fop friends®
Together
Vol 4, Issue 1 Mar 2021

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

For the love of reading and our children

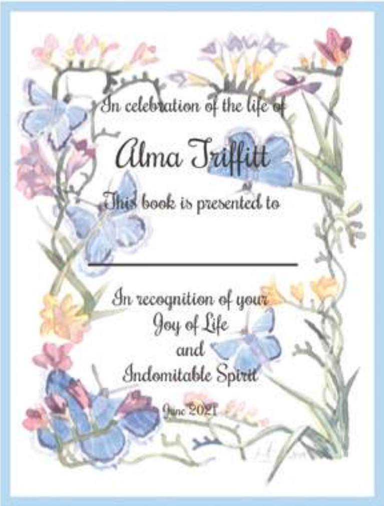
We are excited to announce the launch of the 'Alma Triffitt Book Award'. Professor Jim Triffitt lead the original FOP research team at the University of Oxford which has been a major centre for FOP research since the mid-1970s, when he and Dr Roger Smith began their collaborative studies. This culminated in the co-discovery of the causative gene for FOP, ACVR1, in 2006. Professor Triffitt has since retired, but with Emeritus status he still collaborates with Professor Bullock on the development of ACVR1 inhibitors. Over the years, Jim's wife Alma supported his research and accompanied him on his research trips around the UK, Europe and the USA, meeting the families affected by FOP and taking precious time to befriend them. Alma loved the families and offered support and friendship to them on their journeys.

The FOP families cherished her warmth, humour and kindness: she was just as dedicated to finding a cure for FOP as her husband. Sadly, Alma passed away in July 2018

Alma's interests were many and varied but centred around a love of books and reading. In recognition of her affection for the FOP community, Professor Triffitt would like to share Alma's love of reading and poetry with the children living with FOP. Annually, through a generous grant, four children who have shown exceptional fortitude in overcoming the challenges of living with FOP will be presented with a keepsake book. Every book gifted will be personalised with a beautiful bookplate. Alma's son David inherited her talent for art and lovingly painted the design, inspired by his mother's love of colour and joie de vie.

> Alma was a lady who always left her unique mark wherever she went. A well-known phrase of Alma's was 'You only get out of life what you put into it'. She certainly put her heart and soul into every aspect of her life, including reading books, and she would urge everyone to enjoy every minute of theirs – as she always did! She would want all the children to enjoy reading as much as she did and, by being transported into realms and adventures beyond everyday events, experience the joys of learning of other worlds and life experiences. It is hoped that the inauguration of the annual Alma Triffitt FOP Book Prize will go some way in accomplishing this aim and will be enjoyed by all future recipients.
>
> **Professor Jim Triffitt**

To unveil this most wonderful celebration of our children, all the children living with FOP in the UK will receive a book in June in honour of Alma's birthday, with the Prize continuing annually thereafter. We would like to take this opportunity to thank Professor Triffitt, both for his dedication to FOP research and to our FOP children.



In celebration of the life of

Alma Triffitt

This book is presented to

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In recognition of your
Joy of Life
and
Indomitable Spirit

June 2021

Inside

A word from Fiona


Photo taken October 2019

Hi! Well, here we are with yet another fabulous issue of 'FOP Friends Together'. Once again, it gives me great pleasure in writing a short word from myself in what can only be described as uncertain and sometimes frightening times. Yet as a community and charity, we remain positive and proactive in ensuring families are supported and cared for whilst ensuring the hard work to find a cure for FOP continues. It should not surprise me, but it still does, that during these times, as a community, we are able to spread the message of FOP worldwide. We have had Oliver Collins, an Australian gentleman living with FOP, deliver a podcast in Australia related to the theme 'We are Strong', and we are thrilled to have him with us here this month as a guest writer! At the Marine Education & Research Society, the humpback whale 'Splashy' has become a celebrity. You may remember our friend Miranda, who sadly passed away in April last year due to complications from FOP. A donation from the Canadian FOP Network was made to MERS in her memory, and so Splashy was named after Miranda's soft toy in her honour.

There are so many things to look forward to this year, even if some events do take place in a different way. We must not forget FOP Awareness Day on 23rd April: I am sure we will be getting creative as we always enjoy seeing everyone's pictures celebrating #FunFeet4FOP. We are also looking for people to support us in the Great North Run on the 12th September! So many people have taken up running over this past year: whose running shoes are ready for a challenge?

Once again, thank you to our supporters who continue to be there for us, even when life is particularly busy and can be a struggle at times. Your support as a community is essential if we are to continue to get the message out there and bring us closer to that much needed cure.

Take care and stay safe.

Fiona, FOP Friends Trustee

It's all about the toes

At the end of 2020, 'Let Their Feet Lead the Way: Tools for Early Identification of FOP', was launched.

This was the PeerVoice panel discussion, led by Professor Richard Keen and Dr Angela Cheung (University of Toronto), with Chris participating by providing the perspective of a parent on the journey to diagnosis of a rare condition. The project was supported by an educational grant from Ipsen. The objective of the project is to raise awareness of FOP within the medical community, in order to improve the time to diagnosis of a person with FOP. It is hoped that the online training module will reach over 250,000 professionals. To watch the presentations, or to share with your own medical professionals, visit **fopfriends.com/video-library/**

STOPFOP

Trial update

Covid has hit all clinical trials very hard, with restricted international travel making attendance at a trial site particularly challenging. Nonetheless, the first patient enrolled in the STOPFOP trial has completed the full 6-month randomised controlled trial and is now in the open label phase. The Team are currently working to complete regulatory steps to open the London and German sites for continued enrolment. Each country has independent processes with subtly different questions and data requirements to address, adding to the delays. The STOPFOP team will be giving a further update in the near future, and we look forward to sharing their Q&A with you. For the most up-to-date information or to get directly in touch, visit **en.stopfop.com**

IFOPA Board Meeting 2021

Chris usually travels to Florida for his annual in-person board meeting for the IFOPA. However, due Covid restrictions, that wasn't possible, so the fifteen volunteer board members met virtually, across two days via Zoom.

It was just as productive a meeting and two new board members were welcomed. Topics discussed included reviewing the past year; planning activities and family support for the next few years; research updates; and how to continue to raise awareness worldwide. The Board Meeting 2022 has been pencilled in – let's hope travel is possible once more!

Meet Ollie

Oliver is 27 years old and lives in Brisbane, Australia. He is a solicitor in a litigation team and lives with his sister, Ellie. He was diagnosed with FOP at 18 months of age. He enjoys spending time with friends and family, trying out new bars and restaurants, and travelling (when it's safe to do so). Ollie has a blog where he reflects on the curve balls life has thrown at him. You can follow him at **imolliecollins.com** or on Instagram, where his handle is **@imolliecollins**

*We are delighted to have a guest writer with us for this edition, **Oliver Collins.** Here, he reflects on his experience of living with a disability.*

Why it's important to be a disability advocate

Last year, when we went into a lockdown after COVID came into my country, I started a blog. I had seen a lot of people posting, and had chatted to friends, about how everyone was struggling with the isolation and weren't coping with being forced inside and not being able to do everything they wanted to. I then started to think about how I'd been dealing with a lot of these same feelings for several years thanks to FOP. And maybe if I wrote about how I coped then others would relate and it might help them deal with the difficulties they were facing. Thanks to some quite serious FOP progression in the past few years, I have been in the position where it is really exhausting to even get out of bed on some days. I work full time as a lawyer, and so had to do what I could to preserve my energy so that I was able to fulfil that role during the week. But, I am human. And I'm a social person who gets a lot of benefit out of seeing my friends and loved ones. In order to compromise, I often had to arrange things at my place so that I could see people without exerting too much energy. But, sometimes, even that was too much. Sometimes, despite how much I may have wanted to see people, or go out, I had to say no in order to rest so that I would be able to be alert and fully functional at work. So I've been dealing with similar feelings of isolation for some time now.

The truth is that a lot of the feelings we have and a lot of the emotions we experience in facing FOP can really be applied for any sort of adversity we or those around us are faced with in life. Although the challenges we face may be unique, how they make us feel and the ways we cope with them are similar to how other people face other challenges they're dealing with. That was when it struck me how important it is for us to advocate, in whatever way we can, about disability. That is how we will eventually get to the point where we are not viewed as different or less than, but merely as variations on the human theme. The brutal truth we all need to acknowledge is that we are all perfectly imperfect. Yes, because of my disability, the abilities I lack may be more obvious. But that doesn't mean that I don't equally have a lot of other skills that other people may not possess. It can be difficult talking about disability. It can be difficult acknowledging the difficulties we face, and the pain. Often, when we are trying to cope with it, our best coping mechanism is to just squash and ignore it and get on with our day. But in order to try and help others really understand we need to open up about it. By opening up and talking about it, and by showing people that we with disabilities are just the same as everybody else, we are helping to break down the barriers and working towards the goal of equality. 1 Sunday, 14 February 2021 Another thing is that, by talking about it, we are helping those around us to not feel so uncomfortable about disability. The harsh truth is that disability can happen to just about anybody, and there's no real predicting when this may occur. If we can help open up the conversation and remove the barriers that exist at the moment, then we can help those who may experience disability in the future not feel so alone and know that everything will be ok. And we can also help those who may need to support someone in their lives in the future with disability to know that it will be ok.

You've been 'snow' generous!

We would like to thank all our generous Friends for their support over Christmas.

Through a combination of Christmas card sales, donations, gifts, and small events, we raised over £2,600 to support our small but vital charity. Thank you to everyone who contributed, it's a wonderful way to start 2021.

In memory of Hylda Hadley

On 18th January, Hylda Hadley passed away peacefully at the age of 85.

She was a beloved mum to Sheryl, doting grandma to Lucy and Tom, and much-loved sister and friend to many. There was a quiet celebration of her life in February, with just close family in attendance. As Lucy lives with FOP, the family chose donations to FOP Friends in lieu of flowers. Thank you to everyone who made a donation in Hylda's memory: a treatment for FOP was the thing she hoped for more than anything else. Our hearts go out to those who knew and loved Hylda.

Quiz Night Fun!

The 27th December is normally a big date in the calendar of the Rockall/Oke family.

They take it in turns to host the event with food, banter and game playing. With over 25 family members, it really is a celebration! However, it was clear to Diana that their annual soiree wasn't going to be possible due to the lockdown. Diana felt that without much opportunity to attend or run events in 2020, they hadn't been able to do as much fundraising for Isla and her friends as they usually did. Brilliantly, Diana saw an opportunity to combine the two things!

Her awesome friend Susie runs pub quizzes in Germany and was happy to host an online family quiz for them, with the entrance fee going to FOP friends. It was a great evening full of competitiveness and laughter and even better they got to raise awareness and some funds for FOP. Diana tells us, 'This past year has taught us a lot of things: the importance of our health, our friends and family, and how to get on with life even with barriers in the way. But our FOP warriors knew that anyway, hey!' Everyone at FOP Friends is thankful to Diana and her family for their continued support, and fingers crossed they can get back to 'normal' for 2021!

Lockdown Learning!

The majority of children across the UK have been remote-learning since January, and children with FOP are no different.

Most children (and their parents) were eagerly anticipating their return to school on 8th March. But this comes with additional risks and considerations for children with FOP and will mean some difficult decisions need to be made: this is the reality of parenting a child with FOP. However, during this lockdown, our children have been working very hard for their teachers, so we thought we'd share some of their wonderful work! We'd also like give a big shout-out to all the teachers and school staff who have gone above and beyond to support all our children through these difficult months.

Charlie created a Lego scene for his visual merchandising class.

Ellis made a papier-mache planet for his science project.

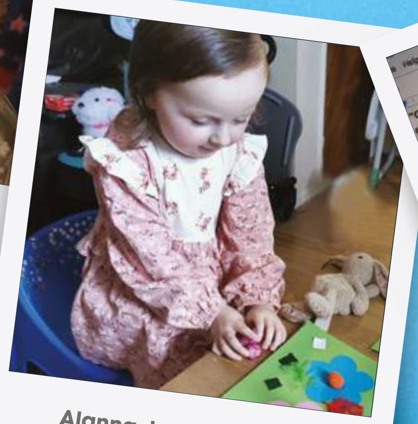
Isla made a model of her headteacher to remind her of the Golden Rules.

For his 'daily walk', Ellis took his new BFF Chester

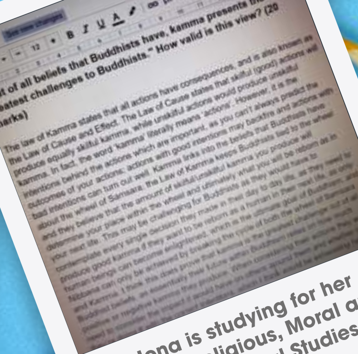
Oliver made a model of the lungs, which won him a Star of the Month award.

Mille's fabulous drawing of a polar bear.

Brodie getting creative at home.



Alanna, busy doing her creative task for nursery.



"Out of all beliefs that Buddhists have, kamma presents the greatest challenges to Buddhists." How valid is this view? (20 marks)

The law of Kamma states that all actions have consequences, and is also known as the Law of Cause and Effect. The Law of Cause states that skilful (good) actions will produce equally skilful kamma, while unskilful actions would produce unskilful kamma. In fact, the word 'kamma' literally means 'actions'. However, it is the intentions behind the actions which are important, as you can't always predict the outcomes of your actions; actions with good intentions may backfire and actions with bad intentions can turn out well.

Iona is studying for her Higher Religious, Moral and Philosophical Studies.

Will you be our Friend?

Lockdown and Covid has been an immense challenge for all of us, in ways too numerous to mention. As a charity, we too have been hit hard by the pandemic and have seen a significant drop in fundraised income.

Although the government has set out a tentative roadmap to see us out of lockdown, we appreciate that it will be a long time yet before we can get back to 'normal' where people are able to organise gatherings and sporting events are held again in-person rather than virtual. However, our work and the work of our team at Oxford still continues.

There are still lots of different ways to support FOP Friends and help us to fund the amazing team at the University of Oxford. If you would like any support or resources to help you set up a virtual fundraiser, just get in touch. **Visit www.fopfriends.com/fundraise** for more ideas of how to support us in a virtual world.

Become a Regular Donor

An easy and hassle-free way to support FOP Friends. Set up a monthly donation for any amount, and we'll send you a virtual warm hug to thank you. No donation is too small! For more information visit: **fopfriends.com/be-a-regular-donor-2/**

Nicky and Isla raised £100 last week with an online family bingo night

Great Ideas

Facebook Fundraiser
If you're celebrating a special occasion, get your friends and family to make a donation in your honour.

Online Quiz Night or bingo evening
If you're not Zoomed out! If you haven't tried it yet, Kahoot is great fun for all the family. Download some bingo cards and play for a full house!

Clear out your clutter!
eBay your clutter and donate the proceeds to FOP Friends, or sell with Ziffit.

Donate your commute
while you're still WFH.

Coin hunt
Have a scavenger hunt around the house and see how much money you can find under the sofa, behind the cushions, in the toy box… Round the amount up and donate online.

Shop for us!
While you shop online, use Amazon Smile or Easyfundraising.com and choose us!

'Climb' a mountain
Take inspiration from Annalise and pick a mountain, then virtually 'climb it' up the stairs, on the climbing frame, or on your 1990's stepper.

Set yourself a challenge
Then get everyone to sponsor you. Even better if people think you won't make it! Set up a fundraising page on **virginmoneygiving.com**

Take a sponsored walk in someone else's shoes-literally!

Hold a movie night
Download Teleparty (formerly Netflix party) for free and then watch a movie with your friends. Donate the price of the ticket and popcorn to FOP Friends.

YourRun. Your Way.

We have a few places for people to take part in the Virtual London Marathon 2021 race.

The beauty of this race is you can do it anywhere – in the world! By taking place in this event, you will be one of the 100,000 people taking part in the world's biggest ever marathon on Sunday 3rd October! And you will be the proud owner of an iconic London Marathon medal.

International Women's Day

We are thankful for all the medical experts around the world who take care of us and who are researching into a treatment and a cure for FOP.

But on International Women's Day, we wanted to celebrate some of the incredible women - doctors, nurses, dentists, researchers, teachers – around the world who make a real difference to the lives of those living with FOP every day. We are thankful to have your knowledge, care and support.

From top left: Corrie Crowe DDS, Jefferson Hospital, Philadelphia; Professor Eileen Shore, University of Pennsylvania; Dr. Eleanor Williams, University of Oxford; Dr. Gehan Abou-Ameira, GOSH; Dr. Geneviève Baujat, Hôpital Necker-Enfants Malades, France; Ms. Jaqueline Vinton, RNOH; Dr. Judith Bubbear, RNOH; Dr. Marelise Eekhoff, Amsterdam UMC; Dr. Mars Skae, RMCH; Mona Al-Mukkadam MD, University of Philadelphia; Ms. Nadine Großmann, M.Sc. Freie Universität Berlin; Patricia Delai MD, Research Institute, Hospital Israelita Albert Einstein, Brazil.

Great North Run 2021

If you're looking for a running challenge, then we still have a few places left for the Great North Run 2021 which is scheduled to take place on 12th September, with runners running across the iconic Tyne Bridge.

As all places were rolled over to 2021, there is no public ballot this year, so places are limited. If you are interested in running for FOP Friends, places are just £25, so get in touch quickly. For more information about how the Great Run team are making the event covid-safe, visit: **greatrun.org/covid-19-event-info/**

This is event is renowned as being one of the best (if not the best!) half marathon in the UK. The supporters and atmosphere are second to none! Be a part of something special, and help us win our race to find a treatment for FOP.

Generous at Heart!

We were thrilled to receive a donation from the Young at Heart dance class in Bearsdon, Glasgow.

Iona's gran Aileen Shand is a member of the class, and since they weren't able to hold a Christmas party they made a donation to FOP Friends instead. Young at Heart is a unique programme of dance classes that are aimed at the over 50s, where the combination of dance and exercise come together to bring a fun, healthy and sociable way of keeping both physically fit and mentally active.

Obviously, the lockdown has meant that in-person classes were paused, but this hasn't stopped the members joining in, in the comfort of their living rooms through the wonder of Zoom! The members were thrilled to be able to support a cause so close to the heart of one of their friends and are looking forward to meeting up again once restrictions are lifted.

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

www.fopfriends.com

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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.

FOP Awareness Day Goes Global!

This year, many of the patient organisations around the world are joining together to collectively raise awareness of FOP.

To launch this united approach, a fabulous new global logo has been created which reflects all the communities involved. The logo will be used by groups all around the world. In the run up to FOP Awareness Day on 23rd April, we will all be sharing facts and stories about living with FOP. We are aiming to increase awareness of FOP and the challenges it poses for people living with the condition, but also to help find those living with FOP but who are yet to be diagnosed. 2021 is a particularly significant year as it marks the 15th anniversary of the discovery of the ACVR1 (FOP) gene, which was a collaboration of a number of research teams. You can show your support for this Global Awareness Day by purchasing one of our new t-shirts from our online shop for just £12.50 inc. p&p. You can also help to make the campaign a success by following us on one of our social media platforms and by sharing the posts far and wide. **fopfriends.com/shop**

Find us on social media

@FOPFriends

/FOPFriends

4 x 4 x Fabulous!

Ever heard of the 4x4x48 Challenge? No, neither had we until Seanie's cousin Aoife decided to set herself the huge challenge to raise money for FOP Friends.

The challenge was created by David Goggins, a retired US Navy SEAL, with the goal to run for 4 miles every 4 hours for 48 hours! Of course, the lack of sleep simply adds to the endurance challenge. It can be done anywhere in the world but must start on the 5th March. The idea is for people to challenge themselves while raising money for good causes. If running isn't your thing, then you can walk, cycle, anything… just do it!

Aoife began her challenge on Friday after a day at work, teaching, leaving school on her bike. She mixed up the challenge with runs, rides and a few hill sprints thrown in for good measure. There were moments when she felt like a Navy Seal, and other times when the donations and support helped to spur her on. Aoife managed to complete the challenge at 4pm on Sunday – and was more than ready for her well-earned reward of a Sunday Roast! At the time of printing, Aoife had raised an amazing £750, smashing her target of £200. And would you believe, she got up and went back to school on Monday morning, ready for the 'new normal' and the challenges that would bring. A huge thank you from everyone at FOP Friend.

We hope you enjoy receiving our newsletter. However, if you no longer wish to be on our mailing list, please email us at **info@fopfriends.com**