# 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

## Trustees

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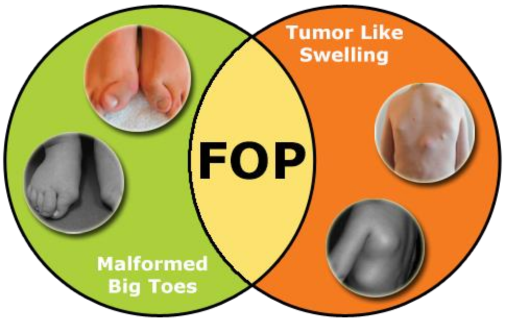
## What is Fibrodysplasia Ossificans Progressiva (FOP)?

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.

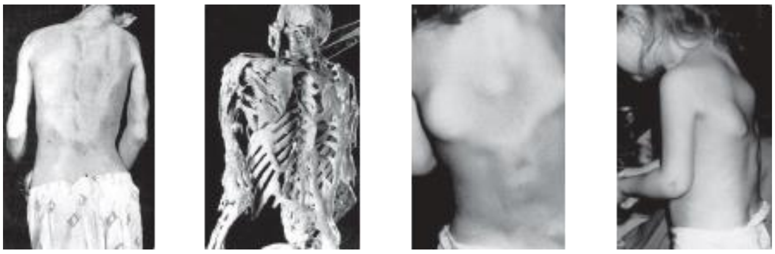
Bridges of extra bone develop across the joints, progressively restricting movement, forming a second skeleton that imprisons the body in bone. There are no other known examples in medicine where one normal organ system turns into another.

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.

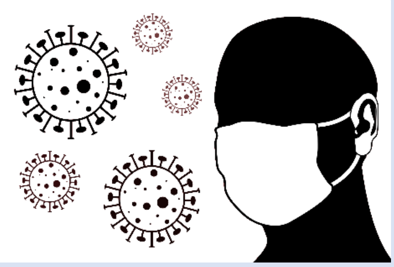
FOP progresses along the trunk and limbs of the body, replacing healthy muscles with bone. These bridges of bone significantly restrict movement and attempts to remove them result in explosive new bone formation because trauma, like surgery, knocks and bumps, accelerates the FOP process. FOP is extremely 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 Gay

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

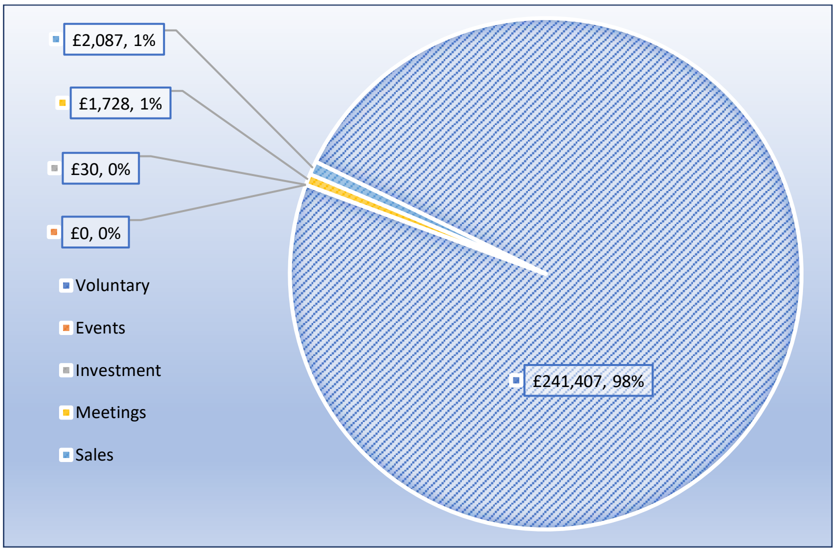
Incyte, a relatively new pharmaceutical company to enter the FOP drug development landscape, has submitted their first FOP trial on ClinicalTrials.gov. Incyte’s potential treatment, currently known as INCB000928, is the third Kinase inhibitor to be tested in a Phase II trial for FOP.

## How we raised our money

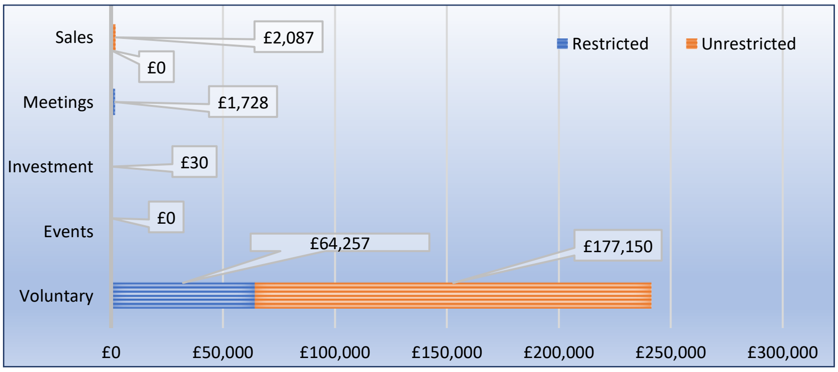
Voluntary income accounts for the majority of money raised within our charity's financial year. A small amount is attributed to investment income (interest on bank balances) and £0 revenue from fundraising events attributed to the continued impact of the Covid-19pandemic.

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.



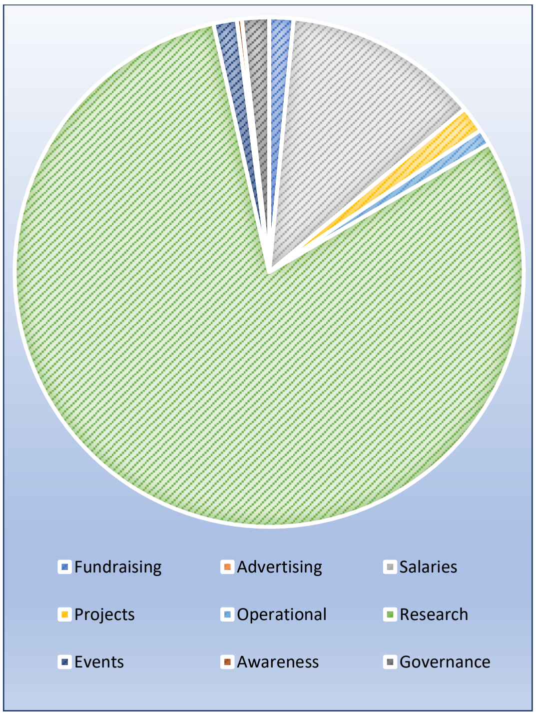
From a total £245,252 incoming resources, £65,985 (27%) were restricted. The remaining £179,267 (73%) were unrestricted.



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]

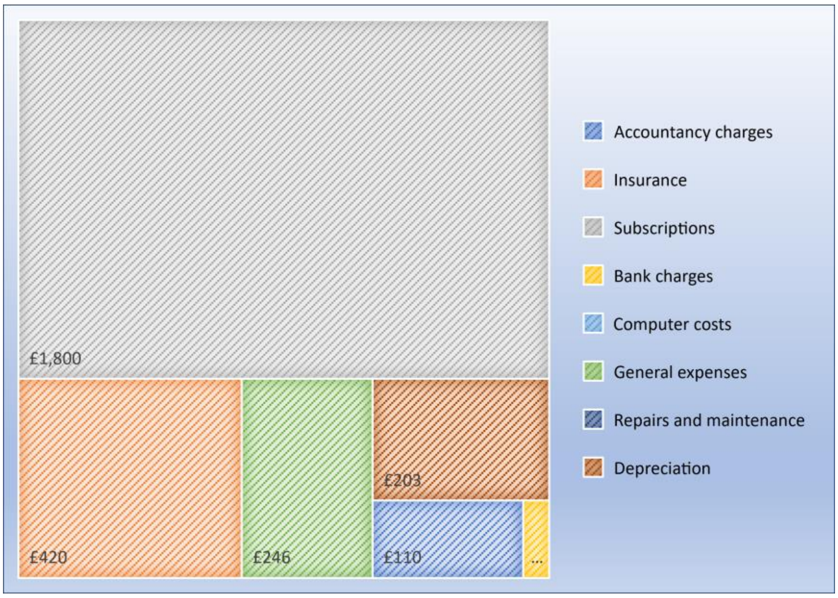
FOP Friends donated a total of £130,000 to FOP research this charity year.

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.

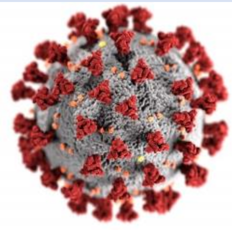
Governance costs of £2,798, a decrease in our previous year, is attributable to the continued operation of the charity.



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.

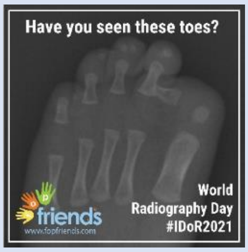
A big thank you to everyone who has donated, run a race, bought Christmas cards... Thanks also to our friends at FOP France for their contribution.

## 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.


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

## 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.


FOP: how to spot this rare genetic disease

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


Introducing

FOP Friends

friends

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


friends

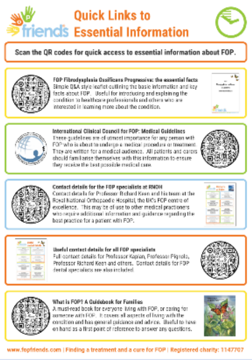
COVID-19 Update December 2020

CORONAVIRUS INFORMATION

NHS

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.


friends **Quick Links to Essential Information**

Scan the QR codes for quick access to essential information about FOP.

**FOP Fibrodysplasia Ossificans Progressiva: the essential facts**
Simple Q&A style leaflet outlining the basic information and key facts about FOP. Useful for introducing and explaining the condition to healthcare professionals and others who are interested in learning more about the condition.

**International Clinical Council for FOP: Medical Guidelines**
These guidelines are of utmost importance for any person with FOP who is about to undergo a medical procedure or treatment. They are written for a medical audience. All patients and carers should familiarise themselves with this information to ensure they receive the best possible medical care.

**Contact details for the FOP specialists at RNOH**
Contact details for Professor Richard Keen and his team at the Royal National Orthopaedic Hospital, the UK's FOP centre of excellence. This may be of use to other medical practioners who require additional information and guidance regarding the best practice for a patient with FOP.

**Useful contact details for all FOP specialists**
Full contact details for Professor Kaplan, Professor Pignolo, Professor Richard Keen and others. Contact details for FOP dental specialists are also included.

**What is FOP? A Guidebook for Families**
A must-read book for everyone living with FOP, or caring for someone with FOP. It covers all aspects of living with the condition and has general guidance and advice. Useful to have on hand as a first point of reference to answer any questions.

www.fopfriends.com | Finding a treatment and a cure for FOP | Registered charity: 1147707

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.


friends **What we do...**

**SUPPORT**

**FUNDRAISE**

**SIGNPOST**

**ORGANISE**

**TRAVEL**

**NETWORK**

**EDUCATE**

**COOPERATE**

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!

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

Isla, daughter of FOP Friends' trustee Nicky Muller, raised a fantastic £100 at her 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

Consolidated statement of financial activities

| - | Notes | Restricted | Unrestricted | 2022 | 2021 |
|---|---|---|---|---|---|
| **<u>Incoming resources</u>** | | | | | |
| **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 |
| | | | | | |
| **<u>Resources expended</u>** | | | | | |
| **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

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

AA Bedford

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

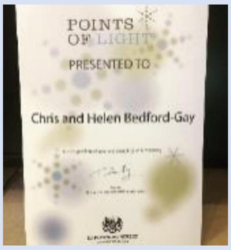
Bex completes a 61-day dryathlon, raising a sparkling £500 in the process.  Meanwhile, Amy celebrates her 50th Birthday in style by jumping 855ft from the top of Las Vegas' Stratosphere Tower and raising an incredible £2,100.

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



POINTS OF LIGHT

PRESENTED TO

Chris and Helen Bedford-Gay

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

BIG LOTTERY FUND

NATIONAL LOTTERY FUNDED

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.

friends

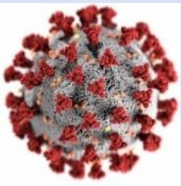
Finding a treatment and a cure for FOP

## 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!

"While the majority of rare diseases currently have no effective treatment, good coordination in the standard of care and effective symptom management can help improve the lives of patients significantly."

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

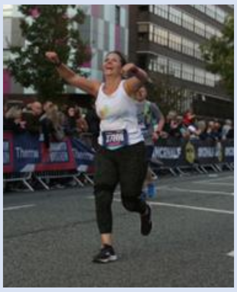
We take part in the first Global FOP Awareness Day, uniting with other FOP patient organisations around the world. We all share the same facts and stories on social media, with a united brand. We also launch the t-shirt for us all to be as one. We are #StrongerTogether

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.

Office for Rare Conditions Glasgow

## 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

www.fopfriends.com

info@fopfriends.com

+44 (0)161 282 0441

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