friends Together

Vol 3, Issue 1 Nov 2019

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

Great runners

Five years after our first 'Team FOP Friends' took part in the iconic Great North Run, we were lucky enough to have another team of fabulous runners to head to Newcastle.

We had friends from all across the country, from Manchester to London, taking part. One very special runner was our very own Dr. Bubbear, who said, "I took on the challenge of the Great North Run to support FOP Friends. All the patients I meet, and their families, are a huge inspiration for me. I dedicated each of the 13 miles to one of the children I have the honour of working with." And for many of our runners, it wasn't the first time they'd donned a pair of trainers to raise money and awareness for FOP Friends. Thank you to Jude, Angela, Emma, Helene, Johnathan, Lorna, Mark, Rebecca, Richard C, Richard W, Sarah and Stuart. You all ran times to be proud of, as well as raising an amazing amount of money to help us in our race to find a treatment for FOP.

Inside

A word from Alison

It's been another fantastic year for the charity, going from strength to strength.

Earlier in the year, we had our second family gathering at Centre Parcs - such a fantastic opportunity to meet up with old friends, meet new families, share stories and more importantly laughs.

What may seem like a small one-off event from the outside is such an important get together in our calendar and to get to see the difference it makes first hand makes all the hard work and effort that the Trustees and Charity staff put into organising it so worthwhile.

On a personal note, it was a year of challenges for me; firstly, a change of job, I now work at UK Biobank which supports the research into improving prevention, diagnosis and treatment of a wide range of health conditions. It feels like this links with the focus of our charity shifting more to working with and supporting the pharmaceuticals leading on clinical trials and bringing the cure even closer; Secondly, whilst clinical trials continue it is ever more important that we support the families involved and the research ongoing at Oxford University by fundraising. I appreciate it can be hard to keep momentum going, and this year I played my part by literally walking over hot coals, which I would do any day to support getting the cure for my nephew and his FOP Friends.

Alison
FOP Friends Trustee

Remembering Ann

In July, Oliver's family were devastated when Grandma Ann passed away suddenly. As many of you know, Ann was one of FOP Friend's oldest supporters having been with the charity from the beginning. Since receiving Oliver's diagnosis when he was just 13 months old, she dedicated her hobby of line dancing to raising money to find a treatment and a cure for Oliver, and everyone else affected by FOP. Ann was well-known and well-loved in the North-East where she held monthly line dancing social events to raise both money and awareness. There was always a raffle and her dancers loved to read the latest developments in FOP research.

Twice a year, Ann would hold her grand dances, where there was (of course) a raffle, some stalls, a singer, and a bring-and-share buffet. Oliver made guest appearances at some of the events, even helping to draw the raffle. Over the years, Ann's dances raised £40,000 for FOP Friends.

Ann's family were overwhelmed at her funeral by the number of people who came to say goodbye: a fitting tribute to just how special she was. Oliver's family would like to thank everyone who sent messages of condolence and to everyone who donated to FOP Friends in Ann's memory. £1750 was gifted to find that treatment for her grandson. She is sadly missed.

Ann with her first grandchild, Oliver

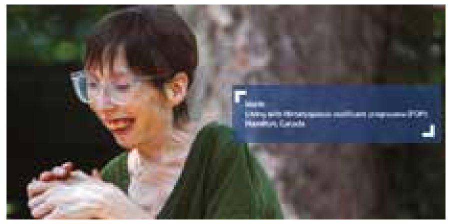
Ann with her family

Ann with her line dancing group

IPSEN
Innovation for patient care

Ipsen enters exclusive agreement with Blueprint Medicines

Ipsen announced it has entered into an exclusive, worldwide agreement with Blueprint Medicines for the development and commercialisation of BLU-782, an investigational ALK2 inhibitor for the treatment of FOP. After acquiring Clementia and its drug palovarotene earlier this year, Ipsen now have two strong complementary drug candidates and the potential to offer the broadest possible treatment options for FOP patients.



Oxford Thank you

We were delighted to be recognised again in the Oxford Thinking Campaign Report 2018/19 for our continued support of their FOP research team, led by Professor Alex Bullock.

Many thanks to each and every one of you who've made this contribution possible.

We look forward to sharing more news from the team at Oxford in our next edition of Together. We look forward to sharing more news from the team at Oxford in our next edition of Together.

BT
Elizabeth Cayzer Charitable Trust
Mr Paul Chadwick
The Drayson Foundation
FOP Friends
Mr Peter Freeman
The late Mr E Michael Garston CBE
The late Mrs Jaleh Hearn
Herbert Smith Freehills LLP
The William Talbot Hillman Foundation
Horne Family Charitable Foundation

The Jeannie Peeper Award for Outstanding International Leadership

Helen and Chris were delighted to win the 2019 Jeannie Peeper Award for Outstanding Leadership this Summer. The award recognised their exceptional commitment to the FOP community through their leadership, service, family support, fundraising and awareness-building, both in the UK and worldwide. The award is so thoroughly deserved for all the hard work, determination, long hours and sacrifice of family time that they have dedicated to supporting families, creating a charity, and helping to find the cure for FOP.

ifopa
ACT FOR FOP
ACCELERATING CURES AND TREATMENTS

Continuing our support for the ACT program

We have continued our support of IFOPA's Accelerating Cures and Treatment Grant Program for another year, as one of their major donors. The research grant provides funding to scientists conducting FOP research, helping to advance the development of effective FOP drug therapies. The trustees recently attended a webinar led by two researchers in recipient of one of the grants and we can't wait to update you soon with their findings.

Conference and Family Gathering 2020 – save the date!

Our UK FOP Family Gathering is taking place from **15th - 17th May 2020.** Once again it will be at the Radisson Blu Hotel, Manchester Airport. This meeting will have a strong community/family focus, with topics covering the challenges many of us face when dealing with FOP. Save the date and spread the word! We can't wait to see you there.

Florida 2019

Chris continued his role as Board member of the IFOPA and as Chair of the International Presidents Committee for FOP, by travelling this month to Florida. He chaired the IPC meeting of 15 national FOP patient organisations, which gave them the rare opportunity to share ideas and talk about projects they were undertaking in their own countries.

One of the most interesting discussions was with Dr Patricai Delai, talking about dermatological issues patients with FOP face, and a possible future study on the issues.

There was a presentation from Amanda Cali about the Tin Soldiers documentary which is receiving critical acclaim after its showings at a number of film festivals across the world. The film aims to discover the undiagnosed people living with FOP. The Tin Soldiers project has just launched its FOP Outreach Program, which is actively searching for those who are unaware they have the condition.

Representatives from some of the pharmaceutical companies also shared updates on their work.

The annual Drug Development Forum was a series of presentations from the world's brightest minds on FOP, discussing the latest progress and research developments. As part of the forum, Chris took part in a panel of patients and parents who spoke and answered questions about the reality of living with FOP; the impact it has on daily lives; and the hopes, fears and dreams of all those affected by FOP.

L-R: Prof. Fred Kaplan (University of Pennsylvania), Dr. Richard Keen (Royal National Orthopaedic Hospital, Stanmore), Chris Bedford-Gay, Prof. Robert Pignolo (Mayo Clinic, Minnesota)

Meet Rohan

Rohan is 20 years old and from Milton Keynes. Diagnosed with FOP when he was three, Rohan does not let his condition stop him. This summer he completed his A-Levels, achieving amazing grades, and now attends university.

When did you receive your FOP diagnosis?

I believe I was diagnosed with FOP at the age of 3, so approximately April 2003.

When and how did you become aware of the FOP community?

I don't have a specific memory of becoming aware of the FOP community, it was always just a thing, an entity; a collective that existed in my life for as long as I remember and i have been a proud member of that collective since.

How has FOP impacted your life?

I think it's very easy to get bogged down with the negative impacts of FOP (the physical limitations, anxiety of being injured etc.) but I prefer to focus instead on the positive connotations. For me, it has allowed me to see the inner warmth and kindness of people that I may have otherwise missed if I did not have FOP. I have a wonderful friendship group, the best family I could truly hope for, my flatmates are all lovely people who have supported my transition into university far more than I could've possibly hoped for.

Congratulations on heading off to university – what are you studying and how have you found your first term?

I have enrolled on a Joint Honours degree of Sociology & Criminology. The transition from A Level study to university is quite a significant leap but I have handled it well, I have been well accommodated and have been supported by the wonderful disability support team at my university as well as compassionate lecturers and fellow students.

What's your favourite way to spend your time?

Without a shadow of a doubt, I love watching TV & film; whether it be going to the cinema with my dad late at night to all-day Netflix binges, televisual media is my passion and my favourite pastime.

Do you have any advice for younger FOPers?

Be wary of yourselves & others, remember that accidents do happen and not to beat yourself up if (and when) they do happen. Mostly; be safe but live your life to the fullest.

Find us on social media

@FOPFriends

/FOPFriends

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.

Farewell Hannah

It is with much sadness that we will be saying farewell to Hannah at the end of November. Hannah started with FOP Friends back in the summer of 2015 as an intern from the University of Manchester. The following year, she joined us part time, along with studying for her Masters degree in Psychology. After graduating in 2018, Hannah then joined our team full time.

Hannah has been an amazing support not only to the Trustees but to all the families FOP Friends serves. She has been central to supporting and celebrating the many different fundraisers; the successful Christmas Cards project now in its second year; managing our social media platforms; seeking grants to support our mission; and working with the many students who have followed in her footsteps. She will be greatly missed, not least by the office guinea pigs!

We are sure you will join us in wishing Hannah all the very best for her future adventures.

Fantastic supporters

Over the years, our community has grown, and we are so fortunate to have the continued support from all our wonderful friends and families, who go above and beyond to raise funds and awareness for FOP.

We are not a big charity. We are not funded by government or big business. Your donations are the difference between research continuing and it stopping completely. Even the smallest donations make a big difference. Thank you to everyone who has joined us so far on this journey to find the cure for FOP.

Little events go a long way

You don't have to organise a big event to make a big difference. Here's just a few of the exciting events that have taken place over the past few months:

Trish Coles organised her annual coffee morning, encouraging all her friends to come along for a catch up, some cake, and a conversation about FOP to help raise awareness of the condition. Josie Steele dedicated her time to knitting a range of felt animals and fairies, selling these in her local community to help raise funds for FOP research. Tracey Mellor nominated FOP Friends as the Charity of the Month at her indoor car boot sale, while Annabelle sold cakes amongst her friends, at her parent's workplace, and then completed a presentation on FOP at her school to help raise awareness.

A handful of half-marathons

Judith and Alistair took on the Glasgow Half-Marathon in aid of FOP Friends of Iona. This was the fourth year that Judith, and the third year that Alistair, has taken on the challenge. Both running an impressive time and doubling their fundraising target.

> It is even more important to us to try and support this Oxford based, research team. It is our hope that their findings will reduce the challenges Iona and others like her, have ahead and offer her a longer life-span.
>
> **Judith**

In Manchester, Clare completed the Wiggle Half for Oliver, battling through the rainy weather to shave 3 minutes off her personal best and raise over £100 for FOP research. Further down south, Steve took on the Bristol Half Marathon for his daughter Alanna and raised £301.25, whilst Annie impressively conquered her 13.1 mile run in Ipswich for her cousin Millie, having only ever ran 10k before, raising just under £900!

> Millie's a special member of my family and I am so proud to support a charity that has made a real difference to her and her close family's life.
>
> **Annie**

Supportive Schools

We felt very lucky that Lambrook School picked us once again as their chosen charity. As part of Jeans for Genes day, everyone came to school in their jeans. All the children and staff got on board, even going the extra mile to sell our FOP Friends merchandise. Everyone had a great day, and the fundraising total raised over £1,100! Thank you so much to everyone involved in raising such a fabulous amount.

Raising awareness

The Yarrow House newspaper team at Christ Church Charnock Richard Primary School chose FOP Friends as their featured charity in their summer edition of their newsletter. Students Jason and Izzy wrote the article, helping to raise awareness of FOP amongst their school community. They then surprised us by donating all the proceeds raised from the newspaper towards FOP research.

FunFeet4FOP @School

#FunFeet4FOP may not be until April but now is a good time to sign your child's school up for the campaign, as many schools plan their charity dates far in advance. We're delighted to hear that Isla's school has already pledged their commitment to take part!

We have produced a Fundraising pack for schools to help them plan the event. So get in touch and sign your school up!

Help us raise awareness of FOP. Together we can #cureFOP.

Brilliant Brodie

Brodie is one of our newest friends, he is just 4 years old.

His mum, Siobhan want to raise some money to support FOP Friends so organised an online Bonus Ball amongst her friends and family – she simply posted a Facebook status raffling off numbers 1-59 for £5 a number. The winner then got half the money, whilst Siobhan donated the other half to FOP Friends, raising an impressive £150.

> As everyone knows, Brodie has a progressive bone disease called `progressive osseous heteroplasia'. It's so rare that we have no charity in the UK doing any research to find a cure. As FOP Friends is a charity to the sister disease Brodie has, they have been so good to me and Brodie - giving us loads of advice and inviting us along to trips. We would love to give something back to them, so we can try find a cure for these horrible diseases.
>
> **Siobhan**

Team FOP Friends

We are absolutely thrilled to announce we have been allocated our first-ever London Marathon place via Virgin Money Giving's 2020 charity ballot. Rebecca Honour, from #TeamIsla, will run the 26.2 miles for us!

This news was made even sweeter when separately two other fundraisers, Jane Deane and Fiona Griffin, got in touch to say they had received places in the individual ballot and wanted to run for FOP Friends. We are delighted to have a superb trio taking on this challenge, all in aid of raising awareness and funds for FOP, in pursuit of that much-desired cure.

> Amazing!!!!!! Thank you so much. I will do Isla proud and raise as many pennies as I possibly can.
>
> **Rebecca**

> A big shout out to Helen and her amazing son Oliver who get me through my long runs. Thinking of you guys and how close that cure is kept me going.
>
> **Jane**

What is POH?

Progressive osseous heteroplasia, or POH, is often considered a 'sister' condition of FOP, due to some similarities the conditions share. Also, the doctors who are experienced in treating patients with FOP, are also the same specialists who care for people with POH.

t is a rare genetic condition in which the body makes extra bone in locations where bone should not form. There are approximately fewer than 60 patients identified in the world. However, it is likely there are others living with the condition who have been misdiagnosed or undiagnosed.

POH causes extra bone to develop below the skin in subcutaneous tissue (fat tissue beneath the skin), muscles, tendons, and ligaments. This "out-of-place extra bone formation" is commonly referred to as heterotopic ossification.

Find us on social media

@FOPFriends

/FOPFriends

Get involved

Whether you're challenging yourself to run your first marathon or setting goals for your next cake sale, remember that the FOP Friends team is here to help you where possible – so please do get in touch.

One of the greatest challenges of fundraising is coming up with new ideas, so we have put together some of our favourite fundraising activities, many of which have already been tried and tested by our fantastic supporters to hopefully inspire you with your next event!

Visit **fopfriends.com** to find out more.

Watch this space…

We are in the final stages of updating our website to make it much more user-Friend-ly, and responsive on all your devices. Our launch date is just around the corner!

A dedicated team at AND Digital, based in Manchester, have kindly donated their time and skills for free, to build us a modern website that truly reflects who we are. We hope the new website will be an invaluable resource for families, patients, new diagnoses, fundraisers and supporters alike! We can't wait!

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

friends
www.fopfriends.com

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

☎ +44 (0)300 323 9989
✉ info@fopfriends.com
@FOPFriends
/FOPFriends

Registered with FUNDRAISING REGULATOR

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.

Ways to help this winter

Our 2019 Christmas cards

This is our second year of running our Christmas card campaign and we are so overwhelmed with the response we have had so far. If you haven't got yours already, visit our eBay for Charity page or email info@fopfriends.com. The cards have a small message on the back to help raise awareness of FOP and all funds raised will go directly to supporting our Oxford University research team. Cards cost just £2 per pack of 10.

Don't buy a card – donate instead!

If cards aren't your thing, then consider making a donation in lieu of cards and stamps.

Contact us to donate directly or visit **dontsendmeacard.com** to send e-cards and make a donation.

Grab a hat!

Your ears will definitely be toasty this winter in one of our new woolly hats.

Harry can testify to that! A great stocking filler, or one to keep your head warm while you train for next year's Great North Run. Email info@fopfriends.com with the numbers and sizes you need.

Instead of Secret Santa be a Festive Friend

Save everyone the time and stress of finding a perfect/appropriate/funny (delete as applicable) Secret Santa gift for your Christmas Night Out and donate the money instead to FOP Friends. It's better for the environment, your sanity …and those living with FOP.

Easy fundraising

It's easy to support us while you do your online Christmas shopping… and at no hassle or expense to yourself! Use Easyfundraising so we can benefit from your online high street purchases, or AmazonSmile and choose FOP Friends as the charity to benefit from your Amazon purchases.

Helpful tip: If you've already signed up to Easyfundraising but keep forgetting to use it, here's a simple trick. The Easyfundraising Donation Reminder will alert you whenever an online purchase could trigger a donation. Follow a few simple steps to install it on your PC or laptop and get helpful reminders: **easyfundraising.org.uk/raise-more/donation-reminder.**

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**

FOP Friends is a Registered Charity in England and Wales 1147704 and Scotland SC046950