



## 2017 Annual Report

### & Financial Statements

Year ending 1<sup>st</sup> March 2017

Charity: #1147704 | OSCR: #SC046950

## Charity name

FOP Friends

## Working Names

FOP Friends of Oliver, FOP Action

## 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

- FOP Friends is 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.
- FOP Friends respects the integrity, ambition and interests of all FOP Patients.
- FOP Friends strives to be both a haven and champion for FOP patients and their families; a centre of excellence for the provision of information on medical research, diagnosis, treatment and care, and participation in clinical trials.
- FOP Friends shall act always with honesty, professionalism and ethical awareness.
- FOP Friends shall work collaboratively with medical researchers and clinicians, patients and families, our donors and supporters to realise our Vision and complete our Mission.

## Registered address

The Cabin, 1 Cumberland Road, Sale, Cheshire, M33  
3FR, United Kingdom

## Registered

March 2012

## Charity number(s)

1147704, SC046950

## Governed by

Trust Deed

## Founding Trustees

Christopher Bedford-Gay, Alison Acosta Bedford,  
Rachel Almeida

## Trustees

Fiona White, John Leaver, Helen Bedford-Gay, Nicky  
Williams

## Independent auditor

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

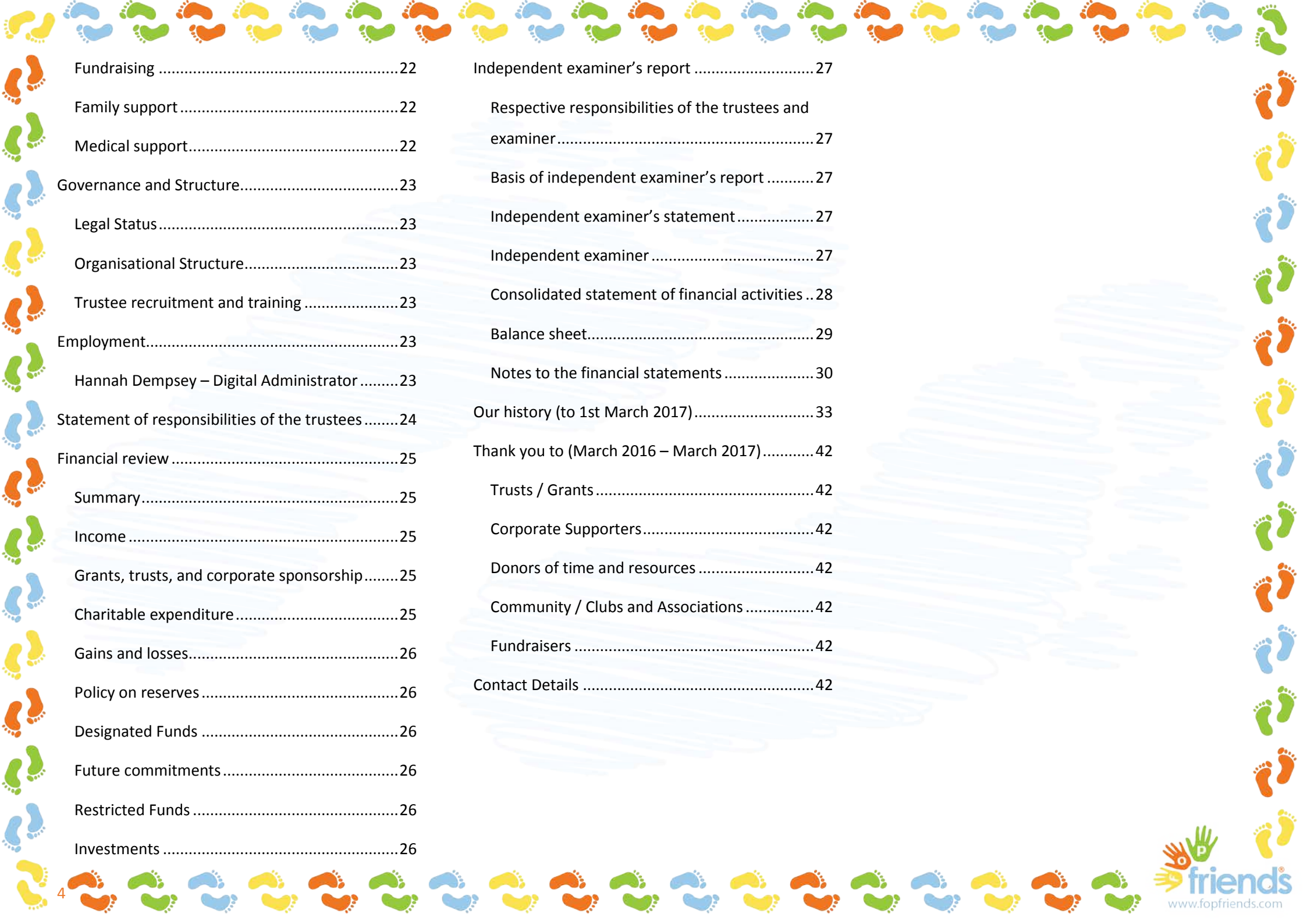


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## What is Fibrodysplasia Ossificans Progressiva (FOP)?

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

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

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

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

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





## Introduction and Chair's Statement

In 2009, I received the devastating news that my eldest son, Oliver, who was then just one, had been born with Fibrodysplasia Ossificans Progressiva (FOP). Following Oliver's diagnosis, I discovered there was no charity in the UK dedicated to raising money for research into FOP.

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 sixth year, we have had success in grant and trust fundraising as well as increased fundraising from FOP families, friends and the public. We continue to grow and are regularly chosen as "charity for the year" by organisations when put forward.

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 a-like. 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.

We are the second FOP organisation to make the transition from family ran into a organisation with a small staff, although all trustees remain unpaid volunteers. This step is wholly funded through grants, trusts and corporate support and is critical for the organisation to remain sustainable regardless of what the future holds for us as a family.

Our initiatives such as #FunFeet4FOP, family focused conferences, family weekends, and our promotional and information items are influencing or being replicated by many. The level of 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 school challenges, the day-to-day and simply "being there" when needed for those in the FOP community. All whilst caring for our own family and our little boy with FOP.

It has taken hard work and time to get this far and it will take even more to make our vision a reality. With continued support, we will get there, and we will change the lives of every FOP family present and future, forever.

Finally, 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.



Chris Bedford-Gay, Founder and Chairman of FOP Friends.



## About us / Who we are

FOP Friends' aim is to further research into Fibrodysplasia Ossificans Progressiva (FOP) and related conditions by supporting current and future research projects.

FOP research has far reaching implications for those with FOP but also those with common bone disorders such as fractures, osteoporosis, osteoarthritis and other forms of heterotopic ossification that occur through trauma such as military and sports injuries, paraplegia and post-hip surgery complications. More recently, research has shown that a rare form of childhood brain cancer, DIPG, could benefit from FOP research and vice versa.

FOP Friends aims to raise public awareness of FOP by holding and promoting charitable events and encouraging the news media to report upon FOP and related conditions. This will serve to educate the public to the existence of FOP and of research projects that will benefit not only FOP sufferers but also those with disorders that are more common.

FOP Friends was founded following the diagnosis of Oliver Bedford-Gay (8) 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



From the moment he received Oliver's diagnosis, Chris became heavily involved in the search for a cure. In addition to founding FOP Friends, Chris served as chairman of FOP Action (which has now been integrated into FOP Friends), continues to serve on the board of the International FOP Association (IFOPA) - a position he has held for 5 years - and is current chairman of the IFOPA International Presidents Council, bringing together FOP organisations and leaders from across the world. Chris also represents the UK FOP community internationally. 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)

### Alison Acosta Bedford - Trustee



Alison is a mum of two and a Chartered Management Accountant who works as Treasury and Investment Manager at Trafford Housing Trust. 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 14 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 16 years and is pleased to be able to put her experience and expertise to good use. Rachel was inspired to completed 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

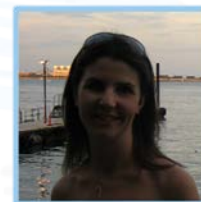
When John heard about Oliver and others with FOP, he wanted to do what he could to help. As a first



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, although she is the most recent addition to the trustee board. 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. Being an experienced teacher also allows her 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 (7) and Harry (4).

### 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 10+ 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.

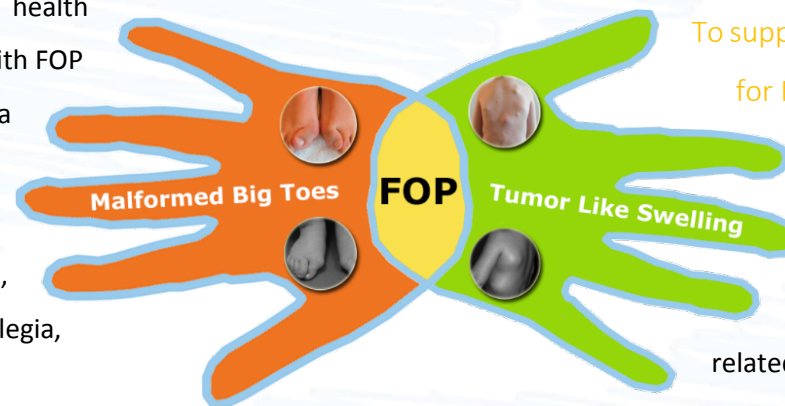
### Principal objects

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

### PhD Scholarship

This year Richard Simcox helped to fund a scholarship at Oxford University to support a postgraduate working on FOP research every year in perpetuity. Only once research into FOP is no longer necessary will the scholarship go towards funding research in another area. "Oxford-The Simcox Family Graduate Scholarship" is in memory of Richard's mother, Constance Mary Simcox nee Killingback.

Regeneron Pharmaceuticals

### Anti-Activin A

Following on from the promising studies in mice, US biotechnology company, Regeneron, is running the first clinical trial of anti-Activin A antibody (REGN2477) in humans. A study in healthy volunteers was initiated in Belgium in June 2016. This is an important step in the clinical development process, as it provides the first information on REGN2477's safety, tolerability and pharmacological activity in people. They plan to review this data before the end of this year and begin clinical studies in patients with FOP as soon as possible based

**REGENERON**

on what has been learned.



Clementia Pharmaceuticals

### Palovarotene Trials

clementia

In October 2016 Clementia announced the top-line results of its phase 2 study of palovarotene. The drug has shown positive trends in reducing bone formation, as well as the pain and severity of flare-ups in those with FOP. Although these trends were not found to be statistically significant this is still positive news. Showing that something is statistically significant is a challenge for all trials of rare diseases, where the number of participants (40 in this trial) makes it harder to prove significant trends. Clementia is extending its phase 2 study of palovarotene to test new dosing regimens and is recruiting 20 new trial participants. The company will be running a phase 3 trial next year. Participants in the extension of the phase 2 trial must be adults or teenagers who are 90% fully grown, and must live in the UK, France, Canada or Argentina. The UK trial centre is Royal National Orthopaedic Hospital in London.

University of Pennsylvania

### Lack of oxygen linked to FOP flare-ups

Scientists from the Centre for Research in FOP and Related



Disorders at the University of Pennsylvania have shown

that tissue cells starved of oxygen (a state known as hypoxia) amplify the formation of bone in FOP flare-ups in both human cells and mice. One of the causes of hypoxia is inflammation, which previous research has identified is associated with FOP lesions. When a cell is hypoxic, the HIF-1 $\alpha$  protein triggers a molecular alarm. In this study, the researchers found that by inhibiting the HIF-1 $\alpha$  protein they could quieten the alarm, which resulted in a reduction of bone formation in FOP mice. Most importantly, in human FOP bone cells this approach resulted in signalling of bone growth slowing to what you would see in non-hypoxic cells. This means the study has identified the HIF-1 $\alpha$  protein as a potential target for treating FOP.

"The implications for targeted clinical trials and for compassionate clinical use of HIF-1 $\alpha$  inhibitors in the treatment of FOP flare-ups are promising, however we need more data on dosing, duration, timing, rebound, resistance and long-term safety," said Robert Pignolo, Associate Professor of Medicine at the Hospital of the University of Pennsylvania.

Findings from the study were published in the Journal of Bone and Mineral Research in May.

## How we raised our money

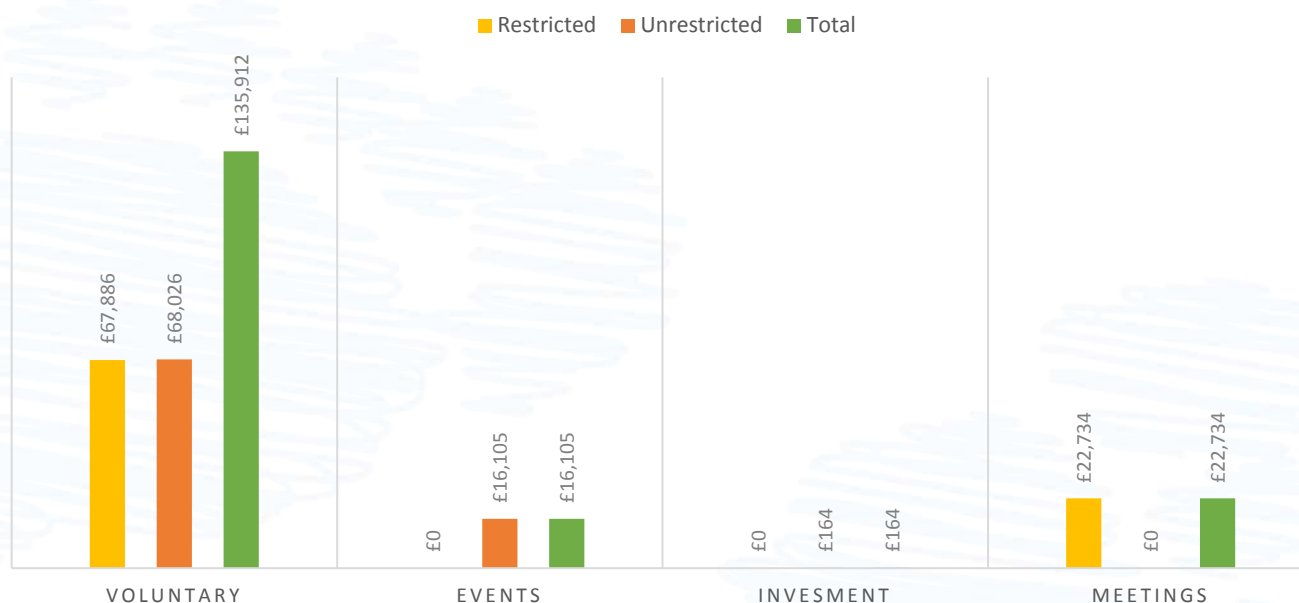
Voluntary income accounts for the bulk of money raised within the charity's financial year. A small amount is attributed to investment income (interest on bank balances) and £16,105 revenue from fundraising events.

In addition, revenue of £22,734 is attributed to meetings which includes outstanding fees associated with the 2016 FOP Friends UK Conference and Family Gathering (£11,663) and the FOP Family Weekend (£11,071).

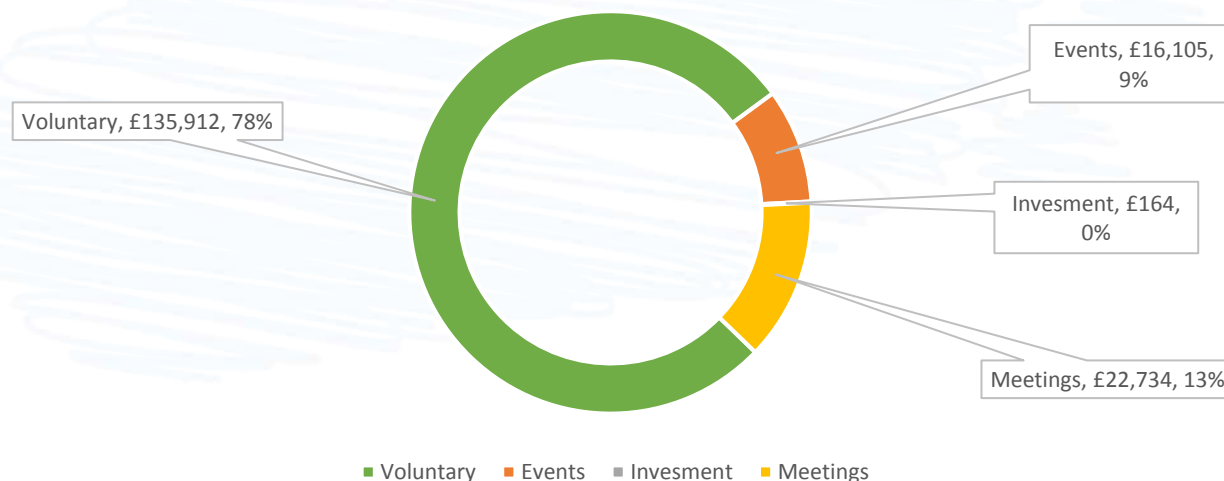
From a total £174,915 incoming resources £90,620 (51%) were restricted. £40,999 of which is attributed to funding from international FOP organisations with the remaining £84,295 (49%) being unrestricted.

Restricted funding has seen a 92% increase however unrestricted funding has seen a decrease with the ratio moving close to 50:50. This is largely due to restrictions being applied to international FOP organisation funding.

## INCOMING RESOURCES £174,915



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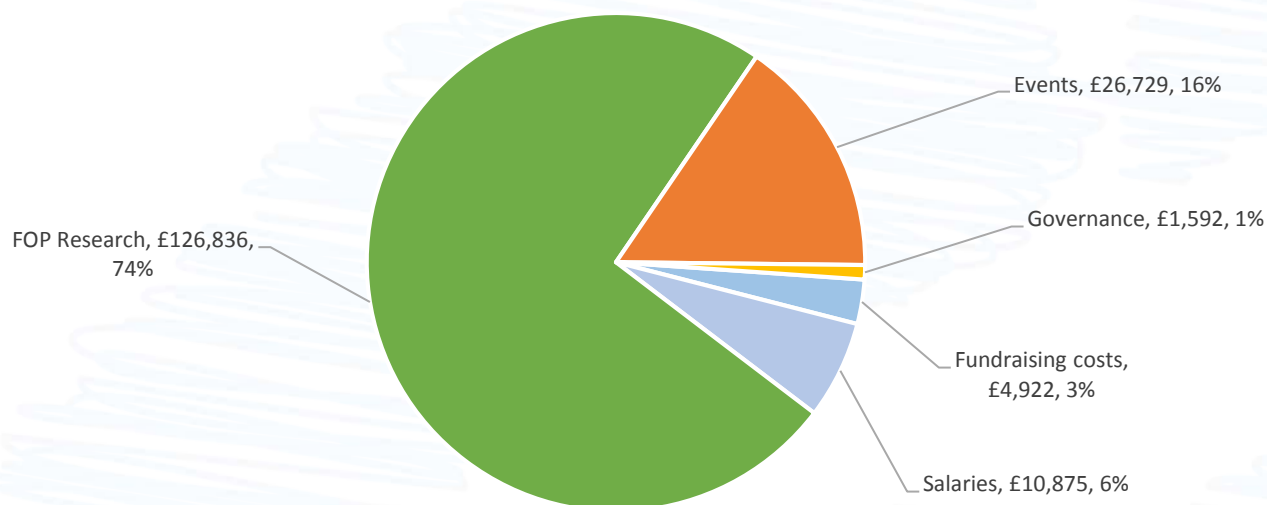




## How money raised was spent

FOP Friends operates with minimal overheads therefore the majority of fundraised money directly supports FOP research and families. Most operating costs (including staffing) are paid thanks to grants and corporate support. 95% of fundraised revenue (events, sponsorship and direct donations) directly supports our objects.

### OUTGOING RESOURCES £173,015



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

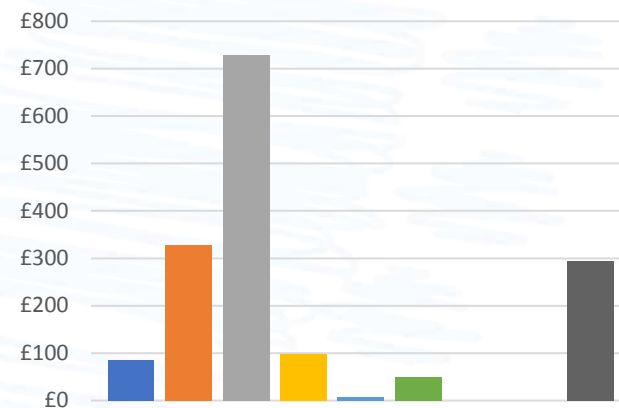
Through the charity year FOP Friends provided £126,836 in research funding which includes £40,999 of funding received from international FOP Associations (FOP France and Associazione Noi Si Amo) restricted to research.

The 2016 UK FOP Conference and Family Gathering costs of £20,652 were covered by grants and attendance fees. A further £6,077 of a total £11,071 was spent running the first FOP Friends Family Weekend. The weekend entirely funded thanks to a BBC Children in Need grant (the remaining due next charity year).

Fundraising costs remained stable at £4,922 and included securing 25 x Great North Run places, provision of fundraising materials and merchandise such as running t-shirts, leaflets and information packs. Money spent on staff salaries of £10,875 was funded thanks to corporate support leaving "fundraised" money untouched.

Governance costs decreased by £857 to £1,592. Governance includes basic operating costs, accounting fees, insurance, postage, professional memberships, and costs associated with training and supporting trustees and staff.

### GOVERNANCE £1,593



- Accountancy charges
- Insurance
- Subscriptions
- Bank charges
- Computer costs
- Staff training
- Recruitment costs
- Travelling expenses
- Depreciation



## Achievements

FOP Friends was successful in several areas most notably with friends, family and public fundraising and through corporate sponsorship as "Charity of the Year".

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, the Swiss FOP association who have also contributed to the Oxford Research Fund via FOP Friends.

### IFOPA

Chairman of FOP Friends, Chris Bedford-Gay remains on the board of the IFOPA for his 5<sup>th</sup> year, chairing the International Presidents Council and serving on the Communications & PR committees.



### 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. 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



There are now 178 FOP patients associated with the FOP Connection patient registry. The initiative - developed by the IFOPA to help understand and learn more about FOP - 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 Drug Development Forum

FOP Friends provided \$15,000 towards the running of the IFOPA Drug Development Forum an annual meeting critical in bringing research, pharmaceutical and patients together to accelerate the search for a treatment and cure for FOP. The \$15,000 was fund-matched ultimately helping provide \$30,000 of funding towards the event.



### IFOPA Competitive Research

FOP Friends continued its support of the IFOPA through the competitive research grant programme in which a partnership saw FOP Friends providing



25% of the funding towards the “Allosteric inhibitors of ALK2 for FOP therapy”, a new and novel project at University of Oxford.



### 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 Regulator (the organisation that replaces the Fundraising Standards Board (FRSB)). 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.

Registered with



FUNDRAISING  
REGULATOR

### 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 2,000 likes, with the top post reaching over 8,000 people. FOP Friends' Twitter account attracts a small but active community, with just over 500 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 Google+, 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. We are, however, very cautious when working with the media and only “go public” when it truly benefits the FOP community.



In January 2017, the novel Rattle by Fiona Cummins was published. Chris consulted on the book, as one of the main characters suffers from FOP, leading to Chris, Oliver, and FOP Friends receiving an acknowledgement in the credits. The book is set to become a best-seller, and with the film rights having already been snapped up this will hopefully prove invaluable in raising awareness of the condition.



Raising awareness of the medical implications of FOP within medical communities and with the public is a key role for FOP Friends, with the aim to improve recognition of FOP symptoms and facilitating diagnosis.

### Attendance at Conferences and meetings

In March 2016, FOP Friends trustee Rachel represented us at the annual UK Genetic Disorders Leadership Symposium in London. Chris again attended the FOP Italia Conference, where twelve countries came



together to update on the search for treatments for FOP. In October 2016, Chris flew to Boston for the IFOPA Drug development forum.

In November 2016, Chris was pleased to attend the prestigious Eurordis Awards and Black Pearl in Brussels, along with many FOP leaders from around the world. Helen and Chris were thrilled to be invited to the Vice Chancellor's Circle of the University of Oxford, and will attend their annual meeting in May 2017.

### FOP Family Weekend

FOP Friends was delighted to receive a grant from BBC Children in Need to fund an Activity Weekend Break for children aged 18 and under who are affected by FOP. Our chosen date is the weekend of 17th - 19th March 2017 and the destination is Center Parcs, Sherwood Forest, Nottinghamshire; a prime location for travel across a wide geographic area.



Center Parcs Sherwood Forest boasts a variety of activities to suit children of all ages including the subtropical swimming paradise, soft play areas, craft activities and treasure trails.

This fun-filled weekend will give FOP children the opportunity to come together and try exciting new activities in a relaxed and safe setting. The Activity Weekend Break also offers a welcome opportunity for parents and family members to meet, share experiences and spend quality time together in an enjoyable environment.

### UK FOP Conference and Family Gathering



On Saturday 21st May 2016, FOP Friends held the UK FOP Conference and Family Gathering in Manchester. This was enabled by a grant from The Big Lottery Fund, Awards for All England programme. As in 2014, it was a chance to learn, share and connect

with others who are in one way or another affected by FOP. Thank you to everyone who contributed by being there, asking questions, answering questions, and generously sharing insights and experiences.

Once again, FOP Friends was privileged to have some of the world's leading researchers and clinical experts in FOP join us at the conference. Families could book





clinical appointments from the Thursday through to the Sunday the event weekend. The Saturday opened with a talk from Professor Fred Kaplan and Dr Robert Pignolo from the University of Pennsylvania, who tackled "What is FOP? The science for non-scientists".



Delegates had the chance to ask questions, so that we could all start with a solid understanding of what it is we're dealing with. Professor Kaplan and Dr Pignolo were followed by their colleague, Professor Eileen Shore, who introduced the session on "How do we fix FOP?" by discussing the foundations for future treatments. This was expanded on by research scientists from Oxford and Harvard and representatives from the pharmaceutical industry.



There was then an update on the FOP Natural History Study and on the progress being made with the FOP Connection Registry. Dr Gehan Abou-Ameira - a paediatric dental consultant from Great Ormond Street hospital - rounded off the presentations talking about FOP and dental treatments, speaking to the adult delegates before



taking her tooth brushes down to the creche to talk to the children about looking after their teeth.

Later in the afternoon, there were three workshops that delegates could attend. The workshop themes were Genetic Counselling, Neuro Linguistic Programming and Meet the Scientists. A workshop leader facilitated discussions, giving delegates the opportunity to share their experiences, ask the scientists more detailed questions and push them on the plans for treatments, which led to some heated and informative debates between the different schools of thought.



More than 100 of the delegates attended the dinner on Saturday evening, where the karaoke music quiz let some real talents shine through!



## Impact and value

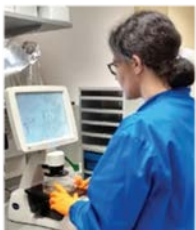
FOP Friends continues to benefit from the fantastic ongoing efforts of FOP families, friends and the wider public. The funding FOP Friends receives allows the search for a treatment and a cure for FOP to continue within the UK. The income generated has allowed the charity to continue its financing of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



FOP Friends continues to grow from strength to strength, capitalising 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.

The community can never be thanked enough, but hopefully this small selection of supporters, events, challenges and activities provides an idea of the backing FOP Friends receives. It may be a small community, but it makes a big difference.

### Hospital Saturday Fund



Following a successful grant application to the Hospital Saturday Fund, FOP Friends was able to help provide a new microscope for the SGC Oxford team. The *EVOS XL Core Imaging System* is used by the researchers daily, letting them examine and compare growth of cells containing the FOP mutation to that of unaffected cells.

### Manchester Money Raisers

A team of Manchester students chose a charity fundraising project as part of a Project Management skills module, raising over £1,500 in aid of FOP Friends. They also held a Charity Raffle Student Night at the end of the month with prizes including a delicious food hamper and tickets to Lords cricket ground.



### A Snippet of Joy

At the young age of 6, Olivia Gooding chose to have a sponsored haircut. She had 12 inches chopped off, with the proceeds being donated to FOP Friends. She donated the hair to the Little Princess Trust for making into wigs for children with alopecia or cancer.

### #FunFeet4FOP



This year it's 10 years since the discovery of the ACVR1 gene that causes FOP was announced on 23rd April 2006. Helen had the fantastic idea to mark this fact - along with International FOP Awareness Day - with a #FunFeet4FOP campaign (fast becoming recognised worldwide) on social media, asking people to share pictures of their feet to help raise awareness. 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.

## Isle of Wight Dance All Night

The L&M Band - a 60's R'n'B band - played at a charity gig on the Isle of Wight, organized by Margot Charlton for the third year in a row.

## Sporting Success

### Savills' Cyclists

In May, a team of 20 colleagues from Savills took on the Surrey Hills in the inaugural Savills 100km Charity Cycle. Together their combined pedal power brought in over



£4,900 which was shared between FOP Friends and Dreams Come True. Not content with just completing 100km, one team member, Bob Shattock, then cycled from Calais to Amsterdam in three days in mid-May, raising a further £2,675 for the two charities.

### Running

Jacqueline Stringer mastered the Mull Half Marathon, Sharon Moore conquered the Cardiff Half Marathon, Judith Gray glided through the Glasgow Half Marathon, whilst



Rebecca Deegan yielded a speedy time at the Yorkshire Marathon. Michael (Mick) Henry dominated the Dublin City Marathon, Nick Coogan laboured through the London Marathon, and Sara and Martyn Cassidy marched through the

Manchester Marathon. Simon Warner ran four races in four days for four charities! Paul Diamond and Jack Punter completed the Great South Run for FOP friends. Team Isla brought out their inner warrior during the Spartan race.

## Other Exciting Activities

Michelle Elmore completed the Fugitive Half Iron Distance Triathlon on the hottest day of the year! Natalie Wood freefell at 125 miles an hour during a 15,000ft skydive in Wiltshire. Supporters of FOP Friends took part in the West London Tough Mudder weekend on both days.



### Coast to Coast

The NERDOC (North East RD owners club) guys biked an amazing 270-mile round trip from one UK coast to another for the second year running!

### Annual Christmas Tree

FOP Friends installed their merry Christmas tree at the annual St Albans Church event, adorned with decorations made by the FOP children and their siblings at the Family Gathering in May.



### Drawing Attention



One of our lovely supporters went the extra mile by getting the FOP Friends logo tattooed on his arm!



## Future plans

FOP Friends plans to hold the third FOP Conference and Family Gathering in May 2018, continuing the biennial event started in 2014. The 2018 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.

A continued growth in staff is planned subject to the success of current staff. This continues the move towards a sustainable organisation whose day-to-day operation is not 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 and long-term strategies

### 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 additional and regular family gatherings across the UK to support and promote the community and provide respite for families
- To provide best advice and information to families, schools, clinicians, and others in understanding FOP and the challenges it poses

### Medical support

- To reach out to health professionals and professional bodies to create interest and awareness of FOP to help prevent misdiagnosis but also to increase the available support for those with FOP
- To help establish UK specialist centres for the care and treatment of FOP patients
- To strengthen the reliability of our information sources by acquiring the NHS Information Standard



## Governance and Structure

### Legal Status

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

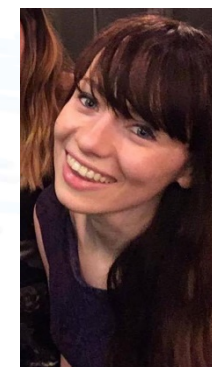
### Trustee recruitment and training

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

### Hannah Dempsey – Digital Administrator

Having worked for FOP Friends as a Marketing and Communications Intern for 8 weeks last summer, Hannah stayed with the charity, working one day a week throughout her final year at the University of Manchester. She continues her hard work, managing all of FOP Friends' social media streams, tracking engagement with the public and writing blog posts to ensure maximum impact.



## 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 7th August 2017 and signed on their behalf by



Chris Bedford-Gay.

Founding Trustee and Chairman



## Financial review

### Summary

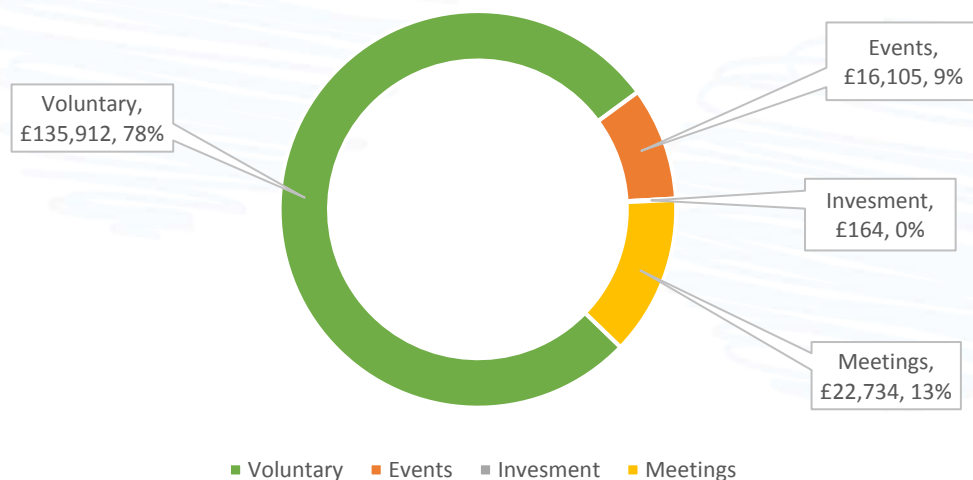
Gross incoming resources for the year amounted to £174,915 with £195,211 being carried forward to the next charity year. Of the amount being carried forward £125,000 is designated to fund future research with £15,000 designated to operating reserves.

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

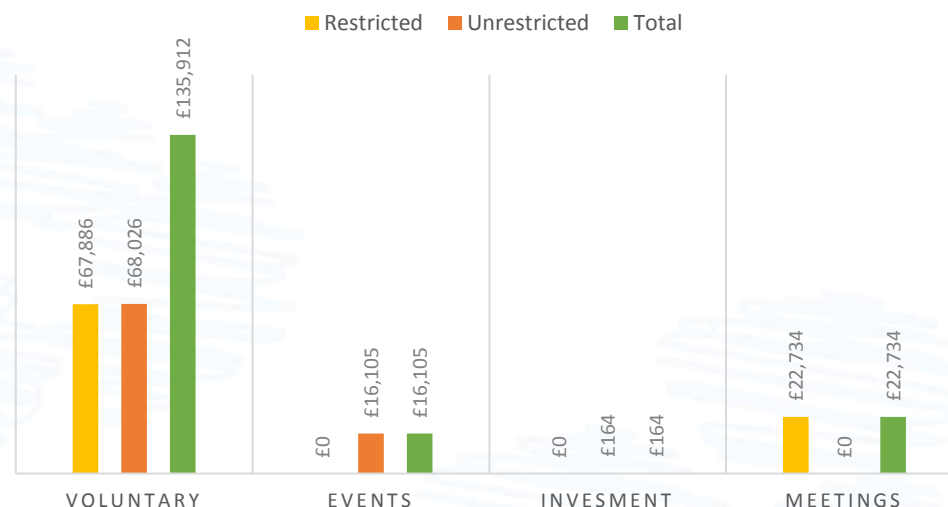
### Income

Income for the year totalled £174,915 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.

## INCOMING RESOURCES £174,915



## INCOMING RESOURCES £174,915



### Grants, trusts, and corporate sponsorship

The charity received £30,756 from grants and trusts, only a small decrease from the previous charity year.

### Charitable expenditure

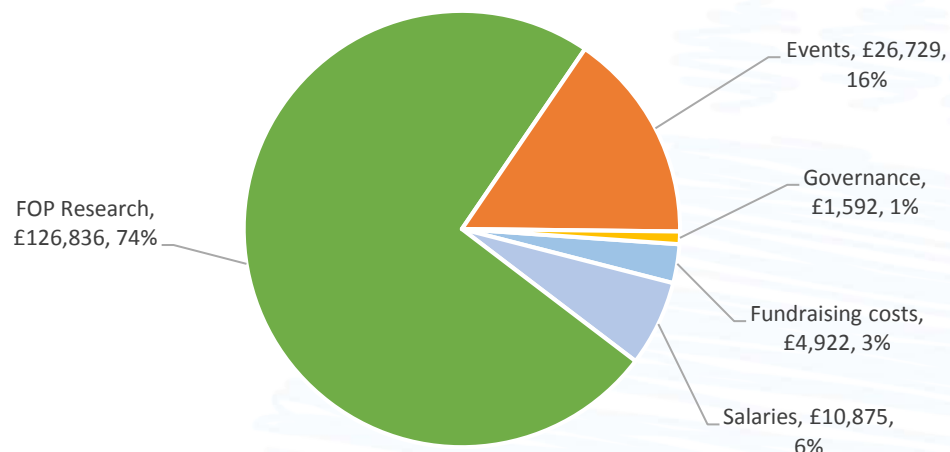
Through the charity year £126,836 was spent on funding FOP research.

Operating costs of £19,449 include costs associated with fundraising of £4,922 (t-shirts, Great North Run places, and support of fundraisers), staff salaries of £10,875, £1,593 in governance costs and £2,060 costs associated with projects.

Governance costs of £1,593 include accounting fees, insurance, postage, professional memberships and costs associated in employing staff.

£6,077 or a total £11,071 was spent on the first FOP Family Weekend. These costs entirely covered by a BBC Children in Need grant but cross a charity year.

## OUTGOING RESOURCES £173,015



### Gains and losses

Income from fundraising, voluntary donations and fundraising activities decreased by 19% from £187,193 to a total of £152,017.

### 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.

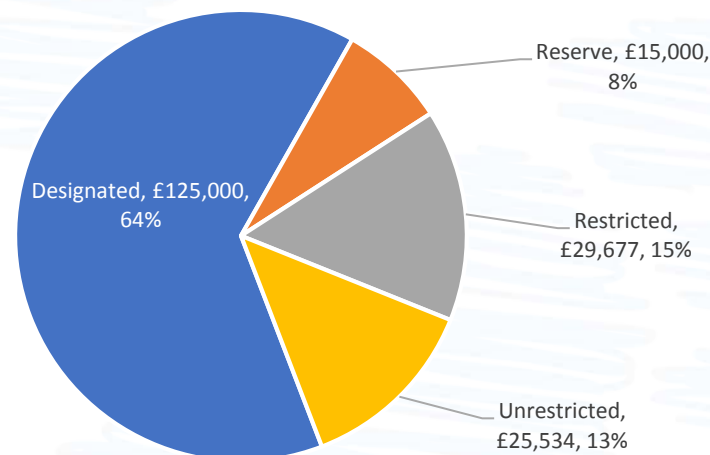
### Future commitments

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.

## Funds Carried Forward £195,211



### Restricted Funds

A total of £90,620 in funding received in this reporting year has been restricted towards research (£40,999 from international FOP organisations) and several projects including the “Be Safe at School” handbook, the FOP Friends ‘Together’ quarterly newsletter, and includes £11,663 in fees from the 2016 FOP Conference and Family Gathering and £11,071 in funding towards the FOP Family Weekend provide by BBC Children in Need.

### 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 28 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

In the course of my examination, no matter has come to my attention:

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

### Independent examiner

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

## Consolidated statement of financial activities

	Notes	Restricted	Unrestricted	2017 Total	2016 Total
<b>Incoming resources</b>					
<b>Incoming resources from generated funds</b>					
Voluntary income	2	£67,886.29	68026	£135,912	£16,9870
Activities for generating funds	3	-	16105	£16,105	£17,323
Investment income		-	£164	£164	£123
		-			
<b>Other incoming resources</b>	4	£22,734	-	£22,734	£21,110
<b>Total incoming resources</b>		<b><u>£90,620</u></b>	<b><u>£84,295</u></b>	<b><u>£174,915</u></b>	<b><u>£208,426</u></b>
<b>Resources expended</b>					
<b>Costs of generating funds</b>					
Fundraising costs	5	-	£4,922	£4,922	£4,100
Salaries	5	£10,875	-	£10,875	£7,000
Project costs	5	£2,060	-	£2,060	-
<b>Charitable activities</b>					
Research	6	£46,978	£79,858	£126,836	£60,000
Events	7	£26,729	-	£26,729	£3,000
Salaries		-	-	-	£8,167
<b>Governance costs</b>	8	-	£1,592	£1,592	£2,450
<b>Total resources expended</b>		<b><u>£86,642</u></b>	<b><u>£86,372</u></b>	<b><u>£173,014</u></b>	<b><u>£84,717</u></b>
<b>Net incoming/(outgoing) resources</b>		<b>£3,978</b>	<b>(£2,077)</b>	<b>£1,901</b>	<b>£123,709</b>
<b>Reconciliation of funds</b>					
Total funds brought forward		<b><u>£25,699</u></b>	<b><u>£167,611</u></b>	<b><u>£193,310</u></b>	<b><u>£69,601</u></b>
<b>Total funds carried forward</b>		<b><u>£29,677</u></b>	<b><u>£165,534</u></b>	<b><u>£195,211</u></b>	<b><u>£193,310</u></b>

The notes on pages 30 to 32 form an integral part of these financial statements.



## Balance sheet

	Notes	2017 £	£	2016 £	£
<b>Fixed assets</b>	9		312		555
<b>Current assets</b>					
Debtors	10	-		68	
Cash at bank		200,783		192,943	
		200,783		193,011	
<b>Creditors: amounts falling due within one year</b>	11	(5,884)		(256)	
<b>Net current liabilities</b>			194,899		192,755
<b>Net assets</b>		£	<b><u>195,211</u></b>	£	<b><u>193,310</u></b>
<b>Funds</b>					
Restricted	12		29,677		25,699
Designated	13		140,000		140,000
Unrestricted			25,534		27,611
		£	<b><u>195,211</u></b>	£	<b><u>193,310</u></b>

Approved by the trustees on 7<sup>th</sup> August 2017 and signed on their behalf by



Alison Acosta Bedford, Founding Trustee.

The notes on pages 30 to 32 form an integral part of these financial statements

## Notes to the financial statements

### 1. Accounting policies

#### *Basis of accounting*

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

#### *Fund accounting*

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

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

#### *Incoming resources*

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

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

Investment income is included when received.

#### *Resources expended*

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

#### *Costs of generating funds*

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

#### *Governance costs*

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

#### *Irrecoverable VAT*

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

### 2. Voluntary Income

	2017	2016
Donations	£105,156	£137,778
Grants	£30,756	£32,092
	<b><u>£135,912</u></b>	<b><u>£169,870</u></b>



### 3. Activities for generating funds

	2017	2016
Fundraising events	£16,105	£17,323
	<b><u>£16,105</u></b>	<b><u>£17,323</u></b>

### 4. Other incoming resources

	2017	2016
Conference fees	£11,663	£21,110
Family weekend (Centre Parcs)	£11,071	-
	<b><u>£22,734</u></b>	<b><u>£21,110</u></b>

### 5. Fundraising costs

	2017	2016
Salaries	£10,875	£15,167
Advertising & promotional items	-	£2,050
Entry fees	-	£2,050
Fundraising costs	£4,922	-
Project costs	£2,060	-
	<b><u>£17,857</u></b>	<b><u>£19,267</u></b>

### 6. Research

	2017	2016
Research payments	<b><u>£126,836</u></b>	<b><u>£60,000</u></b>

### 7. Events

	2017	2016
Conference meeting costs	£20,652	£3,000
Family weekend (Centre Parcs)	£6,077	-
	<b><u>£26,729</u></b>	<b><u>£3,000</u></b>

### 8. Governance

	2017	2016
Accountancy charges	£85	£296
Insurance	£329	£318
Subscriptions	£728	£241
Bank charges	£98	£20
Computer costs	£8	£133
Staff training	£50	£379
Recruitment costs	-	£275
Travelling expenses	-	£511
Depreciation	£294	£277
	<b><u>£1,592</u></b>	<b><u>£2,450</u></b>

### 9. Fixed assets

	Office equipment
Cost	£
At 2nd March 2015	£832
Additions	£51
Disposals	-
<b>At 1st March 2016</b>	<b><u>£883</u></b>
Depreciation	
At 2nd March 2015	£277
On disposals	-
Charge for year	£294
<b>At 1st March 2016</b>	<b><u>£571</u></b>
Net book value	
<b>At 1st March 2016</b>	<b><u>£312</u></b>

## 10. Debtors

	2017	2016
Gift Aid tax recoverable	-	-
Prepaid expenses	-	£68
	-	<b>£68</b>

## 11. Creditors

Amounts falling due within one year:

	2017	2016
HSBC mortgage	-	-
Trade creditors	£6,079	£22
PAYE and NI	(£164)	£144
VAT	(£121)	-
Accrued expenses	£90	£90
	<b>£5,884</b>	<b>£256</b>

## 12. Restricted funds

	Balance	Incoming	Resources	Balance
	b.fwd	resources	expended	c.fwd
Research	-	£5,979	(£5,979)	-
Conference fees	£18,916	£11,663	(£20,652)	£9,927
Family weekend (Centre Parcs)	-	£11,071	(£6,077)	£4,994
Support	£283	£14,738	(£10,875)	£4,146
Be Safe at School Handbook	£3,500	-	-	£3,500
FOP 'Together' Newsletter	£3,000	£6,170	(£2,060)	£7,110
FOP Organisation	-	£40,999	(£40,999)	-
	<b>£25,699</b>	<b>£90,620</b>	<b>(£86,642)</b>	<b>£29,677</b>

Research represents monies received to fund the University of Oxford FOP Research Team. Support represents grant monies received from Genetic Disorders UK to fund the employment of a Charity Support Assistant. Conference fees represents

donations and delegates deposits received in respect of the FOP Conference in May 2016. Be Safe at School Handbook 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. FOP 'Together' Newsletter represents grants awarded to fund the production of a quarterly print/online newsletter to inform the FOP community and support fundraising.

## 13. Designated funds

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

The Charity will sometimes raise funds to meet specific objectives but the donor chooses not to restrict 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 2017)

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

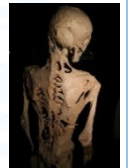
Clementia open first European trial site in Paris, which some of our UK FOP patients then took the opportunity to take part in. Everyone in the FOP community thank you for furthering the research.

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 honored 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.



Jake (7) and Amy (4) have the idea to sell some of their unwanted toys and raise £75 for FOP Friends.

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.

[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.

November 2015

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

clementia

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.

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.

January 2016

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.





FOP Friends approved for full membership of EURORDIS on 8<sup>th</sup> 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.

February 2016

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.

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.

March 2016

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 **#FunFeet4 FOP** 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. Oliver and Annelese's schools both join in to raise money as well as awareness.



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.



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.

October 2016

Chris attends the 2<sup>nd</sup> 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.





## Thank you to (March 2016 – March 2017)

FOP Friends would like to acknowledge our ever-growing supporters, a list that we hope will grow year on year.

### Trusts / Grants

- The Sobell Foundation
- The Astor Foundation
- The Hospital Saturday Fund
- The Manchester Guardian Society Charitable Trust
- Children in Need Small Grants
- The Roger Vere Foundation

### Corporate Supporters

- Avaya
- Roemex Ltd
- 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 and Associations

- Manchester Round Table
- Royal Northumberland Yacht Club
- St Alban's Church, Broadheath

### 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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