fop friends®
together
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www.fopfriends.com

800 Mountainous Miles

This summer Rebecca Deegan hiked 800 miles of the Appalachian trail alone. Her aim was to raise at least £1 a mile for FOP Friends, but the final total was far greater.

"I've wanted to hike the Appalachian Trail since I was a teenager. I realised that I was unlikely to ever take six months away from everything to do the full 2100ish miles, but that I could take the summer off and see if could get from Maine to New York.

Doing something like this gave me a perfect opportunity to raise money for FOP Friends. My sister Jessica has FOP, so whilst she couldn't be with me in person (not that she would want to, she is way too smart to do something this ridiculous), she was with me in spirit every step of the way.

The first month was physically and emotionally draining. I thought it was going to be a walk in the woods (as it appeared to be in Bill Bryson's book that had originally inspired me to do this hike). I didn't realise it would demand covering on average 15 miles and climbing three to four mountains each day.

Jessica's support and the support and encouragement of everyone who donated made even the hardest steps worthwhile. I know if it were the other way around Jessica would walk all day every day to help me."

You can read more about Rebecca's journey and her mutually terrifying bear encounter on our blog.

Thank you, Rebecca. For sharing your experience, and for the £2500+ you raised for FOP Friends.

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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 Alison

With this being the last newsletter of 2017, I wanted to take a moment to reflect on all we've achieved this year. For a small charity I think you'll agree, we have made a massive impact all round! Spectacular fundraising, amazing research results, exciting advancements in clinical trials, as well as continued family support, and new employees.

One of the highlights of my year was the Family Weekend, which was made possible by a grant from Children in Need. I loved spending time with my own family as well as my 'FOP family'. I was also thrilled to hear we had been nominated for Charity of the Year, recognition for the commitment we receive on a daily and weekly basis from all our supporters.

It makes me very proud to be a trustee of such a hard-working and far-reaching charity, and I would like to take this opportunity to thank all of our trustees as well as Hannah, Emily and Karen for all their efforts. We only achieve what we do, by all working together, so one day we can realise the same dream: a treatment for FOP.

Wishing you and your families a very Merry Christmas and a happy and healthy 2018.

Alison

Still happy to receive this newsletter? If you want to be removed from our mailing list (or have moved house and want to update your address) please email info@fopfriends.com. Just so you know, we'll never share your address with any other organisation.

2017 FOP Drug Development Forum

FOP Friends Chairman, Chris Bedford-Gay opened this year's Drug Development Forum in Sardinia in October. In his talk he urged attendees to continue working together as a global community. At the two-day event, leading clinicians discussed the latest scientific findings with patient groups and other clinicians. People also shared their experiences of living with FOP.

We're very excited that a site for the clinical trial for Clementia will be opening in London shortly, and we'll update you on that in the New Year.

Very almost Charity of the Year

We were very happy to be runners up in the Altrincham & Sale Chamber of Commerce Awards' Charity of the Year category. Although we didn't win, it was a great excuse to get dressed up and an opportunity to spread the FOP message. A big thank you to MLP Law for sponsoring this award category. We were honoured to accept the award on behalf of all of our supporters.

L–R: Fiona White, Alison Acosta Bedford, Stephen Attree (MLP Law), Helen Bedford-Gay

Oliver and his great grandmother, Laura

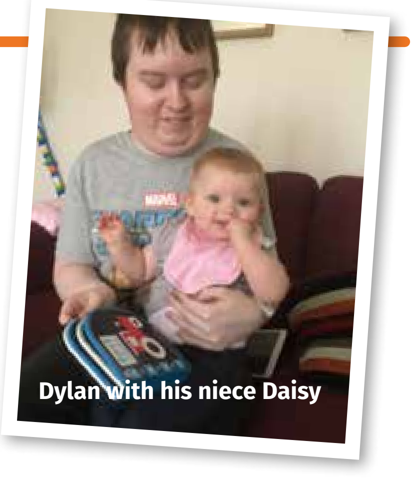
Our oldest supporter...

Sadly, FOP Friends' oldest supporter, Laura Gregory passed away in August following a short illness. She was 103 years young. Laura supported us from the very beginning, donating gifts for the raffle, her lottery wins, even her winter fuel allowances.

As Oliver's great grandmother, she so desperately wanted that treatment for him. She loved to hear about the progress of the trials and took great joy in news that they were getting closer to helping everyone affected by FOP. She will be missed by all her family.

...And our youngest

Without knowing it, baby Daisy – FOP Friend Dylan's tiny niece – became our youngest ever supporter in May! Her parents, Laura and Andrew, asked that instead of gifts, family and friends invited to her naming ceremony make a donation to FOP Friends.



Dylan with his niece Daisy

Our fabulous supporters

This issue is dedicated to the efforts of all our supporters – there was so much fabulousness, we couldn't contain it all on one page and your stories have spilled across all four! We are so sorry we can't mention you all here, but we do appreciate every single one of your efforts and share your awesomeness on our Facebook page and Twitter Feed.

The L&M Band in action at Gig for Isla

A Gig for Isla

Margot Charlton and her husband Adrian are part of a small but dedicated community on the Isle of Wight who have raised thousands of pounds for FOP research over the last four years. Besides supporting their annual dance, locals have taken part in conker competitions, raffles and beetle drives to support us.

"Adrian and I have been close friends with Isla's dad's family for years. We were shocked when she was diagnosed with FOP at just three months old, and soon realised that the only way we could help was to raise money to help find a treatment or, better still, a cure.

We decided to organise a fundraising dance, and the first Gig for Isla was held in October 2014. The L&M Band, who play 60s R&B and includes Adrian and my brother Loris, agreed to play for free. Everyone had a good time and as they left, people were asking when the next one was going to be.

So, Gig for Isla 2 was held the following year, and was again sold out. Our fundraising total included the proceeds of a raffle for a beautiful dolls house held by our local pub, The Sun Inn at Calbourne.

Gig for Isla 3 sold out a week in advance, and so, we came to this year and Gig for Isla 4, held on 30 September. It was packed, and it was lovely to see so many from previous gigs. The L&M Band kept everyone dancing from start to finish, and local people and businesses provided awesome prizes which helped us raise £461 on the raffle alone.

We're delighted that the four gigs have raised £7002, and are thrilled that this plus some very generous donations, and the proceeds of other events organised by close friends of the Williams family – particularly Dave and Debbie Lutas, Debs and Ted Downer, and The Sun Inn – means we've been able to send over £13,000 to FOP Friends so far.

Again, I am having my arm twisted to set a date for next year, so watch this space for an update on Gig for Isla 5!"

See the back page for Margot's tips on organising a fundraising dance

Suz & Rob Grant

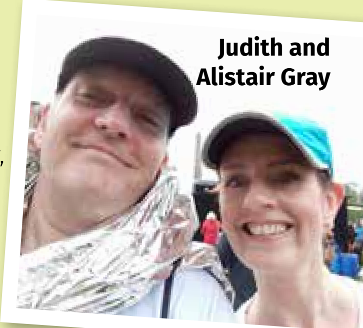
Great runs from great parents

The parents of those with FOP have plenty on their plates already. Yet they still find the time to train and fundraise. Iona (14) and Ellis (8) are two of our FOP Friends whose parents completed half marathons this year.

Suz and Rob Grant were two of the eight people who completed the Great North Run in Newcastle.

"We both felt really nervous on the day. You kind of second guess loads of stuff: have I trained enough? Have I eaten a big enough breakfast? How on earth am I supposed to make it round?!? We did it though, and thanks to some very generous friends and work colleagues we raised just over £4500 (£5100 including Gift Aid) which is just mind blowing! I would run around the world millions of times if it would guarantee a cure for Ellis and all the other amazing FOP Warriors. Considering what they fight daily, 13.1 miles is easy."

Suz Grant, Mum to FOP Warrior, Ellis



Judith and Alistair Gray

A few weeks later, Iona's parents, Judith and Alistair Gray, ran through a sodden Glasgow in the Great Scottish Run.

"Was a very wet and wild, Glasgow day. However, also amazing and emotional to be amongst so many people running for such great causes. Once again, we had fabulous support from friends, family and colleagues, which we never take for granted. My poor sister and brother-in-law even braved the terrible weather to stand and cheer us on! Although I must confess that Ali did beat me this year, there's always next year! Joking aside we are so grateful to have the opportunity to make a small contribution and help keep hope alive."

Judith Gray, Mum to Iona

Stewart's Scottish Cycle

Stewart Simpson on the final and only sunny day of his cycle trip

"I came to hear about FOP through my mate, Alistair Gray. Alistair's daughter Iona has FOP. Until I met Alistair I must admit I had never heard of it.

Every year, I go and do something for seven days to escape the stress of the modern world. This year I decided to cycle from Thurso in the far north of Scotland, across the top of Scotland then down the west coast and home to Helensburgh, a distance of 500 miles. I was just going to do it for fun, but then thought of Iona, and I spoke to Alistair to seek his blessing to raise funds. I then approached the English civil war re-enactment regiment that we're both members of. The rest of the regiment thought I was nuts, but all very willingly and generously agreed to sponsor me to do it.

So, I booked time off work, convinced my missus I hadn't gone mad, and persuaded her to drive me and my trusty bike all the way to the far north of Scotland. Then on 30th June in the cold grey rainy mist of a northern Scots summer I set off. I was by myself, as no one was mad enough to want to cycle 500 miles with me!

Over the next six days I battled through very heavy rain and gales, but count myself lucky it never snowed. On the last leg from, Fort William to Helensburgh, the sun came out."

Our supporters' top fundraising tips

Margot on organising a dance

- Keep the ticket prices low to that it's not an expensive night out.
- Always try to get the money beforehand, then on the night people forget they have already spent that money and are willing to be more generous on the raffle. (Also, people who are unable to come on the night never ask for their money back.)
- If people tell me they can't come but will buy tickets, I always ask for a donation instead as I can always sell the tickets to people who will come.

Stewart's top tip

- No matter how mad your idea for fundraising, just go and do it. Enjoy the moment, and you'll be surprised at folks' generosity.

Support us this festive season

www.easyfundraising.org.uk

If you shop online, register with www.easyfundraising.org.uk and select FOP Friends as your charity. When you visit an online store through easyfundraising, we get a percentage of everything you spend, without it costing you anything.

DontSendMeACard.com

For 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. Saves trees and time.

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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