FOP FRIENDS

England & Wales · Charity number 1147704

Details

Other names	FOP ACTION, FOP FRIENDS OF OLIVER, FRIENDS OF OLIVER
Status	Registered
Legal form	Trust
Registered	2012-06-15
Register	View on the Charity Commission register

Contact

Address	1 Cumberland Road Sale M33 3FR
Phone	01612820441
Email	info@fopfriends.com
Website	www.fopfriends.com

Activities

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.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.TO SUPPORT CHARITIES AND ORGANISATIONS UNDERTAKING CHARITABLE ACTIVITIES IN BOTH THE UK AND ABROAD WHO FUND RESEARCH, PROVIDE HELP, SUPPORT, CARE AND TREATMENT FOR PEOPLE AFFECTED BY FOP AND RELATED CONDITIONS.TO SUPPORT ORGANISATIONS RESEARCHING TREATMENTS AND A CURE FOR FOP AND RELATED CONDITIONS.

Activities: FOP Friends' aim is to further research into Fibrodysplasia Ossificans Progressiva (FOP) and related conditions by supporting current and future research projects together with supporting families impacted. Activities include supporting fundraisers, holding fund raising events, biennial conferences, family weekend and working with doctors and researcher to find a treatment and cure.

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Classification

- **How:** Provides Other Finance, Sponsors Or Undertakes Research
- **What:** The Advancement Of Health Or Saving Of Lives
- **Who:** Other Charities Or Voluntary Bodies, Other Defined Groups, The General Public/mankind

Geography

- United States
- Throughout England And Wales

Finances

Period end	Income	Expenditure	Assets	Employees
2024-12-31	£142,840	£182,893	-	-
2024-03-01	£83,617	£58,322	-	-
2023-03-01	£231,413	£141,357	-	-
2022-03-01	£245,252	£162,748	-	-
2021-03-01	£179,763	£136,207	-	-

Trustees

Name	Role	Appointed
MR CHRIS BEDFORD-GAY	Chair	2012-06-13
ALISON ACOSTA BEDFORD		2012-06-13
Andrew Rankin		2024-02-20
FIONA WHITE		2013-02-12
Helen Bedford-Gay		2015-01-26
RACHEL BEDFORD		2012-06-13

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FOP FRIENDS

England & Wales - Charity number 1147704

Accounts







friends®
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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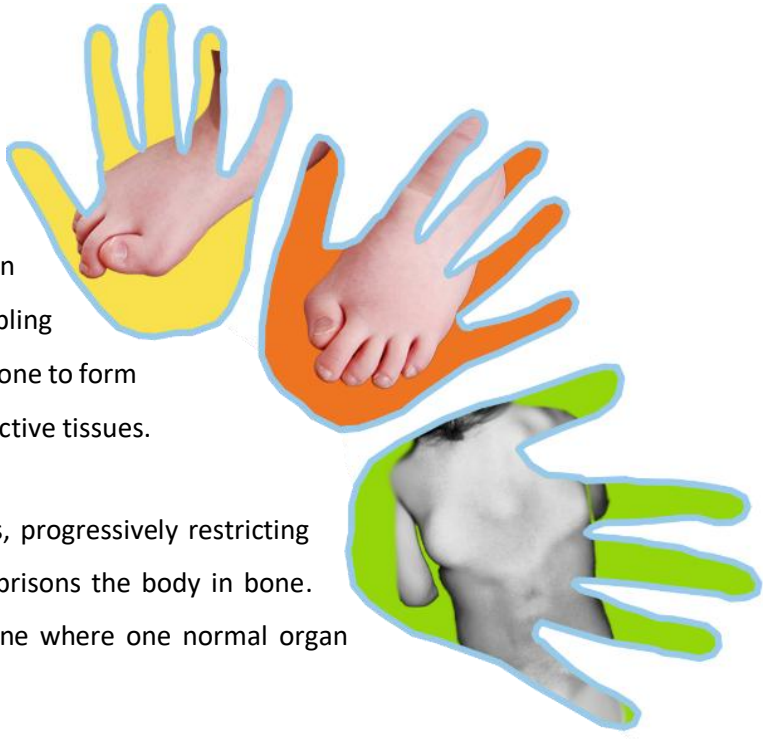
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What is Fibrodysplasia Ossificans Progressiva (FOP)?



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.

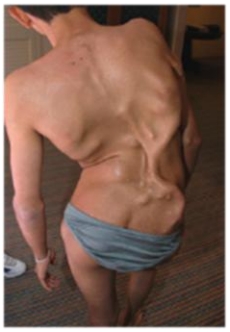


Children with FOP appear normal at birth except for congenital malformation of the great toes. During the first or second decade of life, painful swellings that look like tumours develop over the neck, back and shoulders and mature into bone.

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.

www.fopfriends.com

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.

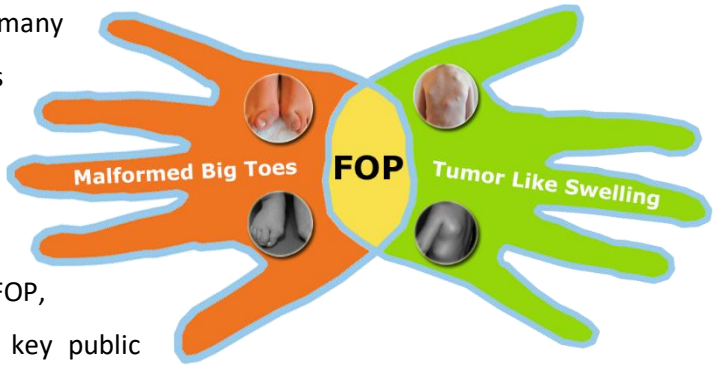
To support charities and organisations in the UK and abroad by undertaking charitable activities to fund research; and to provide help, support, care, and treatment for people affected by FOP and related conditions.

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

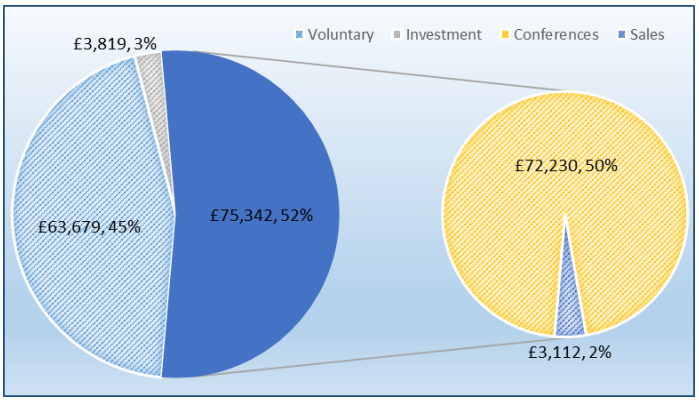
Garetosmab, Regeneron's potential treatment for FOP, continued its OPTIMA trial through 2024. Garetosmab targets a different mechanism of action to StopFOP, Ipsen and Incyte with an antibody designed to block Activin A which is a key driver of unwanted FOP bone formation. This initial trial is restricted 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.

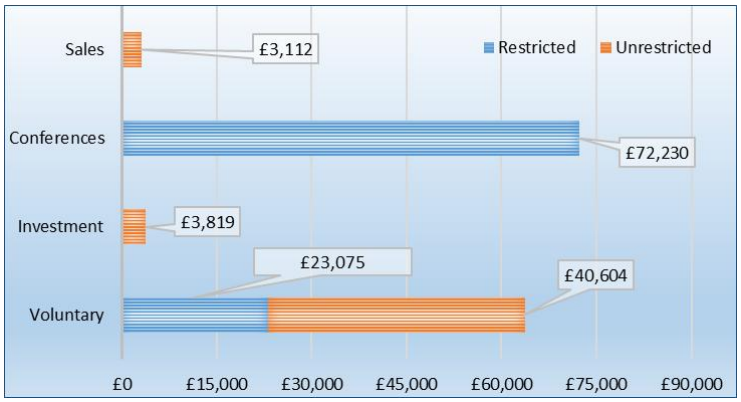
How we raised our money

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.

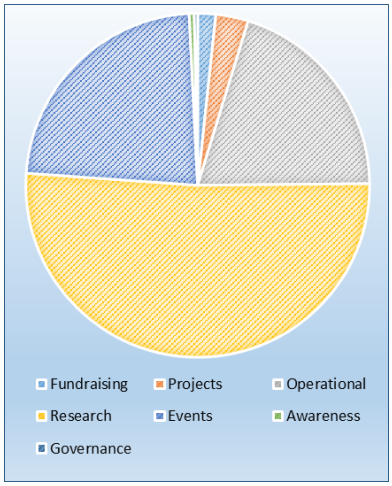
How we spent money raised

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]

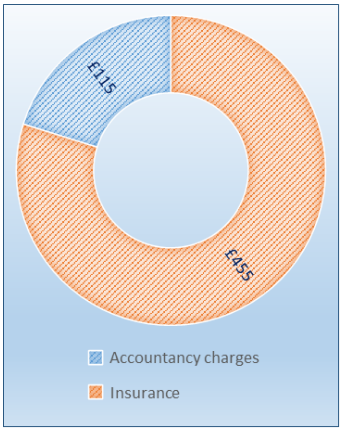
Uniquely, in this charity year, FOP Friends donated **£93,754** to FOP research. This included the continued funding of the FOP research team at the University of Oxford, and funding toward the IFOPA In Pursuit of a Cure campaign to fund conntinued gene therapy research.

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.

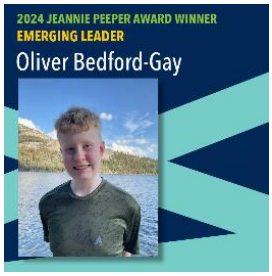
University of Manchester



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



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 .

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.

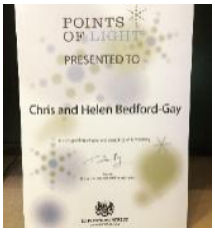
FOP Friends is also awarded Charity of the Week in the "The Week" magazine, December 2017



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.

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.

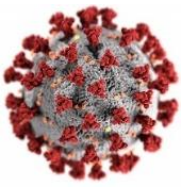




During his visit, Chris and his fellow IFOPA board members have a guided tour of the Mütter Museum where two FOP skeletons are now displayed. Harry Eastlack, a resident since 1973, was joined by Carol Orzell in May 2018. It was Carol's wish to donate her body to be displayed next to Harry to assist future 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.





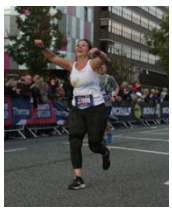
We also hold our #FunFeet4FOP campaign and see people all around the world sharing photos of their fabulous feet! Check out these funky socks being worn by fire-fighters in Australia!

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



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.

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.



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 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.



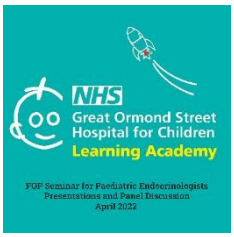
April 2022

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.





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.

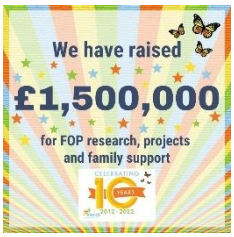


June 2022



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.



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.





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.



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.

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



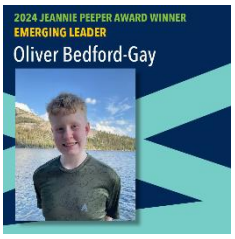
Andrew attends the first meeting of the Adult Rare bone disease collaborative network. Representatives from the founding charities are present, along with a number of medical professionals including Professor Richard Keen.

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

Russel Lang Charitable Trust

Jeans for Genes

Corporate Supporters

Skillsarena

Regeneron Pharmaceuticals

Ipsen

Incyte Corporation

Costco

Kidd & Spoor Solicitors

DHL Foundation

Ecclesiastical

Donors of time and resources

Stephen Fry: Narrated FOP Animation

Skillsarena: Director's time

Foliozine: FOP Friends Logo

Community / Clubs and Associations

Manchester Round Table

Royal Northumberland Yacht Club

Manchester 41 Club

The Willows – Women's Institute

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.

FOP FRIENDS

England & Wales - Charity number 1147704

Accounts

www.fopfriends.com



ANNUAL REPORT

& FINANCIAL STATEMENTS

YEAR ENDING 1ST MARCH 2024

Charity Commission for England & Wales #114770

Office of the Scottish Charity Regulator #SCO46950

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

Independent auditor

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

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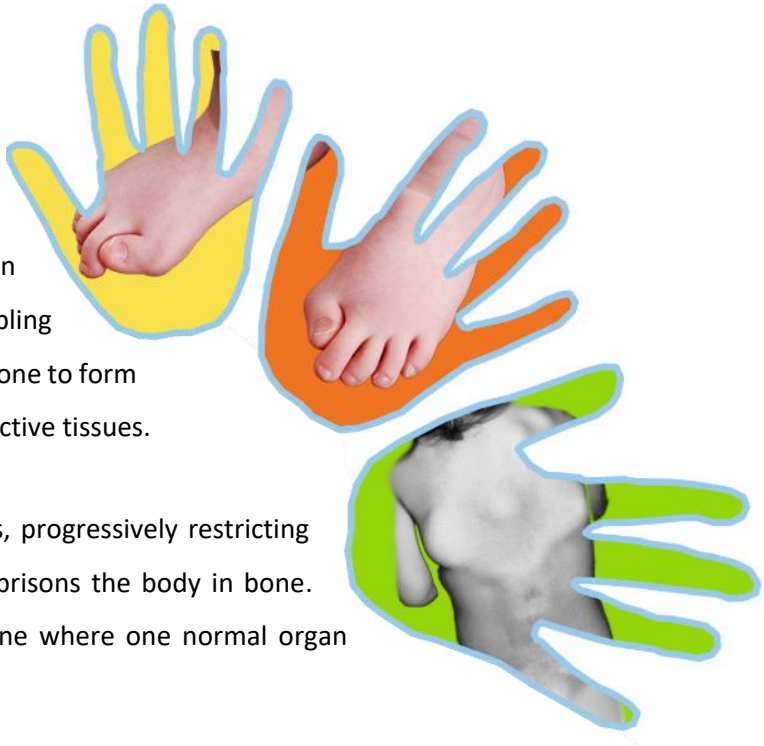
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What is Fibrodysplasia Ossificans Progressiva (FOP)?



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.

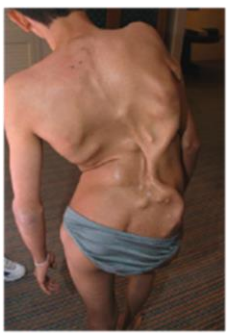


Children with FOP appear normal at birth except for congenital malformation of the great toes. During the first or second decade of life, painful swellings that look like tumours develop over the neck, back and shoulders and mature into bone.

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

As we close our 12th year as a fully registered charity and my 15th year as a parent of a child with an ultra-rare condition, I reflect upon how our lives were changed in 2009 when our then one-year-old son, Oliver, was diagnosed with Fibrodysplasia Ossificans Progressiva (FOP).

At that time there was a patient support group, FOP Action, but no charity dedicated to FOP in the UK, there was however research taking place at the University of Oxford, which is where our journey began, fundraising to support the research team. However, not long after the decision to become a registered charity was made, and "FOP Friends" or rather "FOP Friends of Oliver" as it was, was born.

Starting with a desire to change the future for those with FOP, the charity quickly evolved beyond funding only research, to take on the challenge of finding a treatment, or even a cure for FOP, whilst supporting all the families affected by FOP in the UK. At this time, we became "FOP Friends" with FOP Action merging also.

Registered as a charity in in 2012 over the past 12 years, we've grown from a small grassroots effort into a nationally and internationally recognised organisation involved in everything from awareness raising to policy making and lots in between, but always with one goal, changing the lives of everyone living with FOP.

We have; **funded research**, investing in projects that are bringing us closer to a cure; **supported families**, providing resources, support, and assistance to families, helping them navigate the challenges of this rare condition; and **raised awareness**, through education and advocacy campaigns, increasing public awareness of FOP, leading to earlier diagnoses and improved care for patients.

We are forever grateful for the unwavering support of our community, donors, and volunteers whose invaluable contributions have made this all possible, and who have already made difference in the lives of our FOP community. Together, we will fight for a future where FOP becomes a mere inconvenience.

We hope more will join us in our mission with support, whether through donations, volunteering, or spreading awareness, to help 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 (14) 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.

www.fopfriends.com

Trustees

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

Christopher Bedford-Gay - Founding Trustee and Chairman



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

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

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

Chris is married to Helen, and they live with their 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 in 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' conferences 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 – 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, 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 as a result 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.

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. Dunelm

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.

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.

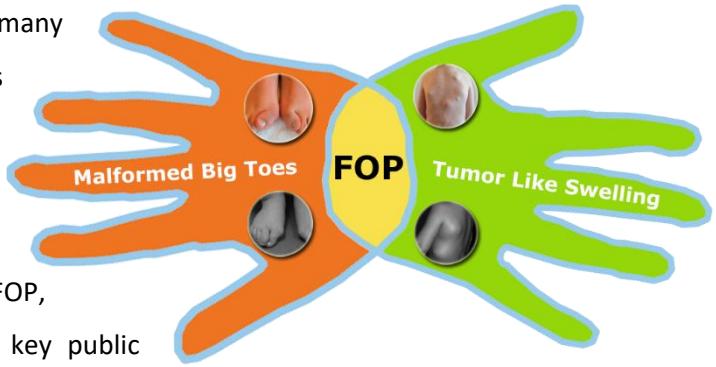
To support charities and organisations in the UK and abroad by undertaking charitable activities to fund research; and to provide help, support, care, and treatment for people affected by FOP and related conditions.

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, saracatinib. The potential treatment itself was discovered by the University of Oxford research team that is funded by FOP Friends.

Ipsen

Ipsen announced that the European Commission has determined not to grant marketing authorisation for palovarotene. Ipsen are continuing to seek regulatory approval in other countries and regions. This will come as a huge disappointment to many, including the UK, as currently there is no approved treatment for FOP.

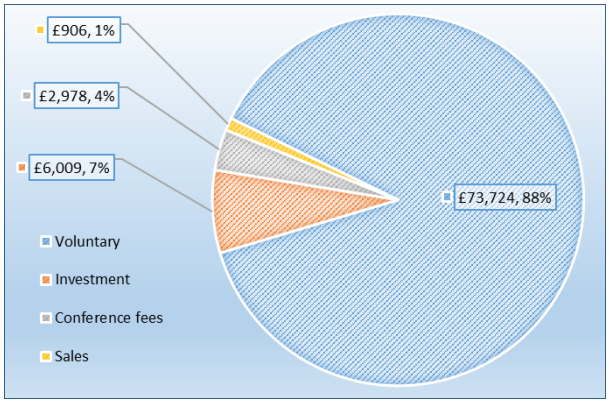
One country that did approve palovarotene as the first treatment for FOP was the USA. Palovarotene, to be marketed under the name, Sohonos, will be available to patients living in America along with Canada and Australia.

University of Pennsylvania

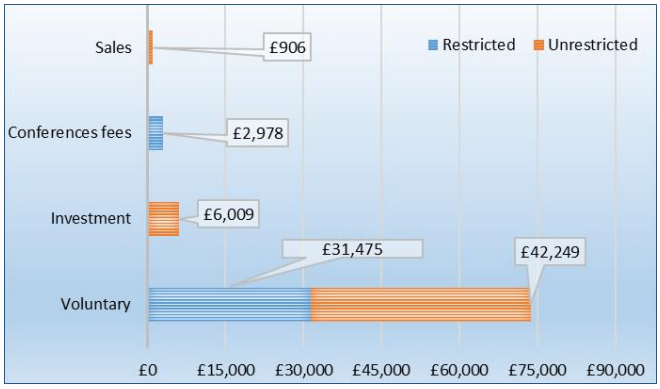
A healthy young man, with classic FOP, had an extreme lack of FOP bone growth and nearly normal mobility. Thanks to his generosity and willingness to be studied the team identified a reduction in the level of an inflammatory protein MMP-9. FOP mouse models subsequently showed that MMP-9 inhibition prevented or dramatically decreased FOP bone growth and amazingly it helped damaged muscle tissue to regenerate. These results suggest that MMP-9 plays a key role in the development of FOP and that targeting this protein could be a potential treatment for the disease and future trials of MMP-9 inhibitors are planned.

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 large decrease of 66% in voluntary income to £73,724 overall with another notable drop in unrestricted funding, mostly from community fundraising efforts of 41% to a total of £42,249 from £71,804 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 a decrease in revenue generated from sales to £906 from £2,009 the previous year. A small value but notable decrease on the previous year.

From a total £83,617 incoming resources, £34,453 (41%) were restricted. The remaining £49,164 (59%) being unrestricted.

This charity year, the distribution of restricted and unrestricted is more closely balanced where in the past there was a large % attributed to restricted only. This is largely due to our focus on completing existing project before seeking funding for future projects. However, as noted above the amount of voluntary, unrestricted, income has dropped significantly, something many charities are facing as the cost-of-living increases ever upwards.

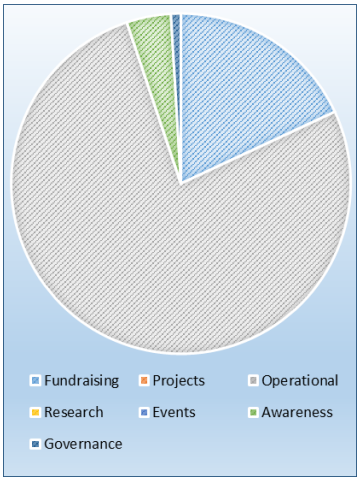
How we spent money raised

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 89% 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]

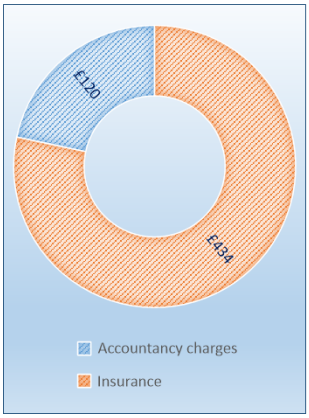
Uniquely, in this charity year FOP Friends donated **£0** to FOP research. Although this would appear to be a dramatic event, this has simply occurred due to research funding requests being delayed to just after the end of this charity year, as such the research funding will therefore show in next year's annual report.

We anticipate providing circa £100,000 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 conduction research into FOP. We also anticipate supporting several other FOP research projects through the In Pursuit of a Cure work.



Fundraising costs of £5,276 is attributed to the provision of fundraising materials and merchandise to support various fundraising activities.

Resources expended on 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 £554 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

Like many other charities, engaging fundraisers continues to be increasingly challenging, especially with a small community to draw from and the effects an ongoing cost-of-living crisis. However, we continue to push forward and motivate our supporters.

We recognise that successfully expanding FOP awareness and fundraising efforts beyond immediate circles is crucial for charity growth and sustainability, so we are using a range of strategies such as social media, media, and networking to engage a broader audience. Our progress owes much to the continued support of FOP families, united in our shared mission.

Regeneron Presentation



As part of their commitment to raising awareness of rare conditions, pharmaceutical company Regeneron invited Oliver and Chris to their office in Uxbridge to give a presentation as part of their Rare Disease Awareness Day events (held in March rather than the official month of February). Oliver continues to grow in confidence when delivering presentations and sharing his story and experience of living with FOP.

IFOPA Board Meeting in Boston, Massachusetts, USA



Helen attended her first in-person board meeting for the IFOPA. She flew to Boston, MA, where she met with many of the staff and board members for the first time. It was a weekend packed with meetings and presentations from both the staff as well as researchers from Boston who spoke about how the IFOPA's support was helping to progress their work. There was also a visit to Massachusetts General Hospital, where Professor Paul Yu gave a presentation. He spoke about current research and the progress with the StopFOP trial and gave Board members a tour of the Yu lab.

The Alma Triffitt Book Award



We continued to remember the lovely Alma Triffitt, the late wife of Professor James Triffitt. Once again, thanks to a generous donation from Jim, we gifted our children and young people a book matched to their interest, in celebration of her life.

Helen and Chris attend The Royal Garden Party at Buckingham Palace.





Helen and Chris were invited to King Charles' Garden Party in celebration of her British Empire Medal. This was King Charles' first Garden Party but unfortunately was unable to attend. HRH Prince William and HRH Princess Catherine were in attendance, along with other Royals. The highlight of the Garden Party was being presented to HRH The Princess Royal. It was an honour to be able to speak with her about the work of FOP Friends, explain about FOP, and talk about our hopes for the future.

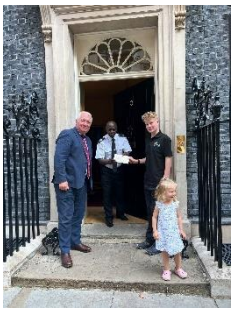


The University of Salford Project continues.

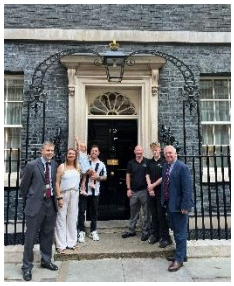


We continued with our partnership with the University of Salford to develop a tool for Rachel to use, to help her be able to feed herself independently and enjoy the social aspects of eating out. We met again with the engineering and occupational therapy students, to look at the challenge and the project in more detail.

FOP Friends Visits Number 10 Downing Street



Following on from the success of our first debate, FOP Friends was given the opportunity to have a full debate in the House of Commons. Oliver and Chris

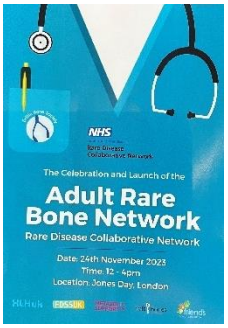


attended the debate, along with Lexi and her parents Dave and Alex Robins, and The Rt. Hon. Mike Penning MP who has worked tirelessly to get our voice heard in Parliament. Oliver and Lexi were also invited to deliver our petition, demanding government funding into FOP, directly to 10 Downing Street.

Launch of the Adult Rare Bone Network



FOP Friends was honoured and delighted to be one of the founding six patient organisations for the newly formed Rare Collaborative Disease Network for adult rare bone conditions. Helen and Rachel attended the launch meeting in London, headed by Professor Kassim Javaid. It is amazing to be a part of this opportunity to improve the care for adults living with FOP.



First, do no harm: Expert reflections on a rare bone disease



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.



There were a host of speakers, including Chris, Oliver, and Professor Alex Bullock, speaking on a range of topics. It was an exclusive event which had a real impact. Guests were able to attend the museum after dark, and medical attendees were also able to see the skeletons of two people who lived with FOP.

Funding FOP Research

Year on year since becoming a registered charity FOP Friends and its supporters have successfully funded the FOP Research Team at the University of Oxford. This has been achieved in collaboration with FOP France who have also contributed to the Oxford Research Fund via FOP Friends this charity year.

Collaboration with Medics for Rare Diseases and the Student Voice Prize

To raise awareness of FOP with the next generation of medical professionals, FOP Friends takes part in the Student Voice Prize and partner with a student, to support them with writing an essay with a focus on rare diseases. This year's student chose the article: *'Turning to stone: a reflective insight into how a rare disease patient's health and wellbeing is influenced within our society.'*

International FOP involvement



Chris continues his role as chair of the IFOP International Presidents Council working on international FOP projects and meeting regularly with the leaders of all the national FOP organisations from around the world. Although we have not met as a group in-person since before Covid we look forward to 2024 when we will have the opportunity to meet, in-person, once more at the next IFOPA Drug Development Forum. The IPC work together to tackle and share challenges faced by FOP families the world over.

Fundraising Regulator

FOP Friends maintains its voluntary registration with the Fundraising Regulator the independent self-regulatory body for UK fundraising. The FR works with member charities, suppliers, and the wider charity sector to encourage commitment to and compliance with best practices in fundraising.

Rare Disease Awareness



We share a series of posts throughout February to show our alliance with other rare disease organisations around the world. We highlight that while each condition may be rare, collectively we are mighty, and we share many of the same challenges. We run a series of media events, articles, #lightupforrare and twitter takeovers as part of the awareness.

FunFeet4FOP and Global FOP Awareness



We continued to raise awareness of FOP with our annual campaign, #FunFeet4FOP, a campaign we launched in April of 2016. We also partnered with the IFOPA to take part in a Global FOP Awareness Campaign. We shared memes across social media platforms along with other patient organisations across the world. We also sold tee-shirts with the updated logo and tagline: Hope. Believe. Wish.



In the media

FOP Friends continues to make use of local and national media where appropriate to raise awareness of FOP and encourage fundraising. We are, however, cautious when working with the media and only "go public" when it truly benefits the FOP community. Members of the FOP community have done some amazing awareness raising of their own by sharing their stories in the media.

Isla and Nicky @ This Morning!



Isla, Nicky and James visited the studio for the popular daytime magazine show This Morning, sitting on the famous couch, to share their stories of the challenges living with FOP brings. Isla spoke about her love of horses and how she has gained much enjoyment from being a part of Riding for the Disabled. Nicky spoke openly and honestly about their story from diagnosis, and the heartbreaking challenges she deals with as a rare mum.

Attendance at Conferences and meetings

Genetic Alliance Meeting in London



Chris attended 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.

A further Parliamentary Meeting



We continued to work with the government to get our voices heard about the reality of living with FOP and why funding into research for a treatment and cure is critical for those living with FOP. This time, Nicky and Dr Andrew Rankin represented FOP Friends and attended the meeting, along with Dave and Alex Robins, and the Rt. Hon Mike Penning MP. They met with the Minister for Heath to discuss further the issues raised in the debate in September. This meeting is then followed up with another meeting in December, where Professor Richard Keen (RNOH) and Professor Alex Bullock (University of Oxford) attend to share their thoughts, insights and expertise.

Helen attends IFOPA Board Meeting in Florida





Helen attends her second in-person Board Meeting for the IFOPA, this time in Florida.

Impact and value

We continue to be the first point of contact for our families, often out of hours when a medical professional is not immediately available, and our families need reassurance and direction. We have welcomed a new family to our community and supported them through the confirmation of diagnosis, and subsequently introducing to them to other families who will be their vital network going forward as they learn to live with FOP. We have continued to offer our families specialist mental health support through our partnership with Rare Minds. This provides dedicated counselling for parents, or adults living with FOP, immediate access to counselling, free of charge. This has been made possible thanks to a grant.

We continue to liaise with the team at RNOH to ensure our families have up to date information. We also signpost our families to reminders about the current best practice regarding the flu vaccine and promote the healthcare videos as produced by the FOP specialists in conjunction with the IFOPA.

We worked with the charity The Hydration Foundation, to coordinate the distribution of long-strawed hydration bottles to those in our community who would benefit from it. We managed to arrange for nearly half of our community to receive a kit, free of charge, thanks to The Hydration Foundation.



We worked with FOP specialist dentist Dr Clive Friedman to survey our patients on their experience of dental care. We are continually looking to find ways to improve the care they receive, and dental care continues to be a source or worry and concern for all our families.

We have spent time working with a wheelchair provider and person with FOP, to source a chair which will me their very specific needs as even a regular specialist wheelchair isn't suitably matched to their needs. This continues to be an ongoing challenge. Now a chair has been sourced, we begin the next battle to arranged funding from the NHS and other sources to pay for the chair.



Our website is constantly being upgraded, with practical advice for our families and signposts to other excellent charities and organisations which can support them with the daily challenges of living with a complex condition.



Our children were particularly thrilled at Christmas to receive a parcel full of wonderful gifts, which were funded through a RaidTrain on twitch. An anonymous fundraiser hosted an event, which gifted box of Biscuiteers Christmas biscuits, a hot chocolate set, an Amazon gift voucher and a personalised Christmas tree ornament for our children and young people. It was the most wonderful of festive treats.

We continue to coordinate a book for all our children and young people as part of The Alma Triffitt award.

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

Fundraisers

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.

Alanna's Awareness Day

Alanna's school marked Rare Disease Day with a special assembly which explained to the pupils about what living with a rare disease means. The school also shared the video: The Same but Different: A Look at Life with FOP from the IFOPA. To help raise further awareness of FOP, Alanna brought in some gorgeous bracelets with a butterfly charm and gave them out to all the class.

Our very own Superheroes



Superhero Series is the UK's one and only disability sports series for the Everyday Superhero! Isla, who lives with FOP, and her friends Kit and Erin, took part in the Superhero Triathlon at Dorney Lake. Isla demonstrated her warrior spirit, completing her part on her adapted trike. The team raised £1120.

London Marathon for FOP Friends!



Our long-standing supporter Jane finally managed to tick a big event off her Bucket List: she ran the London Marathon for FOP Friends! She received a number of messages of support from the FOP families and these messages motivated her through the race. She was thankful and honoured to have been able to play her small part in supporting those living with FOP.

Batchwood Golf Club Charity of the Year



In 2023, Will



Smeulders chose FOP Friends as his charity when he assumed the role of Captain at Batchwood Golf Club in St. Alban's. A fabulous fundraiser was hosted by Will, a family friend of Lexi Robins who lives with FOP. A sunny, fun-filled golf day raised over £2000 for FOP Friends. Throughout Will's year of captaincy, a series of fundraising events were held, including quizzes, games, and raffles. Any 'fines' incurred by members also went to his chosen cause. They held golfing events too, including the Lexi Cup. One of the events was fund-matched by local company Cam Well. In February of this year, the members held their final event. The grand total raised by Batchwood Golf Club was an amazing £10,329!

Trek to Base Camp



Lauren, a good friend of the Grant family, had always had a trek to Everest on her bucket list. Lauren and her team headed off to Everest to achieve one of their dreams and thought it would also be a great opportunity to raise some money for their dear friend Ellis and FOP Friends. Lauren and her team raised an incredible £1500 for FOP Friends.

Chiltern 50 Ultra Challenge



Dr Judith Bubbear, one of our FOP specialists at the Royal National Orthopaedic Hospital, took part in the Chiltern 50 Ultra Challenge this year supporting FOP Friends. The challenging yet stunning 50k trek took Judith 13 hours and 26 minutes and took her through some of the most stunning parts of the UK countryside. She raised an impressive £573 for FOP Friends, and we cannot thank her enough for her time she has dedicated to this remarkable challenge.

Future plans

It's been a tough year for us. Like many other charities, we've felt the pinch from the rising cost of living and global uncertainty. This has led to a significant drop in donations, making it more challenging to fund our vital work.

However, we're not giving up. We've been fortunate enough to build up some reserves during better times. We've invested a portion of these funds in higher-interest savings accounts, generating additional income to

raise some additional funds. These reserves mean also that we can plan to continue funding FOP research and can continue supporting our FOP communities. And while this isn't a long-term solution, it provides some temporary relief.

To ensure we can undertake future projects, and as existing funded projects come to completion, we are looking to revisiting grant and trust applications. An approach that has proven successful in the past and allows us to secure funding, that is not reliant on community fundraising, for crucial initiatives that will benefit the FOP community.

As we look to the future, we're developing a long-term strategy to safeguard the future of FOP Friends and continue our mission to support the FOP community. Soon we look forward to expanding our board of trustees, bringing to the charity new skills and experiences.

We're incredibly grateful for the unwavering support of our donors and volunteers. Their generosity allows us to navigate these challenging times and make a positive impact on the lives of those affected by FOP. We encourage our community to continue fundraising and supporting our efforts. Together, we can overcome these obstacles and build a brighter future for the FOP community.

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

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 1st December 2023 and signed on their behalf by



Chris Bedford-Gay.

Founding Trustee and Chairman

Financial review

Summary

Gross income totalled £83,617 with £460,242 being carried forward to next charity year. Of the amount carried forward, £125,000 is designated to research; £15,000 to operating reserves; and £183,776 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 £83,617 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 £10,000 (was £102,529) in grants. An 90% decrease on the previous charity year. This large decrease is due to a combination of events. Firstly last charity year was our FOP Conference where we receive significant sum in financial support from multiple sources, combined with our current focus being on completing existing, already funded, projects before seeking further funding for future projects.

Charitable expenditure

Through the charity year, £0 was spent on funding FOP research, as described above, this is an anomaly due simply to when funding requests were made by the University of Oxford FOP Research team and other research projects, all of which placed our annual spending into our next charity year, therefore outside the scope of this report.

Operating costs of £55,860 include costs associated with fundraising of £5,276 (t-shirts, event places, and support of fundraisers), operation costs of £44,765, £554 in governance costs, and £5,265 costs associated with projects.

Governance costs of £554 include accounting fees, insurance, professional memberships, and costs associated with training and supporting trustees and staff.

Gains and losses

Income from fundraising, voluntary income and fundraising activities decreased by 66% from £219,354 to a total of £73,724.

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

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.

Future commitments

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.

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 £34,453 in funding received in this reporting year has been restricted towards Community Christmas Gifts, Rare Minds Counselling service, FOP Friends "Together" Newsletter amongst 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 1st March 2023 which are set out on pages 36 to 43.

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	2024	2023
Incoming resources					
From generated funds					
Voluntary income	2	£ 31,475	£ 42,249	£ 73,724	£ 219,354
Investment income		£ -	£ 6,009	£ 6,009	£ 1,524
Other incoming resources	3	£ 2,978	£ 906	£ 3,884	£ 10,535
Total incoming resources		£ 34,453	£ 49,164	£ 83,617	£ 231,413
Resources expended					
Costs of generating funds	4	£ 5,228	£ 5,313	£ 10,541	£ 6,573
Charitable activities					
Research	5	£ -	£ -	£ -	£ 50,535
Events	6	£ -	£ -	£ -	£ 30,483
Awareness		£ -	£ 2,462	£ 2,462	£ 2,548
Projects		£ -	£ -	£ -	£ 9,650
Operational Costs	7	£ 39,080	£ 5,685	£ 44,765	£ 41,031
Governance costs	8	£ -	£ 554	£ 554	£ 537
Total resources expended		£ 44,308	£ 14,014	£ 58,322	£ 141,357
Net incoming/(outgoing) resources		-£ 12,833	£ 38,128	£ 25,295	£ 90,056
Reconciliation of funds					
Total funds brought forward		£ 196,609	£ 238,339	£ 434,947	£ 344,892
Total funds carried forward		£ 183,776	£ 276,467	£ 460,242	£ 434,948

Balance sheet

-	Notes		2024			2023	
Fixed assets	9			£	1,050	£	1,081
Current assets							
Cash at bank		£	462,803			£ 436,823	
Debtors	10	£	326			£ 600	
		£	463,129			£ 437,423	
Creditors: amounts falling due within one year	11	-£	3,936			-£ 3,557	
Net current assets				£	459,193	£	433,867
Net assets				£	460,243	£	434,948
Funds							
Restricted	12			£	183,776	£	196,609
Designated	13			£	140,000	£	140,000
Unrestricted				£	136,467	£	98,339
				£	460,243	£	434,948

Approved by the trustees on 1st December 2023 and signed on their behalf by



Alison Acosta Bedford.

Founding Trustee

The notes on pages **35** to **40** 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

	2024		2023	
Donations	£	63,724	£	116,825
Grants	£	10,000	£	102,529
	£	73,724	£	219,354

3. Other incoming resources

	2024		2023	
Conference fees	£	2,978	£	8,526
Sales	£	906	£	2,009
	£	3,884	£	10,535

4. Cost of generating funds

	2024		2023	
Fundraising costs	£	5,276	£	3,272
Project costs	£	5,265	£	2,542
Operational costs	£	-	£	760
	£	10,541	£	6,573

5. Research

	2024		2023	
UK research	£	-	£	50,535
International research	£	-	£	-
	£	-	£	50,535

6. Events

	2024		2023	
Conference meeting costs	£	-	£	30,483
	£	-	£	30,483

7. Operational

	2024		2023	
Salaries	£	39,080	£	35,666
General expenses	£	2,776	£	2,480
Repairs and maintenance	£	-	£	112
Subscriptions	£	2,233	£	2,150
Bank charges	£	114	£	149
Depreciation	£	562	£	474
	£	44,765	£	41,031

8. Governance

	2024		2023	
Accountancy charges	£	120	£	115
Insurance	£	434	£	422
	£	554	£	537

9. Fixed assets

	Office equipment	
Cost		
At 2nd March 2023	£	3,119
Additions	£	531
Disposals	£	-
As at 1st March 2024	£	3,650
Depreciation		
At 2nd March 2023	£	2,038

On disposals	£	-
Charge for year	£	562
As at 1st March 2024	£	2,600
Net book value		
As at 1st March 2024	£	1,050
At 1st March 2023	£	1,081

10. Debtors

	2024		2023	
Accounts receivable	£	-	£	600
VAT repayable	£	326	£	-
	£	-	£	600

11. Creditors

	2024		2023	
Amounts falling due within one year:				
Accounts payable	£	2,942	£	3,480
PAYE and NI	£	531	£	568
Accrued expenses	£	230	£	225
Other creditors	£	233	£	233
	£	3,936	£	4,507

12. Restricted funds

	Balance b.fwd		Incoming resources		Resources expended		Balance c.fwd	
Conference fund	£	102,620	£	-	-£	5,025	£	97,595
Family getaway	£	7,256	£	-	-£	7,256	£	-
Operational	£	8,375	£	4,600	£	-	£	12,975
Be Safe at School Book	£	35,170	£	-	-£	5,400	£	29,770
Charity leaflet	£	246	£	-	£	-	£	246
FOP & Me	£	22,741	£	-	-£	10,000	£	12,741
FOP Video	£	20,000	£	-	-£	11,824	£	8,176
Alma Triffit Book Award	£	201	£	-	£	-	£	201
Engraver Gamer	£	-	£	1,062	-£	930	£	132
Rare Minds	£	-	£	5,000	-£	2,640	£	2,360
Together Newsletter	£	-	£	5,000	-£	1,233	£	3,767
FOP Organisation	£	-	£	15,813	£	-	£	15,813
	£	196,609	£	31,475	-£	44,308	£	183,776

The Conference fund represents donations and delegates deposits received in respect of the FOP Conference in May 2022. 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 1st March 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.

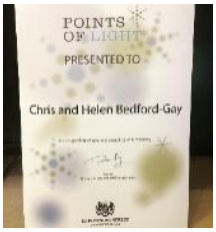
FOP Friends is also awarded Charity of the Week in the "The Week" magazine, December 2017



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.

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.

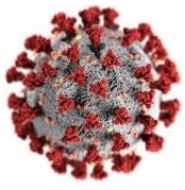




During his visit, Chris and his fellow IFOPA board members have a guided tour of the Mütter Museum where two FOP skeletons are now displayed. Harry Eastlack, a resident since 1973, was joined by Carol Orzell in May 2018. It was Carol's wish to donate her body to be displayed next to Harry to assist future 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.





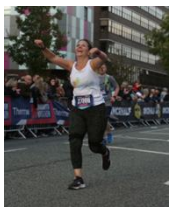
We also hold our #FunFeet4FOP campaign and see people all around the world sharing photos of their fabulous feet! Check out these funky socks being worn by fire-fighters in Australia!

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



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.

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.



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 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.



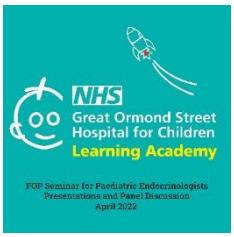
April 2022

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.





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.

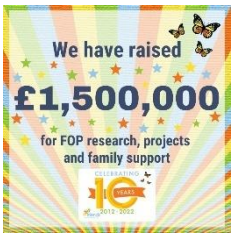


June 2022



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.



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.





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.

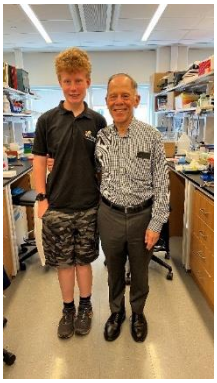


Oliver gives a presentation to his school, sharing his experience of living with FOP. His good friend Rachel came along to share her story and to provide some moral support!

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.



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 2024

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.

Thank you (March 2023 – February 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

Corporate Supporters

Skillsarena

Donors of time and resources

Stephen Fry: Narrated FOP Animation

Skillsarena: Director's time

Foliozine: FOP Friends Logo

Community / Clubs and Associations

Manchester Round Table

Royal Northumberland Yacht Club

Cheadle & Gatley 41 Club

Engraver Gamer

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.

FOP FRIENDS

England & Wales - Charity number 1147704

Accounts

www.fopfriends.com

ANNUAL REPORT

& FINANCIAL STATEMENTS

YEAR ENDING 1ST MARCH 2023

Charity Commission for England & Wales

#1147704

Office of the Scottish Charity Regulator

#SCO46950



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

Independent auditor

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

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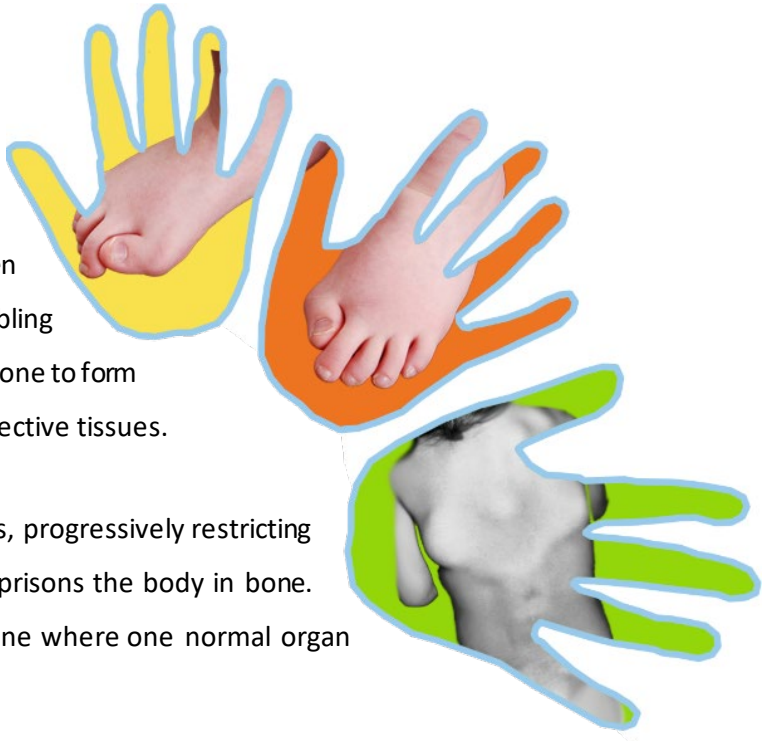
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What is Fibrodysplasia Ossificans Progressiva (FOP)?



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.

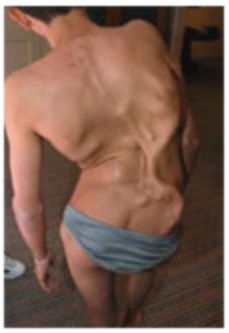


Children with FOP appear normal at birth except for congenital malformation of the great toes. During the first or second decade of life, painful swellings that look like tumours develop over the neck, back and shoulders and mature into bone.

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



In 2009, I received the devastating news that my eldest son, Oliver, who was then just one year old, now 14, had been born with Fibrodysplasia Ossificans Progressiva (FOP). Following Oliver's diagnosis, I began researching the condition to find that FOP was such a rare disease that there was no charity in the UK dedicated to raising money for research into treatments and hopefully a cure.

Along with my wife, family, and friends, we ran fundraising events to support research and raise awareness of FOP. Through this, we encountered barriers to accessing further help and funding from companies and organisations, so we decided to become a fully registered charity. We received full charitable status in 2012.

In June 2022, we celebrated our 10th birthday. In these ten years we have grown from 'mum and dad' fundraiser, to the nationally and internationally respected charity we are today. In recognition of the charity's success, we have been awarded a Points of Light from Number 10 Downing Street; the IFOPA International Leadership Award; runner up as Altrincham's Small Charity of the Year; and Helen was awarded a British Empire Medal for services to charity.

This journey though is not just about us; it's about the community rallying together, and the shared determination to make a difference, and the belief that, even in the face of rare challenges, we can create a lasting impact.

We have had many successes with grants and trusts fundraising, as well as continued fundraising from FOP families, friends, and the public. Grants allow us to offer much needed additional support to our families who are facing daily challenges when living with FOP. They also allow us to develop resources and materials. All whilst protecting "fund raised" money of which we are proud to say 98% of which goes directly to funding FOP research and supporting families.

We are regularly invited to contribute to advisory panels, both as parents of a child with a rare condition, but also to guide and support others wanting to set up their own charity. We continue to go from strength to strength and have even been chosen as "charity for the year" by several high-profile organisations. I am shortly ending my term on the Board of the IFOPA, a term of 11 years, although I will continue to Chair the International President's Council, bringing together all the national FOP organisations from around the world.

It is important we continue to build on our international connections as in the quest to find a treatment and a cure, we truly are stronger together.

We continue to raise awareness of FOP to aid early diagnosis preventing often-devastating progression of the condition, to make our annual fundraising target easier to reach, to support families living with FOP, and to continue to bring the FOP community together.

It has taken dedication, hard work, and time to get this far but we still have a long way to go. We still don't have a game changing treatment or cure for our loved ones, so we continue to push forward. There is still a great deal of work to be done to make our vision a reality. However, with continued support, we will get there, and we will change the lives for not only Oliver but also the other families affected by FOP, both now and in the future.

But we could not do this alone so I would like to extend my personal thanks to all our supporters who continue to fund our work (through events, sponsorship, or direct donations). Without your tireless campaigning, fundraising and support we could not do what we do. You keep hope alive for all those who are touched by this terrible condition.



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 (14) 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.

www.fopfriends.com

Trustees

There must be at least three trustees. Except for the first 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 live with their 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 in 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' conferences 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 – 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, 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 as a result 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 Brasil and Dr. Patricia Delai to update and translate the guide for families in Brasil.

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. Dunelm

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.

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.

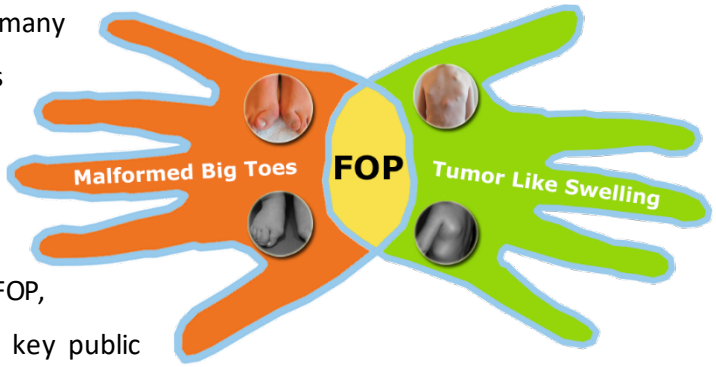
To support charities and organisations in the UK and abroad by undertaking charitable activities to fund research; and to provide help, support, care, and treatment for people affected by FOP and related conditions.

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

Professor Bullock Recognised



Our very own Professor Alex Bullock is named outstanding mentor in 2022 awards. Professor Bullock, who leads our FOP Research team at the University of Oxford, was described as "*an outstanding mentor, leader, and scientist…*" and is known amongst all who work with him as a truly exceptional mentor. When his colleagues describe him as "*…one of the best supervisors/mentors in the department, and likely the entire University…*" we are thankful he is leading the FOP Research team we fund.

Stop FOP

The FOP Research team continues to support work on the StopFOP trial, an academic clinical trial of a potential treatment for FOP, saracatinib. The potential treatment itself was discovered by the University of Oxford research team that is funded by FOP Friends.

A new lab



Whilst renovations are taking place at the FOP research teams original lab they are relocated into a temporary, but fantastically well-equipped alternate lab at the University of Oxford. During a visit arranged for member of the FOP community we had the change to take a tour around the lab. Finding out more about the work the team are doing.



FOP Friends UK Conference and Family Gathering

The Oxford Team attended FOP Friends UK Conference and Family Gathering taking place in Manchester. They present their latest research and give our FOP families a chance to meet and chat with them throughout the conference.

IFOPA Drug Development Forum



The IFOPA held it's first in-person Drug Development Conference since Covid. It was held in Dallas, Texas and provided the opportunity for researchers, clinicians, and drug developers to present on their work, to meet one and other and to network, fostering future collaborations and generating new and exciting ideas to further research into FOP.

UMass Gene Therapy Update



We were excited to hear that Gene Therapy work that IFOPA, FOP Friends and others helped establish was able to reach an important milestone. The milestone was the demonstration by Jae-Hyuck Shim, PhD and Guangping Gao, PhD.



Jae, Dr Goa, and their team showed a proof-of-concept, in a humanized mouse model of FOP, that they could deliver using a bone specific Adeno-associated virus (AAV) vector, a bone-specific carrier, to deliver therapeutic gene(s) to bone cells. Excitingly their work, whilst not yet ready to translate into patients, demonstrated that AAV gene therapy is a potent suppressor of unwanted traumatic and spontaneous extra-skeletal growth as occurs in FOP.

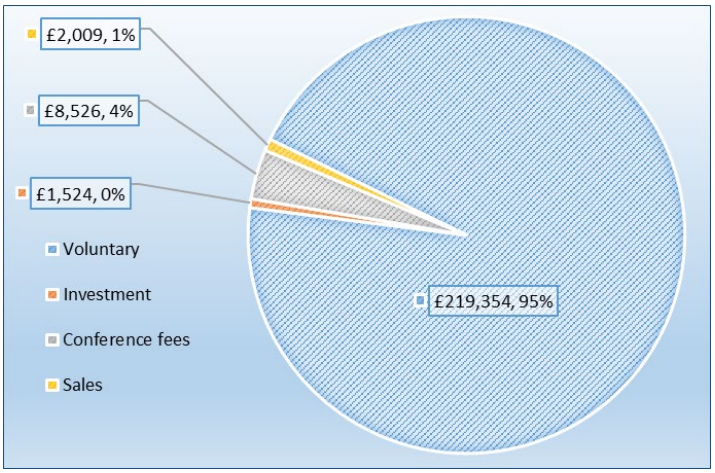
This research, along with other research info FOP also has far reaching implications for more common bone disease such as osteoporosis, fractures, and bone loss due to arthritis.

It is clear the research FOP Friends, the IFOPA, and others are funding into FOP is brining hope of not only potential treatment, but of a possible, cure to the FOP. But until our worldwide community has those things in their hands, we must continue to keep research moving forward, whilst also supporting our FOP community on the journey.

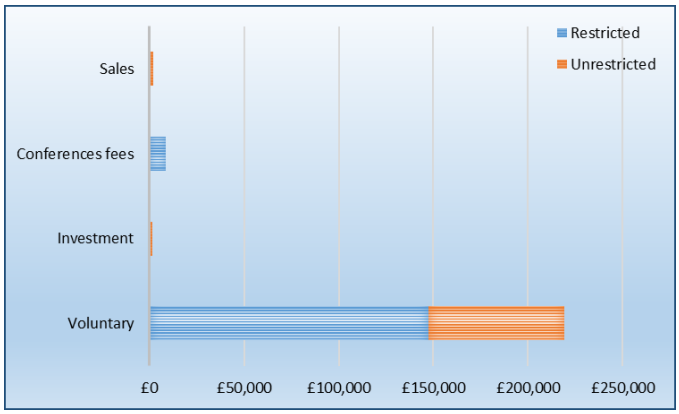
How we raised our money

Voluntary income accounts for most of the money raised within our charity's financial year. A small amount is attributed to investment income (interest on bank balances) and £0 revenue from fundraising events attributed to the continued impact of the Covid-19pandemic.

This year there was decrease of 9% in voluntary income to £219,354 overall which masks a notable drop in unrestricted funding, most from community fundraising efforts of 59% to a total of £71,804 from £177,150 the previous year.



We saw a small increase in revenue generated from sales to £2,009 from £1,728 the previous year. This is another small increase on the previous year.



From a total £231,413 incoming resources, £156,076 (67%) were restricted. The remaining £75,337 (33%) being unrestricted.

This charity year, the distribution of restricted and unrestricted has reversed with significantly more income landing the restricted category. This is largely due to restricted income for the 2022 Conference and Family Gathering and a reduction in funding from our FOP community and supporters.

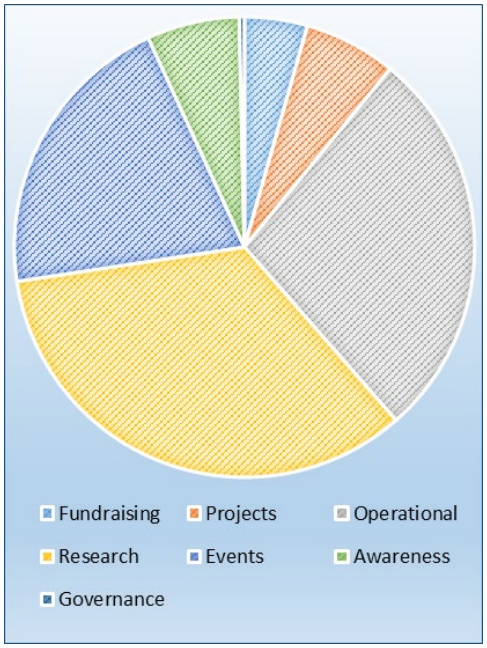
How we spent money raised

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 96% of all fundraised money directly supports our charity objects of; family support; awareness; and funding research. [Note: Voluntary Donations VS Fundraising Costs]

FOP Friends donated a total of £50,545 to FOP research this charity year. A figure lower than that of previous years due to funding provided in 2021 covering a two-year period. We expect this to rise in the next charity year back to typical levels.

The main beneficiary of FOP Friends is the FOP Research team at the University of Oxford. Led by Professor Alex Bullock, the team is one of a small number of teams in the world, conducting research into FOP. This year's funding allowed the team to grow back to three dedicated staff and two support staff.



Fundraising costs of £2,504 is attributed to the provision of fundraising materials and merchandise to support various fundraising events.

Resources expended on 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 £537 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

Like many other charities, engaging fundraisers continues to be increasingly challenging, especially with a small community to draw from and the effects of Covid and a cost-of-living crisis. However, we continue to push forward and motivate our supporters.

We recognise that successfully expanding FOP awareness and fundraising efforts beyond immediate circles is crucial for charity growth and sustainability, so we are using a range of strategies such as social media, media, and networking to engage a broader audience. Our progress owes much to the continued support of FOP families, united in our shared mission.

10 Years as a Registered Charity



This year we reflected on our journey as a patient organisation. We never cease to be amazing by how far we have come yet recognise there is so much more to be done. We marked the occasion – a little bit early – at our Conference in May. We shared memories of the past few years and celebrated the friendships and positives (many unexpectedly) that had borne out of charity. We had cakes and balloons for all our attendees. It was particularly poignant to be able to share the occasion with Janet Plumb, Oliver's past childminder who has supported him, the charity, and our cause from the very beginning after reading a newspaper article about a little boy with a rare condition. She made him a cushion to provide him comfort - which he still sleeps with today - and the rest, as they say, is history.



Funding FOP Research

Year on year since becoming a registered charity FOP Friends and its supporters have successfully funded the FOP Research Team at the University of Oxford. This has been achieved in collaboration with FOP France who have also contributed to the Oxford Research Fund via FOP Friends this charity year.

FOP Friends Conference and Family Gathering

After much deliberation and careful consideration, we made the decision to hold our FOP Friends Conference and Family Gathering in-person at the Manchester Airport Radisson Blu Hotel. We took expert guidance and ensured that we were following all the current protocols. Some international speakers were not able to attend due to travel restrictions imposed on them by their establishment. However, many did attend and were thankful to be able to get together after such a long time apart. The event was a resounding success.



Collaboration with Medics for Rare Diseases and the Student Voice Prize

To raise awareness of FOP with the next generation of medical professionals, FOP Friends takes part in the Student Voice Prize and partner with a student, to support them with writing an essay with a focus on rare diseases. This year's student chose the article: *'Turning to stone: a reflective insight into how a rare disease patient's health and wellbeing is influenced within our society.'*

International FOP involvement



Chris continues his role as chair of the IFOP International Presidents Council working on international FOP projects and meeting regularly with the leaders of all the national FOP organisations from around the world. Although we have not met as a group in-person since before Covid we look forward to 2024 when we will have the opportunity to meet, in-person, once more at the next IFOPA Drug Development Forum. The IPC work together to tackle and share challenges faced by FOP families the world over.

Fundraising Regulator

FOP Friends maintains its voluntary registration with the Fundraising Regulator the independent self-regulatory body for UK fundraising. The FR works with member charities, suppliers, and the wider charity sector to encourage commitment to and compliance with best practices in fundraising.

Rare Disease Awareness



We share a series of posts throughout February to show our alliance with other rare disease organisations around the world. We highlight that while each condition may be rare, collectively we are mighty, and we share many of the same challenges. We run a series of media events, articles, #lightupforrare and twitter takeovers as part of the awareness.

#FunFeet4FOP and Global FOP Awareness



We continued to support the Global FOP Awareness campaign of the IFOPA raising much needed awareness of FOP beyond the immediate FOP community. And we continue to run our #FunFeet4FOP awareness campaign as part of FOP Awareness Day. A campaign we launched in April of 2016.

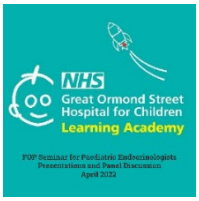
In the media

FOP Friends continues to make use of local and national media where appropriate to raise awareness of FOP and encourage fundraising. We are, however, cautious when working with the media and only "go public" when it truly benefits the FOP community. Members of the FOP community have done some amazing awareness raising of their own by sharing their stories in the media.

Attendance at Conferences and meetings

In March 2022, Chris attended his last IFOPA Board meeting. However, due to lingering Covid travel restrictions and real concerns for the wellbeing of the FOP community, the decision was taken to hold the meeting virtually again. Hopefully, this will be the last year as we all find a way to live with the challenges Covid created.





Helen takes part in an FOP Seminar for GOSH. Presentations are given to paediatric endocrinologists. There are presentations and case studies from Professor Keen, Dr Gehan Abou-Ameria, and Dr Chesover. Helen speaks about their journey to diagnosis for Oliver and answers questions as a panellist.

Chris attends a NICE scoping meeting in preparation for the approval process in the UK for Ipsen's potential treatment palovarotene.





We attend several meetings throughout the year with interested parties and advocacy support groups to help us to prepare for the NICE process. We work with Realise Advocacy to survey the UK's FOP community to establish their needs and challenges, and the potential benefits of having access to a treatment.

Oliver, Chris, and Luciana give a presentation to staff, both in person and via a link, to the staff of Ipsen pharmaceuticals. Oliver talked about his life and living with FOP. Chris and Luciana also shared their experiences of their journeys with FOP, how they are learning to live with the uncertainty of FOP, and why we need desperately need a treatment and eventually a cure for FOP.



Chris flew to Dallas, Texas to attend the first in-person IFOPA Drug Development Forum since Covid. He met in-person with old friends and long-time FOP researchers, and for the first time the FOP Gene Therapy team, a team FOP Friends supports via the IFOPA's "In pursuit of a cure" campaign.





He enjoyed hearing about all the latest FOP research, challenges and successes, and future of FOP drug development. As usual he was persuaded into talking, to being interviewed, to being filmed, but still managed a moment of rest at the Dallas Fort Worth Stockyards cattle drive.

After a chance meeting at a science museum, Helen made a connection with a professor from the University of Salford's engineering department. After explaining the challenges that those living with FOP face with simple everyday tasks





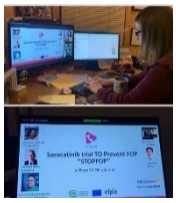
We support the IFOPA's virtual Family Gathering in Septemeber. We host s virtual FOP Friends' room and share our resruoces. We support the event by acting as facilitors in breakout sessions, ahnd hosting virtual bingo.



A fabulous day at the University of Oxford, meeting the new FOP research team. There was a tour of the FOP research lab where families could see where critical research is being carried out as they search for answers and a treatment for FOP. We were also treated to a presentation by Emeritus Professor Jim Triffitt who was instrumental in the discovery of the FOP gene many years ago.

Chris flies to Paris, France, to take part in Ipsen's Global Patientcentricity.





We host a webinar for our families, friends and supporters to update them about the StopFOP trial.

Impact and value

FOP Friends continues to benefit from the enthusiastic and generous support from some of our families. The funding the money FOP Friends receives allows the search for a treatment and a cure for FOP to continue supporting research endeavours both in the UK and beyond. We also continue to increase and improve the way we directly improve the lives of those living with FOP as we wait for the treatment, we all so desperately want and need.



We continue to grow as a charity, and we continue to be a source of information and advice to many. Our reputation now precedes us, and in the rare disease world, we are becoming increasingly known and talked about. We continue to seek out funding from grants, trusts, and companies to allow us to continue our work and fulfil larger projects. However, we continue to be grateful to the tireless efforts of our supports who seem to come up with ever-increasingly creative ways to raise much needed funds to support the research. As a small charity, we truly appreciate every donation, and each-and-every event.

As much as we would like to, we can't thank every supporter, some remain anonymous, but we hope they know how much we, and the FOP community, appreciate them.

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 also arranged to have a book sent out to all our children and young people as part of The Alma Triffitt award.



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, we provide a listening ear to patients and families alike. We are available when our families need us.

Fundraisers

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.

Cycling for a cure



Alanna and her friends organised a sponsored walk on in Bridgwater to raise awareness of FOP. Friends and family went to Victoria Park and walked, scooted, rolled, and cycled. Alanna completed 10 laps (approximately 3 miles!) on her trike. She and her friends surpassed their target of £1000.

Travelling far to fundraise, the Boston Marathon

Becky has been a supporter of FOP Friends for many years. Her latest challenge to raise money and awareness for FOP, was the Boston Marathon. After taking part in shorter runs as training, Becky was pleased to be offered a place in the prestigious race. Her hard work and dedication paid off as she ran a new personal best of new personal best of 3:36:10 and raised over £1000 for FOP Friends.



The Windlesham Picnic



FOP Friends was chosen for the first time as one of the charities to benefit from the Windlesham Picnic fundraising event. It was in honour of Isla, who is a local resident in the village. The picnic is an adult-only event and has been running for 25 years. Many local businesses donate raffle prizes to help raise money during the event. An incredible £2000 was donated to FOP Friends from this event!

Team Lenny's Crowdfunder

After his diagnosis, Lenny's family set up a Crowdfunder to help contribute towards the research into a treatment and a cure. Friends held fundraisers and rallied around to help. To date they have raised over £7,000 with more events to come.



Simon Sings for Alanna



Following on from last year's busking success, Alanna's mum Steph arranged a summer fete with Simon as the headline act. The whole community came together for a beautiful Somerset summer's day, to enjoy music, cakes, raffles, and games. It really was fun for all the family. The event raised £500.

Superhero Triathlon

Isla and her friends took part in the Superhero Tri and raised a whopping £1100 for FOP Friends! It is an all-ability event, with Isla completing her part of the team event on her trike. In Isla's words, she had "the best day ever".



Paddle the Thames



The 'Paddle the Thames' route beings in Lechlade and ends in Teddington – putting the challenge at an impressive 137 miles. With incredible effort they completed the challenge in just 5 days and raised an unbelievable £4100 in the process.

Great North Run

FOP Friends had 15 runners for the 2022 race. Oliver and Chris attended the race and waited at the finish line to greet and cheer on the runners, as well as provide them with a well-earned refreshment. An incredible £10, 599.



Raid Train Fundraiser

Engraver Gamer arranged the first ever Raid Train fundraising event on Twitch on behalf of FOP Friends. Several gamers, crafters and musicians took part in this Raid Train event that lasted for 48 hours. It was a great way to raise awareness of FOP on a global level and collated donations that totalled to £2350. Future events are already being planned.

Little Lexi's Big Party



The party was held at the Shendish Manor Hotel and Golf Course, Hemel Hempstead. It was a fabulous event with DJ, dancing, an auction and more. All funds raised went towards supporting the research into finding a treatment and a cure for Lexi and her friends. The event raised a staggering £13,000 for FOP research!

Leo and Eddie complete the Local Landmarks around Sale



Oliver's brother Leo (13), and his cousin Edison (12) took part in the Local Landmarks around Sale. With the charity FOP Friends being a big part of both of their lives from a young age, they were very aware of the impact of living with a rare condition such as FOP and how it affects people's daily lives. The boys were thrilled with their efforts and their time. Thanks to their generous friends and family, the boys raised an amazing £1000!

Future plans

Just as we were coming out of Covid times and settling into a new-normal we entered a world of international conflict and strife with the invasion of Ukraine by Russia and all that followed, including ratcheting inflation, astronomical energy costs, and seemingly never-ending price increases, all leading into a worsening cost-of-living crisis through 2022, and no doubt beyond.

As one might expect this has had an impact on fundraising activities for us, and all many other charities. As such we look carefully to the future and the funding needs of our FOP research teams. We will navigate these difficult times as best as we can and plan accordingly. However, we remain positive and are in a reasonable position as a charity to ride out the storm, at least for long enough for the world to settle into another new-normal.

On a more positive note, we have already brought our community back together, in-person, for the first time since Covid, which was a resounding success, and we are already looking forward to 2024 when we will hold the next conference and family gathering. And whilst we are able, we will continue to provide much needed funding and support to FOP research and our FOP families.

We hope that our community and supporters will continue to fundraise to support us through these tough times, and still, we look positively to the future, continuing to work on projects that will help and support our FOP communities. Projects that include a major update to our school handbook "Supporting a Child with FOP: a practical guide to their learning experience", a new resource for children with FOP and their siblings, our "FOP and Me" journal, both of which continue to suffer from delays post-Covid.

We continue to work with the engineering and design department of the University of Salford who are building custom tools for patients with FOP in the UK. And we look to changing the day-to-day lives of our FOP community with a drive to improve dental care for FOP patients, and to provide mental health support for our community in the future.

As we look towards the next charity year, we look again at our longer-term strategy for FOP Friends. Aiming to create a more robust charity that can survive beyond the founding trustees and their commitment to the day-to-day operation and success.

We must continue to raise awareness of FOP and encourage fundraising to support FOP Friends and its activities along with looking towards grant and trust funding for future projects that will benefit the FOP community. And, of course, alongside these activities, we will continue to support our FOP community to the best of our abilities.

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 1st December 2023 and signed on their behalf by



Chris Bedford-Gay.

Founding Trustee and Chairman

Financial review

Summary

Gross income totalled £231,413 with £434,984 being carried forward to next charity year. Of the amount carried forward, £125,000 is designated to research; £15,000 to operating reserves; and £196,609 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 £231,413 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 £102,529 (was £20,361) in grants. An 403% increase on the previous charity year. This is attributed largely to funding secured towards the 2022 FOP Conference and Family Gathering.

Charitable expenditure

Through the charity year, £50,535 was spent on funding FOP research. This was entirely directed towards the University of Oxford FOP Research team.

Operating costs of £48,141 include costs associated with fundraising of £3,272 (t-shirts, event places, and support of fundraisers), operation costs of £41,031, £537 in governance costs, and £2,542 costs associated with projects.

Governance costs of £537 include accounting fees, insurance, professional memberships, and costs associated with training and supporting trustees and staff.

Gains and losses

Income from fundraising, voluntary income and fundraising activities decreased by 9% from £241,407 to a total of £219,354.

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

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.

Future commitments

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.

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 £157,626 in funding received in this reporting year has been restricted towards 2022 FOP Conference and Family Gathering, and several projects including 'FOP Video' update, 'FOP & Me' journal for children, "Supporting a Child with FOP: a practical guide to their learning experience" book, and the Alma Triffitt book award amongst other items.

Investments

Presently FOP Friends has no investments.

Independent examiner's report

I report on the accounts of the charity for the year ended 1st March 2023 which are set out on pages 36 to 43.

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	2023	2022
Incoming resources					
From generated funds					
Voluntary income	2	£147,550	£71,804	£219,354	£241,407
Investment income		£-	£1,524	£ 1,524	£30
Other incoming resources	3	£10,076	£459	£10,535	£ 3,815
Total incoming resources		£157,626	£73,787	£231,413	£245,252
Resources expended					
Costs of generating funds	4	£2,530	£4,043	£ 6,573	£27,013
Charitable activities					
Research	5	£-	£50,535	£50,535	£130,000
Events	6	£30,483	£-	£30,483	£ 2,419
Awareness		£-	£2,548	£ 2,548	£518
Projects		£-	£9,650	£ 9,650	£-
Operational Costs	7	£35,666	£5,365	£41,031	£-
Governance costs	8	£-	£537	£537	£ 2,798
Total resources expended		£68,679	£72,679	£141,357	£162,748
Net incoming/(outgoing) resources		£88,947	£1,109	£90,056	£82,504
Reconciliation of funds					
Total funds brought forward		£107,662	£237,230	£344,892	£262,388
Total funds carried forward		£196,609	£238,339	£434,948	£344,892

Balance sheet

-	Notes	2023	2022
Fixed assets	9	£1,081	£1,296
Current assets			
Cash at bank		£ 436,823	£ 348,009
Debtors	10	£600	
		£ 437,423	£ 348,009
Creditors: amounts falling due within one year	11	(£3,557)	(£4,413)
Net current assets		£ 433,867	£ 343,596
Net assets		£ 434,948	£ 344,892
Funds			
Restricted	12	£ 196,609	£ 107,662
Designated	13	£ 140,000	£ 140,000
Unrestricted		£98,339	£97,230
		£ 434,948	£ 344,892

Approved by the trustees on 1st December 2023 and signed on their behalf by



Alison Acosta Bedford.

Founding Trustee

The notes on pages 34 to 36 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

	2023	2022
Donations	£116,825	£221,046
Grants	£102,529	£ 20,361
	£219,354	£241,407

3. Other incoming resources

	2023	2022
Conference fees	£8,526	£1,728
Sales	£2,009	£2,087
	£ 10,535	£3,815

4. Cost of generating funds

	2023	2022
Salaries	£-	£ 20,182
Fundraising costs	£3,272	£2,504
Project costs	£2,542	£2,702
Operational costs	£760	£1,625
	£6,573	£ 27,013

5. Research

	2023	2022
UK research	£ 50,535	£130,000
International research	£-	£-
	£ 50,535	£130,000

6. Events

	2023	2022
Conference meeting costs	£ 30,483	£2,419
	£ 30,483	£2,419

7. Operational

	2023	2022
Salaries	£ 35,666	£-
General expenses	£2,480	£-
Repairs and maintenance	£112	£-
Subscriptions	£2,150	£-
Bank charges	£149	£-
Depreciation	£474	£-
	£ 41,031	£-

8. Governance

	2023	20222
Accountancy charges	£115	£110
Insurance	£422	£420
Subscriptions	£-	£1,800
Bank charges	£-	£19
Depreciation	£-	£203
General expenses	£-	£246
	£537	£2,798

9. Fixed assets

	Office equipment
Cost	
At 2nd March 2021	£2,860
Additions	£259
Disposals	£ -
As at 1st March 2022	£3,119
Depreciation	
At 2nd March 2021	£1,564
On disposals	£ -
Charge for year	£474
As at 1st March 2022	£2,038
Net book value	
As at 1st March 2022	£1,081
At 1st March 2021	£1,296

10. Debtors

	2023	2022
Accounts receivable	£600	£ -
	£600	£ -

11. Creditors

	2023	20222
Amounts falling due within one year:		
Accounts payable	£3,480	£4,251
PAYE and NI	£568	£944
VAT	(£950)	(£892)
Accrued expenses	£225	£110
Other creditors	£233	£ -
	£3,557	£4,413

12. Restricted funds

	Balance b. fwd	Incoming resources	Resources expended	Balance c. fwd
Conference fund	£22,048	£111,055	(£30,483)	£102,620
Family getaway	£7,256	£ -	£ -	£7,256
Operational	£ -	£46,571	(£38,196)	£8,375
Be Safe at School Handbook fund	£35,170	£ -	£ -	£35,170
Charity leaflet	£246	£ -	£ -	£246
FOP & Me	£22,741	£ -	£ -	£22,741
FOP Video	£20,000	£ -	£ -	£20,000
Alma Triffit Book Award	£201	£ -	£ -	£201
	£ 107,662	£157,626	(£68,679)	£196,609

The Conference fund represents donations and delegates deposits received in respect of the FOP Conference in May 2022. 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 1st March 2023)

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.

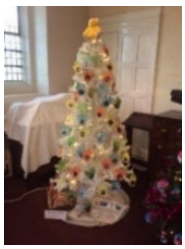


November 2017

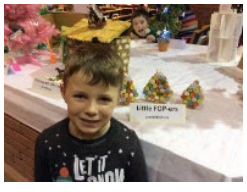
Bex completes a 61-day dryathlon, raising a sparkling £500 in the process. Meanwhile, Amy celebrates her 50th Birthday in style by jumping 855ft from the top of Las Vegas' Stratosphere Tower and raising an incredible £2,100.

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.



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.

BIG LOTTERY FUND
NATIONAL LOTTERY FUNDED

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

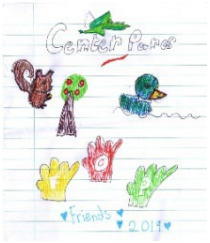
We launch Facebook Fundraiser – supporters can now raise money and awareness for FOP on Facebook for their special celebrations.

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.



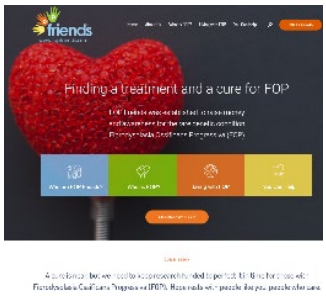
December 2019



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.

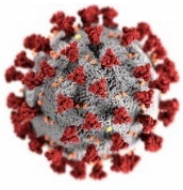




During his visit, Chris and his fellow IFOPA board members have a guided tour of the Mütter Museum where two FOP skeletons are now displayed. Harry Eastlack, a resident since 1973, was joined by Carol Orzell in May 2018. It was Carol's wish to donate her body to be displayed next to Harry to assist future 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.



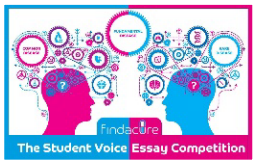
FOP Friends supports the first ever Gene Therapy research programme with the IFOPA as part of the in pursuit of a cure campaign.



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.





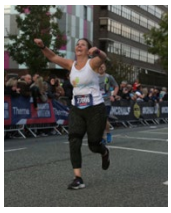
We also hold our #FunFeet4FOP campaign and see people all around the world sharing photos of their fabulous feet! Check out these funky socks being worn by fire-fighters in Australia!

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.

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.



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 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 the 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.



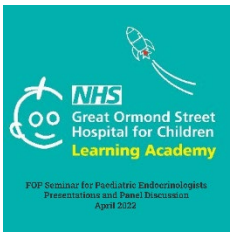
April 2022

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.





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.

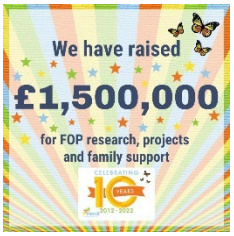


June 2022



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.



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 TuesdayTakeover 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.



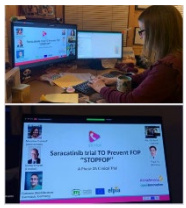


After combined efforts from our charity and our supporters throughout the year, we were able to donate $60,000 to IFOPA In Pursuit of a Cure campaign. Providing further funding toward Gene Therapy research and the IFOPA ACT for FOP grant programme.

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.





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.

Thank you (March 2022 – March 2023)

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

Trusts / Grants

Big Lottery Fund

Corporate Supporters

Regeneron Pharmaceuticals

Ipsen Biopharmaceuticals

Incyte Corporation

BioCryst Pharmaceuticals

Skillsarena

Donors of time and resources

Stephen Fry: Narrated FOP Animation & 2022 FOP Conference welcome.

Skillsarena: Director's time

Foliozine: FOP Friends Logo

Community / Clubs and Associations

Manchester Round Table

Royal Northumberland Yacht Club

Fundraisers

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

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

FOP FRIENDS

England & Wales - Charity number 1147704

Accounts



2022 Annual Report & Financial Statements

Year ending 1st March 2022

Registered with

Charity Commission for England & Wales

#1147704

Office of the Scottish Charity Regulator

#SCO46950

2022 Annual Report & Financial Statements

Year ending 1st March 2022

Vision

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

Mission

To 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.

Values

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.

Respects the integrity, ambition, and interests of all FOP patients, acts as a champion, and provides a haven for patients and families.

Strives to be a centre of excellence for the provision of information on medical research, diagnosis, treatment and care, and participation in clinical trials.

Act always with honesty, professionalism, and ethical awareness.
Work collaboratively with medical researchers and clinicians, patients and families, donors, and supporters to realise our Vision and complete our Mission.

Charity name

FOP Friends

Charity number(s)

1147704, SCO46950

Governed by

Trust Deed

Independent auditor

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

Founding Trustees

Christopher Bedford-Gay

Alison Acosta Bedford

Rachel Almeida

Trustees

Fiona White

John Leaver

Helen Bedford-Gay

Nicky Muller

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Mission 2

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Charity name 2

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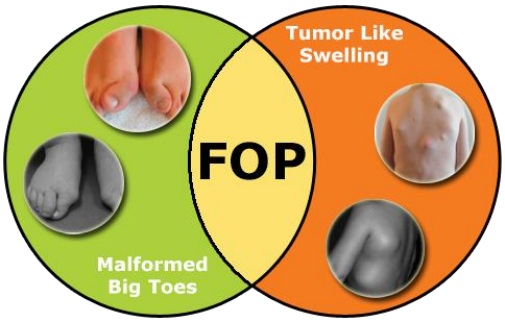
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What is Fibrodysplasia Ossificans Progressiva (FOP)?

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 connective tissues.

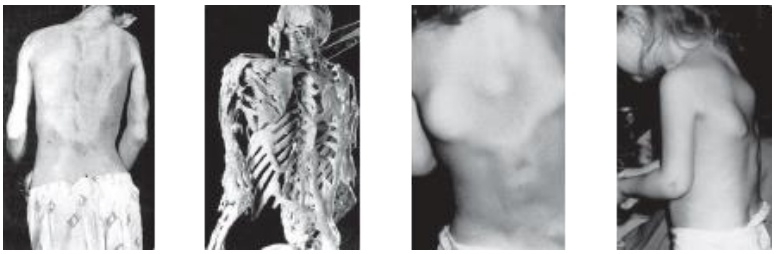
Bridges of extra bone develop across the joints, progressively restricting movement, forming a second skeleton that imprisons the body in bone. There are no other known examples in medicine where one normal organ system turns into another.

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.

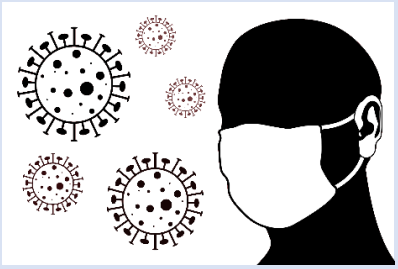


Fibrodysplasia Ossificans Progressiva (FOP) causes progressive debilitation eventually leading to early death.



Introduction and Chair's Statement

As the world slowly leaves behind repeated lockdowns and comes to terms with living with Covid, we too are navigating our new, but hopefully not permanent, normal.



2020 and 2021 have largely be dictated to by the C-word. The impact of Covid has been far-reaching for all. Perhaps most significantly for our community, it has slowed and, in some cases, halted the progress of some FOP clinical trials (StopFOP). It has also created additional challenges for those trials that were able to continue. All FOP trials which were affected by Covid are now back up and running, but the delays have created more hurdles to contend with and there is much 'catching-up' to be done.

As a charity, we are now clearly looking to the future: the future of our activities; the future of fundraising; and the future of our support for FOP research and our FOP community. We are also developing strategies to a ensure we have sustainable future.

One of the most exciting things in our near future will be the rescheduled FOP Conference and Family Gathering, which will take place in May 2022. Looking at the international FOP calendar, it is likely our event will be one of the first in-person FOP conferences post-Covid. We are very conscious of the logistical implications of this, and planning is already underway to ensure we follow the latest good practice guidelines as put out by the government and the events industry, to make certain our event is as Covid-safe for our guests as possible.



As we close-out the 2021 charity year and report on it herein, we look forward to a return to fundraising events, runs, walks, and other activities that are so important to keeping FOP Friends' work going. These events – both big and small - help us to support FOP research in the UK and beyond, and perhaps more importantly, allow us to support our FOP community.

In 2020, I spoke about Covid simply being 'another challenge to be met head-on'. And that we most certainly did. We supported our community; we kept the charity ticking over; we raised funding for future projects; and we secured funding for the 2022 Conference. Thanks to the dedication of our incredible community, we also continued to raise much-needed funds for our FOP research teams.

Although things in the real world feel like they are 'returning to normal,' we are painfully aware Covid hasn't gone away. The health and care challenges it poses to our FOP community remain, including the very real fear it could trigger FOP activity. Vaccines continue to not be an option for many of our friends with FOP. Why? Because intramuscular injections have the potential to trigger FOP. All current Covid vaccines can only be given into muscle and are not known to be effective if delivered sub-cutaneously. Patients with FOP have to weigh up the risks of receiving a vaccine against the risk of catching COVID. Nothing is ever easy for our friends.



This is just one more challenge for our ultra-rare FOP community to figure out, and in time, with their resilience and fight, one which they will overcome. But one thing is certain: we could not face these challenges without your support. You, our champions, keep us moving forward on our most difficult days. You keep hope alive for all those touched by FOP. We are thankful to our friends who continue to stand by us on this journey.



Chris Bedford-Gay, Founder 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 of the existence of FOP, and of research projects that will benefit not only FOP sufferers, but also those with more common disorders.

FOP Friends was founded following the diagnosis of Oliver Bedford-Gay (14) with FOP at the age of 1. The aim of the charity is to support the search for a cure, whilst raising awareness and educating the public and medical world of the condition. FOP Friends supports existing research programmes such as at the University of Oxford and patient organisations; 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 the University of Oxford's FOP Research Team.

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

Trustees

There must be at least three trustees. Except for the three founders, 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.

Chris Bedford-Gay - 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 served as chairperson of FOP Action (which has now been integrated into FOP Friends) and has also been a Board Member of the IFOPA since 2011. He is Chairman of the IFOPA International Presidents' Council, bringing together FOP organisations and leaders from across the world. He carries out this work alongside his day-job as director of UK based technology company, Skillsarena.

EDUCATION

• 1st Class BSc Hons, Computing for Business

EXPERIENCE

• Software engineer and consultant at GlaxoSmithKline

• Software engineer at Defence Evaluation Research Agency

• Technical Director, Turtlez Ltd (10 years)

• Director and CTO, Skillsarena Ltd (current)

• Chairman and Area Chairman, Round Table

• IFOPA Board member

Alison Acosta Bedford - Trustee



As one of the founding trustees, Alison has been on this journey from the beginning. Alison is a Chartered Management Accountant so assists with the financial accounts of the charity, along with other administrative tasks, and supporting fundraising efforts. As chair of the trustee meetings, Alison remains committed to using her professional skills to assist in managing the day-to-day staffing and operation of the charity, as well as utilising personal relationships to raise awareness and funds for research into finding a cure for this terrible condition.

EDUCATION

• BSc Hons, Mathematics, University of Sheffield

• CGMA Chartered Institute of Management Accountants.

EXPERIENCE

- Finance Business Partner at UK Biobank
- Over 16 years' finance experience within social housing

• Experience of long-term financial planning as Treasury and Investment Manager of a housing association with over £60m annual turnover

Alison is proud of how much FOP Friends has grown and of the biennial family symposium held in May, which highlights how important FOP Friends has become to the FOP community.

Rachel Almeida – Trustee



Rachel is Head of Events and Sponsorship for the Association of Colleges, organising education-related conferences. She has worked in events for over 18 years and is honoured to be able to put her experience and expertise to beneficial use. Rachel was inspired to complete her first ever fun-run in aid of FOP Friends, completing the Great North Run half marathon in under 2hr 30 minutes. She has since gone on to complete a full marathon in her hometown of Manchester, with her nephew Oliver cheering her on.

EDUCATION

• BSc Hons, German and Law, University of Surrey

EXPERIENCE

• International trade shows

• International economic research charity dissemination conferences

• Head of Events and Sponsorship (current) – leading a team to deliver forty education conferences per year with direct responsibility for a £1.7m annual turnover

Rachel looks to use her personal drive to work alongside fellow trustees and the whole of the FOP Community to find a cure for FOP.

Fiona White - Trustee



Fiona is a lead teacher working in a primary school. She works as 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.

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

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.

John Leaver - 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 – Trustee



Helen has been with the charity since the very beginning. Having come to terms with the devastating diagnosis that her son, Oliver, had FOP, she felt the need to become proactive in the search to find a treatment, so he could have as normal a childhood as possible. Helen also recognised the need for an effective support network for families affected by FOP. Helen has taken a largely behind the scenes role, supporting and thanking the fundraisers around the country as well as developing much of the charity information that is in circulation. She runs the office and liaises with a range of professionals, from medical to educational to pharmaceutical. Helen also drives many of the fundraising activities in the local community. Unfortunately, since Oliver was diagnosed, there have been more young children in the UK who have received the same news. Helen often acts as the first point of call for families; she can offer parents a network of friends who understand their distress and can offer guidance for the incredibly difficult times ahead. Having been an experienced teacher, Helen has the knowledge and ability to offer practical guidance and support for parents and schools regarding mainstream education for their child.

EDUCATION

• BA (Ed.) QTS Hons. Durham

EXPERIENCE

• Classroom teacher across Key Stages 1 and 2, with experience of KS1 leadership; teacher at a Hospital School

• Fulbright Exchange Teacher to USA

In addition to the work for the charity, Helen continues her career as a primary school teacher, and is also mum to Oliver's younger brothers Leo (13) and Harry (10).

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.

Meeting Charity Commission guidelines

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

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 incorrect 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 / Saracatinib

Covid has significantly impacted the running of clinical trials, with restricted international travel making necessary attendance particularly challenging and, in some cases, impossible. Nonetheless, the first patient enrolled in the StopFOP trial has completed the full 6-month randomised controlled trial and is now in the open label phase. The Team, consisting of Professor Alex Bullock (Oxford), Dr Marelise Eekhoff (Amsterdam, VUMC), Dr Bernard Smilde (Amsterdam, VUMC), Dr Richard Keen (RNOH), is currently working to complete regulatory steps to open the London and German sites for continued enrolment. Each country has independent processes with subtly different questions and data requirements to address, adding to the delays.

IFOPA Drug Development Forum postponed

The biennial drug development forum hosted by the IFOPA which was due to be held in the Netherlands, was postponed due to COVID. As a result, the next forum has been pushed back to 2022 in Dallas, Texas, USA.

Regeneron - Garetosmab

Late in 2020, Regeneron paused the Phase II LUMINA-1 clinical trial for Garetosmab whilst investigation of several adverse reported effects during the trial were thoroughly investigated. The inquiry into these events has continued into 2022.

Ipsen - Palovarotene

In May, Ipsen submitted Palovarotene to the FDA for 'Priority Review.' Unfortunately, just under three months after its submission, the request was withdrawn. This was to allow for additional analysis of the data which was collected during the Palovarotene Phase III MOVE clinical trial. This process has to be conducted and concluded before the Priority Review process can continue.

In addition to this, the 'Pivoine' roll-over study has been launched to further evaluate the safety and efficacy of Palovarotene. The roll-over study allows for the patients who took part in earlier phases, to continue their treatment with Palovarotene.

Alongside Palovarotene, Ipsen have launched the study of another possible treatment for FOP: IPN60130 (formerly BLU-782, licenced by Ipsen from Blueprint Medicines in 2019). This will be known as the 'Falkon' clinical trial. IPN60130 is another Kinase inhibitor, similar to that being trialled in the StopFOP clinical trial. It represents a different treatment pathway to Palovarotene.

Incyte Pharmaceuticals

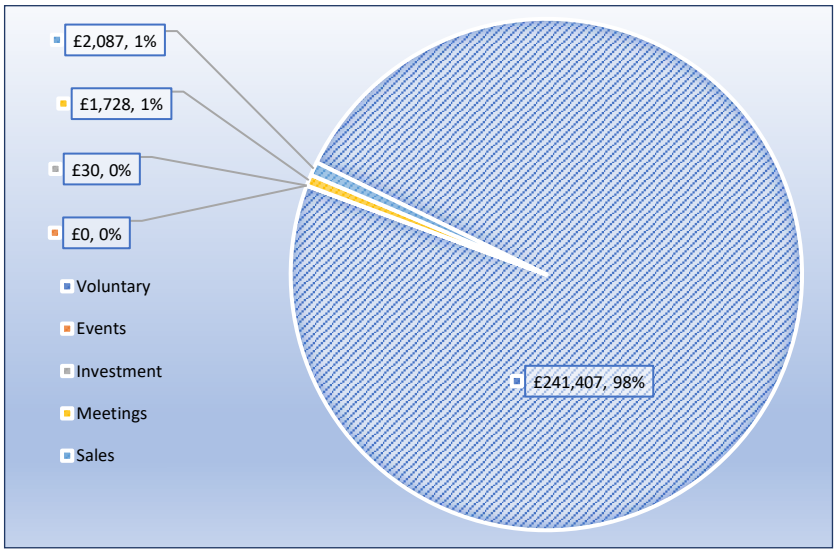
Incyte, a relatively new pharmaceutical company to enter the FOP drug development landscape, has submitted their first FOP trial on ClinicalTrials.gov. Incyte's potential treatment, currently known as INCB000928, is the third Kinase inhibitor to be tested in a Phase II trial for FOP.

How we raised our money

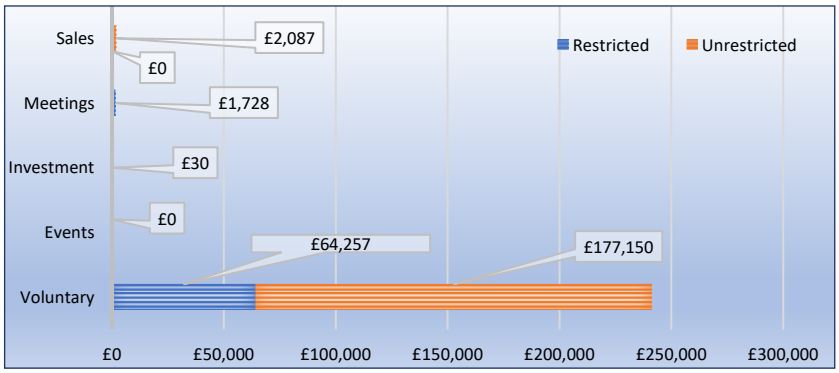
Voluntary income accounts for the majority of money raised within our charity's financial year. A small amount is attributed to investment income (interest on bank balances) and £0 revenue from fundraising events attributed to the continued impact of the Covid-19pandemic.

This year there was an impressive increase of 34% in voluntary income to £241,407 overall. Interestingly, we saw a reversal of fortunes with restricted income dropping by 49% and unrestricted increasing by 234%. This was largely due to the fundraising efforts of a newly diagnosed family and their "Little Lexi" campaign which, when combined with existing and established fundraising activity, resulted in this significant increase.

In addition, revenue of £1,728 is attributed to sales. This is a slight increase on the previous year.



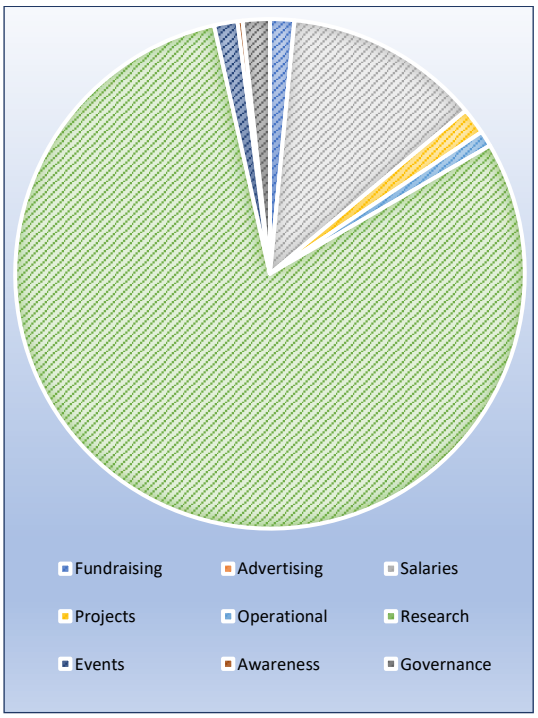
From a total £245,252 incoming resources, £65,985 (27%) were restricted. The remaining £179,267 (73%) were unrestricted.



This charity year, the jump in unrestricted income has gone against the year-on-year decrease in unrestricted revenue (usually attributed to fundraising activity). This increase in fundraising activity can be attributed to a small number of newly diagnosed families becoming active fundraisers who, alongside existing families and long-term supporters, have reversed the trend this charity year. Time will tell if this change can be maintained.

How money raised was spent

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 **99%** of all fundraised money directly supports our charity objects of; family support; awareness; and funding research. [Note: Voluntary Donations VS Fundraising Costs]

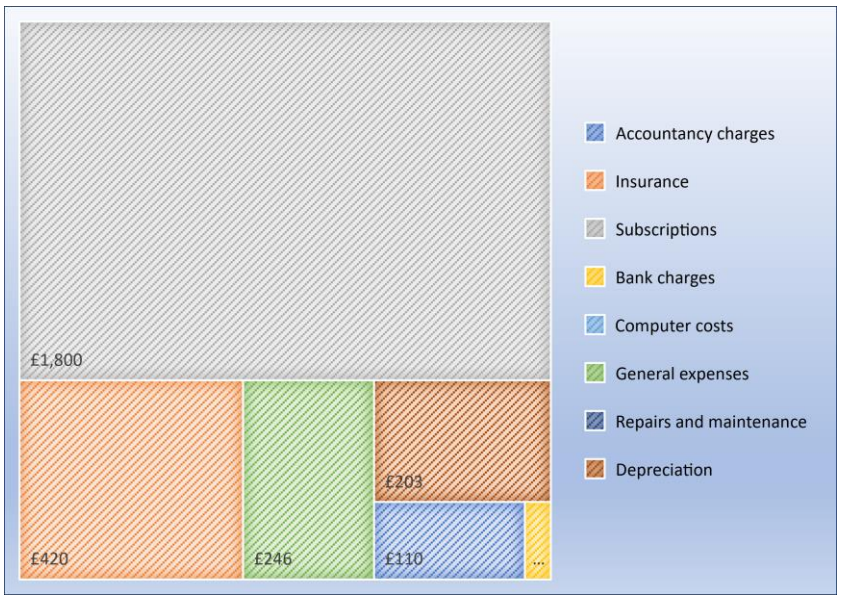
FOP Friends donated a total of £130,000 to FOP research this charity year.

The main beneficiary of FOP Friends is the FOP Research team at the University of Oxford who received the full £130,000 in research funding. Led by Professor Alex Bullock, the team is one of a small number of teams in the world, conducting research into FOP. This year's funding allowed the team to grow back to three dedicated staff and two support staff.

Fundraising costs of £2,504 is attributed to the provision of fundraising materials and merchandise to support various fundraising events.

Resources expended on staff salaries (£20,182) continues to be funded through grants and corporate sponsorship leaving 'fundraised' money designated to the charity objects.

Governance costs of £2,798, a decrease in our previous year, is attributable to the continued operation of the charity.

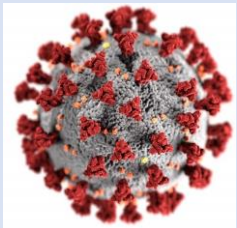


Governance includes basic operational costs, accounting fees, insurance, postage, professional memberships, and costs associated with training and supporting trustees and staff.

Achievements

Supporting families through Covid

As the world began to edge out of lockdowns and into a world learning to live with Covid-19, FOP Friends continued to support the community with updated guidance and the latest advice regarding Covid-19 for people living with FOP, from the International Clinical Council for FOP, a group comprising of many of our FOP experts from around the world.



Unfortunately, due to the risk of triggering FOP by intra-muscular injection, the Covid vaccine was out of reach for many people with FOP, so the risks associated with Covid remain ever present.

We are hopeful that work on alternate vaccine delivery methods will soon come to fruition, to give our patients a real option to protect themselves against this virus.

We, as a community, have also actively contributed to research into Covid and FOP being conducted by Dr Ed Hsiao at the University of California, San Francisco (UCSF).

The World's Rarest Dictionary Project



Helen took part in several workshops, along with other members of the global FOP community, as part of a project developed by Ipsen. Working in partnership with other rare diseases communities, those living with FOP took part in brainstorming sessions to create innovative words to add to the Rarest Dictionary.

Alma Triffitt Book Award Launch

We were honoured and excited to launch the 'Alma Triffitt Book Award.' James Triffitt was one of the professors who had led the original FOP research team at the University of Oxford, which then became part of the international collaboration that ultimately discovered the ACVR1 gene. Alma sadly passed away in 2018 so Jim wanted to create something special in her memory.



Alma whole-heartedly supported his work and accompanied him on his research trips around the UK, Europe, and the USA. She met with the families and took precious time to befriend them. The FOP families cherished Alma's warmth, humour, and kindness: she was just as dedicated to finding a cure for FOP as her husband. In recognition of her affection for the FOP community, Professor Triffitt wanted to share his wife's love of reading and poetry with the children living with FOP and POH. Every book gifted was personalised with a beautiful bookplate. Alma's son David inherited her talent for art and lovingly painted the design, inspired by his mother's love of colour and joie de vie. The books were delivered on her birthday in June. Thanks to Professor Triffitt's grant, this will now be an annual gift for our children and young people.

Rare Disease Awareness

We again marked Rare Disease Month with interesting and informative social media content across all our channels. This ended on 28th February, #RareDiseaseDay2022, where we celebrated all those who are living with a rare disease. We arranged for Trafford Town Hall to be illuminated in blue to show the borough's support for rare diseases. Oliver was proud to attend with local councillors, to represent the FOP and POH communities. We are hopeful this will become an annual event.



While each rare disease may only affect a few people, together Rare is Many

and Rare is Strong. We in the FOP community are some of the lucky ones: we have doctors who know and love us; teams of researchers around the world looking for a treatment and bringing hope; and a strong international family to support us with the challenges living with a rare disease brings.

#FunFeet4FOP and Global FOP Awareness

This year saw our fifth #FunFeet4FOP campaign for FOP Awareness month/day, and our supporters didn't disappoint! We had fabulous feet shared from far and wide! We had toes from Australia, France, Germany, America and much closer to home in the UK.



We were also thrilled to be able to be able to partner with many of the FOP patient organisations around the world to be part of the first Global FOP Awareness Day. FOP facts were shared across social media to provide a united message to the world, and to raise awareness of FOP and the challenges it creates for those living with the condition.



FOP Petition and Debate in Parliament

In September we launched a petition to have FOP debated in the UK parliament. This was not the first time we attempted to have FOP debated in parliament, with our original petition launching in 2012. In 2012 we did not achieve the required number of signatures.

Fast forward to 2021 and Alex Robins, whose young daughter Lexi had recently been diagnosed with FOP, suggested we give it another go.

Thanks to the FOP community and Alex's social media activity the petition gained 111,246 signatures within a month of launch, gaining interest from several celebrities, raising further awareness, and generating donations to the "Little Lexi" GoFundMe page along the way. A fantastic achievement overall.

Chris, Alex, Dave, and Lexi then travelled to Westminster in December 2021 to attend the debate with several FOP community MPs speaking on behalf of the FOP patients within their constituencies.

Significant preparation work was carried out in advance of the debate to provide MPs with accurate information on FOP and ideas on how they could help.

The full debate can be viewed at: committees.parliament.uk/committee/326/petitions-committee/news/159281/research-into-fibrodysplasia-ossificans-progressiva-debated-by-mps/

In the future, with further MP support, we hope to have a debate on FOP in the House of Commons.

Providing funding to Oxford FOP Research

FOP Friends' contribution to the research team at the University of Oxford is recognised in their Annual Philanthropy Report. Our donations to their FOP research program have helped identify the treatment now in clinical trials with the StopFOP trial.

Year on year, FOP Friends and its supporters have successfully funded the FOP Research Team at the University of Oxford. This has been achieved in collaboration with FOP France, who have also contributed to the Oxford Research Fund via FOP Friends.

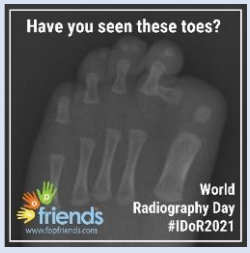
A big thank you to everyone who has donated, run a race, bought Christmas cards... Thanks also to our friends at FOP France for their contribution.

Find-a-Cure: Patient Group Engagement Committee

We're always working away behind the scenes to find ways to improve things for people living with FOP. One of our newest projects is with Chris joining the Patient Group Engagement Committee (PGEC). This is run by the excellent Find-a-cure charity. The PGEC provides insight, thoughts and guidance on issues faced by the rare disease community.



Continuing Medical Education



As part of World Radiography Day, we shared key images of FOP toes to alert radiographers to perhaps the most important diagnostic features of FOP. We followed that up by authoring an article for the Society of Radiographers' magazine to share our diagnosis story and to explain how sonographers and radiographers can assist with early diagnosis.



Chris and Helen continued to raise awareness of FOP within the medical community by taking part in the Glasgow Webinar Series in Rare Condition as part of their rare disease programme.

IFOPA Board Meeting 2022

Chris usually travels to Florida for his annual in-person board meeting for the IFOPA. However, due to continuing Covid restrictions, the volunteer board members met virtually, across two days. It was just as productive as meeting, and two new board members were welcomed. Topics discussed included reviewing the past year; planning activities and family support for the next few years; research updates; and how to continue to raise awareness worldwide.



Impact and value



FOP Friends continues to work with the FOP community in the UK, but also the international community and is recognised as an influential organisation in all fields, from patients and families to pharmaceutical companies and medical professionals.

FOP Friends continues to benefit from the fantastic ongoing efforts of FOP families, friends and the wider public. The funding FOP Friends receives allows the search for a treatment and a cure for FOP to continue. The income generated has allowed the charity to continue funding the University of Oxford FOP Research team, supporting international research, as well as providing increased support and resources for families touched by FOP.

We continue to benefit from our charitable status with success with grants, trusts, and corporate sponsorship.

However, nothing would be possible without the phenomenal support of the communities in which those touched by FOP live; those communities who have gone out of their way to aid the small number of FOP families.

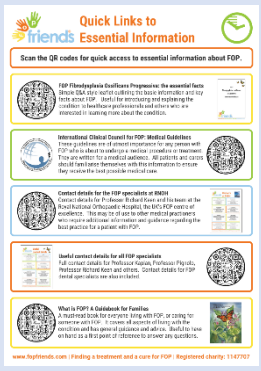
It is only through their generosity, willingness to help with fundraising, and their direct donations, that the search for a cure can continue.

Supporting families

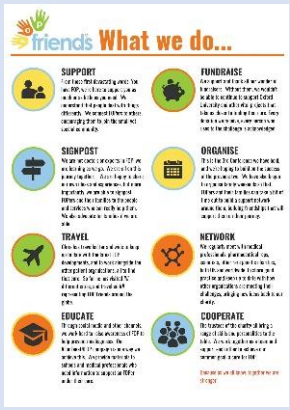


In addition to supporting our FOP families with Covid advice and guidelines, we continue to offer support to our families and the medical professionals who work with them by producing a range of resources. These are free to download, or can be posted out on request, and include a simple leaflet "Fibrodysplasia Ossificans Progressiva: the essential facts," a leaflet which outlines the key points of the condition and is written in a simple to access Q&A style.

We further supported our families by creating and sending out a free information pack for new and existing patients, 'Introducing FOP Friends' containing essential information about FOP, emergency information and details about becoming part of the FOP Community.



Other resources include a list of support guides and support groups available to people living with FOP; information about how we can help people as a charity; directories of the FOP specialists, both in the UK and international; and dental advice for patients with FOP.



We liaise with different agencies; support families with writing documents such as ECHPs; and advocate for patients with educational and medical agencies.

Fundraising

Isla's FOP Charity Bingo!

Isla, daughter of FOP Friends' trustee Nicky Muller, raised a fantastic £100 at her online family bingo night.



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

Fabulous Family Fundraising Fun!

Charlie, who lives with FOP, organised a family fundraiser as part of a college assignment for his Foundational Business Course. Charlie had to plan, invite, and promote the event as part of his course. He also set up an online fundraising page. Charlie arranged the refreshments and created a quiz for some light family fun later in the afternoon. The weather was particularly kind to them, so the festivities were held al-fresco. Family and friends came along to the event, both in-person and virtually, and much fun and laughter was had by all.



Generous at Heart!

We were thrilled to receive a donation from the Young at Heart dance class in Bearsdon, Glasgow. Iona's gran Aileen Shand is a member of the class, and since they weren't able to hold a Christmas party, they made a donation to FOP Friends instead. Young at Heart is a unique programme of dance classes that are aimed at the over 50s. The lockdown meant that in-person classes were paused, but this did not stop the members joining in, in the comfort of their living rooms through the wonder of Zoom!

4 x 4 x Fabulous!

Ever heard of the 4x4x48 Challenge? No, neither had we until Seanie's cousin Aoife decided to set herself the huge challenge to raise money for FOP Friends. The challenge was created by David Goggins, a retired US Navy SEAL, with the goal to run for 4 miles every 4 hours for 48 hours! Of course, the lack of sleep simply adds to the endurance challenge.

A Wheel-y Great Fundraiser



When Sylvie and Izzy learned about FOP from our #FunFeet4FOP campaign, they were inspired to set themselves a challenge to complete 150 cartwheels every day for the month of May. Sylvie and Izzy, both age 8, are in Harry's class at school. Harry's brother Oliver lives with FOP. When they learned about the condition, they wanted to do something to help raise money for research. Since they were both fantastic gymnasts, doing cartwheels seemed like an obvious challenge! They set themselves a fundraising target of £150 – little did they know they would totally smash it and raise a phenomenal £1304!

Isla's art auction



Two of Isla's incredibly talented friends painted original artworks to auction for FOP Awareness Day. Karina Wilgeroth painted 'Isla's World' (pictured) and Bex Foy created 'Sunrise on Isla.' Together, the paintings raised £400.

Ross Jumps for Rachel



In July, Ross took part in a sky dive for his sister Rachel, who is living with FOP. Ross, his girlfriend Andreea, and friends took part in the event in the beautiful Lake District. Ross said, "It was incredible! It was an unreal experience. I loved every minute and can't wait to do it again!".

Crafty Creations

After her friend's little boy, Lenny, was diagnosed, Claire wanted to do something what she could to help. Being a creative crafter, Claire used her talents to make beautiful jewellery and keyrings, while her daughter Ruby-Skye, age 10, helped by sewing scrunchies as well as helping mum with the jewellery making. Ruby-Skye and friend Rosie set up a stall at Ryhall Village Fair to sell their gifts and raise awareness of FOP. A few weeks previously, they had organised a fabulous Spooky Trial for Halloween through the village, and they have lots of other exciting ideas in the pipeline.

Little Lexi's Friends

When Alex and Dave received the devastating diagnosis that their baby girl Lexi had FOP, they wasted no time in rallying round their friends and family to start raising much needed funds for the research into a cure, as well as awareness for this ultra-rare condition.



They set up a Crowdfunder page, with Lexi's story touching the hearts of many. In just a few short months, Alex and Dave smashed their ambitious fundraising target of £100,000 thanks to the generous donations of their followers. Alex and Lexi also appeared on Channel 4's Packed Lunch with Professor Richard Keen.

As a community, we are incredibly grateful to all of Lexi's family, friends and supporters who have so generously donated to help to fund research into a treatment and a cure for Lexi and all her other Friends who are living with FOP.

Slemish Climb

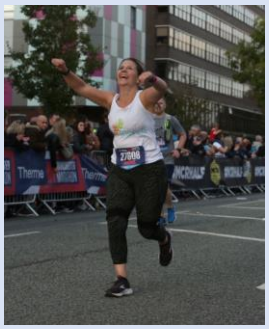


Mike Buxton along with some colleagues climbed the stunning Slemish Mountain in Co. Antrim, Northern Ireland. The legendary first known home of St. Patrick, the mountain rises about 1500ft and is an extinct volcano! It was a beautiful morning for such a walk and the team were delighted to make it to the top – they even took a FOP Friends bear to admire the view! While Zoe and Lucy were unable to join in with the climb due to their FOP restrictions, they went along to support the team.

Running for FOP

The end of most lockdown restrictions and with things returning to 'normal,' we were thrilled to have so many of our supporters get out there and take part in organiser running events to kick-start the fundraising once more.

Hannah and Meri did the Great Manchester Run.



Terri and Dave took part in the Windsor Half.

Trustees Rachel and Fiona completed the Manchester Marathon



Not to be outdone by his wife, Stuart Honour completed the Blenheim Triathlon.

Alice took part in the Luton Half Marathon.

Rachel ran the Rochdale Half Marathon

We had a formidable team of fifteen runners take part in the fantastic Great North Run.



Becky Honour finally got to take part in the London Marathon - in London - in honour of Isla! Postponed from last year, Becky had been training and raising awareness since getting the place back in 2019!

Additionally, Lauren took part in a Virtual London Marathon in honour of Lexi. She set her own route around Hemel Hempstead and had the virtual company of 50,000 runners

Danielle and Sam ran the Hertfordshire Half Marathon.

Christmas card sales

We continued our annual Christmas card campaign with a fresh design and raised over £2,000 to support FOP.



Future plans

As we begin to move out of Covid lockdowns, we hope for a return to normal, with a gradual pick-up in fundraising events.

This is beginning to materialise, as evidenced by our supporters taking on fundraising challenges for FOP from the ever-popular half and full marathons through to bingo and sky diving fundraisers.

This is positive to see, and we can now look towards the future under and brighter light. As this charity year closes, we look towards our postponed FOP Family Gathering and conference, in May 2022. The event is already receiving interest from families and industry alike, with people eager to reconnect after such a long time apart.

We are also now looking to return to our plans of the past which had been put on hold. Those plans include future family respite breaks, patient, and family support programmes, continued FOP awareness and of course FOP Friends fundraising activities. We will continue to assist anyone choosing to run an event in support of FOP themselves.

We continue to work on projects delayed by the Covid years, including the "FOP and Me" journal for children. We also have global revisions, in multiple languages, of our 'Supporting a child with FOP: a practical guide to their learning journey' in the pipeline too.

With all that in mind, we look towards the next charity year as a time to consider our longer-term strategy for FOP Friends. This strategy will be aimed at creating an even more robust charity that can survive beyond the founding trustees and their commitment to the day-to-day operation and success.

Alongside these activities, we will continue to support our FOP community to the best of our abilities.

The FOP community has waited for a treatment for such a long time, and we are now ready to move towards this becoming a reality. This is an exciting period for us as a patient organisation, but the drug approval process is exceptionally complex and time-consuming. We have just begun navigating the National Institute for Care Excellence (NICE) drug Health Technology Assessment (HTA) and Highly Specialised Technologies (HST) approval processes. This will be a huge learning curve for us as a charity, but the knowledge gained from this first application will stand us in good stead for (hopefully) many more potential treatments soon.

Ambition & long-term plans

Charity objectives

• To grow FOP Friends 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 help ensure there are more UK-based FOP experts and centres of excellence 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

• To ensure regular communications are sent to the community and further afield to keep everyone abreast of the work that FOP Friends undertakes, progress with research and to thank those who fundraise for us

Preventing misdiagnosis

• To 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, helping, and encouraging more families to become actively involved

• To expand fundraising activities beyond friends and family, through increased public awareness, 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 update the 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 seek corporate sponsorship as 'Charity of the Year

• To create alternative fundraising campaigns to diversify income streams

• To seek high-profile patrons to increase awareness, generate interest, and to actively encourage and support fundraising.

Family support

• To continue to provide support and advice to existing and recently diagnosed FOP and POH families

• To organise and deliver 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 and POH to help prevent misdiagnosis and 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 engaging medical professional as advisors.

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 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.

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

Under the Charities Act 2011 and the Companies Act 2006, the trustees are required to prepare a report and financial statements in accordance with applicable law and United Kingdom Generally Accepted Accounting Practice. Company law requires the trustees to prepare financial statements for each fiscal year which give a true and fair view of FOP Friends and of its incoming resources and application of resources, including its income and expenditure, that period. In preparing those accounts, 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 and statements of recommended practice have been followed, subject to any material departures disclosed and explained in the financial statements

• Prepare the accounts on the going concern basis unless it is inappropriate to presume that the charity will continue its operations

The trustees are responsible for keeping proper accounting records which disclose with reasonable accuracy at any time the financial position of FOP Friends 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 FOP Friends and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

For the purposes of charity law, the trustees 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 FOP Friends and financial information included on the charity's website.

This report was approved by the trustees on the 16th of December 2022 and signed on their behalf by



Chris Bedford-Gay.

Founding Trustee and Chairman

Financial review

Summary

Gross income totalled £245,252 with £344,892 to be carried forward to next charity year. Of the amount carried forward, £125,000 is designated to research; £15,000 to operating reserves; and £107,662 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 £245,252 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 £20,361 (was £108,663) in grants. An 81% decrease on the previous charity year. This fall attributed largely to grant/project funding secured in the 2020-2021 charity year during which Covid, and lockdowns delaying the completion of larger, funded, projects. As such new project funding was not actively sought in this charity year.

Charitable expenditure

Through the charity year, £130,000 was spent on funding FOP research. This was entirely directed towards the University of Oxford FOP Research team.

Operating costs of £29,811 include costs associated with fundraising of £2,504 (t-shirts, event places, and support of fundraisers), staff salaries of £20,182, £2,798 in governance costs, £1,625 operational, and £2,702 costs associated with projects.

Governance costs of £2,798 include accounting fees, insurance, postage, professional memberships, and costs associated in employing staff.

Gains and losses

Income from fundraising, voluntary income and fundraising activities increased by 34% from £179,763 to a total of £241,407.

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

£125,000 is designated towards future funding of FOP research with £15,000 held in reserve as an operating fund as detailed in our 'Policy on Reserves' above.

Future commitments

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.

Ongoing projects such as the FOP Friends Together newsletter is recognised as a future financial commitment being funded through restricted grants and trusts awards.

Restricted Funds

A total of £65,985 in funding received in this reporting year has been restricted towards research (£32,896 from international FOP organisations) and several projects including 'FOP Video' update, 'FOP & Me' journal for children, and the Alma Triffitt book award.

Investments

Presently FOP Friends has no investments.

Independent Examiner's Report

I report on the accounts of the charity for the year ended 1st March 2022 which are set out on pages 26 to 31.

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 FOP Friends' 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 charity's trustees, as a body, for my work or for this report.

Respective responsibilities of the trustees and examiner

FOP Friends' 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

During 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 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	2022	2021
Incoming resources					
From generated funds					
Voluntary income	2	£ 64,257	£ 177,150	£ 241,407	£ 179,763
Activities for generating funds	3	£ -	£ -	£ -	£ -
Investment income		£ -	£ 30	£ 30	£ 157
Other incoming resources	4	£ -	£ 3,815	£ 3,815	-£ 4,370
Total incoming resources		£ 64,257	£ 180,995	£ 245,252	£ 175,550
Resources expended					
Costs of generating funds					
Fundraising costs	5	£ -	£ 2,504	£ 2,504	£ 328
Advertising and marketing	5	£ -	£ -	£ -	£ -
Salaries	5	£ 20,182	£ -	£ 20,182	£ 18,457
Project costs	5	£ 1,075	£ 1,627	£ 2,702	£ 1,452
Operational	5		£ 1,625	£ 1,625	£ 1,526
Charitable activities					
Research	6	£ 47,896	£ 82,104	£ 130,000	£ 110,000
Events	7	£ 2,419	£ -	£ 2,419	£ 1,112
Salaries	5	£ -	£ -	£ -	£ -
Awareness		£ -	£ 518	£ 518	£ -
Governance costs	8	£ -	£ 2,798	£ 2,798	£ 3,332
Total resources expended		£ 71,572	£ 91,176	£ 162,748	£ 136,207
Net incoming/(outgoing) resources		-£ 7,315	£ 89,819	£ 82,504	£ 39,343
Reconciliation of funds					
Total funds brought forward		£ 114,977	£ 147,411	£ 262,388	£ 223,045
Total funds carried forward		£ 107,662	£ 237,230	£ 344,892	£ 262,388

Balance sheet					
-	Notes		2022		2021
Fixed assets	9		£ 1,296		£ 760
Current assets					
Cash at bank		£ 348,009		£ 264,570	
Debtors	10	£ -		£ -	
		£ 348,009		£ 264,570	
Creditors: amounts falling due within one year	11	-£ 4,413		-£ 2,942	
Net current assets			£ 343,596		£ 261,628
Net assets			£ 344,892	£	£ 262,388
Funds					
Restricted	12		£ 107,662		£ 114,977
Designated	13		£ 140,000		£ 140,000
Unrestricted			£ 97,230		£ 7,411
			£ 344,892		£ 262,388

Approved by the trustees on 16th December 2022 and signed on their behalf by



Alison Acosta Bedford, Founding Trustee.

Notes to 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 comprises those funds which are free to use for any purpose in line with the charitable objects. Unrestricted funds include designated funds where the trustees, at their discretion, have set aside resources for a specific purpose.

INCOMING RESOURCES

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

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

Voluntary income				
		2022		2021
Donations	£	221,046	£	71,100
Grants	£	20,361	£	108,663
	£	241,407	£	179,763

3. ACTIVITES FOR GENERATING FUNDS

Activities for generating funds			
		2022	2021
Fundraising events		£	-
		£	-

4. OTHER INCOMING RESOURCES

Other incoming resources				
		2022		2021
Conference fees	£	1,728	-£	5,465
Family getaway	£	-	£	-
Sales	£	2,087	£	1,095
	£	3,815	-£	4,370

5. FUNDRAISING COSTS

Fundraising costs		2022		2021
Salaries	£	20,182	£	18,457
Advertising & promotional items	£	-	£	-
Fundraising costs	£	2,504	£	328
Project costs	£	2,702	£	1,452
Operational costs	£	1,625	£	1,526
	£	27,013	£	21,763

6. RESEARCH

Research		2022		2021
UK research	£	130,000	£	60,000
International research	£	-	£	50,000
	£	130,000	£	111,000

7. EVENTS

Events		2022		2021
Conference meeting costs	£	2,419	£	1,112
Family weekend (Center Parcs)	£	-	£	-
Stakeholder meeting	£	-	£	-
	£	2,419	£	1,112

8. GOVERNANCE

Governance		2022		2021
Accountancy charges	£	110	£	225
Insurance	£	420	£	360
Subscriptions	£	1,800	£	1,013
Bank charges	£	19	£	4
Computer costs	£	-	£	-
Depreciation	£	203	£	94
General expenses	£	246	£	18
Printing, postage and stationery	£	-	£	-
Repairs and maintenance	£	-	£	1,618
	£	2,798	£	3,332

9. FIXED ASSETS

Fixed assets		Office equipment
Cost		
At 2nd March 2021	£	2,121
Additions	£	739
Disposals	£	-
As at 1st March 2022	£	2,860
Depreciation		
At 2nd March 2021	£	1,361
On disposals	£	203
Charge for year	£	-
As at 1st March 2022	£	1,564
Net book value		
As at 1st March 2022	£	1,296
At 1st March 2021	£	760

10. DEBTORS

Debtors		2022		2021
Accounts receivable	£	-	£	-
			£	1,953

11. CREDITORS

Creditors		2022		2021
Amounts falling due within one year:				
Accounts payable	£	4,251	£	3,228
PAYE and NI	£	944	£	162
VAT	-£	892	-£	678
Accrued expenses	£	110	£	110
Other creditors	£	-	£	120
	£	4,413	£	2,942

12. RESTRICTED FUNDS

Restricted funds							
	Balance b.fwd		Incoming resources		Resources expended	Balance c.fwd	
Research fund	£	5,670	£	32,896	-£ 38,566	£	-
Conference fees fund	£	24,467	£	-	-£ 2,419	£	22,048
Family getaway	£	7,256	£	-	£ -	£	7,256
Operational	£	-	£	13,400	-£ 13,400	£	-
Be Safe at School Handbook fund	£	35,170	£	-	£ -	£	35,170
FOP 'Together' Newsletter fund	£	1,075	£	-	-£ 1,075	£	-
Charity leaflet	£	358	£	-	-£ 112	£	246
Home improvement grant handling	£	500	£	-	-£ 500	£	-
FOP & Me	£	24,981	-£	2,240	£ -	£	22,741
ALK2 - Selective Allosteric Kinase Inh	£	15,000	£	-	-£ 15,000	£	-
Card Factory	£	500	£	-	-£ 500	£	-
FOP Video			£	20,000		£	20,000
Alma Triffit Book Award	£	-	£	201	£ -	£	201
	£	114,977	£	64,257	-£ 71,572	£	107,662

Key items within restricted funding include:

• Research fund describes funding toward FOP research from other international FOP organisations.

• The Conference fees fund represents donations and delegates' deposits received in respect of the FOP Conference in May 2022.

• Family getaway fund is associated with grants to assist in running future family weekend where the charity takes all FOP families with children away for a respite / break.

• Be Safe at School Handbook fund is associated with development of a global, multiple language version of that guide.

• The FOP 'Together' Newsletter fund represents grants awarded to fund the production of a quarterly print/online newsletter to inform the FOP community and to support fundraising.

• Charity leaflet funds were provided to allow for update and re-print of FOP Friends awareness leaflets used at events and fundraisers.

• The "FOP Video" relates to development of an updated FOP Awareness, Diagnosis and Do-No-Harm video.

• "Home improvement grant handling" is associated with a patient who was awarded a grant personally for home-improvements, but the awardees required the funding to be handled via a recognised entity, on their behalf.

• The Alma Triffitt book award is funding in-memory of Alma Triffitt and supports the annual purchase of a selection of hard-copy books for Children with FOP.

13. DESIGNATED FUNDS

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 the safe minimum reserve level as determined by the charity's Reserves Policy.

Our history (to 1st March 2022)

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.

FOP Friends’ chairperson and founder Chris Bedford-Gay 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?” animation, 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 on the International FOP Flare-up survey.

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.

FOP Friends is awarded a grant for £16,000 from GDUK to fund a Charity Administrative Assistant.

December 2013

FOP Friends is 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 organises 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.

August 2014

FOP Friends is 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

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

FOP Friends Founder and chairperson Chris attends the IFOPA Drug Development Forum in Boston, with over 100 researchers and interested pharmaceutical companies in attendance. This is a milestone in the search for a treatment and cure for FOP.

December 2014



FOP Friends decorates their annual Christmas Tree at St. Alban’s Church, Cheshire, with photos of FOP patients from around the country.

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

January 2015

Clementia open the first European trial site in Paris. Some of our UK FOP patients take the opportunity to participate in the trial. 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 FOP Friends as their Charity of the Year.

August 2015

FOP Friends are delighted to announce their 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 and 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.

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

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

February 2016

FOP Friends is 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.

Adobe chooses FOP Friends as beneficiary of their Charity of the Year.

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

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.

FOP Friends celebrate Rare Disease Day by announcing that they, 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 FOPer's 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.

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 are able to 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

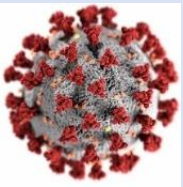


Chris attends the IFOPA in-person board meeting in Philadelphia as part of his role at the IFOPA. Whilst there he attends an early screening of the Tin Soldiers documentary in which he, Oliver, and FOP Friends' trustee Nicky with her daughter Isla all feature.



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

Gene Therapy funding (in pursuit of a cure)



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 CME Video (Med Scape?) 250,000 Health Care Professionals targeted.

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!





Rare disease day. We join with other rare disease organisations around the world, 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



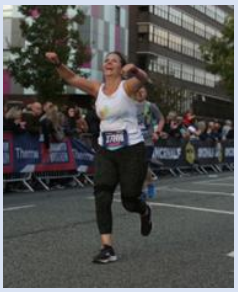
We also hold our #FunFeet4FOP campaign and see people all around the world sharing photos of their fabulous feet! Check out these funky socks being worn by fire-fighters in Australia!

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 2022



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



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.

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.

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.

Thank you to (March 2020 – March 2021)

FOP Friends would like to acknowledge our ever-growing supporters.

Trusts / Grants

Big Lottery Fund

Genetic Disorders UK

Manchester Guardian Society CT

Sobell Foundation

The February Foundation

Corporate Supporters

Ipsen Pharmaceuticals

Regeneron Pharmaceuticals

Skillsarena Ltd

Donors of time and resources

Clarity Comms: FOP Animation

Stephen Fry: FOP Animation Narration; foreword

Keith Hopwood (Herman's Hermits): FOP Animation Music

Skillsarena Ltd: Director's time

Foliozine: Logo design

Community / Clubs & Associations

Gloriana Freemasons Lodge

Manchester Round Table

Royal Northumberland Yacht Club

Uxbridge Rotary Club

Fundraisers

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

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

Contact Details

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@fopfriends

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FOP Friends

FOP FRIENDS

England & Wales - Charity number 1147704

Accounts

2021 Annual Report & Financial Statements

Year ending 1st March 2021

Registered with

Charity Commission for England & Wales

#1147704

Office of the Scottish Charity Regulator

#SCO46950

2021 Annual Report & Financial Statements

Year ending 1st March 2021

Vision

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

Mission

To 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.

Values

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.

Respects the integrity, ambition, and interests of all FOP patients, acts as a champion, and provides a haven for patients and families.

Strives to be a centre of excellence for the provision of information on medical research, diagnosis, treatment and care, and participation in clinical trials.

Act always with honesty, professionalism, and ethical awareness. Work collaboratively with medical researchers and clinicians, patients and families, donors, and supporters to realise our Vision and complete our Mission.

Charity name

FOP Friends

Charity number(s)

1147704, SCO46950

Governed by

Trust Deed

Independent auditor

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

Founding Trustees

Christopher Bedford-Gay

Alison Acosta Bedford

Rachel Almeida

Trustees

Fiona White

John Leaver

Helen Bedford-Gay

Nicky Williams

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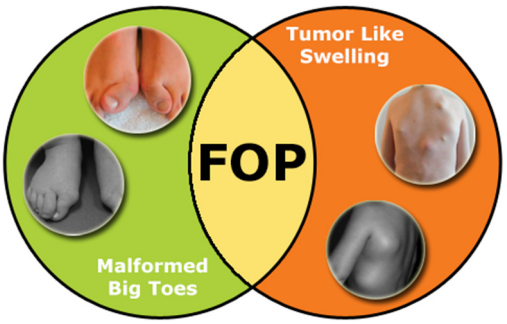
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What is Fibrodysplasia Ossificans Progressiva (FOP)?

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 connective tissues.

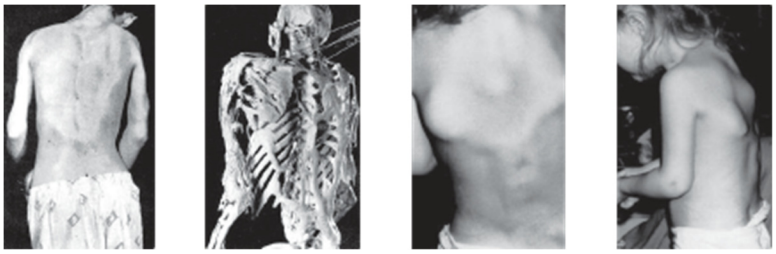
Bridges of extra bone develop across the joints, progressively restricting movement, forming a second skeleton that imprisons the body in bone. There are no other known examples in medicine where one normal organ system turns into another.

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.

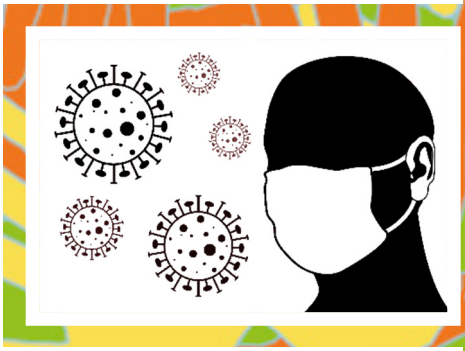


Fibrodysplasia Ossificans Progressiva (FOP) causes progressive debilitation eventually leading to early death.



Introduction and Chair's Statement

Well, another year has gone by so very quickly and the trouble we saw coming at the end of our 2020 charity year certainly materialised, not only for us but the rest of the world!



Days after starting our 2020 charity year, the UK went into its first lockdown as the global pandemic loomed large: the start of what would be a challenging time for all began.

Our first and almost immediate hit was the cancellation of our UK FOP Conference and Family Gathering. For obvious reasons, we took the decision quickly to cancel the in-person event our community looks forward to biennially.



Then we watched as the 2020 plans - events, fundraising activities, charity runs, beer festivals, concerts, bingo nights – which traditionally have helped to raise funds for FOP research, ceased almost overnight.

It was going to be a tough year for us as a charity to fund FOP research. The 2020 – 2021 charity year saw us drop from £22,725 in event fundraising to £0.

But arguably, that was the least of the worries for our FOP community. Whilst Covid posed the same health risks to our FOP community in the same way as the wider community, there were also serious concerns that it would trigger an FOP flare response. FOP medical specialists fear the Covid virus would trigger the FOP in the same was as other viruses such as flu can.

As the year progressed, talk of vaccines across the world gave people hope. However, many minority groups, including the FOP community, were left to make almost impossible decisions. Why? Because FOP patients must avoid into muscle injections (all current Covid vaccines are into muscle) as they too can trigger FOP. Patients were left to make the difficult choice: risk losing more movement as a result of the vaccine, or risk catching Covid and all the complications that could bring.

We supported our community through this time by keeping people updated with the rapidly changing information which was being developed by the International Clinical Council on FOP (the ICC). As scientists learned more about the epidemiology of Covid, the ICC's guidelines for people with FOP evolved too. We ensured that up-to-date information was available on our website and was linked to NHS guidance. We also contacted and supported families directly. As the pandemic shows no signs of ending, we continue to offer this support to our families.

Fortunately, just prior to the global shutdown, we secured funding for two projects that will help support the UK, and international FOP communities.

Those projects will be nearing completion toward the end of 2021 – early 2022. Later in 2020 we reverted to being entirely volunteer ran with our one, part-time, member of staff being furloughed through most of 2020 and part of 2021.

It was a difficult but essential decision, and our trustees picked up the day-to-day work of the charity as well as the ongoing support of our FOP families in these extremely difficult times.

From a personal perspective, it brought back memories of when we founded the charity after our son Oliver (now 13) was diagnosed with Fibrodysplasia Ossificans Progressiva (FOP) at age 1. It was another test to be met head-on and we will survive the challenge of Covid too: we did not get within touching distance of our 10th year as a charity by not fighting.



Even with this charity year being one we might want to forget, we have continued to grow our support locally, nationally, and internationally. FOP Friends continues to raise awareness of FOP to aid early diagnosis, thus preventing the often-devastating progression of the condition. We are also always looking to find new ways to make our annual fundraising target easier to reach; to support our families living with FOP; and to continue to bring the FOP community together.

FOP Friends remains internationally recognised as a key partner and source of support and information by families, researchers, and pharmaceutical companies alike. It is this, with our continued involvement at the board level of the IFOPA and international efforts, which make us the go-to organisation for many.

Our initiatives such as #FunFeet4FOP, family-focused conferences, family weekends, and our promotional and information items are influencing many.

The family support we provide is outstanding, being the first point of contact for the newly diagnosed in the UK, but often internationally too. We make introductions and contacts between families and medical professionals, advising on challenges, the day-to-day, and simply being there as a listening ear when needed.

Hard work and time have got us this far: but it will take more to make our vision a reality. With continued support, we will change the lives of every FOP family - present and future.

My thanks go to our supporters who help to fund our work (through events, sponsorship, or donations), and to the volunteers who are there when we need them. Without your support, we could not keep moving forward. You keep hope alive for all those touched by FOP, now and in the future.



Chris Bedford-Gay, Founder 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 more common disorders.

FOP Friends was founded following the diagnosis of Oliver Bedford-Gay (10) with FOP at the age of 1. The aim of the charity is to support the search for a cure, whilst raising awareness and educating the public and medical world of the condition. FOP Friends supports existing research programmes such as at the University of Oxford and patient organisations; 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 the University of Oxford's FOP Research Team.

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

Trustees

There must be at least three trustees. Except for the three founders, 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.

Chris Bedford-Gay - 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 served as chairman of FOP Action (which has now been integrated into FOP Friends) and has also been a Board Member of the IFOPA since 2011. He is Chairman of the IFOPA International Presidents' Council, bringing together FOP organisations and leaders from across the world. He carries out this work alongside his day-job as director of UK based technology company, Skillsarena.

EDUCATION

- 1st Class BSc Hons, Computing for Business

EXPERIENCE

- Software engineer and consultant at GlaxoSmithKline
- Software engineer at Defence Evaluation Research Agency
- Technical Director, Turtlez Ltd (10 years)

• Director and CTO, Skillsarena Ltd (current)

• Chairman and Area Chairman, Round Table

• IFOPA Board member

Alison Acosta Bedford - Trustee



As one of the founding trustees, Alison has been on this journey from the beginning. Alison is a Chartered Management Accountant so assists with the financial accounts of the charity, along with other administrative tasks, and supporting fundraising efforts. As chair of the trustee meetings, Alison remains committed to using her professional skills to assist in managing the day-to-day staffing and operation of the charity, as well as utilising personal relationships to raise awareness and funds for research into finding a cure for this terrible condition.

EDUCATION

• BSc Hons, Mathematics, University of Sheffield

• CGMA Chartered Institute of Management Accountants.

EXPERIENCE

• Over 16 years' finance experience within social housing

• Experience of long-term financial planning as Treasury and Investment Manager of a housing association with over £60m annual turnover

• Experienced in Workforce Development through Manchester Chamber of Commerce & Industry

Alison is proud of how much FOP Friends has grown since forming and of the biennial family symposium held in May, which highlights how important FOP Friends has become to the FOP community.

Rachel Almeida – Trustee



Rachel is Head of Events and Sponsorship for the Association of Colleges, organising education-related conferences. She has worked in events for over 18 years and is pleased to be able to put her experience and expertise to good use. Rachel was inspired to complete her first ever fun-run in aid of FOP Friends, completing the Great North Run half marathon in under 2hr 30 minutes.

EDUCATION

• BSc Hons, German and Law, University of Surrey

EXPERIENCE

• International trade shows

• International economic research charity dissemination conferences

• Head of Events and Sponsorship (current) – leading a team to deliver 40 education conferences per year with direct responsibility for a £1.7m annual turnover

Rachel looks to use her personal drive to work hard alongside fellow trustees and the whole of the FOP Community to find a cure for FOP.

Fiona White - Trustee



Fiona is a lead teacher working in a primary school. She works as 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.

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

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.

John Leaver - 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 new 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 – Trustee



Helen has been with the charity since the very beginning. Having come to terms with the devastating diagnosis that her son, Oliver, had FOP, she felt the need to become proactive in the search to find a treatment, so he could have as normal a childhood as possible. Helen also recognised the need for a proactive support network for families affected by FOP. Helen has taken a largely behind the scenes role, supporting and thanking the fundraisers around the country as well as developing much of the charity information that is in circulation. Helen also drives many of the fundraising activities in the local community. Unfortunately, since Oliver was diagnosed, there have been more young children in the UK who have received the same news. Helen often acts as the first point of call for families; she can offer parents a network of friends who understand their distress and can offer guidance for the incredibly difficult times ahead. Having been an experienced teacher, Helen has the knowledge and ability to offer practical guidance and support for parents and schools regarding mainstream education for their child.

EDUCATION

• BA (Ed.) QTS Hons. Durham

EXPERIENCE

• Classroom teacher across Key Stages 1 and 2, with experience of KS1 leadership

• Fulbright Exchange Teacher to USA

In addition to the work for the charity, Helen continues her career as a primary school teacher, and is also mum to Oliver's younger brothers Leo (10) and Harry (8).

Nicky Williams – Trustee



Nicky feels 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.

Meeting Charity Commission guidelines

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

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 incorrect 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 / Saracatinib

Covid-19 has impacted us all in different ways. One of the consequences for the FOP community was the challenge it created for clinical trials.

In July, we hosted the StopFOP webinar for families, with FOP specialists from the UK, Europe and beyond. The trial was then put on pause due to Covid. They resumed the trial in Europe in October 2020, but the UK site has been met with further administrative delays.

The team, consisting of Professor Alex Bullock (Oxford), Dr Marelise Eekhoff (Amsterdam, VUMC), Dr Bernard Smilde (Amsterdam, VUMC), Dr Richard Keen (RNOH), spoke about the StopFOP clinical trial.

The team are currently working to complete regulatory steps to open the London and German sites.

Regeneron - Garetosmab

Regeneron pharmaceuticals were pleased to share results from their Phase 1 clinical trial for garetosmab. A big thank you to everyone for their hard work and to the trial patients who make it possible.

Unfortunately, in early November, Regeneron placed a hold on their Phase II Clinical trial for Garatosmab LUMINA-II Trial due to serious adverse effects that needed to be investigated.

Ipsen - Palovarotene

Ipsen announced they could reinitiate palovarotene dosing in patients 14 years of age and older.

Ipsen also announced their results from the global Phase 3 MOVE trial, which was presented at the 2020 Annual American Society for Bone and Mineral Research meeting. Analysis showed a 62% reduction in new bone growth when treated with palovarotene, which is promising news for the FOP community.

At the end of 2020, 'Let Their Feet Lead the Way: Tools for Early Identification of FOP', was launched. This was the PeerVoice panel discussion, led by Professor Richard Keen and Dr Angela Cheung (University of Toronto), with Chris participating by providing the perspective of a parent on the journey to diagnosis of a rare condition. The objective of the project is to raise awareness of FOP within the medical community with the aim of reducing the time to diagnosis of a person with FOP. It is hoped that the online training module will reach over 250,000 professionals.

Keros Therapeautics - KER-047

Keros Therapeutics is developing a small molecule product candidate, KER-047, which is designed to selectively and potently inhibit activin receptor-like kinase-2, or ALK2, a TGF-β receptor. Their lead drug for FOP has completed its first set of Phase I clinical trials in healthy individuals without FOP. The positive results from its Phase I trial meant that preparations for Phase II could begin.

Biocryst

In December 2020, BioCryst also announced positive results from its Phase I clinical trials, pursuing activin receptor-like kinase-2 (ALK2) inhibition in the race to stop FOP. BioCryst's ALK2 inhibitor is an orally administered kinase inhibitor that aims to slow or prevents heterotopic ossification.

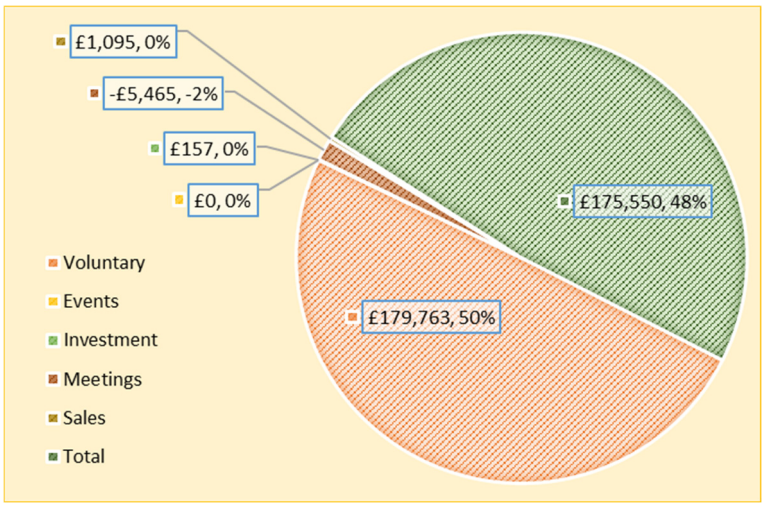
How we raised our money

Voluntary income accounts for the bulk of money raised within the charity's financial year. A small amount is attributed to investment income (interest on bank balances) and £0 revenue from fundraising events, a 100% decrease from 2020. This drop in revenue from events can be directly attributed to the emergency of Covid, the first lockdown of which coincided with the beginning of this charity year.

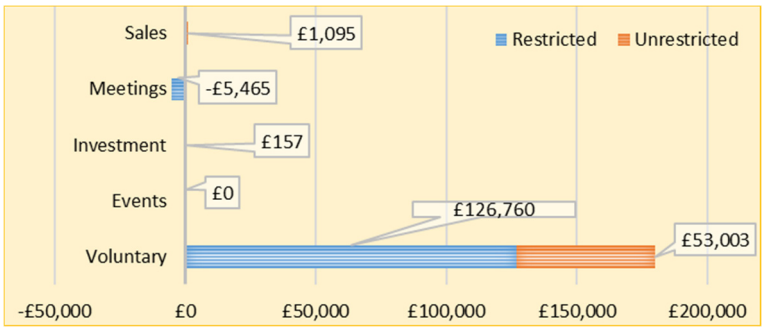
Whilst an impressive increase in revenue from fundraising events occurred, voluntary income from donations overall reduced to £71,100 for the year, an increase of 3% overall.

However, we saw an increase in income from grants awarded for projects in line with our charitable objectives of £108,663 which saw our total voluntary income raised by 80% to £179,763 for the charitable year ending 2021.

In addition, revenue of £1,095 is attributed to sales.



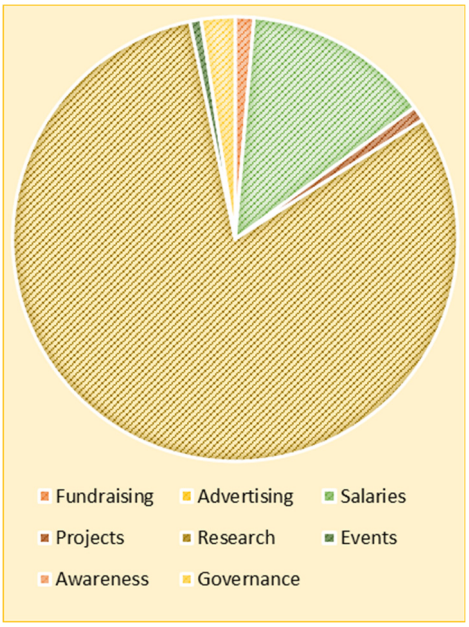
From a total £175,550 (was £141,339) incoming resources, £121,295 (69%) were restricted. The remaining £54,255 (31%) being unrestricted.



Unrestricted income therefore poses our biggest fundraising challenge as it is the main source of FOP research funding. Restricted income mainly be being generate through grants and trusts and restricted to specific projects.

How money raised was spent

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 **95%** of all fundraised money directly supports our charity objects of; family support; awareness; and funding research. [Note: Voluntary Donations VS Fundraising Costs]

FOP Friends donated a total for £110,000 to FOP research this charity year.

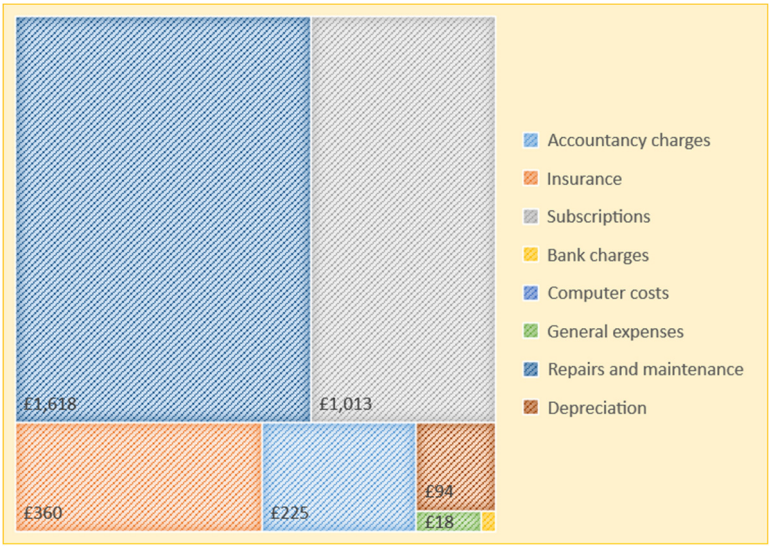
The main beneficiary of FOP Friends is the FOP Research team at the University of Oxford who received £60,000 in research funding. Led by Professor Alex Bullock, the team is one of a small number of teams in the world, conducting research into FOP.

FOP Friends also contributed £50,000 to the worlds fist FOP Gene Therapy research project via the IFOPA. Gene Therapy represents a potential cure for FOP and the project already having positive results.

Fundraising costs of £1,854 is attributed to the provision of fundraising materials and merchandise to support these and other fundraising events.

Resources expended on staff salaries (£18,457) continues to be funded through grants and corporate sponsorship leaving "fundraised" money designated to the charity objects.

Governance costs of £3,332 are attributable to the continued operation of the charity.



Governance includes basic operational costs, accounting fees, insurance, postage, professional memberships, and costs associated with training and supporting trustees and staff.

Achievements

Supporting families through Covid

Lockdown and Covid proves to be an immense challenge for all of us, in ways too numerous to mention. However, FOP Friends continues its support of families by keeping them updated with the latest Covid advice from the ICC.

Rare Disease Awareness

We marked Rare Disease Month with interesting and informative SM content across all our channels, ending on 28th February, #RareDiseaseDay2021, where we celebrated all those who are living with a rare disease.



While each rare disease may only affect a few people, together Rare is Many and Rare is Strong. We in the FOP community are some of the lucky ones: we have doctors who know and love us; teams of researchers around the world looking for a treatment and bringing hope; and a strong international family to support us with the challenges living with a rare disease brings.

FOP Awareness



April is FOP Awareness Day Month, culminating in FOP awareness day on 23rd April and return of FunFeet4FOP. This year saw even more people take part than before, with supporters from around the globe and the launch of Global FOP Awareness and the Uniting to Cure FOP campaign.

Conference and Family Gathering



Although our biennial Conference and Family Gathering had to be cancelled, FOP Friends produced a powerful video message. It featured many of our fabulous specialists and delivered a clear message of hope. We also hosted a zoom family lockdown quiz and virtual scavenger hunt for the kids to mark what would have been our Saturday evening symposium dinner.

Natural History Study

FOP Friends encouraged the community to share their time, knowledge, and experiences to contribute to the Natural History Study, the first study to look at the long-term progression of FOP and its effect on the physical function of people living with the condition. The study's findings will go a long way to further the understanding of the condition and take us nearer to finding a cure.

3,000 Followers

FOP Friends' Facebook page reached 3,000 followers. With only 800 known patients in the world, this means our reach is continuing to grow beyond our FOP families.

Introducing FOP Friends: Information Pack

We carried on supporting our families by creating and sending out a free information pack for new and existing patients, "Introducing FOP Friends", containing essential information about FOP, emergency information and details about becoming part of the FOP Community.

In Pursuit of a Cure: FOP Gene Therapy

FOP Friends contributed to the exciting campaign In Pursuit of a Cure, led by the IFOPA, which expands research into potential gene therapy as a treatment for FOP. It will be a long journey and there are no guarantees, but if successful, gene therapy has the potential to cure FOP.

This builds upon FOP Friends continued support of the IFOPA ACT for FOP Grants that invest in novel FOP research.

Ongoing FOP Awareness

Covid doesn't stop us spreading our news. We distributed 500 newsletters via our mailing list. The newsletter is also distributed via email to our 550 subscribers and is promoted via our Social Media channels.

Providing funding to Oxford FOP Research

FOP Friends' contribution to the research team at the University of Oxford is recognised in their Annual Philanthropy Report. Our donations to their FOP research program have helped identify the treatment now in clinical trials with the StopFOP trial.

Year on year, FOP Friends and its supporters have successfully funded the FOP Research Team at the University of Oxford. This has been achieved in collaboration with FOP France, who have also contributed to the Oxford Research Fund via FOP Friends.

Find-a-Cure: The Student Voice Prize

FOP Friends supported two more students who entered the Student Voice Essay Competition. One essay focused on FOP, the other on Progressive Osseous Heteroplasia (POH) - the sister condition to FOP.

The Student Voice Prize essay competition raises the profile of rare diseases among doctors and scientists, and the next generation of medical professionals. It encourages them to consider rare diseases for the first time or share their personal experience of rare conditions. The best essays have a chance to make a real impact on the work of medical professionals.

A previous FOP essay was runner up for the prize.

Continuing Medical Education

Lights, Camera, Action! Continuing the charity's goal of raising awareness of FOP, Chris took part in an educational teaching presentation as part of Peer Voice "Let Their Feet Lead the Way" and topics "The Difficulties in Diagnosing FOP" and "Testing and Referral of FOP".

Chris was filmed, along with Professor Keen (UK) and Dr Cheung (Canada), with the video covering the early identification of FOP, and the logistics of how patients are tested and referred to FOP specialists.



The video, podcast and learning content will be distributed to 250,000 medical professionals, including endocrinologists, orthopaedists, and paediatricians, worldwide. The objective of the project is to raise

awareness of FOP within the medical community, in order to improve the time to diagnosis of a person with FOP.

Continuing support through Covid

FOP Friends shared, via the website and private family social media groups, all updates from the International Clinical Council for FOP (ICC) with advice regarding Covid-19 for people living with FOP, including all important advice for people with FOP and their carers about receiving the vaccine.

IFOPA Board Meeting 2021

Chris usually travels to Florida for his annual in-person board meeting for the IFOPA. However, due Covid restrictions, the fifteen volunteer board members met virtually, across two days. It was just as productive as meeting, and two new board members were welcomed. Topics discussed included reviewing the past year; planning activities and family support for the next few years; research updates; and how to continue to raise awareness worldwide.

Impact and value

FOP Friends continues to work with the FOP community in the UK, but also the international community and is recognised as an influential organisation in all fields, from patients and families to pharmaceutical companies and medical professionals.



FOP Friends continues to benefit from the fantastic ongoing efforts of FOP families, friends and the wider public. The funding FOP Friends receives allows the search for a treatment and a cure for FOP to continue. The income generated has allowed the charity to continue funding the University of Oxford FOP Research team, supporting international research, as well as providing increased support and resources for families touched by FOP.

We continue to benefit from our charitable status with success with grants, trusts, and corporate sponsorship.

However, nothing would be possible without the phenomenal support of the communities in which those touched by FOP live; those communities who have gone out of their way to aid the small number of FOP families.

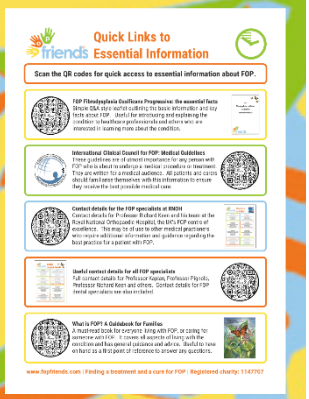
It is only through their generosity, willingness to help with fundraising, and their direct donations, that the search for a cure can continue.

Supporting families



In addition to supporting our FOP families with Covid advice and guidelines, we continue to offer support to our families and the medical professionals who work with them by producing a range of resources. These are free to download, or are posted out on request, and include a simple leaflet “Fibrodysplasia Ossificans Progressiva: the essential facts”, a leaflet which outlines the key points of the condition and is written in a simple to access Q&A style.

We further supported our families by creating and sending out a free information pack for new and existing patients, “Introducing FOP Friends”, containing essential information about FOP, emergency information and details about becoming part of the FOP Community.



Other resources include a list of support guides and support groups available to people living with FOP; information about how we can help people as a charity; directories of the FOP specialists, both in the UK and international; and dental advice for patients with FOP.



We liaise with different agencies; support families with writing documents such as ECHPs; and advocate for patients with educational and medical agencies.

Fundraising

FOP Awareness Day



Trustee Nicky, who is mum to Isla, set herself the personal challenge of running an amazing 262.2 miles, which she completed on the 23rd of April, FOP Awareness Day, with Isla cheering her on at the finish line.

Chop4FOP



Instead of suffering with a bad lockdown hairdo like most of us, Betsy decided she would shave it all off in honour of her beautiful and badass friend Lucy, who is living with FOP. Betsy set up a crowdfunding page with the promise that once she reached £1,500 in donations, she would chop her hair for FOP… and she did!

Betsy went on Facebook Live to prove to all her supporters that she had in fact done the deed! Betsy was also able to get her donations fund matched through the HP Foundation, which brought her total to an incredible £3770!

On your bike



Sarah and Sinead’s Virtual Bike Ride to Paris: 140 miles, and £3,370 for FOP Friends, raised by completing a London to Winchester bike ride.

Virtual London Marathon Ladies!

Becky, Fiona, and Jane all completed the Virtual London Marathon in aid of FOP Friends.

Becky completed a solo marathon on the original marathon date in April and then signed up for the Virtual London Marathon in the middle of August. She raised over £3000. Fiona wanted to use the opportunity to raise money for her friend’s daughter Isla.



Jane had already done a half marathon for FOP Friends so set her sights on a new challenge: the race to find a cure for FOP. She ran through her neighbourhood, doing laps of local streets to make up the miles. It was made the event even more special and memorable, having family and friends standing on the roadside, all safely socially distanced, cheering her on.

Jake Goes Virtual



This year's pandemic meant that long-time supporter Jake was unable to hold his annual yard-sale. Instead,14-year-old Jake created his own virtual 'race' to support our race to find a treatment for FOP. Jake challenged himself to run 300 miles over the course of the lockdown. This impressive sporting achievement raised £100 for FOP Friends.

Christmas card sales



We continued our annual Christmas card campaign with a fresh design and raised over £2,600 to support FOP.

Inspiring young leaders

Amy, a friend of Isla's, delivered a presentation to her class about FOP and reflected on how it affected her friend Isla. She celebrated their friendship and how Isla is always living her best life.



She gave the presentation to her class as part of their Thought for the Week. Amy explained FOP to her classmates and how it had impacted Isla's life yet never stopped Isla making the most of every day. Amy spoke about the fun times she has with her friend and talked about how Isla is always there to cheer her on when she does dance competitions and shows. Amy's favourite thing to do though, is to make up dances with Isla. Amy explained to her friends that her friendship with Isla keeps her grounded and makes sure she makes the most of every day. Amy donated her pocket money to buy some wristbands so she could give them to her classmates. Amy is an amazing ambassador for Isla and FOP Friends.

Future plans

It is no joke to say that current plans revolve largely around surviving the "Covid years", where our usual fundraising sources have taken a large hit. We raised £0 from fundraising events through this charity year.

We have continued to operate throughout the first year of the pandemic by making strategic decisions to best navigate the current situation.

Through the next charity year, we will continue to plan to ensure the charity is here for the long term and is able to continue to fund research and support our FOP families.

Fortunately, in early 2020, we secured funding to take our guidebook "Supporting a child with FOP: a practical guide to their learning journey" but development of this has been delayed and is now due in Quarter 1 of 2022. This project will support the translation of the guidebook into multiple languages and with country-specific adaptations. This expands our support of the global FOP community by following the success of the UK-focused first edition.

In addition, the "FOP and Me" journal for children will be completed in Q1 2022 also. This journal aims to provide honest information for older children who are beginning to understand what the diagnosis of FOP will mean for them. There will be simple to follow explanations, practical tips, and stories from older people who are living with FOP. There will be space for children and young people to make the journal their own, with space to reflect and personalise the journal. The book will be professionally illustrated and aims to support not only the children and young people with FOP, but their siblings, friends, and families too.

After the cancellation of our 2020 FOP Conference and Family Gathering, we decided to plan for the next to take place in May 2022. We are hopeful this can take place in-person and will be able to celebrate our 10th year as a registered charity at the event. It will be a sorely missed opportunity for the UK FOP Community to come together with our international FOP and industry experts to take part in clinical sessions and updates from our researchers and drug developers.

Along with our new projects, we will continue with awareness raising and fundraising activities to ensure research at the University of Oxford continues to be funded, and the level of family support FOP Friends offers can continue.

We constantly aim to move further towards being a sustainable organisation whose day-to-day operation is not entirely dependent upon the time and commitment of the founders and their families (who run the organisation alongside full time jobs and family commitments).

2020 has not been the year to move these plans forward, but we look towards our next charity year as one where we can begin our moves to a sustainable charity less reliant on the commitment of a small number of individuals.

Ambition & long-term plans

Charity objectives

- To grow FOP Friends 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 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

• To ensure regular communications are sent to the community and further afield to keep everyone abreast of the work that FOP Friends undertakes, progress with research and to thank those who fundraise for us

Preventing misdiagnosis

• To 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, helping, and encouraging more families to become actively involved

• To expand fundraising activities beyond friends and family, through increased public awareness, 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 update the 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 seek corporate sponsorship as “charity of the year”

• To create alternative fundraising campaigns to diversify income streams

• To seek high-profile patrons to increase awareness, generate interest, and to 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 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 and 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 engaging medical professional as advisors.

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 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.

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

Under the Charities Act 2011 and the Companies Act 2006, the trustees are required to prepare a report and financial statements in accordance with applicable law and United Kingdom Generally Accepted Accounting Practice. Company law requires the trustees to prepare financial statements for each financial year which give a true and fair view of FOP Friends and of its incoming resources and application of resources, including its income and expenditure, that period. In preparing those accounts, 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 and statements of recommended practice have been followed, subject to any material departures disclosed and explained in the financial statements
- Prepare the accounts on the going concern basis unless it is inappropriate to presume that the charity will continue its operations

The trustees are responsible for keeping proper accounting records which disclose with reasonable accuracy at any time the financial position of FOP Friends 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 FOP Friends and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

For the purposes of charity law, the trustees 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 FOP Friends and financial information included on the charity's website.

This report was approved by the trustees on 20th December 2020 and signed on their behalf by



Chris Bedford-Gay.

Founding Trustee and Chairman

Financial review

Summary

Gross income totalled £75,550 with £262,388 to be carried forward to next charity year. Of the amount carried forward £125,000 is designated to research and £15,000 to operating reserves. The charity has no long-term investments. Cash reserves are held in bank deposit accounts.

Income

Income for the year totalled £175,550 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 £108,663 (was £31,061) in grants. A 250% increase on the previous charity year. This is in part due to crossover of grants towards events within the next (2021/22) charity year.

Charitable expenditure

Through the charity year, £110,000 was spent on funding FOP research. This was directed towards the University of Oxford FOP Research team (£60,000) and FOP Gene Therapy Research (£50,000).

Operating costs of £25,095 include costs associated with fundraising of £1,854 (t-shirts, event places, and support of fundraisers), staff salaries of £18,457, £3,332 in governance costs and £1,452 costs associated with projects.

Governance costs of £3,332 include accounting fees, insurance, postage, professional memberships, and costs associated in employing staff.

Gains and losses

Income from fundraising, voluntary income and fundraising activities increased by 47% from £122,690 to a total of £179,763.

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

£125,000 is designated towards future funding of FOP research with £15,000 held in reserve as an operating fund as detailed in our “Policy on reserves” above.

Future commitments

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.

Ongoing projects such as the “FOP Friends Together” newsletter is recognised as a future financial commitment being funded through restricted ‘grants and trusts’ awards.

Restricted Funds

A total of £122,390 in funding received in this reporting year has been restricted towards research (£31,126 from international FOP organisations) and several projects including “FOP School Book: Going Global” updates, “FOP & Me” journal for children and new research into selective kinase inhibitors for FOP.

Investments

Presently FOP Friends has no investments.

Independent examiner's report

I report on the accounts of the charity for the year ended 1st March 2021 which are set out on pages 26 to 31.

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 FOP Friends' 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 charity's trustees, as a body, for my work or for this report.

Respective responsibilities of the trustees and examiner

FOP Friends' 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

During 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 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

Consolidated statement of financial activities					
-	Notes	Restricted	Unrestricted	2021	2020
Incoming resources					
From generated funds					
Voluntary income	2	£ 126,760	£ 53,003	£ 179,763	£ 99,965
Activities for generating funds	3	£ -	£ -	£ -	£ 22,725
Investment income		£ -	£ 157	£ 157	£ 494
Other incoming resources	4	-£ 4,370	£ -	-£ 4,370	£ 18,155
Total incoming resources		£ 122,390	£ 53,160	£ 175,550	£ 141,339
Resources expended					
Costs of generating funds					
Fundraising costs	5	£ 1,526	£ 328	£ 1,854	£ 5,030
Advertising and marketing	5	£ -	£ -	£ -	£ 52
Salaries	5	£ 18,457	£ -	£ 18,457	£ 40,002
Project costs	5	£ 1,452	£ -	£ 1,452	£ 3,484
Charitable activities					
Research	6	£ 31,126	£ 78,874	£ 110,000	£ 60,500
Events	7	£ 1,112	£ -	£ 1,112	£ 3,253
Salaries	5	£ -	£ -	£ -	£ -
Awareness		£ -	£ -	£ -	£ 667
Governance costs	8	£ -	£ 3,332	£ 3,332	£ 3,486
Total resources expended		£ 53,673	£ 82,534	£ 136,207	£ 116,474
Net incoming/(outgoing) resources		£ 68,717	-£ 29,374	£ 39,343	£ 24,865
Reconciliation of funds					
Total funds brought forward		£ 46,260	£ 176,785	£ 223,045	£ 196,227
Total funds carried forward		£ 114,977	£ 147,411	£ 262,388	£ 221,092

Balance sheet

Balance sheet					
-	Notes		2021		2020
Fixed assets	9		£ 760		£ 137
Current assets					
Cash at bank		£ 264,570		£ 223,980	
Debtors	10	£ -		£ 1,953	
		£ 264,570		£ 225,933	
Creditors: amounts falling due within one year	11	-£ 2,942		-£ 3,025	
Net current assets			£ 261,628		£ 222,908
Net assets			£ 262,388	£	£ 223,045
Funds					
Restricted	12		£ 114,977		£ 46,260
Designated	13		£ 140,000		£ 140,000
Unrestricted			£ 5,458		£ 34,832
			£ 260,435		£ 221,092

Approved by the trustees on 20th December 2021 and signed on their behalf by



Alison Acosta Bedford, Founding Trustee.

Notes to 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 comprises those funds which are free to use for any purpose in line with the charitable objects. Unrestricted funds include designated funds where the trustees, at their discretion, have set aside resources for a specific purpose.

INCOMING RESOURCES

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

Voluntary income is received by way of donations and gifts, and is included in full in the Statement of Financial Activities as received. Investment income is included as 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

Voluntary income				
		2021		2020
Donations	£	71,100	£	68,904
Grants	£	108,663	£	31,061
	£	179,763	£	99,965

3. ACTIVITES FOR GENERATING FUNDS

Activities for generating funds				
		2021		2020
Fundraising events			£	22,725
			£	22,725

4. OTHER INCOMING RESOURCES

Other incoming resources				
		2021		2020
Conference fees	-£	5,465	£	11,169
Family getaway	£	-	£	2,500
Sales	£	1,095	£	4,486
	-£	4,370	£	18,155

5. FUNDRAISING COSTS

Fundraising costs		2021		2020
Salaries	£	18,457	£	40,002
Advertising & promotional items	£	-	£	52
Entry fees	£	-	£	-
Fundraising costs	£	328	£	3,647
Project costs	£	1,452	£	3,484
Operational costs	£	1,526	£	1,383
	£	21,763	£	48,568

6. RESEARCH

Research		2021		2020
UK research	£	60,000	£	60,500
International research	£	50,000	£	-
	£	110,000	£	60,500

7. EVENTS

Events		2021		2020
Conference meeting costs	£	1,112	£	554
Family weekend (Center Parcs)	£	-	£	2,465
Stakeholder meeting	£	-	£	234
	£	1,112	£	3,253

8. GOVERNANCE

Governance		2021		2020
Accountancy charges	£	225	£	100
Insurance	£	360	£	420
Subscriptions	£	1,013	£	1,160
Bank charges	£	4	£	58
Computer costs	£	-	£	943
Depreciation	£	94	£	160
General expenses	£	18	£	645
Printing, postage and stationery	£	-	£	-
Repairs and maintenance	£	1,618	£	-
	£	3,332	£	3,486

9. FIXED ASSETS

Fixed assets		Office equipment
Cost		
At 2nd March 2020	£	1,404
Additions	£	717
Disposals	£	-
As at 1st March 2021	£	2,121
Depreciation		
At 2nd March 2020	£	1,267
On disposals	£	-
Charge for year	£	94
As at 1st March 2021	£	1,361
Net book value		
As at 1st March 2021	£	760
At 1st March 2020	£	137

10. DEBTORS

Debtors		2021		2020
Accounts receivable	£	-	£	1,953
			£	1,953

11. CREDITORS

Creditors		2021		2020
Amounts falling due within one year:				
Accounts payable	£	3,228	£	3,033
PAYE and NI	£	162	£	149
VAT	-£	678	-£	252
Accrued expenses	£	110	£	95
Other creditors	£	120	£	-
	£	2,942	£	3,025

12. RESTRICTED FUNDS

Restricted funds								
	Balance b.fwd		Incoming resources		Resources expended		Balance c.fwd	
Research fund	£	5,670	£	31,126	-£	31,126	£	5,670
Conference fees fund	£	29,949	-£	4,370	-£	1,112	£	24,467
Family getaway	£	7,256	£	-	£	-	£	7,256
Support fund	£	-	£	-	£	-	£	-
Operational	£	-	£	7,411	-£	7,411	£	-
Be Safe at School Handbook fund	£	-	£	47,742	-£	12,572	£	35,170
FOP 'Together' Newsletter fund	£	2,527	£	-	-£	1,452	£	1,075
Charity leaflet	£	358	£	-	£	-	£	358
Home improvement grant handling	£	500	£	-	£	-	£	500
FOP & Me	£	-	£	24,981	£	-	£	24,981
ALK2 - Selective Allosteric Kinase Inh	£	-	£	15,000	£	-	£	15,000
Card Factory	£	-	£	500	£	-	£	-
	£	46,260	£	122,390	-£	53,673	£	114,477

Key items within restricted funding include:

• Research fund describes funding toward FOP research from other international FOP organisations.

• The Conference fees fund represents donations and delegates' deposits received in respect of the FOP Conference in May 2020.

• Family getaway fund is associated with grants to assist in running future family weekend where the charity takes all FOP families with children away for a respite / break.

• The FOP 'Together' Newsletter fund represents grants awarded to fund the production of a quarterly print/online newsletter to inform the FOP community and to support fundraising.

• Charity leaflet funds were provided to allow for update and re-print of FOP Friends awareness leaflets used at events and fundraisers.

• The "Home improvement grant handling" line is associated with a patient who was awarded a grant personally for home-improvements, but the awardees required the funding to be handled via a recognised entity "on their behalf".

13. DESIGNATED FUNDS

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 the safe minimum reserve level as determined by the charity's Reserves Policy.

Our history (to 1st March 2021)

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

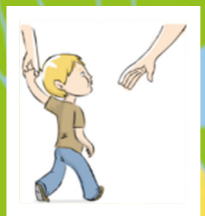
Friends of Oliver website created to celebrate and thank those who are supporting Oliver and the research team at Oxford.

FOP Friends’ chairman and founder Chris Bedford-Gay 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?” animation, 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 on the International FOP Flare-up survey.

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.

FOP Friends is awarded a grant for £16,000 from GDUK to fund a Charity Administrative Assistant.

December 2013

FOP Friends is 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 organises 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.

August 2014

FOP Friends is 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

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

FOP Friends Founder and chairman Chris attends the IFOPA Drug Development Forum in Boston, with over 100 researchers and interested pharmaceutical companies in attendance. This is a milestone in the search for a treatment and cure for FOP.

December 2014



FOP Friends decorates their annual Christmas Tree at St. Alban’s Church, Cheshire, with photos of FOP patients from around the country.

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

January 2015

Clementia open the first European trial site in Paris. Some of our UK FOP patients take the opportunity to participate in the trial. 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 FOP Friends as their Charity of the Year.

August 2015

FOP Friends are delighted to announce their 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 and 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.

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

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

February 2016

FOP Friends is 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.

Adobe chooses FOP Friends as beneficiary of their Charity of the Year.

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

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.

FOP Friends celebrate Rare Disease Day by announcing that they, 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. A very 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 great 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 a great 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.



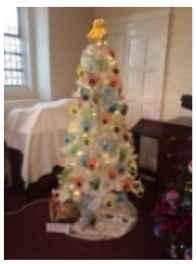
FOP Friends is proud to be listed and recognised in the 2016/17 The Oxford Thinking - The Campaign for the University of Oxford report, as one of their valued donors.

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 FOPer's 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.

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.

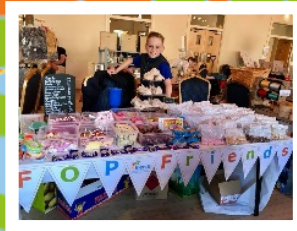
Chris is honoured to receive a letter from Oxford Thinking, which thanks FOP Friends for the generous funding of FOP research at Oxford University.



#FunFeet4FOP is a great 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.

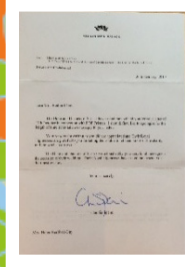
Boxing Day sees a wonderful group get dressed up and visit 35 pubs, Irish dancing whilst raising money for charity. A whopping £973 is raised for FOP Friends.

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.



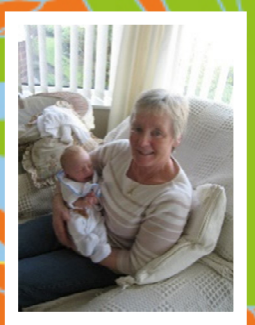
June 2019



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



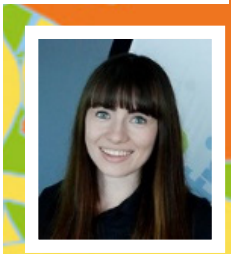
FOP Friends have another team of fundraises take part in the Great North Run including FOP specialist, Doctor Bubbear.

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.

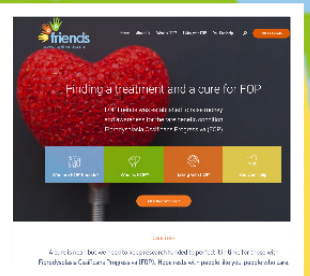
December 2019



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 are able to 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

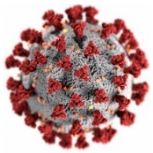


Chris attends the IFOPA in-person board meeting in Philadelphia as part of his role at the IFOPA. Whilst there he attends an early screening of the Tin Soldiers documentary in which he, Oliver, and FOP Friends' trustee Nicky with her daughter Isla all feature.

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 Orzel 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

Gene Therapy funding (in pursuit of a cure)



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 CME Video (Med Scape?) 250,000 Health Care Professionals targeted.

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!



Rare disease day. We join with other rare disease organisations around the world, 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.

Thank you to (March 2020 – March 2021)

FOP Friends would like to acknowledge our ever-growing supporters.

Trusts / Grants

Big Lottery Fund

Genetic Disorders UK

Manchester Guardian Society CT

Sobell Foundation

The February Foundation

Corporate Supporters

Ipsen Pharmaceuticals

Regeneron Pharmaceuticals

Skillsarena Ltd

Donors of time and resources

Clarity Comms: FOP Animation

Stephen Fry: FOP Animation Narration; foreword

Keith Hopwood (Herman's Hermits): FOP Animation Music

Skillsarena Ltd: Director's time

Foliozine: Logo design

Community / Clubs & Associations

Gloriana Freemasons Lodge

Manchester Round Table

Royal Northumberland Yacht Club

Uxbridge Rotary Club

Fundraisers

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

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

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