



2021 Annual Report & Financial Statements

Year ending 1st March 2021

Registered with

Charity Commission for England & Wales

#1147704

Office of the Scottish Charity Regulator

#SCO46950



2021 Annual Report & Financial Statements

Year ending 1st March 2021

Vision

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

Mission

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

Values

Committed to funding medical research to realise a cure for FOP and related conditions; to understand how we can prevent it and improve the life and well-being of those who are afflicted by it.

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

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

Act always with honesty, professionalism, and ethical awareness.

Work collaboratively with medical researchers and clinicians, patients and families, donors, and supporters to realise our Vision and complete our Mission.

Charity name

FOP Friends

Charity number(s)

1147704, SCO46950

Governed by

Trust Deed

Independent auditor

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

Founding Trustees

Christopher Bedford-Gay

Alison Acosta Bedford

Rachel Almeida

Trustees

Fiona White

John Leaver

Helen Bedford-Gay

Nicky Williams

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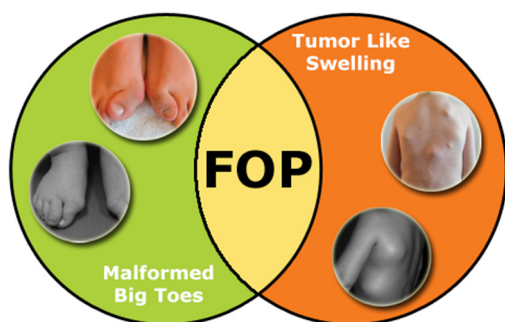
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What is Fibrodysplasia Ossificans Progressiva (FOP)?

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

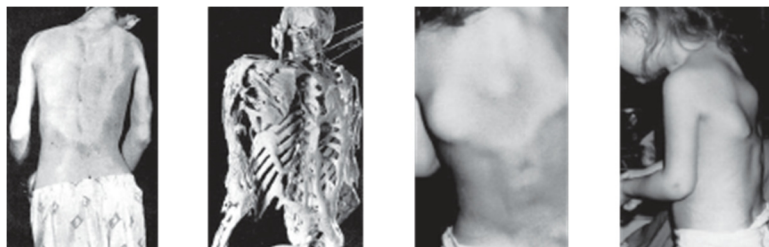
Bridges of extra bone develop across the joints, progressively restricting movement, forming a second skeleton that imprisons the body in bone. There are no other known examples in medicine where one normal organ system turns into another.

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



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

FOP progresses along the trunk and limbs of the body, replacing healthy muscles with bone. These bridges of bone significantly restrict movement and attempts to remove them result in explosive new bone formation because trauma, like surgery, knocks and bumps, accelerates the FOP process. FOP is extremely variable and unpredictable. In some, progression is rapid, while in others it is gradual.



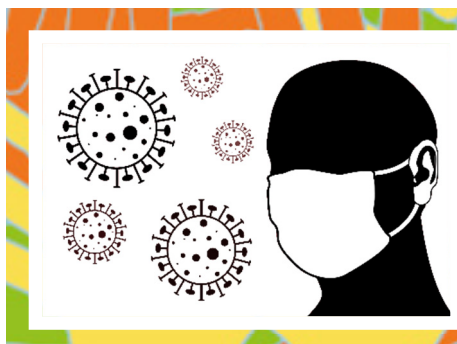
Fibrodysplasia Ossificans Progressiva (FOP) causes progressive debilitation eventually leading to early death.



Introduction and Chair's Statement

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

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



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



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

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

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

medical specialists fear the Covid virus would trigger the FOP in the same way as other viruses such as flu can.

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

We supported our community through this time by keeping people updated with the rapidly changing information which was being developed by the International

Clinical Council on FOP (the ICC). As scientists learned more about the epidemiology of Covid, the ICC's

guidelines for people with FOP evolved too. We ensured that up-to-date information was available on our website and was linked to NHS guidance. We also contacted and supported families directly. As the pandemic shows no signs of ending, we continue to offer this support to our families.

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



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

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

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



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

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

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

The family support we provide is outstanding, being the first point of contact for the newly diagnosed in the UK, but often internationally



too. We make introductions and contacts between families and medical professionals, advising on challenges, the day-to-day, and simply being there as a listening ear when needed.

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

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

A handwritten signature in black ink, reading "Chris Bedford-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 to the existence of FOP and of research projects that will benefit not only FOP sufferers, but also those with more common disorders.

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

Each year, the trustees vote on research or other projects to support with monies raised. To date, this has

been targeted at maintaining the University of Oxford's FOP Research Team.

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

Trustees

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

Chris Bedford-Gay - Trustee and Chairman



Chris has been involved with the FOP community since his son Oliver's diagnosis in 2009. He was one of the founding trustees of FOP Friends, after learning that there was no UK charity to

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

EDUCATION

- 1st Class BSc Hons, Computing for Business

EXPERIENCE

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

- Director and CTO, Skillsarena Ltd (current)
- Chairman and Area Chairman, Round Table
- IFOPA Board member

Alison Acosta Bedford - Trustee

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



EDUCATION

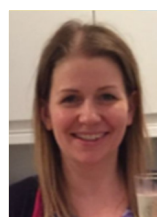
- BSc Hons, Mathematics, University of Sheffield
- CGMA Chartered Institute of Management Accountants.

EXPERIENCE

- Over 16 years' finance experience within social housing
- Experience of long-term financial planning as Treasury and Investment Manager of a housing association with over £60m annual turnover
- Experienced in Workforce Development through Manchester Chamber of Commerce & Industry

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

Rachel Almeida – Trustee



Rachel is Head of Events and Sponsorship for the Association of Colleges, organising education-related conferences. She has worked in events for over 18 years and is pleased to be able to put her experience and expertise to good use.

Rachel was inspired to complete her first ever fun-run in aid of FOP Friends, completing the Great North Run half marathon in under 2hr 30 minutes.

EDUCATION

- BSc Hons, German and Law, University of Surrey

EXPERIENCE

- International trade shows
- International economic research charity dissemination conferences
- Head of Events and Sponsorship (current) – leading a team to deliver 40 education conferences per year with direct responsibility for a £1.7m annual turnover

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

Fiona White - Trustee

Fiona is a lead teacher working in a primary school. She works as a member of the senior leadership team having gained the National Professional Qualification in Senior Leadership (NPQSL). As a close friend of the Bedford-Gay family for many years, Fiona was devastated to learn about their son Oliver's condition. She has grown to understand just how important it is to raise awareness of FOP and ensure much needed funds are raised in order continue the search for a cure.



EDUCATION

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

EXPERIENCE

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

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

John Leaver - Trustee



When John heard about Oliver and others with FOP, he wanted to do what he could to help. As a first step, he produced a video through his creative

company, claritycomms.com, engaging Stephen Fry to provide the voice over and to subsequently tweet to his millions of followers. John is now enjoying exploring some exciting new ideas to help FOP Friends raise awareness and funding. He feels it is a privilege to be part of such an inspiring team, on such an important mission.

Helen Bedford-Gay – Trustee

Helen has been with the charity since the very beginning. Having come to terms with the devastating diagnosis that her son, Oliver, had FOP, she felt



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

EDUCATION

- BA (Ed.) QTS Hons. Durham

EXPERIENCE


- Classroom teacher across Key Stages 1 and 2, with experience of KS1 leadership
- Fulbright Exchange Teacher to USA

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

Nicky Williams – Trustee



Nicky feels passionate around raising awareness of FOP and raising funds to get the cure that is in all our dreams. Nicky's daughter Isla was one of the youngest children to be diagnosed with FOP. After coming to terms with the initial shock of diagnosis, Nicky began fundraising to support the search



for treatments. Along with her network of friends and family, Nicky continues to organise a series of successful events and sponsored sporting activities to raise funds in aid of FOP Friends. Nicky works part-time as a Marketing Campaigns Manager for Avaya, and she has used her business contacts to gain support for the charity from several large companies and organisations.

EDUCATION

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

EXPERIENCE

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

Meeting Charity Commission guidelines

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

Principal objects

THE RELIEF OF DISTRESS AND SICKNESS FOR THOSE AFFECTED BY FIBRODYSPLASIA OSSIFICANS PROGRESSIVA (FOP) A TRAGIC, DEGENERATIVE AND DEBILITATING CONDITION AND TO IMPROVE THE LIVES OF SUFFERERS AND THEIR FAMILIES.

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

TO RAISE PUBLIC AWARENESS AND UNDERSTANDING OF FIBRODYSPLASIA OSSIFICANS PROGRESSIVA (FOP) AND TO PROMOTE EDUCATION AND RESEARCH INTO THE STUDY AND CURE OF FOP AND RELATED CONDITIONS.

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

TO SUPPORT CHARITIES AND ORGANISATIONS IN THE UK AND ABROAD BY UNDERTAKING CHARITABLE ACTIVITIES TO FUND RESEARCH; AND TO PROVIDE HELP, SUPPORT, CARE AND TREATMENT FOR PEOPLE AFFECTED BY FOP AND RELATED CONDITIONS.

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

TO SUPPORT ORGANISATIONS RESEARCHING TREATMENTS AND A CURE FOR FOP AND RELATED CONDITIONS.

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

PREVENTING MISDIAGNOSIS.

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

Research Highlights

University of Oxford -STOPFOP / Saracatinib



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

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

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



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

Regeneron - Garetsmab



Regeneron pharmaceuticals were pleased to share results

from their Phase 1 clinical trial for garetsmab. A big thank you to everyone for their hard work and to the trial patients who make it possible.

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

Ipsen - Palovarotene

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



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

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

Keros Therapeutics - KER-047



Keros Therapeutics is developing a small

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

Biocryst

In December 2020, BioCryst also announced positive

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



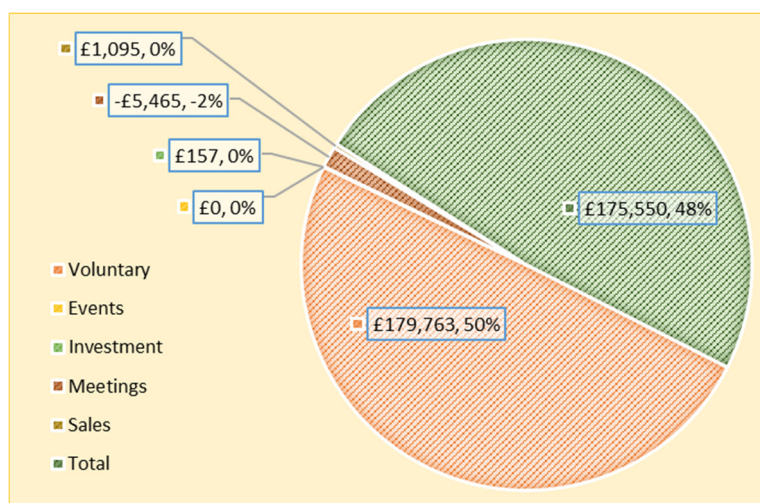
How we raised our money

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

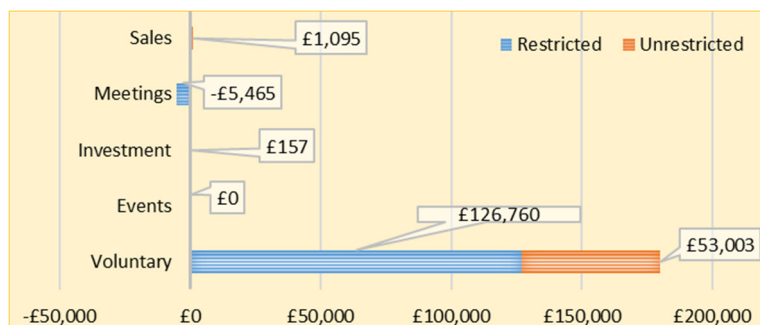
Whilst an impressive increase in revenue from fundraising events occurred, voluntary income from donations overall reduced to £71,100 for the year, an increase of 3% overall.

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

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



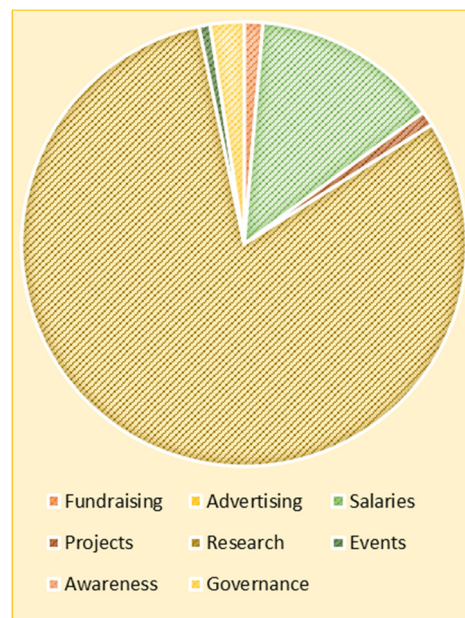
From a total £175,550 (was £141,339) incoming resources, £121,295 (69%) were restricted. The remaining £54,255 (31%) being unrestricted.



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

How money raised was spent

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



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

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

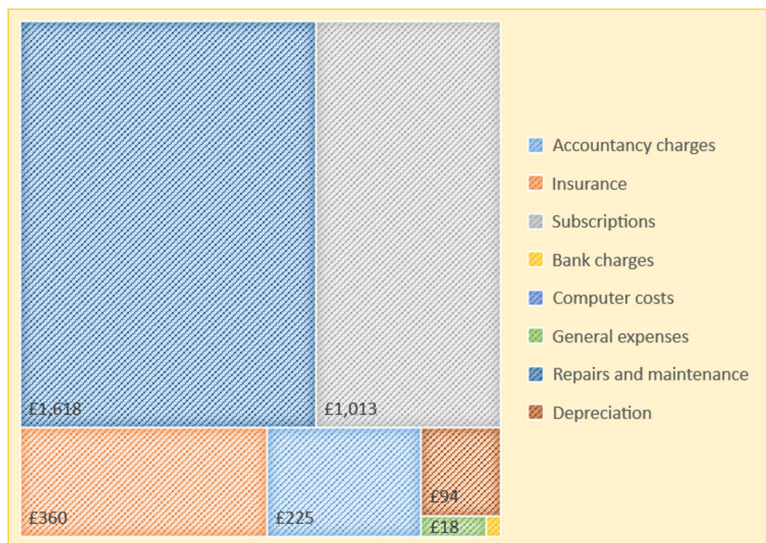
The main beneficiary of FOP Friends is the FOP Research team at the University of Oxford who received £60,000 in research funding. Led by Professor Alex Bullock, the team is one of a small number of teams in the world, conducting research into FOP.

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

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

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

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



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

Achievements

Supporting families through Covid

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

Rare Disease Awareness

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



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

FOP Awareness



April is FOP Awareness Day Month, culminating in FOP awareness day on 23rd

April and return of FunFeet4FOP. This year saw even more people take part than before, with supporters from around the globe and the launch of

Global FOP Awareness and the Uniting to Cure FOP campaign.

Conference and Family Gathering



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

Natural History Study

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

3,000 Followers

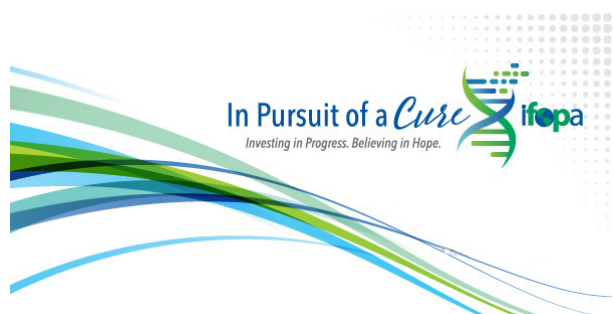
FOP Friends' Facebook page reached 3,000 followers. With only 800 known patients in the world, this means our reach is continuing to grow beyond our FOP families.

Introducing FOP Friends: Information Pack

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

In Pursuit of a Cure: FOP Gene Therapy

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



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

Ongoing FOP Awareness

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

Providing funding to Oxford FOP Research

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

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



contributed to the Oxford Research Fund via FOP Friends.

Find-a-Cure: The Student Voice Prize

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



The Student Voice Prize

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

A previous FOP essay was runner up for the prize.

Continuing Medical Education

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

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



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

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

Continuing support through Covid

FOP Friends shared, via the website and private family social media groups, all updates from the International Clinical Council for FOP (ICC) with [advice regarding Covid-19](#)



[for people living with FOP](#), including all important advice for people with FOP and their carers about receiving the vaccine.

IFOPA Board Meeting 2021

Chris usually travels to Florida for his annual in-person board meeting for the IFOPA. However, due Covid restrictions, the fifteen volunteer board members met virtually, across two days. It was just as productive as meeting, and two new board members were welcomed.

Topics discussed included reviewing the past year;

planning activities and family support for the next few years; research updates; and how to continue to raise awareness worldwide.



Impact and value

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



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

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

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

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

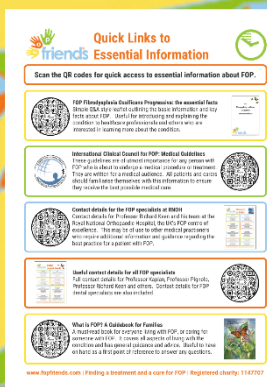
Supporting families

In addition to supporting our FOP families with Covid advice and guidelines, we continue to offer support to our families and the medical professionals who work with them by producing a range of resources.

These are free to download, or are posted out on request, and include a simple leaflet "Fibrodysplasia Ossificans Progressiva: the essential facts", a leaflet which outlines the key points of the condition and is written in a simple to access Q&A style.



We further supported our families by creating and



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

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



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

Fundraising

FOP Awareness Day



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

the finish line.

Chop4FOP

Instead of suffering with a bad lockdown hairdo like most of us, Betsy decided she would shave it all off in honour of her beautiful and badass friend Lucy, who is



living with FOP. Betsy set up a crowdfunding page with the promise that once she reached £1,500 in donations, she would chop her hair for FOP... and she did!

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

On your bike



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

Virtual London Marathon Ladies!

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

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



Jane had already done a half marathon for FOP Friends so set her sights on a new challenge: the race to find a cure for FOP. She ran through her neighbourhood, doing laps of local streets to make up the

miles. It was made the event even more special and memorable, having family and friends standing on the roadside, all safely socially distanced, cheering her on.

Jake Goes Virtual

This year's pandemic meant that long-time supporter Jake was unable to hold his annual yard-sale.

Instead, 14-year-old Jake created his own virtual 'race' to support our race to find a treatment for FOP. Jake challenged himself to run 300 miles over the course of the lockdown.

This impressive sporting achievement raised £100 for FOP Friends.



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

Christmas card sales



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

Inspiring young leaders

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



Future plans

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

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

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

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

In addition, the “FOP and Me” journal for children will be completed in Q1 2022 also. This journal aims to provide honest information for older children who are beginning to understand what the diagnosis of FOP will mean for them. There will be simple to follow explanations, practical tips, and stories from older people who are living with FOP. There will be space for children and young people to make the journal their

own, with space to reflect and personalise the journal. The book will be professionally illustrated and aims to support not only the children and young people with FOP, but their siblings, friends, and families too.

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

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

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

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

Ambition & long-term plans

Charity objectives

- To grow FOP Friends to make the annual fundraising target of £125,000 more easily achievable and to be in a strong position to increase this target soon
- To increase public awareness and expand the fundraising activities beyond friends and family

- To reduce misdiagnosis and help ensure there are more UK-based FOP experts and centres where treatment and possibly future clinical trials can take place
- To continue our involvement with the FOP community worldwide and help advance FOP research and awareness internationally
- To increase support given to FOP Families
- To maximise grant income
- To ensure regular communications are sent to the community and further afield to keep everyone abreast of the work that FOP Friends undertakes, progress with research and to thank those who fundraise for us

Preventing misdiagnosis

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

Fundraising

- To continue to grow fundraising, helping, and encouraging more families to become actively involved
- To expand fundraising activities beyond friends and family, through increased public awareness, to become a charity of choice for the public to support
- To sustain and maximise trusts and grant funding to continue the financial support for research

- To secure and sustain grant funding to enable the charity to support employees on a long-term basis
- To update the Fundraising Pack to help those interested in fundraising to support the charity
- To secure funding to cover core costs and reduce attendee costs for future UK FOP conferences
- To seek corporate sponsorship as “charity of the year”
- To create alternative fundraising campaigns to diversify income streams
- To seek high-profile patrons to increase awareness, generate interest, and to actively encourage and support fundraising.

Family support

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

Medical support

- To reach out to health professionals and professional bodies to create interest and awareness of FOP to help prevent misdiagnosis and to increase the available support for those with FOP
- To help establish UK specialist centres for the care and treatment of FOP patients
- To strengthen the reliability of our information sources by engaging medical professional as advisors.

Governance and Structure

Legal Status

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

FOP Friends registered with The Scottish Charity Regulator (OSCR) in November 2016, SC046950.

Organisational Structure

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

Employment

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

Trustee recruitment and training

Vacancies for trustees are sought through recommendations gained through appropriate networks and associations of trustees and supporters. Candidates

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

Statement of responsibilities of the trustees

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

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

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

For the purposes of charity law, the trustees who served during the year and up to the date of this report are set out on page 2. The trustees are responsible for the maintenance and integrity of FOP Friends and financial information included on the charity's website.

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



Chris Bedford-Gay.

Founding Trustee and Chairman

Financial review

Summary

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

Income

Income for the year totalled £175,550 made up of unrestricted funds from fundraising and voluntary

donations together with income from successful grant and trust applications, conference fees and a small amount of interest on savings.

Grants, trusts, and corporate sponsorship

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

Charitable expenditure

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

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

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

Gains and losses

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

Policy on reserves

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

Designated Funds

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

Future commitments

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

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

Restricted Funds

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

Investments

Presently FOP Friends has no investments.

Independent examiner's report

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

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

Respective responsibilities of the trustees and examiner

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

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

Basis of independent examiner's report

My examination was carried out in accordance with General Directions given by the Charity Commission. An examination includes a review of the accounting records kept by the charity and a comparison of the accounts presented with those records. It also includes consideration of any unusual items or disclosures in the accounts and seeking explanations from you as trustees concerning any such matters. The procedures

undertaken do not provide all the evidence that would be required in an audit, and consequently no opinion is given as to whether the accounts present a 'true and fair' view, and the report is limited to those matters set out in the statement below.

Independent examiner's statement

During my examination, no matter has come to my attention:

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

Independent examiner

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

Consolidated statement of financial activities

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

Balance sheet

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

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



Alison Acosta Bedford, Founding Trustee.

Notes to financial statements

1. ACCOUNTING POLICIES

BASIS OF ACCOUNTING

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

FUND ACCOUNTING

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

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

INCOMING RESOURCES

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

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

RESOURCES EXPENDED

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

COSTS OF GENERATING FUNDS

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

GOVERNANCE COSTS

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

IRRECOVERABLE VAT

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

2. VOLUNTARY INCOME

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

3. ACTIVITIES FOR GENERATING FUNDS

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

4. OTHER INCOMING RESOURCES

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

5. FUNDRAISING COSTS

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

6. RESEARCH

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

7. EVENTS

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

8. GOVERNANCE

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

9. FIXED ASSETS

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

10. DEBTORS

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

11. CREDITORS

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

12. RESTRICTED FUNDS

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

Key items within restricted funding include:

- Research fund describes funding toward FOP research from other international FOP organisations.
- The Conference fees fund represents donations and delegates' deposits received in respect of the FOP Conference in May 2020.
- Family getaway fund is associated with grants to assist in running future family weekend where the charity takes all FOP families with children away for a respite / break.
- The FOP 'Together' Newsletter fund represents grants awarded to fund the production of a quarterly print/online newsletter to inform the FOP community and to support fundraising.
- Charity leaflet funds were provided to allow for update and re-print of FOP Friends awareness leaflets used at events and fundraisers.
- The "Home improvement grant handling" line is associated with a patient who was awarded a grant personally for home-improvements, but the awardees required the funding to be handled via a recognised entity "on their behalf".

13. DESIGNATED FUNDS

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

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

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

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

Our history (to 1st March 2021)

March 2008

Oliver Peter Bedford-Gay born; all the medical professionals just think he has “funny toes”.

November 2008

Oliver has mysterious lump removed from the back of his head.

April 2009

Bedford-Gay family receive devastating diagnosis of FOP.

2010

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

2011

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

FOP Friends' chairman and founder Chris Bedford-Gay elected to the Board of the IFOPA.

April 2011

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

January 2012

FOP Friends of Oliver website goes 'live' together with “What is FOP?” animation, narrated by Stephen Fry.



June 2012

FOP Friends of Oliver becomes a registered charity # 1147704.

December 2012



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

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

March 2013

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



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

December 2013

FOP Friends is awarded a grant to employ a Senior Drug Developer at the University of Oxford.

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

March 2014

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

May 2014

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



June 2014

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

August 2014

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

August 2014

FOP Friends is adopted by companies PwC Manchester and Avaya as their "Charity of the Year".

September 2014

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



October 2014

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

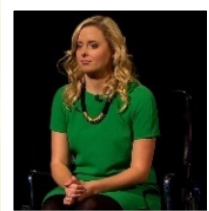
November 2014

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



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

December 2014



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

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

January 2015

Clementia open the first European trial site in Paris. Some of our UK FOP patients take the opportunity to participate in the trial. Everyone in the FOP community thank you for furthering the research.

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

February 2015

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

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

March 2015

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

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



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

June 2015

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

Chris finishes his whistle-stop tour with a quick visit to the FOP lab at the University of Pennsylvania.

PushOn adopt FOP Friends as their Charity of the Year.



August 2015



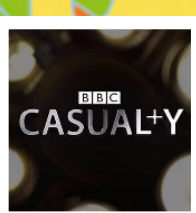
FOP Friends are delighted to announce their first FOP Friends employees, David Pilkington and Mari Jones, funded thanks to GDUK and other minor grants: a milestone in the charity's history

September 2015

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



October 2015



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

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

November 2015

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

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

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

Chris flies out to Amsterdam for the Dutch FOP Symposium.

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



December 2015

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

January 2016

FOP Friends' oldest supporter Mrs. Laura Gregory celebrates her 102nd birthday and donates her gift money to fund a treatment for her great-grandson Oliver.



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

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



February 2016



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

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

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

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



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

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

March 2016

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

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

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

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

April 2016

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

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



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

May 2016

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

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

June 2016

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

Dr Keen presents on the International FOP Association (IFOPA) FOP Connection Registry at Bone Research Society meeting.

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

July 2016

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

August 2016

The eBay Charity UK sale for FOP Friends proves a great success.

September 2016

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

October 2016

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

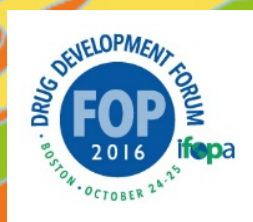
Chris attends the 2nd IFOPA Drug Development Forum in Boston. FOP Friends provides \$15,000 towards the event, generating a total \$30,000 thanks to fund matching.

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

December 2016

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

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



January 2017

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

February 2017

Anoushka, 16, from Azerbaijan, arranges for five groups of swimmers from the Baku Sharks to swim the equivalent of the English Channel over two weeks. Each group swam 32km, and together they raised £360 for FOP friends.

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



March 2017

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

April 2017

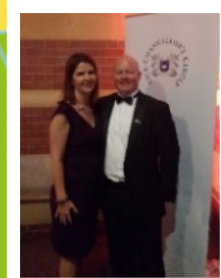


The second #FunFeet4FOP event takes place on International FOP Awareness Day, with some fab feet (including a farm animal or two) helping to boost the profile of FOP.

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

May 2017

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



June 2017

FOP Friends partner with Genetic Disorders UK.

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

July 2017

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

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

August 2017

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



September 2017

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

October 2017

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



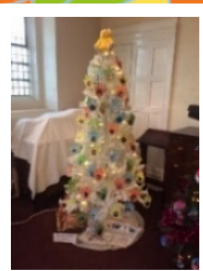
FOP Friends is proud to be listed and recognised in the 2016/17 The Oxford Thinking - The Campaign for the University of Oxford report, as one of their valued donors.

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

November 2017

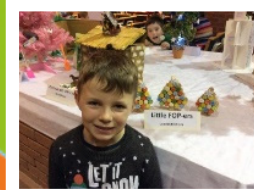
Bex completes a 61-day dryathlon, raising a sparkling £500 in the process. Meanwhile, Amy celebrates her 50th Birthday in style by jumping 855ft from the top of Las Vegas' Stratosphere Tower and raising an incredible £2,100.

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



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

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



January 2018



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

February 2018

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



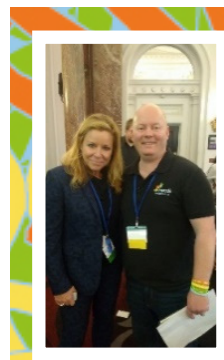
March 2018



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

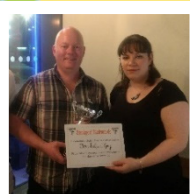
University of Manchester Boat Club take on a 24hr row in aid of FOP, raising £1023.77. Meanwhile, Natalie completes the inaugural London Landmarks Half Marathon, raising £350.

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



April 2018

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



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

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



#FunFeet4FOP is a great success for the third time, with lots of fun feet making an appearance. We are grateful and honoured to see the BalletBoyz choose to help raise awareness for FOP! Hummingbird Bakery in Guildford supplies cakes for a #FunFeet4FOP bake sale, which raises over £230.

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

May 2018

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





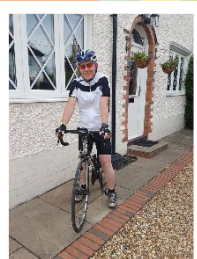
Manchester University Boat Club decides to fundraise for us again, with the team taking on the Manchester 10K.

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



June 2018

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



Julian cycles over 100 miles, from Wolverhampton to Aberdovey, to raise funds and awareness for FOP. Belinda Davis and our wonderful friends at Dell Park Farm Windsor provide parking at the Royal Wedding in aid of FOP Friends & raise £644!

July 2018

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

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

August 2018

Alexis who completes the Three Peaks Challenge for FOP Friends



September 2018



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

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

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

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

October 2018

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



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

November 2018

Chris arrives safely in Baltimore for the International FOP Association (IFOPA)'s 30th Family Gathering.



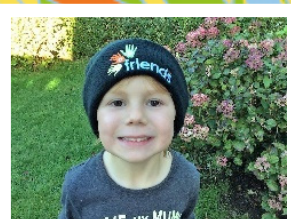
Our first-ever Christmas card campaign is launched.

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



FOP Friends is acknowledged by the University of Oxford as one of their most committed supporters.

December 2018



We launch our FOP Friends beanie hats.

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

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

January 2019

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

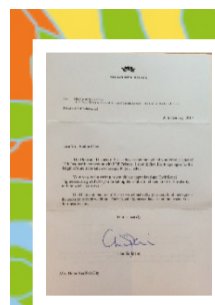
#Swap4FOP. Isla's godmother has a simple strategy: take a bunch of friends each bringing a few unwanted items/gifts, add an entry fee, a raffle and some fizz = fun night, recycles, take away some treasure and raise much needed funds for #FOPFriends. A fabulous night was had by all and the event raises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

February 2019

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

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

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



March 2019



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

April 2019

People say they would walk over hot coals for their kids – well we did!

#FunFeet4FOP and #FireWalkforFOP combine for a most fabulous fundraiser. Twenty-two firewalkers including two FOP families, two local councillors from Trafford, Manchester (Amy Whyte & Steve Longden) and FOP nurse specialists Jackie all burn their toes to raise awareness for FOP.



May 2019



FOP Friends releases “Supporting a Child with FOP: a practical guide to their learning experience” This book is made possible thanks to a generous grant from Regeneron Pharmaceuticals. The book is an essential and informative guide for anyone supporting a child with FOP, offering clear information and advice to parents and teachers to help a child with FOP navigate their school journey as well as their life beyond the classroom.

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

June 2019

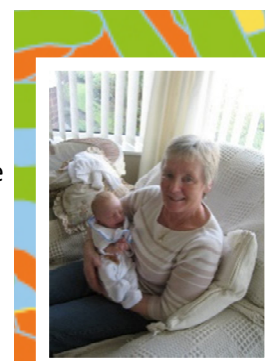


Helen and Chris are delighted to win the 2019 Jeannie Peeper Award for “Outstanding International Leadership”. The award recognises their exceptional commitment to the FOP community through their leadership, service, family support, fundraising and awareness-building, both in the UK and world-wide.



July 2019

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



Sept 2019



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

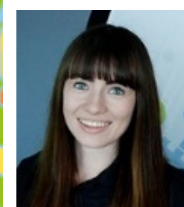
November 2019



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



Hannah, who first worked at FOP Friends in 2015 says farewell as she moves to pastures new to pursue a career in psychology.



December 2019



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

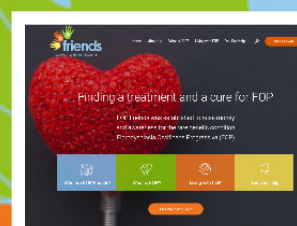
January 2020

We are most thankful to the amazing team at “And Digital” in Manchester, led by Jamie and Mike, who donate their



time and skills for free. The new website has all the information you need about FOP as a condition, and all about FOP Friends as a

charity. We are able to offer downloadable resources to support fundraisers as well as information for people who are coming to terms with a new diagnosis. Perhaps most importantly, there is information for people living with FOP in the case of an emergency including the latest ICC medical guidelines.



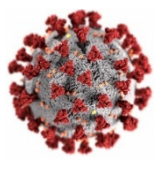
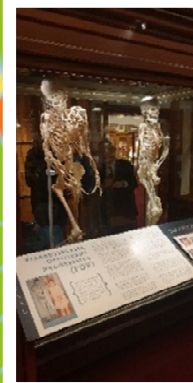
February 2020



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

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

March 2020



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

April 2020

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

May 2020

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



July 2020



We celebrate reaching the milestone of 3000 Facebook followers

Gene Therapy funding (in pursuit of a cure)

We host the StopFOP webinar, with Professor Keen and

Professor Alex Bullock.



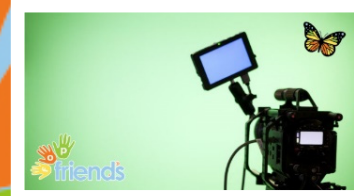
Oct 2020



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

November 2020

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



Jan 2021



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

Feb 2021

IFOPA Virtual Board meeting. The Board meeting is held virtually across two days, a basket of treats is sent to keep Chris well fed and watered for the event!



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

Thank you to (March 2020 – March 2021)

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

Trusts / Grants

Big Lottery Fund

Genetic Disorders UK

Manchester Guardian Society CT

Sobell Foundation

The February Foundation

Corporate Supporters

Ipsen Pharmaceuticals

Regeneron Pharmaceuticals

Skillsarena Ltd

Donors of time and resources

Clarity Comms: FOP Animation

Stephen Fry: FOP Animation Narration; foreword

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

Skillsarena Ltd: Director's time

Foliozine: Logo design

Community / Clubs & Associations

Gloriana Freemasons Lodge

Manchester Round Table

Royal Northumberland Yacht Club

Uxbridge Rotary Club

Fundraisers


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


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

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 FOP Friends