FOP friends®
Together
Vol 6, Issue 2 Sept 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

Truly Superheroes

Ever want to meet a real-life superhero? Well, if you've ever met Isla, age 9, then you most certainly have! Last year, Isla took part in her first Superhero Triathlon. She had so much fun with her friends, she decided to do it all over again this year! Here, in her own words, she tells us about the day (perhaps if her career as a superhero doesn't work out, she could be a journalist instead?!):

"In August I did a Superhero Triathlon with some family and friends at Dorney Lake. It was super fun. There were 3 main activities. Firstly swimming, then cycling and thirdly running. I did the cycling on and then the running at the end.

You can take part in any way you want, using whatever adaptive aids. I used my Tomcat trike for the cycling and then my Special Tomato buggy for the run but managed to walk the finish where we were greeted with cheers and big medals and goodie bags.

Whilst you were waiting there were lots of fun activities and yummy food and drink. One of the activities I took part in was the Marvel Escape Room. It was a great challenge, there were clues to solve a puzzle. You can go to the event with friends and family, we saw lots of inspirational disabled kids and adults."

Superhero Series is the UK's one and only disability sports series for the Everyday Superhero! For all our missions you can either fly solo or team up with family & friends to do as much or as little as you wish, with as much or as little support as you need! Find out more at https://superheroseries.co.uk/".

Thanks to generous donations from Isla, Kit and Erin's friends, **they have raised a superhero-worthy total of £1120**

Inside

A word from Chris

There's never a dull day when you're running a charity from your kitchen table! However, a change recently to the usual run-of-the-mill meetings has been the preparations for the FOP Friends debate in Parliament. This has been months in planning as we have been liaising with MPs across the parties as well as families from around the UK who are affected by FOP. I attended the debate with Oliver and was joined by Alex, Dave and Lexi Robins. It was an incredible opportunity to have our voices heard by those who can really make a difference. There were many positive outcomes from the debate, and this is most certainly just the beginning. We look forward to bringing you a full report on it soon, but for now, I'd just like to express my sincere thanks to Sir Mike Penning and his team, led by Jonathan Mole, and Lexi's mum Alex for their tireless efforts in making this happen.

Following on from the stress of running the charity as well as the day job, I have just returned from another crazy-busy family holiday in America. We love our road trips as it gives us some time away to reconnect as a family, but it also gives us another opportunity – the chance to catch up with just a few of the great people in our global FOP community who we feel blessed to call friends. This year, a trip to the east coast meant we were able to spend time with Nadine, Joey and his parents Suzanne and Joe, and Sienna and her mom Rory and brother Alex. My boys will all tell you that meeting up with their friends is one of the highlights of the holiday – or should I say vacation?!

Chris,
FOP Friends Trustee

Alma Triffitt Book Award

We are now in the third year of the Alma Triffitt Book Award, which was started by her husband, Professor Jim Triffitt, in loving memory of his wife. He wanted to gift the children a book as recognition and admiration for the daily challenges they endure living with FOP. A wonderful selection of booked was picked out by Blackwells at Oxford University – so the children had many different types of books to choose from!

This June, all children living with FOP or POH received a free book of their choice in honour of Alma. All the children loved their books and gave a huge thanks to Professor Triffitt!

Take a look at some of them…

Tea at the Palace

Helen and Chris were honoured to attend a Garden Party at Buckingham Palace in May, in recognition of her BEM Award from HRH Queen Elizabeth's Jubilee Honours List back in 2022. The Garden Party was hosted, on behalf of The King, by The Prince of Wales, who was joined by The Princess of Wales, The Duke and Duchess of Edinburgh, The Princess Royal, and the Duchess of Gloucester. 8,000 guests were welcomed to the Garden Partyin recognition of their services to charity or public life. It was a wonderful occasion for the charity to mark everything to celebrate everything it has grown into, from the dark early days of Helen and Chris' son's diagnosis to the respected organisation it is today.

The afternoon officially began when the National Anthem was played by the military band. There were Beefeaters to ensure guests knew where to walk. Helen and Chris were able to enjoy a delicious afternoon tea -and yes, they did have cucumber sandwiches!

Chris and Helen were thrilled when they were given the opportunity to speak with HRH The Princess Royal and tell her about their work.

> It was an honour to be able to share our story with Princess Anne, and to raise awareness of the many challenges our families face on a daily basis.
>
> Chris

> It was an amazing once-in-a-lifetime experience. To be surrounded by so many inspirational people who have made a difference to others, was so incredibly humbling. A day we'll never forget.
>
> Helen

1 in a Million!

A new prevalence study has recently been released which has found that the prevalence of FOP is now 1 in a million. So, what does this mean for FOP patients? FOP is still classified as an ultra-rare disease, but it is just more common than previously thought! The higher prevalence of FOP may help to attract more scientists and pharmaceutical companies to study FOP and its implications. We also hope that it will lead to healthcare providers learning more about FOP.

www.ifopa.org/fop_prevalence_study_released

Become a Regular Donor!

We are extremely grateful for every single person that contributes to FOP Friends. Big or small, every donation makes an impact in helping our cause in finding a cure for FOP. We are working tirelessly to support our families as they face challenges every day with living with FOP.

If would like to support us and become a regular donor, please visit our website for more information: **www.fopfriends.com/become-a-regular-donor**

A Visit to the Penn Lab

Beach? Check. Theme park? Check. Research lab....? Err... OK, so a visit to a world class research lab probably isn't on most people's holiday bucket list, but when you are living with a rare condition, it is 24/7. You never pass up on the opportunity to see hope in action and learn about the progress researchers are making towards finding a treatment for your condition.

Chris, Helen, and the boys were invited for a tour of the University of Pennsylvania's research lab. Professors Fred Kaplan and Eileen Shore showed them around the lab and introduced them to some of the world class researchers carrying out research into FOP. It had been a few years since Fred and Eileen had seen Oliver- and they couldn't quite believe how much he'd grown! Nadine Grosman, who is on placement at the University as a visiting PhD student, was also on hand to answer questions from a very curious Harry!

> "Being able to see so many great minds all working towards a common goal that will hopefully change our world is incredible. We feel so fortunate to be in this position, but also privileged to be able to see the research first hand," said Helen, "we continue to live in hope."

This Morning!

Isla stole the show when she went on This Morning to meet Phil and Rochelle. She spoke about her hobbies and horse-riding interests, as well as living with FOP. Nicky and Isla sat on the famous couch to chat about Isla's diagnosis journey and how they live theirs to the most. Isla spoke about how she loves horse riding and how she raised an incredible £3000 for Riding for the Disabled during lockdown. Nicky spoke honestly about the early days, and how her first instinct was to wrap Isla up in cotton wool. However, Nicky soon realised that as Isla got older and had the most incredible zest for living her life, that simply wasn't an option! Isla was a natural, chatting to Phil and Rochelle, and was simply delighted to receive some toys as a thank you for appearing on the show.

Save the date!

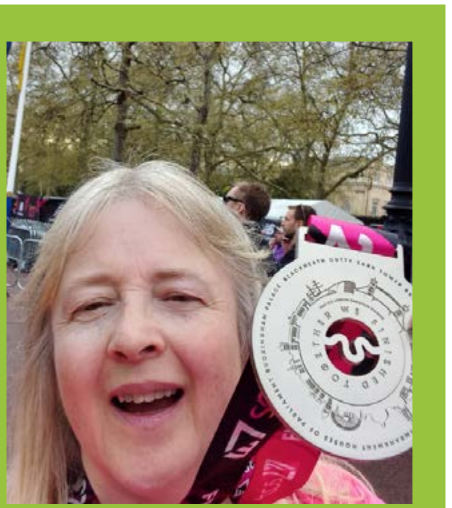
Have you got the date in your diary yet?

We are excited to be returned to the Radisson Blu Manchester Airport Hotel for our fifth Conference and Family Gathering.

Behind the scenes, planning is already underway. All you need to do, is Save The Date! We can't wait to see you there!

Jubilant Jane!

Long-time supporter Jane finally got to realise her dream as she took part in the London Marathon 2023. Jane was thrilled to have received a place in the ballot for 2020, but as Covid changed everyone's plans, Jane changed her plan and did the virtual London Marathon in 2020, but along the streets of her hometown in Sale. Her amazing friends have raised an incredible **£1742** for FOP Friends.



Oliver and Rachel visit Sale High School!

Oliver and Rachel gave an assembly at Oliver's school, Sale High School, to talk about living with FOP.

They gave a comprehensive explanation about the condition to the students, and then spoke openly and honestly about how it affected their day-to-day life. At the end, the students had the opportunity to ask questions.

It was a brilliant opportunity to raise awareness about FOP - we are so very proud of Oliver for speaking with confidence to his peers about his condition. We are also extremely thankful to Rachel for continuing to be an advocate for everyone living with FOP. She is a true shining light in our community! Who knows how many future doctors, nurses, scientists were listening!

Rachel told us a bit more about the experience:

> I absolutely loved doing the talk! The children were amazing, there were so many that wanted to ask questions which I thought was really nice. Oliver did an amazing job getting up in front of 200 children! I hope that we have been able to spread more awareness about FOP and that they will now watch out for Oliver and make sure he doesn't get hurt in any way! They were a really impressive bunch of kids!

Oliver also gave us his take on the experience:

> I really enjoyed speaking to the Year 7s at Sale High School and all the staff that came along, new and old. The children and adults all listened and reacted well to what we were speaking to them about. The children at the end asked very good and sensible questions to me, Rachel, and my dad. I want to thank my teachers Mrs Chapple and Mrs Clark who helped organise this. I hope to be able to do it again next year and the year after and the year after that! I will continue to speak about life with FOP to companies, pharmaceuticals, and schools alike. And as of next year, once I have finished my GCSEs, I will probably volunteer the rest of my time of the school year to Grip Adventure and helping out there. I currently have no plans for the future but one that is concreted in, is continuing to be one of the many faces for FOP friends.

FOP Friends Raid Train

Following from his success last year, @engravergamer hosted his second Raid Train on Twitch to raise awareness and support for FOP. This year, the Raid Train included both gaming and music streams and lasted 48 hours. The Train raised a whopping £3216 to support those with FOP!

Thank you for the streamers involved, especially @ engravergamer, for their massive contribution and to all those who donated!

Dental Survey

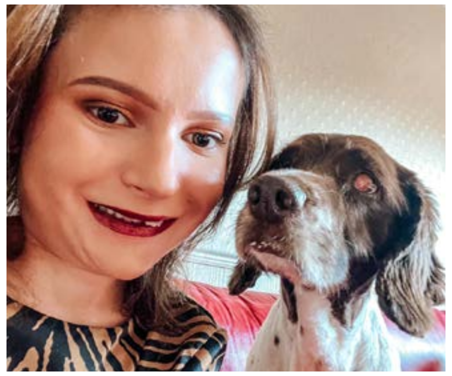
We have been working with Dr Clive Friedman (ICC for FOP, FOP dental specialist) and Dr Jesse Tebbutt (many of you met her at the conference last year) to create a survey to identify the issues our families in the UK and Ireland are facing to receive adequate dental care for those with FOP.

We received many responses from our loyal community of FOP families. Thanks to you, we will be able to analyse the information to gain better insight on the quality of dental care being delivered to those living with FOP and what can be done to improve it.

We are very thankful to both Clive and Jesse for their support and input into this and greatly appreciate their professional specialist expertise on the issue.

Meet Luciana!

> **Hello everyone, my name is Luciana and I am an FOP sufferer, living in the North West of England.** I was diagnosed with FOP at the age of 2, in 2000 by Professor Fred Kaplan as he came over to the UK for a visit to Scotland to meet with another consultant specialising in paediatric care at the time. Since my diagnosis, my parents have always been very positive and have never held me back with regards to my condition, of course we know there are things that I could not do, but I have led a life where I have tried to be as `normal' as possible. I'm not keen on using the word `normal' as we are still normal but in our own way.
>
> I am now 25, and have gone through mainstream primary school, high school and then went onto studying A-Level's at Sixth Form College which then resulted in me getting an Apprenticeship after completion of my A-Levels at local recruitment firm where I achieved a Level 3 Apprenticeship in Business Administration.
>
> Since August 2021, I have been working for the NHS myself in a clerical role at my local Health centre. I work within the treatment room and podiatry department assisting patients with booking of their appointments, administration duties and other clerical tasks. I love my job and find it very rewarding to help with the local community and NHS.
>
> Alongside working, I am always keen to help and get involved with the FOP community and have done some voluntary work for both the IFOPA with some advocacy and guest speaking work at their virtual conference and also participated with Chris and Oliver at the Ipsen Town Hall Event in 2022 down at their head office in Slough. That was such a rewarding experience, sharing first hand life experiences with Ipsen staff to support with their astounding work in research. Following on from this, Ipsen also asked me to get involved with other voluntary tasks to support their research and help those suffering and their families with FOP.
>
> Outside of work, I have a great social life with both family and friends – including holidays, cooking dinner for family and friends, going out for day trips and even nights out in places that I find comfortable and not too busy so I don't get knocked over. I have a Springer Spaniel, called Spangle who is my best friend! I have trained her to pick things up for me if I drop something on the floor and she understands only to do so with a set command. She also is trained to take things to say my mum or retrieve the mail from the post man (after the odd bark of course!) As a little hobby, I also make dog bow ties and bandanas and Spangle is my number one model for them, showing them off on her own instagram @_spanglethespringer – if anyone is interested, don't hesitate to get in touch!
>
> Throughout my life, as we all have, there has been some highs and lows which particularly stood out during lockdown with Covid-19. As we were advised to shield, I was then also working from home which unfortunately combined with the two, resulted in quite a low period of my life whereby I struggled with a low mood and anxiety. Nevertheless, despite me looking back at that time as a `dark place' I often sit and reflect on that time and look at it as a positive as I have grown and developed as a result of going through that period and have a much better lookout on life and also life with FOP.
>
> Living with FOP can be tough, but I am a great believer in keeping upbeat and positive to help with this. As we all know, FOP is so unpredictable and we never can really say when we're getting a flare, but I would advise to remember to try and keep strong, positive, and not to worry too much. Worrying never solves anything and often can make things worse. I used to be such a worrier and overthink so much; however, my attitude has changed and personally I feel this has helped when I do get a flare.



Can't Stop Carly!

A massive thank you to Carly who has been holding several fundraisers over the past few months for her dear friend Rachel.

Carly has arranged clothes sales, guess the name of teddies, guess the number of sweets, and created beautiful hampers to raffle off.

Carly and her friends have raised a whopping £205 for FOP Friends! Thank you so much for your dedication!

Salford Superstars

We are continuing to move forward with our adaptive tool project with the amazing students at the University of Salford. We had a productive virtual meeting in May, which was attended by a member of our community. He shared his tools for eating and spoke about the challenges he overcomes and what he looks for when creating his own adaptive tools.

Following on from this meeting, we then had the opportunity to visit the department at the University. After two very stressful journeys to the university – resulting in both Helen and Julie getting lost on the Salford road network – they all arrived on site! Helen attended with Oliver and his brother Leo, while Julie was chauffeur for our good friend Rachel, and her carer Sara.

The meeting was attended by two OT students and a PhD student of robotics. They spent time speaking with Rachel, simply about her life with FOP and what a day looked like. They then spoke about mealtimes and things which would make life easier for Rachel. They soon learned that Rachel enjoyed socialising and that portability and convenience were vital specifications for the tool. Oliver and Leo were also on hand to share their thoughts and made great contributions to the discussions, coming up with many creative ideas and solutions of their own.

It was a fabulous and productive meeting, and the students were most thankful to Rachel and Sarah for their candid explanations of their day-in-the-life. The students went away with a clearer focus of the task in front of them. We are incredibly excited for our next meeting… watch this space!

Get to know Martyn!

Martyn Dudley is the clinical nurse specialist for FOP at the Royal National Orthopaedic Hospital and works alongside Professor Richard Keen and Dr Judith Bubbear. We asked him a few questions:

Where were you before you joined RNOH?

Middlesex university as a trainee, I moved to London in the summer of 2012 just as the Olympics where finishing. I had completed a year's foundation certificate at Leeds University and been accepted into the degree program for adult nursing. Before this I had worked on the railway as a ticket examiner and then a sales assistant in an electronics store.

When did you first become aware of FOP?

I first became aware of FOP in 2018, when I became a rheumatology deputy clinical nurse specialist and started working alongside Professor Keen and Dr Bubbear. Jackie Vinton was in post and doing a charity fire walk I believe that year. She shared some of her experience and I donated some cash to the cause.

Do you specialise in any other conditions?

My role at RNOH is similar to the consultants, I cover all forms of Metabolic Bone Disease and don't simply get to focus on one area specifically. As a team we look after conditions from Osteoporosis to Osteogenesis Imperfecta and X-Linked Hypophosphatemic Ricketts.

Are you involved in any FOP research projects? What is your role?

I am not directly involved in any of the research projects for FOP, I work with in the greater multidisciplinary team and offer clinical advice and support to my research nurse colleagues when needed.

What is your favourite thing to do in your free time?

I am sport obsessed, in my free time I love watching and playing different sports. Football is my favourite and will take over the TV from August through till end of season.

What is one thing you can't get through the day without?

Hearing my son laugh, but before he was born, I'd probably have said my phone or music. However, for me being able to make him giggle and squeal is the greatest privilege and hearing that daily is one of my happy places.

What 3 things would you take with you to a desert island?

A pen knife, a good sleeping bag and a lighter. I'd be there for the long haul; a quiet desert island ssounds perfect to me!

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

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

info@fopfriends.com
@FOPFriends
/FOPFriends

Registered with FUNDRAISING REGULATOR

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

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**