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

friends® Together

Vol 7, Issue 2 Summer 2024

Our Fifth Fabulous Family Gathering, 2024

After many months of planning, organising and packing, our 2024 Conference and Family Gathering finally came to life! This was our 5th conference, and ten years since our first event back in 2014!

It was an absolutely amazing weekend filled with laughs, love, catch ups, and of course some brilliant presentations from our expert panel of speakers.

We welcomed attendees from all over the world – 14 different countries! We greeted friends and families from Australia, Brazil, Canada, Denmark, Greece, Ireland, Malta, Netherlands, Poland, Scotland, Switzerland, USA, Wales and of course, England!

There were presentations and updates on the progress of current trials as well as the ongoing research into FOP. Professor Robert Pignolo gave a presentation on the exciting announcement of the Resilient Patient (Patient-R) project and the role MMP-9 may play in the activity of FOP. The FOP research team from Oxford University also gave a presentation.

We are most grateful to the physicians who gave up their weekend to attend. As always, the weekend was an emotional rollercoaster, but the families who attended all agreed it was a truly special event.

Cont. inside...

Inside

> Thank you to everyone at FOP Friends for arranging such a memorable weekend. It's the highlight of my calendar, and I always look forward to seeing everyone. Your dedication and hard work make it all possible. We are incredibly lucky to have you, the wonderful charity, and the FOP family you've created. It has enriched all our lives beyond measure.
>
> **Hamish, who lives with FOP**

A word from Andrew

Like many of you, I've been literally basking in the June sunshine following what seemed an endless autumn, winter and spring of rain, July didn't get off to the best start so I'm holding out for the second heatwave we're promised. It was perhaps ironic that what seemed like the first hot and sunny weekend of 10-12 May 2024 was spent by many of us in Manchester at the airport hotel attending the FOP Friends Conference and Family Gathering. However, the glittering silver lining to those cloudless skies was an exciting agenda which triggered stimulating informative sessions from specialist Health Care Professionals and FOP researchers from around the world, along with terrific engagement and participation from our FOP families and community. This was my first Conference and Family Gathering as a trustee, following retirement from a career developing medicines for rare diseases, so I had a different perspective this time and was very impressed how many of the community followed at times some quite in-depth scientific presentations and also posed the presenters some very challenging questions!

In addition to the structured sessions, I'm sure many of you took advantage of the opportunity to meet with medical and dental specialists and we thank them for their contribution of time and expertise, especially on a weekend. Also, thanks and kudos to the leaders and helpers in the FriendZone who kept so many of the kids happy and occupied over the weekend.

Wrapping up, it just leaves me to wish you and your families a lovely summer, whether home or travelling; may you find sunshine at every level.

Andrew, FOP Friends Trustee

STOCKHOLM, SWEDEN • JUNE 26-28, 2024
FOP Drug Development Forum
ifopa

DDF in Sweden

If you follow us on social media, you will already know that Chris has just returned from the DDF in Sweden. The Drug Development Forum is a global, annual event which brings together biotech and pharmaceutical companies, academic researchers and clinician scientists to collaborate and advance research with the same aim: to develop safe and effective treatments for FOP.

The event was held in beautiful Stockholm, with the hotel on the waterfront. The schedule for the three-day event was packed from dawn 'til dusk, with presentations from people involved in the development of treatment options for FOP from around the world. There were also patient panels, where those living with FOP were able to share their stories and the challenges they face with those searching for a cure. Nadine, who is the focus of our Q&A later on in this edition, presented on her findings 'Untargeted Discovery in FOP', following on from her work at the Freie Universitat Berlin and the University of Pennsylvania School of Medicine.

As Chair of the International Presidents Council (IPC), Chris chaired a meeting with other representatives from patient organisations around the world. Professor Fred Kaplan spoke about their latest paper on MMP-9, and Andrew Davies – the Resilient Patient – was also in attendance.

Chris tells us,

> "I've been to every DDF since its founding in 2014. It never ceases to amaze me how many dedicated scientists, researchers, drug developers, and doctors are fighting alongside the FOP community for treatments, and ultimately a cure. I had the honour of opening the second day of talks and also being the hired hand to move chairs on/off stage for the Q&A sessions! Even though we don't meet that often, I'm privileged to say that several of those doctors and scientists in attendance I would now class as friends."

It was another brilliant opportunity for global friends to get together once more, and to demonstrate the power of a community when they work together.

Meet Nadine

"Nadine Grosman is quite simply a superstar! You can't help but be in awe of her when you meet her. She is friendly, good fun, to the point, and smart! She is an amazing human being who has already achieved so much! Nadine truly embodies the warrior spirit of those living with FOP – so without further ado, let's find out a little more about her…

Hallo! Can you tell us a little bit about yourself?

I'm Nadine, 32 years old and currently live in Berlin, Germany. My parents noticed my shortened big toe at birth, but the doctors weren't concerned. I had my first symptoms (heterotopic ossification) in my left hip at the age of 13, but only received my proper FOP diagnosis 10 years later. That is why I celebrated my 10-year-diagnosis anniversary in June.

In 2016, I graduated from the University of Basel, Switzerland with a Bachelor's degree in Biology. Right now, I'm a Ph.D. candidate at Freie Universität Berlin in Biochemistry, studying age-dependent formation of heterotopic ossification and tissue repair in FOP. I'm pretty certain I'm the only person with FOP researching for a treatment for FOP! As well as English, I speak French and Spanish (although they may be a bit rusty now!) and I'm learning Tagalog, the Filipino language.

Within the FOP community, I wear many different hats. On the national level, I am the vice-chair of FOP Germany and co-founded a patient organization called LOUDRARE. We are loud for people with all rare diseases in Germany, and as of this year I will become co-chair. On the European level, I'm an ePAG (a European patient advocacy group) representative in the ERN BOND (European Reference Center for Rare Bone Diseases), and on the steering committee of the European Alliance for FOP.

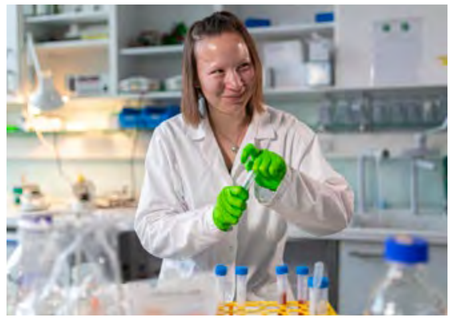

Photo credit: © Patrick Wack

Finally, on the international level, I am currently the vice chair of the IFOPA's Board of Directors, a member of the IPC's steering committee, I also sit on the research committee and volunteer on a bunch of other committees. Fun fact: I broke the record for having the most ribbons on my nametag at this year's DDF!

When did you decide you wanted to become a researcher into FOP?

It wasn't part of a bigger plan; it was only when I was looking for a lab to perform/write my Master thesis in! One of my peers asked why I didn't do FOP research myself, and here I am now!

How did you get involved with FOP Germany?

After receiving my diagnosis in 2014, I attended my first German family gathering in 2016. I got to know the German community, but I didn't want to get involved because, back then, I wasn't interested at all in FOP – as is the case for many young people. Then, in 2018, the vice chair of FOP Germany sadly passed away. Shortly afterwards, I received an unexpected call from Ralf, our chair, who asked me if I would like to co-chair FOP Germany with him. I was honoured and gladly agreed (I think Chris might have suggested me for the role!).

How many countries have you travelled to as part of advocating for everyone living with FOP?

Ooh that's a tough one! Err, seven countries so far - The Netherlands, USA, Belgium, Switzerland, Norway, Italy, Sweden – with three more planned for the near future…France, Phillippines, and UK.

What do you like to do in your spare time?

Spare time??? What's that lol! In my 'spare time', that's when I do all my volunteer work. I also like doing diamond painting, knitting, singing (I love Karaoke), reading a book, hiking, line dancing, going on roller coasters and playing the flute.

You recently spent a year in Philadelphia, PA, researching into FOP with Professor Eileen Shore. How did you feel when you were told you would be getting this opportunity?

I was absolutely thrilled when Eileen agreed to have me in her lab. It took me three months to muster the courage to write to her! She has been a great mentor and I've learned a great deal and had a lot of freedom to explore my own avenues.

What was your favourite part of your trip to the USA?

I have so many great memories but definitely meeting other FOPers, working in the FOP expert lab, visiting the National Parks and hiking through them, finding my new passion: Line Dancing, and treating myself to the cruise to Hawaii.

Telling us something surprising about you!

I recently started taking sports classes - jumping fitness (trampoline) and Zumba - and just signed up for my next class: Step Aerobics!

What are your plans for the future?

Upon completion of my Ph.D., I'd like to move into the pharmaceutical industry and work either in patient partnership, patient advocacy, patient engagement or become a Medical Science Liaison in the rare (bone) disease space. I'd be happy in any position which allows me to work with patients and educate others. I love giving talks.

If you could only take three things to a desert island, what would they be?

This is a tricky question… I think I am going to go with: a book, a musical instrument (guitar or saxophone), and a pet to keep me company.

If you could go on holiday anywhere in the world, where would you go?

South Africa is at the top of my bucket list.

Finally, what do you want our readers to know about living with FOP?

FOP doesn't define me as a person. It is a big and important part of me and shaped me into the person I am today, but it doesn't define me or us. We are so much more than FOP. In the end, we are just people, like everyone else. We are intelligent and funny, siblings, friends and partners – just like anyone else. But the best thing about living with FOP is definitely the community."

Our Fifth Fabulous Family Gathering, 2024 cont...

Medical professionals and families arrived from Friday morning to the Manchester Radisson Blu Airport hotel in a blaze of spring sunshine, and we were right there at the door to welcome them. Clinical consultations were held through the day before we all took time to pause and to just be present with friends. Families, friends and physicians gathered in the Dublin suite to enjoy a few drinks: old friends chatted away while new friendships were made too.

Saturday was a jam-packed day so everyone was up bright and early. We had an amazing panel of esteemed keynote speakers throughout the day. The audience was super engaged and asked some really great questions. Rose Ferreira and Rebecca Doodson spoke about the different therapies which are available and their benefits for those living with FOP and POH. A fabulous lunch buffet was provided by the hotel before attendees headed back to the buzz of presentations and workshops!

Dr Jae-hyuck Shim presented virtually on the topic of gene therapy. We were pleased to welcome Simon Locke from Trafford Carers, speaking about Caring for the Carer. Thanks to a generous donation from Costco, we were able to gift all our unpaid parent carers a little self-care bag to remind them how wonderful they are and to take care of themselves too. We also included information about how to access support in their own area. We followed this up with a session on developing emotional resilience, led by Nina Kundi. Nina then went to the FriendZone to do some wellbeing activities with our younger attendees.

Clinical consultations continued during the day, delivered by our fantastic doctors. For the first time we were able to offer dermatology appointments thanks to Dr Patricia Delai.

While the adults were busy taking notes in the conference room, the kids were having the time of their lives in the FriendZone just a few rooms down! The FriendZone is run every year by our very own trustee, Fiona White, and the wonderful Janet Plumb, assisted by many awesome volunteers. They kept the kids busy the whole day with a ton of different of activities. Perhaps the highlight of many of the children's day was the visit from their furry friends from Noah's Art! From lizards to tortoises to doggies – they brought the whole gang with them! The kids had an absolute blast petting the animals - and we actually had complaints from grown-ups that they weren't allowed to join in too!!!

The incoming mayor for Trafford, Amy Whyte came along to meet the children and young people. A longstanding ally of FOP Friends, she was delighted to be able to meet them and have a chat.

We also delivered another dental workshop for our children and young people in the FriendZone, led by Dr Sarah Hux. She was particularly impressed with how informed they all are! Well done kids!

In no time, the evening and the guests retired to their rooms to get ready for the family dinner and entertainment! Drinks and food were flowing. The evening was hosted by Mikey and Zac who kept the audience laughing throughout with their northern wit – who wouldn't want to win a bottle of warm prosecco??!!

The quiz was back by popular demand and everyone's competitive streak really came out! We were also thrilled to have one round compiled by our very own Disney Aficionado Yorick, from Netherlands, who kindly wrote the questions for us – they certainly had us scratching our heads!

> I'm not quite sure what I was expecting, but this event was so much more - such an unforgettable and uplifting experience. It was a pleasure and privilege to meet healthcare professionals, patients and their families, from around the globe. I learned so much.
>
> **Healthcare professional.**

Perhaps unsurprisingly, it was the scientists who took the win once more (we think it's the only reason they come every year lol!). But it was all in good spirits and fun was had by all!

And just like that, it was a wrap! The hours and months of preparation were all done and the weekend was over in what felt like the blink of an eye – but the warm, tired smiles of our friends and families told stories of joy, friendship and hope. It was all worth it. Until next time….

We would like to thank our sponsors Big Lottery Community Fund, Incyte, Ipsen, Regeneron, and The Zochonis Charitable Trust for their for their generous support.

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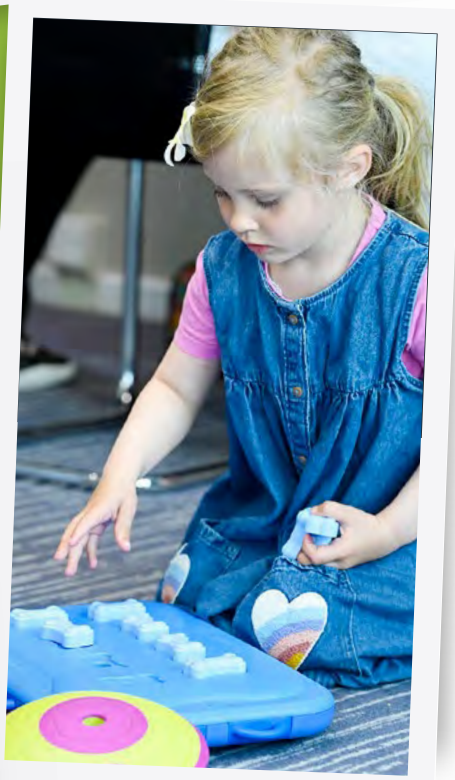
> We got to meet the FOP family from far and wide. We have made some amazing connections and new friends that we have a feeling are going to be part of our lives for a very long time…
> We have met some new FOP mums who are nothing short of incredible and we're in awe of you all. Your strength, passion and complete love is unbelievably inspiring.
> We are so glad to have met you all this weekend.
>
> **Miya, FOP Mum**

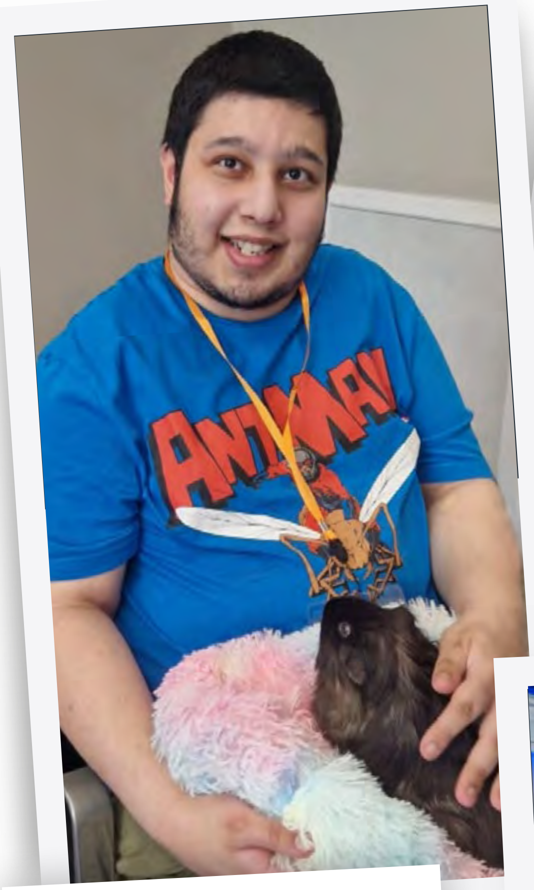
> Not all superheroes wear capes – you guys keep yours well and truly hidden.
>
> **Sheryl, FOP parent**

Conference in numbers

118 attendees
14 countries
25 families
3 new families
11 doctors
54 clinical consultations
3 guinea pigs
1 bearded dragon

> Thank you for our carers' bag. It was such a sweet idea. Thank you too for the information, it's going to be really helpful. I'll check it out this week.
>
> **FOP parent**





> We have attended every FOP Friends conference since they began and, ten years on, you never cease to amaze me with how you keep the content fresh and inspiring. This year was no different. We are so thankful to have your support on this journey. We don't know what we'd do without you."
>
> **FOP Parent**

> I am beyond honoured to be part of your FOP community. It is a big joy for me to do anything I can do to help. You are all special to my heart.
>
> **Dr Patricia Delai, Chair ICC**

Conquering for a Cause: Liz climbs Mount Toubkal, Africa

Liz de Courcey has been a good friend of the Bedford-Gay family for many years. She loves fitness and training, and is an avid hiker.
Liz can often be found up a local mountain at the weekend and has taken on many challenging hikes both in the UK and beyond. Earlier this year, Liz set her sights on climbing Mount Toubkal, North Africa's highest mountain at 4167m. She tells us,

> I felt like a challenge of this magnitude was perfect to help raise awareness of FOP. It was every bit as tough as I anticipated and I'm not ashamed to say I shed a few tears at the summit after battling a combination of gale force winds and extreme tiredness. The breathtaking beauty of the Atlas Mountains made it all worthwhile. Great views, amazing people and a sense of pride that's left me wondering 'what next?'!

We are most thankful that Liz chose FOP Friends to benefit from her personal challenge, and thanks to her amazing friends, she raised £416.

Louisa's Jurassic Jaunt!

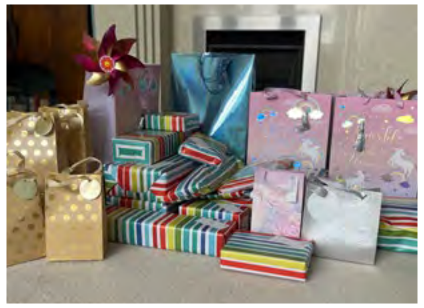
Isla's auntie, Louisa, wanted to do a challenge to raise money and awareness for her gorgeous niece – and she most certainly found one!

In June, Louisa took on the 100K Jurassic Coast Ultra Challenge Walk. This is a continuous 100km walk with a total climb of 2300m along the spectacular south coast of England, starting at Corfe Castle and ending in the vibrant town of Bridport. However, demanding the walk was in place, it was no match for Isla's determined auntie who completed the walk over the two days, raising an equally impressive £590 for FOP Friends. Louisa tells us her story:

> Downhill was definitely worse than uphill, especially the steep sections. Surprisingly my knees were ok but my vertigo wasn't too happy!
>
> The stunning views across the World Heritage site helped, as did fellow challengers, messages from family and friends, walking poles and the rest stops. I never thought that I would enjoy a Pot Noodle!
>
> A surprise thunderstorm hit just after Durdle Door, near halfway. Initially I thought it was fun but walking into Weymouth (58km rest stop) soaking wet, in the dark and tired was the most challenging part.Walking through the night was an adventure with slippery, treacherous footpaths. Thankfully the dark doesn't last long in mid-May, it is amazing how disorientating it is!
>
> After a breakfast stop, it was time to tramp along the infamous shingle of Chesil Beach in the warm sun. A final long steep hill at 97km and then downhill to the finish in Bridport.
>
> I completed it in 29 hours with just one small blister! Adrenaline kept me functioning for a few days afterwards, before total exhaustion hit. It was worth it, and it was a great experience.

Perfect presents

Once again, our children and young people were gifted lovely presents at the conference. The gifts ranged from makeup, giant Jenga, blankets and cushions, to fishing tackle and lacrosse balls.
We were also able to give our adults a small treat too, including some lavender sleep spray and delicious chocolates. We are thankful to our kind, anonymous friend who made this possible.



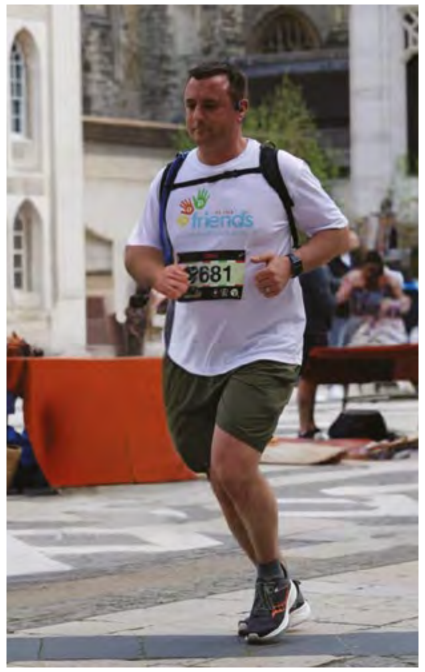
Team FOP Friends at the London Landmarks Half Marathon

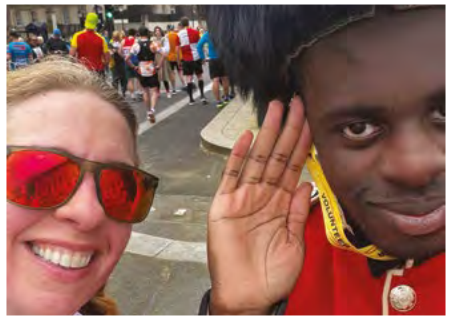
Back in April, we had a team of five runners – Aneta, Alex, Dan, Rob and Will – taking part in the London Landmarks Half Marathon.

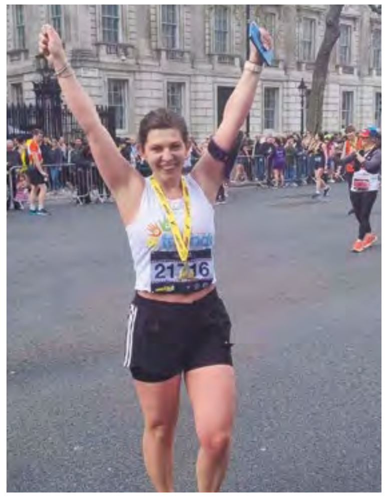
This run takes participants through the streets of London, passing the most iconic buildings along the way. Team FOP Friends had some really strong runners, with completion times of sub two hours – pretty impressive we think you'll agree!

Even more impressive they raised a total of £2856! Thank you to you and your generous friends.

If you would like to take part in the LLHM2025 for FOP Friends, or another running challenge, check out: **www.fopfriends.com/r4c** to see all the races we have entries for. We can't wait to have you on board!







Who Cares for the Carer?

Chris was recently invited to be a panel speaker on a webinar entitled: 'Who Cares? How can we better support caregivers to improve patient outcomes?'

This was aimed at professionals in the healthcare, pharmaceutical and research industries to further highlight the challenges those in an unpaid care-giver role face. Chris spoke candidly about the challenges he faces on a daily basis as a father to someone living with FOP, but also spoke more broadly about the challenges those within our community face. A significant proportion of our community depend on at least one person within their family to assume the role of an unpaid carer, so this is something of real relevance to our families.

It is hoped that by providing patient organisations with a platform and a voice, people within these industries can begin to work effectively with patient organisations to provide real support to those carrying out the most important of jobs. **If you are an unpaid carer for anyone, not just someone living with FOP or POH, scan the code to visit our website for signposts to support:**


Chris Bedford-Gay

Caregiver, and Founding trustee of FOP Friends and Chairman of the IFOPA International Presidents' Council

www.fopfriends.com

Mayor's Charity of the Year

At the beginning of June, Helen and Oliver were cordially invited to a formal evening dinner at Trafford Town Hall for the installation of the new Mayor of Trafford, Amy Whyte. Amy has been a long-time supporter of FOP Friends, completing the GNR for Oliver many years ago as well as organising a 24-hour 'swimathon' with the children from Tyntesfield Primary school when Oliver was a pupil there. We are honoured that Amy has chosen FOP Friends as one of her Charities of the Year for 2024/25. We thank Mayor Whyte for her recognition of FOP Friends and we greatly appreciate the opportunity to further raise awareness of FOP locally!

Dr Andrew Rankin joins the board of Trustees!

We had been working with Andrew for many years when he served as Global Development Head for Rare Disease Programs at Regeneron. Andrew had long wanted to support FOP Friends after his retirement, and we were delighted when he accepted our invitation to become a Trustee.

Andrew has a wealth of knowledge and experience spanning 25 years across the biotech and pharmaceutical industries. He understands the drug development process and is excited to be able to use this to support FOP Friends in their mission to find a treatment and a cure for FOP.

Now he has retired, Andrew is enjoying being with his family and grandchildren. He is also making up for lost time by travelling the world at every opportunity.

Andrew has already visited Canada; Scotland and the Isles; west coast USA, and LA to watch Bruce Springsteen in concert; South Africa including the most south westerly point in South Africa; Vietnam; Barbados; and he has a safari trip planned in the near future too! But don't worry, Helen has plenty of things on her list to keep him busy on the planes!

On behalf of everyone affected by FOP, we thank you for offering your time and expertise to support those living with FOP and our quest to find a treatment and a cure.

FOP Brazil book launched

We were delighted to launch the first adaptation of our schoolbook 'Apoiando uma criança com FOP: um guia prático para sua jornada de aprendizagem' at our Conference.

Dr Patricia Delai presented the book and spoke about the importance of a book like this for the families in Brazil.

This project was made possible thanks to a grant from Regeneron, so we were delighted to be able to give copies of the book to Amanda Seef-Charny to take back to their offices in New York state.

We have now successfully shipped the books to Kryscia in Brazil and they are awaiting distribution to the families. Kryscia's little boy Vitor was on hand for quality control, and grabbed a copy to take a quick read and give it his seal of approval!

As they say,
'O trabalho em equipe faz o sonho funcionar'!

Georgina the Great!

We're not quite sure where the time has gone, but Oliver has now left high school and is ready to move on to college in September. However, while he was a student at Sale High School, he was well known by all his teachers. He was an excellent, conscientious student and was liked by teachers and pupils alike.

Nonetheless, there was one subject where he perhaps was less than enthusiastic – RE! But despite this, he loved his teacher Miss Burke, worked hard in class and asked lots (too many?!) questions! Thanks to her amazing patience and teaching, Oliver came out with a Grade 5 GCSE in the subject last year.

Miss Burke promised Oliver that she would do a fundraiser for Oliver, and although she wasn't a runner, she set herself the challenge to participate in a run to raise money and awareness for one of her more reluctant but characterful students and everyone else living with FOP. Miss Burke stuck to her word and a place in the Manchester Half Marathon was secured.

In May, Miss Burke fastened up her trainers and completed the Manchester Half, motivated by her past student. Keen to raise as much awareness as possible, Miss Burke admitted she took every opportunity to grab the limelight with the cameras, sporting her FOP Friends running vest. Although Miss Burke didn't consider herself to be a 'runner', she completed the race in a very respectable 2 hours, 30 mins and 36 secs.

Thanks to her generous friends and the teachers at the school, Georgina raised an even more respectable £1205! Thank you Miss Burke for keeping your promise – we think you're ace!

Wedding Surprise

Introducing the new Mr and Mrs O'Shaunessy! The O'Shaunessy family were thrilled to welcome Aisling to their family in June. Aaron's brother Adam lives with FOP, so the bride- and groom-to-be wanted to raise awareness of the condition by giving FOP pin badges as a wedding favour. They also made a generous donation to FOP Friends to mark their special day. The bride and groom arranged this as a surprise for Adam and his parents, who were delighted by the thoughtful gesture and were grateful for the conversations they started about FOP. The wedding was held in beautiful Clonakilty, West Cork, Ireland, with Adam as groomsman for his brother. The newly weds are looking forward to their honeymoon in Malta. We wish them every happiness as they start this next chapter together.

Jamie the Journalist!

We always love to hear how people with FOP are getting on.

This week, Jamie's mum got in touch with a Proud Mum Moment. She wanted to tell us that Jamie, who is 15 and lives with FOP, had been winning awards at the prestigious Shine School Media Awards, which recognises written journalism across secondary schools.

Jamie wrote a personal reflection about living with FOP, and the judges were so taken with his honesty and candour, that he won The Harris Cup and £1000 for his school.

Following on from this, Jamie's school's podcast won highly commended. Congratulations to Jamie! We look forward to seeing more of your work.

WHAT ITS LIKE TO BE ME

By Jamie Turvey

I feel like it is quite difficult being me. For a start, my head, shoulders and arms do not work in the way I expect them to.

Each day I feel like my arms are getting stiffer and stiffer. I can get quite overwhelmed and emotional like now. I struggle a lot with all of this and can find it quite hard to cope with lessons at school.

I can get very cross sometimes and need to be reminded to keep calm, which is the hardest thing ever!

I am not the person who gives up on things, although I find it really hard to find the positives. In my head there are no positives, but everyone around says there is. It's pointless being worried sometimes, however, I feel I'm going to be worried all my life.

My teacher bothers me everyday telling me that there are POSITIVES. Here are things to look forward to:

Being with Ben (who never believes me!)
Fun people
People understanding my worries
Hanging with my friends that look out for me
Scrummy Pizza
Drinking Tea
Holidays
An Amazing life, I think
Hot Chocolate
My wonderful Family

The last word: Farewell from Faye

If you have contacted us over the past 18 months you will most certainly have spoken with Faye. She joined us in her second year at Manchester University as an intern, and we were delighted when she accepted our offer to stay on as office admin. Her smile, joy and enthusiasm made her a delight to work with. However, as Faye has now graduated she is moving on to pastures new. It has been a pleasure to work with Faye, never more so than in the run-up to the conference – I'm not sure how we'd have got all through the bag packing without her help! We wish her every happiness and success in her future career.

Hi all!

As I write this, I find myself filled with a mix of emotions—nostalgia, gratitude, and excitement for the future. After an incredible year with FOP Friends, the time has come for me to say goodbye to the wonderful team and community as I embark on a new chapter in both my professional and personal journey.

Looking back, I am immensely grateful for the opportunity to have been part of such a hard-working and compassionate charity that is FOP Friends, and it will always be a cause that I will hold dear in my heart. I have learnt so much in just a year – no day at the office was the same! It was a pleasure working so closely with Helen and getting to see exactly how much work goes on behind the scenes in running a charity (I still don't know how she does it!). From creating social media content, responding to endless streams of emails and managing incoming donations – it truly sharpened my multitasking skills! My most memorable endeavour would have to have been the exciting challenge of helping plan and organise the Family Gathering. The team of trustees put so much hard work into it, and it was so rewarding to be able to play a part in the success of the weekend and seeing it all come together. I was so glad to meet all the lovely members of the FOP community during the weekend and it was definitely an experience I will never forget.

I want to give special thanks to Chris and Helen and the whole family for making my year at FOP Friends such an enjoyable one – it has been an absolute pleasure getting to know them and being able to work alongside them in their mission to help find a cure for FOP and supporting the community. I also want to thank all the members of the FOP community I had the pleasure of meeting and interacting with this past year – I can say with confidence it is one of the strongest and most supportive communities I have ever come across and one that radiates positivity and hope.

While goodbyes are never easy, I am optimistic about the path ahead! I will continue to support FOP Friends from afar, and I look forward to the day we can come together once again to celebrate finding the cure for FOP.

Sending best wishes to you all!

Faye

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

www.fopfriends.com

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

info@fopfriends.com
@FOPFriends
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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**

Alma's Book award

June saw us celebrate and remember Alma Triffitt, her love of books and her love for the FOP community. Our children and young people were excited to receive their books in her honour. A big thank you to Professor Jim Triffitt for his generosity which makes this project possible, and also to the wonderful team at Blackwell's in Oxford, for the time and care they take choosing books for our young people.