fop friends®
together
Vol 1 Issue 3 | March 2017
www.fopfriends.com

A champion of FOP research

Without the support of businessman, Richard Simcox it's hard to imagine where the funding for FOP research in the UK would have come from in the last decade. He's donated hundreds of thousands of pounds, and been unwavering in his support, and in many ways, we have his mother Constance to thank for that.

Richard has championed and funded FOP research for almost 20 years, since he first became aware of the condition through a young boy with FOP who lived near his home in Aberdeenshire. Richard first sponsored a fellowship in FOP research at the University of Pennsylvania in 1999, after having met Dr Fred Kaplan when he visited Aberdeen. This was soon followed by grants at Oxford University to support Professor James Triffitt's research into FOP there.

Since then, there have been some incredible advances in research, as Richard himself describes: "The most exciting development in the research since I've been involved has to be the 2006 discovery of the causative gene." Whilst much of the research to identify the FOP gene had been carried out at the University of Pennsylvania, Richard had also been sponsoring work at Oxford University since 2003. Oxford's Matthew Brown and James Triffitt were collaborating with the team in Pennsylvania and narrowed down the mutant gene's location to a small region on chromosome 2. Previously it had been thought that chromosome 4 was the most likely location. Given that our 46 chromosomes collectively contain approximately 25,000 genes, knowing which chromosome to search and precisely which location on it to search was critical. Soon after this discovery in Oxford, the ACVR1 gene was identified.

With the gene that causes FOP now identified, research could focus on developing a cure, and in 2010 Richard covered the cost of setting up two dedicated FOP research posts at Oxford University, which we at FOP Friends, continue to raise funds for today.

To help make sure we find that cure, Richard has just helped to fund a scholarship at Oxford to support a PhD student working on FOP research every year in perpetuity. Only once research into FOP is no longer necessary will the scholarship go towards funding research in another area. "The Oxford–The Simcox Family Graduate Scholarship" is in memory of Richard's mother, Constance Mary Simcox nee Killingback. Richard explains why:

"We all love our mothers, but mine really was special. She gained a first class honours degree in biology at Imperial College, London, and was doing work on tropical diseases, when she married and had my sister then myself. She was unable to continue the research work she was doing, but I vowed to myself that I would somehow pick up the medical research baton and run with it on her behalf. So, when I became involved with FOP research, it was the ideal way for me to achieve this ambition. That is why the Deed of Gift is dedicated to her."

Thank you Richard, and Constance, from all of us at FOP Friends.

You can read more about Richard and the research he's helped to fund at www.fopfriends.com

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.

FOP Friends is a Registered Charity in England and Wales 1147704

A word from Fiona

Welcome to this third issue of FOP Friends® Together newsletter. What an exciting few months it's been as the pace of FOP research and progress towards possible treatments continues to accelerate.

With the exciting news that the IFOPA and FOP Friends are combining forces to fund a research project at the University of Oxford, we find ourselves closer to that all important and much needed treatment and cure for FOP. This, along with the amazing fundraising efforts by our fantastic supporters, indicates how strong our community has become, raising awareness as it continues to grow.

In December, FOP Friends took part in a Christmas Tree Festival at St Alban's Church, Altrincham. Raising awareness of FOP Friends and the incredible work we do, continues to be of the upmost importance.

I find myself writing this looking into the future and the fun family weekend we all have to look forward to in March. Thanks to the much-needed grant from BBC Children in Need, a large number of families affected by FOP, will be gathering to enjoy fun and games at the Center Parcs in Nottingham. This will allow families, who over the last few years have formed strong friendships, to come together and catch up on the 10 months since our Family Gathering and the exciting progress being made. With swimming, pottery and many other activities taking place, this will be one weekend to remember.

We are early in to 2017, but we continue to work hard and support each other as we come closer to that all important cure.

Fiona White
FOP Friends Trustee

Why we need you

FOP Friends is a tiny charity. Yet since our launch in 2012 together with our supporters we've raised hundreds of thousands of pounds that has gone toward research and events to support other families affected by FOP. And here's something you probably don't know about FOP Friends – almost all the people behind it are volunteers. We do have one paid member of staff who works just one day a week. That's why we would greatly value any bit of help you can offer.

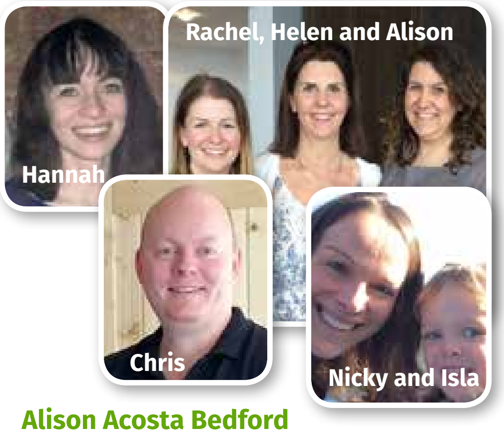
Chances are if you call, email us or contact us through Facebook or Twitter, it's one of these people you'll be chatting to.

Chris and Helen Bedford-Gay

Chris and Helen have three sons, Oliver, Leo and Harry. Their eldest son, Oliver (aged 9) has FOP and is the reason Chris and Helen founded the charity along with Helen's sisters Alison and Rachel.

Chris is the Chief Technology Officer and Products Director at a successful online skills assessment and talent management company. He's chairman of FOP Friends, a board member of the International FOP Association and the current chair for the IFOPA International Presidents Council. He travels regularly to represent FOP families at FOP events around the world.

Helen is a trustee for the charity and between fetching, carrying and loving three adventurous boys she does the admin and organising of events, fundraisers and grant applications. She's there to offer support to families who have had a recent FOP diagnosis too.



Alison Acosta Bedford

Alison is a founding trustee, and mum to Edison, aged 6, and Elise, aged 4. She's a qualified Chartered Management Account and is the Treasury and Investment Manager for Trafford Housing Trust.

Rachel Almeida

Rachel is also founding trustee, mum to Ben, aged 3, and works full time as the Head of Events for The Association of Colleges in London. She's invaluable when it comes to organising our FOP Family Gathering.

Nicky Williams

Nicky is mum to Isla (aged 3) who was diagnosed with FOP when she was three months old. Based in Surrey, Nicky works part time as Marketing Campaigns Manager for Avaya. She's also an FOP Friends trustee and organises regular fundraising events.

Hannah Dempsey

Hannah is a third-year psychology student at the University of Manchester. Having completed an 8-week internship at FOP Friends last summer, she now works one day a week looking after our social media platforms.

FOP Friends is something we all do in our 'spare' time. If you have any expertise or time to offer, we would love to hear from you. Email info@fopfriends.com

Accelerating the search for a cure

The FOP Drug Development Forum

Together with IFOPA, we're doing our best to encourage and support research that could help those with FOP. One way we're doing it is through the FOP Drug Development Forum. The idea is to get everyone from around the world involved in FOP-related research together in a room so that they can share, collaborate and combine their strands of knowledge to find a cure sooner. The IFOPA invite academic researchers, pharmaceutical companies, regulators, doctors treating those with FOP and those involved with patient organisations. The first forum was held in 2014, and the second in 2016. FOP Friends provided IFOPA with $15,000, which they were able to match fund to support the 2016 Boston forum.

Our fabulous young supporters

In this issue we've got the proof that you're never too young to start fundraising! A big, big thank you to all of you wonderful young people for giving up your time to make a difference to those who have FOP.

William's mum, Maria with Oliver and the sweet sellers – William, Archer and Isaac

Lucia

Jake & Amy

William (9)

True to his word, William has continued to raise funds for FOP Friends, as he said he would in our last issue. In February he organised a sweet stall at the Ramsbottom Farmers' Market. He and some of his classmates from St Andrew's CE Primary School got local businesses to donate the sweets for their stall. William organised everything himself, deciding what they should sell and then speaking to the shop owners. Those who couldn't make it to the market on the day would even be able to buy virtual sweets.

Despite it being a cold, wet day, William and his friends raised just under £479, beating the impressive £250 he raised from his run last year.

Somehow we're pretty sure this isn't the last we're going to see of William.

Lucia (7)

Lucia has very big plans for 2017 to help make her friend Isla better. She's going to be doing the Colour Run in London on 11 June, and she's started her training. With two months to go before the race, Lucia has already raised over £1000 – with a little help from her mum. We can't wait to see the pics and hear how it goes!

Jake (10) & Amy (7)

Since 2015, Jake and Amy have organised an annual car boot sale in aid of FOP. On offer are all the toys and books they no longer want or need. As well as giving toys a new home, and raising money and awareness, the toy sale also encourages an annual clear out!

Jake and Amy wanted to do something that could help their friend Isla, who has FOP. The idea for the sale was Jake's: "Isla inspires me to raise money for a charity that supports people with such a rare and complex condition. It would be a dream come true for me for a cure to be found quickly for Isla and her FOP friends."

Amy though it was great too: " As soon as I found out that sweet little Isla had FOP I wanted to help straight away. It felt so unfair that Isla and her friends have to live with FOP and I am so lucky, that I want to help people learn about this condition so we can raise more money to find a cure".

The industrious duo raised £140 from their last car boot sale, and another £40 selling biscuits to peckish passers-by.

The Great North Run

Here's your chance to get the T-shirt

We've still got a few places available for the Great North Run, and you've still got plenty of time to train (even if you've never done a half marathon before). Last year we had 21 runners finish the GNR. This year, the UK's biggest half marathon is on 17 September. Here's what one of our runners, Sinead Ferguson, had to say after she crossed the finishing line:

"Absolutely bloody amazing day. Best race I've done EVER!! Atmosphere was unbelievable. Highlights included high-fiving David Rudisha and about 1000 young children, getting sweets on the way round, the amazing Red Arrows display at the end, and just the fantastic support – I've never seen anything like it. The most fun I've ever had in a race. Loved it so much, want to do it again."

And she is doing it again! Anyone want to join her? Email info@FOPFriends.com.

OUR FOP FAMILY

Meet Luciana Wulkan

2016 was a big year for Luciana: she completed her A-levels, received a Young Achiever Award, joined the Clementia Phase 2 trial, and turned 18 (which meant she could add pubbing and clubbing to her list of hobbies). A lot of that was down to her attitude towards FOP.

"I don't let FOP stop me from working, shopping, going on holiday and going out. I'll soon be starting a Business Admin Level 3 apprenticeship at a recruitment company in Bolton. Besides that, I live life like a normal teen: I love to shop, bake, cook, do makeup, and be social. I especially love to have friends over for tea, cooking them a lovely meal and dessert too. In my spare time I practice my makeup techniques on friends and family, and my makeup bag is constantly growing!

My right hip fused when I was seven, but 12 years on it's certainly got much better. At first I was walking very hunched over due to the extreme pain and discomfort, but now it's a lot straighter and doesn't cause much pain anymore.

My jaw locked five years ago and caused a lot of stress and anxiety when it first happened. Now, I don't really think about it. I've adapted what I eat, and I don't let it stop me – especially if I want some chocolate. I just chop it up so I can manage!

Since September 2016 I've been on the Clementia phase 2 trial. I've noticed a significant change to my mobility and do feel that the drug is working. Many people have noticed I have more movement and am walking with more ease. My past year has been great as I haven't had a flare up either.

I try to be as positive as I can and don't let my disability get in the way. I always remind myself it's okay not to be perfect. Sometimes I do get upset because I do miss out on certain things, and people do look, but I have noticed that it's not as much anymore due to constant awareness being spread about any disability.

I was nominated for the Young Achiever Award from Tower FM in Bolton last year. When I received the phone call to explain that I'd been shortlisted I was over the moon. It was a black-tie event, and so a perfect opportunity to do one of my favourite hobbies, go shopping – just as every girl loves to do!

Once the awards started I was really nervous but excited. I had to provide pictures and a short background to my life and when it came to the Young Achiever Award they played my video! I was so chuffed, and I can't thank Val Hulme, the close friend who nominated me, enough. It was definitely a night to remember!"

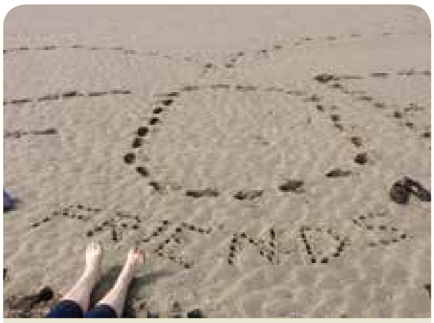
Are your feet ready?

It's almost time for #FunFeet4FOP

23 April is FOP Awareness Day, and we're hoping that this year we see crazier feet than ever before. There's still plenty of time to rope in your family and friends and get crafty and creative with your feet or your footwear. Why not:

- Have a **#FunFeet4FOP** get-together – at school or at work
- Throw a foot decorating party
- Create some fabulous foot-inspired artworks
- Use felt, ribbons or buttons to give your shoes some personality
- Or, if you're very handy with needles, knit up an extra special pair of **#FunFeet4FOP** socks.

Don't forget to share your fantastic feet on Facebook, Twitter or Instagram. And to add that all-important hashtag – **#FunFeet4FOP**. We're toe-tally looking forward to seeing what you come up with.



About FOP

Fibrodysplasia ossificans progressiva, or FOP, is one of the rarest and most disabling genetic conditions known to medicine. In people with FOP, bridges of bone develop across the joints, progressively forming a second skeleton that imprisons the body in bone. Currently, there is no known treatment or cure for FOP.

A cure for the disease could also benefit people living with osteoporosis, arthritis and heart disease, as well as those affected by heterotopic ossification (a major complication in hip replacement surgeries and in sports and military injuries), and other more common bone and muscle disorders.

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Thank you to the following trusts and foundations for their kind support in funding the FOP Friends Together Newsletter:

The February Foundation

Manchester Guardian Society Charitable Trust

The Astor Foundation

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