friends® Together

Vol 4, Issue 4 Dec 2021

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

Racing for a Cure

As we have started returning to 'normal', with restrictions lifting and mass-participation events going ahead once more, we have been blessed with over 20 incredible runners who have laced up their trainers for FOP Friends.

We had a fabulous team of thirteen runners who took part in the iconic Great North Run. Becky finally got to run the race of her dreams, the London Marathon, whilst her husband Stuart took on the challenge of a triathlon at the stunning Blenheim Palace. Lauren ran an incredibly fast time for her Virtual London Marathon. Another husband and wife team, Terri and Dave completed the Windsor Half, running up the famous Long Walk. We were honoured to have some new-to-running team members smashing personal goals with the Rochdale Half and Manchester 10k. Alice took part in the Luton Half, running through the gorgeous countryside and Luton Hoo. Last but not least, trustees Rachel and Fiona both completed their first marathons in Manchester. Whatever your motivation for running, everyone affected by FOP would like to thank you for your dedication to your training, but also to your friends, families and supporters who generously sponsored you all: your combined efforts have raised an incredible £20,000 for FOP Friends.

Inside

A word from Rachel

As I'm writing this, I'm still nursing some knee injuries from the Manchester Marathon that I ran a few weeks ago, in aid of FOP Friends. It was my first marathon, and the months of training were difficult and long at times but also rewarding and enjoyable. When my knees started to hurt as the big day approached, I was nervous but determined to get through the race. I didn't want to let myself or anyone else down, particularly as so many generous people had sponsored me. As I ran (and hobbled) round those 26.2 miles, the thought that frequently came to my mind was no matter what I was feeling on that day, it was nothing compared to what FOP sufferers and their families experience on a daily basis. The marathon felt like a metaphor for our race to find a treatment and cure for FOP and for the work the charity has carried out over the last 10 years. It's been a long haul and sometimes the end feels like it's getting closer, sometimes we feel like it's still far off in the distance. What doesn't change is the determination that I, the other trustees and the community feel to keep going, and keep pushing on, no matter how hard, to find that treatment. Seeing Oliver cheering me on kept me going and I know it's our families, friends and communities that will keep us all going until we have the effective treatment and cure for FOP. Merry Christmas and New Year.

Rachel
FOP Friends Trustee

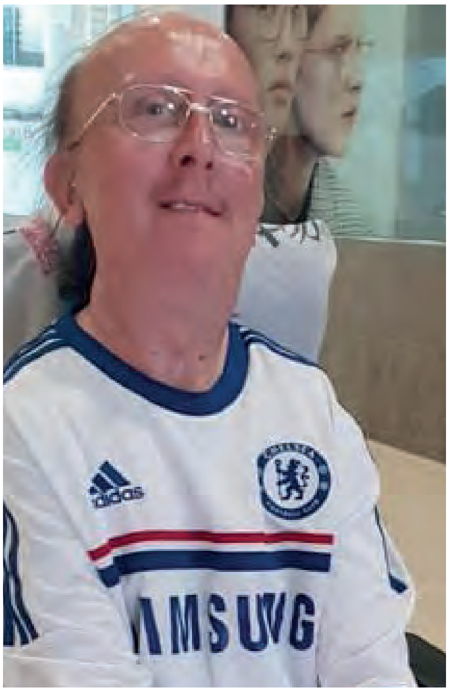
Remembering Paul

It is with heavy heart that we share the news that Paul Sands passed away in September. Our readers will remember he featured in our newsletter back in September talking about how he was fiercely independent, his hobbies, and his love of driving his VW transporter.

Paul was a fabulous brother to Peter, Penny, Petra and Perry, and a great friend to so many. He was a life-long Chelsea FC supporter, and this was reflected by his family and friends who attended Paul's ceremony to remember and celebrate his life. The minister commented on how he had never seen so many football shirts at a service before – Paul would have been so proud!It would be lovely to think one of the goals Chelsea scored on Saturday in their 7 – 0 domination of Norwich City, was for Paul.

Amongst other things, Paul didn't like to throw anything away! His family are now trying to use this for good, by selling things to raise money for FOP Friends, but also giving his treasures away to charity shops and homeless charities so as to help as many people as they can.

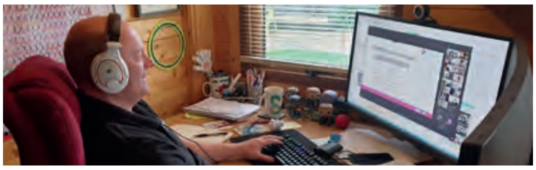
Paul was a remarkable man who never let FOP get in his way and retained as much of his independence as he could, right until the end. His family requested that donations be made to FOP Friends in his memory, and so far over £500 has been gifted to the charity. He is sadly missed.



Crafty Creations

Lenny's friends have been finding creative ways to raise money! After her friend's little boy was diagnosed, Claire wanted to do something what she could to help. Being a creative crafter, Claire used her talents to make beautiful jewellery and keyrings, while her daughter Ruby-Skye, 10, helped by sewing scrunchies as well as helping mum with the jewellery making. Ruby-Skye and her best friend Rosie took care of their beautiful stall at Ryhall Village Fair to sell their gifts and raise awareness of FOP. A few weeks previously, they had organised a fabulous Spooky Trial for Halloween through the village. So far, they have raised over £400 and they have lots of other exciting ideas in the pipeline. Thank you for all your enthusiasm and hard work.

Behind the Scenes



Behind the scenes, Chris has been focussing on working with NICE – the National Institute for Health and Care Excellence – which is responsible for the decisions regarding access to approved treatments on the NHS. Chris has been attending virtual meetings with a number of organisations and agencies to ensure that FOP Friends is recognised as an expert patient organisation and that we will be consulted and able to participate in the decision-making process. This is vital if the voice of people who are living with FOP are heard. Getting a treatment for FOP is just the next step of this journey, the real hurdle will be ensuring patients have access to the treatments on the NHS.

Chris has been selected to join the Patient Group Expert Panel at Find a Cure for the next two years, to help guide and advise on their programming which supports all rare disease patient organisations in the UK. This is an exciting opportunity to enhance FOP Friends' standing with the rare disease community as a whole. Find a Cure is a charity which is dedicated to the support of patient organisations in the UK. FOP Friends is delighted to be able to share its experiences as a developing, as well as to shape.

We are always looking to grow as a charity and as a patient organisation, to ensure we are able to support our patients and our familes effectively. To help us achieve this, Chris has signed up to the Find a Cure Patient Organisation Mentoring Programme. This programme will requires us to reflect on our own current practice and identify two goals for our charity. FOP Friends has identified these to be educating ourselves about the Health Technology Assessment HTA and Highly Specialised Technologies processes; and finding more specialist FOP doctors to ensure patients all across the UK have access to expert specialist care, as local to them as possible.

Find a Cure held a Rare Chat last month, where rare patient organisations had the opportunity to discuss their involvement in clinical trials design and research. Chris shared our experiences of working with a number of different research institutions and pharmaceutical companies, as part of an open discussion, in order to help other patient organisations who are not as far along this journey as we are as a community, Chris took part in the Realise Advocacy HTA training programme. This explains the process for charities and connects FOP Friends with other patient organisations which are at a similar point in their journey to a treatment.

What is an HTA?

HTA stands for Health Technology Assessments. Whilst we are very thankful for our NHS, it is massively underfunded and the demands on its budget massively exceed its capabilities to provide the level of support we all need. When new treatments come to market, orphan drug prices are high. This means that those who have to decide what the NHS can afford have tough access choices to make. The payers -those who hold the purse strings -are looking for 'value for money', a significant improvement in the quality of life for those it will help if they are going to decide to pay for that medication.

Patient groups are well-placed to make the case to the HTA to explain the positive effect the treatment will have on the lives of those they support. By using their knowledge, examples of lived experiences, real word evidence, as well as explaining the unique challenges people with a rare condition face, patient organisations can assist with providing the information the HTA require to prove that the drug will make a significant difference to those living with the condition, provide value for money and ultimately is worth the hefty price tag.

Clinical Trial Update

Just before going to print, Incyte Pharmaceuticals announced that they have submitted their FOP trial for a Phase 2 study of their drug INCB000928. It will be open to eligible participants age 12 and older. Trial locations haven't yet been announced.

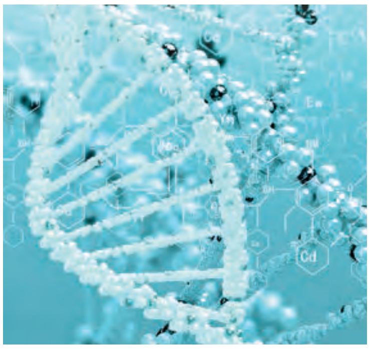
Ipsen is in the process of commencing a Phase 2 study to assess the efficacy and safety of its new drug IPN60130. This will be known as the FALKON study.

Recruitment has not yet started for the trial, although a date is expected soon. Participants from the age of 5 will be able to take part after safety has been proven in adults.

Regeneron published a press release at the end of September that they are now in discussions with the FDA to move forward with plans to design a phase 3 trial of garetosmab, with a hope to recruit patients in early 2022.

Chris attended a webinar at the end of October to get an update on the STOPFOP trial. The meeting was attended by over 20 interested participants, including Professor Alex Bullock, Dr Marelise Eekhoff and Professor Robert Pignolo. An update was giving on the STOPFOP trial, and the UK site is hoping to begin the enrolment of participants in early 2022.

For more information about any of the mentioned trials, visit clinicaltrials.gov or get in touch: info@fopfriends.com



Lexi's Friends!

When Alex and Dave, from Hemel Hempstead, received the devastating diagnosis that their beautiful baby girl Lexi had FOP, they wasted no time in rallying round their friends and family to start raising much needed funds for the research into a cure, as well as awareness for this ultra-rare condition.

Alex and Dave were already parents to gorgeous Ronnie, age 3, so when Lexi was born, they realised her toes were not as they should be, and something wasn't quite right. After a number of visits to specialists, and refusing to rest until they had an explanation, Lexi was diagnosed when she was just five months old, making her one of the youngest people to be diagnosed.

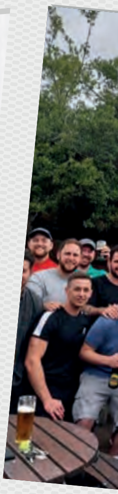
Alex made the decision to share their family's story and diagnosis journey on social media in order to raise awareness of FOP. They set up a Crowdfunder page which was shared far and wide, and Lexi's story touched the hearts of many. In just a few short months, Alex and Dave smashed their ambitious fundraising target of £100,000 thanks to the generous donations of their followers.

In addition to her Instagram posts, Alex has been featured in a number of local and national newspapers and magazines, and local radio stations. Most excitingly, Alex and Lexi also appeared on Channel 4's Packed Lunch with Professor Richard Keen to talk about their journey and experience.

Alex also used her strong social media following to get our petition signed and shared across the UK, gaining interest from a number of well-known celebrities, raising further awareness of the challenges people living with FOP face.

Lexi has been blessed with a strong team of friends who have rallied around her to raise the much-needed funds to support the research to find a treatment and a cure for FOP. To date, Lexi's friends have run marathons and half marathons; a local dance academy held a dance show; friends organised a family fun day in Barton Le Clay; they hosted a golf day for 'Boys v Men'; arranged for local businesses such as their Porsche dealership to promote their fundraising; gained corporate sponsorship from companies; Lexi's supporters held pub collections; organised a 3k run for Lexi; and Alex and her friends organised a spectacular gala Auction Night and Party, and they have recently held a grand raffle for a Christmas Family Break-Away.

As a community, we are incredibly grateful to all of Lexi's family, friends and supporters who have so generously donated to help to fund research into a treatment and a cure for Lexi and all her other Friends who are living with FOP. A big thank you too, to everyone who helped to organise the events. We are excited to share just a few photos of some of the events which have been held for Lexi.



FUNDRAISING TOTAL £135,000


Little Lexi


Gazette & Express
Eight-month-old Lexi needs your help


Chelsea's Run

Happy holidays!

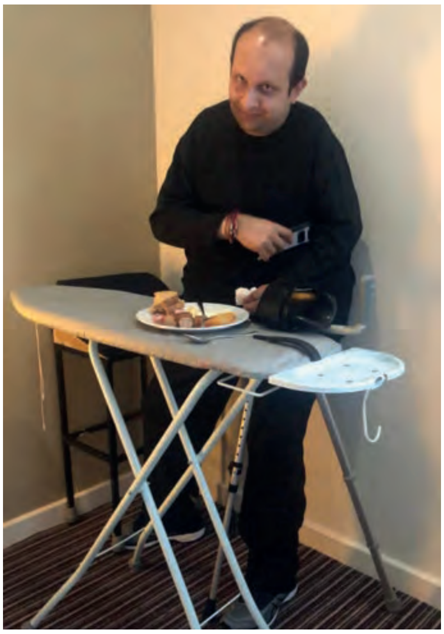
After nearly 18 months of lockdown and uncertainty, we began to appreciate travel and the holidays we had taken for granted for so very long.

Half term also gave many of us the opportunity to get away for a few days, either to explore our beautiful country, or to venture further afield once more in search of some autumn sun. Here, Hamish reflects on his life with FOP and the holidays he has taken over the years.

Every year, people throughout the UK and the world, plan a holiday, whether it's a weekend break or something longer. When you have FOP, or an extremely rare disability, it's not as simple as where to go, how long for or where to stay.

My parents knew from my early FOP diagnosis how restrictive my independence and freedom would become as FOP attacked and enveloped my body. As such, we went on numerous holidays when I was younger and more able. We travelled to India to visit family, and also to tour the southern regions and Goa when I was 3 and 9 years old.

Sandwiched between those trips were holidays to America to visit family and see Niagara Falls when I was 7 and 13 years of age. During these trips, I was fortunate that my FOP was relatively stable, it had predominantly affected my trunk and both arms. We went on a holiday to Tenerife in the summer of 96 for two weeks.



When I started college in September 1996, this coincided with FOP progressing to both hips, knees and ankles. I lost the ability to manoeuvre kerbs, steps or stairs and to sit down on normal chairs. Anything which involved raising my foot more than 4cm off the ground was impossible. In next to no time, my world shrank by 50%, no more going upstairs at home or travelling by car or public transport.

Like each and every one of us with FOP, we find solutions to the hurdles life brings our way. I perched on a high bar stool and used a sturdy box to rest my keyboard or folder on during lectures and exams.

The summer of '97 was my final holiday abroad. My parents realised it was now or never. My mum, younger brother and I spent two months in America, flying to Philadelphia and Atlanta to visit family. My dad joined us when he had annual leave. We spent a week at Disney World in Orlando, it was a holiday of a lifetime! I know I'm blessed to have had the opportunity to see some of the world, thanks to my parents.

We moved to Northampton from London in 2010. My carers often spoke about holidays and asked if I'd like to go away again. We made a plan and aimed to go away for a weekend. I decided I wanted to visit 'The Deep' in Humberside. It's one of the UK's best aquariums. Highly recommended, trust me!

With the help of two carers, one of whom is my best friend, we set off for a weekend's worth of adventure. Although I booked two rooms, I couldn't sleep in the room as I have a specialist standing bed at home. I camped in my van, with a carer, and we returned to the hotel room each morning. I have an electric riser recliner arm chair, which allows me to sleep comfortably in my van. I still remember the stunned faces of the reception staff as we left the hotel, armed with pillows and a duvet and returning the next morning! After washing and getting dressed, the carers would bring breakfast to our room. As you can see, we adapted and used the ironing board as a makeshift table - it worked, as we could adjust the height perfectly.

With careful planning and an open mind, it's possible to have a short break on the UK. When you live with a disability there can be many benefits, it's not just disadvantages. It's given me a huge amount of gratitude and joy and perspective that I would perhaps never have had otherwise. I've met some wonderful people and made lifelong friends along the way. I have made friendships and created memories I'll cherish forever.

For that reason, I would never say it's the worst thing that has happened to me. On the other hand, it's made my life incredibly difficult, and I have ongoing challenges navigating the world.

One of my biggest regrets was not being able to visit Hawaii in person. I have asked my brother and nieces to see if they can fulfil my wish and watch the sun rise and set off a beach in Oahu for me.

My heartfelt thanks go to my carer and Maxine for making it possible for me to have these breaks. It wouldn't be possible without you or your amazing care.

Stay safe

Hamish x

Dx 5, now 41

Petition

In September, we launched our second petition to the UK Government, asking for them to invest in FOP research, which would support the quest to find a treatment for FOP but which would also further understanding of other more common conditions such as osteoporosis, heart disease, hip replacements, DIPG, and other common military injuries.

We smashed the total number of signatures required – 111,082 – thanks to our wonderful community sharing the petition, and also with Lexi's mum Alex getting the petition to go viral and creating interest in our cause far and wide. Many of our families also lobbied their local MPs to get our voices heard. The Government responded to our petition and recognised the challenges that patients of rare diseases face with regards to funding. You can read their full response on our website www.fopfriends.com. Because we reached the required number of signatures, the UK Government will consider the petition for debate in Parliament. Chris has been continuing to work with Sir Mike Penning, Alex Robins and other representatives behind the scenes, to continue our fight for funding and to raise awareness of FOP at government level.

30 YEARS

Jack Murton

The Brick Lane Gallery, 216 Brick Lane

London E1 6SA

July 14th - July 18th

10am - 6pm

Thank you Jack

Jack Murton, cousin to Seanie with FOP, has had a colourful life. He has spent 13 years of his early youth and adulthood, on and off, in prison.

In 1984, Jack was convicted of an armed robbery and sentenced to 12 years. After serving four years at Maidstone, he was moved to Blantyre House prison to complete his sentence. It was whilst at Blantyre House he was given the opportunity to find a new direction, and for Jack this became painting. He fell in love with art and wouldn't leave the studio. Jack was stunned when he sold his first painting for £130 while he was still in prison. Jack's love of painting never left him after he left Blantyre House and he has continued to make a living from it to this day – although often from just decorating houses. In July, Jack was given the opportunity to showcase his works of art, many of which depict events from his life experiences such a court room and prison, at The Brick Lane Gallery, London. Jack's paintings now sell for up to £2000 and he donates 10% of the sales of all his works to FOP Friends in honour of Seanie. To see more of Jack's work, visit: www.jackmurtonartist.com

Slemish Climb

Mike Buxton has only been at his new place of work for a short while, but his amazing colleagues from Doury Road Spar have already put their best feet (boots!) forward to help raise money to help find a treatment for his wife Zoe and her twin sister Lucy, who both live with FOP.

Along with nine of his colleagues, Mike climbed the stunning Slemish Mountain in Co. Antrim, Northern Ireland. The legendary first known home of St. Patrick, the mountain rises about 1500ft and is actually an extinct volcano! It was a beautiful morning for such a walk and the team were delighted to make it to the top – they even took one of our bears to admire the view! While Zoe and Lucy were unable to join in with the climb due to their restrictions as a result of FOP, they went along to support the team and waited in their camper van with hot drinks for the weary walkers when they returned. Thank you to the team and their friends and supporters – an amazing £500 was raised!

www.fopfriends.com/shop

Virgin Money Closing

All charities were notified just two months ago that Virgin Money Giving are closing their fundraising platform at the end of November 2021. Obviously, this has had a huge impact on us as a charity as we have started the process to find a replacement platform. Whilst we find the one that best fits our needs, we are asking our wonderful supporters to use our Just Giving account page for now. Thank you to everyone who continues to fundraise 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

www.fopfriends.com

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

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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.

Recycle 4Charity

Working from home? Working from an office? Not sure what to do with all your used printer cartridges?

Then why not get a Recycle4Charity box and start collecting your used cartridges…it's good for the environment and even better for FOP Friends! We receive a small donation for every cartridge returned at no cost to you! You can also request a box for your office and get your colleagues to bring in their cartridges from home. It's super easy! Get in touch for more information or to arrange for a box to be sent to you.

Christmas cards

Yes! It's that time again! We are excited to reveal our Christmas card design for 2021! Designed to raise awareness of FOP Friends, they also carry a brief description of FOP on the reverse, helping to educate friends, family and colleagues about the condition.

Cards are £2.50 a pack when collected from a Friend, or two packs for £6 including p&p through our eBay shop. If you would like to sell some on behalf of us, please get in touch and we'll send them out to you!
www.fopfriends.com/shop

Save the Date!

Radisson Blu Manchester Airport Hotel
Manchester, England
20th - 22nd May 2022

Find us on social media

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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**