fop friends
together
Vol 2 Issue 7 | November 2018
www.fopfriends.com

# The Great Gathering of 2018

**The 19th May will be remembered by many for a rather spectacular Royal wedding. For us, it will be remembered as a special day of connecting with FOP families and friends: taking strength from the knowledge we are not alone on this journey; taking hope from the updates of the researchers.**

**Our special guests may not have been wearing their wedding finery, but their smiles were more than enough to make them the stars of the 2018 FOP Friends Conference and Family Gathering in Manchester.**

*Continue reading on p. 4*

## 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

We are now into our third year of Together, our old-school FOP Friends newsletter, and it's still going strong! Our readership consists of our FOP community, together with our amazing supporters, whose efforts allow our work to continue. The scope of our work seems to be ever-widening. It's gone beyond what we ever thought necessary when we first founded the charity. We now support more families than ever with the challenges they face whilst living with FOP.

Together, our small but dedicated community has helped to fund critical research that has taken the scientists to the cusp of a potential treatment that we hope will lead to another clinical trial very soon. We've also funded research that's helping to discover novel approaches and therapies for tackling FOP. We've expanded the support we offer to our FOP community and we were thrilled when our conference early this year was another overwhelming success. Next year we're hosting our second family weekend, taking families of children with FOP away, not to talk about FOP, but simply to be 'together'.

But we can only continue to do these things with your support. Please consider talking to someone about FOP; sharing the importance of having a charity advocating for you with your friends; putting us forward at your work as 'dress-down' day or 'Charity of the year' partners; holding a fundraiser; selling Christmas cards to your friends; or simply setting up a monthly donation. There are no limits to the ways you can support your charity.

Because we can only do what we do, if you all continue to do what you can.

Thank you, Chris

We are delighted to announce that, thanks to the generous grants from **The Boshier-Hinton Foundation** and **The February Foundation**, we are able to produce the newsletter for another year.

# Update on FOP clinical trials

Created by Freepik

**In our last newsletter we discussed the two FOP clinical trials currently recruiting in the UK.**

Clementia's Phase 3 trial of palovarotene is called the MOVE trial. Great news is that the trial completed its recruitment of patients four months ahead of schedule. They've enrolled a total of 99 patients at 15 sites in 11 different countries! The UK site for the trial is the Royal National Orthopaedic Hospital (RNOH) in London. For more information, go to: www.fopfriends.com/clementia.

Both UK sites for Regeneron's Phase 2 study of anti-Activin A antibody are still recruiting participants. The trial, known as the LUMINA-1 study, will investigate if the drug can slow/stop bone growth in those with FOP (as it did in mice), and if the drug is well-tolerated in humans. For more information go to: http://www.fopfriends.com/regeneron

https://pngtree.com

# Remembering a very special woman

**Sadly, the very special Alma Triffitt passed away peacefully in July, aged 81, with her husband by her side. Alma was much loved and appreciated by the FOP community for her wonderful sense of humour, her kindness, her warmth, and her dedication to helping us all find a cure.**

Married to Oxford University FOP researcher, Professor Jim Triffitt, she came to know many of us over the years, through both social and fundraising events, where she was always ready with a big smile and words of wisdom.

Alma was simply one of those people who was brilliant to be around. Though she didn't herself have a child with FOP, her empathy and supportive spirit gave comfort to many of us FOP parents.

A true warrior for FOP, she will be very sadly missed by many here and in the wider FOP community. It was a pleasure and a privilege to have known her, and she will always be in our hearts.

# Fundraising stars

**To everyone who tested their endurance, creativity and organisational skills on behalf of FOP research in the last few months: thank you! You're the reason we've been able to raise over £160,000 since 2016. Here are just a few of the great things some of you have been up to.**

## Chop chop for FOP

We had two incredible people take the bold step of cutting their hair in aid of FOP in July.

Freya Brown took the big decision to more than halve her thigh-length hair in aid of FOP Friends. She raised a whopping £1300 and donated her locks to the Little Princess Trust too.

Melissa Borris took the bold step of shaving her head! The £2300 she raised has been split between five charities, one of them being us. Her tresses also went to the Little Princess Trust.

Thank you Melissa and Freya! We're honoured that you had a chop for FOP.

## Row, row, row your boat

The University of Manchester's Boat Club has put in some great strokes on our behalf this year. These included a 24-hour row in March and a team who ran the Manchester 10K in May. In total they've raised over £1200.

## Cross country!

Alexis Palmer conquered the 3 Peaks on behalf of his nephew and FOPer, Daniel. In scaling England, Scotland and Wales' highest peaks within 24 hours, Alexis raised over £700.

## North Run Greats

An enormous thank you to David, Angela, Richard, Stehanie, Kyle, Sarah, Kate, Kate, Andrew, Fiona, Gillian and Graeme, for taking part in this year's Great North Run! You all rocked it.

We've had runners in this event every year since 2013. If you're keen to run next year, get in touch.

## 13 milers

Besides our GNR runners, we've had a number of wonderful people crack a 13 miler for us this year. These include Iona's parents, Alistair and Judith Gray (Glasgow), RNOH consultant Jude Bubbear (Ealing), Seanie's cousin Jack Murton (Windsor), and the speedy Harry Harding (Bristol).

## The full 26.2

And then, as if 13 miles wasn't enough for anyone to run, there are those who went an extra 13 miles, Sharon Moore (Newport Marathon), Matthew Benson (Edinburgh), and father to Rion, Mick Henry (Connemara). A very proud Rion crossed the finish line with his dad. Rion has POH (progressive osseous heteroplasia), which is a condition similar to FOP, although even rarer.

# The FOP Friends Conference and Family

**Although many of those at this year's gathering in Manchester had been before, amongst those sharing the day with us for the first time were Annabel Jenks and Emily Harding. Here's what they thought of the day.**

## Annabel

### What brought you to the Family Gathering?

I had only recently been introduced to FOP Friends, and on finding out Dr Kaplan and his team were attending I thought it a fantastic opportunity to meet him, his team and other fellow FOPers and families. I hadn't previously met anyone with FOP!

### Which of the sessions did you find the most valuable and why?

Oh so many! There was a talk on some side effects which was really interesting to know. I have a very mild variant of FOP, so have only suffered from some to date. The genetics talk by Professor Eileen Shore was really interesting, and the update from the University of Oxford to see if a cure could be tested for in parallel to a treatment for some brain tumours was fascinating.

### What else did you enjoy or find useful?

Meeting Dr Kaplan and the other FOP specialists. Their support is huge and having the chance to sit with them in a room for 20 minutes was invaluable.

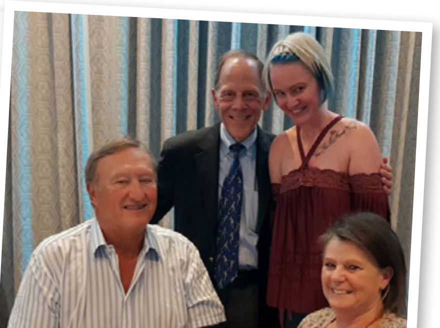
It was especially nice for not only me, but for my mum and husband to feel free to ask whatever questions we wanted to. My mum was so pleased to hear she had done the right thing when raising me. I can only imagine it was a massive strain and worry for my parents.

### Were there any surprises?

Probably how inquisitive the doctors were towards me. I don't think they had seen someone so well with the FOP mutation. Also, how warm and caring Dr Keen, his assistant Jackie and Dr Kaplan were.

### What did you take away from the event?

We all left the event happy and uplifted on the basis that there is medical attention on FOP and that there is such a fantastic support network here in the UK, assisted by Dr Kaplan's US team. Helen (Bedford-Gay) is an incredible lady, as too is her husband. I take my hat off to them. There is a positive future for me and my desire to start a family. And for all other FOPers.



# Gathering 2018

## Emily

### What brought you to the Family Gathering?

I did an internship with FOP Friends last summer. I had just completed a placement year working in a lab as part of my degree (Physiology and Pharmacology), and whilst I enjoyed it thoroughly I couldn't see myself doing it as a career. A summer job in a charity that had a scientific background seemed an ideal option for me.

I learnt that there are many other things you can do with science that aren't your classic research roles! It really got me thinking about ways in which I can use my interest in science and wanting to work with people in a different way.

### Which of the sessions did you find the most valuable and why?

I found all the talks from the professionals very interesting, but the session that had the most impact on me was the talk from Chloe from Dog A.I.D. as it gave real insight to what living with illness is really like, and the amazing effort that is needed to adapt to these changes.

### What else did you enjoy or find useful?

Being able to meet and speak to everyone involved and finally put names to faces!

### Were there any surprises?

I was surprised how frank and open everyone was. I've never been in that kind of environment before and I'm not sure what I was really expecting, but everyone that I met spoke bravely and positively

### What did you take away from the event?

I left feeling inspired. Knowing how life changing FOP is, it amazed me how strong and positive all the patients and families are, and I'm in awe of the level of dedication of the researchers and medics to finding a treatment and cure.

## The Gathering in numbers

| | |
|---|---|
| 1 | **dog** |
| 6 | **resourceful creche volunteers** |
| 6 | **researchers** |
| 11 | **countries represented*** |
| 13 | **pharmaceutical representatives** |
| 14 | **clinicians** |
| 23 | **children** |
| 26 | **families** |
| 131 | **wonderful attendees in total** |

* We had delegates from The UK, The Republic of Ireland, The Netherlands, Sweden, Finland, Denmark, Switzerland, Belgium, Malta, Greece and The USA.

## Puppy Love

As the saying goes, a dog is a man's best friend. Well we all most certainly became friends with Ted that afternoon! Chloe, who suffers from Ehlers-Danlos syndrome, brought her assistance dog to the Conference. She spoke about the difference he has made to her life by helping her to carry out everyday tasks, such as dressing and fetching. Chloe also told us how he's her best friend. brought her assistance dog to the Conference to talk about the difference he has made to her life, to help her carry out everyday tasks, but more importantly as her best friend. Whilst no one could help being smitten with Ted's puppy-dog eyes, it was Chloe who stole the show with her honest and inspirational presentation: her journey touched all our hearts, leaving us inspired by her confidence and strength.

## A researcher's view

Another Gathering newbie was Rosalin Adamson. She's part of the FOP research team at the University of Oxford. In her lovely blog post about her experience of the event, she closes by saying:

"I was moved, touched, inspired and motivated by the people I met at this conference. I felt I had to rush back to the lab and work harder and faster to find something, anything that will help FOP patients. Suddenly, everything feels a lot more personal now."

Thank you Rosalin.

## Making it all possible

A big thank you to our sponsors who supported our event. We would also like to thank our busy friends who volunteered their time: Nicola Toop (Clinical Host); John Morley (Quizmaster); and Louisa Brenner, Gillian Hodgson, Nicky Houghton, Janet Plumb, Natasha Waddington and Deb West (Tireless Creche Troupers).

clementia

BIG LOTTERY FUND
NATIONAL LOTTERY FUNDED

REGENERON
science to medicine®

**The Zochonis**
**Charitable Trust**

# SUMMER SUCCESSES...

**Our friends who are living with FOP are constantly giving us reason to be proud of them, but we've had even more reasons this summer...**

## Exam results

**We've had a number of our FOPers passing important exams this year. Dylan, Iona and Jess all passed their GCSEs. And Rohan succeeded in his A-levels. Well done all of you! We know it hasn't been easy.**

"Jess passed all her GCSE exams at Springwest Academy Feltham this year. She got an A* distinction in English and a B or a C in all other subjects including Photography, Maths and Science. It was a lot of hard work, and she had to catch up with her work and revision in her spare time as she had to take time off because she had lots of flare-ups.

Jess was determined to do well. She's staying on for 6th form at Logic Studio School doing Media Studies (photography) and Business Studies.

I'm so proud of her and glad all that hard work paid off. The smile on Jessica's face was priceless. To see her succeed despite FOP is fantastic!"
*Laura, Jess' mum*

## Well done Luchie!

**Last year, Luchie talked with us about her excitement at starting an internship with a recruitment company. Just eighteen months later, and she has some more good news to share...**

"I started a Business Administration NVQ Level 3 Diploma at Workforce People Solutions Ltd in March 2017. From the very first day I stepped into Workforce for my interview, I felt a warm and friendly welcome. Simon (CEO) and Rebecca (Director) ensured that I felt comfortable and that any adjustments were made prior to me starting. This included starting 1 hour later and having a Wednesday off to ensure that I wasn't over-exerting myself.

On completing my apprenticeship in August this year, I was promoted to Business Development Executive. I was over the moon with the progress that I'd made... [ ]. I just would like to say a HUGE thank you to my supportive colleagues, senior management, and my line manager Phil."

*"From the moment Luciana arrived at Workforce, I saw how people warmed to her and how obvious it was to anyone who worked with her that she was not going to let her condition define her. She has worked really hard over the past 18 months to learn new skills, taking on some very demanding challenges along the way, which culminated this summer in her earning a promotion to Business Development Executive... [ ]*

*Aside from her core job role, Luciana is also one of the first to suggest new ideas that can take Workforce forward, having won awards this year for her ideas, which we hope one day could change the way we all work.*

*Lastly, I have to mention her passion for baking! We hold regular "Workforce Bake Off" events, which are always very competitive, with colleagues looking to deliver the perfect entry. Luciana has now beaten the competition so many times that she has had to semi-retire and become a judge, so the rest of the bakers can have a chance of winning!"*

**Simon Hayton** – CEO Workforce People Solutions Limited

*Read the full story on the FOP Friends blog*

# Ways you can help this winter

**You don't have to organise a big event or run a marathon to support FOP research. Here are a few low-effort, high-impact ideas to help us get closer to the cure we all desperately need.**

## Send FOP-friendly cards

This year you can either use www.dontsendmeacard.com to send e-cards or get your hands on some of our old-school Christmas cards to raise awareness of FOP and help fund Oxford University's research team. Cards cost just £2 per pack of 10.

If you'd like to buy a pack or two, or you think you would be able to sell some to family and friends, email info@fopfriends.com.

## Keep your head warm

Your ears will definitely be toasty this winter in one of our new woolly hats. Harry can testify to that!

A great stocking filler, or one to keep your head warm while you train for next year's Great North Run.

Emailing info@fopfriends.com with the numbers and sizes you need.

## Let the big companies donate on your behalf

Did you know that your next tedious insurance renewal or bagging a bargain on eBay can help us?

If you do one thing to help FOP research before Christmas, let it be signing up to easyfundraising.co.uk. And there's an app for it now too, on iPhone or Android.

Even your insurance renewal or your second-hand shopping counts, with most major insurers and eBay listed among the 3,300+ companies that donate every time you buy from them through easyfundraising.co.uk

It really is easy! Go to www.easyfundraising.co.uk now, or download the app.

P.S. If you've already signed up but keep forgetting to use it, here's a simple trick. The easyfundraising Donation Reminder will alert you whenever an online purchase could trigger a donation. Follow a few simple steps to install it on your PC or laptop and get helpful reminders: www.easyfundraising.org.uk/raise-more/donation-reminder. The great thing is, you won't be making the donation – the company you're buying from will!

## Our new leaflet

**We now have a new leaflet to explain FOP and to raise awareness of the charity. If you would like some leaflets for an event, please drop up an email info@fopfriends.com and we'll happily send some out 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

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

Registered with FUNDRAISING REGULATOR

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

Designed by Helen Joubert Design