fop friends®
together
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Fun in the Forest for FOP Families

Oliver and Jakub

> *"The opportunity to meet other 'rare' families is incredibly important. You feel so isolated but...events such as this make you feel less so."*
>
> JAMIE'S DAD

In March, over a dozen FOP families were able to enjoy a weekend at Centre Parcs Sherwood Forest thanks to funding from Children in Need. Besides the activities, great food and fun, it was a rare opportunity for children and parents to connect and share precious time with others who understand exactly what having a child with FOP means for everyone in the family.

Supported by BBC Children in Need

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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

And even more fun in the water, at the pottery studio, and on the quad bike circuit...


Exploring on the nature trail

Continued from the front page...

On Friday, our first night in Sherwood Forest, there was a welcome event for all the FOP families. For many, the last time we saw each other was the Family Gathering in June 2016, so there was plenty of catching up to do, for both parents and children.

On Saturday morning we all headed across to the pottery studio to make something we could take home with us. In the afternoon, many families chose to splash and paddle in the incredible pool, while others picked an activity from the range on offer: quad biking, teddy-bear making and jet skiing amongst them. Then, on Saturday evening we shared a buffet. A children's entertainer and colouring competition kept the younger ones occupied, and we could all enjoy the dancing together.

What's overwhelming in the most wonderful way when FOP families get together is the positive atmosphere. We may have been brought together by something we never imagined would happen to us, yet we're all choosing to connect and find the best way we can to live with FOP and find a cure for it. Thank you to Children in Need for the grant that made this possible, to all the families who travelled down to Nottinghamshire, and to Helen Bedford-Gay for the many hours that went into making it happen.

> ***"When I am at home, people understand; here, they know."***
>
> ROHAN


Isla, Nicky and Theo


All our FOP kids, ready to party!


Brotherly badminton


Rion


Having fun at our welcome evening


Jamie


Early morning group painting

> ***"The weekend was a wonderful opportunity, not just for the children but the adults too, to spend time together in a fun, relaxed environment with others going through the same struggles."***
>
> MILLIE'S MUM

> ***"Spending time talking to the other families has been one of the most enjoyable parts of the weekend... sharing experiences and realising you're all on this journey together."***
>
> ELLIS'S MUM

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Our fabulous supporters

Sunday Superheroes

For us mere mortals, 13 may be an unlucky number. But for 13 superheroes who took part in the DIFC Superhero Fun Run in London's Regent's Park on 14th May, it served to intensify their powers.

The FOP Heroes team, that counted Wonder Woman and Batman in its numbers, tripled what they'd set out to raise. Netting £3,200 for FOP research is an heroic effort indeed! Thank you so much to everyone who donned lycra, masks and awesome socks to help us find a cure. (Your identities are safe with us.)

24 hours of potting

What can you achieve if you go through with your crazy idea to play pool for 24 hours to raise funds for FOP Friends? Well, you can complete 214 frames, pot 2820 balls, pot the black off the break 3 times, and raise a very much-appreciated £1360.

James Rockall in Windsor persuaded his colleague Nathan to go along with his fundraising idea. They collected sponsorship, and their company, Record Currency Management agreed to match whatever they raised. As fundraising ideas go, this one is definitely a first for FOP Friends. Thanks James and Nathan, and to the rest of the company for supporting them.

Rohan's pocket-sized fundraising

By a member of our FOP family, Rohan Stock

"Recently, two very friendly members of the Special Needs Teaching Assistant Staff at my Sixth Form (The Radcliffe School) came up with the brilliant suggestion of composing tiny stick-figure-esque keyrings made out of old buttons and pieces of string kindly donated by the students and staff. Having been provided with support by both of these wonderful women throughout my secondary school education (6 years+), I really appreciated it when they decided to donate all proceeds to this very charity.

At the beginning, we decided to sell the keyrings for £2 each. Due to the idea being rather spontaneous, we had very little time to advertise the sales and we expected our overall profit from the keyrings to be small, but not totally insignificant. However, the total outcome of all the hard work and crafting was a net profit of £175.00 (rounded up). I'd like to take this opportunity to thank both Miss Palmer for conjuring up the concept, and Miss Masom for tailoring each individual keyring."

Ann Gay (centre right) and the Whitly Bay line dancers

Dancing closer to a cure

In the seaside town of Whitly Bay, on the outskirts of Newcastle, people have been chasséing and toe strutting for more than five years now and have raised nearly £30,000 in aid of FOP research.

In 2011, Ann Gay organised her first line dancing event to raise funds for FOP research. She'd recently found out that her grandson Oliver had FOP. Since then Ann, a line dance teacher who's been dancing for over 20 years, has hosted a fundraiser for FOP on the first Friday of every month.

Three times a year she arranges a bigger event with live music and a bring-and-share buffet. As well as enjoying a good knees-up, locals can take part in a raffle, with prizes donated by Ann and others in the community. Ann also sells scarves, jewellery and handmade cards at the events. To date, she's raised a staggering £28,440 on the dance floor.

A word from Rachel


Rachel and Ben

It's been more than three months since 13 families gathered at Center Parcs in Sherwood Forest, but my three-year old son Ben is still talking about that fantastic time he had staying in the woods.

I attended the weekend with Ben as an outsider really. I'm a trustee of FOP Friends and auntie to Oliver, and when Helen told me about the grant FOP Friends had secured from Children in Need, I knew it was going to be a special weekend.

I'd thought it would be a slow-paced weekend, but the energy and enthusiasm of the children and the adults far exceeded my expectations. From the moment we turned up in the bar on Friday evening to find all the families chatting and laughing together and the kids running around having a great time, it felt like a reunion. From then on, no matter what activity we did – swimming, pottery, exploring the woods – we bumped into friends as we did so, making it feel like a big family trip.

On Saturday, we came together after all the activities to catch up over dinner and drinks, and to watch the kids dancing – and let's face it, we have some serious movers in the group!

When the time came to say goodbye to everyone, it felt quite emotional. Despite being spread out all over the country, the FOP Friends family is a very special, close-knit group of people who truly understand each other's lives and challenges. Having these special opportunities to meet and relax together is truly a wonderful experience. Here's to the next one!

Rachel Almeida
FOP Friends Trustee

Regeneron soon to launch phase II study

We were happy to meet with biotechnology company Regeneron in early June to discuss the launch of their phase II study of Activin A antibody (REGN2477) in the UK later this year. The phase I clinical trial of the drug was completed in healthy volunteers in Belgium last year. For the phase II study, Regeneron will be recruiting participants with FOP. We'll share details of how to participate in the trial as soon as they are confirmed.

Save the date

It's confirmed! The next UK FOP Family Gathering will be held from **18th to 20th May 2018**. Once again it will be at the Radisson Blu Hotel in Manchester. This meeting will have a strong community/family focus, with topics covering the challenges many of us face when dealing with FOP.

Save the date and spread the word! We can't wait to see you there.

Oxford ball


Helen and Chris

In recognition of the funds donated by FOP Friends to fund research into FOP at the University of Oxford, we've been invited to join the Vice-Chancellor's Circle. To celebrate this, Chris and Helen Bedford-Gay were required to don their finest to attend the Oxford Charity Gala in May.

We first started supporting FOP research at the university in 2012. Since then our tiny charity, with the help of its fantastic supporters, has donated over £300,000 to the research team led by Dr Alex Bullock.

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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