



FOP friends[®]
Together

Vol. 6 Issue 3: Christmas

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

The Adult Rare Bone Network



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FOP Friends was chosen to be one of the six founding charities of the NHS Adult Rare Bone Network, which is a rare disease collaborative network.

Helen and Rachel recently ventured down to London to attend the celebration and official launch of the network. The Network is being led by Professor Kassim Javaid, from Oxford University Hospital, who also cares for some patients in our FOP community. The event was generously hosted by the Brittle Bone Society. It was a fantastic event where healthcare professionals and industry experts came together and engaged in informative talks, networking and insights into the network. Speakers included Fiona Marley, who is Head of Highly Specialised Commissioning



NHS England, and Lord Kevin Shinkwin, a leading advocate in the disability sector. We are super excited to be a part of this project and to be able to play a part in supporting those in the wider rare bone disease community, as well as improving access to services for those in our own community. We look forward to bringing you more information in due course.



A word from Fiona

I, like many of you I imagine, am sitting at home wondering where this year is disappearing to. It is hard to believe that winter has arrived and we are in to dark nights and mornings. Yet, there is something magical about this time of year: excitement at impending time with family and friends and an air of hope as one year draws to an end with preparation for a new one.

Looking back at this year, FOP Friends and the wonderful community it represents, has continued to make great strides in its quest to find that cure. From family funruns, FOP Webinars and visits to research centres, to summer events and Royal Garden parties, to special meetings in parliament and making our voices heard.

On this note of looking forward to the new, it may seem a little early, but I am excited to have started planning for our FOP FriendZone (formerly known as the crèche, yet the fabulous children are growing up!) we will be running at our biennial FOP Friends Conference and Family Gathering, taking place on the 10th-12th May 2024. This is always so special, and I absolutely adore seeing the children grow and watching the amazing young people they are becoming.

From me, I'd like to wish you an amazing few months ahead, and I look forward to seeing many of you next year.

Bring on 2024!

Fiona
FOP Friends Trustee

NICE Conference 2023

Chris attended the NICE Conference 2023, earlier this month in Manchester. The National Institute for Health and Care Excellence guides healthcare in the UK. They evaluate treatments, offer guidance, and develop quality standards. NICE ensures healthcare choices are evidence-based, cost-effective, and benefit patients, professionals, and the National Health Service (NHS). As we move closer to getting treatments for FOP, it is crucial that, as an organisation, we are aware of relevant policies and processes. We also want to make sure that the voices of those living with FOP are always part of the conversation.

The event was held at the iconic Hilton Hotel, Manchester and was attended by leaders across a range of institutions. Chris listened to a number of different presentations including the current challenges for health and care, and how NICE is playing a role in supporting an overwhelmed NHS. Networking breaks throughout gave Chris the opportunity to discuss FOP with a wider and influential audience.



London Meeting with Nicky and Andrew

Nicky Muller and Andrew Rankin, along with the Rt. Hon. Mike Penning MP and Lexi's parents Dave and Alex Robins, met with Minister for Health Will Quince MP. It was encouraging to have another opportunity to continue our conversations and discuss the challenges we face as a community. They discussed newborn screening and again highlighted the need for further funding for research into FOP.

Building on this meeting, Chris and Helen met with Mike Kane MP in Manchester to see what else could be done to progress these discussions further. There were lots of actions taken from this meeting and we look forward to working with Mike Kane too.

We are thankful that FOP is part of the conversation in government right now as we continue to strive for a treatment and a cure for everyone living with FOP.



Our Friends Around the World...



Germany

Glückwunsch! Our friends in Germany celebrated their 25th Anniversary in November. This is an incredible achievement, and makes them one of the oldest FOP patient organisations in the world! Here's to the next 25years!
www.fop-ev.de



South Africa - Tin Soldiers Event

FOP Africa and Hear in Africa collaborated with Tin Soldiers in the Tin Soldiers Clinician Champions Alliance Summit to screen the hearing of a group of patients who have FOP. All 17 patients had their hearing tested and will be receiving further support from Hear In Africa.



Brazil

Helen and Kriscia, along with Dr Patricia Delai, have been working hard on translating, editing and updating the practical guide for 'Supporting a child with FOP' - now known as 'Apoiando uma criança com FOP: Um guia prático para auxílio na jornada escolar'. They have updated the guide and translated it into Portuguese so it now meets the needs of our FOP families living in Brazil. They have become an unstoppable team over the last few months and their work is truly appreciated!



Dallas, USA - IFOPA Gathering November 16th-18th

IFOPA held their 2023 Family Gathering in Dallas, USA this year. It was a fantastic event with an array of workshops and presentations to raise awareness of FOP and also highlighted the work the FOP community has achieved this year. There was also no short of laughs and excitement as members of the community got to meet up and catch up over food and drinks!



Australia - Jack's Calendars

Following the success of the 2023 calendars, FOP Australia are very excited to help launch the 2024 Wildlife Photography Calendars.

These wall calendars celebrate Jack's incredible talent as a wildlife photographer. Jack, who is 17 years old and lives with FOP, has kindly developed these calendars with his parents Rory and Melissa as a fundraiser for FOP Australia. For this year's calendar, Jack travelled all way to the most northern point of Australia in Cape York and was able to photograph some amazing wildlife.

All proceeds will go to FOP Australia to support people living with FOP and their fight for a cure.

Buy one here: <https://fopaustralia.org/fundraising/calendars>



Find us on social media

@FOPFriends

/FOPFriends

Kidz to Adultz

Helen attended the Kidz to Adultz exhibition again this year in Manchester. While it's always great to be able to stock up on free pens ad, these exhibitions are a fabulous opportunity to discuss the challenges those living with FOP with the suppliers. FOP progression can often mean that off-the-shelf solutions just aren't fit for purpose, so it's helpful to be able to make companies aware of this. Helen will be sharing the information she gathered with the families over the next few weeks.

Kidz to Adultz arrange four exhibitions around the UK throughout the year. They are free to attend and are fully accessible. If there is one near you, it's a great outing and incredibly useful to be able to speak with all the vendors. And who doesn't want like a free pen? Check out their website for dates and locations: www.kidzexhibitions.co.uk.



Catching up with Faye!

Hi all!

I have been working with Helen to put together this issue and was super excited when she asked if I wanted to write a segment for it!

It has nearly been a year since I first started at FOP Friends – I did my 30 hour placement here last November and now here I am a year later as their Office Administrator! How time has flown.

I have definitely settled in thanks to the whole FOP Friends team here and the incredibly welcoming community!

As office administrator, I've had the opportunity to interact with the FOP and rare disease community both through social media and emailing. I have never seen such an active and supportive community that continuously strives to help those living with rare disease and FOP, and I am glad I get to play a part in the endeavour with FOP Friends.

I have come to realise that no working day is the same here at FOP Friends – and that's the charm of it! I did not realise how much goes on behind the scenes and the amount of work that is put in to maintain a charity. We keep up to date with changes and updates in the community and work accordingly to support those living with FOP. Recently, I have been working with Helen on several projects to help support and raise awareness of FOP (one of them being this newsletter!). We have recently partnered with Run for Charity and I was glad to be able to help out with that process and establish a new avenue of support for FOP Friends.

Another project I am particularly excited about is our upcoming Conference and Family Gathering which will be happening in May. While there is a lot of preparation to be done, I am eager to see it all come together and can't wait to see all the hard work pay off!

My Psychology background has definitely helped me in working within the FOP and the general rare disease community. The mental wellbeing of those living with FOP is a massive factor that we try our best to provide support for. We have worked to compile useful resources to support mental wellbeing in those living with FOP at all ages, and it has been very insightful to see the real life practical application of psychological interventions targeted to help those living with rare diseases as I have only seen this briefly in my studies.

Working with FOP Friends has been such an enjoyable experience so far, and it's hard to believe I got here by stumbling across them as placement opportunity! I look forward to what the new year will bring and excited to see the fruition of all our upcoming projects!

Run for Charity, Run for FOP Friends!



We are super excited to announce our recent collaboration with Run for Charity!

Run for Charity is an organisation that has partnered with over 2000 UK charities to give them an easy and accessible platform to raise funds and awareness for their worthwhile causes.

They advertise charity runs and events all over the UK, from fun runs in theme parks to challenging triathlons, there is something for everyone to contribute whether you are a beginner runner or an experienced one!

We hope this partnership can provide our supporters with a fun and active way to help raise funds and awareness for FOP. We have set up a page dedicated to Run for Charity on our website, and we update it regularly with the newest runs available! Remember to check it out!

<https://www.fopfriends.com/run-for-charity-run-for-fop-friends/>

Exciting event coming soon...

We are delighted to be collaborating with the amazing Medics 4 Rare Diseases and the Royal College of Surgeons to hold an exclusive evening at the prestigious Huntarian Museum in London.

Helen has been working closely with the wonderful Dr Lucy McKay from M4RD to plan the event. There will be presentations from Prof. James Triffitt, Prof. Richard Keen, as well as from members of the FOP community. The event will be held at the museum February 2024. Keep an eye on our socials – more information to follow...



A Golf Fundraiser Frenzy!

A fabulous fundraiser hosted by Will, the caption at Batchwood Golf Club for our little Lexi! A sunny, fun-filled golf day was had and raised over £2000 for FOP Friends!

We greatly appreciate Will and the rest of the members of the club for their generous contributions and efforts in helping support Lexi and the FOP community.



Great North Run 2023

We had a fabulous team of runners representing FOP Friends at the Great North Run in September this year!

We know a tremendous effort was put in by our runners with all time and energy dedicated to this run. Thanks to their endeavours, a phenomenal total of £2,600 was raised for FOP Friends! Massive thank you to Team FOP Friends and congratulations to them for their unbelievable achievements!

<https://www.fopfriends.com/run-for-charity-run-for-fop-friends/>



Oliver takes bronze!

Oliver has always had a passion for Scouts and the outdoors, so when he was given the opportunity to join a local Duke of Edinburgh programme he proverbially jumped at the chance. Some accommodations were made for Oliver to allow him to achieve his potential while giving him the same level of challenge as his friends, proving that Duke of Edinburgh is for everyone!

I was given the opportunity to start my Bronze Duke of Edinburgh earlier this year, and since I enjoy Scouting I figured this was something I would enjoy too.

The course was led by Andy and was run under the arches along the Bridgwater Canal in Sale. Every week I went along with my friends Alex and James. We got to do different activities each week, but a lot of the time we spent on the canal with the canoes. Other activities we did were archery, axe throwing and cooking on camping stoves.

To get my badge I had to do six months of badminton, along with volunteering so I helped at my local park with maintaining the area and supervising the kids on train rides.

My skill was photography, so I took photos on my summer holiday to submit.

For my expedition I did two days and one night. We had to help with the planning of the trip. We canoed down the Bridgwater canal before camping in tents. It was good fun.

I really enjoyed the experience and was proud to receive my award. I'm looking forward to starting silver next month and am already planning what activities I'm going to do. I would totally recommend it to anyone to give it a go. The best part is making new friends and having somewhere to go and hang out in an evening."



FOP Friends Christmas cards!

Our 2023 Christmas cards are now available on our shop! It is never too early to prepare for the festive season!

All purchases will directly contribute to our cause in helping support those living with FOP. Your support truly does make a difference. www.fopfriends.com/shop

We hope all our supporters have a joyful festive season!



A Q&A from Engraver Gamer

A year ago, when Engraver Gamer approached us to say he was going to host a Raid Train to raise awareness and money for FOP Friends, we were intrigued to say the least! While we oldies in the office had never heard of a Raid Train, the likes of Oliver and his friends were all in the know!

Engraver Gamer has now organised and hosted two Raid Train fundraisers for FOP Friends and raised an incredible amount of £3687.35!

So, following on from the tremendous successes of his Raid Train fundraisers on Twitch, we caught up with Engraver Gamer to ask about his impressive progress and learn a bit more...

When did you first begin streaming on Twitch?

I first began streaming back in 2020.

How did you get into it?

I wanted a platform to showcase a unique hobby of mine – wood burning pictures onto plaques... hence the name Engraver Gamer!

So tell us, what exactly is a Raid Train?

A Raid Train is a group of streamers with different interests. They each have an allocated timeslot to stream their live show. Once their time is up, they then Raid i.e., send their viewers onto the next streamer who is lined up and waiting to go! This goes on around the clock for a couple of days – nonstop! This means the streamers are on back-to-back without a break in the live stream. .

What gave you the idea to host a Raid Train as a fundraiser?

I saw what incredible fundraisers other streamers were doing for their preferred charities and saw the magnitude of the generosity of people out there. I thought it would be a fantastic idea to host my own and see what I could do to spread awareness of the condition as well as raising funds for FOP Friends.



You've hosted three Raid Train fundraisers now – how many people have joined and how much have you raised?

We've probably hosted 50-60 streamers across the three Raid Trains. We continue to grow and get more people involved every time which is exciting. I can't believe it, but we have raised over £7000 in just over a year. People really are kind.

So, what do you like to showcase on streams?

I am an art streamer which means I burn designs into wood. I found this to be a unique viewing stream and people are genuinely interested in my work, which is feels good. Creators stream a range of activities from gaming and music to me and my art – everyone is talented in their own right.

What is the most memorable moment you've had while streaming?

Gaining the growth on the platform and seeing people come together to help me with these Raid Trains. It has brought a lot of streamers together, united for the same cause. FOP is such a rare condition, I'm proud to be able to raise awareness of the condition with the viewers who are worldwide. Awareness is key.



What do you have planned for the future?

We're planning on building on our success so far by going bigger and bolder! We have May 2024 pencilled in the diary to host a three- or five-day event. We will start organising that one in February. Because it's for longer, it's going to take more co-ordinating. This is going to be our annual big event.

In the meantime, we are wanting to do a little something for Christmas for the children in the UK with FOP. We're running a fundraiser at the moment, with other creators also doing somethings, to pay for a gift for them all this Christmas.

If any of our friends would like to get involved, how do they do it?

We'd love to welcome any new creators on board. If anyone would like to find out more, they can send me a whisper on twitch to engravergamer88 or send me – engravergamer88 - a message on discord. FOP Friends will also share details of future Raid Trains so keep a look out for us!

Lauren, Rebekah and Mark's trek to Everest Base expedition

Lauren, good friend of the Grant family, had always had a trek to Everest on her bucket list, and this year she decided it was the year to tick it off!

Lauren and her team headed off to Everest to achieve one of their dreams and thought it would also be a great opportunity to raise some money for their dear friend Ellis and FOP Friends. Lauren said, "I did it! Everest base camp (5364m) & Kala Patthar (5644m) - completed!! Another bucket list trip ticked off the list. I've dreamt for years of

trekking in the Himalayas, seeing and experiencing the enormity of Mount Everest and it's surrounding peaks, so those two weeks were an absolute dream come true in every sense. Best of all, I got to do it with my dad, sister, our adopted sister Clare, and the amazing friends, guides & Sherpas we met along the way!" Not only that, Lauren and her team raised an incredible £1500 for FOP Friends.

Thank you so much for choosing us...we can't see what next adventure awaits for you all!





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.

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The Zochonis Charitable Trust



FOP Friends

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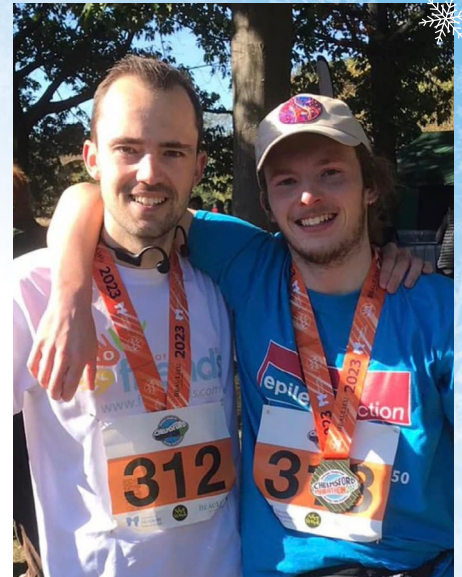


FOP Friends is registered with the Fundraiser Regulator, an independent self-regulatory body for the UK fundraising that encourages commitment and compliance with best practice in fundraising.

Adam takes on the Chelmsford Marathon!

Adam took on the challenge of the Chelmsford Marathon representing Team FOP Friends and Lexi!

He braved the 26.2 miles and completed it with flying colours. His achievement definitely paid off, as he managed to raise over £1300 for FOP Friends! Congratulations and thank you so much Adam!



Chiltern 50 Ultra Challenge is no challenge for Judith!

Judith took part in the Chiltern 50 Ultra Challenge this year supporting FOP Friends. The challenging yet stunning 50k trek took Judith 13 hours and 26 minutes and took her through some of the most stunning parts of the UK countryside. She raised an impressive £573 for FOP Friends, and we cannot thank her enough for her time she has dedicated to this remarkable challenge! Thank you and congratulations Jude!



Let your Christmas shopping benefit FOP Friends



If you aren't able to go out to your high street and have to shop online, please consider using [easypfundraising.co.uk](https://www.easypfundraising.co.uk) and choosing FOP Friends as your charity to benefit from your purchases?

We are also registered as a charity with Amazon Smile so please remember us when you click to buy your Black Friday and Christmas bargains.

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