www.fopfriends.com

Together

Vol 4, Issue 3 Jul 2021

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

A Wheel-y Great Fundraiser

When two friends of Harry, Sylvie and Izzy, learned about FOP from our #FunFeet4FOP campaign, they were inspired to set themselves a challenge to complete 150 cartwheels every day for the month of May.

Sylvie and Izzy, both age 8, are in Harry's class at school. Harry's brother Oliver lives with FOP.

When they learned about the condition, they wanted to do something to help raise money for research into the condition. Since they were both fantastic gymnasts, doing cartwheels seemed like an obvious challenge! They set themselves a fundraising target of £150 – little did they know they would totally smash it and raise a phenomenal £1304! A truly grand total for such young fundraisers!

Harry's mum Helen was also able to give a virtual presentation to the girls' class to explain about FOP, and what it's like to live with the condition, further raising awareness.

A big thank you to Sylvie and Izzy for their fantastic idea for a fundraiser, to their families who had to clear space in the loft for them to continue doing their daily cartwheels when it was raining, and to everyone who so generously sponsored them.

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A word from Alison

Welcome to another fabulous edition of our newsletter! It has been an incredibly challenging time for the charity as everyone has rightly been focusing on getting though the pandemic as best they can.

As we head out of restrictions and look to the summer, we are excited as more new ideas for fundraising are being imagined. We look forward to supporting people in their endeavours to play their part, and are always incredibly grateful for those that support our small but mighty charity, many of whom you'll read about in this newsletter. For the record, I've never been able to do a cartwheel and am so impressed by Sylvie and Izzy! We have been continuing to work hard as Trustees, taking our meetings to Zoom like many organisations, and I am really excited with the announcement of the date for next year's postponed Family Gathering and Symposium. Personally, this is always a highlight in our FOP calendar and quite a milestone for us as we celebrate over 10 years of being a registered charity. Get the date in your diaries folks!

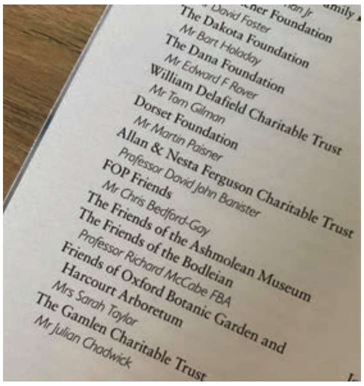
Alison, FOP Friends Trustee

Thank you from the University of Oxford

We were delighted to receive our copy of Oxford University's Annual Report from the Vice Chancellor's Circle.

FOP Friends' donation to the research team is recognised in the list of donors. A huge thank you to everyone who has supported us over the past year which has enabled us to continue to support the team.

ANNUAL REPORT
2020–2021
VICE-CHANCELLOR'S CIRCLE



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Exam Success for Iona

Iona, 17, from Scotland, is celebrating her amazing success after smashing her exam goals! Iona studied hard for her Scottish Highers and was rewarded with 4 A-grades and 2 B-grades, along with another B for her Advanced Higher in English. Iona's excellence was recognised by the school, which awarded her with prizes in Maths, Computer Science, and RMPS (Religious Education). Her teachers wished her well, noting that she never mentions any medical concerns she may have, instead choosing to focus on achieving her best. After relaxing this summer, Iona is heading off to the University of Glasgow to read Film and Television Studies. Iona's mum, dad, brother and family are rightfully extremely proud of her and her deserved and well-earned results. We are sure you will join us in wishing Iona the best of luck as she embarks on this new and exciting chapter of her life.

Regeneron update

REGENERON
science to medicine®

At the beginning of June 2021, Regeneron released an update regarding the pause on their trial for Garetosmab, their potential treatment for FOP, to review the safety and efficacy data they collected as part of the Phase 2 LUMINA-1 trial.

Regeneron are continuing to work with the investigators. They recently had a meeting with the US FDA and they are in ongoing discussions about the states of the clinical programme. FOP Friends will of course keep you informed, as and when we receive the updates.

Ipsen update

IPSEN
Innovation for patient care

Palovaretene, the potential treatment for FOP from Ipsen, is going to be considered for approval by the US Food and Drug Administration (FDA), the European Medicines Agency and Swissmedia MAA in Switzerland.

While it is important to note that this does not mean that palovaretene has been approved as a prescribed medication for FOP, it is a crucial step in taking us ever closer to that goal. It is the first time a drug designed to treat FOP has got this far in the drug development cycle.

Remembering Ollie

It is with great sadness I write with the news that Olllie (Oliver) Collins, who contributed to our last newsletter, passed away on 21st April 2021. Ollie suffered a catastrophic brain injury he sustained after a fall from his wheelchair.

Ollie was a bright light in our community and led the most incredible life, despite the challenges he faced from living with FOP. Ollie was a role model for so many: he wrote for a number of publications and his inspiring words changed lives for the better. Ollie was a source of strength and support in our community, from those dealing with a new diagnosis to young adults trying to navigate their way along this journey.

Ollie was a fierce advocate for all people living with a disability and used his writing as a platform for his voice. His vision was for everyone to be valued for who they are; to always see people for their abilities. He chose to look for the positive and always to look forward.

As anyone living with FOP will tell you, FOP is a painful condition and the suffering for those with the condition can be unbearable at times, yet Ollie tried not to dwell on this, many people may well have been unaware of just what Ollie was going through at times.

While we never had the honour and privilege of meeting Ollie in person, if you ask anyone who has, they will tell you the same thing: he was kind, generous, funny, positive, supportive, gentle, loving, wise and determined.

A celebration of his life was held in Queensland for family and friends. Ollie was loved by everyone who knew him and will be remembered as a lawyer, writer, advocate, fashion icon (those shoes!), role model, and friend.

True to his giving nature, Ollie was an organ donor, and his last gift changed the lives of three people and their families with his generosity and compassion. We send our condolences to his family and friends.

Behind the Scenes

Behind the scenes we have been keeping things going, both supporting families as well as helping to move things forward for the FOP community as a whole. As with many people's daily businesses, through virtual meetings, we have been able to make further strides with the foundations required for us to eventually get a treatment on the bathroom shelf of every patient with FOP.

Chris has been attending multiple meetings as part of his role as a Board Member for the IFOPA. He has attended the NHS Rare Disease framework, to look at their implementation of the UK's Rare Disease Framework. He has also discussed Health Technology Access and patient stories, and begun preparations to start the process of lobbying the NHS to pay for any future treatments for FOP, as and when they become available.

As a founding member, Chris sat on the Board of the European Rare Bone Forum to discuss the specific needs of those living with a rare disease such as FOP. More recently, he Chaired the IPC meeting with representatives from around the world, the IFOPA and listened to updates from the pharmaceutical companies. He has also met with the new Ipsen team members on patientcentricity work. Chris has also attended a number of IFOPA Family Gathering planning meetings. We have also been in conversations with the Oxford-Harrington Rare Disease Centre. As part of our commitment to continue to move the charity, forward, Chris has begun the Find-a-Cure Mentoring Program which started last week and is a year-long programme.

Find us on social media

@FOPFriends

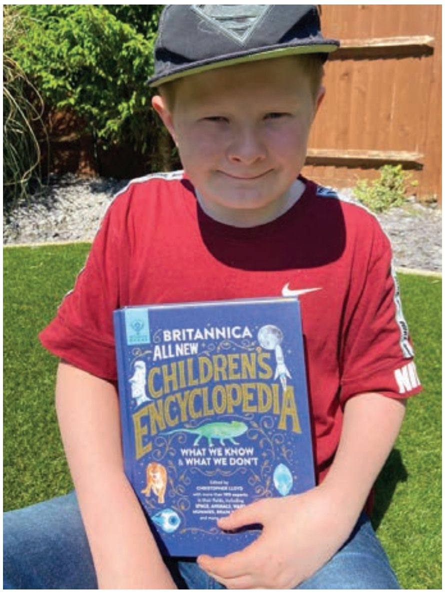
/FOPFriends

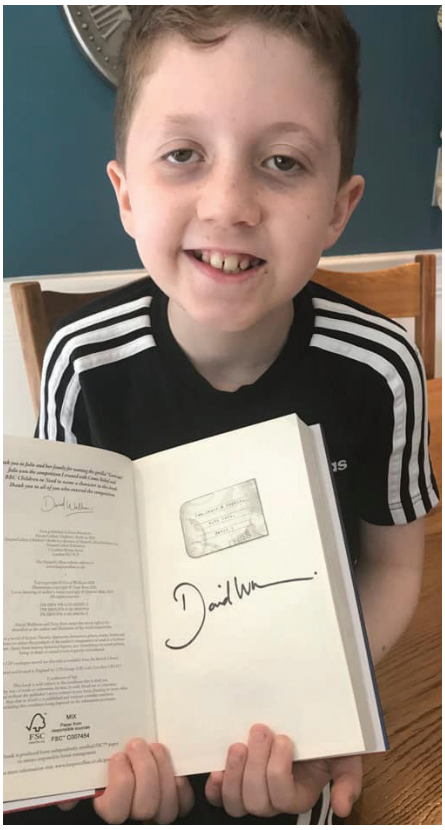
Beautiful, brilliant birthday books!

Last month our children and young people who are living with FOP and POH were thrilled to receive a book from the Alma Triffitt Book Award.

As you will have read in our last newsletter, Professor Jim Triffitt has made a generous grant to FOP Friends in memory of his late wife Alma, to recognise the courage and indomitable spirit our young people show when facing their daily challenges of living with FOP or POH. The books were selected by David Kelly and his team at Blackwell's, Oxford, and were handpicked to match the interests of each child, and beautifully gift-wrapped. Titles ranged from classics such as The Selfish Giant, Troy, Emma, and Rebecca, to the modern classics such as Code Name Bananas – signed by the author himself. Non-fiction titles included The Children's Encyclopaedia Britannica and the Pasta Grannies!

Here is a round-up of just some of the smiles on their faces as they opened their books on the 5th June, what would have been Alma's birthday.





Tell us your story

If you have a story to share about your life with FOP please get in touch. We'd love to hear from you.

We would also like to shout about any of your achievements and challenges you've done for FOP Friends.

#FunFeet4FOP

This year saw our fifth #FunFeet4FOP campaign, and our supporters didn't disappoint! We had fabulous feet shared from far and wide!

We had toes from Australia, France, Germany, America and much closer to home in the UK. We were also thrilled to be able to partner with many of the FOP patient organisations around the world to be part of the first Global FOP Awareness Day. FOP facts were shared across social media to provide a united message to the world, and to raise awareness of FOP and the challenges it creates for those living with the condition. A big thank you to everyone who bought Awareness Day tees to celebrate the day and hopefully strike up conversations with people they met during the day. We were overwhelmed with the demand!

Take a look at some of our favourite photos from the day. Visit our website to watch our short video and remember the day: **www fopfriends.com/funfeet4fop**

Two of Isla's incredibly talented friends painted original artworks to auction for FOP Awareness Day. Karina Wilgeroth painted 'Isla's World' (pictured) and Bex Foy created 'Sunrise on Isla'. Together the paintings raised £400.

Fabulous Family Fundraising Fun!

Charlie, who lives with FOP, organised a family fundraiser for FOP Friends as part of a college assignment for his Foundational Business Course.

Charlie had to plan, invite, and promote the event as part of his course. He also set up an online fundraising page. He arranged the refreshments and created a quiz for some light family fun later in the afternoon. The weather was particularly kind to them so the festivities were held al-fresco.

Family and friends came along to the event, both in-person and virtually, and much fun and laughter was had by all. Charlie's event raised £321.85 for FOP Friends. And in case you're wondering, Charlie's dad won the quiz!

Q&A with Dr Gehan Abou-Ameira

Dr Abou-Ameira is a paediatric dental consultant at Great Ormond Street Hospital and a lecturer at the Eastman Dental Hospital.

She is a highly experienced FOP dental specialist, and has treated patients with the condition for many years. Dr Abou-Ameira qualified in 2001 and her postgraduate education and training took place at the Eastman Dental Institute and Hospital in London. She completed a master's degree (MClin Dent) in Paediatric dentistry in 2005 and gained her membership in Paediatric dentistry from the Royal College of Surgeons of Edinburgh in 2006. She continued further training to consultant level at King's College, St George's and Great Ormond Street Hospitals. In 2010 she was awarded a Fellowship in Paediatric Dentistry from the Royal College of Surgeons of England and she was appointed a Consultant at St George's Hospital. Dr Abou-Ameira transferred to Great Ormond Street Hospital in 2014.

We were delighted to welcome Dr Abou-Ameira to our Conference back in 2016, where she gave presentations to both our delegates and our children. She is passionate about the education all children about the importance of excellent dental health.

When did you first learn of FOP?

When I was referred my first FOP patients in 2014.

Why is preventative dental care so important for people living with FOP, both children and adults?

FOP can have a significant effect on the oral health. Patients diagnosed with FOP are susceptible to have difficulties in brushing due to limited mouth opening and increased anxiety which can make the patients prone for dental caries, periodontal problem which subsequently can compromise their eating, chewing and disturb sleeping

FOP patients are high-risk for general and local anaesthesia with dental treatment exacerbating their medical condition and therefore prevention of dental disease is paramount.

At what age should people start seeing a dentist?

By their first birthday.

What is your favourite way to spend your free time when you're not working?

Going for a run with my dog, or a bike ride.

What three things would you take to a desert island?

My dog, running shoes and playlist.

For further advice on dental care and contact details for Dr Abou-Ameira, visit: **www.fopfriends.com/dental-care/**

Dr Abou-Ameira's Advice to improve your dental health...

1. Tooth brushing tips

- Start brushing your child's teeth as soon as the first baby tooth appears in the mouth, around 6 months of age
- Brush teeth twice a day with fluoride toothpaste
- Look at the information on the toothpaste tube for the fluoride concentration. This is usually written as "ppm" which means parts per million.
  - Children under 3 years: use a smear layer of paste with 1000ppm.
  - Children above 3 years: use a pea size amount of toothpaste with 1450ppm
  - Children above 10 years with high decay rate: ask your dentist to prescribe 2800 Duraphat toothpaste
  - Above 16 years old with high decay rate: ask your dentist to prescribe 5000 Duraphat toothpaste
- Supervise your child's brushing until 7 years of age
- Encourage your child to spit the toothpaste and don't rinse with water after brushing
- Use a small headed toothbrush or ask your dentist for a specialist brush if access is limited
- Make brushing fun, use a brushing app to help your child brush for two minutes

2. Fluoride mouth wash

Children above 7 years can use a daily fluoride mouthwash (0.05% sodium fluoride) at a different time to brushing to maintain high fluoride levels in the mouth throughout the day.

3. Dietary advice

- Avoid sugary snacks and drinks between meals
- Avoid giving the bottle overnight- if this is not possible, fill the bottle with water only
- Stop bottle feeding by 18 months

4. Find a Dentist

Register with a dentist for regular dental check-ups every 4-6 months.

5. Medicines

Ask for sugar free medicines if possible.

Ross Jumps for Rachel

Last week, Ross took part in a sky dive for his sister Rachel, who is living with FOP.

Ross, his girlfriend Andreea, and some other friends took part in the event in the beautiful Lake District. The weather conditions were picture perfect for the jump, with the bright, blue skies giving everyone spectacular views over this stunning part of our country. The jump was a first for both Ross and Andreea, but they felt the challenge was nothing compared to what his sister lives with on a daily basis. Ross said, "It was incredible! It was an unreal experience. I loved every minute and can't wait to do it again!" Ross and Andreea raised a fantastic £221 for FOP Friends in honour of Rachel.

Thank you to the following organisations for their generous support in funding the FOP Friends Together newsletter:

The February Foundation

The Manchester Guardian Society Charitable Trust

The Sobell Foundation

www.fopfriends.com

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

✉ info@fopfriends.com
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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.

Save the Date

Everyone at FOP Friends was understandably disappointed when, last year, we had to cancel our Conference and Family Gathering.

However, we have now tentatively pencilled in 20th -22nd May 2022 for our next in-person event. It will also be our 10th Anniversary as a charity, supporting the patients and families who are living with FOP.

We know people may still be cautious about in-person gatherings even in 2022, but we will ensure that the event will be organised and run, in line with the latest government guidance regarding public events, and the safety and wellbeing of our families, guests and speakers will always be our priority. So what are you waiting for? Pencil us in your diary. We can't wait to see you all in Manchester!

Save the Date!

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

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**