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

Together

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Inside

Meet Your Team!

This October saw the trustees, along with some of our families, visiting the University of Oxford's FOP Research lab. This was an exciting opportunity for us to meet with Professor Alex Bullock and his new researchers: Dr Julian Cros, Dr Lap Hang Tse and PhD student Will Seaton-Burn. The positions of the two new researchers have been made possible thanks to FOP Friends.

We were also honoured to have Professor Jim Triffitt join us to give a presentation on the history of FOP research at the University. Professor Triffitt and his team were instrumental in the gene discovery over 15 years ago, so it was fascinating to hear how they pieced together the information which resulted in the finding of the ACVR1 gene.

Professor Bullock gave an update on the StopFOP trial which is underway at a number of sites and due to open in London at the end of the year. Although Dr Eleanor Williams has moved on to another team, she returned to give our families tours of the FOP research lab and explain how research into crystals is assisting with increasing the understanding of how FOP works, which hopefully will ultimately result in a treatment and cure for FOP.

It was simply wonderful to see the hard work and generosity of our friends and supporters in action through funding these two new positions, and we are excited to follow them all and their work as they strive to learn more about FOP and give everyone living with FOP hope.

A word from Alison

This has been a particularly exciting and rewarding month for me as a trustee, but also as Oliver's auntie: for the first time I got to see our researchers at work!

Along with trustees Helen, Nicky and Chris, we met up with some of our fellow FOP friends and families at the incredible biochemistry facility, the Dorothy Crowfoot Hodgkin Building (a very colourful structure –Google it!) at the world-renowned University of Oxford.

It was a pleasure to catch up again with Professor Jim Triffitt and listen to his talk where he brought the past right up to the future, a totally inspiring journey of which he has been such an integral part. I particularly enjoyed the photos in his presentation – everyone looking a good few years younger!

I was so humbled not only to catch up with our FOP specialists, but to meet the new wave of PhD and Post Doctorates joining the programme to find a cure: inspirational indeed! I'm still not quite sure I grasped the basics of the processes of crystallisation, or how different drugs work to prevent the progression of FOP, but they did an amazing job of explaining and engaging with us all.

It was brilliant to see the laboratories and the tangible side of where all your amazing fundraising efforts go. I think you'll agree that Nicky and I looked quite the part on our tour!

I would like to thank all of the team down at Oxford for taking the time to spend with us, and to all of our fantastic fundraisers who continue to support us on this journey. We all left the day with so much more hope.

Alison, FOP Friends Trustee

Behind the Scenes

It's been another busy few months in The Shed (when is it not?) as we returned from our summer holiday on the West Coast USA. On our trip we had the pleasure of meeting up with some of our international FOP friends - always a highlight of our road trips!

Anyway, once we were back at our desks, we continued to finish up our supporting application for the NICE approval. Working with Realise Advocacy, we have been gathering information and insights from the community to help the decision-makers understand the far-reaching challenges and implications of living with FOP. It's been great to have the input from so many community members to help to get our voices heard in this very important process. As part of this, we conducted a survey of our families to look at the impact of FOP on all aspects of their life.

Helen visited the Kidz to Adultz exhibition in Manchester, to see the latest equipment available to help her to advise members of the community as well as occupational therapists, when they contact the charity for advice.

It's incredibly useful to be able to speak to people in the industry and explain the very specific needs of our friends. Helen has already been able to support some of our families.

Chris attended a virtual meeting, the Voluntary and Community Sector Forum for NICE, where discussions were had about the future of health and social care services provided by NICE. It is an opportunity for patient organisations and communities to share their views and ideas on their priorities. This given patient organisations the opportunity to be involved in the implantation of NICE's 5-year strategy.

There was a virtual STOPFOP meeting, where updates were given on the trial's progress. The London site for the StopFOP trial is now hoping to be up and running by early next year.

Running a small patient organisation whilst also being directly affected by the condition, brings a significant number of challenges for those leading it. This has been recognised by Beacon, who are running a Building Rare Resilience course. Helen and Chris have both signed up for this to help them to manage the daily and longer terms challenges and pressure to ensure the longevity of the charity.

Another Beacon project is the Student Voice Prize and we are delighted to have been paired with another student this year. Helen has been working with Ina, who has also spoken to a number of other people affected by FOP. We look forward to reading Ina's essay and are thankful to the patients who have spent time speaking with her as part of her research for the essay. It is always a wonderful opportunity to make the next generation of medical professionals aware of FOP.

Continuing with our aim to work with and learn from other organisations, Chris is taking part in the Gene People: Leadership Symposium this month.

Finally, we have been invited to join an exciting initiative for getting FOP further recognised on the European stage 'FOP in Focus'. Chris took part in initial meetings to identify areas for improvement and ways to inform policies that could impact care for people with FOP in Europe.

A quick sojourn to Paris

Earlier this month Chris attended a patient-centricity meeting in Paris. Chris was invited to be a member of a Global Patient Organisations Advisory Board, which connected patient group advocates from a number of different medical conditions, not just FOP. It was an exciting opportunity for us to put both FOP and FOP Friends on the global stage, and we were delighted to have been a part of it.

A Trip to Texas

Chris has just returned from the IFOPA's Drug Development Forum (DDF) in Dallas, Texas. The DDF is a biennial event that focuses on drug development for FOP and brings together clinicians, research, industry, and a small number of patients/families together – a truly inspirational event. The event wasn't for the public or families although there were representatives from the community to talk about their journey with FOP. It was incredibly exciting for Chris to be in the same room as over 100 other scientists who are all looking for that treatment we all so need. There were fantastic discussions into new ideas, trials, ACT for FOP and gene therapy – with many 'outside the box' ideas. There was also a presentation into the projects which FOP Friends has financially helped to support. It was also a great opportunity for Chris to reconnect in person to many of the doctors we haven't been able to meet up with due to the pandemic, including the wonderful Professor Kaplan. It was an exhausting and jam-packed three days of meetings, presentations and panels, but it was all worth it. There was so much HOPE at the event, that a treatment for FOP is on the horizon. Thank you to everyone who made the event an incredible success. #StrongerTogether

Clinical Trials

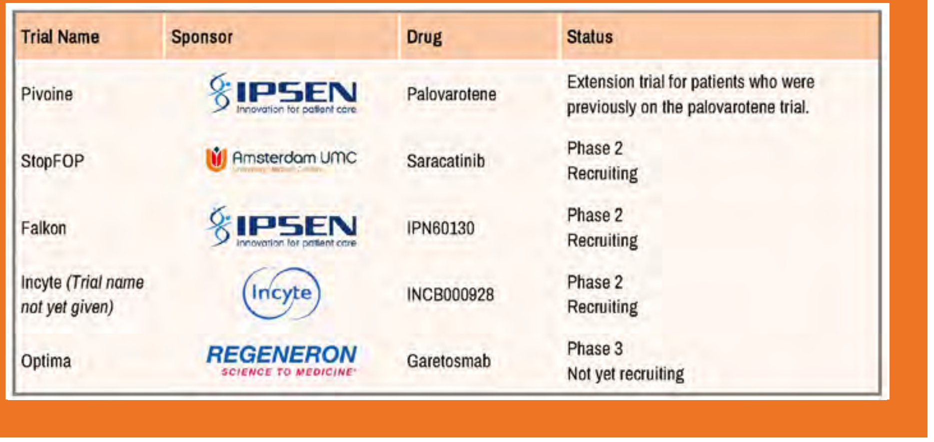
As we know, FOP is an ultra-rare condition, affecting just 1 in a million people worldwide, yet we have five - yes five- active clinical trials underway. This is exciting news for everyone living with FOP. However, the process of a clinical trial takes significantly longer than all of us who are desperately waiting for a treatment want it to take. But each and every trial gives us a little bit more hope.

To learn more about the clinical trial process, the IFOPA have created a short cartoon, check it out: **www.youtube.com/watch?v=SEUM0gNb-1A.**

At the beginning of November, BioCryst sadly announced that they made the difficult decision to discontinue their trial into the development of their ALK-Inhibitor drug BCX9250.

They felt that with three other kinase drugs being investigated, that the clinical trial landscape could become overcrowded and as a result hinder progress in finding a treatment for FOP.

Biocryst have been strong supporters of the FOP community, through their sponsorship of events such as our Conference as well as other projects in conjunction with the IFOPA. We thank them for their support.



Trial Name	Sponsor	Drug	Status
Pivoine	IPSEN Innovation for patient care	Palovarotene	Extension trial for patients who were previously on the palovarotene trial.
StopFOP	Amsterdam UMC	Saracatinib	Phase 2 Recruiting
Falkon	IPSEN Innovation for patient care	IPN60130	Phase 2 Recruiting
Incyte *(Trial name not yet given)*	Incyte	INCB000928	Phase 2 Recruiting
Optima	REGENERON SCIENCE TO MEDICINE	Garetosmab	Phase 3 Not yet recruiting

A Life in the Day

Ever wondered what it must be like to live with a complex health condition? The people at The Method have developed a number of experiences to help people to understand the challenges some people face on a daily basis. FOP Friends, along with FOP community members from the UK and around the world have been chatting to the team to share their experiences of living with FOP. We spoke to Josh at The Method, to find out more.. He tells us, "Over the past few months, we have been working to develop an immersive patient experience about FOP called A Life in a Day.

We have produced a number of A Life in a Day programs for a number of different therapy areas, including Asthma, Lung Cancer, and Chronic Kidney Disease, however the FOP experience was our first foray into rare diseases.

The experience combines an interactive app, medical props and role-plays to put people in the shoes of a patient living with FOP. It is designed to enable industry and healthcare professionals to better understand some of the physical, emotional, social, and financial challenges that people living with FOP face on a daily basis.

In September, we successfully launched the first stage of this experience at an event in Austin, Texas, and in 2023, we will be rolling out a 24 hour version which will challenge participants to experience what it might be like if they had to live with FOP for a single day."

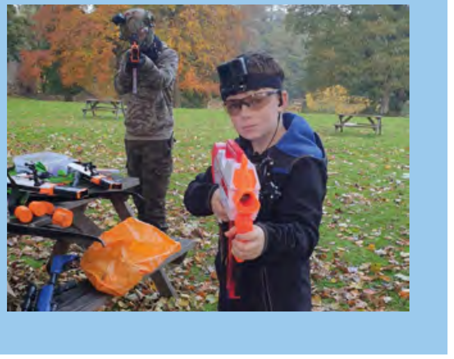
A number of FOP medical professionals, along with representatives from the IFOPA were able to experience the program at the ASBMR2022 Conference, and they found the experience and the patient testimonials to be incredible powerful and insightful.

A LIFE IN A DAY

Battle for the Briefcase!

In another first for the charity, Oliver and Leo took part in a charity nerf battle! The boys eagerly travelled to Appleby Castle in beautiful Cumbria for the event. They were joined by eight other young people who took part in a number of challenges and battles. A briefcase filled with £££ was the target, with the winner taking its contents. Leo was particularly fast at this one, while Oliver excelled in his role as a 'sniper'.

The event was filmed on GoPros on the fighters' helmets, ready to be streamed on YouTube. The day started off gloriously sunny but turned to light rain which created muddy conditions and only added to the enjoyment of the day! The boys managed to raise an impressive amount for the charity too which is to be confirmed once all footage has been reviewed. **We look forward to sharing the YouTube link with you soon!**



Happy Birthday Steve!

Steven Hopwood is one of the UK's longest serving supporters of FOP research at the University of Oxford. He and his family set up FOP Action many years ago to start the fundraising for the research team, laying the foundations for the team we know today. It was therefore no surprise that Steve wanted to raise money for FOP Friends in honour of his daughter Rachel, who lives with FOP, for his 70th birthday celebrations. A huge party was held in Whitworth with family and friends from near and far! Perhaps what made the event even more special was that his daughter Lauren and her family flew over from Australia to celebrate the occasion – and what an occasion it was!

There was an 80's tribute band and disco, as well as a traditional Lancashire pie and pea supper! Steve was joined on stage with ladies from his many years of running the successful salon The Crew. Perhaps the highlight was the poetic tribute from his five children - 5Pac - a humorous look back at Steve's life! It had been five years since all Steve's kids had been together which made his party an even more emotional event. As to be expected from the Hopwood family, there was laughter, smiles and dancing until midnight and beyond. So far his birthday gifts have totalled £700.

Happy Birthday Steve!

Little Lexi's Big Party

Little Lexi's friends held a gala in style last month at the stunning Slendish Manor Hotel and Golf Club, Herts. Guests were given a red-carpet welcome before a fabulous three-course meal with dinner and dancing. The live music was provided by guitarist Josh Robinson, Liz Greenwood entertained with the saxophone, and dancing 'til midnight was made possible thanks to DJ Vinny.

There was a raffle and auction to raise funds for research into FOP. Lexi's mum Alex had pre-recorded an interview with trustee Nicky, to chat about Nicky's family life with FOP and why a treatment and a cure is so vital for everyone living with FOP. It was a truly wonderful event with dancing, laughter and more than a few tears when people reflected on why they were there. The gala raised a staggering £18,000. A huge thank you to everyone who pulled together to make this evening possible.

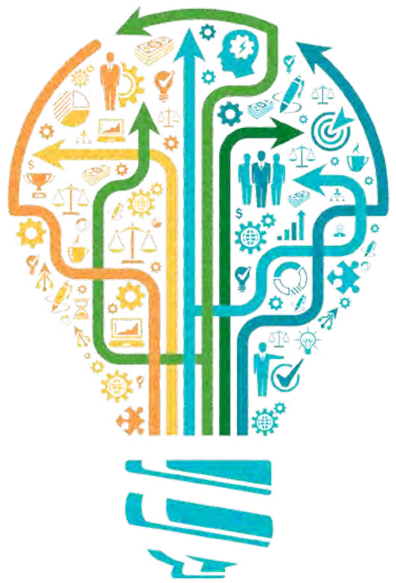
#ThisGirlCan

In October, Isla participated in the South East Disability Gymnastics Competition with her gymnastic school Prime Acrobatics. Isla took the floor with the confidence of a professional to perform her routine which consisted of balances, jumps, rolls and dance. She moved with poise, elegance, grace and control. The routine was simply breathtaking. Her determination paid off as she was awarded a silver medal for her commitment and effort. You can watch her routine on our facebook page – it's our most watched post ever! She is a true FOP warrior and we love her!

Calling all Innovators

A chance encounter at the Manchester Science Festival at the Museum of Science and Industry, led to Helen learning about the amazing Prosthetics and Orthotics team at the University of Salford. Never one to miss an opportunity, Helen chatted to Matt about the challenges people living with FOP live with on a daily basis, and how it was incredibly difficult to find tools 'of the shelf' that would enable them to carry out simple tasks independently. The team at the University of Salford is one of the leading academic centres for excellence, and they are keen and eager to help! Helen will be going to meet with Matt and his team, to see the facilities and to talk about how they may be able to help.

So this is where **we need YOUR help!** What tool would make your daily life easier? It might be a small hand-held device or something larger. You can send a solution you would like to be made… or perhaps just tell us about a challenge you face and we can see if the engineers can come up with a solution. This is an exciting opportunity to make a real difference and we're looking forward to how the project evolves. Send your challenges or solutions to info@fopfriends.com or send us a message via our social media channels.



Best friends bending over backwards to help!

You may remember Sylvie and Izzy from last year…well, our cartwheeling superstars have been bending over backwards – literally - this month to raise money and awareness for FOP Friends! Following on from their success last year of their cartwheel challenge, the girls decided to take on 100 walkovers for four weeks! Sylvie and Izzy even produced their own video to launch their fundraising efforts on social media. They have been doing gymnastics since they were little and it's still one of their favourite hobbies. Thank you again Sylvie and Izzy for being such superstars for FOP Friends! They have raised an amazing £931!

The Greatest of Runs!

We were delighted to have a full team once again for the Great North Run 2022. Although the event was held just days after the sad passing of HM Queen Elizabeth II, so we were in a period of national mourning, the event was a celebration of great people doing a great thing for great causes and a fitting event to our Queen who had dedicated her life to supporting good causes. We had runners from all around the UK travel to attend the event to raise money, awareness, and to just have fun! Chris and Oliver came along to the event to welcome our team across the finish line – and there we some very impressive finish times too! A big thank you to all our runners for committing their time and energy. We are thrilled to announce that #TeamFOPFriends raised an impressive £10,599. Thank you to everyone who donated!

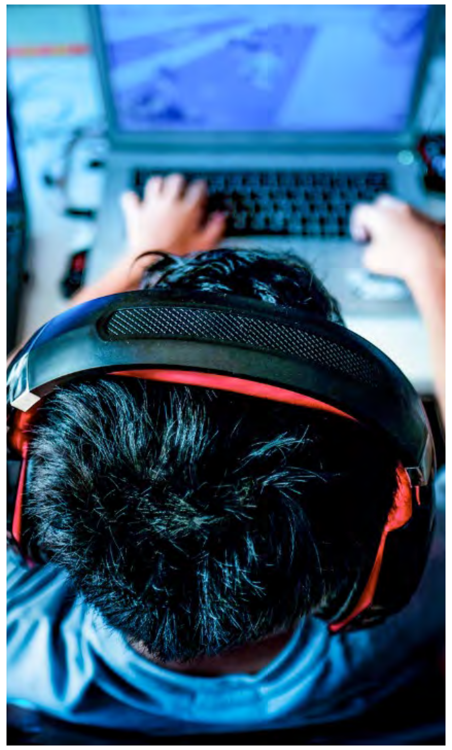
The Really-North Run!

Mum and dad super-duo Judith and Alistair donned their running shoes once again this October to take part in the Great Scottish Run in beautiful Glasgow, in honour of their daughter. This was the fifth time for Judith taking part, and the fourth for Alistair. They both did brilliantly and were pleased with their time. Another run under the belt! Thanks to their generous family and friends, they raised £1394

Raid Train Raises Awareness Around the World!

We were pleased but also rather puzzled when we found out a supporter had arranged a Raid Train to raise money and awareness for FOP! So what is a Raid Train (we had to ask too!)?

Basically, various people on the platform **Twitch** arrange switch their followers from one stream to another. There were gamers, crafters and musicians who all shared their talents. Each artist put on a two-hour broadcast, then all those who were watching were 'raided' and moved to watch the next streamer on their live feed. It was effectively a continually moving broadcast, which lasted 48 hours. The Raid Train was coordinated by Engraver Gamer and required careful planning to take into account time zone and locations around the world. This was most definitely a first for us! Best of all, the raid train raised an incredible £2350 for FOP Friends, but perhaps more importantly it took awareness of FOP all around the world. Planning and preparation for the next train is already underway!



Smiling Simon

Simon Sims was back doing what he's fabulous at this summer -singing and entertaining our friends and supporters in Bridgwater, Somerset for little Alanna. He performed at not one, but two events to raise money and awareness for Alanna. There were stalls, cakes, balloons and smiles a-plenty. And of course, there was lots of laughter and dancing as Simon entertained his crowds. A big thank you to Simon for travelling from Glasgow to support Alanna and her friends.

Paddle the Thames

Measuring 215 miles long, the River Thames is officially the longest river in England. The 'Paddle the Thames' route begins in Lechlade, the uppermost navigable part of the Thames,and ends in Teddington, just before the river flows into central London. This puts the challenge at an impressive 137 miles.

This was another 'first' for a fundraiser, from supporters Rob King and Mark Nott who decided to enjoy a paddle while raising a few pounds for their little friend Lexi. The experience can take anywhere from 6 days to 15, depending on experience, but Rob and Mark smashed these times, completing the paddle in an incredible 5 days! We would also like to give a special shout out to their shore crew, Paul and Lexi Woolly and Jackie Nott who helped to make the challenge possible. Their little paddle raised an impressive £4100 too!

Well done Team Lexi!

Christmas Cards on Sale Now!

Our Christmas cards are back on sale! Buy yours now through our eBay shop. Only £6/two packs, including postage to UK.

www.fopfriends.com/shop

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

www.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.

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**

Congratulations Alex!

Lexi's mum Alex has been a tireless supporter of FOP Friends since her daughter's diagnosis last year.

She has been generously supported by families and friends in her local town of Hemel Hempsted to raise much needed funds and awareness of FOP and the charity. Alex's efforts were recognised at the Above and Beyond Award Ceremony 2022 for local heroes. On behalf of everyone affected by FOP, CONGRATULATIONS on your well-deserved award.

Shop for FOP!

We would always encourage people to shop local, but we also know that online shopping is a popular way of doing our Christmas shopping too. If you are an online shopper, then you can also help FOP Friends at the same time. Select FOP Friends as your charity for Amazon Smile www.smile.amazon.com or if you want to shop your favourite high street stores, then Easyfundraising is for you! Find us at www.easyfundraising.com/fopfriends. So far we have raised over £1670 through Easyfundraising, and £1100 from Amazon this quarter. Every little does help!

Do you tick the box?

We are forever grateful to each and every person who donates to FOP Friends. Every month we are bowled over by your generosity. Meeting the researchers this month was simply wonderful to see your donations make a real difference. But did you know, you can make your donation go even further??

If you are UK taxpayer, you can GiftAid your donation which means we can claim an extra 25% on your gift at no extra cost to yourself. You can tick the box on the Enthuse donation platform, complete a GiftAid form here: www.fopfriends.com/you-can-help/donate/; or you can simply add a note in with your donation with your name, address and instruction for us to claim and we will do the rest!

It really does make a difference too! This quarter, we have claimed £3000 in GiftAid alone!

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