



(Formerly known as FOP Friends of Oliver)

2014 Annual Report &

Financial Statements

(Year Ending 1st March 2014)



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.



FOP Friends

Charity name:	FOP Friends
Working Names:	FOP Friends of Oliver, FOP Action
Registered at:	1 Cumberland Road, Sale, Cheshire M33 3FR, United Kingdom
Registered:	March 2012
Charity #:	1147704
Governed by:	Trust Deed
Trustees:	Christopher Bedford-Gay Alison Acosta Bedford Rachel Almeida Fiona White John Lever
Bankers:	HSBC, Co-operative bank
Independent auditor:	P.S. Hutchinson BSc FCA, 246 Park View, Whitley Bay, Tyne & Wear, NE26 3QX

Contents

Our Vision	1
Our Mission	1
FOP Friends.....	2
What is Fibrodysplasia Ossificans Progressiva (FOP)?.....	6
Introduction and chair's statement.....	7
Thank you to our supporters.....	7
Who we are	8
Trustees	9
Christopher Bedford-Gay	9
Alison Acosta Bedford	9
Rachel Almeida	9
Fiona White	9
John Lever.....	9
Meeting charity commission guidelines.....	10
How we raised our money.....	11
How we spent money raised	11
Achievements	12
Drug developer grant	12
GDUK grant.....	12
Fund Raising Standards Board.....	13

Social media activity	13
Media relations	13
Providing £20,000 to further FOP research.....	13
International FOP Involvement	13
Impact and value	13
Go Team Oliver!	14
Rochdale Spring Fair	14
Dancing the Night Away!.....	14
Anyone for Tea?	15
Our first Car-boot!	15
Making a splash!.....	15
Nidderdale Charity Walk	16
Three Peaks Challenge	16
Cake sale.....	16
@stephenfry.....	16
Worthington Park.....	17
Burning their toes to cure FOP toes	17
Go Joshua!	17
Dress down for FoO.....	17
Bingo Evening	18
Pryke Trust.....	18

St. Alban's Church	18
Millie's coffee morning.....	18
Trish's lunch.....	19
The Castle is king!.....	19
Zumba the night away!	19
Cheadle's Big Bang	19
Brilliant Bake-Off	20
Ladies' Night.....	20
A Tree-mendous Success!	20
A very expensive Christmas card!	20
Millie's Fund	21
100 years young!.....	21
On your marks, get set, bike!	21
Charity Football Match.....	21
Pampered Ladies!.....	22
Super singers!.....	22
Super Sev	22
Future plans.....	22
Ambition and long term strategies.....	23
Preventing misdiagnosis.....	23
Fundraising	23

Family support.....	23
Medical support	23
Governance and structure.....	23
Legal Status.....	23
Organisational Structure	24
Trustee recruitment and training.....	24
Employment	24
Statement of responsibilities of the trustees.....	24
Financial review	26
Summary	26
Income.....	26
Grants and trusts.....	26
Fundraising and donations.....	26
Charitable expenditure.....	26
Net income	26
Gains and losses	26
Policy on reserves.....	26
Future commitments.....	26
Investments	26
Independent examiner's report	27
Responsibilities of the trustees and examiner	27

Basis of independent examiner's report	27
Independent examiner's statement.....	27
Consolidated statement of financial activities	28
Balance sheets.....	28
Notes to the financial statements.....	28
1. Accounting policies	28
2. Voluntary income.....	29
3. Activities for generating funds.....	29
4. Other incoming resources.....	29
5. Charitable activities.....	29
6. Governance.....	30
7. Debtors.....	30
8. Creditors.....	30
9. Restricted funds	30
Our history (to March 2014).....	31
Thank you to (March 2013 – March 2014).....	32
Donors	32
Trusts / Grants.....	32
Corporate	32
Community / Clubs & Associations	32
Fundraisers	32

Donors of time and resources	32
Corporate	32

What is Fibrodysplasia Ossificans Progressiva (FOP)?

FOP turns otherwise healthy children 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".



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 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 in our third year, we have had success in grant and trust fundraising as well as increased fundraising by new FOP families and we continue to go from strength to strength.

We aim to continue raising awareness of FOP to aid in 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 my Oliver but also the many other FOP families present and future.

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

I would like to extend my personal 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 all touched by this terrible condition, now or in the future.



Chris Bedford-Gay

Founder and Chairman of FOP Friends.

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.



Fibrodysplasia Ossificans Progressiva (FOP) causes progressive debilitation eventually leading to early death.

FOP research has far reaching implications for 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**, **post-hip surgery** complications. More recently, a rare form of childhood brain cancer, DIPG, will 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 with FOP at the age of 1 (he is now 6 ½).

Originally setup to thank friends and family who were fundraising toward FOP research in the name of Oliver, it soon became clear that a dedicated UK FOP charity would benefit the whole FOP community, at which point FOP Friends (formerly FOP Friends of Oliver) the charity came to be.

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 support existing patient organisations; existing research programmes such as at the University of Oxford; promotes FOP research worldwide; and helps other FOP families.

As a fully registered charity, FOP Friends became in a position to take advantage of funding opportunities and programmes from which only registered charities can benefit. To date, over £70,000 in grants/trust funding has been won.

Each year the trustees vote on which 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.

As we grow as a charity, 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



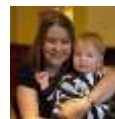
Founder, Chairman, Trustee and Dad to Oliver with FOP. Since Oliver's diagnosis I have become heavily involved in the search for a cure internationally. In addition to founding FOP Friends I serve on the board of the IFOPA, FOP Action and represent the UK FOP community internationally. I do this alongside my day-job as director of UK based technology company, Skillsarena.

Alison Acosta Bedford



I am a mum of two and a Chartered Management Accountant. On entering our third year as a charity, I take a moment to reflect on how much we have grown and learnt. The family symposium held in May was a huge success and proves as a charity the value we add. I remain committed to using my professional skills as well as my personal relationships to raise awareness and funds for research into finding a cure for this terrible condition, for my nephew Oliver and all his FOP Friends.

Rachel Almeida



I am Head of Events for an Association, organising education-related Conferences. I have worked in events for over 10 years so I am hoping to put my experience and expertise to good use, helping raise funds for FOP research. As a family member, I was heartbroken 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 everyone with FOP can live long, healthy and fulfilling lives.

Fiona White



I am a primary school teacher/senior leader and having been a close friend of the Bedford-Gay family for many years, I was devastated to learn about Oliver's condition. I have come 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.

John Lever



As a dad, when I heard about Oliver and others with FOP, I wanted to do what I could to help. As a first step, I produced a video through my creative company and I am enjoying exploring some exciting new ideas. It is a privilege to be part of such an inspiring team, on such an important mission.

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 will also benefit a large number of people suffering with common health conditions.

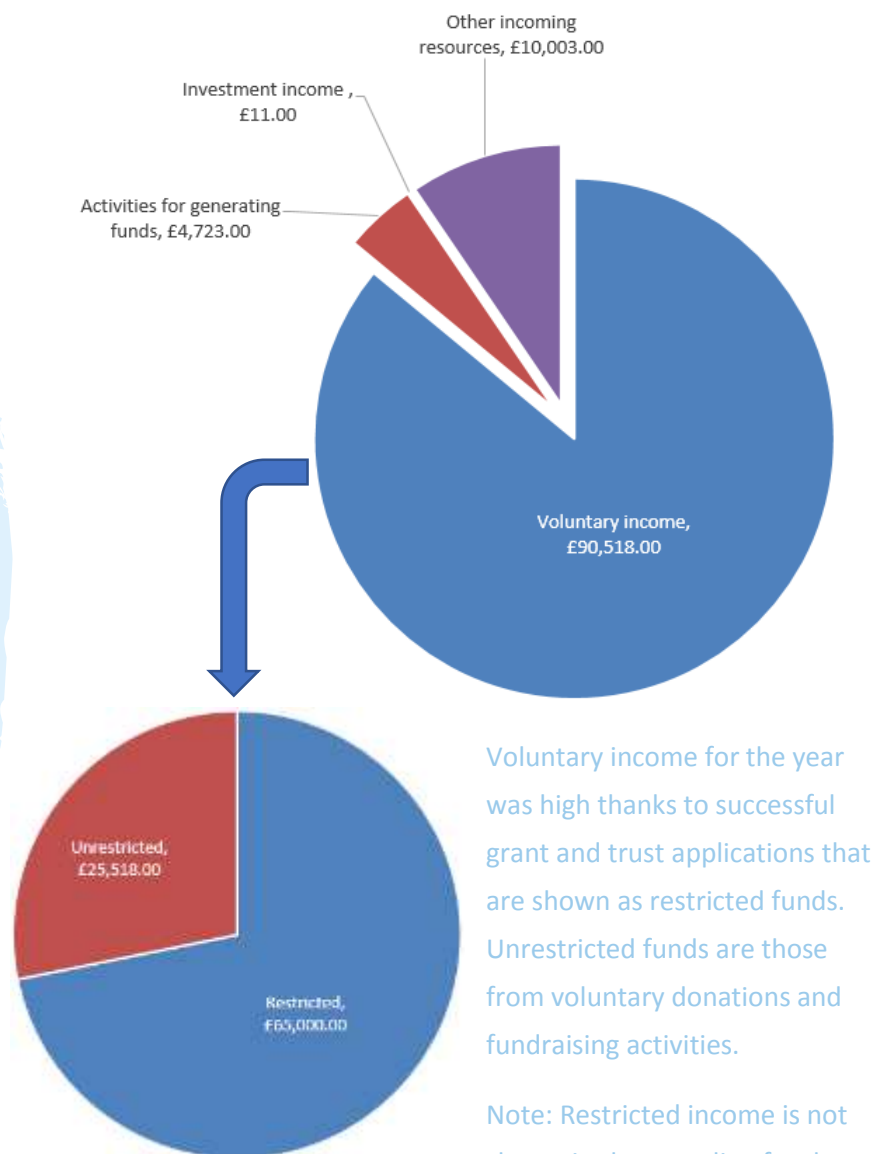
- ✓ To support organisations researching treatments and a cure for FOP and related conditions.

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.

How we raised our money



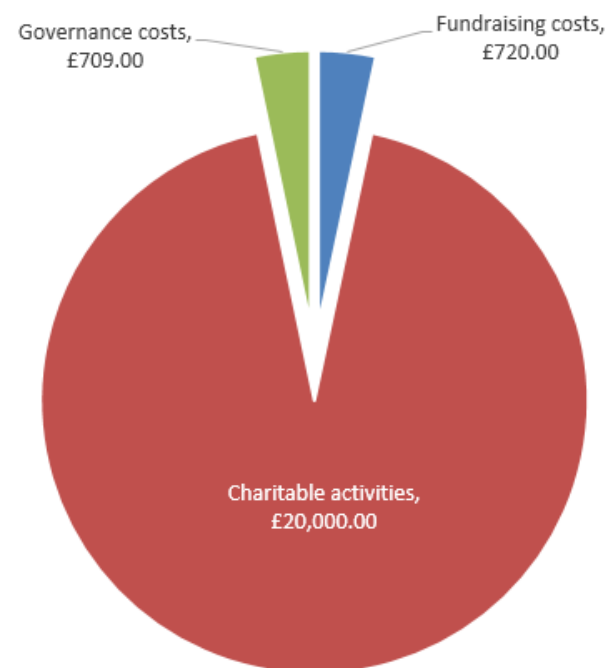
Voluntary income for the year was high thanks to successful grant and trust applications that are shown as restricted funds. Unrestricted funds are those from voluntary donations and fundraising activities.

Note: Restricted income is not shown in the spending for the

year as this falls outside this reporting year, which ended 1st March 2014.

How we spent money raised

Fundraising costs for the year were associated with payments to secure 10 Great North Run 2014 places for our FOP Runners' team.



Charitable activities of £20,000 is expenditure on the University of Oxford FOP Research team.

Governance costs are those associated with running the charity such as accounting and statutory matters.

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

Presently we have minimal overheads, which means that almost every penny donated funds the research to finding a cure for this devastating condition.

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. Oxford is one of a small number of institutions in the world conducting research into a cure for FOP.

Achievements

During the year, we were successful in a number of areas most notably with grant and trust applications and 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 however not be possible without the continue support of other FOP Families.

Major achievements include securing a drug developer grant, a further GDUK grant, funding from trusts and growing awareness through social media activity, traditional media and outreach campaigns.

Drug developer grant

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 University of Oxford.



The chemist will have the challenge of taking the Oxford FOP Research Team's drug designs and turning them into optimised drug candidates.

GDUK grant

Late in 2013, our chairman Chris, successfully presented to a panel of GDUK (Jeans for Genes) representatives seeking a grant of £16,000 to fund a part-time charity assistant.

The assistant will help with the day-to-day running of the charity as well as help to raise awareness and funding through donations, grant and trust applications, and corporate sponsorships.

The search for the assistant will begin late 2014 with the aim of them starting in early 2015.



Fund Raising Standards Board



FOP Friends maintains its voluntary registration with the Fund Raising Standards Board (FRSB).

The FRSB is the independent self-regulatory body for UK fundraising. The FRSB work with member charities, suppliers and the wider charity sector to encourage commitment to and compliance with best practices in fundraising.

Social media activity



The power of social media today is massive and the more we can spread the word about FOP, the more awareness we can raise and hopefully prevent any devastating misdiagnoses whilst also raising funds to support the research. Thank you to everyone who has helped with our campaigns.

Our Facebook page has exceeded 1000 likes and our Twitter followers are ever increasing with multiple posts re-tweeted. LinkedIn continues to grow FOP awareness within the corporate community and Google+ although being used minimally at present is setup and in operation.

Media relations

FOP Friends continue to make use of local and national media where appropriate to raise awareness of FOP and encourage fundraising. We are however very cautious when approaching the media and only "go public" when it benefits the FOP community.

Providing £20,000 to further FOP research

FOP Friends made its second direct disbursement to support the Oxford FOP Research team, a donation double that of 2013.

International FOP Involvement

Chris Bedford-Gay (Chairman of FOP Friends) continues his role on the board of the IFOPA working on international FOP projects and meeting annually with researchers at the



University of Pennsylvania and other board members. In addition



as part of his role as IPC for the UK Chris has also attended his first FOP Italia meeting, this offers the opportunity to meet with researchers and other FOP organisations from across Europe and the wider world (including Japan,

America and China). International collaboration and effort is critical to the pursuit of a cure for FOP.

Impact and value

Now two years old, the charity has grown from strength to strength capitalising on its charitable status with success with grants, trusts, and corporate support.

Our second calendar year culminated in a dispersal of funds in December 2013 to the University of Oxford; double that of the previous year. Topped only by the organisation and success of the first UK FOP Conference and Family gathering for 12 years.



It is this where we feel we had the greatest impact on the on the FOP community: an event that brought families together and provided individuals with access to the world experts in FOP as well as all the latest information on FOP research and future clinical trials.

Nothing we do however 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 fundraise, and donations that ensures the search for a cure can continue.

We have included a small selection of the events, fundraisers, and support we have had in this charity year.

Go Team Oliver!

When Archie, 6, from Oliver's school heard his mum and her friend talking about the Liverpool Half Marathon he was inspired to have a go himself.



Archie decided he would run the 1.5k Manchester Mini Run and having heard about Oliver in assembly, wanted to run for FOP Friends. His little sister Maddie wanted to join in as did friends



Jeremy, Liam, Duncan and Eloise. They all turned up to the Etihad Stadium on a bright but chilly Bank Holiday morning and did a Gangnam style warm-up to get them all going. There was an excited but cooperative atmosphere with everyone cheering each other on. All the children made it past the finish line and although they were exhausted towards the end of the race, being reminded of the good cause they were running for spurred their little legs on! Eloise finished the race on her mummy's shoulders! And the medals, sweets and comics as a prize really finished off a great morning!

Rochdale Spring Fair

Our annual coffee morning at Rochdale Town Hall was a big success! Lots of friends and family braved the rainy spring morning to see what wares were on sale. Some of the attractions included homemade cakes, handmade cards, crafts, bunting, toys, bric-a-brac, a tombola and a raffle. As ever, there was plenty of coffee and tea for all!



Dancing the Night Away!

Grandma Ann's ever-popular line dancing evening continues to raise funds with a bring-and-share table and live music.



The evening was as much fun as ever with nearly one hundred ladies and gentlemen taking to the dance floor to show off their latest moves!

Anyone for Tea?

We were delighted to hear that the Royal Northumbria Yacht Club, Blyth, had selected us to be their charity for a second year running. Their new social secretary, Karen Blenkinsop, felt we were such a worthy cause and wanted to do as much as she could to help. The RNYC held their 2nd charity tea party on the Club ship 'House Yacht Tyne', a former Trinity House Light ship built in 1879. Many of the members baked cakes, pies and scones and donated prizes for the tombola so a splendid array of goodies were on offer. The social committee ladies served the tea and did a splendid job of keeping everyone's cups and plates filled!



A fantastic day was had with over 60 members attending and donations kindly given from those who could not be there. There was a large television screen showing pictures of Oliver and playing our Stephen Fry narrated FOP awareness video.

Our first Car-boot!



After our Spring Fair at Rochdale, we were still left with quite a lot of bric-a-brac, so we had the bright idea of going along to a car boot sale. So, early one Sunday morning, Helen and Alison (with five small people in

tow!) went along to the local high school. The sun came out and as crazy as it sounds, everyone had a great time! We raised more funds for FOP but importantly were able to hand out more leaflets and continue to raise awareness of FOP.

Making a splash!

Oliver has been taking swimming lessons for some time and absolutely loves it! His swimming teacher, Fran, wanted to do something to help Oliver so suggested that Sale Leisure Centre's annual Fun day would be held to raise money for FOP Friends.



The Centre was open to everyone with swimming, bouncy castles, dance mats, climbing walls and more all available for everyone to try out. Fran and her colleagues held a cake sale and raffle to raise extra funds for FOP research. A photographer from the local paper turned up and Oliver was the star of his very own photo-shoot, making the front page of the local paper the following week.

Nidderdale Charity Walk



Martin Coupe of Bamford, Rochdale has been a close friend of Oliver's family for many years, so when the Harrogate Rotary Club held its Nidderdale Charity Walk he decided to pull on his walking boots and

take advantage of Barclays fund matching to benefit FOP Friends.

Martin writes "This year the Harrogate Rotary Club held its 20th Walk and we had a super day on the hills above Pateley Bridge walking for the 8th year in a row up a steep hill to Greenhow. The 8 miles were completed by 8 Members of the Rochdale Rotary Club & their wives.



Three Peaks Challenge

As a trustee, Fiona White wanted to do a big sponsored event for FOP Friends so organised 'Team Oliver' to scale the Yorkshire Three Peaks.



She writes "After months of training the day finally arrived when a team of people would attempt to climb three peaks in Yorkshire, in less than 12 hours. The team included myself, Diane and Mike Winterburn, Paul and Jill Rogan, Vinny Suggit, Lisa Hill and Lesley

Tetlow. The peaks are well known and include Pen-y-Ghent (691 metres), Whernside (736 metres) and Ingleborough (723 metres).".

The team began their challenge at around 8:30am, and between 8 and 11 hours later, all of the team were enjoying well-deserved drinks.

Cake sale

Not only has Diane Winterburn been part of the Yorkshire Three Peaks Challenge, but her beautiful daughter, Rachel, kindly organised a



cake sale at her school, Bacup and Rawtenstall. Rachel is a Year 8 student and on learning about FOP decided she wanted to do something to raise awareness and money for research. Rachel, along with the help of some of her friends, spent a few nights before the cake sale baking delicious cakes which were sold at the students' break time.

@stephenfry

Many of you will have seen our video that explains FOP that was brilliantly narrated by Stephen Fry. Well, in July, Stephen tweeted about his video and encouraged all his followers to visit our website. We were instantly hit with thousands of visitors to our site and over the following days we had more than 20,000 new visitors. Some were so touched by what they learned they donated, signed our petition, and continue to support us today.

Worthington Park

Every year the Sale Lions hold a Father's Day fair at Worthington Park with stalls and rides galore, so this year we decided to go along with a stall to



raise awareness of FOP. We put up our marquee bright and early and set out a tombola to draw the crowds in and raise a little money along the way. We also had a 'Name the Bear' competition, donated by Great Nan Laura, which proved to be very popular (the bear turned out to be called Maisie!).

While Leo and Eddie ran around the field all day, Oliver did a great job selling tombola tickets and practically running the tombola single handedly! We were able to speak to many people about the devastating effects of FOP and hand out leaflets to continue to raise awareness.

Burning their toes to cure FOP toes

On Saturday 16th November, Chris took part in a fire walk with some of his friends from the Cheadle and



Gatley Round Table. Chris, Carl and Lars braved the burning hot embers to walk across and raise money for FOP Friends.



Carl, Lars and Chris all completed the challenge safely. Ticking another thing off the bucket list along the way!

Go Joshua!

Many years ago, Helen taught a lovely family called the Birlesons....Fast forward 10 years and through the joys of Facebook, the family heard about Oliver and his condition. Wanting to help, the family have supported many fundraising events. Then Jane's boyfriend, Joshua Robertson decided to choose FOP Friends as his charity to run for in the Great North Run.



Dress down for FoO

The ladies over on UKScrappers have always been great supporters of FOP Friends, generously donating their beautiful handmade cards for us to sell at our fairs. When Becky Gotch learned about Oliver's condition, she nominated FOP Friends as a charity for one of her companies, BishopsCourt Solutions in Essex, dress down days. We were particularly touched by this kind gesture as Becky has never met Oliver yet felt moved by what she had learned to reach out and help us.

Bingo Evening

We held our second bingo evening at the Moorfield Pub and it was a great night! Despite peculiarly balmy temperatures for summer in Sale, friends and family packed out the room for an evening of bingo with lots of great prizes.



John Morley who has been a friend of Oliver's family for many years hosted the evening. Carlos, Oliver's uncle, ably assisted him. Oliver also helped on the evening doing what he does best: selling raffle tickets!

There were many fabulous prizes to be won which had all been donated by local businesses.

There was much laughter and many nail-biting moments, waiting for someone to call house... but the evening was a resounding success.

Pryke Trust

The Pryke Trust is a small charity in Framlingham, Suffolk who give money to people in need in their local community. When they heard about Millie's diagnosis with FOP they were the first people to make a donation, kick starting Millie's FOP Fund.



St. Alban's Church

Last month we had a lovely surprise when a donation arrived from the Parish Council of St. Alban's Church, Broadheath. Every year, the church



donates to local, national and international organisations and this year we were the very happy beneficiaries of their kindness. Oliver and his family have always been made to feel more than welcome at the church. For the third year running, we will be contributing a themed tree to the delightful Christmas Tree Festival which is held the first weekend in December.

Millie's coffee morning

On November 23rd we held a gathering at Wickham Market Football Club where friends made cakes for a coffee and catch up morning in aid of FOP on behalf of little Millie. We raised a fantastic amount between us all totalling £152.55 which we donated to Millie's fund.



A big thank you to Wickham Market Football Club for hosting it and all those who made cakes and donated which helped make it such a successful fundraising event.

Trish's lunch

Ladies and Gentlemen of Dinnington, Newcastle, enjoyed a delicious afternoon tea, hosted by Patricia Coles and ably assisted by Gail and Matthew, 'Uncle Matty'.



The Tea brightened up a cold, grey afternoon as people arrived at the Sacred Heart Church Hall, Gosforth, to enjoy a selection of homemade sandwiches, muffins and cakes.

There was a tombola and home-baked cake stall too. Thanks to Trish for organising the event and for everyone who came along to make it such an enjoyable afternoon.

The Castle is king!

The Castle Inn in Framlingham is the local village pub of Millie's family and closest friends. Led by the landlords Alan Knight, Henrietta Lewis and their team, they have worked to support Millie's family with their



fundraising efforts since they learned of Millie's. They have supported various fundraising events and held events of their own. They held a Snowflake Disco and the raffle was donated to Millie's fund. They held a Christmas Draw, drawn by local MP DR. Daniel Poulter. The chefs at the Castle

Inn also provided the bacon for the much-needed bacon sandwiches at the Charity Football Match! But perhaps the most entertaining event to date that they have hosted was the Mankini Mile by Pete Borg. Lorraine, Millie and their family are so grateful to both the team at the Castle Inn and the 'regulars' for the generosity they have shown and their continued support, it is thankfully received.

Zumba the night away!

As a Zumba teacher, Vicki Lewis from Kimpton, Hertfordshire, has held many charity Zumba events to raise money for good causes. When she learned about FOP she decided she wanted to help so organised another charity Zumbathon but this time for FOP Friends.



Cheadle's Big Bang

Cheadle and Gatley Round Table held their annual charity Big Bang bonfire and firework family evening. The event was organised by members of the Table.



The night was a huge success and the cold, drizzly weather did not deter people from turning out in their thousands to enjoy the event. There was a fun fair, enormous bonfire and two spectacular firework displays. Thanks to the hard work of the C&G Round Table.

The Round Table fundraise for the fantastic Together Trust charity, but we received a delightful surprise when we found out they were going to donate some of the proceeds to FOP Friends too.

Brilliant Bake-Off

Kelly Doyle, a friend of Millie's mum had the great idea of holding a Bake-Off to raise funds for FOP at Rendlesham Primary School, Suffolk, where she works. The whole school, parents and pupils alike, went to town showing off their baking talents to produce a range of tasty treats to sell, with all proceeds going to FOP Friends.



Ladies' Night

Back in December, Jessica Felton, along with Oliver's former child-minder the lovely Janet Plumb, decided to organise a friendly and informal crochet evening to raise money for FOP Friends. A group of keen beginners braved a chilly December evening to visit Jessica's house to be warmly met with mince pies, making and merriment! After much concentration, laughter and a few glasses of wine, everyone went home with their first ever granny squares.



A Tree-mendous Success!

FOP Friends contributing a tree to the charming 'Festival of Christmas Trees' at St. Alban's Church, Broadheath.

Oliver's classmates all drew pictures of themselves, their teachers and family, and the portraits were then stuck onto 'hands' and glittered up. Visitors to the Festival were then invited to vote for their favourite tree and the tree they found most thought-provoking. We were truly surprised and honoured when we learned that we had won 'Most Thought Provoking' tree for a second year running. Whilst Oliver was delighted to have won, we were pleased that we are achieving our aim of raising awareness of FOP.



A very expensive Christmas card!

A number of people decided not to send Christmas cards this year, instead choosing to donate the money to FOP Friends. Well, we're delighted to tell you that we raised nearly £800 from 'not-sent' cards!



We would particularly like to mention the Shiremoor Community Association and all its members who collectively raised £145 and Mactech who chose us as their Christmas charity to receive an amazing £500!

Millie's Fund

Since receiving the devastating diagnosis only a few month ago, Millie's friends and family have been working tirelessly to raise money to support the race to find a cure for FOP.



The way the local community have rallied around to support Millie overwhelmed Millie's mum Lorraine and her family.

Millie's band of supporters have had some fabulous ideas to raise money, whilst everyone involved has had a good time into the bargain!

100 years young!

FOP Friends feels honoured to have a centenarian, Mrs Laura Gregory, as one of their supporters. Laura is also Oliver's Great-Nan. We were all proud and excited to be able to celebrate her 100th Birthday in January, and if truth be told. By the time you get to 100 years of age, you pretty much have everything you want (!!) so instead of gifts, Laura asked for donations to FOP Friends and raised an impressive £400!



On your marks, get set, bike!



The staff at Millie's old nursery school The Granary, decided to do a fundraiser to help little Millie. Allie Green writes, "It was a staff decision to support FOP Friends. We always have some kind of sponsored activity to support Children in Need or Comic Relief and this time we decided we would like to also share any raised monies with FOP Friends".

Almost 60 children took part in our sponsored pedal. They were challenged to pedal on a tractor, bike or trike a minimum 3 times around a circuit in the nursery playground. Donors sponsored per lap or a lump sum.

Charity Football Match

In December last year, a charity football match was held at Framlingham Town Football Club in aid of Millie and FOP Friends.

It was the bright idea of Andy Upton and he arranged it with his good friend and Lorraine's partner, Chris Thomas.

Despite the cold December weather, there was an enthusiastic turnout and people dug deep to make generous contributions to the event. There was a raffle and warming bacon sandwiches for the keen supporters.

There was plenty of banter between the two teams and the excitement built up in the weeks



before the big game, with both teams wanting to claim the honour of being the winner of Millie's Football Match

Pampered Ladies!



A group of lovely ladies were treated to a lively evening of good food, wine and fun!

Oliver's neighbour Nicola decided to host a Pampered Chef evening to raise money for FOP and over twenty

ladies enjoyed her hospitality whilst admiring her rather impressive kitchen!

There was a fun cookery demonstration using gorgeous stoneware and nifty tools whilst we enjoyed a glass or two of wine. We were also allowed to sample the delicious food too!

There was a raffle with, amongst other things, a cute cupcake cushion donated by Janet. Nicola kindly donated her hostess's commission to FOP Friends.

Super singers!

Pauline Black writes: "The choir concert was the first ever "public" performance of The Moor Cottage

Singers. We are a group of mums from Didsbury who have been meeting for about a year. The audience was made up of a select



group of friends and family and, as we thought it presumptuous to charge for entry, asked for donations for FOP Friends on the night.

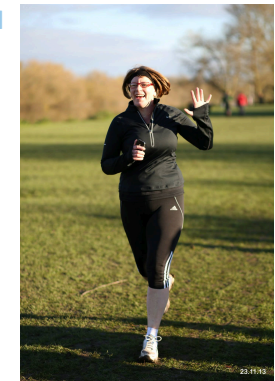
Super Sev



Sev Konieczny from Reading, wasn't looking for a challenge but when she heard about Millie and her diagnosis, Sev wanted to do something to help. We caught up with her, "I did say that I would never do another half marathon but

changed my mind when I read the devastating

message of my friend Lorraine about her daughter Millie's diagnosis with FOP. The shocking reality to have no cure and solely relying on donations to fund research was the incentive I needed to sign for my local half marathon, the popular Reading half.



Sev was proud to have represented FOP Friends and even prouder to have contributed a little to the "cure pot".

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 Child Support Assistant who will work within the charity.

Ambition and long term strategies

Our ambition and long term strategies remain consistent.

- ✓ To grow the charity to make the annual fundraising target of £125,000 more easily achievable.
- ✓ To increase public awareness and expand beyond friends-and-family fundraising.
- ✓ 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.

Preventing misdiagnosis

- Increase public awareness 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 by helping and encouraging more FOP families to become actively involved.
- Through increased public awareness to expand beyond friends and family fundraising to become a charity of choice for the general public to support.
- We will increase efforts in trust and grant fundraising which is a new route to financial support.

- Actively seek corporate sponsorship as “charity of the year” as another route to funding.
- Alternative fundraising campaigns such as “letter campaigns”
- Seeking celebrity patrons to both increase awareness and actively encourage and support fundraising.

Family support

- We aim to run more regular family gatherings to with a social gathering being investigate for 2015.
- Continue to provide support and advice to existing and recently diagnosed FOP families.

Medical support

- 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.
- Helping to set-up UK clinical sites for future clinical trials and patient based research.

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 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;

- ✓ 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; 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 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 **31st October 2014** and signed on their behalf by



Chris Bedford-Gay

Chairman

Financial review

Summary

Total incoming resources for the year amounted to £105,255 with net incoming resources of £83,826.

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

Income

Income for the year totalled £105,255 made up of unrestricted funds from fundraising and voluntary donations together with income from successful grant and trust applications and UK FOP conference fees.

Grants and trusts

The charity received a total of £65,000 from grants and trusts.

Fundraising and donations

Income from fundraising and voluntary donations totalled £30,241.

Charitable expenditure

On the 16th December 2013 disbursement of £20,000 were made to the University of Oxford FOP Research Fund. This contributed to the £120,000 annual running costs of the FOP Research team. Other expenditure included FRSB membership, costs incurred through awareness and fundraising and general running costs.

Net income

FOP Friends' net income for the year was £83,826. Of this £65,000 is to fund a Medicinal Chemist at the University of Oxford and £10,003 towards running the UK FOP Conference in May 2014.

Gains and losses

Income from fundraising and voluntary donations rose by over £13,000 to a total of £30,241.

Policy on reserves

The Trustees have reviewed the reserves of the charity. Our policy is to aim to maintain fundraising reserves in unrestricted funds at a level of £5,000 - £10,000 to cover any unforeseen costs.

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, funds have been committed to fund a Medicinal Chemist at the University of Oxford together with running the UK FOP Conference.

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 2014, which are set out on pages 4 to 6.

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), and;
- ✓ 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:

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

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

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

Consolidated statement of financial activities

	Notes	Restricted £	Unrestricted £	2014 £	2013 £
Incoming resources					
Incoming resources from generated funds					
Voluntary income	2	65,000	25,518	90,518	13,964
Activities for generating funds	3	-	4,723	4,723	3,053
Investment income			11	11	3
Other incoming resources	4	10,003	-	10,003	-
Total incoming resources		75,003	30,252	105,255	17,020
Resources expended					
Cost of generating funds					
Fundraising costs		-	720	720	37
Charitable activities	5	-	20,000	20,000	10,480
Governance costs	6	-	709	709	50
Total resources expended		-	21,429	21,429	10,567
Net incoming resources		75,003	8,823	83,826	6,453
Reconciliation of funds					
Total funds brought forward		-	6,453	6,453	-
Total funds carried forward		75,003	15,276	90,279	6,453

Balance sheets

	Notes	2014		2013	
		£	£	£	£
Current assets					
Debtors	7	1,488			
Cash at bank		89,391		6,453	
		90,879		6,453	
Creditors: amounts falling due within one year	8	(600)		-	
Net current liabilities			90,279		6,453
Net assets		£	90,279	£	6,453
Funds					
Restricted	9		75,003		-
Unrestricted			15,276		6,453
		£	90,279	£	6,453

Notes to the financial statements

1. Accounting policies

Basis of accounting

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

Fund accounting

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

Unrestricted income funds comprise those funds which the trustees are free to use for any purpose in furtherance of the charitable objects. Unrestricted funds include designated funds

where the trustees, at their discretion, have set aside resources for a specific purpose.

Incoming resources

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

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

Investment income is included when received.

Resources expended

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

Costs of generating funds

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

Governance costs

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

Irrecoverable VAT

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

2. Voluntary income

	2014	2013
	£	£
Donations	55,518	13,964
Grants	35,000	-
	90,518	13,964

3. Activities for generating funds

	2014	2013
	£	£
Fundraising events	4,723	3,053

4. Other incoming resources

	2014	2013
	£	£
Conference fees	10,003	-

5. Charitable activities

	2014	2013
	£	£
Research payments	20,000	10,000
Conference meeting costs	-	480
	20,000	10,480

6. Governance

	2014	2013
	£	£
Accountancy charges	600	-
FRSB membership fee	50	50
Bank charges	59	-
	709	50

7. Debtors

	2014	2013
	£	£
Gift Aid tax recoverable	1,438	-
Prepaid expenses	50	-
	1,488	-

8. Creditors

Amounts falling due within one year:

	2014	2013
	£	£
Accrued expenses	600	-

9. Restricted funds

	Balance brought forward	Incoming resources	Resources expended	Balance carried forward
	£	£	£	£
Research fund	-	65,000	-	65,000
Conference fees fund	-	10,003	-	10,003
	-	75,003	-	75,000

The Research fund represents monies received to fund the employment and equipment of a Senior Medicinal 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 Conference fees fund represents donations and delegates deposits received in respect of the FOP Conference in May 2014.

Our history (to March 2014)

2008 (March)	Oliver Peter Bedford-Gay born.
2008 (November)	Oliver has mysterious lump removed from the back of his head.
2009 (April)	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.
2011	Chris attends FOP Action meeting in Oxford.
2011	First of many line dancing evenings held, which have been one of our biggest fundraisers.
2012	FOP Friends of Oliver website goes “live” together with “What is FOP?” animated video narrated by Stephen Fry.

2012 (June)	FOP Friends of Oliver becomes a registered charity # 1147704.
2012 (December)	Chris becomes an “informal” member of University of Pennsylvania FOP research team to collaborate in development of the International FOP Flare-up survey which helps guide future clinical trial and natural history study designs.
2012 (December)	First donation to the University of Oxford to support its research team: £10,000.
2013 (March)	First newsletter is published to celebrate the many different fundraising events being held across the country.
2013 (December)	Awarded a grant to employ a Senior Drug Developer at the University of Oxford.
2013 (December)	Annual donation to the University of Oxford’s research team, this time £20,000.

Thank you to (March 2013 – March 2014)

Donors

We would like to acknowledge our ever-growing collection of generous direct donors. A list that we hope will grow year on year.

Trusts / Grants

Genetic Disorders UK

The Amateurs Trust

Corporate

Roemex Ltd

Proctor and Gamble

Community / Clubs & Associations

Cheadle & Gatley Round Table

Royal Northumberland Yacht Club

St. Alban's Church, Broadheath

Fundraisers

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

Donors of time and resources

Corporate

Foliozine: Logo and website design.

Clarity: Stephen Fry narrated FOP Animation.

Benchbyte Ltd: Website hosting and maintenance.

Panopus Printing: Leaflet printing and conference materials.

Armstrong Design: Leaflet design.

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