



FOP Friends

2019 Annual Report
& Financial Statements

Year ending 1st March 2019

Charity name

FOP Friends

Working names

FOP Friends of Oliver, FOP Action

Registered Address

The Cabin

1 Cumberland Road, Sale, Cheshire, M33 3FR

Registered

March 2012

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

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.

Respect the integrity, ambition and interests of all FOP Patients.

Strive to be a haven and champion for patients and their families; a centre of excellence for the provision of information on medical research, diagnosis, treatment and care, and participation in clinical trials.

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.

Founding Trustees

Christopher Bedford-Gay

Alison Acosta Bedford

Rachel Almeida

Trustees

Fiona White

John Leaver

Helen Bedford-Gay

Nicky Williams



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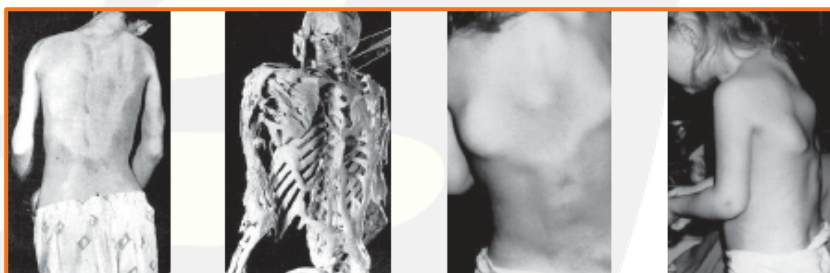
What is Fibrodysplasia Ossificans Progressiva (FOP)?

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

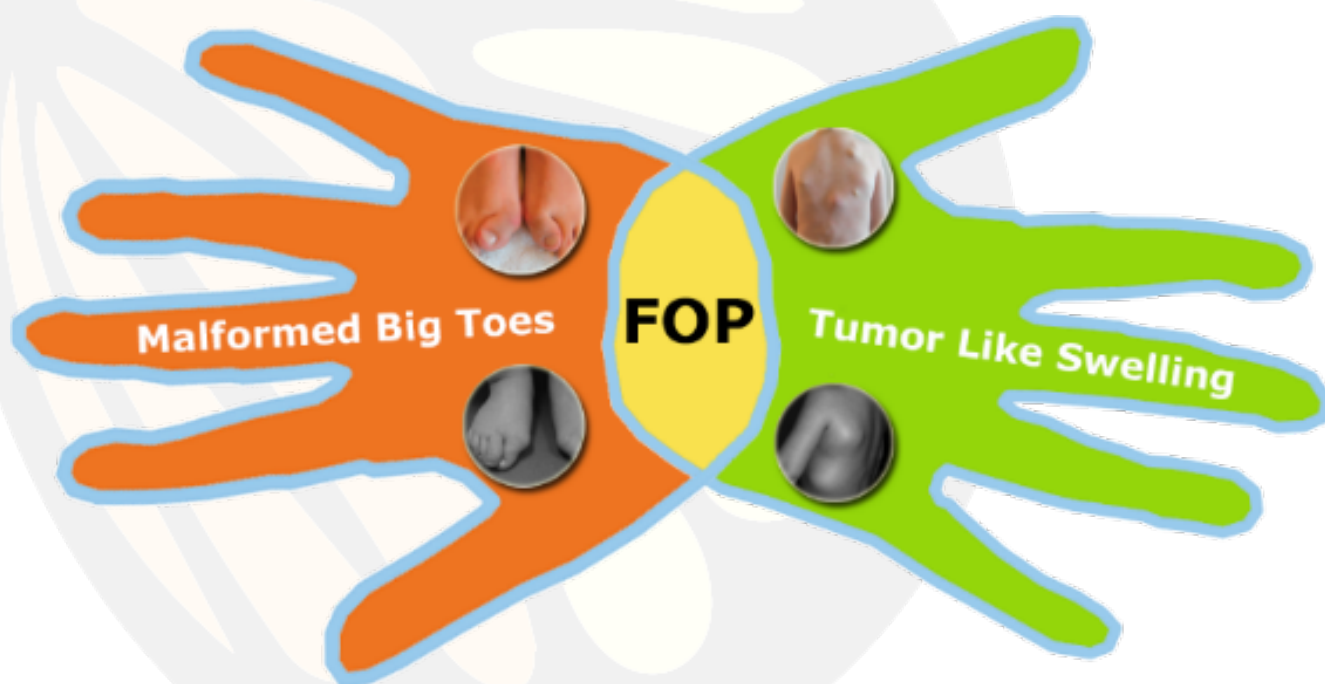
Bridges of extra bone develop across the joints, progressively restricting movement, forming a second skeleton that imprisons the body in bone. There are no other known examples in medicine where one normal organ system turns into another.

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

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



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



Introduction and Chair's Statement

11 years ago, our family was given the news that our first child, Oliver, had been born with Fibrodysplasia Ossificans Progressiva (FOP). He was just one years old at the time. This year he started at high school!

At that time there was a small patient group, FOP Action, but no UK charity dedicated to supporting FOP families and funding research.

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

Since then we have continued to grow our support locally, nationally and internationally. Entering our eighth year, we have had success in grant and trust fundraising as well as increased fundraising from FOP families, friends and the public. We continue striving to grow.

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

FOP Friends is now recognised internationally as a key partner and source of support and information by families, researchers and pharmaceutical companies alike. It is this increasing profile, together with continued involvement at the board level of the IFOPA and through chairing international efforts that we are the go-to organisation for many.

Our initiatives such as #FunFeet4FOP, family focused conferences, family weekends, and our promotional and information items are influencing or being replicated by many. The family support we provide is outstanding, being the first point of contact for the newly diagnosed, making introductions and contacts between families and medical professionals, advising on challenges, the day-to-day and simply being there when needed.

Hard work and time have gotten us this far. 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 personal thanks go to all our supporters who help fund our work (through events, sponsorship or donations), and to the volunteers who step-up to help. Without your campaigning, fundraising and support we could not keep moving forward. You keep hope alive for all touched by this terrible condition, now and in the future.

A graphic in the top right corner featuring three handprints in yellow, orange, and green, each with a small butterfly on it. The background of the entire page has a large, faint, light-colored handprint.

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 disorders that are more common.

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 (and growing) the University of Oxford's FOP Research Team.

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



Trustees

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



Christopher 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 slowly 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 is able to 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 (9) and Harry (6).

Nicky Williams – Trustee



Nicky feels passionate around raising awareness of FOP and raising funds to get that 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.

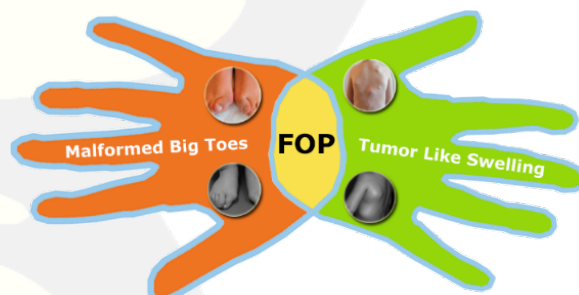
Public Benefit: Raising awareness will help to reduce misdiagnosis of the condition, which has been mistaken for cancer in the past (to the degree that some sufferers have undergone aggressive cancer treatments and harmful surgeries unnecessarily). It will also help to promote research into the condition,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

SARACATINIB (AZD0530)

Over the past year the Oxford team together with collaborators across Europe have been preparing grant applications to secure the €1 million funding to run a small clinical trial using saracatinib. In parallel, they are also working on longer term plans to make bespoke ACVR1/ALK2 inhibitors (i.e. specifically designed for use in FOP). The hope of this approach is that it may allow for an even safer drug.



Blueprint Medicines

Blueprint Medicines

Blueprint Medicines presented their preclinical data in October 2018 supporting the development of BLU-782 – a new treatment that targets the underlying cause of FOP.



Their Phase 1 trial of BLU-782 in healthy volunteers began at the beginning of 2019, and at the end of February 2019 they announced that the FDA has granted Fast Track Designation to BLU-782 for the treatment of FOP.

Regeneron Pharmaceuticals

ANTI-ACTIVIN A

Following on from the promising Phase I clinical trial of anti-Activin A antibody (REGN2477) in healthy volunteers, Regeneron announced their Phase II trial, which is investigating if the drug can slow/stop bone growth in those who are living with FOP, and if the drug is well-tolerated (i.e. limited side effects, and correct dose amount).

There are currently a number of clinical trial sites across the world, including London, that are still recruiting approximately 40 individuals to take part in their 19-month trial.



Clementia Pharmaceuticals

PALOVAROTENE TRIALS

In August 2018, Clementia completed patient enrolment on their Phase III MOVE Trial four months ahead of schedule. This trial is a global, open-label (no placebo) trial for the drug palovarotene. Trials are being conducted internationally, with 99 patients signed up from 15 sites in 11 different countries. The current sites are in the USA, Argentina, Australia, Brazil, Canada, France, Italy, Japan, Spain, Sweden, and the UK. The UK trial centre is Royal National Orthopaedic Hospital in London.

Clementia announced in February 2019 that they



would file the first-ever application to seek FDA regulatory approval for a potential treatment for FOP.

University of Pennsylvania

A new and improved conditional FOP mouse model has been developed at The Center for Research in FOP and Related Disorders. UPenn are also working to produce a model of the human FOP ACVR1 mutations in zebrafish, which may more closely mimic human FOP than the current mouse model, which causes embryonic lethality.



Alongside this, the team are also attempting to identify alternate therapeutic targets through whole exome genetic analysis of FOP patients and their non-FOP family members. The work is focused on FOP patients with unusually mild or severe disease presentations. They anticipate finding modifier genetic variants that will help us understand what mitigates or worsens FOP presentations.

These genes may also be useful alternative therapeutic targets if they display higher tissue specificity or can be targeted by drugs with lower toxicity. Together this study will establish a foundation for understanding the genetic contributors to the severity of FOP.

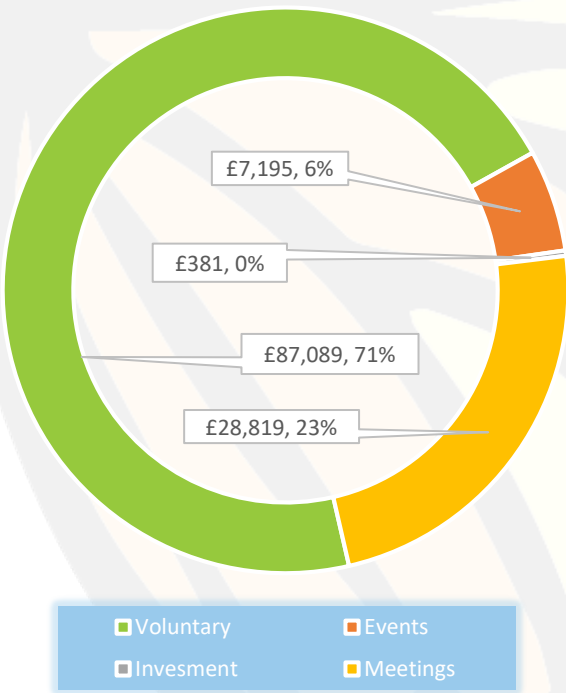
The International Clinical Council (ICC) on FOP

The ICC is an autonomous and independent group of 21 internationally recognised physicians who are clinical experts in FOP continues to act as a global voice for the best practices for clinical care and clinical research for people who live with FOP. The ICC publishes the FOP Treatment Guidelines, which is used internationally to guide the management of patients with FOP. The ICC also has published key recommendations for clinical trials testing potential therapies for FOP.

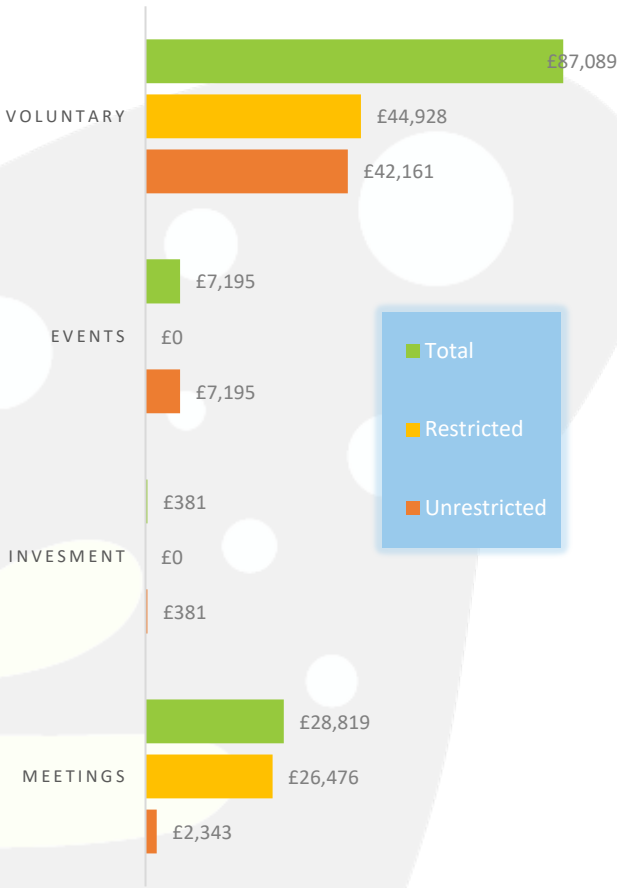
How we raised our money

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 £7,195 revenue from fundraising events.

In addition, revenue of £32,638 is attributed to meetings which includes early fees associated with the 2018 FOP Friends UK Conference and Family Gathering (£25,797) and the FOP Family Weekend (£6,841).



From a total £123,484 incoming resources, £71,404 (58%) were restricted. The remaining £52,080 (42%) being unrestricted.



Restricted funding has seen a 28% decrease, unrestricted funding has seen a further decrease of 13% to £52,080. This is one of our biggest challenges to address as unrestricted funding is the main source of research funding and additional family support.

How money raised was spent

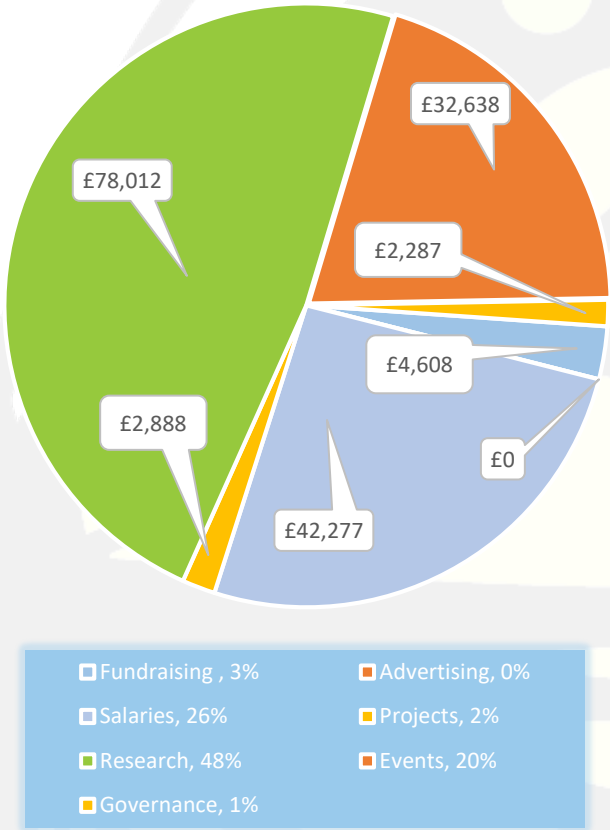
FOP Friends operates with minimal overheads therefore most of the fundraised money directly supports FOP research and families. Most operating costs (including staffing) are paid thanks to grants and corporate support.

95% of our fundraised revenue (events, sponsorship and direct donations) directly supports our charity objects.

The main beneficiary of FOP Friends is the FOP Research team at the University of Oxford. Led by Dr Alex Bullock, The University of Oxford is one of a small number of institutions in the world conducting research into a cure

for FOP. In addition, we provide a smaller amount of funding toward novel research projects via the IFOPA ACT (Accelerating Cures and Treatments) for FOP Grant Program.

Through the charity year FOP Friends provided £78,012 in research funding which includes £30,761 of funding received from international FOP Association (FOP France) restricted to research.

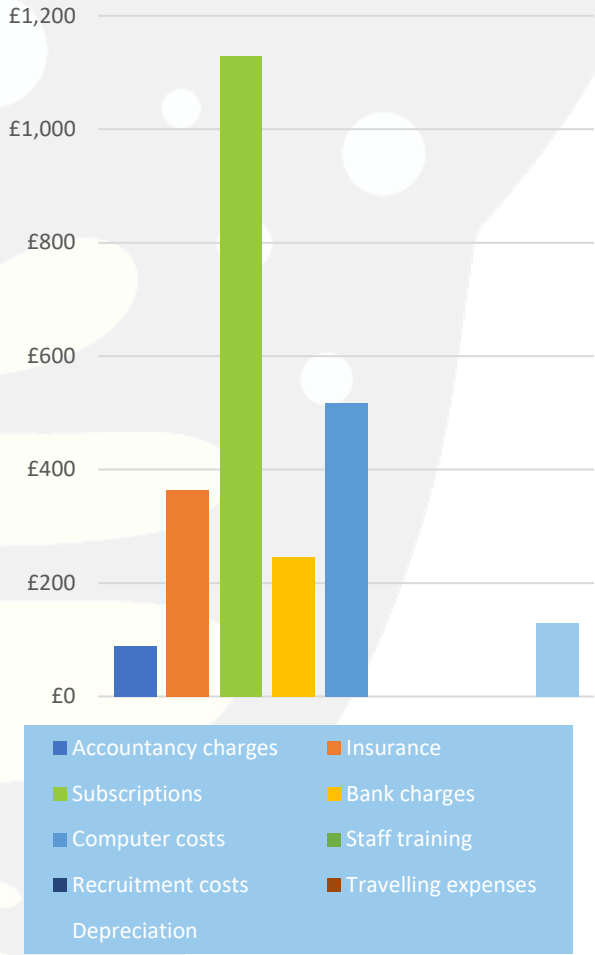


Fundraising costs increased to £4,608 almost 65% more than last year and included securing 15 x Great North Run places, provision of fundraising materials and merchandise such as running t-shirts, leaflets and information packs and running #FunFeet4FOP awareness/fundraising events.

Money spent on staff salaries of £42,277 was funded thanks to corporate support leaving “fundraised” money untouched. Salaries increased significantly as we complete grant funded projects and attempt again to move to a sustainable organisation not dependant on volunteer time.

Governance costs decreased slightly to £2,475.

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



Achievements

FOP Friends was successful in several areas most notably with friends, family and public fundraising.

FOP Friends has had success in growing awareness of FOP and taking fundraising efforts beyond FOP families. This remains critical to the growth and sustainability of the charity and the ability to continue to fund research and support families.

Major achievements include continuing to support the FOP research teams and their efforts, being involved in international FOP efforts and raising awareness of FOP.

Providing funding to Oxford FOP Research



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 and Associazione Noi ci Siamo (Swiss FOP association), who have also contributed to the Oxford Research Fund via FOP Friends.

International FOP involvement



Chris Bedford-Gay (Chairman of FOP Friends) continues his role on the board of the International FOP Association (IFOPA)

working on international FOP projects and meeting annually with researchers at the University of Pennsylvania and other board members for his 7th year.

Additionally, as part of his role as Chair of the IFOPA International Presidents Council (IPC), Chris has also attended many international FOP meetings and works to bring together national FOP leaders to tackle the search for a treatment/cure for FOP and to share challenges faced by FOP families the world over.

The FOP Connection Registry



The number of FOP patients associated with the FOP Connection patient registry continues to increase. The initiative, developed by the

IFOPA, is to help understand and learn more about FOP. It is an international database that collects demographic and health data from individuals living with FOP worldwide using a secure web-based survey tool. Patient registries are essential in rare disease research and drug development and are critical in showing pharmaceutical companies that FOP patients are pro-active in the search for a cure.

FOP Friends continues to assist the IFOPA with this effort, by raising awareness of the registry with the UK FOP community.

IFOPA ACT for FOP Grant Program



FOP Friends continued its support of the IFOPA through their ACT for FOP Grant Program (formerly known as the Competitive Research Grant Program).

The ACT for FOP Grant Program helps support investigators interested in researching and accelerating the development of safe and transformative therapies for FOP. The ACT for FOP Grant Program provides, through a competitive application process, funding to scientists conducting research on FOP. As a result of this program, the IFOPA, with the support of FOP Friends, other international organizations and local fundraisers, has awarded over \$475,000 in research grants since 2015.

EURORDIS



FOP Friends remains a full member of the European Rare

Disease Organisation (EURORDIS). EURORDIS is a non-governmental patient-driven alliance of patient organisations and individuals who are active in the field of rare diseases, dedicated to improving the quality of life of all people living with rare diseases in Europe.

EURORDIS seeks to achieve this through advocacy at the European level, support for research and medicines development, facilitating networking amongst patient groups, raising awareness, and many other actions designed to reduce the impact of rare diseases on the lives of patients and family.

Fundraising Regulator



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

Social media activity



The power of social media today is massive and the more that FOP Friends can raise awareness about FOP, the easier it will be to prevent any devastating misdiagnoses, whilst also raising funds to support the research. Thank you to everyone who has helped with our campaigns this year. FOP Friends continues to grow its network of supporters on social media, and we are especially proactive on Facebook and Twitter. The FOP Friends Facebook page has now exceeded 2,650 likes, with the top post reaching over 4,000 people.

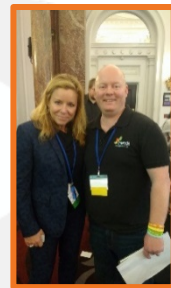
FOP Friends' Twitter account attracts a small but active community, with over 550 followers who help to spread the word and increase the reactions to our posts by up to 7 times that number! LinkedIn continues to grow FOP awareness within the corporate community and Instagram, although being used minimally at present, is set up and in operation. FOP Friends uses social media to post news on recent research discoveries and upcoming clinical trials, to promote the activities of fundraisers and to make and maintain contact with companies and people that support FOP Friends; these go a long way to help raise awareness of FOP and the charity.

Media relations

FOP Friends continues to make use of local and national media where appropriate to raise awareness of FOP and encourage fundraising.

Attendance at conferences and meetings

Chris spoke at the 2018 Genetic Disorders UK Leadership Symposium. His "In It to Win It! Changing the Future for Children Born with Fibrodysplasia Ossificans Progressiva (FOP)" presentation focused on building a sustainable, small charity, supporting patients and families and punching above your wright in pursuit of your charity's ultimate goals.



Chris travelled to Baltimore for the International FOP Association (IFOPA)'s 30th Family Gathering and Conference in November.

In December 2018, Oliver and his dad Chris were invited to speak at Regeneron's Christmas Conference, they were asked to "inspire" – and they most certainly did! It was Oliver's first solo presentation entitled 'FOP and Me' and he was quite simply amazing!



Vice-Chancellor's Circle



Chris and Helen were honoured to receive a letter from Oxford Thinking and the Vice Chancellor's Circle, which thanked FOP Friends for the generous funding of FOP research at Oxford University and acknowledge the charity as one of their most committed supports

UK FOP Conference and Family Gathering



Our third Conference and Family Gathering took place in May and was a resounding success. We were so pleased to have

been awarded a grant from the Big Lottery Fund to help fund the weekend. Other organisations who also supported us included Clementia, Regeneron and The Zochonis Charitable Trust.

Our conference brought together world-renowned FOP experts, representatives from pharmaceutical companies who are at the forefront of FOP research, and FOP families.

The conference was structured with morning talks and afternoon workshops, so families could be updated with FOP news and learn about how to manage their condition.

The main theme in 2018 was living with FOP, with a clear focus on patients and families. Clinical appointments were also offered, so that FOP patients have access to a consultation with world leading FOP experts (24 of our FOPers had a consultation).

FOP Family Weekend

Our second Family Weekend Break Away is taking place in



March 2019. We were so delighted to receive a grant from Genetic Disorders UK (GDUK) to help fund the weekend.

The destination will again be Center Parcs, Sherwood Forest, Nottinghamshire; a prime location for travel across a wide geographic area, with many UK FOP families in attendance. This weekend away provided a brilliant opportunity for all the families to connect and share precious time with others who understood.

The aim of the weekend is to give our FOP children the opportunity to come together and try exciting new activities in a relaxed and safe setting. It also offers the opportunity for family members to meet, share experiences and spend quality time together. This weekend is a necessity to provide vital support and improve emotional wellbeing for our FOP families.



Impact and value

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 within the UK. The income generated has allowed the charity to continue its financing of the University of Oxford FOP Research team, supporting international research, as well as providing increased support and resources for families touched by FOP.

FOP Friends continues to capitalise on its charitable status with further 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.

We include below a selection of supporters, events, challenges and activities providing an idea of the backing FOP Friends receives. The FOP community may be small, but it makes a big difference.

#FunFeet4FOP

The third #FunFeet4FOP campaign was a huge success. Why feet? Because the first sign of FOP is malformed big toes. This classic sign is seldom recognized because of a lack of awareness of FOP, and this leads to FOP being misdiagnosed in many cases (often as cancer).

People from around the world shared pics of their decorated feet or flamboyant footwear.



Sporting Success

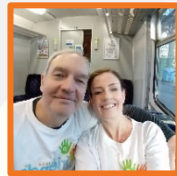
RUNNING

NORTH RUN GREATS

Twelve runners headed to Newcastle to take on the Great North Run this year

13 MILERS

Beside our GRN runners, we've had a number of wonderful people crack a 13 miler for us this year. These include Iona's parents, Alistair and Judith Gray (Glasgow), RNOH consultant Jude Bubbear (Ealing), Seanie's cousin Jack Murton (Windsor), speedy Harry Harding (Bristol) and Natalie, who completed the inaugural London Landmarks Half Marathon.



THE FULL 26.2

And then, as if 13 miles wasn't enough for anyone to run, there are those who went an extra 13 miles, Sharon Moore (Newport Marathon), Jane Deane (Manchester Marathon), Matthew Benson (Edinburgh Marathon) and Mick Henry, dad to Rion who has POH (Connemara).



CYCLING

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



OTHER EXCITING ACTIVITIES

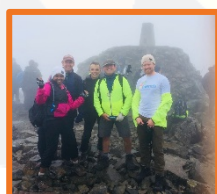
MUBC 24HR ROW

University of Manchester Boat Club took on a 24hr row in aid of FOP, raising £1023.77



ALEXIS' 3-PEAKS CHALLENGE

Alexis completed the 3-peaks challenge (23-miles, Snowdon, Scafell



Pike, Ben Nevis, a total ascent of 3064 metres) for FOP Friends.

Chops for FOP

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



Youth Philanthropy Initiative

A group of inspiring girls took part in the Scottish Youth Philanthropy Initiative representing FOP Friends. After holding multiple fundraising events, including a raffle and a Battered morning serving lots of lovely treats, the programme culminated with the girls getting on stage and presenting why FOP Friends should win a £3000 donation. The girls were disappointed not to win but we were so very grateful for all the awareness that they raised for FOP.



FOP-friendly Christmas Card Campaign

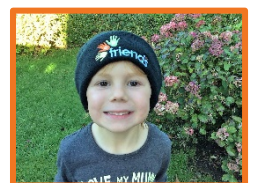


This year we revealed our first ever old-school Christmas card to help raise awareness of FOP and to help continue funding the work of our Oxford University

research team and supporting our UK FOP families. We challenged all our FOP families to take part and see who could sell the most cards. 23 families got on board and a staggering £1479.60 was raised, with 10,000 cards distributed across the country.

Merchandise

We launched our FOP Friends' beanie hats and they've been a great tool to raise awareness.



Supporter Spotlight

In January 2019, we launched our Supporter Spotlight programme. This programme let's us celebrate the many people who have joined us on our journey to find a treatment and a cure for FOP.



University of Manchester Interns

We were so lucky to be joined in the office during the 2018 Christmas period by Nicola and Keane, two Manchester University students, who completed a 30-hour placement as part of their Psychology course. They were the masterminds behind our '12 Days of Christmas' social media campaign.



Team Isla

Isla's FOP Fight fundraising page that was set up just over 4 years ago recently exceeded its target of £60,000! This achievement is thanks to the collective effort of all the members of Team Isla, who constantly go above and beyond with a variety of different events to raise awareness of FOP.

GIG FOR ISLA CELEBRATES ITS 5TH YEAR

The first Gig for Isla was held in October 2014. The L&M Band, who play 60s R&B agreed to play for free. Everyone had a great time and as they left, people were asking when the next one was going to be. Four gigs later, Gig for Isla has thousands of pounds in support of FOP Friends.

MASONIC BALL

Sue Woodard organized a special evening in aid of FOP Friends, raising £2845.

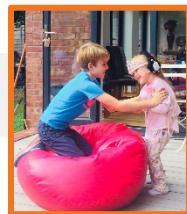


BEETLE DRIVE

Over on the Isle of Wight, Debs, Debbie and Margot held their annual Calbourne Beetle Drive evening, where a great time was had by all and over £300 was raised.

LAMBROOK SCHOOL

Isla's cousin Toby, along with his mum, raised over £1000 at school to help Isla and her FOP friends find a cure for FOP.



GIVING TUESDAY

Did you know the Tuesday after Black Friday in November is called Giving Tuesday? Every year this day is the chance for individuals to give back to charities. We were so lucky that Sophos Plc kindly fund-matched every donation made on the day to Team Isla's Giving Tuesday page.

SWAP4FOP

Take a bunch of friends, each bring a few unwanted items, add an entry fee, a raffle, and some fizz and you've got a fun night! Recycle, take away some treasure, and raise much needed funds for FOP Friends. Isla's godmother did just that but with 20 friends and raised a whopping £800.



BOXING DAY FUNDRAISER

On Wren day a brilliant group got dressed up and visited 35 pubs, Irish dancing whilst raising money for our charity.

CREATIVE EFFORTS

Heather and her twin sister Paula were both keen to see if they could sell their work at craft fairs to benefit FOP Friends and they've definitely been successful.

AFTERNOON TEA

Clair and Mary hosted a fabulous afternoon tea, raising an amazing £406.25. Showing how a small, fun event can make such a difference to our small but special charity.



All in all, this has been a fun, fruitful year of fundraising.

Future plans

FOP Friends plans to hold the fourth FOP Conference and Family Gathering in May 2020, continuing the biennial event started in 2014. The 2020 event is expected to be well attended and many side-meetings are scheduled to take place between clinicians, researchers and pharmaceutical companies, all alongside clinical appointments for patients, a creche for children, workshops and presentations.

Plans are underway to gain funding and support to run subsequent Family Weekends. These are weekends where families dealing with FOP can step-away and enjoy a relaxed atmosphere with others in the same situation. After the success of our first Weekend Away in 2017, our second is fully funded and will take place in March 2019.

We continue in the attempt to move towards 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).

An increase in the support provided to families is planned with production of new support materials such as the “Be Safe at School” handbook together with refreshing fundraising materials and information leaflets.

Finally, continued awareness and fundraising is planned to ensure research at the University of Oxford continues to be funded and the level of family support FOP Friends offers can be increased.

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, through increased public awareness, expand fundraising activities beyond friends and family to become a charity of choice for the public to support
- To sustain and maximise trusts and grant funding to continue the financial support for research
- To secure and sustain grant funding to enable the charity to support employees on a long-term basis
- To develop a Fundraising Pack to help those interested in fundraising to support the charity
- To secure funding to cover core costs and reduce attendee costs for future UK FOP conferences
- To seek corporate sponsorship as “charity of the year”

- To create alternative fundraising campaigns to diversify income streams
- To seek high-profile patrons to both, increase awareness and 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. The trustees give their time freely and receive no remuneration or other financial benefits.

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

Organisational Structure

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

Trustee recruitment and training

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

Employment

FOP Friends continues moving towards being a sustainable and professional organisation through employment of appropriate staff. The aim, to reduce the reliance on a small number of unpaid volunteers to run the charity. To this end Hannah Dempsey, has moved into a fixed-term full time role of “Operations Manager”. Salary’s for FOP

Friends staff continues to be funded by grants and trust support, leaving fundraised monies to meet the charities main objectives. With currently 95% of all fundraised money directly supporting the charities objectives.

Employee time is currently split 80:20, where 80% of their time is in supporting the charities objectives and 20% in generating / supporting fundraising.

Hannah – Operations Manager



Having worked for FOP Friends as a Marketing and Communications Intern for 8 weeks in summer 2016, and then working with the charity two days a week through 2017 – 2018 while completing her Master's year at the University of Manchester, Hannah became a full-time employee in September 2018. She continues her work, managing all of FOP Friends' social media streams, tracking engagement with the public and overseeing fundraisers and fundraising projects. Her role will now expand to include operational support and future grants and trust applications in support of the charities objectives.

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 30th December 2018 and signed on their behalf by

A handwritten signature in blue ink, appearing to read 'Chris Bedford-Gay'.

Chris Bedford-Gay.

Founding Trustee and Chairman

Financial review

Summary

Gross incoming resources for the year amounted to £123,484 with £196,226 being carried forward to the next charity year. Of the amount being carried forward £125,000 is designated to fund future research with £15,000 designated to operating reserves.

The charity currently has no long-term investments. Cash reserves are held in bank deposit accounts.

Income

Income for the year totalled £123,484 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 £14,165 from grants and trusts. A 66% decrease from the previous charity year. However, this is in part due to crossover of grant funded projects from the previous charity year and incoming grants arriving just after the 2018/19 charity year end.

Charitable expenditure

Through the charity year £78,012 was spent on funding FOP research. Which includes £65,000 in support of the University of Oxford FOP Research team and \$15,000 in support of the IFOPA Accelerating Cures and Treatments (ACT) Grant.

Operating costs of £52,060 include costs associated with fundraising of £4,608 (t-shirts, event places, and support of fundraisers), staff salaries of £42,277 (a large increase as we complete grant funded projects, those grants covering salaries), £2,475 in governance costs and £2,888 costs associated with projects.

Governance costs of £2,475 include accounting fees, insurance, postage, professional memberships and costs associated in employing staff.

£6,841 was spent on the FOP Family Weekend. These costs being covered by project grants.

Gains and losses

Income from fundraising, voluntary donations and fundraising activities decreased by 31% from £137,257 to a total of £94,284.

Policy on reserves

The Trustees have reviewed the reserves of FOP Friends. Our aim is to maintain reserves in unrestricted funds at a level 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. Each year the trustees decide where to make disbursements to achieve the aims and objectives of the charity. At the time of writing £125,000 has been designated from funds carried over towards FOP research.

Ongoing projects such as the “Be Safe at School” handbook and “FOP Friends Together” newsletter is recognised as future financial commitments being funded through restricted grants and trust awards.

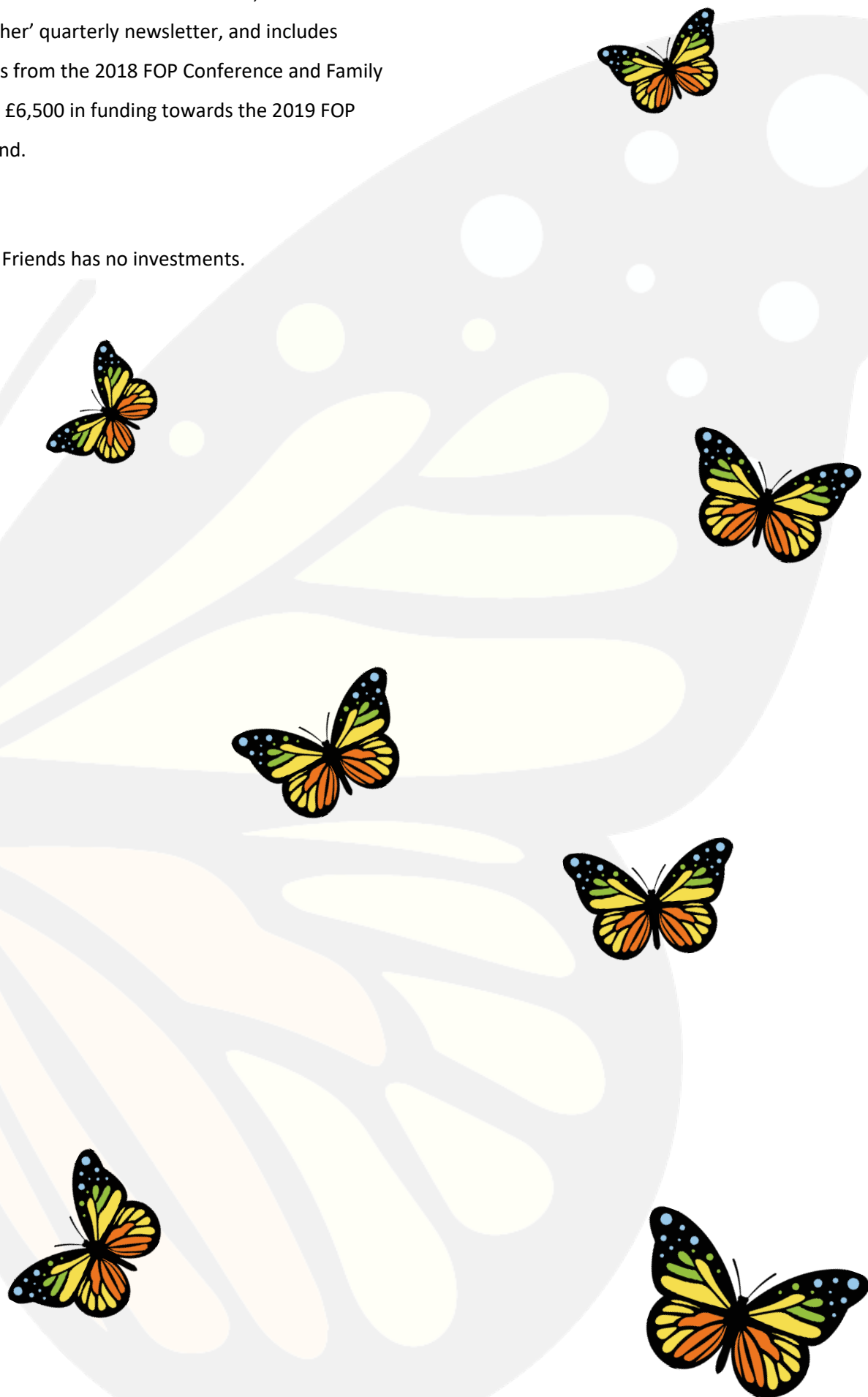
Restricted Funds

A total of £71,404 in funding received in this reporting year has been restricted towards research (£30,761 from international FOP organisations) and several projects

including the “Be Safe at School” handbook, the FOP Friends ‘Together’ quarterly newsletter, and includes £19,977 in fees from the 2018 FOP Conference and Family Gathering and £6,500 in funding towards the 2019 FOP Family Weekend.

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 2017 which are set out on pages 27 to 32.

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

Respective responsibilities of the trustees and examiner

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

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

Basis of independent examiner's report

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

Independent examiner's statement

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

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

Independent examiner

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

Consolidated statement of financial activities

	Notes	Restricted	Unrestricted	Totals	
				2019	2018
<u>Incoming resources</u>					
From generated funds					
Voluntary income	2	£44,928	£42,161	£87,189	£127,682
Activities for generating funds	3	-	£7,195	£7,195	£9,575
Investment income		-	£381	£381	£136
Other incoming resources	4	£26,476	£2,343	£28,819	£21,576
Total incoming resources		£71,404	£52,080	£123,484	£158,969
<u>Resources expended</u>					
Costs of generating funds					
Fundraising costs	5	-	£4,608	£4,608	£2,802
Advertising & PR	5	-	-	-	£28
Salaries	5	£8,455	-	£8,455	£12,864
Project costs	5	£2,888	-	£2,888	£1,716
Charitable activities					
Research	6	£30,761	£47,251	£78,012	£95,063
Events	7	£32,638	-	£32,638	£3,112
Salaries	5	33,822	-	33,822	-
Governance costs	8	£2,287	£188	£2,475	£2,955
Total resources expended		£110,851	£52,047	£162,898	£118,540
Net incoming/(outgoing)		(£39,447)	£33	(£39,413)	£40,429
<u>Reconciliation of funds</u>					
Total funds brought forward		£70,871	£164,769	£235,640	£195,211
Total funds carried forward		£31,424	£164,802	£196,227	£235,640

Balance sheet

	Notes	2019	2018
Fixed assets	9	£114	£243
Current assets			
Cash at bank		£200,434	£238,466
		£200,434	£238,466
Creditors: amounts due within one year	10	(£4,321)	(£3,069)
Net current liabilities		£196,113	£235,397
Net assets		£196,227	£235,640
Funds			
Restricted	11	£31,424	£70,871
Designated	12	£140,000	£140,000
Unrestricted		£24,802	£24,769
		£196,227	£235,640

Approved by the trustees on 30th December 2018 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 & 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

	2019	2018
Donations	£72,924	£86,248
Grants	£14,165	£41,434
	£87,089	£127,682

3. ACTIVITIES FOR GENERATING FUNDS

	2019	2018
Fundraising events	£7,195	£9,575
	£7,195	£9,575

4. OTHER INCOMING RESOURCES

	2019	2018
Conference fees	£19,976	£15,4073
Family getaway	£6,500	£5,500
Sales	£2,343	£669-
	£28,819	£21,576

5. FUNDRAISING COSTS

	2019	2018
<i>Salaries</i>	£42,277	£12,864
<i>Advertising & PR</i>	-	£28
<i>Fundraising costs</i>	£4,608	£2,802
<i>Project costs</i>	£2,888	£1,716
	£49,773	£17,410

6. RESEARCH

	2019	2018
<i>UK Research</i>	£66,146	£80,000
<i>International Research</i>	£11,866	£15,063
	£78,012	£95,063

7. EVENTS

	2019	2018
<i>Conference costs</i>	£25,797	£180
<i>Family weekend</i>	£6,841	£2,932
	£32,638	£3,112

8. GOVERNANCE

	2019	2018
<i>Accountancy</i>	£90	£90
<i>Insurance</i>	£364	£330
<i>Subscriptions</i>	£1,129	£1,096
<i>Bank charges</i>	£246	£167
<i>Computer costs</i>	£517	£686
<i>Staff training</i>	-	-
<i>Travel expenses</i>	-	£179
<i>Depreciation</i>	£129	£407
	£2,475	£2,955



9. FIXED ASSETS

	Office equipment
Cost	
At 2 nd March 2018	£1,221
Additions	-
Disposals	-
At 1 st March 2019	£1,221
Depreciation	
At 2 nd March 2018	£978
On disposals	-
Charge for year	£129
At 1 st March 2019	£1,107
Net book value	
At 2 nd March 2018	£114
At 1 st March 2019	£243

10. CREDITORS

Amounts falling due within one year:

	2019	2018
Trade creditors	£4,521	£3,153
PAYE and NI	£288	(£164)
VAT	(£668)	(£10)
Accrued expenses	£180	£90
	£4,321	£3,069

11. RESTRICTED FUNDS

	<i>Balance b.fwd</i>	<i>Incoming resources</i>	<i>Resources expended</i>	<i>Balance c.fwd</i>
<i>Conference fees fund</i>	£25,154	£19,977	(£25,797)	£19,334
<i>Family getaway</i>	£7,562	£6,500	(£6,841)	£7,221
<i>Support fund</i>	-	-	-	-
<i>Operational</i>	£3,483	£14,166	(£17,649)	-
<i>School Handbook fund</i>	£24,009	-	(£23,815)	£194
<i>FOP 'Together' Newsletter</i>	£9,063	-	(£5,880)	£3,183
<i>Charity leaflet</i>	£1,600	-	(£108)	£1,492
<i>FOP Organisations</i>	-	£30,761	(£30,761)	-
	£70,871	£71,404	(£110,851)	£31,424

The Support fund represents grant monies received from Genetic Disorders UK to fund the employment of a Charity Support Assistant.

The Conference fees fund represents donations and delegates deposits received in respect of the FOP Conference in May 2018.

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

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.

12. DESIGNATED FUNDS

	<i>Balance b.fwd</i>	<i>Incoming resources</i>	<i>Resources expended</i>	<i>Balance c.fwd</i>
<i>Research fund</i>	£125,00	-	-	£125,000
<i>Operating fund</i>	£15,000	-	-	£15,000
	£140,000			£140,000

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

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

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



Our history (to 1st March 2019)

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 onto 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.

2012



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

June 2012

FOP Friends of Oliver becomes a registered charity #1147704.

December 2012

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

December 2012



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

March 2013

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

March 2013



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.

December 2013

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 organizes 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

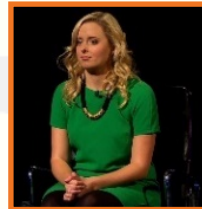
Website is updated with personalised "Friends" pages to recognise and celebrate the amazing people who make up FOP Friends.



FOP Friends Founder and chairman Chris attends the IFOPA Drug Development Forum in Boston, with over 100 researchers and interested pharmaceutical companies in attendance. 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!

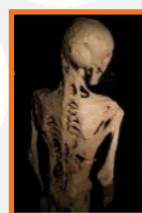
January 2015



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

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

February 2015



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

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

March 2015

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



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

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

June 2015

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



PushOn adopt FOP Friends as their Charity of the Year.

August 2015



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

September 2015



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

October 2015

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

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

November 2015



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

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

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

Chris flies out to Amsterdam for the Dutch FOP Symposium.



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

December 2015

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

January 2016

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



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



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

February 2016



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



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

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



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



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

the world.

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

March 2016

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

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

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

Chris attends his second FOP Italia meeting in Livorno. 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.



We launch our first national (now international) social media campaign, encouraging all our 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 organization was established by Lara Boniface, mum of FOPer Jarvis.

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 London to Brighton cycle.

October 2016

Organized 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 Centre 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 at 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 received 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 were able to enjoy a weekend at Centre 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

Enjoying the University of Oxford Vice-Chancellors Circle evening. An invite extended to us thanks to all the support we as a community have been able to give to our FOP Research team at Oxford.



June 2017

FOP Friends partner with Genetic Disorders UK.

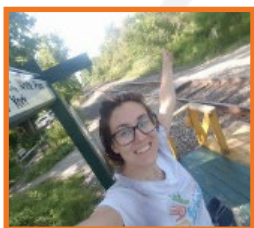
Savills continue their support by holding a Golf Day and raising over £165.

July 2017

Sophie, Becky and friends host a Garden Fundraiser and raise £670 taking FOP Friend 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

8 runners took on the Great North Run, raising over £5,000 for FOP research, with special support from 6 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.

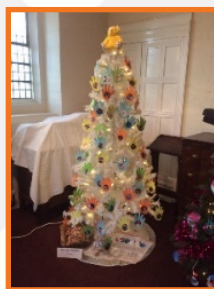
November 2017

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

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

The charity 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, contributed 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.

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 were pleased to announce that we had been awarded a grant from the Big Lottery Fund to help fund our 2018 UK FOP Conference and Family Gathering.



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



Chris spoke 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 focused on building a sustainable, small charity, supporting patients and families and

punching above your wright in pursuit of your charity's ultimate goals.

April 2018

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



T-UK Stockport Taekwon-Do chose FOP Friends as their Charity of the Year and Chris was thrilled to attend their evening dinner and accept a cheque of

£613.

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



#FunFeet4FOP was a great success for the third time, with lots of fun feet making an appearance. We were so grateful and honoured to

see that the BalletBoyz chose to help raise awareness for FOP! Hummingbird Bakery in Guildford supplied cakes for #FunFeet4FOP bake sale, which raised over £230.



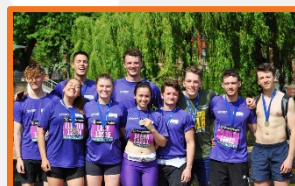
Mick Henry ran the Connemara Marathon for Friends of Rion, while Sharon Moore took on the Newport Marathon for Friends of Annalese.

May 2018



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

awareness for FOP.



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



Our third Conference and Family Gathering took place and was a resounding success! With talks from the world leading FOP

experts, workshops and clinical consultations – everyone in attendance had a wonderful time connecting with one another.

June 2018

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



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

July 2018



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

We were thrilled to unveil our new FOP Friends leaflet.

August 2018

Alexis who completed the 3-peaks challenge for FOP Friends

September 2018

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



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

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

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



October 2018

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

We drummed 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 has arrived safely in Baltimore for the International FOP Association (IFOPA)'s 30th Family Gathering.

Our first-ever Christmas card campaign was launched.

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



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

December 2018

We launched our FOP Friends beanie hats.



Oliver gave an amazing presentation talking about FOP & Me, to the colleagues of Regeneron UK at their Christmas conference.

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

January 2019



Launched our Supporter Spotlight programme.

A Team Isla Swap4FOP raised a staggering £800!

February 2019

Launched 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.



Thank you to (March 2018 – March 2019)

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

Trusts / Grants

Big Lottery Fund

The Boshier-Hinton Foundation

Bruce Wake Charitable Trust

The February Foundation

Genetic Disorders UK

The Zochonis Charitable Trust

Corporate Supporters

Avaya

Clementia Pharmaceuticals

Regeneron Pharmaceuticals

Skillsarena Ltd

Donors of time and resources

Clarity Comms: FOP Animation

Stephen Fry: FOP Animation Narration

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

Skillsarena Ltd: Director's time

Foliozine: Logo and website design

Community / Clubs & Associations

Manchester Round Table

Royal Northumberland Yacht Club

Fundraisers

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

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

Contact Details



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