



friends[®] Together

Vol. 8 Issue 2 Summer 2025

Thank you Mayor Amy

May marked the end of Councillor Amy Whyte's year as Mayor of Trafford. We'd like to thank her for choosing FOP Friends as one of her Charities of the Year. We would also like to thank Mayoress Sarah Hooks, Mayor Consort, who embraced the role while juggling it with studying for her ministerial formation to become a Reverend, to be by Amy's side for many of the events. We were thrilled to receive a generous donation from the Mayoral Charity, made possible by the wonderful organisations she engaged with throughout the year. Alongside the fabulous Chestnut Drive Christmas lights event, various groups hosted fundraisers such as raffles and bake sales, all to raise money for her chosen causes.

Trustees Alison and Helen were honoured to attend her Mayoral Dinner in March at Manchester United's stadium, an event celebrated by all the Mayors of Greater Manchester. Amy has been a much-loved mayor this year, and her warmth, humour, and crazy ability to rise to any challenge have made her truly memorable. Oliver's Explorer group was pleased to meet with Amy in the parlour to learn about local democracy, the role of the mayor, and their own roles and responsibilities to democracy.

Amy shares, "FOP friends is a charity has been very special to me for a number of years so I was delighted to be able to support them throughout my mayoral year. The whole year was a complete whirlwind and an absolute privilege. Being able to shine a light on so many people from all over Trafford who do such amazing things to help our communities thrive was wonderful and something I will never forget. I am so grateful to everyone who helped raise funds for my chosen charities."

We've enjoyed watching Amy's journey from PTA school-mum extraordinaire, who organised our virtual English Channel Swim long before 'virtual' was a thing, to attending our conference last year, and finally to putting FOP Friends front and centre in our local borough for a year. Thank you for your service - we hope you've found time to put your feet up, though we highly doubt it! And thank you for your most generous donation of £4201. We are incredibly grateful.



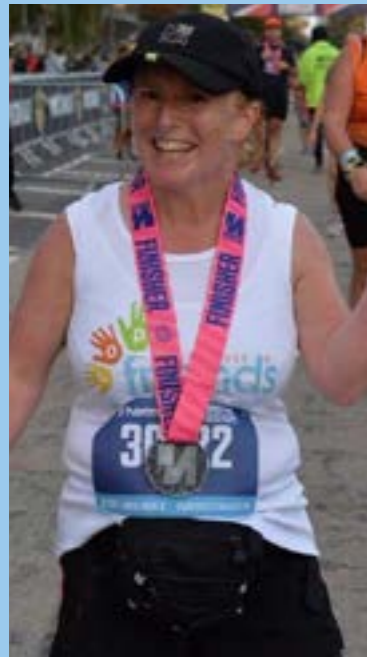
FOP Friends exists to **help find a treatment and a cure** for the rare genetic condition fibrodysplasia ossificans progressiva (FOP), and to **support the families** affected by it.

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A word from Fiona



So, summer is upon us once more! Longer days—filled with early sunrises and bright evenings—bring a sense of optimism, and that's something our FOP community has in abundance. With continued progress in clinical trials and a strong focus on the needs of our families, there's much to look forward to.

This September, we're especially excited for our upcoming 'FOP Friends Safari Weekend'. It promises to be a wonderful time of connection and adventure—visiting the West Midlands Safari Park, enjoying delicious food at Spring Grove House, and relaxing together in the evening at Stone Manor. Any opportunity to come together as a community is special: a time to reconnect, share stories, and remind ourselves that we're in this together. Community is at the heart of everything we do at FOP Friends. As a trustee and someone who helps run the crèche at our family conferences, I can't wait to see the children—who are growing up so fast—reunite with their friends and have a blast. We know these are challenging times, yet the dedication to fundraising continues—and must continue—if we are to maintain the momentum in supporting both families and research. In this summer edition of our newsletter, I want to personally thank each and every one of you who has gone the extra mile (sometimes quite literally!) to raise funds and support the FOP community. Your efforts make a real difference, and we're deeply grateful. Wishing you all a fun and sunshine-filled summer

Fiona, FOP Friends Trustee

Alma's Books

June brought around one of our favourite times of year: the **Alma Triffitt Book Award**.

This project is made possible thanks to a generous grant from Professor Jim Triffitt. Now in its fifth year, the grant is given in memory of his late wife, Alma, who cared deeply for those with FOP and also had a love of reading.

The books are carefully handpicked by the experts in the children's department at Blackwells in Oxford. We love to see the breadth of interest – from picture books to girl power to page-turner fiction. It just highlights how amazingly diverse and interesting our community is!

If you'd like to learn more about the project, visit: <https://fopfriends.com/the-alma-triffitt-book-award/>.



Research Roundup

Dr Andrew Rankin

In recent newsletters I have given updates on **Ashibio, a California-based start-up Biotech who have entered clinical trials in patients living with FOP with andecaliximab, a humanised antibody that specifically inhibits MMP-9 with a once weekly subcutaneous dosing regimen.**

The first participants have now been dosed in its ANDECAL study, a Phase 2/3 clinical trial with Part 1 initially in the USA evaluating the safety, efficacy, pharmacokinetics (PK) and pharmacodynamics (PD) of andecaliximab in up to 12 participants. If Part 1 is successful, Part 2 will then be rolled out globally, hopefully as early as 2026, in approximately 80 participants, including younger people, and will be a double-blind, placebo-controlled 1 year registration study with measures of efficacy and safety. The entire study is estimated to complete February 2029.

A 2024 publication described case studies in 4 people living with FOP from Israel and California who demonstrated significant reductions in inflammatory flares with off-label anti-IL1 therapies. A subsequent observational study is underway studying 11 participants aged 6-17 years old, with a self-reported flare frequency of at least 6 flares/year (3 times above the average reported FOP population flare frequency of 2 flares/year) or with an intractable flare that has lasted greater than 3 months. To emphasize, this is only an exploratory study at UCLA, estimated to complete in 2027, and if successful could lead to a formal Ph2 clinical trial. Watch this space!

The FOP community is always keen to learn about new possibilities, and Tofacitinib (Xeljanz), a Janus Kinase (JAK) inhibitor used for certain inflammatory conditions like polyarticular juvenile idiopathic arthritis (JIA), has caught some attention. (Note this is a completely different mechanism from the ALK2 Kinase inhibitors currently in clinical trials.) Interest stems from "Successful experience" of tofacitinib treatment in patients with FOP aged 2 to 19 years in Russia, published in 2023 by Nikishina et al. The authors proposed that the anti-inflammatory effect of tofacitinib can control the flares of FOP and prevent or reduce the ossifications, even for use in children.

While such early observations can spark hope, it's crucial for families to understand the limitations of the Nikishina et al. study. This was a retrospective, observational "experience" involving only 13 patients, not a controlled clinical trial. This means key factors like medication control during the initial period were not standardised, efficacy endpoints varied, and treatment duration differed among patients. Consequently, drawing definitive conclusions about Xeljanz's effectiveness for FOP based solely on this limited data would be premature.

In addition to this, it's important to be aware of significant safety concerns linked to Xeljanz when used for its approved conditions. The FDA has noted that JAK inhibitors, including Xeljanz, have been associated with a higher rate of serious safety signals in some patient groups when compared to alternative treatments.

These serious considerations emphasise that it is always essential to weigh both the potential benefits and the risks carefully with your medical team. This is especially true when considering a treatment like Xeljanz that is not specifically approved for FOP, and even more so for children.



Your FOP specialist and healthcare providers are your best resource to guide you through informed decisions tailored to your child's specific condition.

There are no further updates on the other interventional clinical trials for FOP, which are ongoing but not yet completed. These trials all target different elements of the mutant activin A receptor type 1 encoded by the ACVR1 gene:

- **OPTIMA** (garetosmab) - ActivinA mAb
- **Three tyrosine kinase inhibitors:**
 - PROGRESS (zilurgisertib)
 - FALKON (fidrisurtib)
 - STOPFOP (Saracatinib)
- **ANDECAL** - andecaliximab, a humanised antibody that specifically inhibits MMP-9

Regarding OPTIMA: If this trial reads out successfully, the next expected steps would be to file garetosmab for regulatory approval in adults and simultaneously conduct a clinical trial in children. Neither of these steps are confirmed and are entirely dependent upon the outcome of OPTIMA.

Watch this space!

Thank you 10 Percent Foundation

We were delighted to receive a grant of £500 from the 10 Percent Foundation. This will go towards our Wellbeing Programme which allows us to provide a series of counselling sessions for our parents or patients with the wonderful Rare Minds charity. fopfriends.com/wellbeing/



Meet Amy and Kayleigh

Many of our younger patients and their parents have already had the pleasure of meeting Amy and Kayleigh, the clinical nurse specialists on the FOP Team at RNOH. They both work with patients with a range of different conditions; Amy is a paediatric rheumatology nurse while Kayleigh supports the paediatric metabolic bone patients.

However, FOP is the condition where they get to work together, alongside Dr Chesover and the adult FOP team. They've already made a huge impact on our community! Parents frequently tell us how fabulous they are and what invaluable support they've provided to their children and families. In April, they hosted an FOP Awareness Day stand and bake sale in the hospital to raise awareness of FOP with other medical professionals as well as much needed funds. We're thrilled to have them on our team!

So, without further ado, let's hear from Amy and Kayleigh...

What inspired you to become a nurse?

Amy: I knew I wanted to work with children from a young age (when I was in primary school and my friend's mum was childminder). Then, when I was 14, my older brother was volunteering at a disabled children's holiday camp which runs in my local area and took me along with him. At 16, I officially began helping with the camp and remain involved to this day. After that, I pursued a BTEC in Nursery Nursing at college, which led to a four-year role at a special needs school - a job I truly loved. Through this experience and my volunteering, I received training in gastrostomy feeding and administering routine and emergency medication, I think it was all of these factors which collectively inspired me to take my career a step further, prompting me to return to education and train as paediatric nurse.

Kayleigh: I honestly cannot remember the specific inspiration; I just knew from a young age that I always wanted to be a nurse. For a short time, I worked in a care home and as much as I loved this, it also reinforced that I am better suited looking after young people, hence the reason I choose to become a paediatric nurse.



When did you first learn about FOP?

Amy: I recall watching a documentary about the condition many years ago. Then, when I started my role as a CNS in paediatric rheumatology, I had the privilege of attending FOP clinics with the paediatricians and met a couple of patients living with FOP. While I was working part-time then, my increased hours now allow me to fully support these patients and their families. I look forward to growing our paediatric service.

Kayleigh: I had also watched a programme about the condition but had limited understanding until starting this role in February of this year. I feel honoured to be learning more about this condition from the expert health care professionals and the families that have been living with it. We are looking forward to developing the support offered.

How long have you been a member of the FOP CNS Team at RNOH?

Amy: It's a new and exciting development within my role. It has been recognised that there was a lack of paediatric CNS support within FOP. When I increased my hours in September 2024, I was able to start attending the clinics and became officially involved in the paediatric FOP service.

Kayleigh: I have worked at the RNOH for many years within different roles. I joined this team in February as the paediatric metabolic bone CNS which includes FOP.



What is your favourite thing about being a nurse?

Amy: As a clinical nurse specialist, the best part is getting to know the families. Prior to this role, I worked in ITU and recovery - both jobs I loved. However, there's something very special about working closely with families, getting the opportunity to help support them, and hopefully making living with a long-term chronic illness a little bit better.

Kayleigh: For me, it has always been the caring side of the role which I've enjoyed and found the most rewarding. I previously worked as a ward manager but I really missed the patient contact during this time - hence my decision to move onto something new. Since starting in this CNS role, I really love how it has such a positive impact to the patients and the fact that I am the point of contact when needed.

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

Amy: My morning cuppa!!!! I cannot function until I have a good cup of tea... I usually need a top up by mid-morning as well!

Kayleigh: Similar to Amy, but I prefer a cup of coffee to tea!



On behalf of all our families who use the paediatric service at RNOH, thank you for all you have done for us so far, and in such a short space of time. We feel very blessed to have you caring for us.

When you're not working, what do you love doing?

Amy: Spending time with my family! I love our days out, and holidays with my husband and kids... even just sitting down altogether and watching a film makes me happy! A few years ago, I started going to an adult tap class a few years ago, and it's something I absolutely adore! Believe it or not, I even found myself in a show in 2024, and the next performance is already lined up for 2026! My daughter and two of my nieces are in the same dance company so it's wonderful fun to do this with them.

Kayleigh: Spending time with my family. Holidays are definitely something I love doing with my siblings, nieces and nephews. Much of my time is also spent looking after my adorable (naughty) cats Millie and Billy!! I love going to my caravan whenever I have opportunity (and I can find someone who will look after the trouble makers!!!).

If you weren't a nurse, what would you be?

Amy: Probably a primary school teacher! It was very much that or nursing when choosing what to do. I think I made the right choice though - home schooling my kids during Covid was enough teaching for me!!! I think if I had gone into teaching, I probably would have ended up working in a special needs school to be honest.

Kayleigh: Running my own business in something creative. I've previously made patchwork quilts and I am a dab hand at baking... I often bake cakes for friends, and for my family's special occasions, as well as charity events (including the cakes for the FOP cake sale we ran on Awareness Day).

What three things would you take to a desert island?

Amy: Having just watched the film Cast Away with the family... a GPS tracker, a source of fire and something to collect fresh water in... all very boring and practical!!!

Kayleigh: I would take an umbrella so I can use it upside down to collect water, and the right way up to give me shade from the sun. As someone who is very pale, I definitely need this! A comfy chair and a good book would be my other two essentials - I may as well enjoy the peace and quiet while I'm there!

Oliver @ Arval UK

Oliver was invited to Arval UK's office in Trafford Park to give a presentation about FOP and his life. He and Helen attended one afternoon to speak to the staff about what FOP is, the impact on his life and how he continues to live well. Oliver delivered another powerful presentation, while Helen gave her first presentation (Oliver was very encouraging!). He also spent some time after the presentation, chatting with David McKie, Head of Internal Sales, about his life with FOP, his interests, and his upcoming Duke of Edinburgh expedition.

For those who know Oliver, you may be interested to learn that he drove there too - with his L plates on of course - which made the afternoon even better! The staff were really interested in everything he had to say and moved by his strength and determination. We are thankful to have had the opportunity to raise awareness of FOP.



Brodie's School Fundraiser for FOP Friends

We were delighted to receive a donation of £359 from Brodie's school, following a fantastic fundraiser for FOP Friends!

Brodie, who lives with POH (the sister condition to FOP) and his schoolmates took advantage of the sunny weather and sold ice pops and fruit cups at their school sports day.

Brodie is a real superstar, and we love following his adventures and his style! It's a pleasure to work with Brodie and his family to help raise awareness of POH to a wider audience. This is especially important as only around 100 people worldwide are known to have been diagnosed with the condition.

We've been able to share Brodie's story through "Take Overs" with our partners at Rare Revolution.

You can learn more about POH here: fopfriends.com/what-is-poh/



Fabulous Fundraisers!

Our fundraisers have been incredible over the past few months! They've done so many wonderful things to raise money and awareness for FOP, all in honour of someone special they know who lives with the condition. Here's just a few of them...

Phil completed a 7.5 mile open water swim, the full length of Lake Ullswater. He completed the challenge in an impressive 3h 18m, earning him a well-deserved bronze medal! Phil swam in honour of his son Harry who has been recently diagnosed with FOP.

Lexi, Hadley, Marlie and Katie took advantage of the gloriously warm weather to set up their very own lemonade stall to sell lemonade and raise money for their special friend Little Lexi. Passers by were very thankful for the cool treats on their way past!

Trustee Rachel challenged herself to her second marathon in honour of her nephew Oliver. It was an unseasonably warm day in April, with the heat making the run an even bigger challenge for many. There were crowds at every turn, and Auntie Rachel had her own cheer squad all along the route, with a special hug at the finish line from her proud little boy,

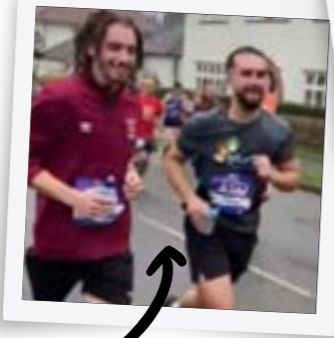
Congratulations to Matthew and Anupa who have just opened their own dental practice in Sheffield. To celebrate, they are holding fundraising events in honour of Monroe.

It was a beautiful sunny day for the London Landmarks Half, and Linda, another of our London runners, truly enjoyed the experience. There's no better way to take in our capital city! Linda was inspired to run for Oliver, thanks to her good friend Jane.

Liam took on the challenge of a hilly half through the streets of Sheffield. While not really a runner, he was motivated to push himself to the finish line by his friend Oliver.



Isla took part in the Parallel Windsor 1km Trike Challenge with James. Cheered on by her family, friends and Ralph she proved that This Girl Can. The day was made even better when she met up with one of her idols Annabelle Davis, who stars in the BBC The Dumping Ground.



Out and About

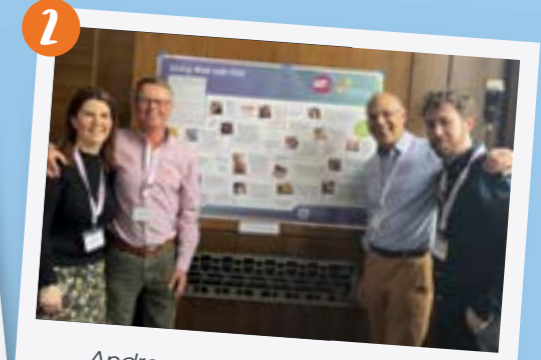
We've had an incredibly busy and productive few months, getting out and about to raise awareness of both rare disease and FOP.

It's been a fantastic experience, allowing us to listen to presentations from leading FOP experts and collaborate with remarkable rare disease organisations across the UK and further afield. Our goal is always to improve life for everyone affected by FOP and make a real difference.

We're incredibly grateful for the grants and stipends that have helped cover travel costs associated with this vital work.



Helen and Andrew attend the Rare Disease Day



Andrew and Helen attend the launch of the Living Well Campaign



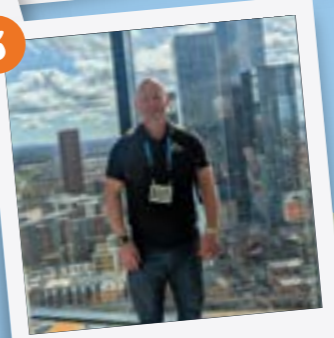
Chris attends FOP Italia's Family Conference



Leo attends the final University of Salford OT project



Andrew and Chris, who also gives a presentation, attend IDR2025



Chris attends the NICE Conference



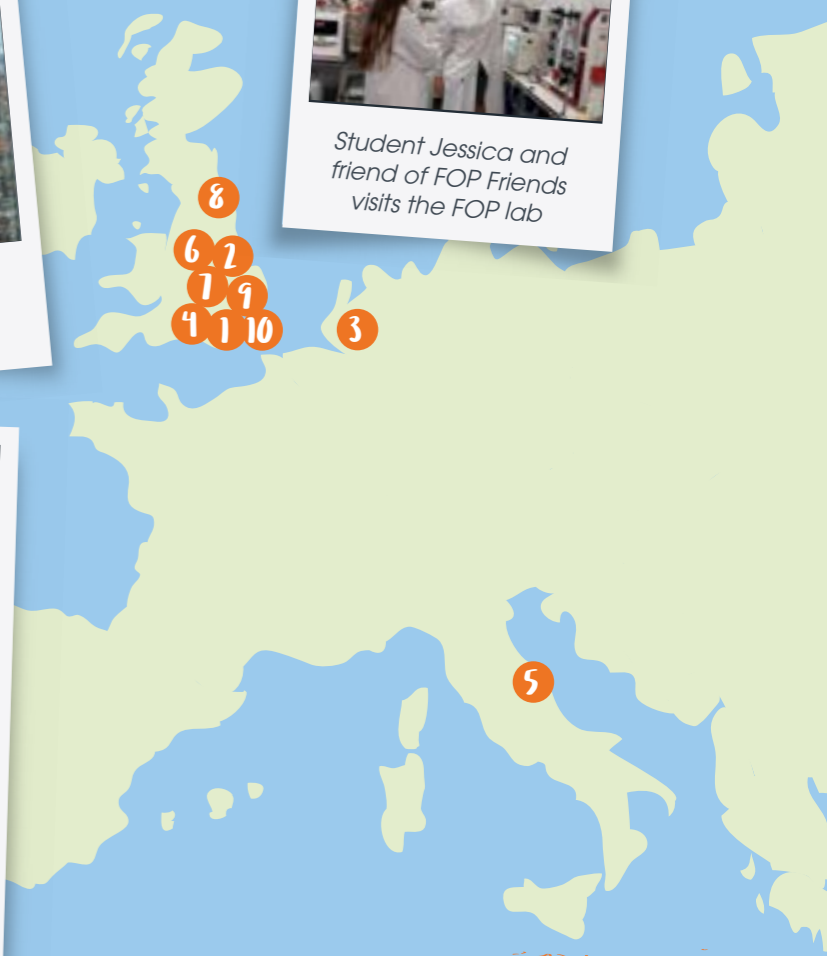
Student Jessica and friend of FOP Friends visits the FOP lab



Helen represents FOP Friends at the MARD-led IAG to develop recommendations for the DoHSC



Helen attends the 'True Faces of Rare: Shaping Visual Representation Together' conference in London

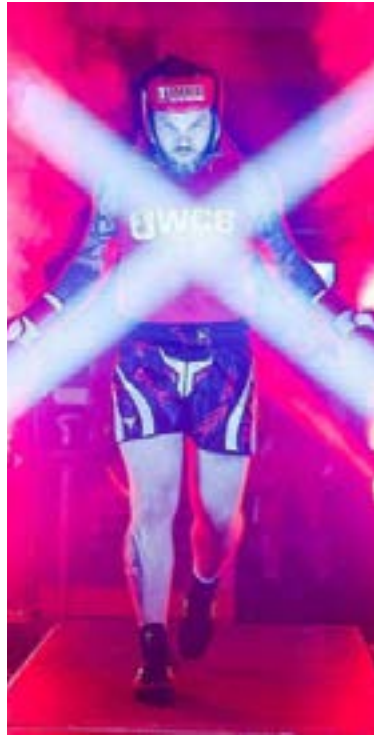


Fighting for FOP

Lenny's dad Mick, and his good friend, Baz, had been looking for a challenge and something to work towards, so in a moment of madness they signed up for the Ultimate White Collar Boxing match.

They both took their training very seriously, putting in runs as well as time in the ring and the gym. When the evening came, luckily they were matched with different opponents so are still mates! Both men put up great performances in the ring, but unfortunately neither of them came away with the result they were hoping for.

However, they did raise a brilliant amount for FOP Friends. For what it's worth, they are both winners in our eyes! And determined to take the crown, Mick is back in the ring in November! Thank you Mick and Baz for fighting for everyone living with FOP.



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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

FOP Friends at the Vice-Chancellor's Afternoon Tea

It was an honour and a privilege for Helen and Chris to represent all our friends and supporters at the University of Oxford's Vice-Chancellor's Afternoon Tea. FOP Friends was invited as a thank you and in acknowledgement of their generous donation, which supports the FOP research team at the university.

This year's event was a little different. Guests were given an exclusive first look at the University's stunning new Life and Mind Building, which is on track to open to students in 2025. The University believes this building has the potential to change the world by revolutionising how researchers undertake projects in the fields of psychological and biological sciences.

Following a tour of the building, guests were served a delicious afternoon tea at Linacre College. Attendees then listened to a presentation from Vice-Chancellor Professor Irene Tracey, who updated them on the progress across the university and its vision for the future.

