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

friends® Together

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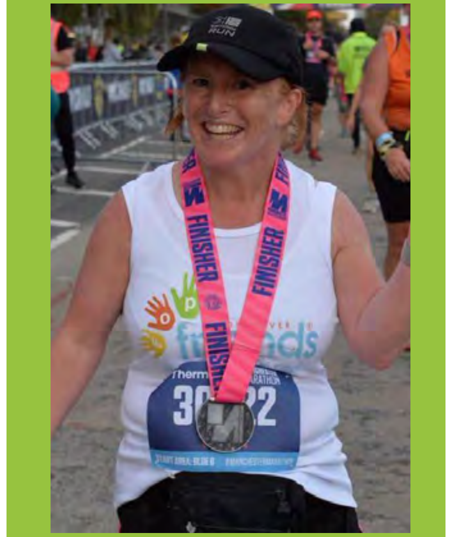
Inside

Our Gathering is Back!

We're back! We can't wait to welcome our family and friends from near and far to Manchester for our 4th Conference and Family Gathering. These have been a challenging couple of years and have made us realise all the more how important our friends and family are. This will be the ideal opportunity for us all to reconnect with old friends and make new friends too.

We are delighted to be hosting FOP specialists from the UK as well as around the world. We are also excited to be screening the UK premiere of the Tin Soldiers film. To read the full programme and see the list of speakers and events, visit: **https://fopfriends.com/conference-and-family-gathering-2022/**

A word from Fiona



Well, the time has finally arrived! Our Conference and Family Gathering 2022 can at last take place and we could not be more excited. After two difficult years which saw our 2020 conference and family gathering cancelled, for it to be taking place again is very special to us as a charity. We are so thrilled that families are able to meet once again, bringing our FOP community together in exciting times for trails and new developments. With doctors, dentists and pharmaceutical companies attending, it promises to be a conference of renewed hope for the future. To welcome the children, or as many are now, young adults, is going to be extra special as we get to be reminded of their resilience and determination to live life to the fullest. Over the past two years, many of the children have been through some very challenging times but again shown their ability to adapt and continue to smile with the biggest of smiles. Our 'FriendZone' promises to be full of mischief, fun and laughter as the children rekindle their friendships of previous years. To be able to run this conference and family gathering in 2022, as FOP Friends celebrates its 10th anniversary, is amazing and a dream come true. What a journey it has been but a one which is definitely not finished!

Fiona, FOP Friends Trustee

Behind the Scenes

Well, the first quarter of 2022 has continued with the same pace as 2021 closed with! The workload and plate-spinning has been heading into "running off-the-chart" territory for the last few months. But we see that as a positive challenge to be embraced…

As we reported, we concluded 2021 with our day in UK parliament where FOP as a condition, along with the urgent need for research, was given a platform and we, as a charity, were given a voice. Early in 2022, Chris then had a follow-up meeting with a minister at the DHSC to discuss the rare disease framework, support for FOP research, diagnosis and FOP awareness. This is going to be a long journey, and things will never move with the speed we most desperately need, but we can already see many positives to come out of this. We will continue to keep you updated with all the progress.

As the world starts to return to some sort of new 'normal', so has the engagement of the pharmaceutical companies who are all striving to find treatments for FOP. All these require meetings and Zoom calls, all with positive outcomes but again, things always take much longer than our families would like.

Chris also spent three days participating in the IFOPA's Virtual Annual Board meeting, fulfilling his role as a board member and also as the chair of the IPC. These meetings were made all the sweeter thanks to the delicious bag of goodies which were shipped out to all the members, along with some thoughtful gifts too!

We have continued to build our network, collaborating with the excellent organisations out there supporting rare disease communities. We have recently become Partners with Rare Revolution as well as Genetic Alliance UK, to name but two. We are also sharing our experiences of setting up a patient organisation from scratch, through our connections at Beacon, to support other groups who are in the early days of their organisational journey.

Juggling these meetings and conversations require finely tuned scheduling as we work them around 'day job' commitments and, of course, family life – including our own journey as parents of a child with FOP.

We were honoured to be invited to participate in a webinar organised by the Glasgow Office for Rare Conditions, which allowed us to raise awareness of FOP with paediatric specialists. We have a number of other presentations with medical audiences scheduled over the next few months, including GOSH, which give us an opportunity to further raise awareness. If we can prevent even just one misdiagnosis, then it will have been worth it.

We continue to support families in a variety of ways, including advising how to manage Covid in patients with FOP, as well as advocacy and a listening ear.

Perhaps the biggest challenge at the moment is pulling together all the pieces of the jigsaw for our conference, so that it will be the fantastic source of support, information and friendship our families have come to expect. We hope to see you there!

FUND RESEARCH, FIND A CURE, SUPPORT FAMILIES ... WORLDWIDE

Oxford Update

We were delighted to receive a letter from Professor Gain Screaton at the University of Oxford, thanking us for our donation to the university for their FOP research team. We would also like to take this opportunity to thank our friends at FOP France who also generously contributed to the grant of £130,000. Dr Eleanor Williams put together an update on the work which is being carried out at the university.

We invited members of our community to put some questions to Professor Alex Bullock, who leads the FOP research team. To read the full Q&As, along with Dr Williams' report, visit: www.fopfriends.com/oxford

Here are just a few of the questions we asked…

HEAD OF THE MEDICAL SCIENCES DIVISION

Professor Gavin Screaton

Medical Sciences Divisional Office, Level 3,
John Radcliffe Hospital, Headley Way,
Headington, Oxford OX3 9DU

Mr Chris Bedford-Gay
FOP Friends

21 March 2022

Dear Mr Bedford-Gay

Thank you so much for FOP Friends' most recent gift of £130,000 to the FOP Research Fund at the University of Oxford, which is very much appreciated.

As you will have read in their recent report to you, Professor Alex Bullock and his team are carrying out some exciting work alongside their global collaborators. They are focussing in particular on diagnosis and treatment, with further research aiming to develop new drug treatment strategies by developing a better understanding of how certain gene variants cause FOP. The Friends' kind gift directly supports this important work.

We are all so grateful for the Friends' dedicated and continued support for this vital area of research, and would like to thank you once again for your philanthropy.

Yours sincerely

Professor Gavin Screaton
Head of the Medical Sciences Division

What collaborations do you have around the world?

The FOP research community is a small and close-knit group that meets regularly enabling collaborations across the globe. Along with teams around the UK, we collaborate with teams in seven countries around the world.

What is your current research focus and what does that mean for us?

Our work can be described around the three areas below:

- Diagnosis: assisting clinical geneticists
- Treatment: the STOPFOP clinical trial
- Research: Understanding of how ACVR1 gene variants cause FOP and using this knowledge to help develop additional drug treatment strategies for FOP

What are your significant goals for the next few years?

Over the next year we would like to

i. show that the wrench idea for ACVR1 inhibition is tractable for further chemistry; and

ii. define the wider set of proteins that help to regulate the ACVR1 ON/OFF switch (i.e. they may act to further lock it, or make it easier to activate).

Over the next 3 years we aim to

i. complete the STOPFOP clinical trial; and

ii. have a 3D structure for the active ON state of ACVR1 to learn more about its mechanism.

How is the fund-raised money from FOP Friends with FOP France being spent?

All the monies generously donated to FOP research at the University of Oxford are spent on research. About 80% of the money is spent on personnel while 20% is spent on the raw materials needed to perform experiments (antibodies, chemicals, plasticware, DNA and protein purification kits, nutrients for growing cells etc). Perhaps 1% is spent on attendance at scientific conferences where research results are reported to other scientists and clinicians.

To read the full interview, visit:
www.fopfriends.com/oxford

RARE DISEASE DAY®

Rare Disease Awareness Month

February was Rare Disease Awareness Month.

In the UK, a rare disease is defined as affecting fewer than 1 in 2000. There may only be 70 people in the UK with FOP, but with all the rare diseases combined, there are 3 million people living with a rare disease in the UK.

There are estimated to be around 300 million people worldwide living with a rare disease. In February we stood with our Rare friends to raise awareness of the challenges we all face.

Oliver and his family went to Trafford Town Hall to watch it be lit up in blue, as part of a global chain of lights. All around the world, significant buildings such as the Leaning Tower of Pisa, the Colosseum, and the Eiffel Tower, were lit up to show their support. Most excitingly, Rare Disease Day has now been put in the calendar in Trafford, with the Town Hall being lit every year going forward. A big thank you to Cllr Cath Hynes, Deputy Leader of the Council and Executive Member for Children's Services and Cllr Amy Whyte for supporting the event.

Our friends with POH

Progressiva osseous heteroplasia, or POH, is a rare bone disease which affects around just 100 people worldwide. POH is caused by a mutation in the GNAS gene. POH causes extra bone to develop just below the skin in subcutaneous tissue, muscles, tendons and ligaments. Sometime the new bone can appear like grains of rice under the skills. It is often misdiagnosed, with patients having to endure painful and unnecessary treatments until the correct diagnosis is reached. Their awareness day is celebrated on 28th February to coincide with Rare Disease Day. We invited Christine Fennell, the President of the POHA Association, to share an update:

Busking Brilliance!

When Simon Sims heard Alanna's story, he immediately knew he wanted to help raise awareness of Alanna's condition as well as funds to support the research.

As a busker, he decided to do what he does best: sing! Originally from Kenya, he is in the UK to study for his discipleship training in Glasgow. He visited his friend in Somerset last year and fell in love with the area. He was visiting again this February and learned of Alanna's story so decided to use his gift of song to raise money on the streets of Bridgwater. Children from Alanna's school also came along on the Saturday afternoon to support Simon. His music brightened up a cold February day, with passers-by going mad for his music, sharing across their social media feeds. Friends from Alanna's school also came along to support Simon in his efforts. Alanna's mum, Steph, said, "I can't thank Simon enough for what he's done for my little girl and everyone living with FOP. He's such an incredibly talented man with a heart of gold. Thank you for a day we'll never forget!". An amazing £375 was donated by the generous people of Bridgwater, showing their appreciation for Simon's music.

You can follow Simon on Instagram. **@simon_sims!**

Hello from the POHA! We are so grateful to work alongside the FOP and our mutual efforts to find a cure for POH and FOP alike.

We have grown somewhat in patient numbers with 130 diagnosed patients. We have about 50 active members within the US, South Africa, England, and Ireland.

COVID offered us an opportunity to connect easier and more frequently. We held a zoom Patient Symposium in January of 2021 and added smaller more specified sessions in an attempt to meet the needs of our community.

The POHA held a POH and Child Development and POH and Family Planning sessions which offered our families a chance to connect and share our concerns throughout COVID. Next, we plan to offer a session on POH and Mental Wellness. We may not have had these opportunities had zoom not become part of our everyday life.

Currently the POHA and The Rice Foundation are working on a four phased five-year plan. We are currently committed through stage two and working towards stage three.

The plan was created by parent and board member Michael Rice. The plan includes funding for RNA Sequencing, 1 full time post doc, 1 full time experienced post doc, 50% of mouse model research and more specific goals as well.

In closing, the POHA is committed to work and fundraise for a cure for POH and work with the IFOPA, FOP Friends and other patient organisations around the world in order for all of us to see a cure for our families!

POHA

To learn more about POH or the work of the POHA, visit **http://www.pohdisease.org/** or follow them on social media.

Lexi's Golf Day

A gorgeous spring day provided the perfect backdrop for a gala golf day in aid of Lexi. Lexi's dad Dave, along with family and friends organised the day-long golf event at the stunning The Grove Hotel and Spa in Hertfordshire. Eighty-eight golfers were welcomed bright and early with breakfast before a shot-gun start.

Along with a traditional round of golf, there were a number of challenges throughout the day including two 'closest to the pin' competitions and one 'longest drive' where players had the opportunity to 'out drive' Tiger Woods (which, we're told, no-one did!)

The day was topped off with a three-course evening dinner, raffle and auction to raise funds for FOP Friends of Lexi as well as further awareness of FOP. It was Andrew Pepperal who reigned supreme and took home the trophy after the day's event.

However, the true winners are those affected by FOP, with the event raising an amazing £6,225, at what will now become an annual event. A big thank you to everyone who made the event such a success!

Cake Sale at School.

A big thank you to the pupils, parents, PTA and staff at Wembdon St. George School in Bridgwater who held a cake sale which raised £230 for Friends of Alanna.

Unfortunately, Alanna wasn't able to attend as she had Covid (which we're delighted to say she has since recovered from) . A Guess the Bear's Name competition also added to the fun – the bear was won by a pupil in Year 5, who decided he wanted to gift the bear to Alanna! What a wonderful gesture!

Thank you Barratt Homes

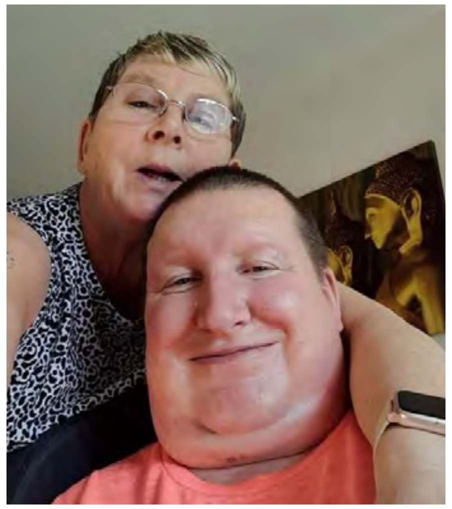
We were delighted to receive a generous donation of £1000 from the Barratt Homes Community fund to support our work helping families in the Hertfordshire and surrounding areas. Sian Tyler, a close friend of Lexi, nominated us as a charity, and we were delighted to have been selected for the award.

Ever thought about Assisted Technology?

We all take technology for granted these days, but how much of the technology we use is necessary and how much is simply entertaining?

For people living with FOP and other disabling conditions, technology is literally a lifeline. Paul Coleman, who lives with FOP, has shared his thoughts on how improvements in technology and have changed his life for the better.

> Technology is very much a part of everyone's daily life, each and every one of us uses technology at some point during the day. Some people can be frightened and apprehensive about using more advanced technology, but it can have very practical uses especially for people diagnosed with FOP. Due to the sometimes very restrictive nature of the condition, assisted technology can have many practical uses to help a person diagnosed with FOP. to maintain some independence. Simple tasks like turning lights on, operating the heating, opening and closing doors, windows, curtains can be extremely difficult - if not impossible - for patients. Depending on how far you want to take it, assisted technology can open new worlds of opportunity for a person with FOP. Of course, everyone wants to know the ultimate answer to 'how much does all this cost?'. There is no short answer to that, as it depends just how far you wish to go. Your first stop should be your occupational therapist, if you don't have one contact your areas duty occupational therapist.



What kind of options do you have?

A popular voice-controlled system is Alexa, to this kind of system you can add:

Lights - these can be lamps operated through the purchase of an Alexa-compatible plug or Alexa-compatible light bulb.

Heaters or heating system - here you have several options:

- A normal electric heater connected to an Alexa plug
- An Alexa-compatible heater
- An Alexa-compatible heating thermostat such as Hive

Operate the TV by voice - compatible smart TVs only.

Alexa can also take notes, set reminders, play music.

For further range of products available please see **https://www.amazon.co.uk.**

Possum controls also offer some good assisted-technology products. More details can be found on their website **https://www.possum.co.uk/.**

Another popular assisted technology company can be found here **https://www.steepergroup.com/assistive-technology/**

Further information regarding assisted technology can be found on the following websites: **https://www.bataonline.org.uk/** and **https://www.gov.uk/government/publications/assistive-technology-definition-and-safe-use/assistive-technology-definition-and-safe-use**

While upgrading your home to a tech-enabled home can be costly, there are grants available to help with the costs. The IFOPA offer a L.I.F.E Award up to the value of $1800 for every person with FOP, so it may be worth enquiring with them to see if your purchase is eligible for grant support. Visit: https://fopfriends.com/grants-for-families/ for further information.

The IFOPA Ability Toolbox is also another fabulous resource to offer suggestions for ways to add technology into your home that will aid your independence. Visit: https://guidebook.ifopa.org/ to check it out!

If you are living with FOP and would like to share your story or experiences, please get in touch. We'd love to hear from you.

April is Global FOP Awareness Month

Available in Kids', Women's and Men's

Hope. Believe. Wish.
2022 GLOBAL FOP AWARENESS DAY

It's not too late to order your Global Awareness Day tees! Show your support with your friends around the world with this year's tee. Visit: **www.fopfriends.com/shop** and order yours for delivery before 23rd April.

What will your feet wear?

We will be holding our **#FunFeet4FOP** campaign again this year... what will your feet wear?

Our annual awareness day event is back for its 6th year! It's wonderful to see our friends around the world join in with photos of their fabulous feet! Why not organise an event at work or school to raise awareness of FOP… remember to share your photos on social media with **#FunFeet4FOP**!

enthuse

Enthuse is our new fundraising platform

We have now launched our new fundraising platform for our supporters. Visit fopfriends.enthuse.com to set up your fundraising page! You can make a direct donation, set up a fundraising page, or create a team. You can also upload your story as well as provide updates about your progress. A big thank you to our supporters who have already taken it out for a spin!

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

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How can you help?

Organise a fundraiser. For fundraising ideas visit: **www.fopfriends.com/funfeet4fop** and download our fundraising pack