fop friends Together

Vol 6, Issue 1 Apr 2023

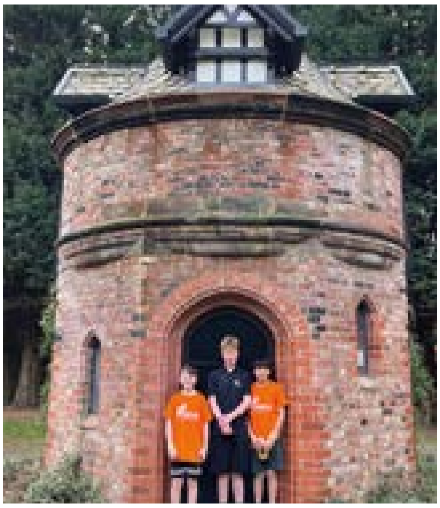
FOP Friends exists to **help find a treatment and a cure** for the rare genetic condition fibrodysplasia ossificans progressiva (FOP), and to **support the families** affected by it

A Family Fun Run!

Oliver's brother Leo (13), and his cousin Edison (12) decided to put their trainers to good use this year - to raise funds and awareness of FOP. With the charity FOP Friends being a big part of both of their lives from a young age, they were very aware of the impact of living with a rare condition such as FOP and how it affects people's daily lives.

Leo and Edison are both keen sportsmen, enjoying a range of sports including lacrosse and football, but this was their first long run.

The Local Landmarks Virtual 10K invites participants to plan their own route around their local area, stopping at points of local interest. Living in Sale, Leo and Eddie had plenty of fabulous parks and buildings of interest to incorporate into their run. They put together their own running training plan before completing the event in half term.

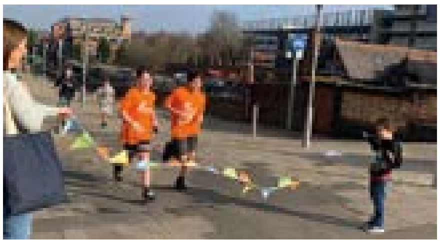


Oliver, along with family and friends, was there to start them off at the beginning of their run at the iconic Dovecote in Walkden Gardens, and then met them as they crossed the finish line at Trafford Town Hall. They took just over an hour to make their way round Sale, visiting Worthington Park, Walton Park, the Manchester Bee tree carving, the secret (and haunted?) cemetery tunnel, and the Bridgwater Canal to mention a few of the places they passed. Leo said, "I wanted to raise money to find a cure for my brother. He makes me mad some of the time, but I worry about him and want him to be able to carry on doing all the things he loves. This seemed like a good way of raising awareness of FOP around our local area and I was proud to represent FOP Friends,".

Inside

Eddie commented, "Running isn't really my thing, but I've enjoyed my training and the run because I know it's going to make a difference. Oliver's just the best cousin and I want Oliver and all the other kids I know with FOP to have a treatment that will help them."

The boys were thrilled with their efforts and their time. Thanks to their generous friends and family, the boys raised **an amazing £1000!**



A word from Rachel

The year has already got off to a flying start! I was thrilled to be able to join my nephews, Leo and Eddie, as they completed their first ever 10k run, raising funds for FOP Friends. I joined them, along with other family members and friends, for the last mile. To see the kids all push themselves and ignore their tired legs to be greeted at the finish line by Oliver, Helen and other family members was so heart-warming and wonderful to see. The boys raised an outstanding £1k. It also inspired me to put my running shoes back on, especially with the lighter evenings, and get myself signed up to a race. We have places available at the Great North Run – the first ever race I did and absolutely one of the best so get in touch if you'd like to be part of our team! I've enjoyed reading not one but two articles in this issue, written by members of our community, I'm sure you will too. Spring is a time for hope and positivity – something we all need in our wonderful community – I wish you all a happy one!

Rachel, FOP Friends Trustee

STOP FOP Webinar

In January we hosted our second webinar for the STOPFOP trial. It was led by Professor Alex Bullock, University of Oxford, Associate Professor Marelise Eekhoff, Amsterdam UMC, and Professor Richard Keen, Royal National Orthopaedic Hospital, London.

The webinar was an explainer about the different approaches the researchers are taking to finding a way to stop the FOP gene creating new bone. It also discussed the progress which has been made so far with the STOPFOP trial, and also provided information to patients about how they too could participate in the trial and what the requirements were. It was extremely well-received, and it was attended by participants from 15 countries world-wide. We were most grateful to the speakers for giving their time on a Sunday evening.

In case you missed it, or would like to watch it again, the webinar is available to watch now on our YouTube channel: **www.fopfriends.com/video-library**

The STOPFOP trial has been made possible, in part thanks to the money raised by FOP Friends – people like you who are reading our newsletter today. **You are making a difference to the future for those living with FOP.**

Great North Run Places Available

Looking for a challenge and a way to make a difference to those living with FOP?

We still have some places left for the Great North Run on Sunday 10th September. The Red Arrows are attending this year's event to do their flypast over the Tyne Bridge to start the event and put on a display at the finishing line in South Shields for the supporters. So, what are you waiting for? To secure your place for just £30, visit: www.fopfriends.com/gnr

Hope. Believe. Wish.

APRIL 23–GLOBAL FOP AWARENESS DAY

Global FOP Awareness Day 2023

We are proud to be partnering again with the IFOPA and all the other patient organisations around the world to raise awareness and understanding of FOP. If you don't already, ask your friends and family to follow us on one of our social media platforms and then share, share and share away with our posts.

Hurray for Hydration!

Dehydration is the single biggest issue facing healthcare in Britain today. Many of us take for granted just grabbing a quick drink from the fridge, or putting the kettle on, when we're thirsty. But for many people, access to a drink just isn't that simple. For those with limited mobility, such as people with FOP, easy access to fluids can be at least a challenge, at its hardest – impossible. We were therefore delighted to learn of The Hydration Foundation, which has designed a unique hands-free drinking system.

We were able to arrange for the delivery of these systems to nearly half of our FOP families in the UK. One of our families replied, "Omg!! We just got Josh's water bottle. It's amazing he absolutely loves it. He can't wait to take it to school tomorrow. It'll definitely makes his wee life so much easier!"

We are so thankful to The Hydration Foundation for supplying these to our families.

If you would like to learn more about the work of the Foundation, or to order a bottle system for yourself or a loved one, visit: **www.thehydrationfoundation.org**, follow them on Facebook, or get in touch with us.

FunFeet4FOP

Yes! It's back and in its 7th year!
One of the key diagnostic flags for FOP is the turned in toes…as they say, Let their Feet Lead the Way… And so Fun Feet was born…

Please help to raise awareness of 'the toes' by sharing your Fun Feet and tag us on social media **#FOPFriends #FunFeet4FOP.**

We love seeing your creativity!

RARE DISEASE DAY®

RARE DISEASES CURRENTLY AFFECT 5% OF THE WORLDWIDE POPULATION

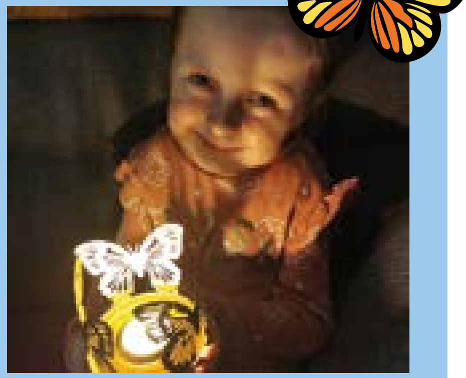
70% OF GENETIC RARE DISEASES START IN CHILDHOOD

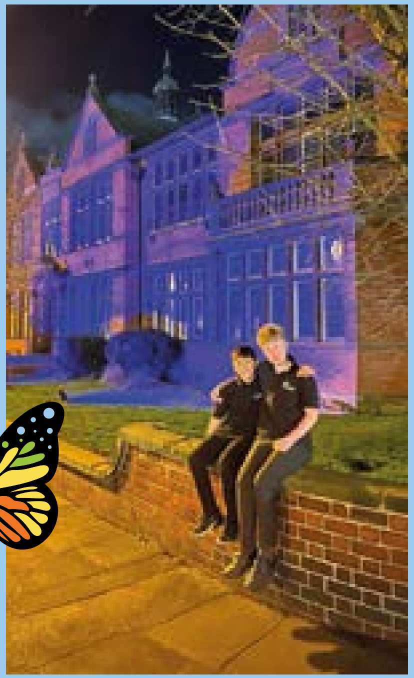
Progressive Osseous Heteroplasia is considered the sister condition of FOP. It is even rarer than FOP, affecting around just 100 people worldwide.

Rare Disease Day 2023

Once again, we stood with those affected by all rare diseases to recognise Rare Disease Day. While there are only around 70 people in the UK living with FOP, and two people living with POH, there are an estimated 3.5 million people in the UK with a rare disease.

FOP Friends arranged for Trafford's town halls to be illuminated in recognition of everyone living with a rare disease, and some of our families lit candles on the 28th February as part of the Global Chain of Lights. #StrongerTogether





Rare Disease Heroes: Nicky shares her story

This year, Nicky shared Isla's diagnosis story as part of the Rare Disease Day Organisation's 'Heroes' project. Nicky speaks about how Isla's toes were noted as 'congenital bunions' – bunions are a common misdiagnosis for FOP – and then went to the internet to learn more. It was there she read about FOP and so began her journey to diagnosis. You can read Nicky and Isla's story here: **https://www.rarediseaseday.org/heroes/the-answer-is-in-the-toes/**

A rare disease is defined (in Europe) as a condition which affects fewer than 1 in 2,000 However, there are an estimated 350 million people worldwide living with a rare disease.

Rare diseases are chronic, progressive, degenerative, and often life-threatening. There is NO CURE for the vast majority of diseases, and very few effective treatments.

Alanna's Awareness Day

Alanna's school marked Rare Disease Day with a special assembly which explained to the pupils about what living with a rare disease means. They spoke about how living with a rare disease can make everyday tasks more difficult and that sometimes, people may be struggling and it may not even be visible. They used FOP to illustrate some of the challenges that a person with a rare condition may have to live with. The teacher explained that when someone has FOP, you have to take extra care around them so as not to hurt them. The school also talked about how when people have a disability, they may need special equipment such as a special chair, to keep them comfortable and safe. Alanna's chair also raises and lowers, which allows her to join in with all her friends.

The school also shared the video: The Same but Different: A Look at Life with FOP from the IFOPA. To help raise further awareness of FOP, Alanna brought in some gorgeous bracelets with a butterfly charm and gave them out to all the class. Alanna's friend Isla was delighted with hers!

Rare disease patients face a wait (on average) of between 5 - 7 years before they get a diagnosis. The average time to get a diagnosis of FOP is 4 years.

FOP in the News.

ITV's local news channel for the north-west, Granada, ran a feature on FOP for a living with a rare disease. The segment featured Avi, Rachel and Oliver who all live in the Granada region. Professor Zulf Mughal, from the Royal Manchester Children's Hospital who has been an expert in FOP and caring for patients for many years, explained the condition. He spoke about some of the ways researchers are trying to find ways to block the abnormal bone growth and his hope that they will find a treatment soon.

Avi and his mum Rashmita gave an honest account of the way FOP has impacted their lives and their emotional wellbeing, with Rashmita admitting one of the hardest things about her son having FOP was not being able to hug him. Rachel spoke about her FOP journey, and how she just wished she could take the pain away from the younger children she knows with FOP and whom she considers friends.

Oliver was able to share his hobby of model trains, and talk about how reaching out to others in the community, making friends with others the same age as him and living with FOP, has helped him deal with the condition, because, as he put it, 'you get to talk about stuff with them you wouldn't want to talk about with your other friends, they don't understand'. To watch the feature, visit: www.fopfriends.com/video-library

A Fun Day for Friends.

Isla's school continued to raise awareness of rare diseases by holding a school assembly for RDD. They learned about how living with a rare condition can make simple everyday tasks a challenge. They too shared the video Same but Different. All the classes were delighted to receive their own FOP Friends bear to keep safe in their classroom. Then, the pupils in Year 6 organised and held a Fundraising Day. It was a wonderful event which the whole school enjoyed. The money raised was split between FOP Friends and to buy a school pet. We were delighted to have been chosen as one of their charities and thank the pupils and parents for their support. We also can't wait to meet the school's new addition… watch this space!

A Rare Presentation

Oliver travelled to Regeneron in March to give a presentation about living with FOP. The pharmaceutical company held a Lunch and Learn for their team, as part of their commitment to rare diseases as a whole. Oliver spoke again about his condition and his attitude to living his life. Chris gave an emotional presentation about the journey FOP Friends has travelled so far, the challenges he has faced as a parent, and his dream and vision for a treatment for Oliver and everyone affected by FOP.

Helen @ the IFOPA

As Chris put down his notebook and pen, so Helen picked it up. After 13 years of serving on the Board of the IFOPA, Chris handed the baton over to Helen when she was elected to the Board back in December 2022. Helen tells us about her first ever 'business trip'…

Travelling for business was a whole new experience for me. Having been a teacher for most of my career, I'd never had the opportunity to travel, so this was a whole new experience for me. The meeting was in Boston, Massachusetts, and it was my first opportunity to meet many of the members 'in real life', though it felt like I had known them for years! I was incredibly honoured and excited to meet Nadine and Emma – two incredible young women who are living with FOP, and who are dear members of our community.

My meeting began a day earlier as I had my induction onto the Board. I met the amazing team behind the IFOPA, and also learned more about my role and responsibilities. Michelle and her staff are even more impressive when you meet them in person.

After lunch, Board members visited Paul Yu's Research Lab at Massachusetts General Hospital. There were presentations from some inspirational and talented researchers, who spoke about the many and varied aspects of FOP they are studying. Paul Yu spoke about the StopFOP trial, and it was great to see FOP Friends' name as one of the organisations who have made the trial possible. We were given a tour of the labs to see where the research happens.

Dinner that evening was at the hotel, where the IFOPA welcomed some of the Boston-area researchers. I was amazed at just how many great people are working on FOP. There are so many bright minds investigating the complexity of FOP and looking for innovative ways to stop it in its tracks.

On Friday, the meeting formally began with in-depth updates on FOP Research in Boston. Much of what was said was confidential, but I couldn't retell it if I tried. So much of the science was beyond me, but what I did understand was the passion they all have for their work. As the parent of a child with FOP, I was overwhelmed yet filled with hope at the same time. Subsequent sessions focussed on projects as well as the administrative side of running a global patient organisation. It was great to be able to listen to the services and support which are available to all our community members, worldwide. We also had another lovely dinner where we were able to meet Boston-area families.

I had a few hours on Sunday before my flight home, which gave me time to wander around the beautiful city of Boston as well as visit Harvard. I also managed to pick up some gifts for the boys whom I'd missed dearly. I had survived my first ever business trip! It had been so many things: interesting, informative, emotional, tiring but I was leaving with so much hope.

Without hesitation, the best part of the trip was meeting the people. It's always about the people. People are making the difference. There are so many days when we feel alone, but if we pause and look around, we can see we are surrounded by a family of friends who are all working towards the same dream: a cure for FOP. I feel incredibly blessed and lucky that there is so much positive energy and action being directed towards a treatment for Oliver, and everyone affected by FOP.

My FOP Story

FOP: three little letters which invariably have a life-changing impact for parents, siblings and of course the person with FOP. I recall my own particular story aged 5…

I'd fallen over at school and mum was helping me shower when she noticed my glands were swollen. This resulted in an emergency appointment with our GP who came up with an unconfirmed misdiagnosis of tuberculosis. My parents had so many questions but instead of answers they were told 'if my symptoms continued, it was highly probable I wouldn't survive'…

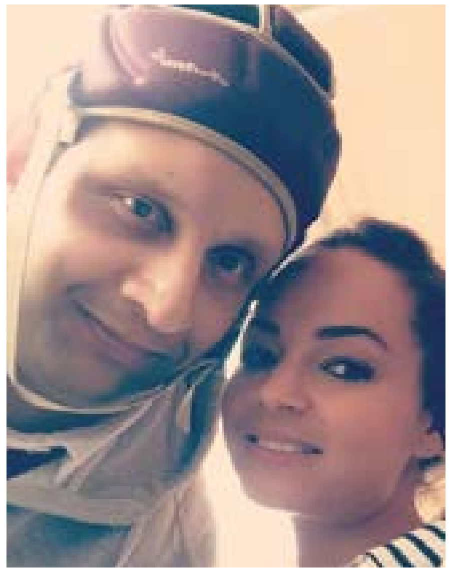
By good fortune, a visiting consultant from Great Ormond Street took interest in my case. I was transferred to GOSH and a definitive diagnosis of FOP soon followed: a full body x-ray was carried out and compared with another FOP child of a similar age.

Our lives changed, literally overnight. With the words of the doctor etched on my parents' minds, they made the decision to have another child, and 18 months later a healthy baby boy arrived. There was genuine trepidation that my sister may end up an only child.

We moved to London when I was 9 because it became impossible to run a shop, raise a young family and attend all my appointments at GOSH.

Growing up, I did the usual things other children did - riding my BMX bike, doing the Sunday morning paper round, and playing football.

My family were all too aware of the progressive nature of FOP. My parents wanted me to see family and experience the joy of travelling whilst it was physically still possible.



This culminated in a trip of a lifetime in the late 1990s when they surprised me with a family holiday to America. We spent the entire summer flying to different states to visit family, going to see Niagara Falls, and a week at Disney World. These are experiences I still cherish to this day.

My education followed a mainstream pathway. I didn't want to attend a specialist school, it was my limbs that were predominantly affected, not my brain.

I'm blessed with an extremely loving family. My mum gave up work, dedicating her life to care for me, while my dad worked 12-hour shifts to provide for us. Many sacrifices have been made by my parents and siblings over the years, none of which have gone unnoticed or unappreciated by me.

I feel immense guilt in the case of my siblings - having a brother who is ill has impacted their life too. From the outside, people see a family with a child that's disabled, but not many people see the impact it has on their siblings or family unit.

FOP impacts a person and their family more than just physically. Creating positive memories is crucial. As symptoms progress, reflecting back on memories is a source of comfort. It's about living for the moment and living your life whilst you're able to do things. It requires you to weigh up the level of risk and decide how comfortable you are. It's about what works for each family, the level of risk you find acceptable in terms of giving your child the freedom to experience life.

We are all unique with our families and opinions. Find what works for you and your family, live your best life and be happy. Don't put off things if they are possible, because life is just as unpredictable as FOP.

Being trapped within my body has been the greatest challenge of my life. It's a tiring battle which drains me emotionally and physically but I'm still grateful. I'm fully aware there are people worse off than I.

Blessed with a wonderful family, my FOP journey hasn't been alone by any means. By the grace of God, I'll turn 43 in April, so I have made it past the average life expectancy. I'm still here and I'll keep fighting each day, knowing I have the unconditional love and support of my amazing family, friends and the best team of carers anybody could hope for. My life may be completely different to the one I'd envisaged but it's mine. FOP won't define me.

I've been incredibly fortunate to have met some truly inspirational people thanks to FOP Friends and made lifelong friends in the process including doctors and carers whom I wouldn't have met otherwise. I'm beyond grateful for having you all in my life. Along with my family, you've made a tangible difference and I wouldn't be the person I am or lived the life I have without you all.

Much love, Hamish xxx

Shop4FOP!

You will probably have heard that Amazon ended its Smile programme in February. We would like to thank everyone who chose us as their charity to benefit. We would always encourage people to shop local, but we also know that online shopping is a popular way of fundraising.

We are registered with both easyfundraising and Give as You Live, so your shopping can continue to benefit FOP Friends. We thank you in anticipation of your support.

Give as you Live®

easy fundraising .org.uk feel good shopping

This newsletter has been made possible thanks to a grant from **The Zochonis Charitable Trust.**

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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.

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**

Meet Charlie

Charlie has been a dynamic member of our community for many years, and we have loved watching him grown up from a cheeky chappy to a high-achieving young man.

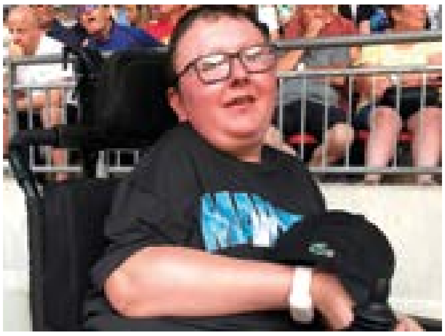
Here, Charlie tells his story and talks about his hobbies

“My name is Charlie, although my friends call me Chaz! I have FOP but I don’t let it stop me from having fun. Last year we got an amazing standard poodle named Duke who is my best buddy.

I enjoy watching films such as Marvel Super-Heroes, DC Super-Heroes and the Harry Potter films. Also, I enjoy collecting both prop replicas and signatures from those franchises.

Another interest of mine is playing video games such as the Batman Arkham series on my XBOX 1. The best holiday I had was when my Mum, Dad, sister Rae and I went to America. During this holiday, we spent most of our time at Universal Studios Florida where we were able to spend to two weeks just doing what we wanted. My favourite ride was a ‘Men in Black’ ride, where everyone had blasters, shooting lasers aliens when they popped out. We also enjoyed the Marvel and Transformers 4D experiences. In Universal, there are two amazing Harry Potter rides too.

I also enjoy going to music concerts. I have been to see a range of different bands and last summer, we went to see Coldplay live at Wembley Arena. As well as that, I have been to the Palace Theatre in the London’s West End to see Harry Potter and the Cursed Child, which was a spectacular experience.



Over the years I have developed resilience as my superpower. I do this by keeping going and finding my own unique ways to perform tasks that a normal person can do. On top of that, I have not long since finished studying business at college. Whilst I was there, I helped set up and manage a business called Strategic Solutions. This was a consultancy company which has helped improve my skill set and my confidence. I had been a part of this to grow my business skills and support my career options.

Currently, I am studying for a BA in Business Management at the University of Derby. So far, I am excited for the opportunities available for me on this course. I have already been elected as the course representative. In the short time I have been there, I have felt welcome, and the University is disabled friendly.

One piece of advice that I would give future students is to make sure that if you are going to need any care or support at university, then get in touch with the Disabled Student Allowance to give them all the information they need as soon as possible. I would also recommend that anyone with additional needs, to get in touch with different universities before they apply, to see what support they can offer.

Despite having FOP, I am determined to do all the things I can, to enjoy every day and to achieve all that I want to achieve.”

How can you help?

Organise a fundraiser. For fundraising ideas visit:
www.fopfriends.com/funfeet4fop and download our fundraising pack