



friends Together

Vol 3, Issue 2 Mar 2020

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

Brotherly love!

Amish Patel saw 2019 out in style when he took part in a skydive for his brother Hamish, who has FOP.

Amish, who lives in Queenstown, New Zealand took a leap of faith and completed a 12,000 ft tandem skydive for Hamish who lives in the UK. Having watched his brother suffer with FOP and not lead the life so many other people take for granted, Amish wanted to raise as much money as he could to support the research into a cure for his brother and everyone else living with FOP, to help to build a better future for them. Amish's skydive raised an incredible £1513 for FOP Friends.



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Save the Date

FOP Friends Conference and Family Gathering
Manchester
15th - 17th May 2020



A word from Helen

I think it's a bit late to wish our readers a Happy New Year, but we have definitely hit the ground running with 2020. It was so exciting to start the year with a new website, one that reflects and celebrates all the amazing things we are doing as a charity to support our families, as well as raise awareness.

It doesn't seem like two minutes since we were wheeling boxes and bags into the Radisson Airport Hotel for our 2018 conference, yet here we are, two years later and busily pulling everything together for our Conference 2020. It is now a significant date in the international FOP calendar, and we are excited to be welcoming keynote speakers from both the UK, USA and beyond once more.

Perhaps what makes it the most notable of all the events we arrange as a charity, is the ever-increasing closeness of the community, and how real friendships are growing where we all support each other. Whilst we are getting nearer to an effective treatment for FOP, we are not there yet and we still have a long road ahead of us. But one thing is for certain: that journey will be easier if we have friends to support us along the way.

Helen
FOP Friends Trustee

STOPFOP trial is a Go!

In May 2019 a new clinical trial, STOPFOP, was launched to test the drug Saracatinib's effectiveness in treating FOP.

FOP is caused by a mutation in the gene that codes for a protein called ALK2. Saracatinib was identified as potentially being of interest in FOP by the Oxford FOP research lab, headed by Dr. Alex Bullock and funded by FOP Friends. Research in Oxford and in Boston showed that Saracatinib bound very tightly to ALK2 and not to too many other near neighbours of ALK2, while also stopping bone formation in mice with the FOP mutation, preserving the limb movement of the mouse.

Saracatinib was originally developed by the company AstraZeneca (so sometimes is also called AZD0530) for use in some cancers and its potential role in FOP had not previously been considered. Dr Eleanor Williams, from the University of Oxford explains, "Because Saracatinib is a repurposed drug, it has already gone through extensive clinical trials. It has passed Phase 1 trials in humans, and it is known to be a well-tolerated drug."



The STOPFOP trial is split between the UK, Germany and The Netherlands and is looking to recruit 20 adult patients to test whether Saracatinib works in humans to reduce FOP-induced bone formation. Funding for the trial comes from the Innovative Medicines Initiative (IMI) and AstraZeneca and is overseen by Dr. Marelise Eekhoff. Preparations are now underway to recruit patients across the research sites. The trial will run until April 2022.

Dr Bullock said, "We would like to extend our sincere thanks to all the FOP foundations and families whose donations have supported this research to make this trial possible."

Anyone interested in learning more about the trial, or to contact the researchers, visit www.stopfop.com

REGENERON Trial news

2020 got off to a great start for pharmaceutical company Regeneron, who announced promising results from their Phase 2 trial of garetosmab, or REGN2447.

The company reported that patients who were taking the drug had a 25% reduction in the number of bone lesions. They also found that the drug reduced the number of new bone lesions by nearly 90%.

Garetosmab is designed to reduce the formation of new FOP (heterotopic) bone by neutralising the the Actvin A protein. There was also evidence that the drug reduced the number of flare-ups in the FOP patients. There is still a long way to go, but Regeneron are now applying to the FDA in America for fast-track approval. They are also planning to start a paediatric trial for garetosmab. We look forward to learning more, and hearing from Regeneron at our Conference in May.



News from Philadelphia

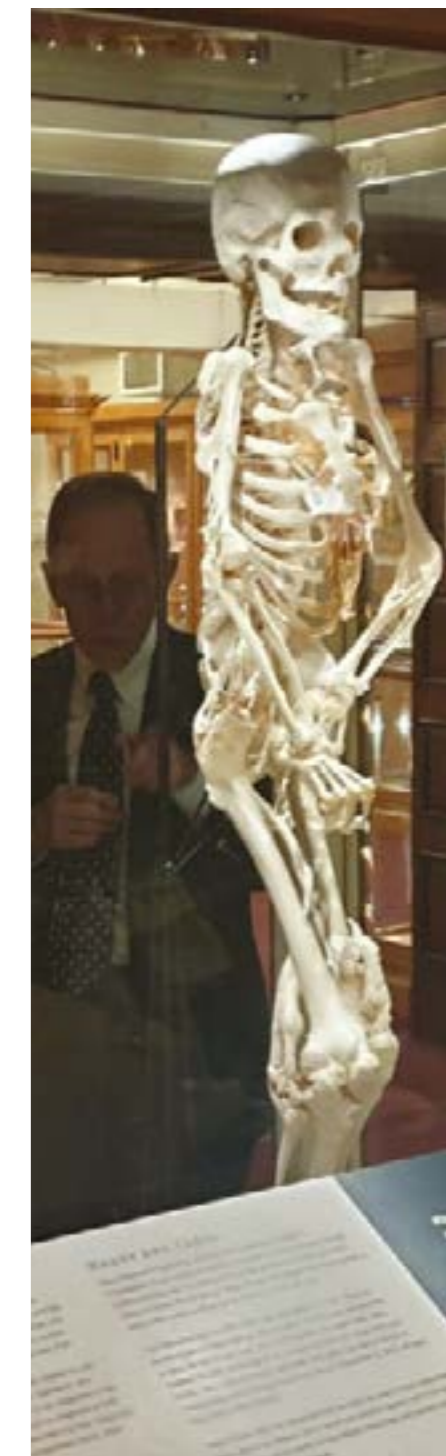
In his role as an IFOPA Board Member, Chris flew to Philadelphia, USA for the annual Board Meeting.

His trip started with a guided tour of the research lab at the University of Pennsylvania, meeting some of the Penn researchers looking into the treatments for FOP. There was then a private screening of the award-winning film *Tin Soldiers*, a documentary that has been produced to raise awareness of FOP and find the undiagnosed. This was followed by a panel discussion with the inspirational team behind the project: Amanda Cali, Odette Schwegler, Fred Kaplan, and FOP parent Suzanne Hollywood.

The following day, the Board were given a personal tour of the Mutter Museum by Fred Kaplan. The FOP skeleton of Harry Eastlack has rested there since 1979, but last year, Harry was gifted a 'companion' when Carol Orzel who had FOP, passed away. It was her lasting wish that she too be displayed in the museum.

Sessions to discuss the business of the IFOPA, along with updates from Dr Mona Al-Mukaddam, Dr Clive Friedman, and the IFOPA's other projects, completed the three-day meeting.

Whilst these trips are always crammed with information sharing and conversations, they further build FOP Friends' connections with other patient organisations around the world, reaffirming our commitment to working collaboratively to find a treatment for FOP whilst supporting patients and families.



L-R: Rory Otto, Kristi Gonzales (Board Chair), Chris Bedford-Gay, Rebecca Wallace, Megan Olsen (Vice Chair)

Website

We were thrilled to launch our much needed and refreshed website in January.

We are most thankful to the amazing team at AndDigital in Manchester, led by Jamie and Mike, who donated their time and skills for free. The new website has all the information you need about FOP as a condition, and also all about FOP Friends as a charity. There are downloadable resources to support fundraisers as well as information for people who are coming to terms with a new diagnosis. Perhaps most importantly, there is information for people living with FOP in the case of an emergency including the latest ICC medical guidelines.

We hope you enjoy it!



AND Digital

Carys and Alesha

Carys and Alesha were inspired by their friend Annabelle when she told them about our charity as part of her Brownie badge. Carys and Alesha decided they wanted to support FOP Friends too. They made their own leaflets and posters to raise awareness of FOP and then sold cakes to raise money. **A huge thank you to you both for your caring, creativeness, and initiative.**



Find us on social media
 @FOPFriends
 /FOPFriends

Rowe Avenue Surgery

A big thank you to the staff and patients at Rowe Avenue Surgery, who raised **£122.40** from a collection pot.



St. Clement's Church

FOP Friends were delighted to be chosen as St. Clement's Church, Rochdale as their charity of the year. They shared information about FOP with the congregation, and collected money through the year from coffee mornings and a raffle, **raising £250.**



A trio of fundraisers

Friends and family of Isla supported not one but three fundraisers over the Christmas and New Year for FOP Friends. Clair and Phyllis organised a Christmas wreath-making evening; The Wren made a Boxing Day collection raising £620 alone; and then they held an afternoon tea. In total, over £1000 was raised for Isla and her friends. **A huge thank you to everyone who made cakes or wreaths... you made us smile.**



Dress Down Day

We were delighted to accept a cheque for **£468.70** from Express Solicitors in Manchester after FOP Friends was chosen as their charity of the month. We were nominated by Laura, who wanted to do something to support her cousin Jasmine who has the condition. **A huge thank you to everyone who contributed.**



Meet Ellis

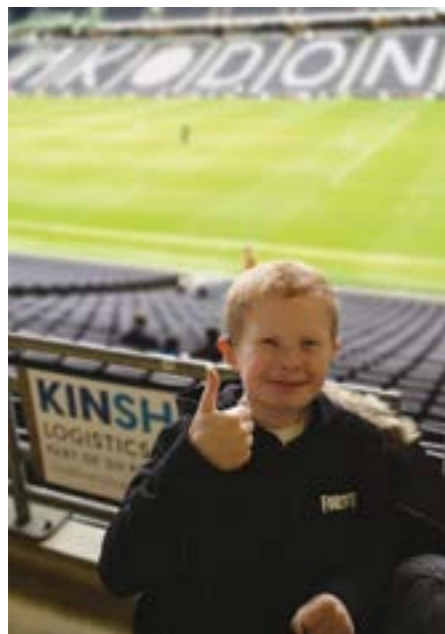
Ellis is a cheeky 10-year-old boy. He loves playing on his Nintendo Switch, winding up his sister or helping at the school farm. Ellis lights up any room with his infectious personality and wicked sense of humour. We had a chat with his mum, Suz, about how they are living with FOP.

How old was Ellis when he was diagnosed?

Ellis was diagnosed with FOP in August 2015 when he was six years old. We had gone through more than three years of numerous tests to get to the bottom of what was wrong with him. It was only when we read an article about FOP in a newspaper, raising awareness for Genes for Jeans Day, that we recognised the symptoms and requested a test for FOP: a genetic test confirmed our worst nightmare.

How does FOP affect Ellis' day to day life?

For Ellis, up until 2019, FOP was nicely sitting in the background. However, in February 2019, Ellis tripped whilst we were out and broke his elbow which required a cast. Despite everyone's best efforts, Ellis' left arm fused at a 90 degree angle, just as it was held in the cast. Our life is now about adapting to a new one-armed way! But Ellis deals with it and takes it all in his stride, and constantly proves to us that nothing is impossible!



When did you become aware of the charity FOP Friends?

We were given the name of FOP Friends by the Professor, the day Ellis was diagnosed. I emailed them that day, scared and alone. Helen called me back that night, after she had put her boys to bed and listened whilst I sobbed. All I could see was the endless darkness in front of me, what Helen gave me was hope for the future. Quite simply FOP Friends saved our family that night.

What is the one thing Ellis couldn't live without?

YouTube

How does Ellis like to spend his free time?

Playing FIFA 20, or watching people play games we already own and could just play ourselves on YouTube. It drives me and his dad crazy!



What is it like living with FOP?

It's tough. I know FOP holds all the cards: it will choose when it strikes, where it strikes, and what it wants to take. The only choice FOP cannot make is how we deal with this. And we choose to be as strong as we can be, and fight this as a family. Some days are harder than others.

What are your hopes for Ellis in the future?

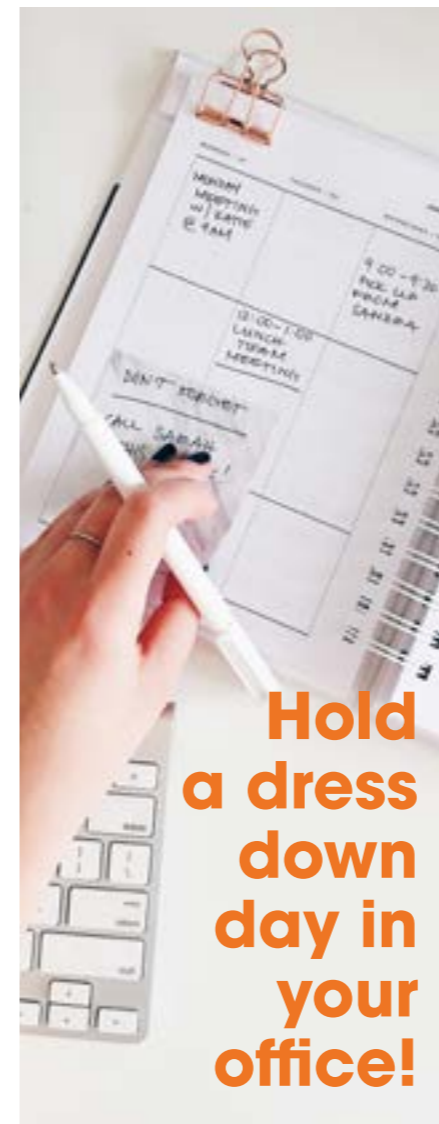
Obviously, Ellis' personal dream is to become a YouTuber! As his parents, we are hoping and praying for a treatment and a cure for FOP and it can't come soon enough. But in the short term, we hope every day that FOP doesn't steal any more of his mobility, and that he continues to be his amazing fearless, brave and determined self. We are so incredibly proud of him.



Brodie

Staff at the Ferguslie Park Housing Association in Glasgow hold a dress down day on the last Friday of every month and staff who participate make a small donation. Brodie's grandma, Margaret, nominated FOP Friends and her colleagues unanimously voted in favour. They had great fun on their Halloween dress-down and Christmas jumper day and were delighted to help raise awareness of the wonderful work FOP Friends does to support patients with POH as well as FOP. They donated £210 to the charity. The staff were even more excited when Brodie came into the office to accept the cheque on your behalf.

Learn more about POH on our website: www.fopfriends.com/what-is-fop/what-is-poh/



Kids' Council's Christmas Kindness

The School Council at St. Mary's CE Primary school in Droylsden chose FOP Friends as their Christmas charity.

Rachel Winnard's sister works at St. Mary's, and her niece also attends the school. They raised £140 from a Christmas jumper day, and from the proceeds from their tea and coffee sales at the Christmas concerts. Rachel went into the school to meet the Council members and receive the donation on behalf of FOP Friends.



St. Paul's National School, Limerick, Ireland

Before Christmas, St. Paul's National School held a Colours Day fundraiser for FOP Friends, in honour of Adam, who was a former pupil of the school. Adam's sister Rebecca still attends the school. The school raised an incredible 650€ for the charity.

We would like to say a huge thankyou to the pupils, staff, and families for their generous support.





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.

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



FOP Friends

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

✉ info@fopfriends.com

🐦 @FOPFriends

📘 /FOPFriends



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.

Facebook fundraisers

Did you know that you can set up a Facebook fundraiser for FOP Friends in celebration of a special occasion? To date, we have **raised over £3,800** from generous people choosing to support us as a charity. It's easy to do on your Facebook page, just select FOP Friends as your charity. It's that simple! **A big thank you to those who've chosen us!**



Great North Run

The Great North Run celebrates its 40th anniversary this year, so this already iconic run promises to be even more memorable this year. We have a limited number of places available for just £25. If you would like to run for FOP Friends, please get in touch info@fopfriends.com



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