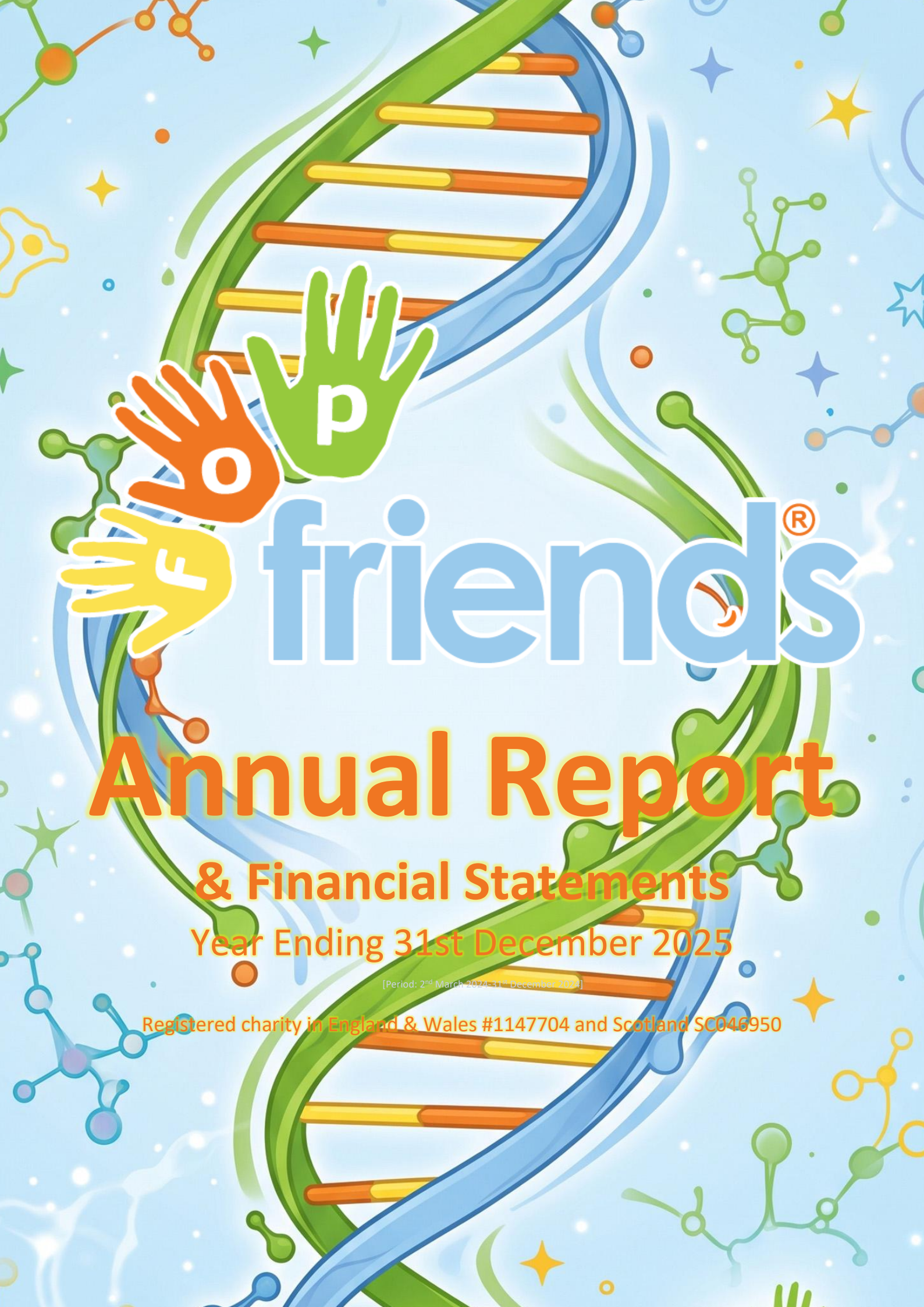


Annual Report

& Financial Statements

Year Ending 31st December 2025

[Period: 2nd March 2024-31st December 2024]

Registered charity in England & Wales #1147704 and Scotland SC046950

Our Vision

One day, no one will suffer the full effects of Fibrodysplasia Ossificans Progressiva (FOP) and related conditions.

Our Mission

Promote programmes of research, advocacy, education, support, and awareness to discover treatments and a cure for Fibrodysplasia Ossificans Progressiva (FOP) and improve the lives of all it affects.

Our Values

- We are committed to funding medical research to realise a cure for FOP and related conditions; to understand how we can prevent it and improve the life and well-being of those who are afflicted by it.
- We respect the integrity, ambition, and interests of all FOP Patients.
- We strive to be both a haven and champion for FOP patients and their families, a centre of excellence for the provision of information on medical research, diagnosis, treatment and care, and participation in clinical trials.
- We shall act always with honesty, professionalism, and ethical awareness.
- We shall work collaboratively with medical researchers and clinicians, patients and families, our donors, and supporters to realise our Vision and complete our Mission.

Charity name

FOP Friends

Working Names

FOP Friends of Oliver, FOP Action

Registered address

The Cabin, 1 Cumberland Road, Sale, Cheshire, M33 3FR, United Kingdom

Registered

March 2012

Charity number

1147704

Governed by

Trust Deed

Founding Trustees

Alison Acosta Bedford

(founding trustee)

Christopher Bedford-Gay

(founding trustee)

Rachel Bedford

(founding trustee)

Trustees

Fiona White

John Lever

Helen Bedford-Gay

Nicky Williams

Andrew Rankin

Independent auditor

P.S. Hutchinson BSc FCA, 246 Park View, Whitley Bay, Tyne, and Wear, NE26 3QX

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What is Fibrodysplasia Ossificans Progressiva (FOP)?



Fibrodysplasia Ossificans Progressiva (FOP) turns otherwise healthy people into human statues: a healthy mind locked inside a frozen body. FOP is one of the rarest and most disabling genetic conditions known to medicine, causing bone to form in muscles, tendons, ligaments, and other connective tissues.

Bridges of extra bone develop across the joints, progressively restricting movement, forming a second skeleton that imprisons the body in bone. There are no other known examples in medicine where one normal organ system turns into another.

Most cases of FOP are new, meaning no-one else in the family has FOP. This happens because unexpected changes (mutations) occur as the genes are passed along from each parent. Many of these changes, such as the mutation that leads to FOP, are accidents of nature that happen for no apparent reason.

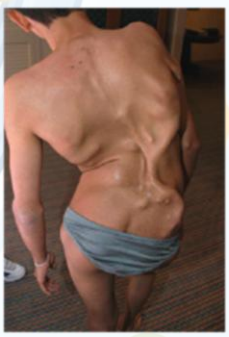


Children with FOP appear normal at birth except for congenital malformation of the great toes. During the first or second decade of life, painful swellings that look like tumours develop over the neck, back and shoulders and mature into bone.

FOP progresses along the trunk and limbs of the body, replacing healthy muscles with bone. These bridges of bone significantly restrict movement and any attempts to remove them result in explosive new bone formation because trauma, like surgery, knocks and bumps, accelerates the FOP process. FOP is extremely variable and unpredictable. In some, progression is rapid, while in others it is gradual. Fibrodysplasia Ossificans Progressiva (FOP) causes progressive debilitation eventually leading to early death.







Introduction and Chair's Statement

As I sit and review the incredible milestones we've achieved over the past twelve months, I find myself looking back at the path that led us here. It is hard to believe how much the landscape of FOP has transformed since our journey first began. The journey began with the words "fibrodysplasia ossificans progressiva" written on a piece of paper when we found ourselves facing one of the most disabling conditions known to medicine, with no treatment, no cure, and almost nowhere to turn.

Driven by a need to do something we set up "Friends of Oliver." We simply wanted to keep our family and friends updated on Oliver's progress and raise a little money for research. But as time went on, we realised we weren't just fighting for Oliver; we were fighting for a whole community that needed a voice, a support network, and a shared sense of hope.

In March 2012, we evolved into FOP Friends. Becoming a registered UK charity dedicated to bringing families together, raising medical awareness, and funding world-class research. Looking at 2025, the dream of an effective treatment feels much closer.

The research we helped fund has left the lab and has taken us to the point of having safe, effective treatments for the management of FOP. Our continued support of dedicated research, including our brilliant partners at the University of Oxford, ensures that the UK remains at the absolute forefront of the fight against this condition.

Beyond the science, 2025 has been a testament to the strength of our community. Seeing families connect, share advice, and lift each other up reminds me exactly why this charity was formed.

None of this progress would be possible without our tireless fundraisers, our clinicians, researchers, and my fellow trustees who give their time and expertise so generously. And most importantly, to the families living with FOP: your resilience, courage, and spirit are the very heartbeat of this charity.

We are closer than ever to our goal of changing the future for everyone touched by FOP. Thank you for continuing to stand by our side.



Chris Bedford-Gay, Founder and Chairman of FOP Friends.

About us / Who we are

FOP Friends' aim is to further research into Fibrodysplasia Ossificans Progressiva (FOP) and related conditions by supporting current and future research projects.

FOP research has far-reaching implications for those with FOP but also those with common bone disorders such as fractures, osteoporosis, osteoarthritis, and other forms of heterotopic ossification that occur through trauma such as military and sports injuries, paraplegia, and post-hip surgery complications. More recently, research has shown that a rare form of childhood brain cancer, DIPG, could benefit from FOP research and vice versa.

FOP Friends aims to raise public awareness of FOP by holding and promoting charitable events and encouraging the news media to report upon FOP and related conditions. This will serve to educate the public to the existence of FOP and of research projects that will benefit not only FOP sufferers but also those with disorders that are more common.

FOP Friends was founded following the diagnosis of Oliver Bedford-Gay (17) with FOP at the age of 1. The aim of the charity is to support the search for a cure while raising awareness and educating the public and medical world of the condition. FOP Friends supports existing patient organisations; existing research programmes such as at the University of Oxford; promotes FOP research worldwide; and helps other families impacted by FOP.

Each year the trustees vote on research or other projects to support with monies raised. To date, this has been targeted at maintaining (and growing) the University of Oxford's FOP Research Team.

FOP Friends continues to support the search for a cure that will not only benefit those with FOP but many other related conditions.

Trustees

There must be at least three trustees. Except for the founding trustees, trustees are appointed for a term of two years by a resolution of the trustees passed at a special meeting called under clause 15 of the Trust Deed. Selection of new trustees must have regard to the skills, knowledge and experience needed for the effective operation of the charity.

Christopher Bedford-Gay - Founding Trustee and Chairman



Chris has been involved with the FOP community since his son Oliver's diagnosis in 2009. He was one of the founding trustees of FOP Friends, after learning that there was no UK charity to support families with FOP. Chris has served on the Board of the IFOPA for eleven years and is now stepping down. He will continue to be involved in the wider FOP community as he continues to serve as Chairman of the IFOPA International Presidents' Council. The IPC brings together FOP organisations and leaders from across the world. Chris is a published author on several FOP papers and was instrumental to the success of the world-wide FOP Flare-up study.

He has been an active member of the Manchester Round Table for many years and helped them to raise thousands of pounds for local good causes. Now too senior for the Round Table, he has helped to set up a new 41 Club – for the ex-Tabler!

Chris is the Chief Technical Officer for his company Skillsarena, a UK-based technology company.

Chris is married to Helen, and they have three children Oliver, Leo, and Harry. In his spare time, Chris enjoys going to the gym, playing badminton, and swimming. He has most recently decided to follow his younger sons' hobby – lacrosse. Chris also enjoys his annual road-trips around America as it gives him chance to take some time out from the busyness of his life.

Education

- 1st Class BSc Honours Degree, Computing for Business.

Experience

- Software engineer and consultant at GlaxoSmithKline.
- Software engineer at Defence Evaluation Research Agency.
- Technical Director at Turtlez Ltd (10 years).
- Chief Technology Officer and Director at Skillsarena Ltd (current).

Alison Acosta Bedford - Founding Trustee



As a founding trustee, Alison has been an integral part of the FOP Friends journey since its inception. Leveraging her expertise as a Chartered Management Accountant, she manages the financial accounts of the charity and tackles diverse administrative tasks and actively contributes to fundraising initiatives. In her role as the Chair of trustee meetings, Alison employs her professional skills to oversee the day-to-day staffing and operations of the charity.

Alison takes immense pride in the remarkable growth of FOP Friends and the biennial family symposiums held in May, showcasing the pivotal role the organisation now plays in the FOP community.

Education

- BSc Honours Degree, Mathematics, University of Sheffield.
- CGMA Chartered Institute of Management Accountants.

Experience

- Finance Business Partner UK Biobank, a large-scale biomedical database and research resource.
- Over 16 years of finance experience in social housing.
- Demonstrated expertise in long-term financial planning as the Treasury and Investment Manager of a housing association with an annual turnover exceeding £60m.

Rachel Bedford – Founding Trustee



Rachel is Head of Events and Sponsorship for the Association of Colleges. With over 18 years of expertise in the world of events, she oversees educational conferences with a passion for making a positive impact. Rachel uses this experience to help to coordinate the FOP Friends conference and other events.

Her connection with FOP Friends resulted in Rachel embracing a new challenge – her first-ever fun run. The Great North Run half marathon became a canvas for her determination, as she crossed the finish line in under 2 hours and 30 minutes, all in support of FOP Friends. But Rachel didn't stop there. Her marathon journey unfolded in her hometown of Manchester, with the cheers of her nephew Oliver echoing in the background.

In Rachel's world, events are not just gatherings; they are platforms for change. As she continues to lace up her running shoes and organise impactful conferences, Rachel embodies the spirit of using one's skills and passion to create a meaningful difference in the world.

Education

- BSc Honours Degree, German and Law, University of Surrey.

Experience

- International trade shows.
- International economic research charity dissemination conferences.
- Director of Events (current) – leading a team to deliver 40 education conferences per year with direct responsibility for a £2.5m annual turnover.

Fiona White - Trustee



Fiona is a KS2 primary school teacher. She has worked as a lead practitioner and member of the senior leadership team, having gained the National Professional Qualification in Senior Leadership (NPQSL). As a close friend of the Bedford-Gay family for many years, Fiona was devastated to learn about their son Oliver's condition. She has grown to understand just how important it is to raise awareness of FOP and ensure much needed funds are raised in order continue the search for a cure. Over the years of support, Fiona has taken happiness from watching the children with FOP, grow into amazing young people.

Fiona is dedicated to using her professional skills to support FOP Friends' vision. The growth of the charity and its ability to support the FOP community makes her more determined to be part of the progress towards finding a cure.

Education

- BEd. (Hons.) Degree in primary education.
- National Professional Qualification in Senior Leadership.

Experience

- Classroom teacher across Key Stages 1 and 2.
- Advanced Skills Teacher - supported schools with curriculum development, and teaching and learning.
- Primary School ICT Manager, Computing lead, and Science lead.
- Lectured at Newcastle University – OFSTED.
- Lectured at Leeds University - Teaching Students.

Helen Bedford- Gay, BEM – Trustee



Helen is the Director of Operations, running the charity's office on a day-to-day basis. She manages the fundraisers who hold events for FOP Friends, ensuring that people who support and donate to the charity know that their contributions are valued and making a difference. Helen develops and maintains the website, runs the social media accounts, writes the newsletters, delivers projects, and is responsible for all the promotional materials for the charity.

Drawing from her background as an experienced teacher, Helen extends a compassionate hand to families in need. Acting as the first line of support, she offers a network of understanding friends and practical guidance for parents navigating the challenging road ahead.

Helen oversees any projects which need to be fulfilled because of successful grant applications and to deliver the missions of the charity. The well-received school guide, 'Supporting a child with FOP,' is a testament to her commitment to empowering parents and teachers alike. Collaborating on an international scale, she's working with FOP Brazil and Dr Patricia Delai to update and translate the guide for families in Brazil. A third edition for families living with FOP in China, is underway.

In 2022, Helen was elected to the Board of the IFOPA, a testament to her impact. Her pride in this work goes hand in hand with genuine care for the families she supports. Her efforts were not only recognised but celebrated, as she received a British Empire Medal in the Queen's Jubilee Honours list for services to charity and the FOP community in June 2022.

Education

- BA (Ed.) QTS Hons. From the University of Durham

Experience

- Classroom teacher across Key Stages 1 and 2, with experience of KS1 leadership.
- Fulbright Exchange Teacher to USA.
- Teacher at Manchester Hospital School 2020 – 2022.

Helen is married to Chris, and they have three children, Oliver, Leo, and Harry.

Dr Andrew Rankin, PhD DipPharmMed - Trustee



During his professional life, Andrew spent more than 20 years developing orphan drugs, including leading teams to global approval of four novel medicines for rare diseases; most latterly he was overall head for the clinical development of a new therapy for people living with Fibrodysplasia Ossificans Progressiva (FOP). During his career, he had close interactions with patient advocacy groups, charities and government organisations which were key in fighting for the rights of patients and facilitating development of new therapies, including FOP patient groups around the world.

His is also involved with the KAT6 Foundation, another ultra-rare genetic condition charity. His commitment to the KAT6 Foundation stems from a deeply personal connection to a young child with this devastating, condition.

Since retiring and relocating back to the UK, he has become a Trustee of FOP Friends to continue his commitment to the FOP community, formed during his professional career. Andrew also represents FOP Friends on the NHS Rare Disease Collaborative Network Steering Committee for Adult Rare Bone Diseases, as a patient group representative.

He continues to be inspired and humbled by working with the rare disease community and is delighted to be able to leverage his expertise, passion and experience, both professionally and personally, in support of the FOP community as a trustee of FOP Friends.

Education

- PhD DipPharmMed

Experience

- Andrew's professional experience in the pharmaceutical industry spans over 25 years, beginning in the UK, where he led drug discovery, experimental/translational medicine, and late-stage development programs. He has led the development of medicines from ‘first-in-human’ studies through all stages of clinical trials to global regulatory approval and making them available.
- Andrew has worked across numerous therapeutic areas, including Pain, Central Nervous System, Cardiovascular/Metabolism, Auto-Immune, Oncology, Biosimilars, and Rare Diseases.
- He has held global leadership positions with responsibilities for clinical and the overall development of new medicines. His roles included serving as the global development head for several rare disease programs including for Fibrodysplasia Ossificans Progressiva (FOP).

- Andrew has led five new medicines to regulatory approval, with three of those being in the rare disease space.

Before his pharmaceutical career, he was a physiology professor in Canadian medical schools.

Departing Trustees

We were sad to say goodbye to trustees Nicky Williams (17th Jan 2025) and John Lever (14th July 2025) who chose to step down as a trustee of FOP Friends, but who continue to support the work of the charity with their time, volunteering, and fundraising efforts. We thank Nicky and John for all the hard work they put into FOP Friends during their time as trustees.





Meeting Charity Commission guidelines

In setting our objectives and planning our activities, the Trustees have considered the Charity Commission's general guidance on public benefit.

Our principal objects

The relief of distress and sickness for those affected by Fibrodysplasia Ossificans Progressiva (FOP) a tragic, degenerative, and debilitating condition and to improve the lives of sufferers and their families.

Public Benefit: Removing FOP as a disabling health condition will greatly improve the lives of those with FOP and related conditions through prevention of a degenerative, life shortening disease. Related conditions which may reap the rewards of FOP research, include fractures, osteoporosis, osteoarthritis, military and sports injuries, paraplegia, and post-hip surgery complications.

To raise public awareness and understanding of Fibrodysplasia Ossificans Progressiva (FOP) and to promote education and research into the study and cure of FOP and related conditions.

Public Benefit: Raising awareness will help to reduce misdiagnosis of the condition, which has been mistaken for cancer in the past (to the degree that some sufferers have undergone aggressive cancer treatments, and harmful surgeries, unnecessarily). It will also help to promote research into the condition, which will benefit FOP sufferers, but also other more common related conditions.

To support charities and organisations in the UK and abroad by undertaking charitable activities to fund research; and to provide help, support, care, and treatment for people affected by FOP and related conditions.

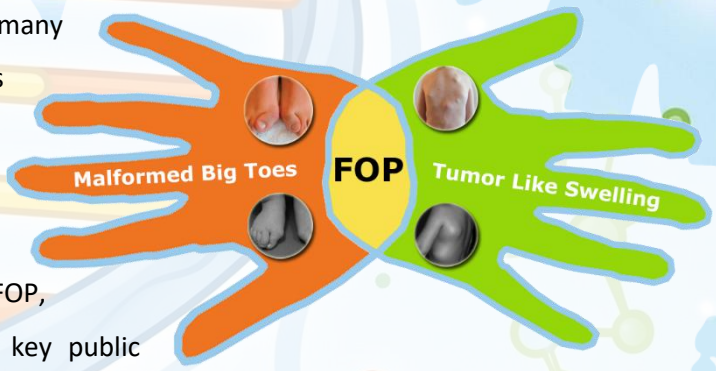
Public Benefit: Supporting other charities and organisations of this nature will benefit the public by providing care for those with FOP but also by furthering research that will lead to treatments and ultimately a cure for FOP, thus eliminating FOP as a health concern. FOP research projects will also benefit many people suffering with more common health conditions.

To support organisations researching treatments and a cure for FOP and related conditions.

Public Benefit: Research into a treatment, and eventually a cure, for FOP will benefit all existing suffers and all those in the future diagnosed with the condition. It will also benefit many more common related conditions, which affect a larger section of the public and the Armed Forces.

Preventing Misdiagnosis.

Public Benefit: The rarity of FOP has resulted in many cases of misdiagnosis. This has led to FOP patients receiving wrong information and interventions, resulting in a more rapid progression of the condition and unnecessary surgery and treatments. As children will continue to be born with FOP, preventing misdiagnosis is one of FOP Friends' key public benefits and achieved through our previously stated aims of awareness, education, and advocacy.



Research Highlights and Industry Updates

In 2025, the Fibrodysplasia Ossificans Progressiva (FOP) landscape experienced major developments across clinical trials, regulatory preparation, and academic research. Highlighs of the year were the completion of long-term clinical trials (such as STOPFOP), progression in novel targeted treatments from (Incyte, Regeneron, and Ashibio), and updates from industry trials (Ipsen), and continued research discoveries funded by FOP Friends in collaboration with the University of Oxford.

University of Oxford and StopFOP

The FOP Research Team

As we celebrate 13 years as a registered charity, FOP Friends and its supporters continue to successfully fund the FOP Research Team at the University of Oxford.

The Oxford research team, led by Prof. Alex Bullock, originally identified Saracatinib's specificity for the ALK2 mutant receptor, the breakthrough that triggered and enabled the StopFOP academic clinical trial. Throughout 2025, the University of Oxford continued driving preclinical research into ALK2/ACVR1 mechanisms, disease-modifying targets, and supporting translational study frameworks.

The team shared their research within the wider scientific community in the UK and internationally. Professor Alex Bullock gave the keynote talk entitled "Understanding and Treating Neomorphic Mechanisms in Fibrodysplasia Ossificans Progressiva" at the 2nd Oxford-International Chinese Musculoskeletal Research Society Forum in Oxford and lectured on "Fibrodysplasia Ossificans Progressiva (FOP)" as part of the University of Oxford MSc course in Musculoskeletal Sciences. Alex also attended the 14th International BMP Conference in Philadelphia, where he presented the talk "Understanding and Treating Neomorphic Mechanisms in FOP and Cancer".

In the past year, graduate students Will and Kyle have been exploring approaches from two rapidly advancing areas of modern drug discovery and applying them to FOP. Guided by structural biology, their projects aim to develop new ways of targeting the faulty FOP protein, ACVR1. Both presented talks on their doctoral studies on FOP at the Centre for Medicines Discovery DPhil Symposium in Oxford. In the summer they welcomed FOP Friend Jessica, the daughter of a long time FOP Friends supporter, into the lab to gain some work experience in the lab before she begins a career in science.

In July, Alex met with FOP Friends trustees to present recent research findings and discuss plans for the future. The team continue to share research updates through the FOP Friends website and newsletters, helping keep the community informed about the progress their support makes possible.

StopFOP

The Oxford FOP Research team, funded by FOP Friends, played a key role in identifying saracatinib as a potential treatment for FOP. This led to the European StopFOP clinical trial investigating saracatinib as a potential treatment for FOP. Throughout 2025, the Oxford team continued to work with the trials team who are now evaluating the findings.



Chris attended the StopFOP stakeholders meeting in October alongside Professor Alex Bullock. The StopFOP team also presented a poster at the American Society for Bone and Mineral Research Annual Meeting titled "StopFOP: A Phase II Clinical Trial Investigating Saracatinib for Fibrodysplasia Ossificans Progressiva."

The StopFOP trial, a Phase 2 clinical trial investigating the repurposed kinase inhibitor saracatinib reached its formal trial conclusion at the end of 2025. Conducted across sites in the Netherlands, and Germany in 17 adult participants, the study evaluated Saracatinib's ability to prevent new heterotopic ossification (HO) by blocking ALK2 kinase overactivity. The trial concluded at the end of 2025, and formal, peer-reviewed trial results are awaiting publication.

We now look forward to hearing the outcome of the trial soon and next steps.

University of Pennsylvania

Continued research

In 2025, the University of Pennsylvania (UPenn) continued to lead the world in studying FOP. Researchers focused on a specific "typo" in the patients' DNA. This typo essentially breaks the body's stop sign for bone growth. Because of this error, when the body tries to heal normal wear and tear, it gets confused and tells stem cells to build extra, unwanted bone instead of fixing the soft tissue.

A major focus of UPenn's work was figuring out exactly why muscles fail to heal properly in people with FOP. Scientists discovered that the genetic typo makes certain healing cells stick around way too long after a muscle is injured. This logjam of cells not only stops the muscle from repairing itself, but it also creates the perfect environment for that unwanted bone to start growing whenever the muscle is bumped, bruised, or swollen.

Medical education

On the medical care side, UPenn's doctors worked hard to educate other healthcare providers around the world to prevent accidental harm. Because FOP is so rare, doctors who aren't familiar with it might try to take a tissue sample (a biopsy) or give a standard muscle injection. Unfortunately, any physical trauma like a needle prick can accidentally trigger a massive, painful explosion of new bone growth. Backed by global support groups and charities, UPenn is working to ensure that both lab research and patient safety keep moving forward to eventually find a cure.

University of Massachusetts

FOP Gene Therapy

The FOP Gene Therapy research was part funded from the start, in collaboration with the IFOPA and other national FOP organisations since the team have continued to make progress on this “longer term” therapy for FOP.



In 2025 this work focused heavily on addressing the disease at its genetic roots. A major effort is being led by researchers at UMass Chan Medical School, specifically Dr. Jae-Hyuck Shim and Dr. Guangping Gao, who co-founded the startup AAVAA Therapeutics to translate their lab discoveries into clinical treatments.

Their approach uses an AAV (adeno-associated virus) gene therapy. Scientists use a harmless virus as a way to sneak new instructions directly into a patient's cells. The UMass/AAVAA therapy is unique because it carries a two-part payload:

1. A Genetic "Silencer": This acts like a molecular pair of scissors to turn off the mutated *ACVR1* gene that is misfiring and triggering the abnormal bone growth.

2. A Healthy Replacement: Simultaneously, it delivers a healthy copy of the gene so the cell can produce the normal protein it needs.

By targeting the exact soft-tissue cells responsible for the rogue bone formation, this combination approach has successfully prevented both trauma-induced and spontaneous extra bone growth in FOP mouse models and human patient-derived cells.

The continued development of this therapy by UMass Chan and AAVAA Therapeutics represents a monumental shift for the FOP community. Because this gene therapy treats the root cause rather than just the symptoms, it holds the potential to halt the disease's progression entirely, allowing children born with the mutation to retain their mobility and avoid life-altering surgeries.

The FOP community aims big when tacking FOP.

Industry

Alongside StopFOP academic trial there are a number of industry-sponsored clinical trials active in 2025, summarised in the table below.

Company	Drug name	Phase – Trial name	Status in 2025
Ashibio	Andecaliximab	Phase 2/3 - ANDECAL	Progressed Part 1 safety/efficacy phase (targeting MMP9).
Incyte	Zilurgisertib	Phase 2 - PROGRESS	Active trial enrolment and double-blind phase completion in 2025.
Ipsen	Fidrisertib	Phase 2 - FALKON	Concluded in Dec 2025 (did not meet primary endpoint).
Regeneron	Garetosmab	Phase 3 - OPTIMA / 2.0	Completed Phase 3 data preparation; submitted for FDA/EMA approvals.

Āshibio

In 2025, Āshibio reached a significant milestone in its efforts to treat Fibrodysplasia Ossificans Progressiva (FOP) through the clinical advancement of its lead therapeutic candidate, Andecaliximab.

On January 23, 2025, Āshibio announced the dosing of the first patient in the ANDECAL trial. This Phase 2/3 clinical study evaluates the safety and efficacy of andecaliximab in patients living with FOP. Andecaliximab is a humanized monoclonal antibody designed to inhibit matrix metalloproteinase-9 (MMP-9).

The drug works by blocking a specific protein in the body that triggers this abnormal bone growth. Scientists got the idea for this treatment after discovering a unique person who had the FOP gene but never developed the disease because their body naturally lacked this exact protein, the “resilient patient.”

Because the treatment shows promise in stopping unwanted bone formation, Āshibio also expanded their research in 2025 to help a second group of people. They began testing the same drug on patients who experience abnormal bone growth following severe physical trauma, such as spinal cord injuries, to see if the same treatment can help them too.

Ipsen

In 2025, the pharmaceutical company Ipsen was conducting a mid-stage clinical study called the "FALKON" trial. The goal of this study was to test an experimental drug named fidrisertib on patients living with Fibrodysplasia Ossificans Progressiva (FOP), a rare and severe disease where bone abnormally grows in muscles, tendons, and ligaments.

In December 2025, Ipsen shared the results of the trial, revealing that the drug unfortunately failed to meet its main medical goals. Because fidrisertib did not show the expected benefits in stopping or slowing the abnormal bone growth for patients with FOP, the company made the decision to officially close the study.

Incyte

In 2025, Incyte Pharmaceuticals focused its efforts on advancing the clinical evaluation of its investigational daily pill, zilurgisertib, for the treatment of FOP. A major milestone was reached in June 2025, which served as the primary completion date for the initial double-blind testing phase of the global Phase 2 PROGRESS clinical trial. During this 24-week period, enrolled patients 12 years of age and older were randomly assigned to receive either a 100 mg daily dose of zilurgisertib or a placebo to carefully assess the drug's safety, tolerability, and effectiveness.

Following the completion of this primary 24-week evaluation phase in 2025, Incyte transitioned participating patients into a long-term, open-label extension period of the PROGRESS trial. This critical phase allowed participants who had initially been assigned to the placebo group to cross over and begin receiving the active zilurgisertib treatment. The extension was designed to track patients for an additional 292 weeks, enabling researchers to gather extensive, long-term data on the drug's ongoing safety and sustained effects for patients actively managing FOP.

Regeneron

Regeneron shared highly encouraging news from its late-stage clinical trial for garetosmab. During the Phase 3 trial, adult patients taking the drug saw a dramatic 90% or greater drop in the formation of new abnormal bone lesions over a 56-week period compared to those who received a placebo.

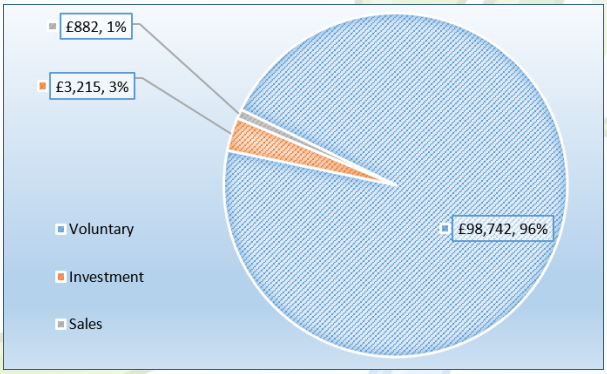
The trial's results were so successful that an independent safety monitoring committee stepped in and recommended that all patients in the study be switched to the active medication as soon as possible. The drug works by acting as an antibody that blocks a specific protein, Activin A, which Regeneron's scientists had previously discovered was responsible for triggering this unwanted bone growth in people with the disease.

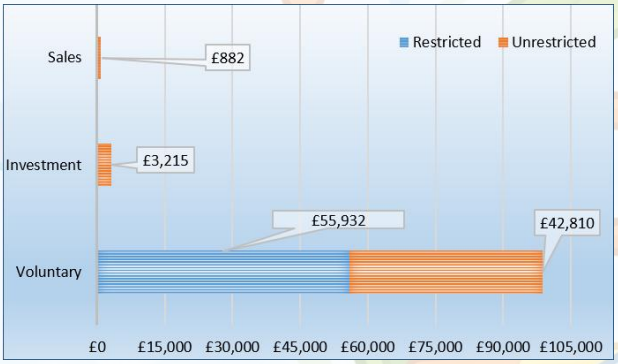
Regeneron focused the rest of 2025 on preparing its application to the U.S. Food and Drug Administration (FDA), with the goal of submitting it for approval by the end of the year. At the same time, the company laid the groundwork to expand its research by planning a new trial specifically for children.

How we raised our money

Voluntary income accounts for most of the money raised within our charity's financial year. Investment income increased in value as we took advantage of higher interest rates on longer term funds. Fundraising from dedicated events remained low.

This year there was further increase in voluntary income of 36% in voluntary income to £98,742 overall with a smaller increase in unrestricted funding, mostly from community fundraising efforts of 5% to a total of £42,810 with restricted funding seeing the larger jump from £23,075 to £55,932 an increase of 59% on the previous year.





We saw a decrease in revenue generated from sales to £882 from £3,112 the previous year. From a total £102,839 incoming resources, a 39% decrease on last year, £55,932 (54%) were restricted. The remaining £46,907 (36%) being unrestricted.

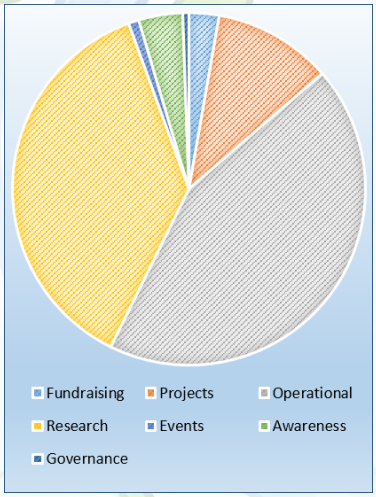
Within this charity year we were pleased to see a slight increase in funds raised through community efforts, although a small increase of 5% this has reversed the trend of ever decreasing unrestricted voluntary income experienced over a few years.

How we spent money raised

Since 2013, FOP Friends has operated with paid staff and volunteers. Staff and operational costs continue to be largely supported with restricted grants and donations in line with our charitable objects.

This means 94% of all fundraised money directly supports our charity objects of; family support; awareness; and funding research. This is a small % increase from previous years largely due to an increase in fundraising and stability in costs associated with fundraising, for example sponsorship platform fees. [Note: Voluntary Donations VS Fundraising Costs].

In this charity year, FOP Friends donated £40,000 to FOP research, a smaller sum than in previous years but which met the immediate funding needs of the University of Oxford FOP Research team with the trustees committing to provide further funding, likely to be needed in 2026.



We anticipate providing further funding to support other FOP research activities, most likely via the IFOPA 'In Pursuit of a Cure' work, but this is also likely to be in 2026.

Fundraising costs of £2,968 is attributed to the provision of fundraising materials and merchandise to support various fundraising activities.

Resources expended on the operation of the charity, which includes salaries, memberships and subscriptions, maintenance, and general expenses, all continue to be funded through grants and corporate sponsorship leaving 'fundraised' money designated to the charity objects.



Governance costs of £610 are attributable to the continued operation of the charity. Governance includes accounting fees, insurance, professional memberships, and costs associated with training and supporting trustees and staff.

Achievements

2025 was a big year for FOP and FOP Friends. With new treatments and clinical trials on the horizon, we focused significantly on supporting our amazing community, continuing our advocacy work, and funding of the incredible, world-class research happening at the University of Oxford.

We continue to work hard to make sure no one ever faces FOP alone. To do that, we're putting our energy into three main areas: keeping our community strong, continued and targeted FOP research, and spreading awareness in the UK and internationally.

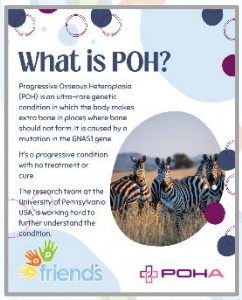
Some of our work is touched upon below.

Awareness

FOP Awareness

Providing up-to-date, layperson-friendly information regarding the progress of ongoing clinical trials and regulatory approvals in the UK and Europe.

POH Awareness



We remain dedicated to supporting our POH families and raising awareness at every opportunity. Recently, we partnered with *Rare Revolution Magazine* for their #TakeOverTuesday campaign, sharing essential POH facts and insight with a broader international audience. Above all, we strive to ensure that no POH family ever feels alone.

Alma Triffitt Book Award



At FOP Friends, we know just how challenging living with rare conditions like FOP and Progressive Osseous Heteroplasia (POH) can be for young people and their families. That's why, in 2021, we were delighted to accept Professor Jim Triffitt's generous offer of a grant to establish the Alma Triffitt Book Award in his dear wife's memory.

Through this annual initiative, we have the great joy of gifting books to children and young adults navigating these conditions, offering them an engaging escape into new worlds and a comforting reminder that our entire community is cheering them on. We work with the booksellers at Jim's favourite bookshop in Oxford, to ensure each book is hand-picked to perfection.

Alma was a cherished and deeply valued member of our FOP Friends' family who sadly passed away in July 2018 at the age of 81. Alma always held a profound appreciation for the families affected by FOP and POH. By sharing the magic of reading each year, we keep her beautiful legacy alive and ensure that her warmth, generosity, and spirit continue to touch the lives of the children she cared so much about.

Funding UK FOP Research



Through 2025, FOP Friends has played a pivotal role in advancing research for FOP through a sustained, decades long partnership with scientists and researchers.

We have, and continue to provide long-term, direct financial support to the FOP research team at the University of Oxford. This funding allows the team to take initial, tentative laboratory leads and meticulously develop them into viable clinical applications.

The most significant milestone of this funding was advancing research from the "bench to the bedside" in the form of the StopFOP clinical trial. A trial whose treatment was discovered by the FOP research team at the University of Oxford. In 2025, a major focus was the Phase 2 StopFOP study, which investigated the repurposed drug Saracatinib for its potential to reduce flare-ups and slow abnormal bone growth.



In addition to research funding, FOP Friends financed and facilitated direct collaboration between researchers and the patient community. Researchers regularly attended patient meetings and translate complex science into accessible language, ensuring the research direction was consistently guided by the actual needs of those living with FOP.



Ultimately, the charity's focused funding strategy through 2025 successfully bridged the crucial gap between early-stage laboratory research and active clinical trials, bringing the FOP community significantly closer to meaningful, targeted therapies.

Funding International Research

By partnering directly with the IFOPA and co-funding their Accelerating Cures and Treatments (ACT) for FOP grant programme, we ensure that the vital funds raised by our UK community directly support high-value, peer-reviewed research. Channelling some resources into the IFOPA's international efforts such as the global FOP registry and shared scientific resources allows us to maximize every pound, bridging the gap between early laboratory discoveries and viable clinical trials.

While backing global research, we also remain committed to strengthening our local scientific network by funding world-class research teams right here in the UK, including at the University of Oxford. This collaboration with the IFOPA empowers us to represent the patient voice on the international stage, ensuring that promising research translates into real, life-changing therapies for everyone living with FOP.

Manchester Rare Conditions Centre



Chris serves directly as a Patient Representative on the non-executive Advisory Panel of the Manchester Rare Conditions Centre. In this role, he leverages his lived experience as a rare disease advocate and parent of a child with FOP to ensure patient voices actively shape the centre's initiatives and strategies.

University of Manchester

We are proud of our long-standing partnership with the University of Manchester's Volunteering Department, and this year was no exception. Student volunteer Lauren joined us to research, compile, and design a brand-new Family Guidebook.

As a small charity, FOP Friends cannot always provide every resource our community needs directly. While there are many incredible UK charities doing exceptional work, navigating and finding the right support can often feel overwhelming for families. To help, we brought together details of trusted organisations offering services that our families might benefit from, along with other helpful resources and practical advice. Everything has been collated into an easy-to-use guide, complete with QR codes, to make accessing support as simple as possible.

We were also fortunate to have two native Mandarin-speaking students who were keen to help translate our School Guidebook into Mandarin. Due to differences between education systems, significant adaptations were required. Yi and Jiru have been invaluable, bringing immense dedication, enthusiasm, and expertise to the project. They have also liaised directly with families and members of the FOP community in China, and we look forward to finalizing and releasing this resource later in 2026.

RareFest, Cambridge



Andrew and Helen attended the CamRARE RAREsummit at the Wellcome Genome Campus in Cambridge earlier this month. The summit, which celebrated the 10th anniversary of the Cambridge Rare Disease Network (CamRARE), successfully brought together over 300 experts, researchers, industry leaders, and patient advocates to collaborate and debate challenges in the rare disease space.

We were also pleased to have the opportunity to showcase a science poster at the event, raising further awareness of FOP. In addition to the presentations, it was a great opportunity for networking with other organisations who are key in driving improvement forward to improve the lives of everyone living with a rare condition.

Helen at Sheffield with M4RD



Helen was thrilled to have the opportunity to volunteer for the amazing organisation Medics for Rare Disease again. She delivered a presentation to first-year doctors at North General Hospital, Sheffield, to help M4RD fulfil their mission to educate and encourage medical professionals to Think Rare. It was an important presentation for the next generation of doctors, introducing the importance of being aware of the challenges faced by those living with a rare diagnosis. These challenges range from the diagnostic odyssey to get the initial diagnosis and the difficulties of managing and juggling appointments, to the lack of available treatments, and more.

Safari Weekend



In September, thanks to a generous grant from The Russell Lang Charitable Trust, we were thrilled to host an unforgettable three-day Family Safari Weekend in Kidderminster, our first in-person family weekend post-COVID. Bringing together both new and returning FOP and POH families, the event kicked off on Friday with a lively welcome reception at the Premier Inn. Saturday was packed with adventure at West Midlands Safari Park, featuring a safari drive, walking trails, rides, and a quiet crafting hub at Spring Grove House, capped off by an evening celebration at Stone Manor. The gathering concluded on Sunday with a peaceful stroll through the autumnal gardens of Arley House and Arboretum. Above all, it gave our community a long-awaited opportunity to reconnect, build lasting friendships, and create cherished memories together in person once again.

Adult Rare Bone Disease Network



In November, Andrew and Helen represented our community at the 3rd Annual Adult Rare Bone Disease Network (ARBDN) meeting in Birmingham, hosted by Dr Kassim Javaid from the University of Oxford. The ARBDN is a collaborative, nationwide initiative dedicated to improving healthcare pathways, specialist training, and long-term outcomes for adults living with rare bone conditions.

The day focused on evaluating progress against the UK Rare Disease Strategy, refining key performance indicators to improve care standards, and developing stronger educational resources. Interactive table discussions ensured that the patient voice remains central to setting objectives for the coming year,

particularly around self-advocacy rights, healthcare professional training, and expanding collaborative care networks across the UK.

Impact and value

We are proud to be the first and most reliable contact for our families. We know that worries don't stick to business hours, so we're here to provide urgent reassurance and clear guidance when a medical professional isn't immediately available. This immediate support is vital during times of stress and uncertainty.

Building Our Community

We make a special effort to welcome every new family into our community. We gently guide them through the confirmation of diagnosis. Crucially, we instantly connect them to a supportive peer network - other families who truly understand what they're facing. This network quickly becomes a vital tool as they begin their journey of living with FOP.

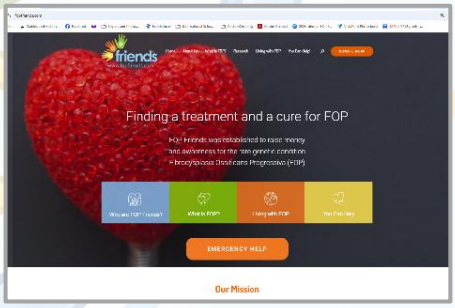
Prioritising Mental Health

The emotional health of everyone in our community is a top priority. Through our dedicated partnership with Rare Minds, we continue to provide specialist mental health support. This means both parents and adults living with FOP can access free, dedicated counselling immediately, helping them navigate the unique challenges of this condition.

Staying Informed

We ensure our families are always connected to the latest information. We consistently liaise with the expert team at RNOH to gather the most current updates and advice. We then actively share essential best practice reminders, such as guidance on the flu vaccine, and promote the excellent healthcare videos created by FOP specialists in collaboration with the IFOPA. Our goal is to make sure every family has the knowledge they need to make the best health decisions.

Supporting families



We continue to support our families in many ways. We have worked alongside educational professionals to advise on suitability of the school environment for one of our families. We have also supported families with the completion of their EHCP plan. We continue to share updates with the community about any updates to the Covid and advice guidance for patients with FOP, as advised by the ICC for FOP.

We have been updating the website with information and signposts to other organisations which can help to support our families with the challenges FOP brings. We have sourced charities which provide wishes and special treats for adults. We have advised OTs on specialist equipment for patients and liaised with families and their GPs to ensure prompt access to medical advice.

Perhaps most importantly, our families know we are always there for them, whenever they need us.

Fundraisers

The challenge of engaging new fundraisers is amplified by both our relatively small community and the persistent pressure of the increased cost of living. To counter this, we remain absolutely committed to moving forward.

Critical to our future is the need to significantly raise FOP awareness and broaden our search for funding beyond established circles. This strategic necessity is made possible by the essential foundation of support we receive from our strong, dedicated trustees, supporters, and FOP families. We are profoundly thankful for their continued commitment to achieving our mission, which makes our progress possible.

We have chosen a small selection of supporters, events, challenges, and activities to illustrate just how mazing our supporters are. We may be a small community, but we make a big difference. Many of our supporters have joined our cause when they hear our stories or meet members of our community and every fundraiser, big or small, makes a huge difference.

Kilburn Ceili Night



A traditional Quex Road Ceili organised by long-time supporter Phyllis Brosnan, alongside Patricia and Dell is held in Kilburn, London, in honour of Isla, the event is a great success.

Manchester United Mayoral Dinner



Trustees Alison and Helen attended a prestigious dinner at Manchester United's stadium as part of Mayor Amy Whyte's Mayoral Charity fundraising initiative. This concludes a year of Mayoral support from Councillor Amy Whyte, Mayor of Trafford, who concluded her official year by donating over £4,000. These funds were raised through a variety of community events, including raffles and bake sales.

Fast Friends

Over the past year, we have been incredibly fortunate to have so many friends and family members lace up their running shoes to raise vital funds for our cause. From novices finding the inspiration to take on their very first race to seasoned athletes pushing themselves to new distances, every single step makes a difference. No matter the distance run or the amount raised, we are grateful to every person who goes the extra mile for us.

FOP Friends Trustee Rachel successfully completed her second full marathon in honour of her nephew Oliver during an unseasonably warm April day. Young supporters Hettie and Phoebe completed the London

Mini Marathon in honour of Isla. Linda navigated the scenic route of the London Landmarks Half Marathon through the capital in honour of Oliver. Liam took on the challenging inclines of Sheffield's streets, completing a hilly half marathon for his friend Oliver. A dedicated team, including Jane, Rebecca, Richard, Simon, Mick (running for Lenny), and Hope (running for Ellis), completed the iconic 13.1-mile course. Oscar celebrated his 100th 5k Parkrun in honour of his friend Harry, contributing £314 to the cause.

RNOH Awareness Day & Bake Sale



Clinical Nurse Specialists Amy and Kayleigh hosted a dedicated FOP Awareness Day stand and bake sale at the Royal National Orthopaedic Hospital (RNOH) to boost both funds and clinical awareness.

Ullswater Open Water Swim

Phil completed a gruelling 7.5-mile open water swim across Lake Ullswater in 3 hours and 18 minutes in honour of his son Harry.

Parallel Windsor Trike Challenge



Isla, accompanied by James and her dog Ralph, participated in the Parallel Windsor 1km Trike Challenge. She also got to meet one of her heroes from the tv!

Snowdon Mountain Ascent



Joe and his friends reached the summit of Mount Snowdon in honour of his daughter Monroe, significantly exceeding their initial fundraising goal.

Railway Inn Beer Festival

The staff and patrons at The Railway Inn in Framingham hosted a successful beer festival in the sun, in honour of Millie.

Sports Day Refreshments

Brodie and his schoolmates saw a business opportunity with the warm weather. They sold ice pops and fruit cups at their school sports day.

American Tennis Tournament



Christine Kay organised a tournament at Brooklands Tennis Club with prizes presented by Oliver; raised £1,130.

White Collar Boxing

Lenny's dad Mick took on several challenges this year to raise funds in honour of his son. He and his good friend Baz completed intensive training and fought in an Ultimate White Collar Boxing match to raise funds.

Hamper Raffles and more…

Lexi's friends have generously donated throughout the year through a range of events, including coin collections, hamper raffles at the local football club, and the Lexi Cup golf tournament at Batchwood Golf Club, organised by Lexi's grandad. Lexi, Hadley, Marlie, and Katie cooled down their community with a lemonade stall, raising funds in honour of Little Lexi.

Pet Portrait Commissions

Isla's friend Heather is a talented artist, and kindly paints custom pet portraits on Christmas baubles and cushions, in return for donations to FOP Friends in honour of Isla.

FOP France



With FOP affecting just one in a million people, international partnerships are vital to keeping scientific momentum alive. For many years, FOP Friends has worked hand-in-hand with our friends at FOP France to fund ground-breaking research at the University of Oxford.

As part of our ongoing commitment, FOP Friends aims to raise £120,000 every year to keep the Oxford research laboratory open and active. We are incredibly grateful to FOP France, whose generous financial contributions directly support this goal. By joining forces, our two organisations ensure that Dr Alex Bullock and his expert team have the dedicated funding they need to push forward in the search for effective treatments.

The Future

Like many charities, fundraising continues to be a tough road for us right now. Between the ongoing cost-of-living squeeze and broader global uncertainty, we've seen a noticeable drop in donations, which makes funding our everyday work a lot harder. If things stay on this path, we'll naturally need to lean more on the financial reserves we've set aside precisely to help steer us through challenging times like these.

The good news is that we're keeping a close eye on our finances to stay on solid ground. By keeping a portion of our funds in higher-interest accounts, we're generating extra income to cover core operations and keep our promises. These reserves are vital. They give us the confidence and stability to keep funding life-changing FOP research and essential support for our community.

To make sure we can keep launching exciting new projects as our current ones wrap up, we're going to be applying for more grants and trusts. We've had great success with this approach before! It helps us secure funding for big initiatives without putting all the weight on community fundraising alone, which directly benefits everyone affected by FOP

Looking to the future, we're shaping a long-term plan to ensure FOP Friends remains strong and resilient for years to come. Part of this plan includes reviewing our board of trustees and welcoming new volunteers who bring fresh skills, fresh energy, and new experiences to help drive our mission forward.

Through it all, our commitment to our FOP community hasn't wavered for a second. We're here to support, provide resources, speak up for the community's needs, raise awareness, and push forward research toward potential treatments and cures.

We thankful for our incredible donors and volunteers, whose generosity is what keeps us going, helping us navigate these choppy waters and make a real difference for everyone affected by FOP. Please keep up your wonderful fundraising efforts and support. Together, we can tackle these challenges and build a much brighter future for our community.

Ambition and long-term strategies

Charity objectives

- To grow the charity to make the annual fundraising target of £125,000 more easily achievable and to be in a strong position to increase this target soon.
- To increase public awareness and expand the fundraising activities beyond friends and family.
- To reduce misdiagnosis and to help ensure there are more UK-based FOP experts and centres where treatment and possibly future clinical trials can take place.
- To continue our involvement with the FOP community worldwide and help advance FOP research and awareness internationally.
- To increase support given to FOP Families.
- To maximise grant income through clearly defined projects.
- To ensure regular communications are sent to the community and supporters. To keep everyone informed of work the charity undertakes, progress with research and to thank those who fundraise.

- To become a sustainable charity not reliant on the efforts of a small number of committed volunteers.

Preventing misdiagnosis

- Increase awareness of FOP with both health professionals and the public to reduce misdiagnosis and therefore the fallout from investigations that often trigger devastating episodes of FOP bone growth.

Fundraising

- To continue to grow fundraising efforts, helping, and encouraging more FOP families to become involved.
- Through increased public awareness to expand fundraising activities beyond friends and family to become a charity of choice for the public to support.
- To sustain and maximise trusts and grant funding to continue the financial support for research.
- To secure and sustain grant funding to enable the charity to support employees on a long-term basis.
- To develop a Fundraising Pack to help those interested in fundraising to support the charity.
- To secure funding to cover core costs and reduce attendee costs for future UK FOP conferences.
- To actively seek corporate sponsorship as “charity of the year.”
- To create alternative fundraising campaigns to diversify income streams.
- To seek high-profile patrons to both, increase awareness and actively encourage and support fundraising.

Family support

- To continue to provide support and advice to existing and recently diagnosed FOP families.
- To organise and deliver additional and regular family gatherings across the UK to support and promote the community and provide respite for families.
- To provide best advice and information to families, schools, clinicians, and others in understanding FOP and the challenges it poses.

Medical support

- To reach out to health professionals and professional bodies to create interest and awareness of FOP to help prevent misdiagnosis but also to increase the available support for those with FOP.
- To help establish UK specialist centres for the care and treatment of FOP patients.
- To strengthen the reliability of our information sources by acquiring the NHS Information Standard.

Governance and Structure

Legal Status

FOP Friends is a charitable trust registered with the Charities Commission in England and Wales, #1147704. It was founded in March 2012 and is governed by its “Trust Deed”. The trustees are responsible for the

management and administration of the charity. FOP Friends also registered with The Scottish Charity Regulator (OSCR) in November 2016, SC046950.

Organisational Structure

Ultimate responsibility for the governance of FOP Friends is with the trustees. The trustees are appointed by the founding trustees as detailed within the Trust Deed dated March 2012. The trustees meet in-person (defined as physically or via video conference) at least twice each year. Interim meetings are also held throughout the year. Trustee duties include ensuring compliance with all relevant laws and ensuring that its activities are in accordance with its charitable objectives and operation for the public benefit. Certain functions are delegated to individual trustees, and it is expected in the future there will be several committees with specific responsibilities for the charity. Any change to the Trust Deed including the appointment of trustees is subject to 10 days' notice of the intention to discuss prior to any meeting.

Trustee recruitment and training

Vacancies for trustees are sought through recommendations gained through appropriate networks and associations of trustees and supporters. Candidates shortlisted are those whose skills and expertise will complement those of the existing trustees. Short-list candidates are reviewed by the existing trustees with a decision to appoint made at a special general meeting. New trustees are provided with a copy of the Trust Deed with any amendments made to it and a copy of the charities latest Annual Report and Financial Statements. All trustees are required to complete a 'Trustee Declaration' form. They will subsequently be inducted into the workings of the charity by an existing trustee, including appropriate safeguarding training.

Employment

FOP Friends continues moving towards being a sustainable and professional organisation through employment of appropriate staff.

Trustee recruitment and training

Vacancies for trustees are sought through recommendations gained through appropriate networks and associations of trustees and supporters. Candidates shortlisted are those whose skills and expertise will complement those of the existing trustees. Short-list candidates are reviewed by the existing trustees with a decision to appoint made at a special general meeting. New trustees are provided with a copy of the Trust Deed with any amendments made to it and a copy of the charities latest Annual Report and Financial Statements. All trustees are required to complete a 'Trustee Declaration' form. They will subsequently be inducted into the workings of the charity by an existing trustee, including appropriate safeguarding training.

Statement of responsibilities of the trustees

The charity trustees are responsible for preparing an annual report and financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

The law applicable to charities in England and Wales requires the charity trustees to prepare financial statements for each year which give a true and fair view of the state of affairs of the charity and of the incoming resources and application of resources of the charity for that period. In preparing the financial statements, the trustees are required to:

- Select suitable accounting policies and then apply them consistently.
- Observe the methods and principles in the Charities SORP.
- Make judgements and estimates that are reasonable and prudent.
- State whether applicable accounting standards have been followed, subject to any material departures disclosed and explained in the financial statements.
- Prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charity will continue in business.

The trustees are responsible for keeping proper accounting records which disclose with reasonable accuracy at any time the financial position of the charity and enable them to ensure that the financial statements comply with the Charities Act 2011, the Charity (Accounts and Reports) Regulations 2008 and the provisions of the trust deed. They are also responsible for safeguarding the assets of the charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

The trustees for the purposes of charity law who served during the year and up to the date of this report are set out on page 2. The trustees are responsible for the maintenance and integrity of the charity and financial information included on the charity's website. This report was approved by the trustees on 27th October 2025 and signed on their behalf by



Chris Bedford-Gay.

Founding Trustee and Chairman

Financial review

Summary

Gross income totalled £102,839 with funds of £415,283 being carried forward to next charity year. Of the amount carried forward, £125,000 is designated to research; £15,000 to operating reserves; and £185,026 restricted (mainly projects associated with grants and trust fundraising). The charity has no long-term investments. Cash reserves are held in bank deposit accounts.

Income

Income for the year totalled £102,839 and is made up of unrestricted funds from fundraising and voluntary donations together with income from successful grant and trust applications, conference fees, and a small amount of interest on savings.

Grants, trusts, and corporate sponsorship

The charity received £17,600 (was £5,000) in grants. A 72% increase on the previous charity year. We anticipate a larger increase into the following charity year as we enter a conference year, which usually attracts grant, trust, and industry funding. We also continue to complete already funded projects from previous years.

Charitable expenditure

Through the charity year, £40,000 was spent on funding FOP research at the University of Oxford.

Operating costs of £47,051 includes salaries, general expenses, repairs and maintenance, rent, bank charges, and costs of subscriptions. Governance costs of £610 include accounting fees and insurance. £2,968 was spent generating funds (t-shirts, event places, and support of fundraisers), and £11,739 was associated with projects.

Gains and losses

Income from fundraising, voluntary income and fundraising activities increased by 36% from £63,679 to a total of £98,742.

Policy on reserves

The trustees' aim is to maintain reserves in unrestricted funds of £15,000 to cover operational, support, governance costs, and unforeseen expenditure over at least a 3-month period.

Designated Funds

FOP Friends remains committed to funding FOP research internationally. The trustees decide where disbursements are made to achieve the aims and objects of the charity. Presently, £125,000 is designated from funds carried over towards FOP research.

Future commitments

Ongoing projects such as the FOP Friends Together newsletter, and updates to the "Supporting a Child with FOP: a practical guide to their learning experience" book are recognised as future financial commitments being funded through restricted grants and trusts awards.

Restricted Funds

A total of £55,932 in funding received in this reporting year has been restricted towards the FOP Friends together newsletter, providing professional counselling services to our FOP community, the 2025 family getaway and a larger amount from FOP France which is restricted to funding the University of Oxford FOP Research team.

Investments

FOP Friends invested a proportion of its available funds into the CAF Charity Deposit Platform, managed by Flagstone, these funds were placed into two high-interest fixed period savings accounts to take advantage of currently high interest rates.

Independent examiner's report

I report on the accounts of the charity for the year ended 31st December 2025 which are set out on pages 40 to 47.

This report is made solely to the charity's trustees, as a body, in accordance with section 145 of the Charities Act 2011 and regulations made under section 154 of that Act. My work has been undertaken so that I might state to the charity's trustees those matters I am required to state to them in an independent examiner's report and for no other purpose. To the fullest extent permitted by law, I do not accept or assume responsibility to anyone other than the charity and the charity's trustees, as a body, for my work or for this report.

Respective responsibilities of the trustees and examiner

The charity's trustees consider that an audit is not required for this year (under section 144(2) of the Charities Act 2011) and that an independent examination is needed. It is my responsibility to:

- ✓ examine the accounts (under section 145 of the Act)
- ✓ to follow the procedures laid down in the General Directions given by the Charity Commission (under section 145(5)(b) of the Act)
- ✓ to state whether particular matters have come to my attention

Basis of independent examiner's report

My examination was carried out in accordance with General Directions given by the Charity Commission. An examination includes a review of the accounting records kept by the charity and a comparison of the accounts presented with those records. It also includes consideration of any unusual items or disclosures in the accounts and seeking explanations from you as trustees concerning any such matters. The procedures undertaken do not provide all the evidence that would be required in an audit, and consequently no opinion is given as to whether the accounts present a 'true and fair' view, and the report is limited to those matters set out in the statement below.

Independent examiner's statement

In the course of my examination, no matter has come to my attention:

1. which gives me reasonable cause to believe that, in any material respect, the requirements:
    a. to keep accounting records in accordance with section 130 of the Act; and
    b. to prepare accounts which accord with the accounting records and comply with the accounting requirements of the Act; have not been met; or
2. to which, in my opinion, attention should be drawn in order to enable a proper understanding of the accounts to be reached.

Independent examiner

P. S. Hutchinson BSc FCA, Chartered Accountant, 246 Park View, Whitley Bay, Tyne & Wear, NE26 3QX

Consolidated statement of financial activities

-	Notes	Restricted	Unrestricted	2025	2024
Incoming resources					
From generated funds					
Voluntary income	2	55,932	42,810	98,742	63,679
Investment income		-	3,215	3,215	3,819
Other incoming resources	3		882	882	75,342
Total incoming resources		55,932	46,907	102,839	142,840
Resources expended					
Costs of generating funds	4	-	2,968	2,968	3,105
Charitable activities					
Research	5	16,325	23,675	40,000	93,754
Events	6	1,033	-	1,033	42,220
Awareness		-	4,343	4,343	880
Projects		11,739		11,739	5,586
Operational Costs	7	19,208	27,843	47,051	36,778
Governance costs	8	-	610	610	570
Total resources expended		48,306	59,439	107,745	182,893
Net incoming/(outgoing) resources		7,626	(12,532)	(4,906)	(40,053)
Reconciliation of funds					
Total funds brought forward		185,026	235,163	420,189	460,242
Total funds carried forward		192,652	222,631	415,283	420,189

Balance sheet

-	Notes	2025	2024
Fixed assets	9	1,090	1,730
Current assets			
Cash at bank		413,316	421,797
Debtors	10	5,328	1,100
		418,644	422,897
Creditors: amounts falling due within one year	11	(4,451)	(4,439)
Net current assets		414,193	418,458
Net assets		415,283	420,189
Funds			
Restricted	12	192,652	185,026
Designated	13	140,000	140,000
Unrestricted		82,631	95,163
		415,283	420,189

Approved by the trustees on 30th September 2026 and signed on their behalf by



Alison Acosta Bedford.

Founding Trustee

The notes on pages **43** to **47** form an integral part of these financial statements

Notes to the financial statements

1. Accounting policies

Basis of accounting

The financial statements have been prepared under the historical cost convention and in accordance with the Statement of Recommended Practice: Accounting and Reporting by Charities (SORP 2005) issued in March 2005 and applicable UK Accounting Standards and the Charities Act 2011.

Fund accounting

Restricted funds are funds which are to be used in accordance with specific restrictions imposed by the donor or trust deed.

Unrestricted income funds comprise those funds which the trustees are free to use for any purpose in furtherance of the charitable objects. Unrestricted funds include designated funds where the trustees, at their discretion, have set aside resources for a specific purpose.

Incoming resources

All incoming resources are recognised once the charity has entitlement to the resources, it is certain that the resources will be received, and the monetary value of incoming resources can be measured with sufficient reliability.

Voluntary income is received by way of donations and gifts and is included in full in the Statement of Financial Activities when receivable.

Investment income is included when received.

Resources expended

Liabilities are recognised as resources expended as soon as there is a legal or constructive obligation committing the charity to the expenditure. All expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all costs related to the category.

Costs of generating funds

Costs of generating funds comprise the costs associated with attracting voluntary income and the costs of fundraising.

Governance costs

Governance costs include those costs associated with meeting the constitutional and statutory requirements of the charity and include costs linked to the strategic management of the charity.

Irrecoverable VAT

Irrecoverable VAT is charged against the category of resources expended for which it was incurred.

2. Voluntary income

	2025	2024
Donations	81,142	58,679
Grants	17,600	5,000
	98,742	63,679

3. Other incoming resources

	2025	2024
Conference	-	72,230
Sales	882	3,112
	882	75,342

4. Cost of generating funds

	2025	2024
Fundraising costs	2,968	3,105
Project costs	11,739	5,586
	14,707	8,691

5. Research

	2025	2024
UK research	40,000	75,000
International research	-	18,754
	40,000	93,754

6. Events

	2025	2024
Conference meeting costs	1,033	42,220
	1,033	42,220

7. Operational

	2025	2024
Salaries	38,117	31,916
General expenses	3,545	3,413
Repairs and maintenance	150	123
Subscriptions	1,144	623
Bank charges	46	60
Depreciation	750	643
Rent	3,300	-
	47,051	36,778

8. Governance

	2025	2024
Accountancy charges	115	115
Insurance	495	455
	610	570

9. Fixed assets

	Office equipment
Cost	
At 1st January 2025	4,973
Additions	110
Disposals	-
As at 31st December 2025	5,083
Depreciation	
At 1st January 2025	3,243
On disposals	-
Charge for year	750
As at 31st December 2025	3,993
Net book value	
At 1st January 2025	1,730
As at 31st December 2025	1,090

10. Debtors

	2025	2024
Prepayments	3,300	-
VAT repayable	2,028	1,100
	5,328	1,100

11. Creditors

	2025	2024
Amounts falling due within one year:		
Accounts payable	3,225	3,327
PAYE and NI	533	534
Accrued expenses	460	345
Other creditors	233	233
	4,451	4,439

12. Restricted funds

	Balance b.fwd	Incoming resources	Resources expended	Balance c.fwd
Conference fund	99,604	-	(10,562)	89,042
Family getaway	4,425	5,000	(9,425)	-
Operational	14,725	10,751	(4,522)	20,954
Be Safe at School Handbook	25,396	-	(5,759)	19,636
Charity leaflet	246	-	-	246
FOP & Me	12,741	-	-	12,741
FOP Video	8,176	-	-	8,176
Alma Triffit Book Award	(34)	750	(191)	525
Engraver Gamer	132	-	(132)	-
Rare Minds	798	2,500	(425)	2,873
Together Newsletter	2,491	2,800	(964)	4,327
FOP Organisation	16,325	34,131	(16,325)	34,131
	185,026	55,932	(48,306)	192,652

The Conference fund represents donations and delegates deposits received in respect of the FOP Conference in May 2026. Operational funds are those restricted to day-to-day operations of the charity.

The family getaway fund is restricted to providing FOP families with a weekend getaway with all other FOP families in the UK. A chance to be with others in the same situation in a relaxed environment.

The Be Safe at School Handbook fund represents grants awarded towards the cost of producing/updating a handbook that families can provide to their child's school to detail best practice procedures for caring for a FOP child throughout their life in education.

FOP & Me funding is for a children's journal taking them through their journey with FOP, either as a patient or a sibling of a person with FOP. Both the FOP Video and Charity leaflet funds are focused on raising FOP awareness with the FOP Video have a particular focus on awareness and "do no harm" within the medical communities.

The Alma Triffitt book award are funds towards the purchase, annually, of a book for every child with FOP within the UK. The fund was setup in the memory of Alma Triffitt whose husband, Prof James Triffit is also a

long time FOP researcher, being involved in setting up FOP research at the University of Oxford, being instrumental in the FOP gene discovery, and who has continued involvement in the FOP world.

Finally, the FOP Organisation fund holds monies received by other FOP organisations prior to them being distributed in accordance with the organisations wishes. This is primarily fund from FOP France destined to help fund the FOP research team at the University of Oxford.

13. Designated funds

	Balance b.fwd	Incoming resources	Resources expended	Balance c.fwd
Research fund	125,000	-	-	125,000
Operating fund	15,000	-	-	15,000
	140,000	-	-	140,000

The Charity will sometimes raise funds to meet specific objectives, but the donor chooses not to restrict the Charity in how the funds are to be used. These funds are legally unrestricted, but the Trustees choose to designate the purpose for which the funds are to be used as follows:

The Research fund represents monies received which the Trustees have designated to be used to fund research in future years.

The Operating Fund is the greater of £15,000 or three months' operating costs, which the charity's Reserves Policy defines as the minimum safe reserve level.

Our history (to 31st December 2025)

December 2025



Following on from a presentation Oliver gave last year, FOP Friends is chosen to benefit from Arval's Christmas Raffle. Helen and Oliver visit the offices to sell raffle tickets. We are thrilled to return to the office in spring to receive the cheque.

For our Christmas fundraising this year, we create a virtual Christmas tree for our families. Friends and families can sponsor a bauble on the tree in return for a donation of their choice. The tree is very popular and brings in over £3,000 in donations.





Oliver and Helen make a trip to Uxbridge to give a presentation to the staff at Regeneron as part of their Christmas festivities. It has been ten years since Oliver gave his first ever presentation – to the staff at Regeneron. Many of the team are still there and still remember Oliver as a young boy. His speech is as moving this year as it has ever been.

November 2025



Andrew attends the MHRA Rare Disease Workshop in London, which brings together regulators, healthcare organisations, industry, researchers, and patient representatives. The meeting explores how the UK regulatory system could better support the development and approval of treatments for rare diseases, where small patient numbers can make traditional evidence gathering challenging.



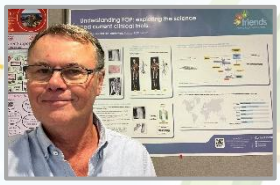
Helen and Andrew attend the third Adult Rare Bone Disease Network meeting in Birmingham.

Beacon hosted The Manchester Rare Disease Showcase at the Bridgwater Hall, so Andrew, Alison, Chris, and Helen were all pleased to attend. The Showcase brings together patients, advocates, clinicians, and researchers from across the UK. It features lightning talks, breakout



sessions, and networking aimed at addressing health inequalities and driving collaborative research.

presentations, and networking aimed at addressing health inequalities and driving collaborative research.



CamRare provides more networking opportunities for Helen and Andrew. FOP Friends are pleased to have the opportunity to display a poster at the event, raising awareness of FOP and its challenges to a wider audience.



Chris attends the LifeArc Translational Centres for Rare Disease Annual Showcase in London which brings together researchers, clinicians, patient organisations, and partners from across the rare disease community. The event shares progress and explores how collaboration and patient involvement can help move research towards treatments and better outcomes.

October 2025



Chris attends the iDR2025 in Amsterdam to hear how vital drug repurposing can be in the rare disease space. There is a presentation from the StopFOP team – with saracatinib being a repurposed drug itself. He meets with other members of the FOP community as well as members of the International President's Committee.



Helen volunteers for Medics for Rare Disease to deliver an educational presentation to first-year doctors at Northern General Hospital in Sheffield. The session introduces the next generation of medical professionals to the principles of "Think Rare," highlighting the everyday challenges patients face, from lengthy diagnostic journeys to managing complex care.

September 2025



FOP Friends hosts a weekend getaway for families at the West Midlands Safari Park. The highly anticipated event features a safari drive, family activities, a dinner reception at Stone Manor, and a visit to Arley Arboretum to bring the UK FOP community together. This incredible opportunity is made possible thanks to a generous grant from the Russell Lang Charitable Trust. This is our first family weekend we have been able to host, post-Covid, so it is truly appreciated and well-received.



Once again, a fabulous team of runners lace up for us in the Great North Run in Newcastle. We have friends, a sister, and a dad all running in honour of someone they know and love who is living with FOP.



We represent our community at the NHS Specialised Rheumatology Clinical Reference Group meeting in London to help shape the future of care. Ahead of the session, we gathered vital feedback from adult patients, parents, and carers through an anonymous survey. Bringing these real-world experiences directly to NHS commissioners, we advocated for our community's core priorities as new service specifications and the NHS Ten-Year Plan are developed.

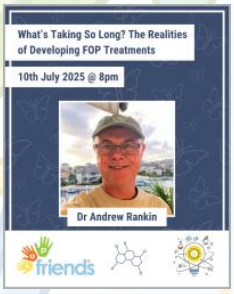


Building on the relationship from the University of Salford project, Helen delivers training to OTs in Tameside about living with FOP. The presentation also includes examples of how some conditions require the patients and carers to think outside the box when looking for adaptive tools.

July 2026



Helen attends a conference in London, organised by Chiesi and co-hosted by MSUK. The focus is on the importance of true visual representations of those living with a rare condition. FOP Friends is proud to sign a pledge to use authentic visuals in their printed and digital resources.



To support our community's understanding of research, we hold our first webinar exploring how FOP treatments move from initial lab research through clinical trial phases to regulatory approval.

June 2026



Helen travels to Birmingham for M4RD's workshop aimed at shaping DHSC recommendations on healthcare professional awareness of rare diseases. Participants discuss Priority 2 topics, working through targeted worksheets to map out current versus desired behaviours, key action points, and measurable outcomes.



We are thrilled to gift more beautiful books to our children and young people in memory of Alma Triffitt, thanks to a generous, ongoing grant from Professor Triffitt in honour of his wife.



Helen attends the Cambridge Rare Disease Showcase, networking, and sharing ideas with other small patient organisations. She also takes part in filming for a Rare Rolodex project.

May 2025

Helen and Chris attend the Vice Chancellor's Afternoon Tea event at Linacre College, Oxford.



We publishes "Living Well with FOP: A Conversation with Julie" on the FOP Friends blog to share patient experiences and promote living well with Fibrodysplasia Ossificans Progressiva.

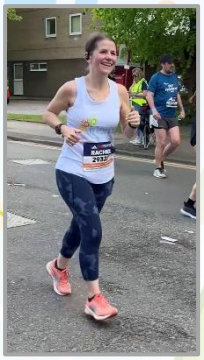


Chris attends the iDR2025 in Amsterdam to hear how vital drug repurposing can be in the rare disease space. There is a presentation from the StopFOP team – with saracatinib being a repurposed drug itself.

The newly appointed clinical nurse specialists at the RNOH hold an awareness stall and fundraiser for FOP Friends.



April 2025



Trustee and auntie, Rachel takes on the challenge of the Manchester Marathon. It's the then-hottest day of the year, and a tough run for many of the participants. However, Auntie Rachel isn't deterred and crossed the finish line with pride.

April 2025

Chris attends FOP Italia's meeting in Ancona. It is another opportunity to network and collaborate with others within our global FOP community.





We join with other patient organisations for FOP Awareness Day with the aim of raising awareness of FOP with tees and totes.

March 2025

Chris attends the Manchester Rare Conditions Centre conference in Manchester.

Helen and Alison attend the Mayor of Trafford's Civic Reception at Old Trafford, in celebration of her year in office. We are thrilled to have been chosen one of Mayor Amy Whyte's Charities for 2024/2025.





FOP Friends joins the Living Well Movement, driven by Metabolic Support UK. It is a celebration of those living well with a rare condition, to recognise how they are choosing to live well with a rare disease, rather than just waiting for a treatment which, in reality, may never come. Helen and Andrew attend the conference and share a poster honouring many people from our community who sharing how they live well with FOP.

Helen and Leo, along with community member Rachel, attend a closing meeting at the University of Salford. We have been collaborating with designers and occupational therapists to design a tool to enhance Rachel's life – to enjoy pizza independently. It's always the simple things people take for granted.



February 2025

International Rare Disease Day. FOP Friends marked International Rare Disease Day by publishing a reflective piece on their blog, titled "More than a date on the calendar," to raise awareness for the community.



Andrew and Helen attend the Houses of Parliament for meeting to recognise Rare Disease Day. Presentations were made by MPs, Genetic Alliance, and other patient organisations.

December 2024

Andrew and Helen attend the Adult Rare Bone Disease Network meeting in London as founding members. We are interested to hear how the Network is progressing, and the meeting provides insights into the collaborative efforts underway. It is inspiring to see the strategic advancements being made to improve care pathways and research access for adults living with rare bone conditions.



November 2024



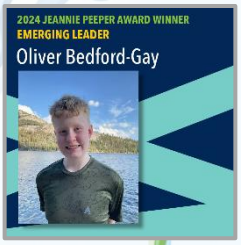
We are pleased to be paired with Athena as part of the Medics for Rare Diseases Student Voice Essay prize. Athena worked with some of our families, and then submitted an essay entitled *'Are the priorities of young people represented in rare disease policy and action? A case study on fibrodysplasia ossificans progressiva (FOP)' which is shortlisted* by the judges.



Andrew and Helen attend RareFest in Cambridge. The event offers many valuable opportunities to network and connect with fellow advocates and researchers, all dedicated to improving the rare disease landscape. Importantly, the event also hosts the launch of the new Rare Disease Research Network, an initiative we are proud to be involved in.

October 2024

Oliver's tireless advocacy and awareness-raising for those living with FOP is recognised with the Emerging Young Leader Award from the International FOP Association (IFOPA).





We make a substantial donation to the International FOP Association's (IFOPA) 'In Pursuit of a Cure' campaign. Our donation directly supports

vital global research, funding the scientific investigations and clinical trial readiness programmes essential for accelerating the discovery of treatments.

September 2024



Helen holds a stall at the Student Volunteer Fair at the University of Manchester. Over the years, students from the university have provided us with much-needed support for our projects.

August 2024

Andrew attends the first meeting of the Adult Rare bone disease collaborative network. Representatives from the founding charities are present, along with a number of medical professionals including Professor Richard Keen.



July 2024



Helen attends a Manchester Rare Conditions conference at City Labs 1.0. There are many impactful speakers including from Dr Lucy McKay from Medics for Rare Disease. Kath Bainbridge, Head of Rare Diseases and Emerging Therapies discusses the UK Rare Disease Framework and action plan.

June 2024



In June, Chris travels to Sweden to the IFOPA Drug Development Forum. He opens the afternoon session.



Our annual donation to the FOP research team at the University of Oxford is gratefully acknowledged, demonstrating our partnership and commitment to the team, led by Professor Alex Bullock.

May 2024



In May, we hold our fifth Conference and Family Gathering in Manchester. We are delighted to welcome attendees from 15 countries. We have presentations from medical professionals, pharmaceutical companies, and researchers. Those living with FOP or POH are able to attend up to three private clinical appointments with FOP specialists from the UK and beyond.

We launch the second version of our schoolbook: *Apoiando uma criança com FOP: Um guia prático para auxílio na jornada escolar*. This is an updated guide, translated into Portuguese for families living with FOP in Brazil.



May 2024



We are honoured to be selected as Amy Whyte's Charity of the Year, as she becomes Mayor of Trafford. Throughout the year, will have the opportunity to Mayor Whyte raise money and awareness for our charity across the borough.

April 2024



We recognise FOP Awareness month with our annual #FunFeet4FOP and welcome contributions from around the world. We also partner with other patient organisations as part of Global FOP Awareness month and sell logo tees. We are United in Hope.



February 2024

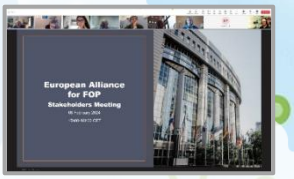
It was a privilege to be invited to work with Medics for Rare Diseases, in collaboration with the prestigious Hunterian Museum at the Royal College of Surgeons, to host an evening reception for healthcare professionals, examining the contributions of patients and families to medical advances in FOP.





Helen attends her second Board Meeting with the IFOPA, this time it is in Florida.

Chris participates in a virtual conference for the emerging, European Alliance for FOP, a new Europe wide (and UK) group focusing on FOP activies within Europe and the rare disease landscape.



January 2024



Helen attends an Occupational Therapists' Conference at Salford University to support the students giving a presentation on FOP.

December 2023



Chris continues the conversation with The Right Honourable Mike Penning about the need for funding for research into FOP. This time, Professor Keen (RNOH) and Professor Bullock (Oxford University) bring their views and insights.



Engraver Gamer and their friends hold an online gaming fundraiser to buy treats for the children. Our children receive beautiful hand-iced biscuits, a hot chocolate set - and a gift card too!

November 2023



Helen attends the Kids to Adultz expo in Manchester. She raises awareness of FOP with companies and professionals, and also looks at solutions available for those living with a disability.

Chris attends the NICE Conference in Manchester. There were focusses on improving patient care, optimizing resources, and leveraging technology.



Helen attends a training session, led by Beacon, to improve the charity's communications. This is held at the Royal Institution in London. As well as being incredibly useful content, it also gives Helen the opportunity to network with others in the rare disease space.



Andrew and Nicky attend a meeting in London, to meet with the Minister for Heath, to discuss further the issues raised in the debate in September, and the challenges those living with FOP face every day.

Rachel and Helen are honoured to represent FOP Friends at the Adult Rare Bone Disease Collaborative Network Launch. This is an initiative to provide improved and coordinated care for adults living with a rare bone condition.



September 2023

Oliver's brother Leo features in an article about the challenges of having a sibling with a complex condition and what it means to be a young carer.





Oliver and Chris attends a debate on FOP in the Houses of Parliament. Along with Lexi and her family, they also deliver a petition demanding government funding into FOP to 10 Downing Street.

August 2023

On a detour from a family holiday, Helen, Chris and family, make a visit to the FOP research lab in Philadelphia, and meet with Professor Kaplan and Professor Shore.





Isla demonstrates her warrior spirit, taking part in the Superhero Triathlon with her friends Kit and Erin.

July 2023



Another meeting with the students of Salford University to move our adaptive device project forward. We are joined by Rachel, her mum Julie, and her carer.

June 2023

We remember Alma Triffitt this year once more, with our children and young people receiving their book.



Chris is back in London, this time for the Genetic Alliance Westminster All Parliamentary Group on Rare, Genetic and Undiagnosed Conditions. The aim of the meeting was to discuss the latest report about coordinating the care of those living with rare conditions.



Oliver gives a presentation to his school, sharing his experience of living with FOP. His good friend Rachel came along to share her story and to provide some moral support!

June 2023



We are delighted to receive a letter of thanks from HRH King Charles III and Queen Camilla, thanking us for our good wishes on the occasion of their Coronation.

May 2023



FOP Friends trustee Nicky, Isla and James visit the UK TV show, This Morning, to chat about living with FOP and raise awareness of the condition. Their appearance also generates a flurry of donations.



Helen and Chris are invited to King Charles' Garden Party in celebration of Helen's British Empire Medal. It was an honour to be able to speak with Her Royal Highness The Princess Royal about FOP.

March 2023



Oliver gives another impactful presentation, sharing his story about living with a rare disease. Chris reflects on the challenges of being a rare parent and patient organisation.





Helen attends her first meeting for the IFOPA as a member of the Board. This is the first time she has met many of the team in real life! As part of the Board meeting, a visit to the University of Massachusetts is arranged. Helen meets Professor Paul Yu and hears promising research updates.

April 2023

April brings our annual Global Awareness campaign. We share photos of fun feet from around the world in continuation of our #FunFeet4FOP awareness campaign.





February 2023



Oliver, Rachel, and Avi share their story of living with FOP for a Granada News report for Rare Disease Day. The report further raises awareness of FOP and Rare Diseases. The segment was broadcast on Granada News, and we are very excited to expand and spread awareness on television.

We collaborate with Trafford Council, who show their support for those living with rare diseases by lighting up their town halls as part of the Global Chain of Lights. Oliver and Eddie travel around the borough to see them. We are grateful to the buildings team at the council for making it happen.

As part of Rare Disease Day, trustee Nicky shares her diagnosis story to a global audience.

January 2023

The report, for which Leo and Harry shared their experiences, is released. The report by Rare Revolution and Alexion details the impact of rare diseases on siblings. Anonymous quotes from their experiences are included in the final publication.





We are honoured to host a StopFOP webinar with a fabulous panel of professionals. StopFOP is an academic clinical trial of a treatment discovered by the FOP Research team at the University of Oxford. Marelise Eekhoff, MD, PhD, Amsterdam University Medical Center and Alex Bullock, PhD, University of Oxford, give a brief overview of the StopFOP Phase II clinical trial. Dr. Richard Keen, Principal Investigator for the UK site, explains what participation in the trial would entail for those in the UK.

December 2022



Chris flies to Paris to participate in Ipsen's Global Patient Centricity advisor board, helping inform Ipsen's approach to ensuring patients are the centre of the drug development journey.



We take part in our second Tuesday Takeover with Rare Revolution Magazine to raise awareness of progressive osseous heteroplasia, POH. POH is the sister condition to FOP, and we support families living with the condition as part of our mission to support families.



Helen receives her British Empire Medal at The Monastery, Manchester, with her family. The award is present by the Lord Lieutenant of Manchester on behalf of Her Majesty the Queen who sadly passed away earlier in the year.



After combined efforts from our charity and our supporters throughout the year, we are able to donate $60,000 to IFOPA In Pursuit of a Cure campaign. This provides further funding toward Gene Therapy research and the IFOPA ACT for FOP grant programme.

November 2022

The FOP Burden of Illness study is now published as a Plain Language Summary. This study outlines the complex implications of living with FOP, and how it impacts every area of a person's life. A big thank you to everyone who contributed to the survey and shared their experiences. FOP Friends was proud to be a part of such an important study and to have the opportunity to work alongside world class patient organisations and medical professionals.





Chris heads off to Dallas, Texas, for the first in-person IFOPA Drug Development Forum since COVID. It is a welcome chance to talk once again in-person with FOP researchers, drug developers, and clinicians from around the world.



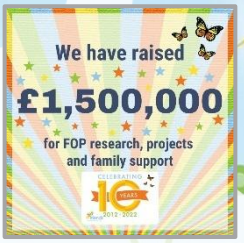
We start our project with the engineering department at the University of Salford to develop a tool to assist those living with FOP.

June 2022



Helen, one of our trustees and mum to Oliver, receive a British Empire Medal in the Queen's Jubilee Honours List. The award is given in recognition of her services to those living with FOP and their families. She is invited to receive her BEM from the Lord Lieutenant of Manchester at a presentation ceremony at The Monastery, Manchester.

We are delighted to announce on social media that, to date, FOP Friends has raised £1.5million for research, project, and family support. This is down to the love, commitment, and dedication of our small but mighty community. #HopeWins





We celebrate 10 years of being a registered charity. We have come such a long way, but there is still more work to do…



Leo and Harry take part in a research project, commissioned by Alexion and Rare Revolution, to establish the impact of living with a sibling who has a rare condition. Findings are to be reported later in the year.

Jessie Tebbutt, dentist, who attended our conference in May, shares her thoughts and learning from the experience in the British Dental Journal, raising desperately needed awareness of FOP within the professional dental community.

May 2022



We welcome family, friends, and speakers from around the world for our 4th Conference and Family Gathering. We have a wide range of presentations and workshops, as well as lots of laughs and catch ups over the three-day event. It is a weekend filled with energy and once again reminded us of the heart and soul the FOP community has.

Stephen Fry sends a video to open our conference and welcome our friends from all around the world.



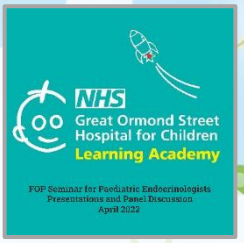
April 2022

During the month of April, we work hard as a charity and as part of the FOP community to raise awareness about FOP.



Oliver, along with Luciana and Chris, delivers a very impressive presentation to Ipsen. He shares his experience of living with FOP from a young age and provides unique insight into his daily life.

Helen is invited to take part in a virtual presentation to paediatric endocrinology students as part of Great Ormond Street Hospital's Learning Academy. Alongside Professor Keen, Dr Abou-Ameira and Dr Chesover, Helen gives a presentation about her family's journey to diagnosis and how they are learning to live with FOP. She also answers questions as part of the panel discussions.





23rd April sees our FunFeet4FOP campaign again. The campaign is now global, with people around the world sharing photos of their fun or wacky toes to raise awareness of one of the key diagnostic features of FOP: the turned in big toe. It's not just for people – pets join in too!



Helen gives a virtual presentation to radiology students at Canterbury Christ Church University.

March 2022

Chris attends his last meeting for the IFOPA as a Board member, as his term comes to a. Due to ongoing concerns regarding Covid, the meeting is held virtually once more.





We switch fundraising platforms to Enthuse, after the sudden and unexpected closure of Virgin Money Giving.

Chris attends a virtual NICE scoping meeting, as we continue to learn more about what the approval process for palovarotene will look like.





Chris attends a virtual meeting, led by Professor Matt Brown, about Genomics England and their vision for the next few years. Professor Brown is also a FOP expert who was instrumental in the FOP gene discovery.



We partner with Rare Revolution Magazine to allow us to increase our following and raise awareness of FOP with a wider audience. Our feature on Takeover Tuesday sends our charity and cause global.

December 2021



Chris attends Parliament to listen live in the debating chamber to the debate on FOP, with 7 MPs talking on behalf of FOP patients in their constituencies. Alex, David, and Lexi Robins who were instrumental to the success of the petition meet MPs.

February 2022

Trafford Council agree to light up the town hall in blue to join with iconic buildings around the world: uniting to raise awareness of rare diseases. Oliver speaks with representatives from the council about living with FOP. We are hopeful this will become an annual event.



We continue to raise awareness of FOP within the medical community by taking part in the University of Glasgow "Rare Bone" Webinar Series as part of their rare disease programme. This coincides with rare disease day.

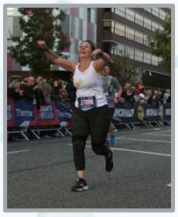
November 2021



As part of World Radiography Day, we shared key images of FOP toes to alert radiographers to one of the key diagnostic features of FOP. We publish an article in the Society of Radiographers' magazine to explain how sonographers and radiographers can assist with early diagnosis.

An inability to say no, sees Chris join the Find-a-Cure Patient Group Engagement Committee (PGEC). The PGEC provides insight, thoughts and guidance on issues faced by the rare disease community.

September 2021



As we return to 'normal' after the pandemic, we are thankful to our many runners who take part in organised events to raise money for FOP Friends. We have runners across the UK, from London to Newcastle. Our largest team is our 15-strong Great North Run team. Trustees Rachel and Fiona both take part in the Manchester Marathon.

We make our second attempt to launch a petition to ask the UK government to dedicate funding to FOP research. The petition achieves the required 100,000 votes required for debate.



June 2021



Thanks to a generous donation from Professor James Triffitt, honour of his late wife Alma, we launch the Alma Triffitt Book Award. This will be an annual event where we will gift a book to our children and young people living with FOP and POH. Books will be presented in June, in memory of Alma's birthday.

April 2021

We take part in the first Global FOP Awareness Day, uniting with other FOP patient organisations around the world. We all share the same facts and stories on social media, with a united brand. We also launch the t-shirt for us all to be as one. We are #StrongerTogether.





We also hold our #FunFeet4FOP campaign and see people all around the world sharing photos of their fabulous feet! Check out these funky socks being worn by fire-fighters in Australia!

March 2021



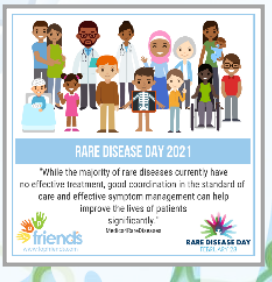
The research team at the University of Oxford send us their latest update, explaining how our donations to their team are making a real impact.

Feb 2021



Due to Covid, the IFOPA's Annual Board meeting must be held virtually. It will be held over two days so a basket of treats is sent to keep Chris well fed and watered for the event!

We join with other rare disease organisations around the world for rare disease day, to show that whilst FOP may be rare, we are a small part of a mighty rare community. We share facts about rare diseases and the battles patients face to get the diagnosis, treatments and support they need.



Jan 2021

Covid support continues. We continue to update the website as and when the guidance changes, as well as reaching out to families to ensure they have all the information they need.



November 2020



Chris is filmed against a green screen for an important FOP CME Video produced with Med Scape aiming to educate 250,000 Health Care Professionals about FOP.

Oct 2020

We are delighted to be able to support two more students as part of the Find-a-Cure student essay competition. One student focusses on FOP, while the other discusses Progressive Osseous Heteroplasia (or POH) the other rare condition we support.



July 2020

We celebrate reaching the milestone of 3000 Facebook followers.



FOP Friends supports the first ever Gene Therapy research programme with the IFOPA as part of the in pursuit of a cure campaign.



We host the StopFOP webinar, with Professor Keen and Professor Alex Bullock.

May 2020



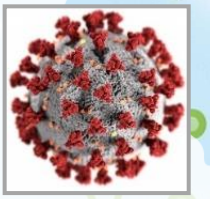
As the world comes to a standstill, our conference is cancelled, another casualty of Covid. We are incredibly disappointed. We create a message of hope for the community by asking friends, medical professionals, and researchers to create a message of unity for our followers. We share it across our social media platforms and around the world.

April 2020

For Global FOP Awareness Day, we work together with other FOP patient groups around the world by sharing facts to raise awareness of FOP and to educate people about the condition.

March 2020

The global pandemic begins. The impact of Covid-19 on the FOP community as well as the wider world has yet to be realised.



February 2020

Chris attends the IFOPA in-person board meeting in Philadelphia as part of his role at the IFOPA. Whilst there he attends an early screening of the Tin Soldiers documentary in which he, Oliver, and FOP Friends' trustee Nicky with her daughter Isla all feature.





During his visit, Chris and his fellow IFOPA board members have a guided tour of the Mütter Museum where two FOP skeletons are now displayed. Harry Eastlack, a resident since 1973, was joined by Carol Orzell in May 2018. It was Carol's wish to donate her body to be displayed next to Harry to assist future surgeons and medical professionals – her only request: that her jewellery collection goes with her!

January 2020

We are most thankful to the amazing team at "And Digital" in Manchester, led by Jamie and Mike, who donate their time and skills for free. The new website has all the information you need about FOP as a condition, and all about FOP Friends as a charity. We can offer downloadable resources to support fundraisers as well as information for people who are coming to terms with a new diagnosis. Perhaps most importantly, there is information for people living with FOP in the case of an emergency including the latest ICC medical guidelines.



December 2019



Amish Patel sees 2019 out in style when he takes part in a skydive for his brother Hamish, who has FOP. Amish, who lives in Queenstown, New Zealand takes a leap of faith and completes a 12,000 ft tandem skydive for Hamish who lives in the UK.

November 2019

Chris attends the IFOPA Drug Development Forum in Florida. Whilst attending Forum, Chris also runs the meetings for the national FOP leaders from around the world, followed by taking the stage as part of a panel of patients and parents talking about FOP and answering questions.







Hannah, who began her career at FOP Friends in 2015 as a student volunteer, says farewell as she moves to pastures new to pursue a career in psychology.

September 2019



FOP Friends have another team of fundraises taking part in the Great North Run. We have a special guest runner this year – one of our FOP specialists, Doctor Bubbear, from the RNOH.

July 2019



In July, Oliver's family are devastated when Grandma Ann passes away suddenly. Ann was well-known and well-loved in the North-East where she held monthly line dancing social events to raise both money and awareness. Over the years, Ann's line-dance fundraisers have raised over £40,000 for FOP Friends. She is sadly missed. Donations to FOP Friends are requested in lieu of flowers.

June 2019



Helen and Chris are delighted to be awarded the 2019 Jeannie Peeper Award for "Outstanding International Leadership". The award recognises their exceptional commitment to the FOP community through their leadership, service, family support, fundraising, and awareness-building, both in the UK and world-wide.

May 2019



FOP Friends releases "Supporting a Child with FOP: a practical guide to their learning experience" This book is made possible thanks to a generous grant from Regeneron Pharmaceuticals. The book is an essential and informative guide for anyone supporting a child with FOP, offering clear information and advice to

parents and teachers to help a child with FOP navigate their school journey as well as their life beyond the classroom.



Helen and Chris are delighted to represent FOP Friends at the Oxford University's Vice-Chancellor's Dinner. They receive the invitation in recognition of the charity's contribution to their excellent FOP research team, led by Dr Alex Bullock.

April 2019



People say they would walk over hot coals for their kids – well we did! #FunFeet4FOP and #FireWalkforFOP combine for a most fabulous fundraiser. Twenty-two firewalkers including two FOP families, two local councillors from Trafford, Manchester (Amy Whyte & Steve Longden), and FOP nurse specialist Jackie, all burn their toes to raise awareness for FOP.

March 2019



FOP Friends hosts its second FOP Family Weekend. They take children with FOP and their families for another weekend together at Center Parcs. This has been made possible thanks to grants secured by the charity.

February 2019

We launch Facebook Fundraiser – supporters can now raise money and awareness for FOP on Facebook for their special celebrations.



Helen receives acknowledgement from The Duke and Duchess of Sussex, coincidentally on Rare Disease Day.

FOP Friends donate $15,000 towards the IFOPA ACT for FOP Grant program helping to fund novel FOP research.

January 2019

We launch our Supporter Spotlight programme. We are thrilled to be able to celebrate the many people who have joined us on our journey to find a treatment and a cure for FOP.

Isla's godmother has a simple idea to raise funds for FOP Friends: take a group of friends, each bringing a few unwanted items/gifts, add an entry fee, a raffle, and some fizz… what you have is a great night, recycling, the thrill of finding some treasure – all while raising much-needed funds for #FOPFriends. A fabulous night is had by all.

December 2018



We launch our FOP Friends beanie hats.

Oliver gives an amazing presentation talking about FOP & Me, to the colleagues of Regeneron UK at their Christmas conference. He receives a standing ovation – he's following in his dad's footsteps.

Boxing Day sees a wonderful group get dressed up and visit 35 pubs, Irish dancing whilst raising money for charity.

November 2018

Chris arrives safely in Baltimore for the IFOPA's 30th Family Gathering.



Our first-ever Christmas card campaign is launched.



Oliver visits Sale Grammar School, where he speaks to sixth form students for an hour about FOP.

FOP Friends is acknowledged by the University of Oxford as a valued supporter.

October 2018

Gig for Isla 5 is another success - the dedicated community on the Isle of Wight dance the night away to the fabulous L & M Band, raising thousands of pounds for FOP research.

We drum up some local support in Manchester with Slater Heelis holding a Dress Down Day; Altspace Coworking Office holding a brilliant bake-off; and COS Bookkeeping holding a charity raffle.

September 2018

Harry, Jack, Judith, Alistair, and one of our FOP specialists Dr Bubbear, all take on half marathons across the country.



Twelve runners head to Newcastle to take on the Great North Run this year, while Josie Heade runs an impressive 100k to raise awareness and funds for FOP.

Manchester Round Table & Cheadle & Gatley Ladies Circle host the first ever Cheadle Big Charity Pub event, with 25% of the profits going towards FOP Friends.



Wonderful members of Team Isla organise a charity ball exceeding £2500!

August 2018

Alexis completes the Three Peaks Challenge for FOP Friends.

July 2018

The wonderful Melissa and Freya both take a 'Chop for FOP,' raising funds for FOP and donating their hair to the Little Princess Trust.



We are thrilled to unveil our new FOP Friends' leaflet.

June 2018

FOP Friends receives a grant from Jeans for Genes to help fund the 2019 FOP Family Weekend.



Julian cycles over 100 miles, from Wolverhampton to Aberdovey, to raise funds and awareness for FOP.

Belinda Davis and our wonderful friends at Dell Park Farm Windsor provide parking at the Royal Wedding in aid of FOP Friends & raise £644!

May 2018



William Jones, 11, has supported FOP Friends through lots of different fundraisers and decides to hold another sweet stall to raise funds and awareness for FOP.



Manchester University Boat Club decides to fundraise for us again, with the team taking on the Manchester 10K.



Our third Conference and Family Gathering takes place and is a resounding success! With talks from the world leading FOP experts, workshops, and clinical consultations – everyone in attendance has a wonderful time connecting with one another.

April 2018

Jane Deane takes on the Manchester Marathon, while DAC Beachcroft LLP holds a dress down day at work to raise FOP awareness and funds.



T-UK Stockport Taekwon-Do choose FOP Friends as their Charity of the Year and Chris is thrilled to attend their evening dinner and accept a cheque of £613.

Chris is honoured to receive a letter from Oxford Thinking, which thanks FOP Friends for the generous funding of FOP research at Oxford University.



#FunFeet4FOP is an immense success for the third time, with lots of fun feet making an appearance. We are grateful and honoured to see the BalletBoyz choose to help raise awareness for FOP! Hummingbird Bakery in Guildford supplies cakes for a #FunFeet4FOP bake sale.

Mick Henry runs the Connemara Marathon for Friends of Rion, while Sharon Moore takes on the Newport Marathon for Friends of Annalese.

March 2018

FOP Friends are pleased to announce that they have been awarded a grant from the Big Lottery Fund to help fund their 2018 UK FOP Conference and Family Gathering.

University of Manchester Boat Club take on a 24hr row in aid of FOP, raising £1023.77. Meanwhile, Natalie completes the inaugural London Landmarks Half Marathon, raising £350.

Chris presents at the Genetic Disorders UK 2018 Leadership Symposium. His 'In it to win it! Changing the future for children born with FOP' presentation focuses on building a sustainable, small charity, supporting patients and families and 'punching above your weight' in pursuit of your charity's ultimate goals.



February 2018



Chris attends the 7th edition of the EURORDIS Black Pearl Awards alongside other FOP leaders from Italy, Germany, and France.

January 2018



Chris and Helen are named the UK's 883rd and 884th Points of Light. The Points of Light programme recognises outstanding volunteers who are making a real difference in their communities. It is awarded by The Prime Minister, Downing Street.

November 2017

Bex completes a 61-day dry-athlon, raising a sparkling £500 in the process. Meanwhile, Amy celebrates her 50th Birthday in style by jumping 855ft from the top of Las Vegas' Stratosphere Tower.

FOP Friends feature on the University of Manchester's Volunteer Hub to help raise awareness and recruit student volunteers.

FOP Friends is also awarded Charity of the Week in the "The Week" magazine, December 2017



FOP Friends present their ‘Tree of Thanks for Children in Need’ at the annual St. Alban’s Church Tree Festival. Oliver's little brother, Leo, contributes his own ‘Little FOPers’ trees.



October 2017

Chris attends the 3rd IFOPA Drug Development Forum in Sardinia, Italy, and opens the event with his inspirational ‘Along for the Ride’ speech.

FOP Friends is proud to be listed and recognised in the 2016/17 The Oxford Thinking - The Campaign for the University of Oxford report, as one of their valued donors.



The charity is awarded Runner-Up as Charity of the Year at the Altrincham & Sale Chamber of Commerce Awards.

September 2017

Eight runners take on the Great North Run, raising over £5,000 for FOP research, with special support from six different Nationwide branches.

August 2017



Trekking an impressive 800 miles, Rebecca completes her Appalachian Trail journey, raising an incredible £2,000 along the way.

July 2017

Sophie, Becky, and friends host a Garden Fundraiser and raise £670, taking FOP Friends of Isla’s fundraising page to over £40,000

Stewart and friends cycle over 500 miles across Scotland to raise awareness for FOP.

June 2017

FOP Friends partner with Genetic Disorders UK.

Savills continue their support by holding a Golf Day.

May 2017

Helen and Chris attend the University of Oxford Vice-Chancellor's Circle evening. The invite is extended to us to thank us for the support we, as a community, give to the FOP Research team at Oxford. Helen and Chris are honoured to represent all the families and friends.



April 2017



The second #FunFeet4FOP event takes place on International FOP Awareness Day, with some fab feet (including a farm animal or two) helping to boost the profile of FOP.

Jo and Jack take on a marathon each, with Jo running in London and Jack in Southampton.

March 2017

In March, over a dozen FOP families are able to enjoy a weekend at Center Parcs Sherwood Forest thanks to funding from Children in Need.

February 2017

Anoushka, 16, from Azerbaijan, arranges for five groups of swimmers from the Baku Sharks to swim the equivalent of the English Channel over two weeks. Each group swims an impressive 32km.



Chris attends the Eurordis Black Pearl Rare Disease Gala in Brussels.

January 2017

Chris, Oliver, and FOP Friends receive an exciting acknowledgement in Fiona Cummins' debut novel 'Rattle'. Chris consulted on the book as one of the main characters suffers from FOP. One to look out for in the cinemas soon!

December 2016

FOP Friends decorates a Christmas tree at the annual event at St. Albans, with decorations made by the FOP families from the Family Gathering in May.

The “Don’t send me a card” appeal proves an effective way of saving the trees and raising some £s for FOP Friends.

October 2016

Organised by Margot Charlton for the third year in a row, the charity Gig for Isla is held on the Isle of Wight. The L&M Band play 60’s tunes to dance the night away with attitude.

Chris attends the 2nd IFOPA Drug Development Forum in Boston. FOP Friends provides $15,000 towards the event, generating a total $30,000 thanks to fund matching.

Helen and the boys visit Center Parcs to check out the facilities for the FOP Family Weekend.

September 2016

Several FOP Friends champions take part in the Great North Run, and the London to Brighton cycle.



August 2016

The eBay Charity UK sale for FOP Friends proves an enormous success.

July 2016

Kevin Gordon completes a sponsored cycle from Lands’ End to John O'Groats in 15 days, helping to raise awareness of FOP.

June 2016

The NERDOC guys ride an amazing 270-mile round trip from one UK coast to another for the second time.

Dr Keen delivers a presentation on the IFOPA’s FOP Connection Registry at the Bone Research Society meeting.

FOP Australia holds an official launch, marking one year since the organisation was established by Lara Boniface, mum of Jarvis with FOP.

May 2016

Savills take part in a 100k bike ride to raise funds and awareness for FOP Friends and the charity Dreams Come True.

The second 'FOP Friends Family Gathering' is a remarkable success; Dr Keen sees patients in the morning before going to run the Manchester 10k to support FOP Friends, then is back to see more patients after!

April 2016



FOP Friends launch the #FunFeet4FOP campaign in celebration of FOP Awareness Day.

This is the first national (now international) campaign, encouraging supporters to wear #FunFeet4FOP.

The weekend is an incredible success with many people posting photos of their weird and wonderful footwear.

March 2016

Rachel Winnard appears on ITV's 'Emergency Room with Jeremy Kyle' to raise awareness.

Trustee Rachel Almeida is proud to attend at the Genetic Disorders UK Conference, London, on behalf of FOP Friends.

The Hospital Saturday Fund awards FOP Friends a grant that will fund a new microscope for the FOP research team at Oxford.

Chris attends his second FOP Italia meeting in Livorno. An incredibly positive conference with lots of exciting developments in the field of research, from all around the world.

February 2016

FOP Friends approved for full membership of EURORDIS on 8th February.

Chris heads off to Florida for a few days in the sun his annual in-person board meeting for the IFOPA.

Luciana tells her story to a national newspaper to raise awareness of FOP.

Adobe choose FOP Friends us as beneficiary of their Charity of the Year.

FOP Friends is honoured to be invited to the prestigious Eurordis Awards and Black Pearl Evening in Brussels, along with many FOP leaders from around the world.

We celebrate Rare Disease Day by announcing that we, along with FOP France, Swiss FOP, and other donors, have funded the excellent research team at Oxford for yet another year.

January 2016

FOP Friends' oldest supporter Mrs. Laura Gregory celebrates her 102nd birthday and requests donations to FOP Friends, in lieu of gifts, to support the search for a treatment for her grandson Oliver.

We are excited to announce the award of a grant from The Big Lottery Fund to help us fund the UK FOP Conference and Family Gathering 2016 .

FOP Friends supports the IFOPA competitive research grant programme which sees FOP Friends providing 25% of the funding towards the "Allosteric inhibitors of ALK2 for FOP therapy" project at the University of Oxford.

December 2015

We are thrilled to be selected as part of BG Group's share dealership programme.

November 2015



The Natural History of Flare-Ups in FOP is published in the Journal of Bone and Mineral Research. Chris is credited as one of the contributors.

PwC Manchester present us with the cheque from their Charity of the Year activities; they raise over £30,000. It is their most successful fundraising year to date.

Clementia open their Clinical Trial Site in London, UK, under the supervision of Dr Richard Keen.

Chris flies out to Amsterdam for the Dutch FOP Symposium.

Amy Whyte organises a 'Channel Swim' at the local swimming baths which is attended by CBBC's Katie Thistleton.

October 2015

BBC's Casualty run a story about a character with FOP. Whilst FOP was only touched upon briefly, it did put FOP 'out there' once more, hopefully raising further awareness.

FOP Friends is selected as Avaya's Charity of the Year; many exciting fundraising activities are planned.

September 2015

The amazing Great North Run Team 2015 raise £14,000.

August 2015

We are delighted to announce our first FOP Friends employees, David Pilkington, and Mari Jones, funded thanks to GDUK and other minor grants: a milestone in the charity's history.

June 2015

Chris flies to Boston for the first IFOPA Strategic Planning meeting. He visits the FOP research team and laboratory at Harvard University, who are collaborating with the team at Oxford to find a treatment. Next he visits Blueprint Pharmaceuticals to learn of their progress and then goes on to Regeneron Pharmaceuticals in Tarrytown, New York. Chris finishes his whistle-stop tour with a quick visit to the FOP lab at the University of Pennsylvania.

PushOn adopt us as their Charity of the Year.

Jake (7) and Amy (4) have the idea to sell some of their unwanted toys and raise £75 for FOP Friends.

March 2015

Chris is honoured to be invited to and attend, the 1st UK Genetic Disorders Leadership Symposium in London.

An update meeting at Oxford with the excellent FOP research team. Chris, Rachel, Nicky, George, and Marian all attend.

Chris visits Rome for the FOP Italia conference: twelve countries coming together to find a cure for FOP.

February 2015

Chris visits a very cold Philadelphia for his in-person IFOPA board meeting. He visits the Mutter Museum to see the world-famous skeleton of Harry Eastlack.

Rachel Winnard and her family travel to Australia to visit their new little FOP buddy Jarvis, a friendship they formed at the Gathering.

January 2015

Clementia open first European trial site in Paris, which some of our UK FOPers then took the opportunity to take part in. Everyone in the FOP community thank you for furthering the research.

The Scotts and the Bedford-Gays are delighted to attend Richard Simcox's Burns Night Gala in aid of FOP in Aberdeen. A superb evening, hosted by one of FOP's greatest and longest supporters.

December 2014

FOP Friends decorate their annual Christmas Tree at St. Alban's Church, Cheshire, with photos of FOPers from around the country.



BBC's Katie Thistleton appears on Celebrity Mastermind and her chosen charity is…FOP Friends!

November 2014

The website is updated with personalised "Friends" pages to recognise and celebrate the amazing people who make up FOP Friends.

Chris attends IFOPA's first Drug Development Forum in Boston with over 100 researchers and interested pharmaceutical companies in attendance. A milestone in the search for a treatment and cure for FOP.

October 2014

FOP Friends makes an incredible donation of £70,000 to help maintain the research team at the University of Oxford for another year

September 2014

Two teams of FOP Friends' runners take part in the Great North Run and the Windsor Half Marathon, raising £21,000 in total.



August 2014

FOP Friends' Drug Developer begins work at the University of Oxford, alongside the excellent existing team.

We are adopted by companies PwC Manchester and Avaya as their "Charities of the Year"

June 2014

Friends of Oliver proudly becomes FOP Friends® to reflect the growing number of UK families now raising money together to support FOP research

May 2014



FOP Friends organise a family gathering in Manchester, uniting UK FOP families for the first time in 12 years. The world's experts in FOP are also in attendance, including Prof. Kaplan

March 2014

£65,000 in funding is provided by FOP Friends to employ a full-time medicinal chemist within the University of Oxford's FOP Research team

December 2013

We are awarded a grant to employ a Senior Drug Developer at the University of Oxford

We make our annual donation to the University of Oxford's research team, this time for £20,000.

March 2013

Our first newsletter is published to celebrate the many different fundraising events being held across the country.

We are awarded a grant for £16,000 from GDUK to fund a Charity Administrative Assistant.

December 2012

We make our first donation to the University of Oxford to support its research team: £10,000.

December 2012

Chris becomes an 'informal' member of University of Pennsylvania FOP research team to collaborate in development of the International FOP Flare-up survey.

June 2012

FOP Friends of Oliver becomes a registered charity in England and Wales #1147704.



January 2012

FOP Friends of Oliver website goes 'live' together with "What is FOP?" animated video, narrated by Stephen Fry.

April 2011

Grandma Ann hosts the first of many line dancing evenings. They prove to be one of our biggest fundraisers, raising £16,000 to date.

2011

Chris is elected to the Board of the IFOPA.

2011

Friends of Oliver is website created to celebrate and thank those who are supporting Oliver and the research team at Oxford.

2010

Oliver's family and friends begin fundraising to support the research team at Oxford.

April 2009

The Bedford-Gay family receive the devastating diagnosis that their son, Oliver, has FOP.

November 2008

Oliver has mysterious lump, which appeared from nowhere, removed from the back of his head at just 8 months old.

March 2008

Helen and Chris welcome Oliver Peter to the world. He is a beautiful baby and much-loved. He is perfect apart from his turned in toes. All the medical professionals just think he has 'funny toes' and no one gives any cause for concern.

Thank you (2025)

We would like to acknowledge our ever-growing supporters. A list that we hope will grow year on year.

FOP National Organisations

FOP France

Trusts / Grants

The Zochonis Charitable Trust

Russell Lang Charitable Trust

Jeans for Genes

Corporate Supporters

Skillsarena

Regeneron Pharmaceuticals

Ipsen

Incyte Corporation

Costco

Kidd & Spoor Solicitors

DHL Foundation

Ecclesiastical

Donors of time and resources

Stephen Fry: Narrated FOP Animation

Skillsarena: Director's time

Foliozine: FOP Friends Logo

Community / Clubs and Associations

Manchester Round Table

Royal Northumberland Yacht Club

Manchester 41 Club

The Willows – Women's Institute

Uxbridge Rotary Club

Fundraisers

We would like to thank everyone who undertook a fundraiser or personal challenge to raise awareness and funding for FOP Friends.

Please accept our apologies if we have omitted anyone. If you notice any omissions or would like to be removed, please contact us.