



2015 Annual Report & Financial Statements
(Year ending 1st March 2015)



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 in order 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 at all times 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

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

Bankers

HSBC, Co-operative bank

Independent auditor

P.S. Hutchinson BSc FCA, 246 Park View

Whitley Bay, Tyne and Wear, NE26 3QX

Contents

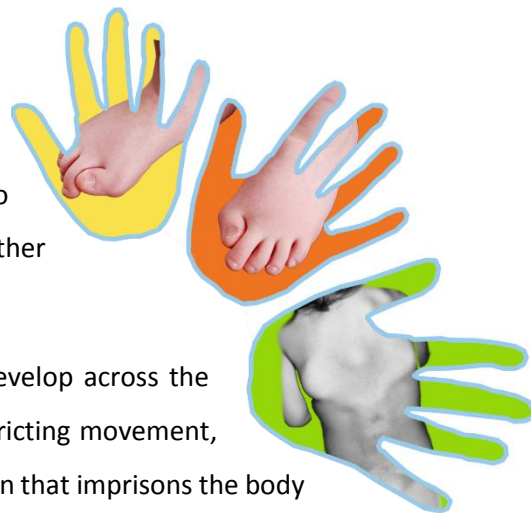
2015 Annual Report & Financial Statements	1
What is Fibrodysplasia Ossificans Progressiva (FOP)?	6
Introduction and Chair's Statement	6
Thank you to our supporters	7
About us / Who we are	7
Trustees.....	8
Christopher Bedford-Gay - Founding Trustee and Chairman	8
Alison Acosta Bedford - Founding Trustee.....	8
Rachel Almeida – Founding Trustee	9
Fiona White - Trustee.....	9
John Lever - Trustee	10
Helen Bedford- Gay – Trustee.....	10
Meeting Charity Commission guidelines	10
Our principal objects are:.....	11
Research Highlights.....	12
University of Oxford.....	12
Clementia Pharmaceuticals.....	12
IFOPA Drug Development Forums	13
How we raised our money	13
How we spent money raised.....	13
Achievements.....	14
UK FOP Conference and Family Gathering	14
Drug developer at Oxford	15
“How Oxford is working to cure a devastating rare disease” recognises FOP Friends commitment.....	15
Providing £135,000 to Oxford FOP Research.....	16
International FOP involvement.....	17
FRSB	17
Social media activity.....	17
Media relations	17

Genetic Disorders UK Leadership Conference	17
Impact and value	18
Autumn Fair	18
Live Music Night, Lightwater	18
Jammin' for Jamie	19
Ice Bucket Challenge	19
Gig for Isla	19
Sporting events	19
Skydive	20
Asda Community Life	20
Bingo evening.....	20
Grandma's Line Dance Evenings	20
Not too scared to donate!	20
Celebrity Mastermind	21
Windlesham Christmas Shopping	21
Christmas Tree Festival	21
Future plans	21
Ambition and long term strategies	21
Preventing misdiagnosis	22
Fundraising.....	22
Family support	22
Medical support	22
Governance and Structure	23
Legal Status	23
Organisational Structure	23
Trustee recruitment and training	23
Employment.....	23
Statement of responsibilities of the trustees	23
Financial review	24
Summary	24

Income	24
Grants, trusts, and corporate sponsorship	24
Charitable expenditure	24
Gains and losses	25
Policy on reserves	25
Designated Funds.....	25
Restricted Funds	25
Future commitments	25
Investments.....	25
Independent examiner's report.....	26
Our history (to March 2015)	31
Thank you to (March 2014 – March 2015)	33
Trusts / Grants	33
Corporate Supporters	33
Donors of time and resources.....	33
Community / Clubs and Associations.....	33
Fundraisers.....	33

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.



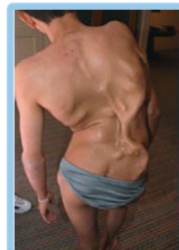
Bridges of extra bone develop across the joints, progressively restricting movement, forming a second skeleton that imprisons the body in bone. There are no other known examples in medicine where one

normal organ system turns into another.

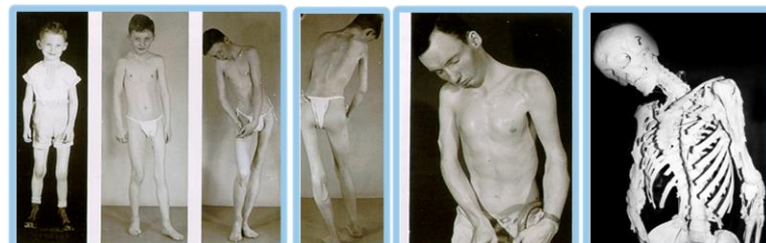
Most cases of FOP are new, meaning no-one else in the family has FOP. This happens because unexpected changes (mutations) occur as the genes are passed along from each parent. Many of these changes, such as the mutation that leads to FOP, are accidents of nature that happen for no apparent reason.



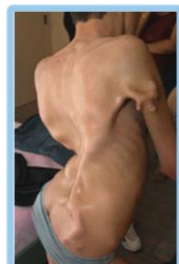
Children with FOP appear normal at birth except for congenital malformation of the great toes. During the first or second decade of life, painful swellings that look like tumours develop over the neck, back and shoulders and mature into bone.



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 began to run fundraising events to raise funds and awareness of FOP. Through this, we encountered numerous barriers 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 and nationally. Now entering our fourth year, we have had success in grant and trust fundraising as well as increased fundraising from new FOP families, friends and the general public. We continue to go from strength to strength.

We will 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 and to continue to bring FOP families together.

We will continue to capitalise on our charitable status in the pursuit of our aims and objectives over the coming months and years, endeavouring to go beyond keeping a small research team funded and instead fund research, education and awareness on a much bigger scale.

It will be hard work. However, with all of 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.

Thank you to our supporters

I would also like to extend my personal thanks to all our supporters who generously 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 research for a cure progressing. You all keep hope alive for all touched by this terrible condition, now or 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 (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 what 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 Project.

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. With the exception of 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 administration 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 serves as chairman of FOP Action, on the board of the International FOP Association (IFOPA) and as current chairman of the IFOPA International Presidents Council (IPC) bringing together FOP organisations from across the world. Chris also represents the UK FOP community internationally. Chris does this alongside his day-job as director of UK based technology company, Skillsarena.



Education

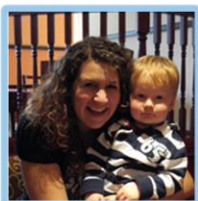
- 1st Class BSc Honours Degree, Computing for Business

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 vice-chairman of Manchester's Cheadle and Gatley Round Table, a charitable organisation providing 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 to 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 (6) and Harry (3).

Meeting Charity Commission guidelines

In setting our objectives and planning our activities, the Trustees have given careful consideration to the Charity Commission's general guidance on public benefit.

Our principal objects are:

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.

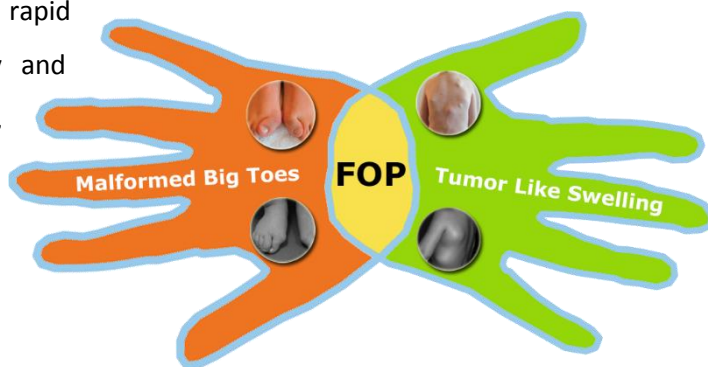
Public Benefit: Supporting other charities and organisations of this nature will benefit the public by providing care for those with FOP but also by furthering research that will lead to treatments and ultimately a cure for FOP, thus eliminating FOP as a health concern. FOP research projects will also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

FOP and Cancer research coming together



News of an exciting new collaboration with Dr Chris Jones at the Institute of Cancer Research, London came this year, having discovered that the mutation in the ACVR1 gene that causes FOP is present in one in four children diagnosed with the incurable brain stem tumour diffuse intrinsic pontine glioma (DIPG for short). It is important to note that these findings show no known cancer risks with FOP and vice versa. This discovery encourages more interest into finding a drug that targets the ACVR1 gene as this has the potential to benefit both conditions. Shared research interest with cancer researchers working on DIPG gives an added incentive for drug companies to consider working on treatments for FOP.

Continued progress of drug development

With a grant secured by FOP Friends and the support of the Amateur's Trust and Roemex Ltd the FOP research team at Oxford have recruited Dr Aicha Boudhar as a medicinal chemist. Aicha's expertise will help progress the design of a safer and more specific drug molecule to target the faulty ACVR1 protein which causes FOP. The Structural Genomics Consortium, have discovered more about the structure of the ACVR1 protein and this critical information will be useful for Aicha and the rest of the Oxford team when looking to "perfect" drug molecules as possible FOP treatment.



Scientific Conferences

The Oxford Research team has been in frequent contact with FOP researchers across the world to discuss recent findings and improve understanding of FOP. In April, 2014, Alex Bullock and Jim Triffitt attended the "8th International Meeting on Fibrodysplasia Ossificans Progressiva" held in Genoa, Italy, for FOP research experts and families affected by FOP.

The team at Oxford were also pleased to attend the UK FOP Conference and Family Gathering in Manchester, hosted by the FOP Friends charity in May 2014. Alex Bullock and Jim Triffitt presented their research findings and enjoyed the opportunity to meet again with national and international friends and meet new faces in the FOP community.

The team has also presented their research work at scientific meetings in Oxford and Berlin.

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 Palovarotene blocks the formation of bone in mouse models of FOP but 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 will investigate 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.

IFOPA Drug Development Forums

The IFOPA hosted the first ever FOP Drug Development Forum in Boston, Massachusetts on 21 and 22 November 2014. The Forum was a ground breaking event that brought together researchers from universities and biopharmaceutical companies from around the world to discuss the important questions and challenges of developing a treatment for FOP.



The two-day meeting was designed to support the IFOPA's vision for a safe and transformative therapy for FOP. The goals of the meeting were to address questions and knowledge gaps that exist in FOP drug development; stimulate new ideas to help advance development of potential therapies as quickly and efficiently as possible; and facilitate dialogue, foster collaboration, and form connections among interested researchers.

There are two videos from the conference with powerful messages available here: [Change My Life](#),

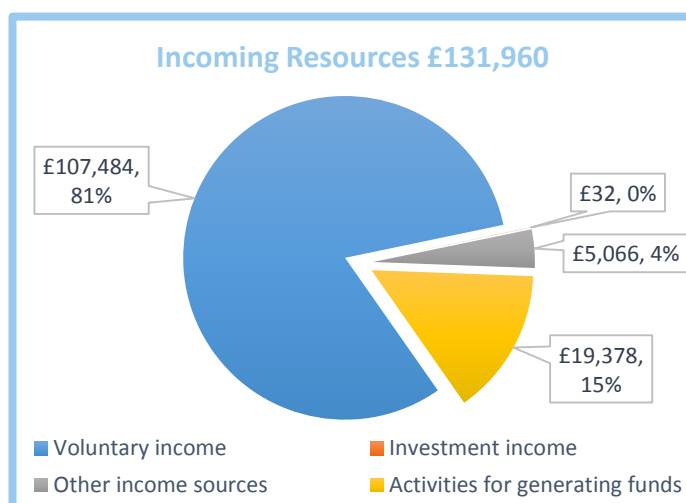
[FOP DDF 2014](#).

How we raised our money

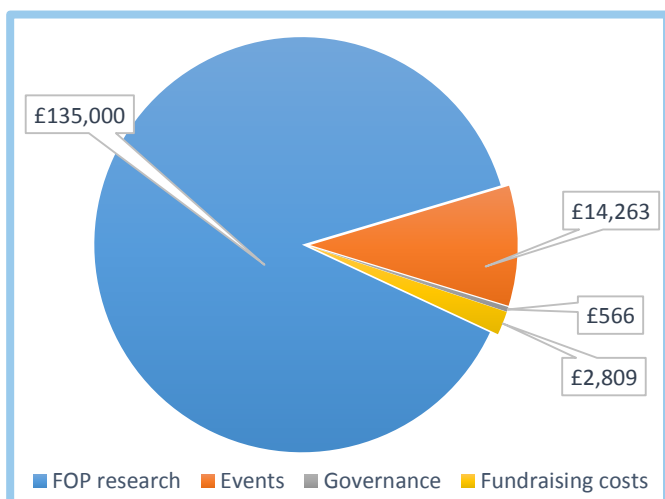
Voluntary income accounts for the bulk of money raised within the charities financial year. A small amount is attributed to investment income (interest on bank balances) and £5,066 revenue from events.

How we spent money raised

The charity has minimal overheads, which means that almost every penny donated funds the research into finding a cure for this devastating condition.



As a small charity, FOP Friends' trustees, friends and kind volunteers carry out most fundraising activities, promotions, administration and tasks involved in the day-to-day running of a charity. Everyone donates their time, energy and enthusiasm for no financial reward.



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 4th March and the 6th October 2014, FOP Friends made donations of £65,000 and £70,000 (£135,000) respectively to the University of Oxford FOP Research team. £65,000 funded the addition of a medicinal chemist while £70,000

contributed toward the existing teams running costs. £14,263 was outstanding from the UK FOP Conference and Family Gathering held in 2014. This cost was however entirely covered by grants, corporate sponsorship, and delegate fees.

Costs associated with fundraising for the year totalling £2,809 were associated with securing 20 x 2015 Great North Run places (which raised over £12,000 in return) and production and provision of fundraising materials and merchandise such as running t-shirts, leaflets and information packs. Governance costs of £556 covered basic operating costs such as accounting fees, insurance, postage and FRSB membership.

Achievements

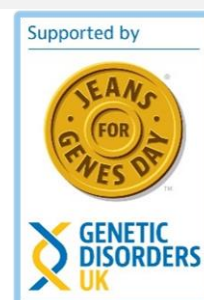
During the year, we were successful in a number of areas most notably with increasing friends, family and general public fundraising and with corporate sponsorship with FOP Friends regularly picked as “Charity of the Year”.

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 organising the first UK FOP conference for families in 12 years; funding a medicinal chemist at The University of Oxford; continuing to support the FOP research teams and their efforts; being involved in international FOP progress and further raising awareness of FOP.

UK FOP Conference and Family Gathering

Under the banner of FOP Action, FOP Friends organised the first UK FOP conference in 12 years for FOP families to meet, hear the latest research updates and take part in clinical sessions with world renowned FOP clinicians. Assisted by a grant from Genetic Disorders UK, the aim of the event was to gather families of FOP sufferers in a relaxed environment allowing them to meet others living with the same circumstances. The reality turned out to be much more.



After a year of planning, the event started in the early hours of Friday morning with Drs. Kaplan, Pignolo and Shore flying into Manchester, UK. They ran clinical appointments all day long, meeting many patients, some who they had met previously, others new – all overwhelmed at meeting their “heroes”.

The clinical waiting area overlooked a sunny Manchester Airport and the atmosphere was happy and hopeful. Behind the scenes, the team were busy getting ready for the evenings meet and greet reception as well as preparing for the following

day's conference sessions. At 7pm, families gathered for the reception – with attendees coming from, amongst others, the UK, Sweden, Greece, Malta, the Netherlands and even South Africa and Australia. The 1-hour reception ended when the bar closed 3 hours later!

Saturday dawned and the families gathered. A crèche was provided for the young children which proved to be a real hit. Staffed by qualified teachers, the children had a great time playing and meeting each other, and particularly enjoyed the trips to the hotel penthouse to



see the planes taking off! The crèche enabled the parents to enjoy the conference, taking the time to listen to the presentations and meet other parents.

Presentations were given by doctors and researchers from the Universities of Oxford, UK and Pennsylvania, USA as well as the IFOPA and Clementia Pharmaceuticals. Delegates had the opportunity to ask questions of all the speakers in the afternoon which was extremely well received. Families had different levels of understanding of FOP, often dependent on when they received a diagnosis, and the doctors and researchers were able to answer all their questions. News of Clementia's clinical trial provided real hope for the sufferers and their families, with many hearing about this for the first time. The day was topped off by a dinner and quiz, which ended with an unexpected karaoke round, creating some fun competition – Dr Christiaan Scott from South Africa was the unexpected star of the night.

"We were so pleased to meet again with our national and international friends and colleagues and to have a great opportunity to make many new ones. Such events can only inspire us to return to the laboratory and work even harder to find a new medicine", Oxford FOP Research team.

The feedback from the 3-day event was overwhelming. Lasting friendships were made and many delegates received support they didn't know existed. Tears were shed and hugs were exchanged – the FOP community came together in spectacular style! Planning is now underway for the next Conference and Family Gathering in 2016.

Drug developer at Oxford

In 2013 we were delighted to announce the securing of a £65,000 grant to fund the employment of a Senior Medicinal Chemist and their equipment at the FOP research team, University of Oxford. Dr Aicha Boudhar, was recruited and began to work with the FOP team in August 2014. She had the challenge of taking the Oxford FOP Research Team's drug designs and turning them into optimised drug candidates.

"How Oxford is working to cure a devastating rare disease" recognises FOP Friends commitment

An Article published on Oxford Thinking on 27th February available [here](#), recognises FOP Friends' continued commitment to find a treatment / cure for FOP. Full article below, courtesy of Oxford Thinking.

How Oxford is working to cure a devastating rare disease

Fibrodysplasia Ossificans Progressiva (FOP) is one of the rarest and most disabling genetic conditions known. The University of Oxford is one of the few places in the world where this disease is being researched, with support from donations.

FOP causes bone to form in muscles, tendons and ligaments. As the disease progresses, movement becomes restricted by a 'second skeleton'. It affects one in every two million people, with only 47 cases confirmed in the UK. People with FOP face a dramatically shorter life expectancy – the average is 40 years. "It is one of the most devastating conditions known to man," says Christopher Bedford-Gay, whose six-year-old son Oliver was diagnosed with FOP a few years ago. "It is also frequently misdiagnosed as cancer, because it's so rare, which often results in quite rapid progression of the disease through mistreatment." This is because any lesion, such as those caused by taking a biopsy or having surgery, can trigger excessive bone growth.

Christopher is one of the founding trustees of the charity FOP Friends, which raises money to support research on FOP. Since the charity was set up three years ago, it has raised over £135,000 for the FOP research programme in Oxford, which is one of the few institutions in the world that work on the disease.

Getting close to a clinical trial

Thanks to the support from FOP Friends and other donors, research at Oxford has kept going and is now close to a potential therapeutic breakthrough. Through collaboration with scientists at Harvard University, the Oxford team has been able to inhibit the progression of FOP in mice. “We hope that within the next two years we can put these drug molecules into clinical trial,” says Dr Alex Bullock, who leads the research team on FOP at Oxford.



The latest gift from FOP Friends of £70,000, has enabled the recruitment of a medicinal chemist who is working on making these drug molecules safe and stable for use in a clinical trial in humans. If the trial is successful, this drug could potentially be developed into a cure.

The benefits of FOP research, however, go beyond understanding FOP. Finding a treatment or even a cure for it would also help tackle other medical conditions. “There are quite a lot of situations where you get excessive or unwanted bone formation, for example: surgical hip replacements, military injuries, paraplegia and vascular disease,” says Professor James Triffitt, Emeritus Professor of Bone Metabolism at the University, who has been involved in FOP research for the last four decades. On the other hand, understanding how to stop bone from growing could potentially help to figure out how to make bone grow. This knowledge would help in treating osteoporosis.

A close patient-researcher relationship

Studying a rare disease with such devastating impact puts scientists and patients closer together than in other medical research. “Knowing the patients stimulates our day-to-day effort. It feels different to other medical research because you can see the face that you’re trying to help,” says Dr Bullock.

This proximity brings hope to the patients and their families as well. “The researchers are emotionally involved and extremely motivated to work on our behalf,” says Christopher. With a treatment, or even a cure, near, it becomes even more important to make sure the research can keep going. “Curing FOP would be amazing. It would be amazing to have played a part in it, and to have helped to give Oliver and everyone else with FOP a much brighter future.” – Article as on Oxford Thinking, 27th February 2015.



Providing £135,000 to Oxford FOP Research

On the 4th March 2014, FOP Friends provided £65,000 to the Oxford FOP Research team to fund the employment of a medicinal chemist for one year to assist in the search for the “perfect” drug molecules to treat FOP.

Later in the year, FOP Friends dispersed a further £70,000 to the Oxford FOP Research team to allow them to continue their search for a treatment / cure for FOP. This disbursement was made on the 6th October 2014.

inspirational charities similar in size to FOP Friends also presented their experiences.

To top it off our chairman, Chris had the opportunity to meet and talk with Warwick Davis - Actor, comedian and television presenter, about his charity and experiences.



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 money FOP Friends receives from fundraising allows the search for a treatment and a cure for FOP to continue. The support received in the year March 2014 – March 2015 has allowed the charity to support the University of Oxford's FOP Research team with £70,000 donated to fund the existing research and a further £65,000 to expand the research team for a year with a dedicated medicinal chemist. A total of £135,000 of support given which is an increase of £115,000 over 2013/2014.



In this charity year, FOP Friends also hosted the first UK FOP Conference and Family Gathering in 12 years, bringing together FOP patients, families, FOP researchers, clinicians and pharmaceutical companies under one roof to provide the latest news and updates to the FOP community. It was so well received by the FOP community that the next is being planned for 2016.

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 events, challenges and activities provides an idea of the support FOP Friends receives.

Autumn Fair

FOP Friends held their first Autumn Fair at St. Alban's Church Hall, Broadheath. There were many stalls, face painting, cakes and refreshments, games for the children, a tombola as well as stalls. The event was very well attended and everyone came away with bargains galore!



Live Music Night, Lightwater

Supporters and friends of Isla held a live music gig which raised £4000 as well as increasing awareness of FOP. There were bands, a raffle and plenty of good food and good fun!

Jammin' for Jamie



Another hugely successful event was the Jammin' for Jamie fundraiser which was held in London. There was a live band, a raffle and an auction with some incredible prizes, all of which had been donated. It was well supported and the evening raised nearly £6000.

Ice Bucket Challenge

As the Ice Bucket challenge swept the nation, many of our friends and supporters chose to accept the challenge in aid of FOP Friends.

Even Oliver's mum braved the cold, simply to raise further awareness.



Gig for Isla

The Isle of Wight saw a fabulous 60's themed event, Gig for Isla in October. There was a live band with much dancing! There was also food and a raffle, with nearly 200 people in attendance it was one of our largest fundraisers yet.

Sporting events



FOP Friends has had so many runners, running so many different races, it's almost impossible to keep track of them all! We were delighted to have some new names on the starting block too: Friends of Sarah, Dylan, Annalese, Lucy & Zoe, and Lucy.

This year also saw the charity's first marathon run in a kilt! Joan ran for FOP Friends of Dylan, proudly wearing her kilt and FOP Friends t-shirt!



In addition to individual runners, the charity also had teams running for the cause. The sight of a group of FOP Friends t-shirts still amazes. A large team ran for FOP Friends of Isla in the Windsor Half marathon and also an amazing 14 people ran for Team FOP Friends at the Great North Run 2014. What made this team especially special was that it consisted of Friends from across the country, all united and running for one cause. Many of the people who ran in

the team said it was an experience like none other. The largest donation came from their oldest supporter and Oliver's great-nan, aged 101! Helen and Oliver were there at the finish line to welcome each and every runner through, and

to thank them personally on behalf of every FOP patient in the UK for their dedication and commitment. The Great North Run alone raised an impressive £12,000.

FOP Friends even had celebrity support with CBBC's Katie Thistleton running the Manchester 10k in support of FOP Friends and one brave cyclist riding one hundred miles to support FOP Friends.



Skydive

Mark Barry realised a lifelong ambition for a 40th birthday experience: a skydive. He also increased awareness for FOP Friends of Isla and raised much needed funds.



Asda Community Life

FOP Friends were fortunate to be selected for the Asda Community Life scheme and were delighted when they won their round and received a cheque for £100 from Christine Ashton on behalf of the company. Being promoted within a busy store enabled the charity to further raise awareness of the condition within their local community.



Bingo evening

Our annual Bingo evening was a fantastic success raising in excess of £1,000, now in its third year and not losing any of its popularity. We never cease to be amazed by how seriously people take it on the night. The evening was a sell-out prompting us to look for a larger venue for the 2015 event.



Grandma's Line Dance Evenings

The line dancing events organised by Oliver's grandma still make a significant and consistent contribution to our annual fundraising total. Oliver and his brother love to go along and "help" grandma with the raffle, they've yet to join in with the dancing though!

Not too scared to donate!

The charity had two 'scary' themed fundraisers this year: the first was a Zombie Walk in Sprowston. Some young people heard about FOP and wanted to do something to help so they organised a zombie themed walk around the local lake one Sunday morning, raising much awareness, a few eyebrows and £350 too!

The second event was held for Friends of Oliver at a local pub which had just reopened. They held a Halloween themed event with fancy dress competitions, face painting and games. They kindly donated the proceeds to the charity. Oliver, his brothers and his friends attended and had a scream! It was a frighteningly good event!



Celebrity Mastermind

FOP Friends were both thrilled and excited to learn that CBBC presenter Katie Thistleton had chosen us as her charity when she took part in the Christmas Celebrity Special. Her specialist



subject was Friends, but of the American variety, not the charity! Alison and Helen also felt very honoured to be invited to the screening and to be invited to the Green Room afterwards. Not only did she get FOP Friends mentioned on national television, she also earned us a generous donation to the fundraising pot too.



Windlesham Christmas Shopping

The charity continues to receive support from small businesses who cannot help but be moved by the stories of people affected by FOP so desperately want to do whatever they can to help. Savannah's Gift Shop in Windlesham held a Christmas shopping event to kick off the Christmas season, holding a raffle amongst other things, and raising £200.



Christmas Tree Festival

In our fourth year of being invited to participate in the St. Alban's Church Broadheath's Christmas



Tree Festival, FOP Friends decided to showcase many of their community members and supporters. This year they were proud to contribute a tree which was decorated with the faces of their small but very special FOP community: from the sufferers of FOP themselves, to their family and friends who support them. In addition, the Church's charity committee continues to recognise our hard work and dedication by selecting us as one of their charities and making a donation. The charity is ever grateful for this recognition.

Future plans

On 5th March 2014 the charity received news of a grant from Genetic Disorders UK, the national charity that organises the annual fundraising day, Jeans for Genes Day. Funds raised on the day will be used to fund the salary of a Grant and Trusts Manager who will work within the charity. Recruitment started in late February 2015 with the hope of finding a suitable employee to start in summer 2015.

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.

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 in the near future
- 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 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 general 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 general public to support
- To sustain and maximise trusts and grant funding in order 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 a number of committees with specific responsibilities for the charity. Any change to the Trust Deed including the appointment of trustees is subject to 21 days' notice of the intention to discuss prior to any meeting.

Trustee recruitment and training

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

Employment

FOP Friends does not presently have any employees but has funding in place to recruit the first in 2015-2016.

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 state of affairs 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 22nd December 2015 and signed on their behalf by



Chris Bedford-Gay.

Founding Trustee and Chairman

Financial review

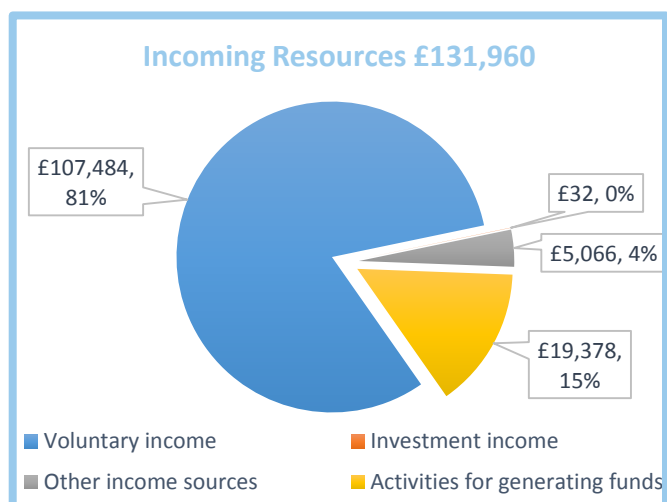
Summary

Gross incoming resources for the year amounted to £131,960 with £69,601 being carried forward to the next charity year.

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

Income

Income for the year totalled £131,960 made up of unrestricted funds from fundraising and voluntary donations together with income from successful grant and trust applications.



Grants, trusts, and corporate sponsorship

The charity received £5,000 from grants and trusts.

Charitable expenditure

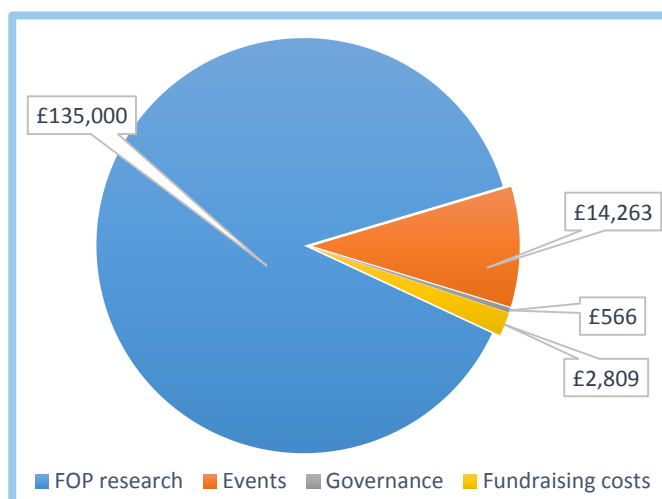
On the 4th March 2014, a disbursement of £65,000 was made to the University of Oxford FOP Research fund. This funded the employment of a medicinal chemist to aid in the search for drug molecules to treat FOP.

On the 6th October 2014 a further disbursement of £70,000 was made to the University of Oxford Research fund. This contributed to the £120,000 annual running costs of the FOP Research team.

Operating costs of £3,375 include costs associated with fundraising of £2,809 (t-shirts, Great North Run places...) and £566 governance costs.

Governance costs of £566 include accounting fees, insurance, postage and professional memberships.

£14,263 was associated with remaining costs of holding the UK FOP Conference and Family Gathering in 2014. Those costs entirely covered by grants, corporate sponsorships and delegate fees. Other expenditure (Governance costs) included FRSB membership, costs incurred through awareness and fundraising as well as governance costs totalling £566.



Gains and losses

Income from fundraising and voluntary donations rose by over £60,000 to a total of £121,862.

Policy on reserves

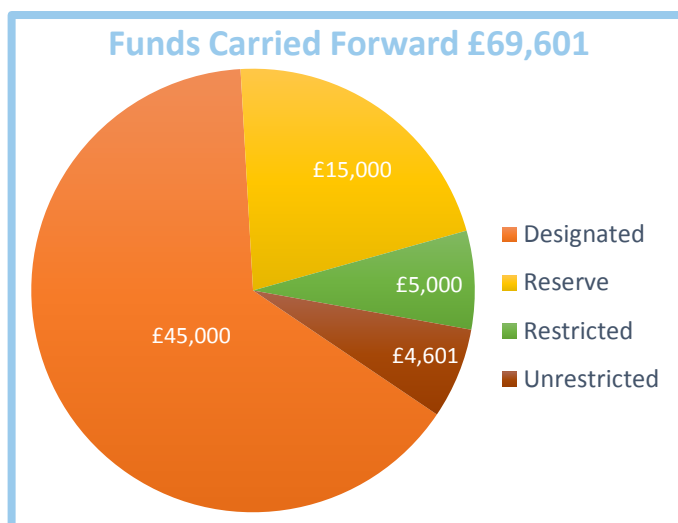
The Trustees have reviewed the reserves of the charity. Our aim is to maintain reserves in unrestricted funds at a level of £15,000 to cover operational costs and unforeseen expenditure.

Designated Funds

£45,000 is designated towards future funding of FOP research.

Restricted Funds

A total of £5,000 in funding received from GDUK grant has been restricted towards the employment of FOP Friends first staff in late 2015.



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 £45,000 has been designated from funds carried over towards FOP research, £5,000 is restricted to fund employment of FOP Friends first staff.

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 2015 which are set out on pages 26 to 30.

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.

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

		Totals			
	Notes	Restricted	Unrestricted	2015	2014
		£	£	£	£
Incoming resources					
Incoming resources from generated funds					
Voluntary income	2	5,000	102,484	107,484	90,518
Activities for generating funds	3		19,378	19,378	4,723
Investment income			32	32	11
Other incoming resources	4	5,066		5,066	10,003
Total incoming resources		10,066	121,894	131,960	105,255
Resources expended					
Costs of generating funds					
Fundraising costs	5		2,809	2,809	720
Charitable activities					
Research	6	65,000	70,000	135,000	20,000
Events	7	14,263		14,263	
Governance costs	8	275	291	566	709
Total resources expended		79,538	73,100	152,638	21,429
Net (outgoing)/incoming resources		(69,472)	48,794	(20,678)	83,826
Reconciliation of funds					
Total funds brought forward		75,003	15,276	90,279	6,453
Total funds carried forward		5,531	64,070	69,601	90,279

Balance sheet

		2015		2014	
	Notes	£	£	£	£
Current assets					
Debtors	9	50		1,488	
Cash at bank		69,641		89,391	
		69,691		90,879	
Creditors: amounts falling due within one year	10	(90)		(600)	
Net current liabilities			69,601		90,279
Net assets		£	69,601	£	90,279
Funds					
Restricted	11		5,531		75,003
Unrestricted			64,070		15,276
		£	69,601	£	90,279

Approved by the trustees on 22nd December 2015 and signed on their behalf by



Alison Acosta Bedford.

Founding Trustee

Note: The notes on pages 28 to 30 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.

<i>2. Voluntary income</i>	2015	2014
	£	£
Donations	102,484	55,518
Grants	5,000	35,000
	107,484	90,518

<i>3. Activities for generating funds</i>	2015	2014
	£	£
Fundraising events	19,378	4,723

<i>4. Other incoming resources</i>	2015	2014
	£	£
Conference fees	5,066	10,003

<i>5. Fundraising costs</i>	2015	2014
	£	£
Research payments	1,349	10
Entry fees	1,460	710
	2,809	720

<i>6. Research</i>	2015	2014
	£	£
Research payments	135,00	20,000

<i>7. Events</i>	2015	2014
	£	£
Conference meeting costs	14,263	

8. Governance

	2015	2014
	£	£
Accountancy charges	90	600
FRSB membership fee	75	50
Bank charges		59
Recruitment costs	275	
Travelling expenses	126	
	566	709

9. Debtors

	2015	2014
	£	£
Gift aid tax recoverable		1,438
Prepaid expenses	50	50
	50	1,488

10. Creditors

	2015	2014
	£	£
Amounts falling due within one year:		
Accrued expenses	90	600

11. Restricted funds

	Balance b. fwd	Incoming resources	Resources expended	Balance c.fwd
Research fund	65,000		(65,000)	
2014 Conference fees fund	10,003	5,066	(14,263)	806
Support fund		5,000	(275)	4,725
	75,003	10,066	(79,538)	5,531

The Research fund represents monies received to fund the employment and equipment of a Senior Medical Chemist at the University of Oxford FOP Research Team. These funds were paid to the University of Oxford FOP Research Team on 4th March 2014.

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 2014.

Our history (to March 2015)

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

November 2014 The website is updated with personalised “Friends” pages to recognise and celebrate the amazing people who make up FOP Friends



“ 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.

Thank you to (March 2014 – March 2015)

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

Trusts / Grants

Genetic Disorders UK

Corporate Supporters

Roemex Ltd

Skillsarena

Avaya

PwC

Clementia Pharmaceuticals

ASDA

Donors of time and resources

Foliozine: Logo and website design

Clarity: Stephen Fry narrated FOP Animation

Skillsarena: Directors time

Costco: Bingo Night Prizes

Sainsbury's: Bingo Night Prizes

Community / Clubs and Associations

Manchester's Cheadle & Gatley Round Table

St Alban's Church, Broadheath

Royal Northumberland Yacht Club

Fundraisers

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

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