of regular donors who generously give every month. Any donation amount is most gratefully received, as the old adage goes 'take care of the pennies and the pounds will take care of themselves'.

Since the update of our website, we have a special page where we celebrate our regular donors. If you would like a simple way to make a lasting contribution to FOP Friends, get in touch info@fopfriends.com and we can help you to make a difference.

Every little helps!

A big thank you to Alanna and her mummy who raffled off a gorgeous wooden duck, to mark Rare Disease Day. The raffle raised £40 for FOP Friends.

Chop4FOP

Instead of suffering with a bad lockdown hair-do like most of us, Betsy decided she would shave it all off in honour of her beautiful and badass friend Lucy, who is living with FOP. Betsy set up a crowdfunding page with the promise that once she reached £1,500 in donations, she would chop her hair for FOP…
and she did!

Betsy went on Facebook Live to prove to all her supporters that she had in fact done the deed! Betsy was also able to get her donations fundmatched through the HP Foundation, which brought her total to an incredible £3770! A huge thank you to Betsy and her friends for raising such an amazing amount of money. A hat is on its way to you in the post!

Tell us your story

If you have a story to share about your life with FOP please get in touch. We'd love to hear from you.

We would also like to shout about any of your achievements and challenges you've done for FOP Friends.

Thank you to the following organisations for their generous support in funding the FOP Friends Together newsletter:

The February Foundation

The Manchester Guardian Society Charitable Trust

The Sobell Foundation

FOP Friends
The Cabin, 1 Cumberland Road,
Sale, Cheshire, M33 3FR.

✉ info@fopfriends.com
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FOP Friends is registered with the Fundraiser Regulator, an independent self-regulatory body for the UK fundraising that encourages commitment and compliance with best practice in fundraising.

Facebook fundraisers

Another amazingly easy way to support FOP Friends is to hold a Facebook fundraiser in celebration of a special occasion. To date we have raised over £7000 to support our work to find a treatment and a cure for FOP.

Thank you to everyone who chose to celebrate with FOP Friends!

FunFeet4FOP

Lockdown most certainly didn't stop our supporters in their stride, sharing fabulous photos of their funny or funky feet to raise awareness of FOP with their friends and families.

This year saw even more people take part than before, with supporters from around the globe. In January, trustee Nicky, who is mum to Isla, set herself the personal challenge of running an amazing 262.2 miles, which she completed on the 23rd April, with Isla cheering her on at the finish line. A big thank you too, to everyone who shared our posts on social media to help raise awareness of FOP and to hopefully prevent misdiagnoses in the future.

Easyfundraising and Amazon Smile

We have learned over these past few months that our local community is more important than ever, and at FOP Friends we would encourage you all to shop as local as possible to support your independent traders.

However, as shopping as we knew it, doesn't look like it will be returning to 'normal' any time soon, you may find yourself spending more money at online retailers. If you use the platforms Easyfundraising or Amazon Smile when you shop, and choose us as your charity, we will get a small commission from your purchases, at no cost to you. **And if lots of our supporters sign up, then it will really make a difference to our fundraising total every year.**

Find us on social media
@FOPFriends **/FOPFriends**

We hope you enjoy receiving our newsletter. However, if you no longer wish to be on our mailing list, please email us at **info@fopfriends.com**

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