



2013 Annual Report & Financial Statements





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FOP Friends of Oliver

FOP Friends of Oliver is a charity registered in England and Wales with the charities commission.

Name/s: FOP Friends of Oliver, Friends of Oliver

Registered at: 1 Cumberland Road, Sale, M33 3FR

Registered: March 2012

Charity #: 1147704

Organisation: Charitable Trust

Governed by: Trust Deed

Trustees: Christopher Bedford-Gay

Rachel Almeida

Alison Acosta Bedford

Fiona White

John Lever

Bankers: Co-operative Bank

Our Vision

A cure for Fibrodysplasia Ossificans Progressiva (FOP) and related conditions.



Our Mission

Fund research to find a cure for Fibrodysplasia Ossificans Progressiva (FOP) and related conditions while raising awareness through education and advocacy.





What is FOP?



FOP turns otherwise healthy people like Oliver into human statues: a healthy mind locked inside a frozen body.

Fibrodysplasia Ossificans Progressiva (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 and 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.

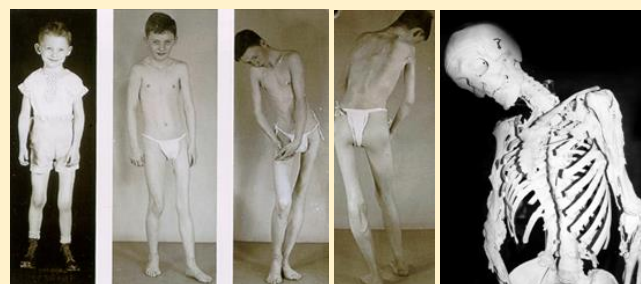
Most cases of FOP are new, meaning no-one else in the family has FOP. This happens because unexpected changes (mutations) occur as the genes are passed along from each parent. Many of these changes, such as the mutation that leads to FOP, are accidents of nature that happen for no apparent reason.



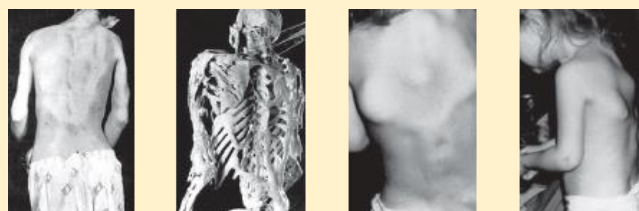
Children with FOP appear normal at birth except for congenital malformation of the great toes.

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. One day a person may be able to turn their head or bend an arm, the next they become frozen forever in a locked position.



FOP is also known as "Stone Man Syndrome".





About Us



FOP Friends of Oliver's aim is to further research into Fibrodysplasia Ossificans

Progressiva (FOP) and related conditions by financially

supporting current and future research projects within the United Kingdom and in the United States of America.



Fibrodysplasia Ossificans Progressiva (FOP) causes progressive debilitation eventually leading to early death. FOP research projects have far reaching implications for not only those with FOP but also those with common 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.

In particular, soldiers who suffer combat injuries are prone to heterotopic ossification, a severely debilitating complication. An estimated 64% of soldiers with blast injuries develop heterotypic ossification, compromising functional mobility and prosthesis use.

Friends of Oliver 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 those with more common disorders.

Friends of Oliver was founded following the diagnosis of Oliver Bedford-Gay with FOP at the age of 1 (he is now 5). As no UK charity existed, Oliver's family decided to set up Friends of Oliver. The aims of Friends of Oliver are to support the search for a cure while raising awareness; and educating the public and medical world of the condition.

This was undertaken with the view of supporting existing patient organisations such as FOP Action; supporting existing research programmes as at the University of Oxford; and also to promote FOP research worldwide.

As a fully registered charity, Friends of Oliver is in a position to take advantage of funding opportunities and programmes from which only registered charities can benefit.

Each year the trustees decide which research or other projects to support with monies raised. To date, this has been targeted at maintaining the University of Oxford's FOP Research Project which is one of the few key players in the search for a cure for FOP and related conditions.

Presently **100%** (99.5% in year to 28th Feb 2013) of all monies raised goes directly to supporting the charities main objective of finding a cure. While feasible the trustees will cover the operating costs of the charity from 2013 onwards.





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 progressive disabling and 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 directly 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 ultimately 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 are also expected to benefit a large number of people suffering from 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 a number of more common related conditions which impact 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 Friends of Oliver's key public benefits and will be achieved through our previously stated aims of awareness, education and advocacy.





Objective in Focus: Preventing Misdiagnosis

90% of all cases of FOP are initially misdiagnosed resulting in serious trauma, injury and accelerating progression of the condition. This **can** be prevented.

Fibrodysplasia Ossificans Progressiva (FOP) is so rare that few medical professionals have encountered it, most never will.

Oliver was diagnosed just after his first birthday following multiple investigations and undergoing neurosurgery.

Luckily Oliver's medical professionals drew the connection between the tumour-like lumps forming on the back of his head and his "turned in toes". This early diagnosis undoubtedly prevented Oliver being subjected to tests that would have caused major FOP-related fallout and a more rapid progression of the disease.

Oliver was lucky! Many are diagnosed incorrectly (with the lumps suggesting some form of cancer) and undergo treatments, biopsies or further investigations all of which accelerate the progression of FOP. One misdiagnosis resulted in the unnecessary amputation of Ashley Kurpiel's arm, she was just 3 years of age. For another of Oliver's friends it resulted in years of chemotherapy. Other known sufferers have had biopsies, operations and treatments, all of which make the condition worse!



The frustration is that diagnosis is simple: "Turned in Toes" or malformed toes in medical terminology is an immediately visible indication of FOP.

Malformed big toes, together with tumour like swellings, means with almost 100% certainty that the diagnosis is FOP. Confirmation is a simple genetic test, a pin prick or a swab taken to confirm.



Friends of Oliver has made progress with raising awareness within the medical community to help prevent misdiagnosis through contact with the numerous medical professionals. This includes:

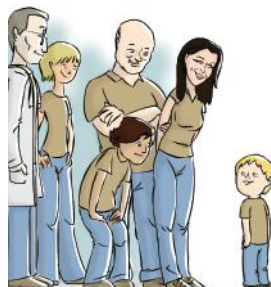
Dr Mughal, Royal Manchester Children's Hospital.

Oliver's paediatric bone specialist, who takes a professional and personal interest, has been educating consultants both within his field and those he meets as part of a wider network of professionals. One of Dr Mughal's contacts is due to include a section on FOP in a medical publication.

Dr Ledi, Educational Paediatrician

Through training locally and nationally, Dr Ledi has been introducing FOP to her medical students and has been lecturing nationally on the topic. She is planning on taking her newly acquired knowledge of FOP to both educate medical professionals and to support sufferers in North Africa.

Further expansion of FOP awareness within the medical community is planned, to include the distribution of information packs and presentations to sonographers, midwives, paediatricians and podiatrists.





Research Highlights



University of Pennsylvania, The University of Pennsylvania launched the Comprehensive Survey of FOP Flare-ups. It is necessary for researchers to obtain this information from FOP patients to help them determine the optimal design for clinical trials. The survey is a key stepping stone to future clinical trials.



University of Oxford, The FOP Research Team published their latest research in the Journal of Biological Chemistry. The publication described the 3D structure and activity of the FOP-associated protein, ACVR1. Variant forms of the protein found in FOP patients were shown to have increased activity that likely explains the unwanted bone. The structure revealed the ACVR1 protein was normally tightly shackled to prevent excessive activity, whereas variant proteins were missing these controls. The work also showed how the variants could be managed by a prototype drug molecule called "dorsomorphin".



University of Cambridge, A new collaboration was established between Oxford's FOP Research team and scientists at University of Cambridge to derive renewable stem cells from FOP patients to investigate the causative mechanisms of FOP and the actions of potential drug molecules.



Harvard University, Researchers at Harvard Medical School and the Harvard School of Dental Medicine found that by mimicking FOP in a dish they can rewind the internal clock of a mature cell and drive it back into an adult stem-cell stage. Dr Kaplan, at the University of Pennsylvania School of Medicine and an expert on FOP said "While we want to use this knowledge to stop the renegade bone formation of FOP, these new findings provide the first glimpse of how to recruit and harness the process to build extra bone for those who desperately need it."



La Jolla Pharmaceutical, received "orphan drug" designation from the FDA for LJPC-6417. LJPC-6417 is a kinase inhibitor that targets the bone morphogenetic protein (BMP) type-1 receptor, which is mutated in FOP. LJPC-6417 is a possible drug candidate for the treatment of FOP. Orphan Drug status offers La Jolla significant tax break in the USA to help progress research and development of "orphan drug" candidates.

Clementia Pharmaceuticals (Montreal), Licensed Palovarotene from Roche Pharmaceuticals, culminating months of collaboration among Dr Pacifici and Dr Masahiro Iwamoto from CHOP, and Dr Fred Kaplan, Dr Bob Pignolo, and Dr Eileen Shore from the University of Pennsylvania. Palovarotene is a nuclear retinoic acid receptor γ agonist, which is a potent inhibitor of heterotopic ossification. Information on Palovarotene research is available here: <http://1.usa.gov/10vRRSy>. While much work remains to be done, this is an important step forward.





Chairman's Statement



In 2009 I received the devastating news that my eldest son, Oliver, who was then just one, had been born with 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, I began to run fundraising events to raise funds and awareness of FOP. This was done to support FOP Action (a UK-based support group for FOP) and directly fund research at the University of Oxford. Through this we encountered numerous barriers accessing further help and funding from companies and organisations all of whom only work with "charities" and so the decision was made to become a fully registered charity.

Since then we have continued to grow our support both locally and nationally. We have built a new website; set up Virgin Money Giving pages; organised deals with events companies to allow our supporters to go on "once in a lifetime fundraising trips"; launched our own You Tube, Facebook, LinkedIn, Google+ and Twitter pages; and created charitable accounts with PayPal, eBay, and Easy Fundraising. We have received donations from many organisations in support of our cause including Starbucks, Costco, ASDA and many smaller local companies. We have also produced an awareness video, narrated by Stephen Fry.

We hope to continue to capitalise on our charitable status in the pursuit of our aims and objectives over the coming months and years. We endeavour to get to the stage where we can go beyond keeping a small research team funded and instead fund research and education of FOP and related conditions on a much bigger scale.

It will be hard work. We will need luck as well as the help and support of our families and the wider public but we will get there.

Every delay reduces the quality of life and life expectancy of a person with FOP but together we can make a real difference.

THANK YOU TO OUR SUPPORTERS

Finally, I'd like to extend my thanks to all our supporters who have generously continued to fund our work (through events, sponsorship or direct donation), and to the volunteers who continue to help us. Without your tireless campaigning, fundraising and direct support we could not keep research for a cure progressing. You all help to keep hope alive for Oliver, his FOP friends and all those touched by this terrible condition now or in the future.



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





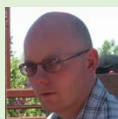
FOP Friends of Oliver Trustees

There must be at least three trustees. With the exception of the first trustees, every trustee must be 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 individuals for appointment as trustees must have regard to the skills, knowledge and experience needed for the effective administration of the charity.

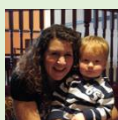
Trustees as at approval of this annual return (the Trustees met on 5 occasions in this reporting year)

Chris Bedford-Gay



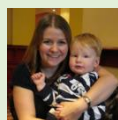
Founder and Chairman.

Alison Acosta Bedford



I'm Alison Acosta Bedford, one of the founding trustees of Friends of Oliver and one of Oliver's Aunties, fondly known as Mummy Al by Oliver and his younger brother Leo. I am a mum of 2. When I'm not being a full time mum, I work as a Chartered Management Accountant for one of the most successful Housing Associations in the country. I am committed to using my professional skills, as well as my personal relationship with Oliver, to make Friends of Oliver a thriving and successful charity and to raising awareness and funds for research into finding a cure for this terrible condition, for Oliver and all his FOP friends.

Rachel Almeida



My name is Rachel Almeida and I'm Oliver's Auntie.

I live in London and in my day job I'm Head of

Events for an Association, organising education-related Conferences. I have worked in events for over 10 years so I'm hoping to put my experience and expertise in events to good use helping raise funds for FOP research. As a family member, I was devastated when I found out about Oliver's condition, but what is important now is that we work hard to raise funds for research and raise awareness of this disease to ensure that Oliver can live a long, healthy and fulfilling life.

Fiona White



My name is Fiona White and I'm a close friend of

Christopher and Helen Bedford-Gay and a trustee of

FOP Friends of Oliver. I live in Manchester and am a

teacher and Senior Leader at a primary school in Rochdale.

Having been a close friend of the Bedford-Gay family for many years, I too was devastated to learn about Oliver's condition. I am aware of the fantastic research being done at Oxford University and in America and have come to understand just how important it is to raise awareness of the condition and ensure much needed funds are raised in order for this vital research to continue and help find a cure! I look forward to using my professional skills to help Friends of Oliver grow.

John Lever



As a dad, when I heard about Oliver, I wanted to do what I could to help. As a first step I produced a video through my creative company and I'm

enjoying exploring some exciting new ideas. It's a privilege to be part of such an inspiring team, on such an important mission.





Achievements

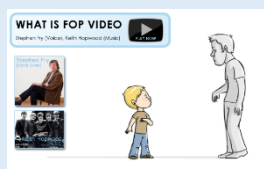
March 2012 saw the formation of FOP Friends of Oliver as a charity registered in England and Wales with the charities commission. The first year since its formation has been fast paced and for the trustees a steep learning curve. Notable events include:

FOP Friends of Oliver Website

The Friends of Oliver website was brought to life. This promotes the charity and provides important information on research being carried out for FOP and the impact and benefit this research can have on other related medical conditions. As well as raising awareness of FOP, it is continuously updated with charitable events (both past and future). The website also provide links to Friends of Oliver's Virgin Money Giving pages and offers fundraising support and advice.



FOP Awareness Video (Stephen Fry, Keith Hopwood)



Available on the website and YouTube is a short animation, kindly narrated by Stephen Fry with backing music by Keith Hopwood (of Herman's Hermits).

The video helps to explain the condition and raise awareness.

Virgin Money Giving

Registered with Virgin Money Given to facilitate easy donations from supporters (and reclamation of Gift Aid) as well as allowing our supporters to easily create their own fund raising pages linked directly to the charity.



EasyFundraising.org



Registered with EasyFundrasing.org which allows our supporters to donate as they shop online at zero cost to themselves.

Google Grants



Successfully applied for \$10,000 per month of Google AdWord grants to increase search traffic. Advantage of this is yet to be taken.

Government Petition



Friends of Oliver created the e-Petition "Fund FOP Research at Oxford University" for debate in parliament.

Friends of Oliver Information Leaflets

The original 2011 Friends of Oliver information leaflet has been updated for 2012 onwards with full charity details and updated information.

Fund Raising Standards Board



Friends of Oliver is a registered member of the FRSB. The FRSB is the independent self-regulatory body for UK fundraising. They work with their member charities, suppliers and the wider charity sector to encourage commitment to and compliance with best practice in fundraising. They do this to help encourage the public to give with confidence to charity.

Social media activity



Friends of Oliver Facebook page has exceeded 240 likes and Twitter, Google+ and LinkedIn accounts have been setup and are in operation.





Media Relations

Friends of Oliver have developed close links to reporters at the Sale and Altrincham Advertiser and Manchester Evening News which provides much needed, positive press for the charity and the work it carries out. Many of the local charitable events have been covered raising the profile of the charity, of FOP and helping to encourage support from many local people and organisations.

Providing £10,000 to further FOP research



Friends of Oliver made its first significant direct disbursement to support the Oxford FOP Research Project.

Hosting FOP Action Meeting

In January 2013, Friends of Oliver hosted the annual FOP Action research meeting in Oxford. The meeting was well attended by the FOP Research Team, FOP France and key members of FOP Action.



International FOP Efforts



Chris Bedford-Gay (Chairman of Friends of Oliver) has been appointed board member for a 2nd term with the International FOP Association (IFOPA) where he attends annual meetings in Florida, USA with the board and key researchers from the University of Pennsylvania. He has also been appointed as International Presidents Council Member for the UK. He has been instrumental in the development of the FOP Natural History Survey with the University of Pennsylvania which has been distributed to FOP sufferers in over 20 countries.

The information gathered from this international survey will be essential to the design of future clinical trials for FOP treatments.

Chris is also a board member of FOP Action and has recently been appointed to the European FOP Consortium as one of a number of UK representatives.





Impact and Value

In its first year as a charity Friends of Oliver has dispersed £10,000 to the University of Oxford FOP Research Fund who have now been able to maintain their number of researchers into FOP. Supporting the University in its research brings hope to many families affected by FOP and hope that a cure is close to being found.

Throughout the year Friends of Oliver and supporters held a number of fundraising events and challenges a few of which are detailed below.

Line Dance Evenings

Oliver's Grandma Ann has been holding charity line dancing social evenings in Shiremoor, Tyne and Wear, to raise money for FOP for over two years. In fact, they are one of our biggest events, both for raising funds and awareness. They are always



well attended by enthusiastic ladies and gentlemen. Twice yearly, Ann holds a grand evening with a live singer and buffet.

Rochdale Coffee Morning

We have held coffee mornings for two years now at the spectacular Rochdale Town Hall. As well as hot refreshments, there are craft stalls, cakes stalls, raffles and games. It also provides us with the opportunity to keep our friends, family and followers up to date with progress with FOP research on a local and international



scale. Rachel Winnard, a local Rochdale girl who also suffers from FOP, comes to the coffee mornings and helps to draw the raffles. FOP has already begun to affect Rachel and she has restrictions of movement in her upper body and legs. Along with the Mayors of Rochdale, little Oliver has attended these mornings and been the star of the show. His strong character and lively personality helps to highlight the importance of finding a treatment and cure for this terrible disease before he and many others are more severely impacted.

Bingo Fun Night



We held our first Bingo Evening at our local pub. There were many fantastic prizes to be won, donated from local business, Manchester United and Sale Sharks. It all got

rather dramatic and nail-biting as we waited for "House" to be called! Everyone who came along had a fabulous time whilst raising funds for Friends of Oliver. Due to its popularity, we are planning to hold the event annually.

Sale Lions Golf Tournament

After reading about 'Brave Oliver' in the local newspaper, the Sale Lions chose Friends of Oliver to be one of the benefactors from their Charity Golf Tournament. We were delighted to go down to their Club House to receive a cheque for £500.





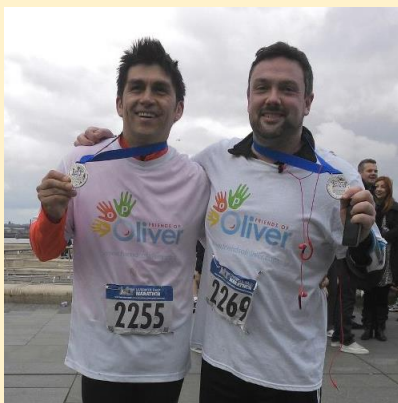
Great North Run



Auntie Fiona, and trustee of Friends of Oliver ran the Great North Run for Friends of Oliver. Whilst she enjoyed the personal challenge, she was also glad to be flying the flag for Friends of Oliver.

Liverpool Half Marathon

Blessed with sporty relatives, Oliver's Uncle Carlos and friend Tom Holmes ran the Liverpool Half Marathon. Carlos was pleased he crossed the line in under two hours, whilst Tom was delighted to have taken 45 minutes off his previous time. They were both also very proud to be the first people to model the new Friends of Oliver t-shirts.



Other Runs

Friends of Oliver was represented in the London Marathon this year by Craig Allen, a friend of Sheryl Hadley whose daughter suffers from FOP. Caroline Colquhoun-Lynn learned about Oliver through her child's school and decided to run the Tatton 10K for us. We feel it was a real step forward for us as a charity to be represented at various sporting events across the country.

Walk Around Moor Nook

When Oliver's neighbour Enid, who at the time had never met him, heard about his condition she immediately wanted to help. Enid, over 80 years young, organised a sponsored walk around the local park and arranged for the Rainbows, Brownies and Guides to step up and help a local child. Many children turned up on the sunny but cold February morning and raised over £1000 for Friends of Oliver. But for Enid, the best outcome for her was making a new little best friend!



Waitrose Local Charity Prize

Friends of Oliver applied to be one of Waitrose's charities of the month and was delighted to receive a cheque for our share.



Musical Evening



Sandra Sharp of Holy Innocents Church, Kidderminster, organised a classical music evening with talented local musicians including 10 year old Ben Horobin who amazed the listeners with his accomplished trumpet playing. The evening brought the plight of FOP sufferers to a whole new audience who had previously never heard of the condition.





The Royal Northumberland Yacht Club at Blyth

As Rear Commodore of the yacht club, Oliver's granddad suggested they adopted Friends of Oliver as their charity for the year and the sailors gladly obliged. Through a wide range of fundraising activities, the Yacht Club supported our fundraising efforts. We have also been lucky enough to be chosen again as their Charity for 2012-13.

Amanda Bloom

When Amanda read about Oliver in the local newspaper she decided there had to be something she could do to help, so she arranged a Ladies' Night In evening at her hair and beauty salon



in Sale. There were jewellery demonstrations, cocktails, nibbles, a raffle and beauty treats with proceeds going to Friends of Oliver. Oliver attended for the early part of the evening

and again was a real charmer, 'encouraging' all the ladies to buy his raffle tickets. A fabulous evening was had by all, with smiles all around!

Oliver's generous friends

As we have continued to raise awareness of FOP with our friends and family, we have been overwhelmed by their generosity. The rarity of FOP has meant that every person in our lives we tell has to learn and understand about the condition. When Oliver started nursery, he made a whole new set of friends. One of his friend's mums was having a 'special' birthday and decided to forgo the usual birthday presents and asked for donations to Friends of Oliver instead. Similarly, when friends Annabelle and

Emily were Christened in autumn, their mum asked for donations rather than more toys.

St Alban's Church Christmas Tree Festival



Our local church holds an annual Christmas Tree festival where groups can decorate a tree. Friends of Oliver has decorated trees for the past two years now, enabling us to educate more people about FOP. In the first year, our tree entitled 'Oliver's Favourite Things'

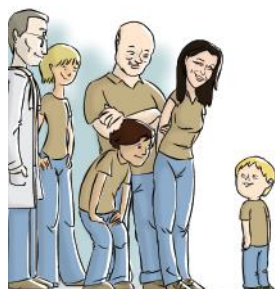
came runner up in the vote. Last year, our tree which was decorated with the handprints of Oliver's friends, won the award for 'The Most Thought-Provoking Tree'. We were particularly pleased to win this award as it illustrated how we are continuing to increase the public's awareness of this condition.



Afternoon Tea

A friend of Oliver's Grandma held an afternoon tea party in her own home and raised awareness and donations to FOP research. She is planning to hold this event every other year for the foreseeable future.

It is only thanks to our friends, family and wider public support that we can keep research into FOP and related conditions progressing giving hope to Oliver and his FOP friends.





Ambition and long term strategies

Friends of Oliver aims to improve the public awareness of FOP and related conditions with the aim of increasing the level of annual donations to make funding research both home and abroad more sustainable.

Presently the University of Oxford requires £120,000 per year to keep a small research team looking for a cure. This target, whilst small in terms of research projects, is a challenge for Friends of Oliver and others to raise due to the small number of directly impacted families within the UK (40 confirmed to date).

Funding this research has been fully on the shoulders of families and friends of those impacted by FOP and a small number of enlightened supporters. It is our goal over the longer term to expand beyond friends and family and reach the wider public to make meeting the fundraising targets a comfortable challenge instead of a yearly struggle.

If we can bring only a few hundred members of the wider public on board as donors or fundraisers, the fund raising targets become instantly more achievable and we can focus on raising more to expand research instead of only maintaining it.

If we can reach only two hundred and fifty people to commit to raising £500, then maintaining research becomes a thing of the past and instead we are fundraising to increase it.

To this end, we will be embarking on further publicity and marketing in the hope of drawing in support from the wider public. This will include further promotional videos with “celebrity” credentials. We will aim to capitalise on celebrity

social media reach with a planned “tweet” from Stephen Fry later in 2013 to his 4.5 million followers.

We are also investigating the possibility of national advertising to encourage “impulse” donations through text-giving and will continue to promote FOP via the news media.

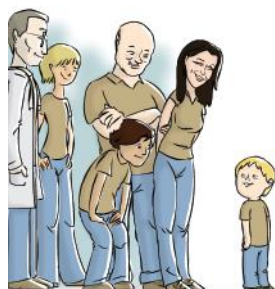
Friends of Oliver is working on a 3D cartoon about FOP. The idea is to help parents explain the condition to young sufferers of FOP, such as Oliver, but it would also serve to explain FOP clearly to their peers and classmates. In addition we would include this in information packs for the wider public.

Additionally we will continue to hold our own and support others with future fundraising events, some of which include:

- Line Dancing Events
- Yorkshire Three Peaks
- Trek Kilimanjaro
- Children’s Mini Run
- Sale Lions Father’s Day Fair
- FOP Bingo Night

We plan to explore other fundraising methods such as “letter campaigns” and applications for grants from foundations, trusts and corporations who annually give large sums to worthy causes.

As a “shot to nothing” we are also working on a mobile game in partnership with a number of individuals who will donate 50% of all revenue to Friends of Oliver.





Governance and Structure

Legal Status

Friends of Oliver 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".

Organisational Structure

Ultimate responsibility for the governance of Friends of Oliver 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 Friends of Oliver's 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.

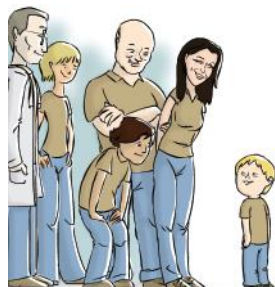
New trustees are given a copy of the Trust Deed with any amendments made to it and a copy of the charities latest Annual Report and Financial Statements. They will be expected to complete a "Trustee Declaration" form:

<http://www.charitycommission.gov.uk/Library/guidance/sampledeccc30.pdf>.

They will subsequently be inducted into the workings of the charity by an existing experienced trustee.

Employment

Friends of Oliver does not have any employees.





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;
- ✓ 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; and
- ✓ 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 maintaining proper accounting records which disclose with reasonable accuracy at any time the financial position of the charity and to enable them to ensure that the financial statements comply with the Companies Act

2006 and the regulations under Section 42(1) of the Charities Act 1993. 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.

This report was approved by the trustees on 29th May 2013 and signed on their behalf by



Chris Bedford-Gay
Chairman





Financial Review

Summary

Friends of Oliver raised £16,917.49 in the year to 28th Feb 2013 and incurred only negligible operating costs against money raised and as such is happy to report that **99.5%** of all monies raised was used directly to fund research into FOP and its related conditions.

Income and Fundraising

In the year 1st March 2012 to 28th Feb 2013 Friends of Oliver had income of £16,917.49. This income came from fundraising, events and direct donations.

Charitable Expenditure

On the 2nd January 2013 Friends of Oliver made a disbursement to the University of Oxford FOP Research Fund of £10,000 this contributed to the £120,000 annual running costs of the FOP Research project. Other expenditure of £86.96 was incurred for FRSB membership and fundraising t-shirts. £480 was spent hosting the FOP Action meeting however a designated donation was given to cover this cost.

Net Income

Friends of Oliver's net income for the period 1st March 2012 to 28th Feb 2013 was £6353.11.

Gains and losses

This is the first financial year of Friends of Oliver and as such there is no data for comparison against previous years.

Policy on Reserves

No reserves are currently held. However, It is the Trustees' intention to sustain unrestricted reserve funds at a level which will cover the charity's management and administration costs and allow the charity to capitalise on fundraising opportunities.

Future Commitments

Friends of Oliver remains committed to funding FOP research internationally. Each year the trustees decided where to make disbursements to best achieve the aims and objectives of the charity. The Trustees have decided, from 2013 onwards, that for as long as it is feasible they will fund the operating costs themselves to ensure 100% of monies raised from events goes to research into FOP.

Investments

At present Friends of Oliver has no investments.





Friends of Oliver – Balance Sheet [Period 1st March 2013 to 28th Feb 2013]

As of February 28, 2013

ASSETS

Current Assets

Current/Savings

Current Account

839.87

High Interest Account

5,613.24

Total Current/Savings

6,453.11

Total Current Assets

6,453.11

NET CURRENT ASSETS

6,453.11

TOTAL ASSETS LESS CURRENT LIABILITIES

6,453.11

NET ASSETS

6,453.11

Equity

Opening Balance Equity

100.00

Net Income

6,353.11

Total Equity

6,453.11





Friends of Oliver – Profit and Loss [Period 1st March 2013 to 28th Feb 2013]

March 2012 through February 2013

Ordinary Income/Expense

Income

Gifts and Donations Income

Company Donations	1,800.00
Events Donations	3,053.00
General Donations	1,929.87
Individual Donations	5,779.50
PayPal Donations	723.87
Virgin Money payments	3,631.25

Total Gifts and Donations Income 16,917.49

Total Income 16,917.49

Expense

Dues and Subscriptions	50.00
Gifts and Donations	10,000.00
Miscellaneous	516.96

Total Expense 10,566.96

Net Ordinary Income 6,350.53

Other Income/Expense

Other Income

Interest Income	2.40
Other Income	0.18

Total Other Income 2.58

Net Other Income 2.58

Net Income 6,353.11





Friends of Oliver – Itemised Profit and Loss [Period 1st March 2013 to 28th Feb 2013]

	Type	Date	Description	Split	Amount	Balance
Ordinary Income/Expense						
Income						
Gifts and Donations Income						
Company Donations						
	Deposit	18/05/2012	Roemex Ltd	Current Account	1,800.00	1,800.00
Total Company Donations					1,800.00	1,800.00
Events Donations						
	Deposit	23/04/2012	Great North Run Donations	Current Account	345.00	345.00
	Deposit	30/05/2012	Bingo Night Event	Current Account	24.00	369.00
	Deposit	31/05/2012	Bingo Night Event	Current Account	24.00	393.00
	Deposit	09/07/2012	Bingo Night Event	Current Account	2,636.00	3,029.00
	Deposit	27/07/2012	Bingo Night Event	Current Account	24.00	3,053.00
Total Events Donations					3,053.00	3,053.00
General Donations						
	Deposit	23/04/2012	Consolidated Donations	Current Account	189.87	189.87
	Deposit	04/05/2012	Cash Donations	Current Account	50.00	239.87
	Deposit	25/10/2012	St. Albans Church	Current Account	100.00	339.87
	Deposit	25/10/2012	General Donations	Current Account	850.00	1,189.87
	Deposit	05/02/2013	Donation Cheques	Current Account	740.00	1,929.87
Total General Donations					1,929.87	1,929.87
Individual Donations						
	Deposit	16/04/2012	Individual Donation	Current Account	2,670.50	2,670.50
	Deposit	24/05/2012	Individual Donation	Current Account	500.00	3,170.50
	Deposit	06/06/2012	Recurring Donation	Current Account	10.00	3,180.50
	Deposit	02/07/2012	Recurring Donation	Current Account	10.00	3,190.50
	Deposit	02/08/2012	Recurring Donation	Current Account	10.00	3,200.50
	Deposit	03/09/2012	Recurring Donation	Current Account	10.00	3,210.50
	Deposit	10/09/2012	Individual Donation	Current Account	2,529.00	5,739.50
	Deposit	02/10/2012	Recurring Donation	Current Account	10.00	5,749.50
	Deposit	02/11/2012	Recurring Donation	Current Account	10.00	5,759.50
	Deposit	03/12/2012	Recurring Donation	Current Account	10.00	5,769.50
	Deposit	02/01/2013	Recurring Donation	Current Account	10.00	5,779.50
Total Individual Donations					5,779.50	5,779.50
PayPal Donations						
	Deposit	08/06/2012	PayPal	Current Account	172.69	172.69
	Deposit	17/07/2012	PayPal	Current Account	280.83	453.52
	Deposit	12/10/2012	PayPal	Current Account	98.40	551.92
	Deposit	12/10/2012	PayPal	Current Account	98.40	650.32
	Deposit	23/10/2012	PayPal	Current Account	73.55	723.87





Total PayPal Donations					723.87	723.87
Virgin Money payments						
	Deposit	26/09/2012	Virgin Money Giving	Current Account	265.45	265.45
	Deposit	10/10/2012	Virgin Money Giving	Current Account	19.31	284.76
	Deposit	17/10/2012	Virgin Money Giving	Current Account	19.31	304.07
	Deposit	24/10/2012	Virgin Money Giving	Current Account	115.86	419.93
	Deposit	31/10/2012	Virgin Money Giving	Current Account	308.95	728.88
	Deposit	14/11/2012	Virgin Money Giving	Current Account	235.37	964.25
	Deposit	21/11/2012	Virgin Money Giving	Current Account	203.70	1,167.95
	Deposit	28/11/2012	Virgin Money Giving	Current Account	9.65	1,177.60
	Deposit	05/12/2012	Virgin Money Giving	Current Account	48.27	1,225.87
	Deposit	12/12/2012	Virgin Money Giving	Current Account	38.62	1,264.49
	Deposit	19/12/2012	Virgin Money Giving	Current Account	241.37	1,505.86
	Deposit	28/12/2012	Virgin Money Giving	Current Account	1,046.12	2,551.98
	Deposit	03/01/2013	Virgin Money Giving	Current Account	62.68	2,614.66
	Deposit	09/01/2013	Virgin Money Giving	Current Account	2.89	2,617.55
	Deposit	16/01/2013	Virgin Money Giving	Current Account	96.54	2,714.09
	Deposit	23/01/2013	Virgin Money Giving	Current Account	328.39	3,042.48
	Deposit	30/01/2013	Virgin Money Giving	Current Account	47.30	3,089.78
	Deposit	13/02/2013	Virgin Money Giving	Current Account	184.91	3,274.69
	Deposit	20/02/2013	Virgin Money Giving	Current Account	31.86	3,306.55
	Deposit	27/02/2013	Virgin Money Giving	Current Account	324.70	3,631.25
Total Virgin Money payments					3,631.25	3,631.25
Total Gifts and Donations Income					16,917.49	16,917.49
Total Income					16,917.49	16,917.49
Expense						
Dues and Subscriptions						
	Bill	19/10/2012	Fundraising Standards Board	Accounts Payable	50.00	50.00
Total Dues and Subscriptions					50.00	50.00
Gifts and Donations						
	Cheque	02/01/2013	University of Oxford FOP Research	Current Account	10,000.00	10,000.00
Total Gifts and Donations					10,000.00	10,000.00
Miscellaneous						
	Cheque	24/01/2013	Kustom Clothing Ltd (FoO T-Shirts)	Current Account	36.96	36.96
	Cheque	30/01/2013	The Oxford Hotel (FOP Action Meeting 30/1/2013)	Current Account	480.00	516.96
Total Miscellaneous					516.96	516.96
Total Expense					10,566.96	10,566.96
Net Ordinary Income					6,350.53	6,350.53
Net Other Income/Expense						
Other Income						
Interest Income						





	Deposit	04/05/2012	Interest	Current Account	0.03	0.03
	Deposit	03/08/2012	Interest	Current Account	0.22	0.25
	Deposit	03/09/2012	Interest	Current Account	0.27	0.52
	Deposit	05/10/2012	Interest	Current Account	0.10	0.62
	Deposit	05/10/2012	Interest	High Interest Account	1.78	2.40
Total Interest Income					2.40	2.40
Other Income						
	Deposit	12/04/2012	PayPal - Verification Transaction	Current Account	0.02	0.02
	Deposit	12/04/2012	PayPal - Verification Transaction	Current Account	0.16	0.18
Total Other Income					0.18	0.18
Total Other Income					2.58	2.58
Net Other Income					2.58	2.58
Net Income					6,353.11	6,353.11

Notes to accounts

Friends of Oliver incurred costs of £566.96. However, of those costs £480 were covered by a designated donation toward hosting the FOP Action meeting. As such, costs against fundraising are £86.96. This means that of all fundraising **99.5%** is directly contributed to funding research projects for FOP and related conditions.

