www.fopfriends.com

Annual Report

& Financial Statements

Year Ending 31st December 2024

[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 Almeida

(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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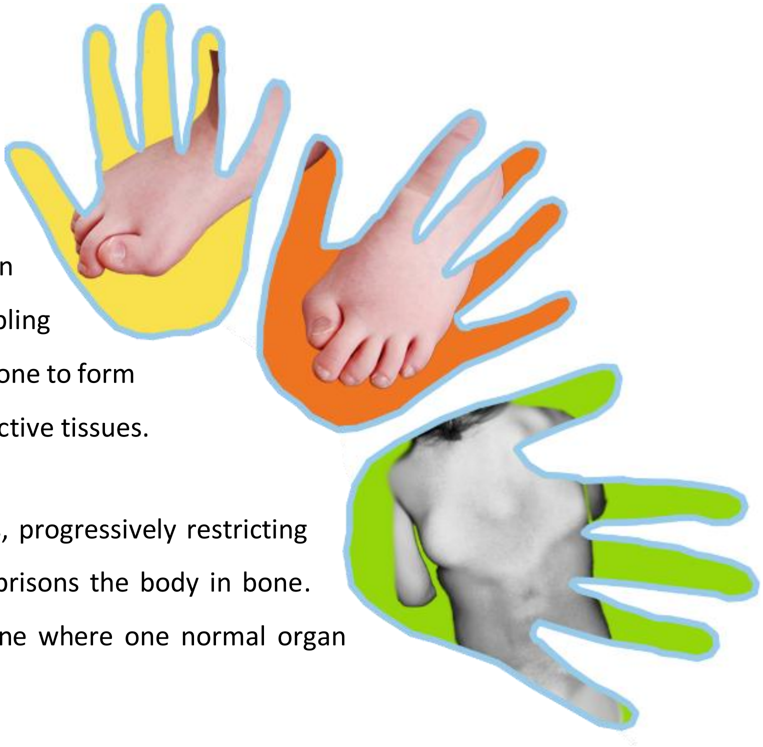
What is Fibrodysplasia Ossificans Progressiva (FOP)?



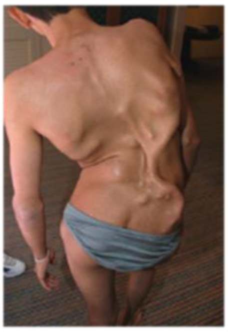
Fibrodysplasia Ossificans Progressiva (FOP) turns otherwise healthy people into human statues: a healthy mind locked inside a frozen body. FOP is one of the rarest and most disabling genetic conditions known to medicine, causing bone to form in muscles, tendons, ligaments, and other connective tissues.

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 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

A Shorter Year, A Stronger Focus

Welcome to our annual report! I know it feels like we were just talking about our last one, which ended in February 2024. And you’re right, this report covers an eventful nine to ten months in the FOP world: 2nd March 2024 – 31st December 2024. This shorter period is due to a decision by our trustees to move our charity's financial year end to align with the calendar year.

We’re making this change so that, moving forward, our annual report will match the ‘end of the year’ most people think of – December 31st – rather than an earlier date tied to our formal registration. We hope this shift will help us all reflect each December on the closing year and set our charity's New Year's resolutions and plans for the year ahead.16 Years of Hope and Action

We are now celebrating our 13th year as a fully registered charity and an amazing 16 years of working for the FOP community to fund research, support families, and find effective treatments and a cure.

Our journey began in 2009 when my eldest son, Oliver, was diagnosed with Fibrodysplasia Ossificans Progressiva (FOP) at the age of one. That day changed our lives, but it ultimately led to the creation of FOP Friends. Together, with our trustees and community, we have been changing the lives of many living with FOP.

At the time, there was a patient support group, FOP Action, but no UK charity focused solely on FOP. There was, however, critical research taking place at the University of Oxford. Our first goal was simple: fundraising to support that research team. Soon after, we became a registered charity, initially as ‘FOP Friends of Oliver’.

Our ambition quickly evolved from solely funding research to taking on the wider challenge of finding a treatment or cure, while fully supporting all UK families affected by FOP. This pivotal moment led to the creation of 'FOP Friends,' consolidating our mission as FOP Action officially merged into our organisation.

Since registering in 2012, we've spent the past 13 years growing from a small, grassroots effort into a nationally and internationally recognized organisation. Our work now spans everything from awareness-raising to policymaking, but always with one central goal: improving the lives of everyone living with FOP.

- **We fund research**, investing in projects that are bringing us closer to a cure.
- **We support families**, providing resources and assistance to help them navigate the challenges of this rare condition.

- **We raise awareness**, through education and advocacy campaigns, increasing public knowledge of FOP, which can lead to earlier diagnoses and improved patient care.

United in Hope

We are not done yet, of course, but as the theme of 2024’s Global FOP Awareness Day declared, we remain ‘United in Hope’. We are incredibly lucky to have so many people working tirelessly toward our shared goals. This includes our research team in Oxford, our international research partners, our network of doctors, and all the committed individuals moving forward together.

It is remarkable that such a small community has attracted significant attention from multiple pharmaceutical companies. We currently have four pharmaceutical companies running trials for FOP treatments, alongside one academic trial (Stop FOP), and advanced Gene Therapy research that FOP Friends helped fund with the IFOPA and other national FOP organisations. This is all happening while our researchers continue to unlock the secrets of FOP, offering more possible treatment options and knowledge that can change lives.

However, we can’t do this without your support.

We are forever grateful for the dedicated support of our community, donors, and volunteers. Your invaluable contributions have made all this possible and have already made a significant difference in the lives of our FOP community. Together, we are fighting for a future where FOP becomes a mere inconvenience.

In these challenging times, we hope more people will join us in our mission. Your support, whether through donations, volunteering, or spreading awareness, helps us continue to bring hope to families affected by FOP and accelerate our progress towards treatment and, ultimately, a cure.

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.

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Trustees

There must be at least three trustees. With the exception of 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 Almeida – 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 lead teacher, working in a primary school. She is a 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.
- Lectured at Newcastle University – OFSTED.
- Lectured at Leeds University - Teaching Students.

John Lever - Trustee

When John heard about Oliver and others with FOP, he wanted to do what he could to help. As a first step, he produced a video through his creative company, claritycomms.com, engaging Stephen Fry to provide the voice over and to subsequently tweet to his millions of followers. John is now enjoying exploring some exciting innovative ideas to help FOP Friends raise awareness and funding. He feels it is a privilege to be part of such an inspiring team, on such an important mission.

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.

Nicky Muller – Trustee

Nicky is passionate around raising awareness of FOP and raising funds to get the cure that is in all our dreams. Nicky's daughter Isla was one of the youngest children to be diagnosed with FOP. After coming to terms with the initial shock of diagnosis, Nicky began fundraising to support the search for treatments. Along with her network of friends and family, Nicky continues to organise a series of successful events and sponsored sporting activities to raise funds in aid of FOP Friends. Nicky works part-time as a Marketing Campaigns Manager for Avaya, and she has used her business contacts to gain support for the charity from several large companies and organisations.

Education

- 1st Class Management degree from University of Brighton.
- More recently completed various Marketing courses around social media, speaking engagements, event management, digital marketing.

Experience

- After graduating, Nicky worked for the UK charity The Duke of Edinburgh's Award where she was a Marketing Coordinator and managed events and a large show trailer that travelled the UK. The last 11+ years have been spent as a marketer within the IT industry with a wide variety of experience in campaign management and field marketing.

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 disease 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 hase become a Trustee of FOP Friends to continue his commitment and affection for 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.

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 will 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.

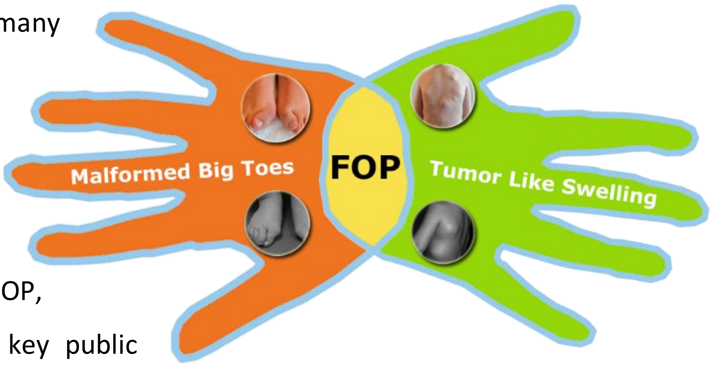
To support charities and organisations in the UK and abroad by undertaking charitable activities to fund research; and to provide help, support, care, and treatment for people affected by FOP and related conditions.

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

University of Oxford

StopFOP

The FOP Research team continues to support work on the StopFOP trial, an academic clinical trial of a potential treatment for FOP, repositioning saracatinib (AZD0530), a drug initially developed for cancer by Astra Zeneca. This potential treatment was identified by the University of Oxford research team utilising multiple scientific techniques over many months to review and compare several kinase inhibitors to identify one that might demonstrate specificity for ALK2 kinase. The overactivity of this enzyme plays a key role in the rogue pathway that leads to abnormal bone formation (heterotopic ossification) in people with the genetic mutations leading to FOP; identification of saracatinib by the Oxford team entirely triggered and enabled the StopFOP clinical trial and optimised the probability of a successful outcome and identification of a future effective treatment. This critical research at the University of Oxford was funded by FOP Friends.

The primary goal of the StopFOP trial is to assess its safety and efficacy in preventing new bone growth in adult FOP patients. Most participants moved from the initial phase to the open-label extension phase where they all receive saracatinib, this progression suggests patients tolerated the treatment well and as such wish to remain on the trial. We expect formal results from the trial late in 2025.

University of Pennsylvania

Resilient Patient

As detailed in last year's annual report, UPenn were investigating a FOP patient who was a healthy young man with classic FOP but who had an extreme lack of FOP bone growth and nearly normal mobility. The results of this study were published in February 2024 in the 'Resilient Patient Project' publication in the Journal of Bone and Mineral Research.

The paper confirmed earlier findings that the patient has decreased production of MMP-9 leading to the conclusion that the MMP-9 enzyme, an inflammatory protein, is a critical driver of the abnormal bone formation in FOP. A finding confirmed in mice models, where blocking MMP-9 prevented FOP bone formation. This discovery directly led to the advancement of andecaliximab (an MMP-9 inhibitor) being developed as a potential treatment for FOP by Āshibio.

ASBMR Recognition

We were also pleased to see our long time FOP research leader, Professor Eileen Shore, being recognised for her significant contributions to FOP research by the American Society for Bone & Mineral Research (ASBMR) in September 2024.

University of Massachusetts

FOP Gene Therapy

Via the IFOPA, FOP Friends were one of the first contributors to the FOP Gene Therapy programme, something we continue to support to date. This research, led by Dr Jae-Hyuck Shim and Dr Guangping Gao, concluded its initial proof-of-concept work and is now focused on the essential steps required to take their work into human trials. Gene therapy is a key area of hope for FOP, which is caused by a single-gene mutation (ACVR1). This work has the potential to offer a long-term cure to permanently correct the underlying FOP gene mutation, although there remains a long way to go. We are hopeful that Dr Shim will attend a future FOP Friends' Conference and Family Gathering in-person to share their work directly with our UK FOP community.

Industry

Ipsen

Ipsen's second trial for a second potential FOP treatment, known as FALKON, continued through 2024. FALKON is studying fidrisertib an ALK2 kinase inhibitor. Since Ipsen's first potential treatment, Palovarotene (Sohonos), will not be available within the UK or Europe, fidrisertib provides more hope for a potential treatment from this company. The FALKON trial is active but is no longer recruiting. Participating patients are aged 5 years and older. We await the results of this trial which are hoped in late 2025 or 2026

Incyte

Incyte's clinical trial for FOP is known as PROGRESS. This trial is testing zilurgisertib, an ALK2 kinase inhibitor. It has continued through 2024, actively recruiting patients from the age 6 to 12 throughout 2024. The adult cohort has already completed enrolment. The trial continues throughout this year with initial results late 2025 or 2026.

Regeneron

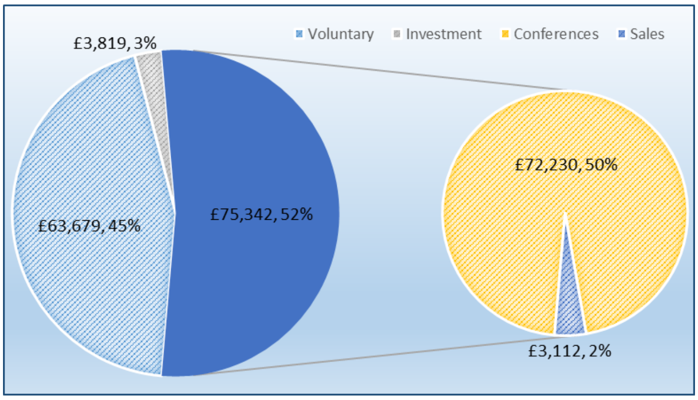
Garetosmab, Regeneron's potential treatment for FOP, continued its OPTIMA trial through 2024. Garetosmab targets a different mechanism of action to StopFOP, Ipsen and Incyte with an antibody designed to block Activin A which is a key driver of unwanted FOP bone formation. This initial trial is restricted to adults only and is active but not recruiting. Initial results are anticipated late in 2025.

Āshibio

In 2024 Āshibio enrolled its first patient in their ANDECAL clinical trial. Initially limited to sites within the USA, this trial is investigating the safety and efficacy of andecaliximab for FOP. Excitingly, this is yet another different mechanism of action to be targeted and was discovered thanks to the work of the UPenn and Mayo labs following the 'Resilient Patient' study which was published in 2024. This patient, with the classic FOP mutation, was protected from severe HO due to an additional mutation in the MMP-9 gene. Andecaliximab looks to inhibit the production of MMP-9. We hope that, following this initial phase in the USA, the trial will be expanded internationally. Āshibio are hoping to allow recruitment of children from as young as 2 years old if safety data indicates, with progressive steps down in patient ages.

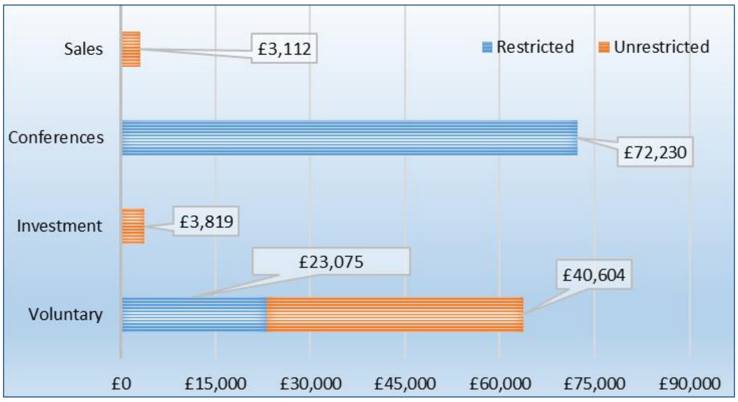
How we raised our money

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 decrease of 14% in voluntary income to £63,679 overall with another drop in unrestricted funding, mostly from community fundraising efforts of 4% to a total of £40,604 from £42,249 the previous year. This is partly due to a non-conference year but also as we have focused on completing existing projects before seeking further funding for future work.

We saw an increase in revenue generated from sales to £3,112 from £906 the previous year. From a total £142,840 incoming resources, £95,305 (67%) were restricted. The remaining £47,535 (33%) being unrestricted.



Within this charity year we held our biennial conference and family gathering which resulted in the large increase in income from "Conference". Unfortunately, we also saw a continue reduction in unrestricted voluntary income, continuing the trend from previous years, although the rate has slowed.

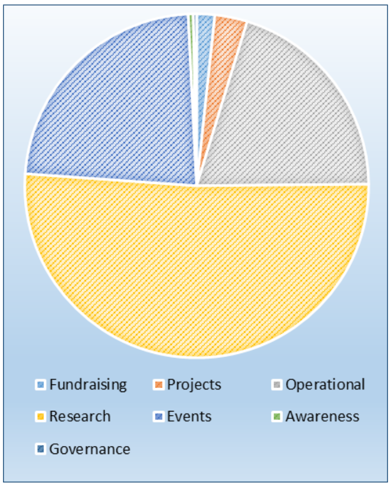
How we spent money raised

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 93% of all fundraised money directly supports our charity objects of; family support; awareness; and funding research. This is a small % drop from previous year is largely due to an increase in fundraising costs and reduction in fundraising itself. [Note: Voluntary Donations VS Fundraising Costs]

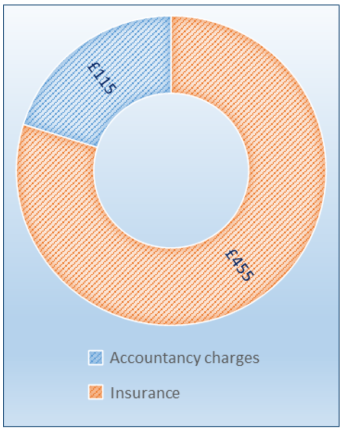
Uniquely, in this charity year, FOP Friends donated **£93,754** to FOP research. This included the continued funding of the FOP research team at the University of Oxford, and funding toward the IFOPA In Pursuit of a Cure campaign to fund conntinued gene therapy research.

We anticipate providing circa £60,000 in research funding to the University of Oxford, as the main beneficiary of FOP Friends, and one of a small number of teams in the world conducting research into FOP. We also anticipate supporting several other FOP research projects through the 'In Pursuit of a Cure' work.



Fundraising costs of £3,105 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 £570 is 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

Our achievements continue to be a testament to the power of dedication over size. Operating with a very small team and bolstered by the addition of Dr. Rankin as a trustee, we have maintained an intense pace of work throughout this reporting period. We have attended many meetings and engagements, conducted both in-person and virtually, and reaching across the UK and internationally. Crucially, every single action we have taken is driven by our steadfast commitment to our cause and the well-being of the families we support. It is this deep-seated determination that ensures our focused activity translates directly into a significant and positive impact where it matters most.

FOP Awareness

We recognised FOP Awareness Month with our #FunFeet4FOP campaign to draw attention to the 'funny toes' – a key indication to a possible FOP diagnosis. We also shared social media posts with facts about living with FOP and sold t-shirts with the Global FOP Awareness Day logo, partnering with other FOP patient organisations around the world.

POH Awareness

We partnered with Rare Revolution magazine again, this time to raise awareness of progressive osseous heteroplasia, or POH, the sister condition to FOP. POH is even rarer than FOP, with fewer than 100 people worldwide known to have the condition. Including our families with POH remains a priority for us as a charity, reinforcing our belief that we are truly stronger together.

FOP Friends Conference and Family Gathering

Our biggest success this year was hosting our fifth Conference and Family Gathering in Manchester. We believe in the strength of a global community, and although the event is UK-focused, we were thrilled to welcome attendees from 15 different countries! This international participation confirms our conference's standing on the global FOP calendar and underscores the significant positive difference it makes for our community.

At the conference, we were also proud to launch the second version of our schoolbook: “*Apoiando uma criança com FOP: Um guia prático para auxílio na jornada escolar”*. This was an updated guide, translated into Portuguese for families living with FOP in Brazil. FOP Friends collaborated with a parent of a child with FOP in Brazil, along with Dr Patricia Delai to translate the guide as well as update the information to ensure it was relevant for their school system.

Mayoral recognition

We were honoured to be selected as Mayor Amy Whyte’s Charity of the Year, as she became Mayor of Trafford. Throughout the year, Mayor Whyte raised money and awareness for our charity across the borough.

Alma Triffitt Book Award

June brought the Alma Triffitt Book Award, where we distribute books to all our children and young people who are living with FOP or POH. This now annual project is made possible thanks to a generous gift from Professor Jim Triffitt in loving memory and celebration of his wife.

IFOPA Drug Development Forum

Chris has attended every drug development forum since its inception in 2014. In June, he travelled to Sweden for the 2024 DDF and was delighted to be asked to open the afternoon session. The drug development forum brings together doctors, research, and a small number of patient representatives with the goal of growing FOP research internationally.

Funding UK FOP Research

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

Manchester Rare Conditions Conference

Helen attended a Manchester Rare Conditions conference at City Labs 1.0. There were several impactful presentations, including from Dr Lucky McKay from Medics for Rare Disease. Kath Bainbridge, Head of Rare Diseases and Emerging Therapies discussed the UK Rare Disease Framework and action plan.

Partnering with MedicAlert

We partnered with MedicAlert to support our families in case of emergency. Helen set up a number of meetings between MedicAlert and the FOP team at the RNOH. This was to ensure MedicAlert had the necessary information on their system in case one of our families needed to call in an emergency.

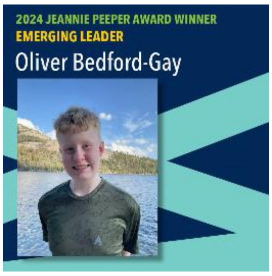
Adult Rare Bone

Andrew attended the first meeting of the Adult Rare bone disease collaborative network. Representatives from the founding charities, which includes FOP Friends, were present, along with medical professionals including Professor Richard Keen.

University of Manchester

Helen recently attended 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. The fair was a success, and we were fortunate to attract the interest of many high-quality students keen to volunteer. We are grateful for the opportunity to partner with such dynamic young people.

Jeannie Peeper Awards



Oliver's tireless advocacy and awareness-raising for those living with FOP was recognised with the Emerging Young Leader Award from the International FOP Association (IFOPA). This prestigious international award recognises young people who have made a significant impact on the FOP community through their leadership and service.

Oliver's contributions include championing campaigns like #FunFeet4FOP to educate the public and medical community about early symptoms; presentations to groups from Beaver Scouts to pharmaceutical companies; attending fundraising events; sharing his story, and more.

Funding International Research

We were delighted to 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. Our commitment underscores our belief in working collaboratively with the worldwide FOP community to make a future free from FOP a reality. Together with the IFOPA, FOP Italia and other we were also amongst the first to fund groundbreaking FOP Gene Therapy research, research that continue to this day.

Kidz to Adultz

We were delighted to attend the Kidz to Adultz exhibition once again. Helen's attendance ensured we could effectively raise vital FOP awareness and learn about new resources available on the market, ultimately strengthening the practical support we offer to our families navigating the condition.

Medics for Rare Diseases

We were delighted to be paired with Athena as part of the M4RD (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)'*. In an unexpected coincidence, Helen was pleased to bump into Athena at the CamRare Event! Athena was delighted to have her essay shortlisted by the judges.

RareFest, Cambridge

We were delighted that Andrew and Helen attended RareFest in Cambridge. The event offered many valuable opportunities to network and connect with fellow advocates and researchers, all dedicated to improving the rare disease landscape. Importantly, the event also hosted the launch of the new Rare Disease Research Network, and we are proud to be involved in this initiative. It was an inspiring event that reinforced our shared commitment to this vital work.

Educating the next generation

Andrew gave a presentation to students at Oundle School. He spoke about his experiences in developing therapies for people living with rare diseases. We welcomed the opportunity to connect with the next generation of scientists, researchers, medical professionals and more.

Adult Rare Bone Disease Network

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

FOP Festivities

Oliver attended the annual Chestnut Drive Lights Switch-On with Mayor Amy, as part of her commitment to raising funds and awareness for FOP Friends throughout her year in Office.

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.

The Women's Institute

Long-time supporter and friend, Janet, choses FOP Friends as the Charity of the Year for The Willows Women's Institute. Helen attended one of their meetings to gratefully receive the cheque on behalf of FOP Friends.

Manchester Round Table, Tough Mudder Team!

A 15-strong team, led by Chris and Oliver's brother Leo, took on the Manchester Tough Mudder! A 10 kilometre, muddy, obstacle course run. The team were all successful and had a great time – although a run of sunny weeks meant it was more tough and less mud – but a good-spirited time was had by all!

A Very Long Walk!

Isla's auntie Louisa took on the ultra-challenge of walking 100km along the stunning yet demanding Jurassic Coast to raise money and vital awareness for her niece's condition.

A Terrific Teacher

The strength of our community connection was evident when Oliver's R.E. teacher laced up her shoes to tackle the. It was a testament to her dedication, running 13.1 miles to raise both money and awareness inspired by her very special student.

An International Challenge

Liz took on a truly monumental challenge by summiting Mount Toubkal, the highest peak in North Africa. Her incredible effort in conquering this formidable 4,167m mountain raised vital funds and awareness for FOP Friends of Oliver.

Starting Young

Our youngest fundraisers this year were undoubtedly Aurora and Benjamin. Demonstrating a wonderful entrepreneurial spirit, they organised and ran their very own lemonade stall in sunny Scotland. They baked their own cupcakes and made refreshing lemonade to raise funds for their aunt. Their delicious homemade treats were enthusiastically supported by customers enjoying the warm summer's day.

Great North Run 2024

We can't remember a time when we didn't have a team of Great North Runners for FOP Friend and we were thrilled to have another wonderful and dedicated team for the 2024 Great North Run, one of our most notable events in the calendar. Our friends and runners took on the iconic half-marathon challenge in September, all driven by their commitment to raising essential funds and vital awareness for the FOP for their friends who are affected by FOP.

A Big Half

Supporter Izzy took on the challenge of the London Big Half Marathon for her sister, Annabel. Her sister and gorgeous nephew met her at the finish line to make it all worthwhile!

The Future

Like many charities, fundraising remains a significant challenge for us. The continued rise in the cost of living and increased global uncertainty have led to a noticeable drop in donations, making it harder to fund our vital work. If this trend continues, it will naturally begin to draw on the reserves we have strategically built up to see us through these difficult times.

We are, however, proactively managing our finances. We continue to hold a portion of our funds in higher-interest savings accounts, generating additional income to support our core charitable goals and operational costs. These reserves are crucial; they allow us to plan with confidence to continue funding FOP research and essential support for our FOP community.

To ensure we can undertake future projects as existing funded initiatives conclude, we plan to revisit grant and trust applications. This has been successful for us in the past. It allows us to secure funding for crucial initiatives without being reliant on community fundraising, which directly benefits the FOP community.

As we look ahead, we are actively developing a long-term strategy to safeguard the future of FOP Friends. We plan to review our board of trustees and engage with volunteers to bring new skills and experiences to the charity and to strengthen our mission and support the FOP community.

In the meantime, we remain absolutely committed to providing support and resources. We will continue to advocate for the community's needs, raise awareness about FOP, and fund research into potential treatments and cures.

We are incredibly grateful for the unwavering support of our donors and volunteers. Their generosity is what allows us to navigate these challenging times and make a positive impact on the lives of those affected by FOP. We encourage our entire community to continue their fundraising efforts and support our work. Together, we can overcome these obstacles and build a brighter future for the FOP 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 £142,840 with £420,189 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 £142,840 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 £5,000 (was £10,000) in grants. An 50% decrease 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, £93,754 was spent on funding FOP research at the University of Oxford and via the IFOPA Act for FOP grant programme.

Operating costs of £36,778 includes salaries, general expenses, repairs, maintenance and costs of subscriptions. Governance costs of £570 include accounting fees and insurance. £3,105 was spent generating funds (t-shirts, event places, and support of fundraisers), and £5,586 was associated with projects.

Gains and losses

Income from fundraising, voluntary income and fundraising activities decreased by 14% from £73,724 to a total of £63,679.

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 £95,305 in funding received in this reporting year has been restricted largely towards the FOP Friends conference and family gathering that took place in May 2024. £5,000 was restricted to Family Weekend the remaining restricted to other items.

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 2024 which are set out on pages 38 to 45.

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	31.12.2024	01.03.2024
Incoming resources					
From generated funds					
Voluntary income	2	£ 23,075	£ 40,604	£ 63,679	£ 73,724
Investment income		£ -	£ 3,819	£ 3,819	£ 6,009
Other incoming resources	3	£ 72,230	£ 3,112	£ 75,342	£ 3,884
Total incoming resources		£ 95,305	£ 47,535	£ 142,840	£ 83,617
Resources expended					
Costs of generating funds	4	£ -	£ 3,105	£ 3,105	£ 10,541
Charitable activities					
Research	5	£ 15,813	£ 77,941	£ 93,754	£ -
Events	6	£ 42,220	£ -	£ 42,220	£ -
Awareness		£ -	£ 880	£ 880	£ 2,462
Projects		£ 4,106	£ 1,481	£ 5,586	£ -
Operational Costs	7	£ 31,916	£ 4,862	£ 36,778	£ 44,765
Governance costs	8	£ -	£ 570	£ 570	£ 554
Total resources expended		£ 94,055	£ 88,839	£ 182,893	£ 58,322
Net incoming/(outgoing) resources		£ 1,250	-£ 41,304	-£ 40,053	£ 25,295
Reconciliation of funds					
Total funds brought forward		£ 183,776	£ 276,467	£ 460,242	£ 434,948
Total funds carried forward		£ 185,026	£ 235,163	£ 420,189	£ 460,243

Balance sheet

-	Notes		31.12.2024		01.03.2024
Fixed assets	9		£ 1,730		£ 1,050
Current assets					
Cash at bank		£ 421,797		£ 462,803	
Debtors	10	£ 1,100		£ 326	
		£ 422,897		£ 463,129	
Creditors: amounts falling due within one year	11	-£ 4,439		-£ 3,936	
Net current assets			£ 418,458		£ 459,193
Net assets			£ 420,189		£ 460,243
Funds					
Restricted	12		£ 185,026		£ 183,776
Designated	13		£ 140,000		£ 140,000
Unrestricted			£ 95,163		£ 136,467
			£ 420,189		£ 460,243

Approved by the trustees on 27th October 2025 and signed on their behalf by

AABedford

Alison Acosta Bedford.

Founding Trustee

The notes on pages 30 to 35 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

	31.12.2024	01.03.2024
Donations	£ 58,679	£ 63,724
Grants	£ 5,000	£ 10,000
	£ 63,679	£ 73,724

3. Other incoming resources

	31.12.2024	01.03.2024
Conference	£ 72,230	£ 2,978
Sales	£ 3,112	£ 906
	£ 75,342	£ 3,884

4. Cost of generating funds

	31.12.2024	01.03.2024
Fundraising costs	£ 3,105	£ 5,276
Project costs	£ 5,586	£ 5,265
Operational costs	£ -	£ -
	£ 8,691	£ 10,541

5. Research

	31.12.2024	01.03.2024
UK research	£ 75,000	£ -
International research	£ 18,754	£ -
	£ 93,754	£ -

6. Events

	31.12.2024	01.03.2024
Conference meeting costs	£ 42,220	£ -
	£ 42,220	£ -

7. Operational

	31.12.2024	01.03.2024
Salaries	£ 31,916	£ 39,080
General expenses	£ 3,413	£ 2,776
Repairs and maintenance	£ 123	£ -
Subscriptions	£ 623	£ 2,233
Bank charges	£ 60	£ 114
Depreciation	£ 643	£ 562
	£ 36,778	£ 44,765

8. Governance

	31.12.2024	01.03.2024
Accountancy charges	£ 115	£ 120
Insurance	£ 455	£ 434
	£ 570	£ 554

9. Fixed assets

	Office equipment
Cost	
At 2nd March 2024	£ 3,650
Additions	£ 1,323
Disposals	£ -
As at 31st December 2024	£ 4,973
Depreciation	
At 2nd March 2024	£ 2,600
On disposals	£ -

Charge for year	£ 643
As at 31st December 2024	£ 3,243
Net book value	
As at 31st December 2024	£ 1,730
At 2nd March 2024	£ 1,050

10. Debtors

	31.12.2024	01.03.2024
Accounts receivable	£ -	£ -
VAT repayable	£ 1,100	£ 326
	£ 1,100	£ 326

11. Creditors

	31.12.2024	01.03.2024
Amounts falling due within one year:		
Accounts payable	£ 3,327	£ 2,942
PAYE and NI	£ 534	£ 531
Accrued expenses	£ 345	£ 230
Other creditors	£ 233	£ 233
	£ 4,439	£ 3,936

12. Restricted funds

	Balance b.fwd	Incoming resources	Resources expended	Balance c.fwd
Conference fund	£ 97,595	£ 72,230	-£ 70,220	£ 99,605
Family getaway	£ -	£ 5,000	-£ 575	£ 4,425
Operational	£ 12,975	£ 1,750	£ -	£ 14,725
Be Safe at School Handbook	£ 29,770	£ -	-£ 4,374	£ 25,396
Charity leaflet	£ 246	£ -	£ -	£ 246
FOP & Me	£ 12,741	£ -	£ -	£ 12,741
FOP Video	£ 8,176	£ -	£ -	£ 8,176
Alma Triffit Book Award	£ 201	£ -	-£ 235	-£ 34

Engraver Gamer	£ 132	£ -	£ -	£ 132
Rare Minds	£ 2,360	£ -	-£ 1,562	£ 798
Together Newsletter	£ 3,767	£ -	-£ 1,276	£ 2,491
FOP Organisation	£ 15,813	£ 16,325	-£ 15,813	£ 16,325
	£ 183,776	£ 95,305	-£ 94,055	£ 185,026

The Conference fund represents donations and delegates deposits received in respect of the FOP Conference in May 2024. Operational funds are those restricted to day-to-day operations of the charity.

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 Triffit 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 Triffit 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 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.

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 represents the higher of £15,000 or 3 months operating costs which is considered to be the safe minimum reserve level as determined by the charity's Reserves Policy.

Our history (to 31st December 2024)

March 2008

Oliver Peter Bedford-Gay born; all the medical professionals just think he has ‘funny toes’

November 2008

Oliver has mysterious lump removed from the back of his head

April 2009

Bedford-Gay family receive devastating diagnosis of FOP

2010

Family and friends begin fundraising to support the research team at Oxford

2011

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

2011

Chris elected to the Board of the IFOPA

April 2011

First of many line dancing evenings held, which have been one of our biggest fundraisers, raising £16,000 to date

January 2012

FOP Friends of Oliver website goes ‘live’ together with “What is FOP?” animated video, narrated by Stephen Fry

June 2012

FOP Friends of Oliver becomes a registered charity # 1147704

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

December 2012

First donation to the University of Oxford to support its research team: £10,000

March 2013

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

Awarded a grant for £16,000 from GDUK to fund a Charity Administrative Assistant

December 2013

Awarded a grant to employ a Senior Drug Developer at the University of Oxford

Annual donation to the University of Oxford's research team, this time £20,000

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

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

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

August 2014

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

Adopted by companies PwC Manchester and Avaya as their "Charity of the 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

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

November 2014

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

FOP Founder and chairman 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.

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!

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.

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.

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.

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.

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.

September 2015

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

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.

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.

December 2015

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

January 2016

FOP Friends’ oldest supporter Mrs. Laura Gregory celebrates her 102nd birthday and donates her gift money to find a treatment for her great-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 .

LOTTERY FUNDED

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.

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.

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.

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.

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!

June 2016

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

Dr Keen presents on the International FOP Association (IFOPA) FOP Connection Registry at 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.

July 2016

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

August 2016

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

September 2016

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

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.

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.

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!

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 swam 32km, and together they raised £360 for FOP friends.

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

March 2017

Fun in the Forest for FOP Families - 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.

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.

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.

June 2017

FOP Friends partner with Genetic Disorders UK.

Savills continue their support by holding a Golf Day and raising over £165.

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.

August 2017

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

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.

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.

November 2017

Bex completes a 61-day dryathlon, 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 and raising an incredible £2,100.

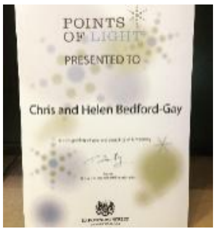
FOP Friends feature on the University of Manchester’s Volunteer Hub to help raise awareness and recruit student volunteers.

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.

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.



POINTS OF LIGHT

PRESENTED TO

Chris and Helen Bedford-Gay

February 2018

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

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 fibrodysplasia ossificans progressiva (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.

April 2018

Jane Deane takes on the Manchester Marathon raising £1,180, while DAC Beachcroft LLP holds a dress down day at work to raise FOP awareness and collects £185.

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, which raises over £230.

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

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.

June 2018

FOP Friends receives a grant from Jeans for Genes to help fund the 2019 FOP Family Respite 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!

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.

August 2018

Alexis who completes the Three Peaks Challenge for FOP Friends

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!

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.

November 2018

Chris arrives safely in Baltimore for the International FOP Association (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 one of their most committed supporters.

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. A whopping £973 is raised for FOP Friends.

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.

#Swap4FOP. Isla's godmother has a simple strategy: take a bunch of friends each bringing a few unwanted items/gifts, add an entry fee, a raffle, and some fizz = fun night, recycles, take away some treasure and raise much needed funds for #FOPFriends. A fabulous night was had by all, and the event raises a whopping £800!

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.

March 2019

FOP Friends runs its second FOP Family Weekend. They take children with FOP and their families for another weekend together at Center Parcs.

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 specialists Jackie all burn their toes to raise awareness for FOP.

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.

June 2019

Helen and Chris are delighted to win 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.

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.

Sept 2019

FOP Friends have another team of fundraises take part in the Great North Run including FOP specialist, Doctor Bubbear.

November 2019

The IFOPA Drug Development Forum in Florida. Whilst attending the Drug Development 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 first worked at FOP Friends in 2015 says farewell as she moves to pastures new to pursue a career in psychology.

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.

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.

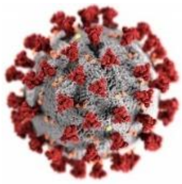
February 2020

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!

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.



April 2020

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.

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.

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.

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 focussed on FOP, while the other discusses Progressive Osseous Heteroplasia (or POH) the other rare condition we support.

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.

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.

Feb 2021

IFOPA Virtual Board meeting. The Board meeting is held virtually across two days, 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.

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.

April 2021

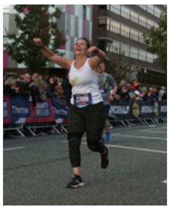
We take part in the first Global FOP Awareness Day, uniting with other FOP patient organisations around the world. We all share the same facts and stories on social media, with a united brand. We also launch the t-shirt for us all to be as one. We are #StrongerTogether.

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!

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.

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 was our 15-strong Great North Run team. Trustees Rachel and Fiona both take part in the Manchester Marathon.

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

November 2021

FOP: how to spot this rare genetic disease

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.

friends
www.fopfriends.com
Is excited to be part of the:
Patient Group Engagement Committee
findacure
7,000 rare diseases, 1 common goal

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 spoke with representatives from the council about living with FOP. We are hopeful this will become an annual event.

Office for
Rare
Conditions
Glasgow

We continued 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 coincided with rare disease day.

March 2022

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

We are excited to announce our new fundraising platform
friends
www.fopfriends.com
fopfriends.enthuse.com

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.


We are excited to announce our partnership with

RARE REVOLUTION MAGAZINE

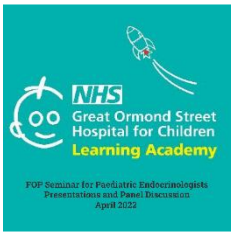
CHARITY PARTNER

April 2022

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

Oliver, along with Luciana and Chris, delivered a very impressive presentation to Ipsen. He shared his experience of living with FOP from a young age and provided great 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.


NHS Great Ormond Street Hospital for Children Learning Academy

FOP Seminar for Paediatric Endocrinologists Presentations and Panel Discussion April 2022

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.

May 2022

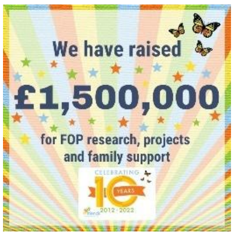
We welcomed family, friends, and speakers from around the world for our 4Th Conference and Family Gathering. We had a wide range of presentations and workshops, as well as lots of laughs and catch ups over the 3-day event. It was a weekend filled with energy and once again reminded us of the heart and soul the FOP community has.

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

June 2022

Helen, one of our trustees and mum to Oliver, received a British Empire Medal in the Queen’s Jubilee Honours List. The award was given to commend Helen for her services to those living with FOP and their families. She received her BEM from the Lord Lieutenant of Manchester at the presentation ceremony at The Monastery and also invited to one of the Queen’s Garden Parties at Buckingham Palace in 2023.

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.

RARE REVOLUTION

The impact of RARE disease on sibling experience

ALEXION

BDJ
British Dental Journal

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.

November 2022

The FOP Burden of Illness study, which was released a few weeks ago, has now been 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.

Wishing Chris safe travels as he heads off to Dallas, Texas, for the first in-person IFOPA Drug Development Forum since COVID. 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.

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 were able to donate $60,000 to IFOPA In Pursuit of a Cure campaign. Providing further funding toward Gene Therapy research and the IFOPA ACT for FOP grant programme.

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.


The impact of RARE disease on sibling experience
Impact report

We were 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, gave a brief overview of the StopFOP Phase II clinical trial. Dr. Richard Keen, Principal Investigator for the UK site, explained what participation in the trial would entail for those in the UK.

February 2023

Granada News for Rare Disease Day. Oliver, Rachel, and Avi shared 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 broadcasted on Granada News, and we were very excited to expand and spread awareness on television broadcast.

Trafford Council Lights Up for Rare Disease Day. FOP Friends collaborate with Trafford Council showed 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 travelled around the borough to see them. We showed great gratitude 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.

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.

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 were 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.

June 2023

We were also 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.

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!

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.

August 2023

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

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

September 2023

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

YOUNG CARERS

NEWSLETTER

YOUNG CARER PROFILE

Charity begins at Leo's home

Oliver and Chris attended 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.

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

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

Rachel and Helen were 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.

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!

January 2024

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

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.

European Alliance for FOP

Stakeholders Meeting

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.

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.

We are honoured to be selected as Mayor 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.

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.

July 2024

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

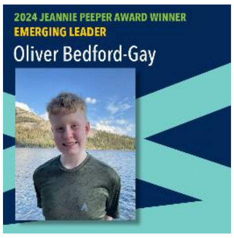
August 2024

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.

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.

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.

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.

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.

Thank you (March 2024 – December 2024)

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

Jeans for Genes

Russel Lang Charitable Trust

Corporate Supporters

Skillsarena

Ipsen

Costco

DHL Foundation

Regeneron Pharmaceuticals

Incyte Corporation

Kidd & Spoor Solicitors

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

Manchester 41 Club

Royal Northumberland Yacht Club

The Willows – Women's Institute

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.