friends together

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www.fopfriends.com

Individual Efforts Add Up

> ***"Twelve months ago I could barely run to the end of the road – so to think that I have just completed 13.1 miles seems crazy!! It was beyond a shadow of a doubt the most inspiring thing I have ever done!"*** – Suz Grant (Ellis' mum) on completing the GNR

> ***"Muddy, cold and wet! The bruises, cut and scrapes I got on the day have all healed but the sense of achievement has stuck."*** – Rob Grant (dad to FOPer Ellis), post Spartan Race

The last four months have seen our supporters getting up to all kinds of things to raise a jaw-dropping amount for FOP research.

The two biggest events were the Great North Run (GNR) and the muddy Windsor Spartan Race. We had 21 runners join Mo Farah on the start line of the GNR – we can't list you all here, but you were all fantastic! And Isla's 12 Spartan Warriors managed a very impressive 17th place in the Spartan Sprint race in Windsor, tackling mud, logs, sand bags and barbed wire over the 5km course.

But Great North Runners and Spartan Warriors are only part of the story… **See p.3 for more FOP fundraisers and their grand fundraising total**

INSIDE

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 Chris

Welcome to this second issue of FOP Friends® Together newsletter. It has been a few months now since our UK family gathering and still the pace of FOP research and progress towards possible treatments accelerates. Not more than 5 months later I found myself in Boston at the 2nd IFOPA Drug Development Forum at which over 150 researchers, scientists and pharmaceutical representatives where in attendance. They were there again fighting on our side to find a cure for FOP. And more than being just doctors or researchers, they have become friends, of the parents and patients, of the one in two million touched by FOP. Familiar faces were seen, new faces were welcomed and new friendships were formed of the most unlikely kind. Can you imagine in a different life being friends with your doctors, planning clinical trials with researchers, educating pharmaceutical companies and bringing worlds normally so far apart together? That is what FOP has done; that is what we as a small but strong community have done; and that is what it means to be FOP Friends.

Chris Bedford-Gay
FOP Friends Chairman

NEWSflash

Anti-Activin A now in trial

June

Following on from the promising studies in mice, US biotechnology company, Regeneron, is running the first clinical trial of anti-Activin A antibody (REGN2477) in humans. This study in healthy volunteers started in Belgium in June 2016.

Palovarotene top-line results & phase 2 study extended

October

In mid-October pharmaceutical company Clementia announced the top-line results of its phase 2 study of palovarotene. The drug has shown positive trends in reducing bone formation and the pain and severity of flare-ups in those with FOP. Although these trends were not found to be statistically significant this is still positive news. Showing that something is statistically significant is a challenge for all trials of rare diseases, where the number of participants (40 in this trial) makes it harder to prove significant trends. Clementia is extending its phase 2 study of palovarotene to test new dosing regimens and is recruiting 20 new trial participants, and the company will be running a phase 3 trial next year.

Participants in the extension of the phase 2 trial must be adults or teenagers who are 90% fully grown, and must live in the UK, France, Canada or Argentina. The UK trial centre is Royal National Orthopaedic Hospital in London. To find out more visit http://clementiapharma.com/clinical-trials/phase-ii-part-b/

The FOP Connection Registry turns 1

July

On 29 July the FOP Connection Registry was officially one. In their first year they have managed to register 178 patients from 28 different countries. The registry will be a valuable resource to support FOP research in the future and we encourage all FOP patients to join if you haven't already. To sign up go to fopconnection.org

EURODIS Rare Barometer Voices launches first survey

September

The Rare Barometer Voices initiative aims to strengthen the voice of rare disease patients in Europe and transform your opinions and experiences into facts and figures that can be shared with policy makers and other influential figures. The first survey to assess the impact of rare diseases on daily life was opened in September and is open to patients, parents, siblings or other family members. To find out more go to www.eurordis.org/voices

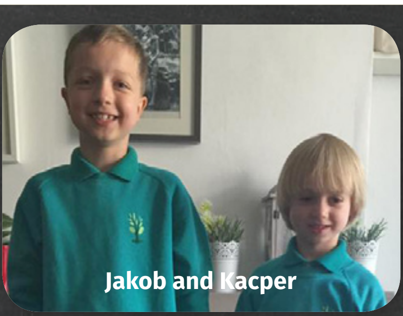
**Have news, views or stories to share? We would love to hear from you.
Email us – info@fopfriends.com**

FOPers head back to school

The first day back at school is an exciting time for most kids, and our small FOPers are no different!

Avi

Rion



Jakob and Kacper

Hope and Ellis

Isla

Millie and Ethan

Oliver and Leo

Our Fantastic Supporters

Whether you're raising awareness of FOP or raising funds, we value every pence and every moment you spend doing it immensely. Here are just a few of the lovely people who have helped us get closer to our goal in the last few months.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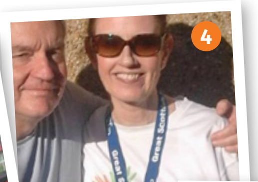
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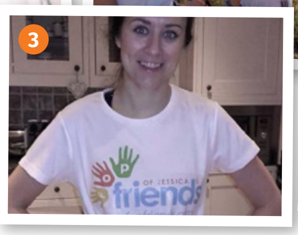
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A royal tea drinker

The lovely Belinda Davies took her FOP wrist bands to a garden party at Buckingham Palace over the summer.

① An intrepid (half) ironwoman

Michelle Elmore has always liked a challenge and a half ironman – that's a 1.9km swim, 85km bike and 20km run – seemed like a good one. On the hottest day in 2016 she completed the Fugitive Half Iron Distance Triathlon for us.

② A super skydiver

Natalie Wood found the courage to jump out of a plane at 15,000ft and freefall at 125 miles per hour above the very distant Wiltshire countryside.

③ Two much-appreciated marathoners

Rebecca Deegan ran her very first marathon in aid of FOP Friends. She was one of the 7,000 runners to set out this year's Yorkshire Marathon, and she was still smiling at the end of it. And across the Irish sea Mick Henry picked up a medal in the Dublin City marathon and raised an impressive sum for us at the same time.

④ A quintuple of half-marthoners

Besides our Great North Runners, three brave women took on the 13.1 miles in other parts of the country: Jacquline Stringer mastered the Mull Half Marathon, Judith Gray glided through Glasgow, and Sharon Moore conquered Cardiff. Paul Diamond and Jack Punter flew the flag for FOP on the south coast, completing the Great South Run.

⑤ A tenacious JOGLEr

To raise funds, Kevin Gordon completed the epic John O'Groats to Land's End all on his own. He cycled and camped all the way down the country, taking two weeks to cover the 847 miles.

⑥ A long-haired little girl

Six-year-old Olivia Gooding got sponsored to cut 12 inches off her long locks to raise funds for FOP research. She then sent the hair to The Little Princess Trust to be used in making wigs for children with alopecia or cancer.

A foot-tapping 60s R&B band

For the third year in a row, residents on the Isle of Wight enjoyed some great dance tunes courtesy of the L&M Band at a charity gig organised by Margot Charlton.

⑦ Four fantastic cyclists

Four energetic cyclists dedicated their efforts over the 54 miles from Clapham Common to Brighton to FOP Friends.

A 9-year-old first

We're delighted that William Jones did his first ever sponsored run for us!

"Hi, my name is William Jones and I am 9 years old. At the beginning of October I took part in the first ever Bury Family Fun Run. It was for ages 9–14 and for the first time ever I ran a race on my own. The race was 1.4km long through the centre of Bury.

On the day I was really excited but the run was great. I managed to run well and came 4th! I was really proud of myself.

I asked my mum if she knew any charities and she told me all about FOP Friends. I decided then this was what I wanted to do. We set up a fundraising page on the Virgin Money website and sent this to people by Facebook, Twitter and email. I also made a letter and leaflet which I gave to everyone in my class at school. To my surprise lots of people and friends donated money and once I did the run I found out I had raised £275.

I was so happy and I thought in my head I will do more for FOP Friends.

I did it for FOP Friends because I believe we can find a way to fight this nasty disease. In the future I plan to do a lot more for this fabulous charity. I would be so happy and proud of anyone who raises money for FOP Friends, it put a really big smile on my face. When I do another sponsored run I would be so happy if I could raise £300 or more."

THE GRAND TOTAL
Together our runners, cyclists, warriors and other creative and enthusiastic souls raised a very impressive total of £30,000.

OUR FOP FAMILY

Meet Rachel Winnard

Rachel's from Rochdale near Manchester. She was diagnosed with FOP when she was 12. At 32, she's been with her husband Paul for nine years now and they recently moved into a new house. Over the years Rachel's done more than most to raise awareness of FOP, giving media interviews and speaking openly about what it means to have FOP. She's also taken part in recent clinical studies – which involved regular trips to Paris and London.

Rachel is one of the most positive people we know and has had more fabulous hairstyles than we can possibly keep track of (not forgetting the time she shaved it all off to raise money for FOP research). Her favourite song lyric – which she has tattooed on her – is "always look on the bright side of life"!

"I was diagnosed at 12 years old, and FOP has affected movement in my arms, jaw, hips and feet. We became aware of an FOP community at the age of 14 when we got in touch with Dr Kaplan. I love all the FOP family. It's great to keep in contact with people who understand what you go through!

This past year I've had quite a lot of pain with my hips, but touch wood they haven't gotten any worse! When I do have a flare, I try to keep moving and don't let it beat me! It definitely works for me, as my jaw fully locked and I kept it moving and can now open it again!

I hate to sit still and am always looking to get out and about: I go shopping; love hanging out with my little princess, Lainey; going out drinking and dancing with my friends; or simply chilling at our caravan in Wales.

My friends and family raise awareness all the time by wearing the FOP bands and people asking what they are. We sell books and bands in my dad's hairdresser. Last month my grandma held a jewellery and beauty party which raised £100; and now my mum is knitting gingerbread men to raffle off. We really are Team Rachel, Team FOP!"

We would love to introduce other members of our FOP family in future newsletters. Please get in touch if you'd be happy to be included.

How you can help us over the festive season

Christmas and New Year are a super-busy time for most of us, and fundraising is often the last thing on our minds. But here are two low-effort ways you can support us over the holiday period.

1 Use easyfundraising when you shop online

If you're going to be doing your Christmas shopping online, this is an easy and secure way to support us. Simply register with **www.easyfundraising.org.uk**, select FOP Friends as your charity and start shopping! So long as you go through easyfundraising to visit your online store, we get a percentage of everything you spend, without costing you a penny extra.

2 Send E-cards instead of paper Christmas cards

This one not only gives us extra funds, it also saves you lots and lots of time. And there's no stamp licking required either. For the cost of a donation to FOP Friends you can design and send your own E-cards through the **DontSendMeACard.com**. How much you donate is entirely up to you.

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.

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

www.fopfriends.com

info@fopfriends.com

@FOPFriends

www.facebook.com/fopfriends

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The Astor Foundation

The Sobell Foundation

Give with confidence
FOP Friends is registered with the Fundraising Standards Board, an independent self-regulatory body for UK fundraising that encourages commitment and compliance with best practice in fundraising.

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