



friends[®] together



2016 Annual Report & Financial Statements

(Year ending 1st March 2016)

Charity number: #1147704

Our Vision

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

Our Mission

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

Our Values

- We are committed to funding medical research to realise a cure for FOP and related conditions; to understand how we can prevent it and improve the life and well-being of those who are afflicted by it.
- We respect the integrity, ambition and interests of all FOP Patients.
- We strive to be both a haven and champion for FOP patients and their families; a centre of excellence for the provision of information on medical research, diagnosis, treatment and care, and participation in clinical trials.
- We shall act always with honesty, professionalism and ethical awareness.
- We shall work collaboratively with medical researchers and clinicians, patients and families, our donors and supporters to realise our Vision and complete our Mission.

Charity name

FOP Friends

Working Names

FOP Friends of Oliver, FOP Action

Registered address

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

Registered

March 2012

Charity number

1147704

Governed by

Trust Deed

Trustees

Christopher Bedford-Gay

(founding trustee)

Alison Acosta Bedford

(founding trustee)

Rachel Almeida

(founding trustee)

Fiona White

John Lever

Helen Bedford-Gay

Nicky Williams

Bankers

HSBC

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 began researching the condition to find that FOP was such a rare disease that there was no charity in the UK dedicated to raising money for research into treatments and hopefully a cure.



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

Since then we have continued to grow our support both locally, nationally and internationally. Now entering our fifth year, we have had success in grant and trust fundraising as well as increased fundraising from new FOP families, friends and the public. We continue to go from strength to strength and have even been chosen as "charity for the year" by several high-profile organisations.

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

It has taken hard work and time to get this far and it will take even more to make our vision a reality. With all your continued support, we will get there, and we will change the lives for not only Oliver but also the many other FOP families present and future.

I would also like to extend my personal thanks to all our supporters who continue to fund our work (through events, sponsorship or direct donations), and to the volunteers who continue to help us. Without your tireless campaigning, fundraising and support we could not keep searching for a cure. You keep hope alive for all touched by this terrible condition, now or in the future.

A handwritten signature in black ink, appearing to read "Chris Gay". The signature is fluid and cursive, with a large, stylized 'C' and 'G'.

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 (7) with FOP at the age of 1. The aim of the charity is to support the search for a cure while raising awareness and educating the public and medical world of the condition. FOP Friends supports existing patient organisations; existing research programmes such as at the University of Oxford; promotes FOP research worldwide; and helps other families impacted by FOP.

Each year the trustees vote on research or other projects to support with monies raised. To date, this has been targeted at maintaining (and growing) the University of Oxford's FOP Research Team.

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



Trustees

There must be at least three trustees. Except for the first trustees, trustees are appointed for a term of 2 years by a resolution of the trustees passed at a special meeting called under clause 15 of the Trust Deed. Selection of new trustees must have regard to the skills, knowledge and experience needed for the effective operation of the charity.

Christopher Bedford-Gay - Founding Trustee and Chairman

Since 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 held for 5 year 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

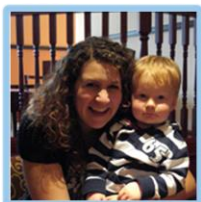
- 1st Class BSc Honours Degree, Computing for Business

Experience

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

Chris is also chairman of Manchester Round Table, a charitable organisation that provides volunteer and financial support to many local charities.

Alison Acosta Bedford - Founding 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 as well as personal relationships to raise awareness and funds for research into finding a cure for this terrible condition.

Education

- BSc Honours Degree, Mathematics, University of Sheffield

- CGMA Chartered Institute of Management Accountants.

Experience

- Over 10 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 first family symposium held in May 2014, which highlighted how important they have become to the FOP community.

Rachel Almeida – Founding Trustee

Rachel is Director of Events for the Association of Colleges, organising education-related conferences. She has worked in events for over 14 years and is pleased to be able to put her experience and expertise to good use. In 2014, Rachel completed her first ever run in aid of FOP Friends, completing the Great North Run half marathon in under 2hr 20 minutes.



Education

- BSc Honours Degree, German and Law, University of Surrey

Experience

- International trade shows
- International economic research charity dissemination conferences
- Director of Events (current) – leading a team to deliver 40 education conferences per year with direct responsibility for a £2.5m annual turnover

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 an advanced skills 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 and has grown to

understand just how important it is to raise awareness of the condition 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 the charities 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 Lever - Trustee

When John heard about Oliver and others with FOP, he wanted to do what he could to help. As a first step, he produced a video through his creative company, claritycomms.com, engaging Stephen Fry to provide the voice over and to subsequently tweet to his millions of followers. John is now enjoying exploring some exciting 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



Although only recently a 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 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. Dunelm

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 is the latest Trustee to join FOP Friends and 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 our objectives and planning our activities, the Trustees have considered the Charity Commission's general guidance on public benefit.

Our principal objects

The relief of distress and sickness for those affected by Fibrodysplasia Ossificans Progressiva (FOP) a tragic, degenerative and debilitating condition and to improve the lives of sufferers and their families.

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

To raise public awareness and understanding of Fibrodysplasia Ossificans Progressiva (FOP) and to promote education and research into the study and cure of FOP and related conditions.

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

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

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

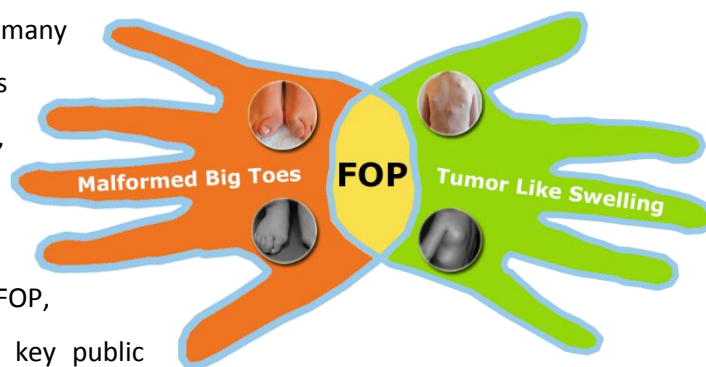
To support organisations researching treatments and a cure for FOP and related conditions.

Public Benefit: Research into a treatment, and eventually a cure, for FOP will benefit all existing 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 wrong information and interventions, resulting in a more rapid progression of the condition and unnecessary surgery and treatments.

As children will continue to be born with FOP, preventing misdiagnosis is one of FOP Friends' key public benefits and achieved through our previously stated aims of awareness, education and advocacy.



Research Highlights

University of Oxford

Scientific Conferences



The Oxford FOP Research team has been in frequent contact with FOP researchers across the world to discuss recent findings and improve understanding of FOP. In February 2016 Dr Ellie Williams also attended the Birmingham Rare Disease Paediatrics Conference on behalf of FOP Friends as well as attending the first meeting of "Associazione Noi ci Siamo" in Switzerland.

The team has also worked collaboratively with research teams across the world including at the University of Harvard and as members of the EU FOP Consortium. They continue to collaborate with pharmaceutical companies looking at developing potential treatments for FOP.

More recently they have partnered with Cancer Research considering a rare form of childhood brain cancer (DIPG) that shares one of the its genetic mutations with FOP (R206H).

Potential FOP Treatment Discovery

The team in Oxford have been taking lessons from the decades of cancer research. Just like the bone in FOP, many tumours grow because of excessive growth factor signals that are sent from mutated receptors found on cancer cells. Pharmaceutical companies have developed many drug molecules that bind to the mouths of these receptors to block their messages. The team in Oxford searched through libraries of these drug molecules to see if any of them could also bind to the mouth of the FOP receptor. Excitingly, they discovered that one of these clinical molecules bound well and was effective in stopping the FOP signals too. This compound has advanced to late stage clinical trials for various human cancers. Encouragingly, it meets all the criteria the team have been striving to achieve: it is potent, selective, stable and safe to use.

Following the discovery of the drug candidate, the team performed several additional experiments to validate the suitability of the compound for clinical trials in FOP. This has included collaborating with a colleague Dr Yu in Boston to test the compound in FOP mice. After a nervous wait, the team were delighted to hear that the compound had successfully prevented the mice from developing the bone lesions typical of FOP. A hopeful and incredible discovery! The team are now preparing grant applications to request funding to support a clinical trial in FOP patients late next year. Note, this is a different research path to the one being trialled by Clementia who are using an experimental drug called palovarotene that acts elsewhere to prevent the biological path of building cartilage and bone. The Oxford FOP Research team has been in frequent contact with FOP researchers across the world to discuss recent findings and improve understanding of FOP.

FOP Friends UK Conference and Family Gathering

Oxford Team to attend FOP Friends UK Conference and Family Gathering taking place in Manchester during May 2016.

Clementia Pharmaceuticals

Clementia started phase II clinical trials in both the US and Europe to test Palovarotene as a treatment for FOP. Research has shown that the Palovarotene compound blocks the formation of bone in mouse models of FOP and research into its effect on humans is not yet known. Palovarotene is a retinoic acid receptor gamma (RAR γ) agonist which has already been tested in animals and in humans as a possible treatment for emphysema. This trial investigates the effect (if any) of Palovarotene on excess bone growth in FOP patients. Additionally, the trial should provide information into optimal drug dose and possible side effects of Palovarotene in FOP patients.

Great progress has been made with the Clementia phase II clinical trial during 2015/16, including the expansion of the study to enrol children affected by FOP at a clinical site in the UK and in Paris.

Regeneron

A new research finding announced by the pharmaceutical company Regeneron in September 2015 could potentially lead to a novel approach for treatment of FOP.

FOP is caused by a genetic mutation which makes a faulty ACVR1 protein, a receptor that regulates bone growth. Regeneron's findings show that this mutated receptor has abnormal activity in the presence of Activin-A, a growth factor which is often released in response to inflammation and injury. Activin-A normally blocks the receptor, preventing bone growth. However, Regeneron report that Activin-A has an opposite effect on the mutated receptor, triggering excess bone growth, suggesting its role in FOP.

This finding helps scientists understand why FOP bone formation is often linked closely to an injury and/or tissue swelling. An antibody that blocks Activin-A was tested in mice which are genetically modified to develop FOP, and this treatment helped prevent the growth of excess bone in these mouse models. There is still a lot to learn before human trials for such treatments can be considered but this discovery has certainly raised hope for an alternative treatment approach.

This discovery has generated so much excitement and attention in the media that FOP was trending on Facebook soon after it was announced!

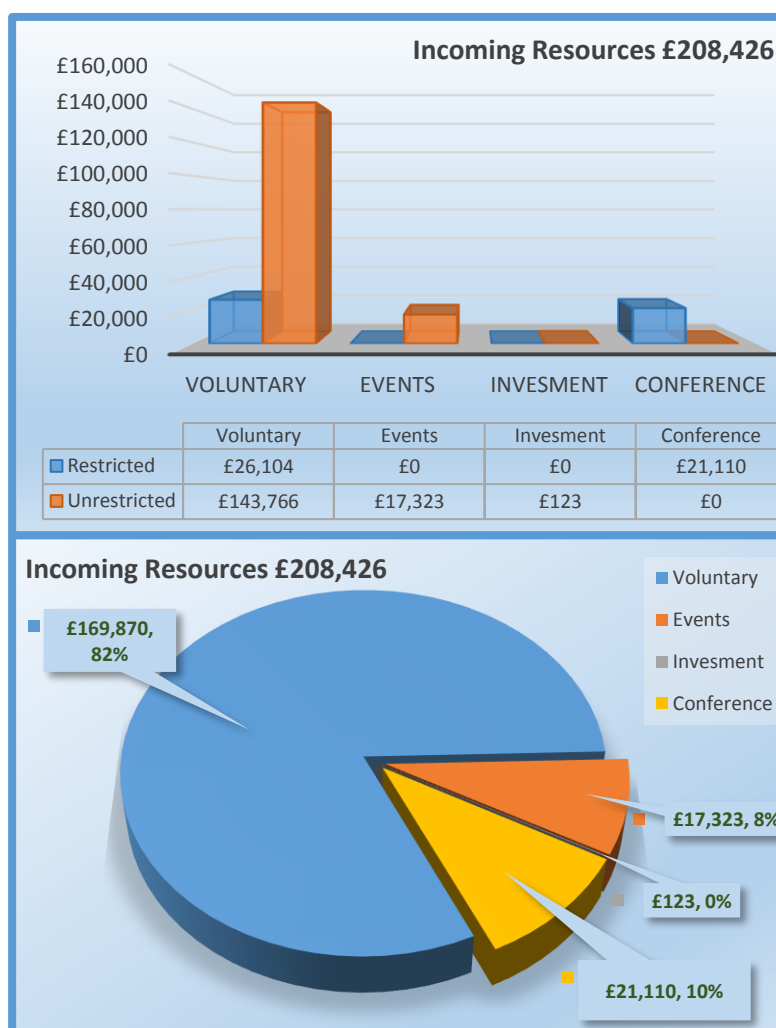
How we raised our money

Voluntary income accounts for the bulk of money raised within the charities financial year. A small amount is attributed to investment income (interest on bank balances) and £17,323 revenue from fundraising events.

In addition, revenue of £21,110 is attributed to fees associated with the upcoming 2016 FOP Friends UK Conference and Family Gathering.

From a total £208,426 incoming resources £47,214 (23%) were restricted to projects or events with £161,212 (77%) unrestricted.

Restricted funding represents a significant increase in successful grants and trust applications.

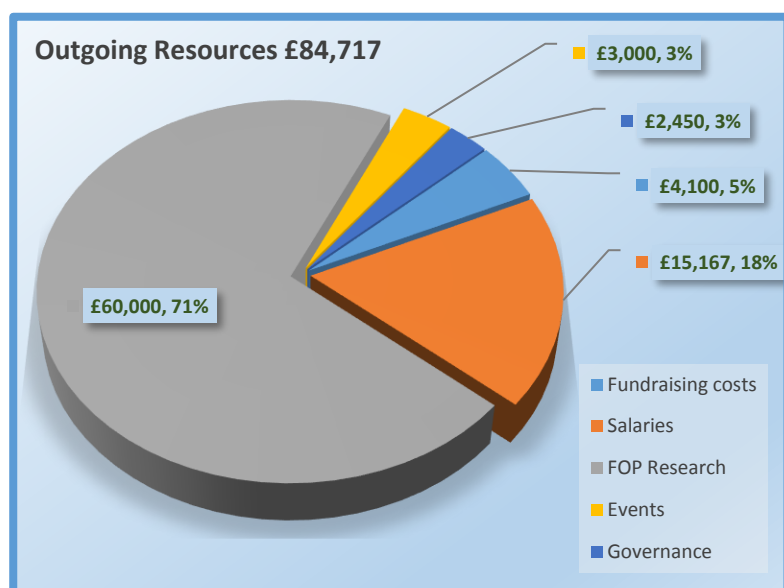


How we spent money raised

The charity maintains minimal overheads, which means a large proportion of fundraised money supports research into finding a cure for this devastating condition and supporting FOP families. Since employing our first part-time staff our governance costs have increased however costs associated with staff salaries have to date been paid thanks to restricted grants and corporate support.

Within this charity year we were also able to use a Genetic Disorders UK grant awarded to fund FOP Friends first paid staff with the team going from solely volunteers to a having a Fundraising and Medical Liaison Officer and a Grants and Trusts Manager.

As a small charity, FOP Friends' trustees carry out the organisations activities, promotions, administration and task involved in the day-to-day running of a charity donating their time, energy and enthusiasm for no financial reward. Friends and kind volunteers support the charity and through this help support FOP families and ongoing research through fundraising activities throughout each year.

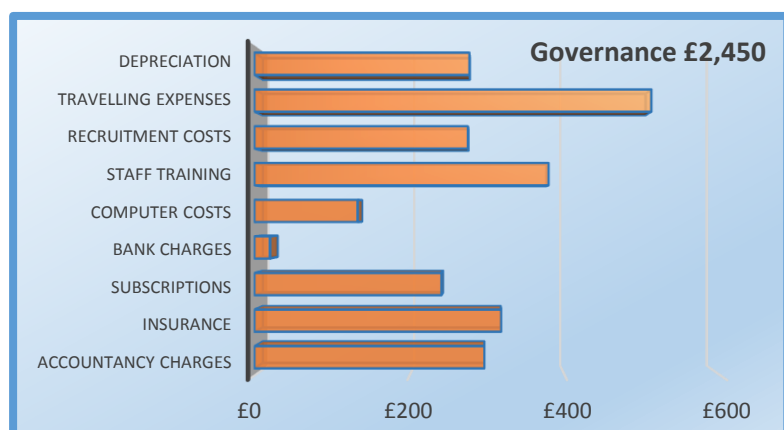


The main beneficiary of FOP Friends is presently the FOP Research team at the University of Oxford. Led by Dr Alex Bullock and Professor James Triffitt, The University of Oxford is one of a small number of institutions in the world conducting research into a cure for FOP.

On the 29th February 2016, FOP Friends donated £60,000 to the University of Oxford FOP Research team. Which

together with donations from FOP France and Associazione Noi Si Amo funded the team for a further year. £3,000 was outlaid as deposit for the FOP Friends UK Conference and Family Gathering being held in May 2016. A cost covered by grants, corporate sponsorship, and delegate fees.

Fundraising costs increased to £4,100 which included securing 25 x 2016 Great North Run places, provision of fundraising materials and merchandise such a running t-shirts, leaflets and information packs. The investment in staff of £15,167 was financed through the GDUK grant awarded in the previous charity year. Investment in staff at the time of writing generated £5,988 in research funds and £26,104 in project funding totalling £32,092 in additional revenue.



Governance costs increased to £2,450 which includes basic operating costs such as accounting fees, insurance, postage, professional memberships, and costs associated with recruiting, training and supporting our first staff members.

Achievements

During the year, we were successful in several areas most notably with increasing friends, family and public fundraising and through corporate sponsorship with FOP Friends regularly picked as “Charity of the Year”.

We have also been successful in growing awareness of FOP and taking fundraising efforts beyond FOP families and their immediate friends and family. This is critical to the growth and sustainability of the charity and the continued search for a cure. It would not, however, be possible without the continued support of other FOP Families.

Major achievements include continuing to support the FOP research teams and their efforts; securing our first charity employees; being involved in international FOP progress and further raising awareness of FOP.

Providing funding to Oxford FOP Research

Year on year since becoming a registered charity FOP Friends and its supporters have



successfully funded the FOP Research Team at the University of Oxford. This has been achieved in collaboration with FOP France and Associazione Noi ci Siamo, the Swiss FOP association who have also contributed to the Oxford Research Fund via FOP Friends.



FOP Friends first employees

In August 2015, thanks to the support of Genetic Disorders UK, and other minor grants, FOP Friends employed a Grants and Trust Manager and a Fundraising and Medical Liaison Officer. Their combined skills have helped the charity grow; increasing revenue from Trusts and Foundations and developing exciting new projects which will benefit the FOP Community. Until now the charity has been run solely by the charity trustees on a volunteer basis and we hope the addition of our first employees will help us meet our annual fundraising targets and reduce some of the trustees' workload.

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 and shares challenges faced by FOP families the world over.

The Natural History of Flare-Ups in Fibrodysplasia Ossificans Progressiva

The Natural History of Flare-Ups in Fibrodysplasia Ossificans Progressiva was published in the Journal of Bone and Medical Research, November 2015. This is the first comprehensive global assessment of FOP flare ups and is an extremely valuable resource for the design of future clinical trials. FOP Friends' Chris Bedford-Gay is credited as one of the contributors.

The FOP Connection Registry

The FOP Connection patient registry is an exciting initiative developed by the International Fibrodysplasia Ossificans Progressiva Association (IFOPA) to help understand and learn more about FOP. Patient registries are essential in rare disease research and drug development. Not only will the registry help increase knowledge of FOP, aid research and help guide clinical trial design but it will critically show pharmaceutical companies that FOP patients are pro-active in the search for a cure.

The aim is to get as many of the FOP patient community world-wide registered as possible. The FOP Friends charity continues to assist the IFOPA with this effort, by raising awareness of the registry with the UK FOP community.

EURORDIS

FOP Friends became a full member of Eurordis, the European Rare Disease Organisation. EURORDIS is a non-governmental patient-driven alliance of patient organisations and individuals active in the field of rare diseases, dedicated to improving the quality of life of all people living with rare diseases in Europe.



EURORDIS
Rare Diseases Europe

EURORDIS seeks to improve the quality of life of people living with rare diseases in Europe 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.

FRSB

FOP Friends maintains its voluntary registration with the Fund Raising Standards Board (FRSB). The FRSB is the independent self-regulatory body for UK fundraising. The FRSB works with member charities, suppliers and the wider charity sector to encourage commitment to and compliance with best practices in fundraising. Later in 2016 the role of the FRSB is moving to the UK Charity Regulator and FOP Friends will at that time move to full members of the UK Charity Regulator to maintain best practice in fundraising.



Social media activity

The power of social media today is massive and the more we can spread the word about FOP, the more awareness we can raise and hopefully prevent any devastating misdiagnoses whilst also raising funds to support the research. We thank you to everyone who has helped with our campaigns. FOP Friends continues to grow its network of supporters on social media, and we are especially proactive on Facebook and Twitter. Our Facebook page has exceeded 1500 likes and our Twitter followers are ever increasing with multiple posts re-tweeted. LinkedIn continues to grow FOP awareness within the corporate community and Google+ although being used minimally at present is setup and in operation. We use social media to post news on recent research discoveries and upcoming clinical trials, promote activities of our fundraisers and make and maintain contact with companies and people that support us; 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.

Raising awareness of the medical implications of FOP within medical communities and with the public is an important role for FOP Friends, with the aim to improve recognition of FOP symptoms and facilitating diagnosis. On Saturday, 17th October 2015, BBC’s Casualty included an FOP storyline, reaching an impressive 5.79 million UK viewers. FOP Friends were contacted by the BBC before production of this episode and



although we had no direct input on the production, we could answer the BBC’s questions and advise on the condition. We made the most of this opportunity by promoting the episode on Social Media and were delighted when celebrity Stephen Fry retweeted a Twitter post; one Stephen Fry retweet resulted in 65 retweets!

Members of the FOP community have done some amazing awareness raising of their own by sharing their stories in the media. FOP has featured in national newspapers and even on ITV’s ‘Emergency Room’ programme with Jeremy Kyle.

Attendance at Conferences and meetings



In March 2015, Chris was honoured to attend the first UK Genetic Disorders Leadership Symposium in London. This month, Chris also visited Rome for the FOP Italia Conference where twelve countries came together to update on the search for treatments for FOP.

In June 2015, Chris flew to Boston for the first FOP Strategic Planning meeting. He then visited the FOP research team and laboratory at Harvard University, who are collaborating with Oxford to find a treatment. Next, Chris visited Blueprint Pharmaceuticals and Regeneron Pharmaceuticals in New York to learn of their progress in drug development. The final stop was a visit to the FOP laboratory at the University of Pennsylvania.



In November 2015, the FOP Friends Team travelled to Oxford for the day to visit the dedicated FOP research team. Dr Alex Bullock and Professor Jim Triffitt presented their most recent research findings and plans. As new members of the FOP Friends team, our Grants and Trusts Manager and Fundraising and Medical Liaison Officer especially enjoyed the opportunity to look around the research laboratory, with Dr Ellie

Williams and Dr Georgina Kerr on hand to answer their many questions.

Later in November, Chris was pleased to attend the Dutch FOP Symposium in Amsterdam.

February 2016 was another busy month for Chris as he travelled to Florida for his annual in-person board meeting as Chairman of the International President's Council for the IFOPA. Later in February, Chris was honoured to attend the prestigious Eurordis Awards and Black Pearl in Brussels, along with many FOP leaders from around the world.



Impact and value

As we grow, FOP Friends continues to benefit from the fantastic, ongoing support 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 support received has allowed the charity to continue its support of the University of Oxford FOP Research team as well as providing increasing support for families touched by FOP.



The charity continues to grow from strength to strength, capitalising on its charitable status with further success with grants, trusts, and corporate support. 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 support 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 can never thank our supporters enough but hopefully this small selection of supporters, events, challenges and activities provides an idea of the support FOP Friends receives. We may be a small community but we make a big difference.

PwC

PwC Manchester presented a cheque of £20,800 to FOP Friends in November 2015 following a year of fundraising for FOP Friends as their chosen charity. As part of PwC's amazing fundraising effort, members of the Financial Services Assurance team rode a challenging 170-mile coast to coast route, from Morcambe to Bridlington over three days. The total raised by PwC was more than £30,000.



Avaya UK

Avaya UK chose FOP Friends as their Charity of the Year and raised an astonishing amount, including winning \$10,000 in Avaya's Month of Giving prize. In July, 2015, Avaya also held an 8km charity walk in the Surrey Hills in aid of FOP Friends, raising a further £10,151.25!



PushOn

We were delighted to be selected as PushOn's Charity of the Year and enjoyed following their creative fundraising activities throughout the year. One member of the team ran the Bupa Electric Run – the world's brightest 5k, whilst other members of the team took to their bikes riding all the way from Manchester to Blackpool! The PushOn team were also very busy raising money and awareness on Social Media over



Christmas with a 'build a gingerbread house' challenge and Christmas jumper day.

Swap for FOP

Friends of Isla came up with a new fundraising initiative where communities get together, bringing their unused and outgrown items with them, and swapping



for a more desirable item for a donation. The first event was a great success and more have been held since...
Festive Swap for FOP?

Bingo night

FOP Friends held their fourth Bingo event in September, this time at a bigger venue due to increasing demand for tickets. We had some fantastic prizes donated from local businesses and a great evening was had by all!



Autumn Fair

In November 2015, FOP Friends held their second Autumn Fair at St. Alban's Church Hall, Broadheath. There was fun for all the family with face painting, a fine selection of cakes and refreshments, tombola, games for the children and stalls where you were sure to find a bargain!

Close shave

One man was brave enough to grow a moustache throughout the month of November and collected sponsorship in aid of FOP Friends.

Channel Swim

In November, a team of young swimmers (including Oliver and his younger brother), made a splash at their local Leisure Centre by swimming the distance of the channel in a relay. The children had a fantastic time – many exceeding expectations and swimming much further than asked of them. The children were even more excited when CBBC presenter Katie Thistleton came to show her support.



We were also delighted to have a supporter organise a Channel Swim fundraiser in Azerbaijan. Anoushka and friends from the Baku Sharks swimmers, aged 11 to 16 set out to swim the equivalent of the English Channel in two weeks. Each group collectively swam 32km and friends and family pledged money for their hard work.

Fitness retro 80's weekend

A group of ladies in Sale got creative and luminous, holding a retro 80s fitness weekend in aid of FOP Friends and one other charity. Together they raised their heart rates and a much appreciated £580.



Coast to Coast

A group of friends rode from Easington Village to Whitehaven and back on small 50cc motorbikes – an amazing 270 mile round-trip.

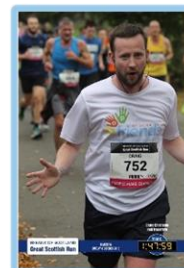


Running feats

Our supporters have been signing up for running challenges across the UK whilst raising money and much needed awareness for FOP. Craig ran the Great Scottish Marathon in aid of FOP and was rewarded for his efforts by having a photo taken with non-other than Paula Radcliffe! Also in Scotland,



James took on the Glencoe Marathon. While in the South, Robin and Emma completed the Ealing Half Marathon. Brothers Adam and Alex were flying the FOP Friends flag in Wales at the Cardiff Marathon, and Dawn in Ireland for the Dublin Marathon.



Some of our supporters even ventured beyond the UK; Mark completed an Ultramarathon challenge - a 53km off-road mountain running race in the Alps, France, while Charlotte travelled all the way to the US for the New York Marathon!

Great North Run

We were lucky enough to have a team of runners sporting the distinctive white running t-shirts and taking on the world's biggest half marathon in aid of FOP Friends. We were once again blown away by the commitment of those on the FOP Friends Team who between them raised over £13,000.



Future plans

FOP Friends plan to hold another UK FOP Conference and Family Gathering in 2016 with a strong focus on providing advice and support for all FOP families when dealing with care, schooling and support. This being in addition to research updates and offering families the opportunity to have clinical appointments with the world FOP experts.

We also plan to increase our support of families in addition to continuing to fund FOP research.

Ambition and long term strategies

- To grow the charity to make the annual fundraising target of £125,000 more easily achievable and to be in a strong position to increase this target soon
- To increase public awareness and expand the fundraising activities beyond friends and family
- To reduce misdiagnosis and to help ensure there are more UK-based FOP experts and centres where treatment and possibly future clinical trials can take place
- To continue our involvement with the FOP community worldwide and help advance FOP research and awareness internationally
- To increase support given to FOP Families.
- To maximise grant income through clearly defined projects
- To ensure regular communications are sent to the community and further afield to keep everyone abreast of work the charity undertakes, progress with research and to thank those who fundraise for us

Preventing misdiagnosis

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

Fundraising

- To continue to grow fundraising efforts, helping and encouraging more FOP families to become actively involved
- Through increased public awareness to expand fundraising activities beyond friends and family to become a charity of choice for the public to support
- To sustain and maximise trusts and grant funding to continue the financial support for research
- To secure and sustain grant funding to enable the charity to support employees on a long-term basis
- To develop a Fundraising Pack to help those interested in fundraising to support the charity
- To secure funding to cover core costs and reduce attendee costs for future UK FOP conferences
- To actively seek corporate sponsorship as “charity of the year”
- To create alternative fundraising campaigns to diversify income streams
- To seek high-profile patrons to both, increase awareness and actively encourage and support fundraising.

Family support

- To continue to provide support and advice to existing and recently diagnosed FOP families
- To organise and deliver additional and regular family gatherings across the UK to support and promote the community and provide respite for families

- To provide best advice and information to families, schools, clinicians, and others in understanding FOP and the challenges it poses

Medical support

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

Governance and Structure

Legal Status

FOP Friends is a charitable trust registered with the Charities Commission in England and Wales, #1147704. It was founded in March 2012 and is governed by its “Trust Deed”. The trustees are responsible for the management and administration of the charity. The trustees give their time freely and receive no remuneration or other financial benefits.

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

Following a thorough and robust recruitment exercise, including interviews and skills and personality tests, FOP Friends recruited its first employees, a Grants and Trusts Manager and a Fundraising and Medical Liaison Officer.

David Pilkington, a very experienced project and fundraising specialist, took up the post as Grants and Trusts Manager. His notable successes include a grant from the Big Lottery Fund which has enabled us to subsidise places for FOP patients and their families to attend the upcoming Conference and Family Gathering in May 2016. Unfortunately, due to ill health, David left the charity later in 2016. We were extremely sad to see him go but are very appreciative of all his hard work.

Mari Wynn-Jones, a Genetics graduate joined the team as Fundraising and Medical Liaison Officer. With her background, she has been able to get a firm grasp on the scientific and medical aspects of FOP and translate that into understandable information for patients and family members. She took on the fundraising support role ensuring all our supporters had the information they needed to assist with their efforts as well as promoted the charity on the website and through social media. Mari also worked alongside David on



Grants and Trusts proposals and on David's departure, she took on this additional work. Mari will be presenting at the upcoming conference on the work of the charity so that our families and supporters can clearly see the work we do and the impact their fundraising has on it.

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 the charity 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 the charity and enable them to ensure that the financial statements comply with the Charities Act 2011, the Charity (Accounts and Reports) Regulations 2008 and the provisions of the trust deed. They are also responsible for safeguarding the assets of the charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

The trustees for the purposes of charity law who served during the year and up to the date of this report are set out on page 2. The trustees are responsible for the maintenance and integrity of the charity and financial information included on the charity's website. This report was approved by the trustees on 13th December 2016 and signed on their behalf by



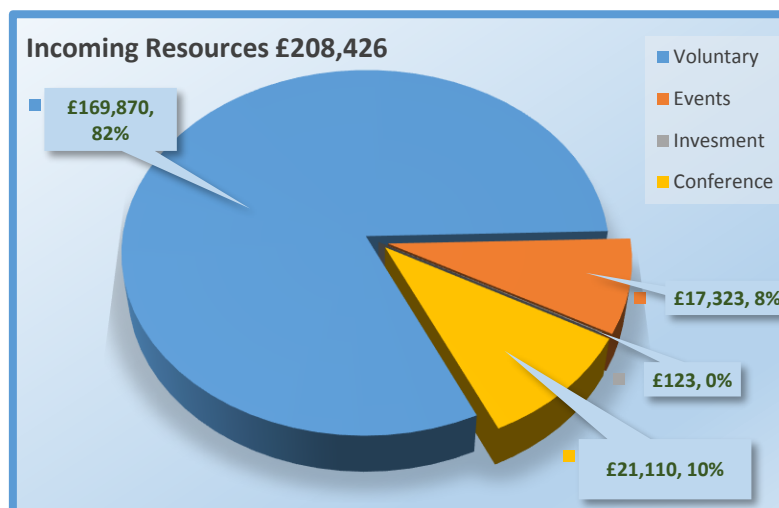
Chris Bedford-Gay.

Founding Trustee and Chairman

Financial review

Summary

Gross incoming resources for the year amounted to £208,426 with £193,310 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 £208,426 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.

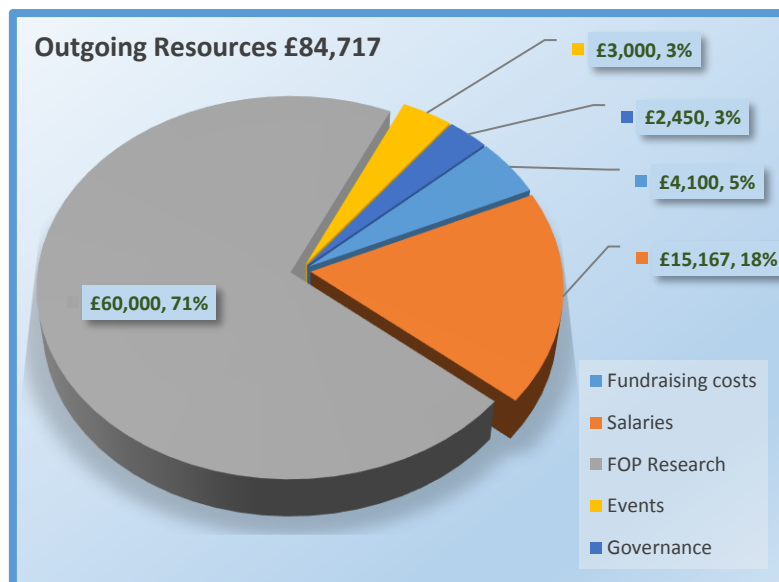
Grants, trusts, and corporate sponsorship

The charity received £32,092 from grants and trusts a 642% increase on the previous charity year.

Charitable expenditure

On the 29th February 2016, a disbursement of £60,000 was made to the University of Oxford FOP Research fund. This provided ongoing funding to the University of Oxford FOP Research Team.

Operating costs of £19,167 include costs associated with fundraising of £4,100 (t-shirts, Great North Run places, and support of fundraisers), staff salaries of £15,167 and £2,450 in governance costs.



Governance costs of £2,450 include accounting fees, insurance, postage, professional memberships and costs associated in employing staff.

£3,000 was the venue deposit for the 2016 UK FOP Conference and Family Gathering. This cost will be covered by grants, corporate sponsorships and delegate fees.

Gains and losses

Income from fundraising and voluntary donations rose by 32% from £126,862 to a total of £187,193.

Policy on reserves

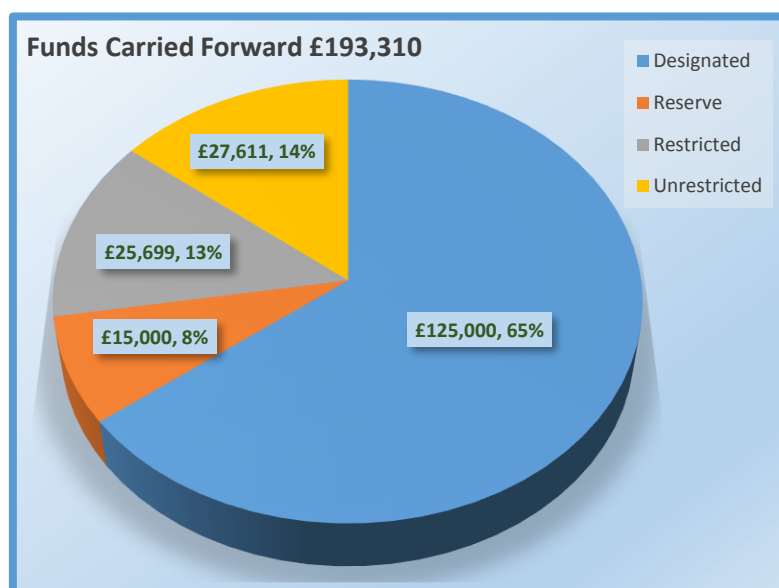
The Trustees have reviewed the reserves of the charity. Our aim is to maintain reserves in unrestricted funds at a level of £15,000 to cover operational costs and unforeseen expenditure.

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 decided 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 are also recognised as future financial commitments being funded through restricted grants and trust awards.

Restricted Funds

A total of £47,214 in funding received in this reporting year has been restricted towards several projects including the “Be Safe at School” handbook and the FOP Friends ‘Together’ quarterly newsletter, and includes £21,110 in fees towards the 2016 FOP Conference and Family Gathering.

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 2016 which are set out on pages 32 to 38.

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

Respective responsibilities of the trustees and examiner

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

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

Basis of independent examiner's report

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

Independent examiner's statement

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

1. which gives me reasonable cause to believe that, in any material respect, the requirements:
 - a. to keep accounting records in accordance with section 130 of the Act; and
 - b. to prepare accounts which accord with the accounting records and comply with the accounting requirements of the Act; have not been met; or

2. to which, in my opinion, attention should be drawn in order to enable a proper understanding of the accounts to be reached.

Independent examiner

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

Consolidated statement of financial activities

| | Notes | Restricted £ | Unrestricted £ | Totals 2016 £ | 2015 £ |
|------------------------------------------------|-------|-----------------|-------------------|---------------------|----------------|
| Incoming resources | | | | | |
| Incoming resources from generated funds | | | | | |
| Voluntary income | 2 | 26,104 | 143,766 | 169,870 | 107,484 |
| Activities for generating funds | 3 | - | 17,323 | 17,323 | 19,378 |
| Investment income | | - | 123 | 123 | 32 |
| Other incoming resources | 4 | 21,110 | - | 21,110 | 5,066 |
| Total incoming resources | | <u>47,214</u> | <u>161,212</u> | <u>208,426</u> | <u>131,960</u> |
| Resources expended | | | | | |
| Costs of generating funds | | | | | |
| Fundraising costs | 5 | - | 4,100 | 4,100 | 2,809 |
| Salaries | | 7,000 | - | 7,000 | - |
| Charitable activities | | | | | |
| Research | 6 | 8,604 | 51,396 | 60,000 | 135,000 |
| Events | 7 | 3,000 | - | 3,000 | 14,263 |
| Salaries | | 8,167 | - | 8,167 | - |
| Governance costs | 8 | 275 | 2,175 | 2,450 | 566 |
| Total resources expended | | <u>27,046</u> | <u>57,671</u> | <u>84,717</u> | <u>152,638</u> |
| Net incoming/(outgoing) resources | | 20,168 | 103,541 | 123,709 | (20,678) |
| Reconciliation of funds | | | | | |
| Total funds brought forward | | <u>5,531</u> | <u>64,070</u> | <u>69,601</u> | <u>90,279</u> |
| Total funds carried forward | | <u>25,699</u> | <u>167,611</u> | <u>193,310</u> | <u>69,601</u> |

The notes on pages 34 to 36 form an integral part of these financial statements

Balance sheet

| | Notes | 2016 | | 2015 | |
|-------------------------------------------------------|-----------|----------------|-----------------------|---------------|----------------------|
| | | £ | £ | £ | £ |
| Fixed assets | 9 | | 555 | | - |
| Current assets | | | | | |
| Debtors | 10 | 68 | | 50 | |
| Cash at bank | | <u>192,943</u> | | <u>69,641</u> | |
| | | 193,011 | | 69,691 | |
| Creditors: amounts falling due within one year | 11 | <u>(256)</u> | | <u>(90)</u> | |
| Net current liabilities | | | <u>192,755</u> | | <u>69,601</u> |
| Net assets | | | <u><u>193,310</u></u> | | <u><u>69,601</u></u> |
| Funds | | | | | |
| Restricted | 12 | | 25,699 | | 5,531 |
| Designated | 13 | | 140,000 | | - |
| Unrestricted | | | <u>27,611</u> | | <u>64,070</u> |
| | | | <u><u>193,310</u></u> | | <u><u>69,601</u></u> |

The notes on pages 34 to 36 form an integral part of these financial statements

Approved by the trustees on 10th December 2016 and signed on their behalf by



Alison Acosta Bedford.

Founding Trustee

The notes on pages 34 to 36 form an integral part of these financial statements

Notes to the financial statements

1. Accounting policies

Basis of accounting

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

Fund accounting

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

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

Incoming resources

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

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

Investment income is included when received.

Resources expended

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

Costs of generating funds

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

Governance costs

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

Irrecoverable VAT

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

2. Voluntary income

| | 2016 | | 2015 |
|-----------|----------------|--|----------------|
| | £ | | £ |
| Donations | 137,778 | | 102,484 |
| Grants | 32,092 | | 5,000 |
| | <u>169,870</u> | | <u>107,484</u> |

3. Activities for generating funds

| | 2016 | | 2015 |
|--------------------|---------------|--|---------------|
| | £ | | £ |
| Fundraising events | 17,323 | | 19,378 |
| | <u>17,323</u> | | <u>19,378</u> |

4. Other incoming resources

| | 2016 | | 2015 |
|-----------------|--------|--|-------|
| | £ | | £ |
| Conference fees | 21,110 | | 5,066 |

5. Fundraising costs

| | 2016 | | 2015 |
|---------------------------------|--------------|--|--------------|
| | £ | | £ |
| Advertising & promotional items | 2,050 | | 1,349 |
| Entry fees | 2,050 | | 1,460 |
| | <u>4,100</u> | | <u>2,809</u> |

6. Research

| | 2016 | | 2015 |
|-------------------|--------|--|---------|
| | £ | | £ |
| Research payments | 60,000 | | 135,000 |

7. Events

| | 2016 | | 2015 |
|--------------------------|-------|--|--------|
| | £ | | £ |
| Conference meeting costs | 3,000 | | 14,263 |

8. Governance

| | 2016 | | 2015 |
|---------------------|-------|--|------|
| | £ | | £ |
| Accountancy charges | 296 | | 90 |
| Insurance | 318 | | - |
| Subscriptions | 241 | | 75 |
| Bank charges | 20 | | - |
| Computer costs | 133 | | - |
| Staff training | 379 | | - |
| Recruitment costs | 275 | | 275 |
| Travelling expenses | 511 | | 126 |
| Depreciation | 277 | | - |
| | 2,450 | | 566 |

9. Fixed assets

| | Office equipment |
|-------------------|------------------|
| | £ |
| Cost | |
| At 2nd March 2015 | - |
| Additions | 832 |
| Disposals | - |
| At 1st March 2016 | 832 |
| Depreciation | |
| At 2nd March 2015 | - |
| On disposals | - |
| Charge for year | 277 |
| At 1st March 2016 | 277 |
| Net book value | |
| At 1st March 2016 | 555 |

10. Debtors

| | 2016 | | 2015 |
|--------------------------|------|--|------|
| | £ | | £ |
| Gift Aid tax recoverable | - | | - |
| Prepaid expenses | 68 | | 50 |
| | 68 | | 50 |

11. Creditors

| Amounts falling due within one year: | 2016 | 2015 |
|--------------------------------------|------|------|
| | £ | £ |
| Trade creditors | 22 | - |
| PAYE and NI | 144 | - |
| Accrued expenses | 90 | 90 |
| | 256 | 90 |

12. Restricted funds

| | Balance b.fwd | Incoming resources | Resources expended | Balance c.fwd |
|---------------------------------|---------------|--------------------|--------------------|---------------|
| | £ | £ | £ | £ |
| Research fund | - | 8,604 | (8,604) | - |
| Conference fees fund | 806 | 21,110 | (3,000) | 18,916 |
| Support fund | 4,725 | 11,000 | (15,442) | 283 |
| Be Safe at School Handbook fund | | 3,500 | - | 3,500 |
| FOP 'Together' Newsletter fund | | 3,000 | - | 3,000 |
| | 5,531 | 47,214 | (27,046) | 25,699 |

The Research fund represents monies received to fund the University of Oxford FOP Research Team.

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

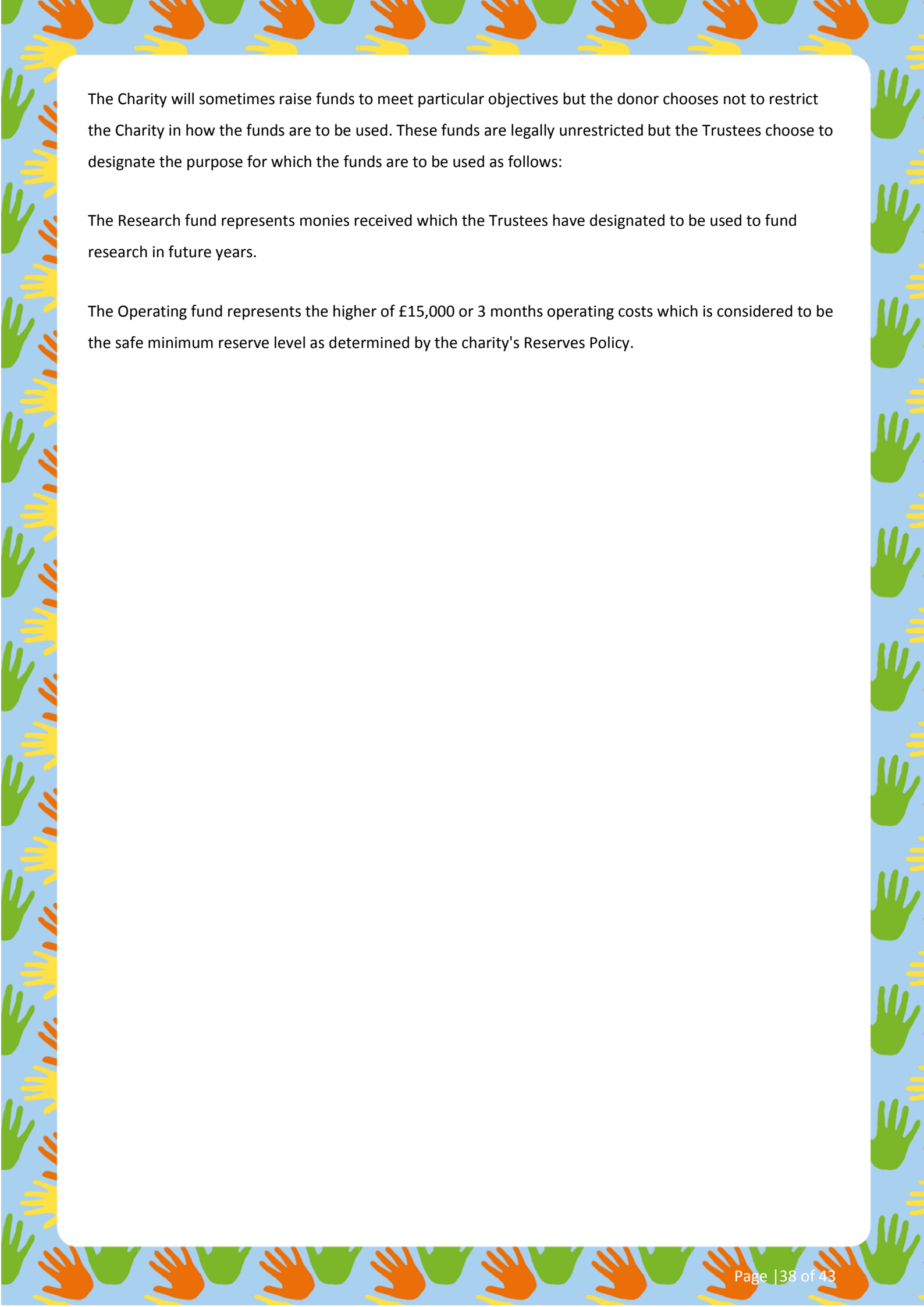
The Conference fees fund represents donations and delegates deposits received in respect of the FOP Conference in May 2016.

The Be Safe at 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.

13. Designated funds

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





A decorative border surrounds the page, featuring a repeating pattern of stylized hands in green, orange, and yellow against a light blue background.

The Charity will sometimes raise funds to meet particular 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 2016)

| | |
|---------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| March 2008 | Oliver Peter Bedford-Gay born, all the medical professionals just think he has 'funny toes' |
| November 2008 | Oliver has mysterious lump removed from the back of his head |
| April 2009 | Bedford-Gay family receive devastating diagnosis of FOP |
| 2010 | Family and friends begin fundraising to support the research team at Oxford |
| 2011 |  Friends of Oliver website created to celebrate and thank those who are supporting Oliver and the research team at Oxford |
| 2011 | Chris elected 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 |   Awarded a grant for £16,000 from GDUK to fund a Charity Administrative Assistant |
| December 2013 | Awarded a grant to employ a Senior Drug Developer at the University of Oxford |
| 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 organise a family gathering in Manchester, uniting UK FOP families for the first time in 12 years. The world's experts in FOP are also in attendance, including Prof. Kaplan |
| June 2014 | Friends of Oliver proudly becomes FOP Friends® to reflect the growing number of UK families now raising money together to support FOP research |
| August 2014 | FOP Friends' Drug Developer begins work at the University of Oxford, alongside the excellent existing team. |

August 2014 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

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

November 2014



FOP Founder and chairman attends 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 decorate their annual Christmas Tree at St. Alban's Church, Cheshire, with photos of FOPers 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 FOPers then took the opportunity to take part in. Everyone in the FOP community thank you for furthering the research.

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



February 2015



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

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

March 2015

Chris is 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 us as their Charity of the Year.

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

August 2015

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



September 2015



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

October 2015

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

Selected as Avaya's Charity of the Year, many exciting fundraising activities are planned.

November 2015

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



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



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

Chris flies out to Amsterdam for the Dutch FOP Symposium.

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



December 2015 We are thrilled to be selected as part of BG Group's share dealership programme.

January 2016 FOP Friends' oldest supporter Mrs. Laura Gregory celebrates her 102nd birthday and donates her gift money to fund a treatment for her great-grandson Oliver.

We are excited to announce the award of a grant from The Big Lottery Fund to help us fund the UK FOP Conference and Family Gathering 2016



February 2016



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

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



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



Adobe choose FOP Friends us as beneficiary of their Charity of the Year.

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



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

Thank you to (March 2015 – March 2016)

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

Trusts / Grants

Big Lottery Fund

Clara E Burgess

Genetic Disorders UK

Cameron McKenna Foundation

February Foundation

Hamamelis Trust

Corporate Supporters

Avaya

Clementia Pharmaceuticals

PushON

Rosemont Pharmaceuticals

BG Group

PwC

Roemex Ltd

Skillsarena

Donors of time and resources

Clarity: Stephen Fry narrated FOP Animation

Foliozine: Logo and website design

Skillsarena: Director's time

Costco: Bingo Night Prizes

Sainsbury's: Bingo Night Prizes

Community / Clubs and Associations

Manchester Round Table

Skillsarena: Director's time

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.