



# FOP Friends

## 2020 Annual Report

## & Financial Statements

Year ending 1<sup>st</sup> March 2020



### Charity name

FOP Friends

### Working names

FOP Friends of Oliver, FOP Action

### Registered Address

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

### Registered

March 2012

### Charity number(s)

1147704, SCO46950

### Governed by

Trust Deed

### Independent auditor

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



## Vision

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

## Mission

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

## Values

Committed to funding medical research to realise a cure for FOP and related conditions; to understand how we can prevent it and improve the life and well-being of those who are afflicted by it.

Respects the integrity, ambition, and interests of all FOP patients, acts as a champion, and provides a safe haven for patients and families.

Strives to be a centre of excellence for the provision of information on medical research, diagnosis, treatment and care, and participation in clinical trials.

Act always with honesty, professionalism, and ethical awareness.

Work collaboratively with medical researchers and clinicians, patients and families, donors, and supporters to realise our Vision and complete our Mission.

## Founding Trustees

Christopher Bedford-Gay

Alison Acosta Bedford

Rachel Almeida

## Trustees

Fiona White

John Leaver

Helen Bedford-Gay

Nicky Williams



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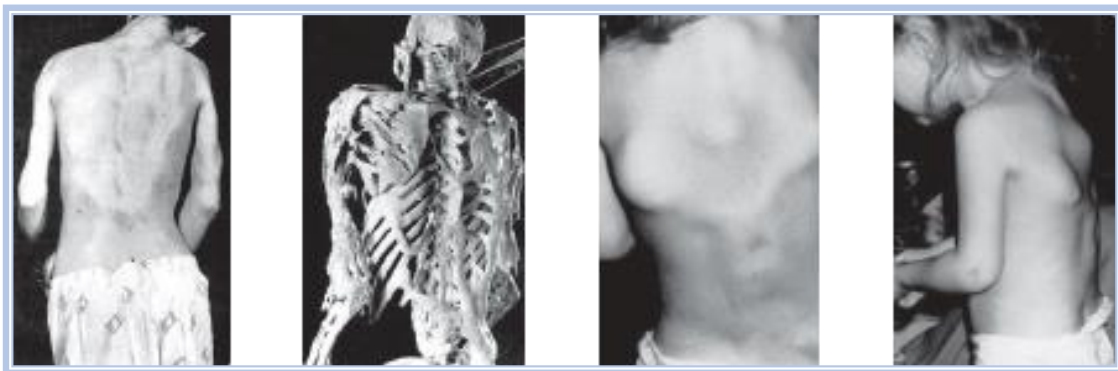
## What is Fibrodysplasia Ossificans Progressiva (FOP)?

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

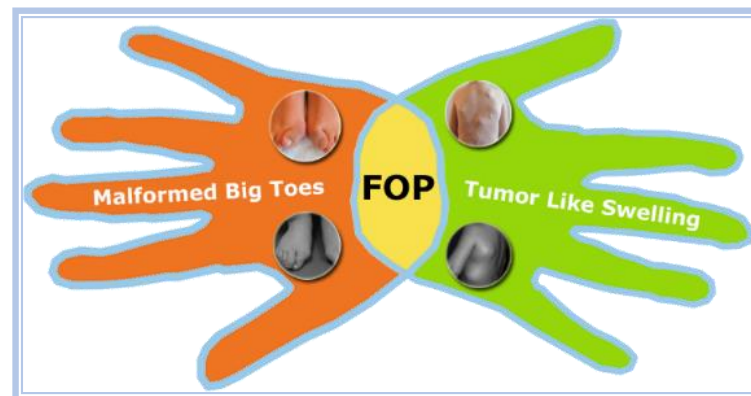
Bridges of extra bone develop across the joints, progressively restricting movement, forming a second skeleton that imprisons the body in bone. There are no other known examples in medicine where one normal organ system turns into another.

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

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



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



## Introduction and Chair's Statement



As we say goodbye to another year as a registered charity, we can see on the horizon some trouble brewing. That trouble is in the form of a virus which has the potential to make our next charity year an interesting one, in particular our planned biennial conference and family gathering scheduled for May 2020. However, for now we will focus on the year just ended and celebrate all that we have achieved.

12 years ago, our family found out that our first child, Oliver, had been born with Fibrodysplasia Ossificans Progressiva (FOP). He was just one year old at the time. There existed a small patient group, FOP Action, but no UK charity dedicated to supporting FOP families and funding research.

My wife and I, along with family and friends, ran fundraising events to support research and raise awareness of FOP. Through this, we encountered barriers to accessing further help and funding so decided to become a fully registered charity, receiving full charitable status in 2012.

We have continued to grow our support locally, nationally, and internationally. We have had continued success in grant and trust fundraising but an increasing struggle with community fundraising. This is an issue we need to address because it is our fundraising that funds FOP research at Oxford University and help us raise FOP awareness and support families.

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

We are internationally recognised as a key partner and source of support and information by families, researchers, and pharmaceutical companies alike. It is this, with our continued

involvement at the board level of the IFOPA and international efforts that we are the go-to organisation for many.

Our initiatives such as #FunFeet4FOP, family focused conferences, family weekends, and our promotional and information items are influencing many. The family support we provide is outstanding, being the first point of contact for the newly diagnosed in the UK, but often internationally too. We make introductions and contacts between families and medical professionals, advising on challenges, the day-to-day and simply being there when needed.

Hard work and time have got us this far: it will take more to make our vision a reality. With continued support, we will change the lives of every FOP family present and future.

My thanks go to our supporters who help fund our work (through events, sponsorship, or donations), and to the volunteers who help. Without your support we could not keep moving forward. You keep hope alive for all touched by this terrible condition, now and in the future.

Chris Bedford-Gay, Founder of FOP Friends.



## About us / Who we are



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

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

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

FOP Friends was founded following the diagnosis of Oliver Bedford-Gay (10) with FOP at the age of 1. The aim of the charity is to support the search for a cure, whilst raising awareness and educating the public and medical world of the condition. FOP Friends supports existing research programmes such as at the University of Oxford and patient organisations; promotes FOP research worldwide; and helps other families impacted by FOP.

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

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

## Trustees

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

### Christopher Bedford-Gay - Trustee and Chairman



Chris has been involved with the FOP community since his son Oliver's diagnosis in 2009. He was one of the founding trustees of FOP Friends, after learning that there was no UK charity to support

families with FOP. Chris served as chairman of FOP Action (which has now been integrated into FOP Friends) and has also been a Board Member of the IFOPA since 2011. He is Chairman of the IFOPA International Presidents' Council, bringing together FOP organisations and leaders from across the world. He carries out this work alongside his day-job as director of UK based technology company, Skillsarena.

## EDUCATION

- 1st Class BSc Hons, Computing for Business

## EXPERIENCE

- Software engineer and consultant at GlaxoSmithKline
- Software engineer at Defence Evaluation Research Agency
- Technical Director, Turtlez Ltd (10 years)
- Director and CTO, Skillsarena Ltd (current)
- Chairman and Area Chairman, Round Table
- IFOPA Board member

### [Alison Acosta Bedford - Trustee](#)



As one of the founding trustees, Alison has been on this journey from the beginning. Alison is a Chartered Management Accountant so assists with the financial accounts of the charity, along with other administrative tasks, and supporting fundraising efforts. As chair of the trustee meetings, Alison remains committed to using her professional skills to assist in managing the day to day staffing and operation of the charity, as well as utilising personal relationships to raise awareness and funds for research into finding a cure for this terrible condition.

## EDUCATION

- BSc Hons, Mathematics, University of Sheffield
- CGMA Chartered Institute of Management Accountants.

## EXPERIENCE

- Over 16 years' finance experience within social housing
- Experience of long-term financial planning as Treasury and Investment Manager of a housing association with over £60m annual turnover
- Experienced in Workforce Development through Manchester Chamber of Commerce & Industry

Alison is proud of how much FOP Friends has grown since forming and of the biennial family symposium held in May, which highlights how important FOP Friends has become to the FOP community.

### [Rachel Almeida – Trustee](#)



Rachel is Head of Events and Sponsorship for the Association of Colleges, organising education-related conferences. She has worked in events for over 18 years and is pleased to be able to put her experience and expertise to good use. Rachel was inspired to complete her first ever fun-run in aid of FOP Friends, completing the Great North Run half marathon in under 2hr 30 minutes.

## EDUCATION

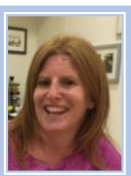
- BSc Hons, German and Law, University of Surrey

## EXPERIENCE

- International trade shows
- International economic research charity dissemination conferences
- Head of Events and Sponsorship (current) – leading a team to deliver 40 education conferences per year with direct responsibility for a £1.7m annual turnover

Rachel looks to use her personal drive to work hard alongside fellow trustees and the whole of the FOP Community to find a cure for FOP.

### Fiona White - Trustee



Fiona is a lead teacher working in a primary school. She works as a member of the senior leadership team having gained the National Professional Qualification in Senior Leadership (NPQSL). As a close friend of the Bedford-Gay family for many years, Fiona was devastated to learn about their son Oliver's condition. She has grown to understand just how important it is to raise awareness of FOP and ensure much needed funds are raised in order continue the search for a cure.

## EDUCATION

- BEd. (Hons.) Degree in primary education
- National Professional Qualification in Senior Leadership

## EXPERIENCE

- Classroom teacher across Key Stages 1 and 2
- Advanced Skills Teacher - supported schools with curriculum development and teaching and learning
- Primary School ICT Manager

- Lectured at Newcastle University - OFSTED
- Lectured at Leeds University - Teaching Students

Fiona is dedicated to using her professional skills to support FOP Friends' vision. The growth of the charity and its ability to support the FOP community makes her more determined to be part of the progress towards finding a cure.

### John Leaver - Trustee




When John heard about Oliver and others with FOP, he wanted to do what he could to help. As a first step, he produced a video through his creative company, claritycomms.com, engaging Stephen Fry to provide the voice over and to subsequently tweet to his millions of followers. John is now enjoying exploring some exciting new ideas to help FOP Friends raise awareness and funding. He feels it is a privilege to be part of such an inspiring team, on such an important mission.

### Helen Bedford-Gay – Trustee



Helen has been with the charity since the very beginning. Having come to terms with the devastating diagnosis that her son, Oliver, had FOP, she felt the need to become proactive in the search to find a treatment, so he could have as normal a childhood as possible. Helen also recognised the need for a





proactive support network for families affected by FOP. Helen has taken a largely behind the scenes role, supporting and thanking the fundraisers around the country as well as developing much of the charity information that is in circulation. Helen also drives many of the fundraising activities in the local community. Unfortunately, since Oliver was diagnosed, there have been more young children in the UK who have received the same news. Helen often acts as the first point of call for families; she is able to offer parents a network of friends who understand their distress and can offer guidance for the incredibly difficult times ahead. Having been an experienced teacher, Helen has the knowledge and ability to offer practical guidance and support for parents and schools regarding mainstream education for their child.

#### EDUCATION

- BA (Ed.) QTS Hons. Durham

#### EXPERIENCE

- Classroom teacher across Key Stages 1 and 2, with experience of KS1 leadership
- Fulbright Exchange Teacher to USA

In addition to the work for the charity, Helen continues her career as a primary school teacher, and is also mum to Oliver's younger brothers Leo (10) and Harry (8).

#### Nicky Williams – Trustee



Nicky feels passionate around raising awareness of FOP and raising funds to get the cure that is in all our dreams. Nicky's daughter Isla was one of the youngest children to be diagnosed with FOP. After coming to terms with the initial shock of diagnosis, Nicky began fundraising to support the search for treatments. Along with her network of friends and family, Nicky continues to organise a series of successful events and

sponsored sporting activities to raise funds in aid of FOP Friends. Nicky works part-time as a Marketing Campaigns Manager for Avaya and she has used her business contacts to gain support for the charity from several large companies and organisations.

#### EDUCATION

- 1st Class Management degree from University of Brighton
- More recently completed various Marketing courses around social media, speaking engagements, event management, digital marketing

#### EXPERIENCE

After graduating, Nicky worked for the UK charity The Duke of Edinburgh's Award where she was a Marketing Coordinator and managed events and a large show trailer that travelled the UK. The last 11+ years have been spent as a marketer within the IT industry with a wide variety of experience in campaign management and field marketing.



## Meeting Charity Commission guidelines

In setting FOP Friends' objectives and planning activities, the Trustees have considered the Charity Commission's general guidance on public benefit.

### Principal objects

THE RELIEF OF DISTRESS AND SICKNESS FOR THOSE AFFECTED BY FIBRODYSPLASIA OSSIFICANS PROGRESSIVA (FOP) A TRAGIC, DEGENERATIVE AND DEBILITATING CONDITION AND TO IMPROVE THE LIVES OF SUFFERERS AND THEIR FAMILIES.

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

TO RAISE PUBLIC AWARENESS AND UNDERSTANDING OF FIBRODYSPLASIA OSSIFICANS PROGRESSIVA (FOP) AND TO PROMOTE EDUCATION AND RESEARCH INTO THE STUDY AND CURE OF FOP AND RELATED CONDITIONS.

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

TO SUPPORT CHARITIES AND ORGANISATIONS IN THE UK AND ABROAD BY UNDERTAKING CHARITABLE ACTIVITIES TO FUND RESEARCH; AND TO PROVIDE HELP, SUPPORT, CARE AND TREATMENT FOR PEOPLE AFFECTED BY FOP AND RELATED CONDITIONS.

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

TO SUPPORT ORGANISATIONS RESEARCHING TREATMENTS AND A CURE FOR FOP AND RELATED CONDITIONS.

Public Benefit: Research into a treatment, and eventually a cure, for FOP will benefit all existing sufferers and all those in the future diagnosed with the condition. It will also benefit many more common related conditions, which affect a larger section of the public and the Armed Forces.

PREVENTING MISDIAGNOSIS.

Public Benefit: The rarity of FOP has resulted in many cases of misdiagnosis. This has led to FOP patients receiving incorrect information and interventions, resulting in a more rapid progression of the condition and unnecessary surgery and treatments. As children will continue to be born with FOP, preventing misdiagnosis is one of FOP Friends' key public benefits and achieved through our previously stated aims of awareness, education, and advocacy.



## Research Highlights

### University of Oxford -Stop FOP / Saracatinib

We continue to support the research team at Oxford University. The team, led by Professor Alex Bullock, continue to research FOP and potential treatments. Investigations by the team led to the identification of saracatinib as a potential drug candidate for FOP.



Since identification, further testing and continued positive results have led to the formation of an international team to move forward with an academic lead clinical trial.

The StopFOP trial is a collaborative effort, with other centres of FOP research around Europe. The trial sites will be split between the UK, Germany, and Netherlands. They are currently looking to recruit 20 adult patients. Funding for the trial comes from the Innovative Medicines Initiative. AstraZeneca provides in-kind support through provision of the drug compound and expertise. It will be overseen by Dr Marelise Eekhoff. [StopFOP.com](https://www.stopfop.com)

The Phase II study of saracatinib is planned to begin in March 2020. The team includes experts from VU University Medical Center, Royal National Orthopaedic Hospital NHS Trust, Klinikum Garmisch-Patenkirchen, University of Oxford, Brigham and Women's Hospital, AstraZeneca, Innovative Medicines Initiative, and several national FOP Patient Organisations from across the EU, including FOP Friends.

However, the work does not stop there. The Oxford team continue to research to understand FOP and continue to look for other potential treatments that could change the future for patients living with FOP.

### Regeneron -Garetoismab



In January 2020, Regeneron started their year by announcing promising results for their Phase 2 trials of garetoismab. Garetoismab is an anti-activin-a antibody that came to the fore after Regeneron's discovery of the critical role Activin-A appears to play in FOP's unwanted bone-growth.

The trial enrolled 44 patients between the ages 18 – 60. Further analysis of the trial data continues but it is hoped that this could be used as the basis of future regulatory submissions for Garetoismab's use as a treatment for FOP.

Paediatric studies are also yet to be undertaken but this is another exciting step towards a possible treatment for FOP.

### Ipsen - Palovarotene



Palovarotene is a RAR $\gamma$  agonist being developed as a potential treatment for FOP. Original by Clementia Pharmaceutical's and continuing with Ipsen following their acquisition of Clementia early in 2019.

Unfortunately, due to safety reports (of early growth plate closure in children), late in 2019 a partial clinical hold was issued for the paediatric population (14 years and younger) taking part in palovarotene trials. This hold remains in place whilst questions from regulatory bodies are answered.

## How we raised our money

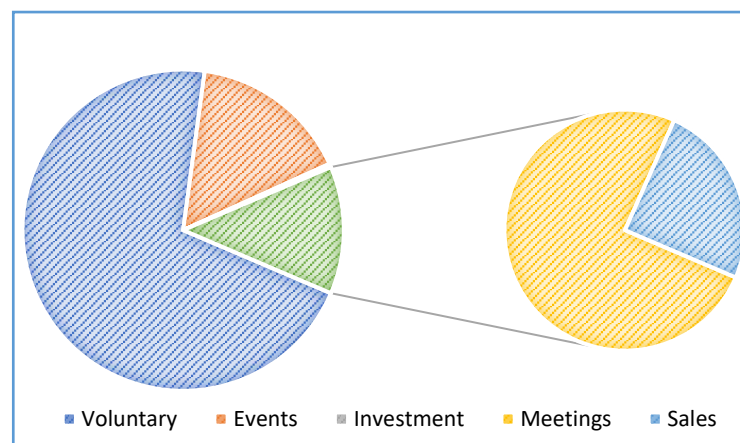
Voluntary income accounts for the bulk of money raised within the charity's financial year. A small amount is attributed to investment income (interest on bank balances) and £22,725 revenue from fundraising events, a 215% increase from 2019.

Whilst an impressive increase in revenue from fundraising events occurred, voluntary income from donations overall reduced to £68,904 for the year, a decrease of 6% overall.

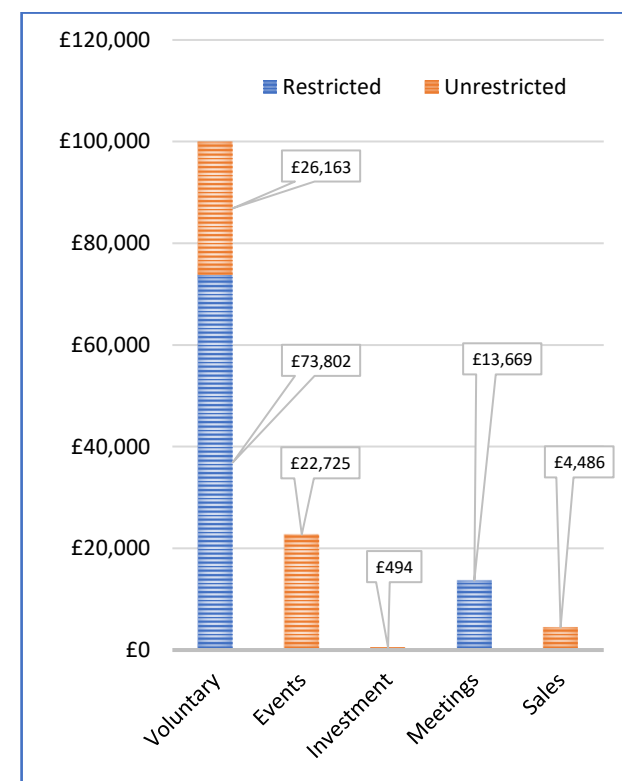
However, we saw an increase in income from Grants awarded for projects in line with our charitable objectives of £31,061 which saw our total voluntary income raise by 15% to £99,965 for the charitable year ending 2020.

In addition, revenue of £18,155 is attributed to conference fees (£11,169), FOP Family Weekend (£2,500) and sales (£4,486).

Type	Total	%
<b>Voluntary</b>	£99,965	70.73%
<b>Events</b>	£22,725	16.08%
<b>Investment</b>	£494	0.35%
<b>Meetings</b>	£13,669	9.67%
<b>Sales</b>	£4,486	3.17%
<b>Total</b>	<b>£141,339</b>	<b>100%</b>



From a total £141,339 incoming resources, £87,471 (62%) were restricted. The remaining £53,868 (38%) being unrestricted.



Since 2015 unrestricted income has declined year-on-year, except in this charity year which saw a modest 3.4% increase on 2019.

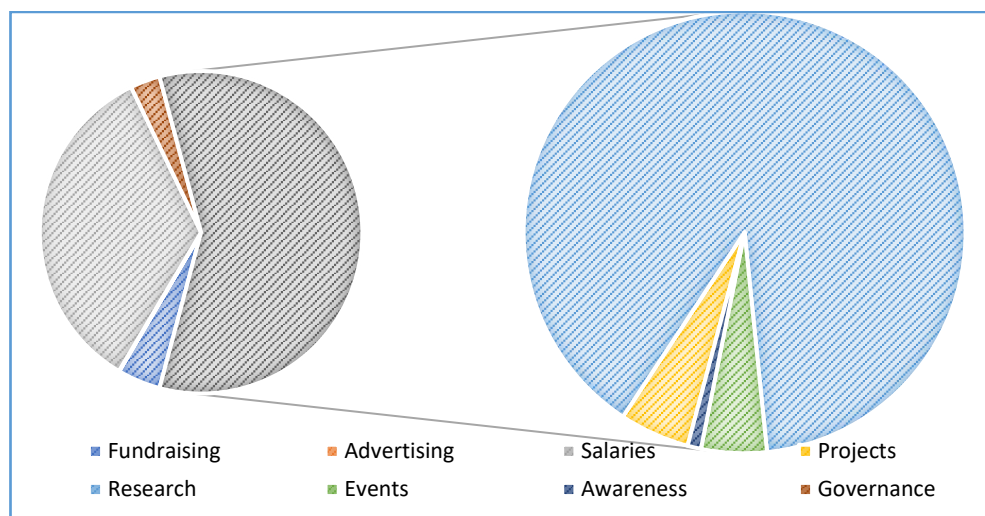
Unrestricted income therefore poses our biggest fundraising challenge as it is the main source of FOP research funding. Restricted income mainly be being generate through grants and trusts and restricted to specific projects.





## How money raised was spent

Since 2013, FOP Friends has operated with paid staff and volunteers. Staff and operational costs continue to be largely supported with restricted grants and donations in line with our charitable objects. This means 95% of all fundraised money directly supports our charity objects of; family support; awareness; and funding research. [\[Note: Voluntary Donations VS Fundraising Costs\]](#)

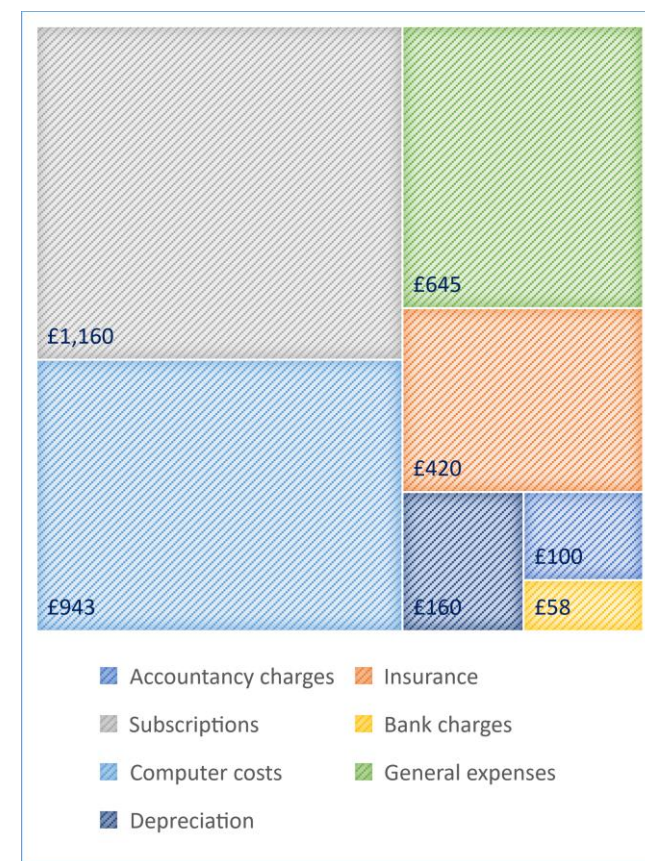


The main beneficiary of FOP Friends is the FOP Research team at the University of Oxford who received £60,500 in research funding. Led by Professor Alex Bullock, the team is one of a small number in the world conducting research into FOP.

Fundraising costs of £5,030 are attributed to securing 15 x Great North Run places, 1 x London Marathon place, and the provision of fundraising materials and merchandise to support these and other fundraising events.

Resources expended on staff salaries (£40,002) continues to be funded through grants and corporate sponsorship leaving “fundraised” money designated to the charity objects.

Governance costs of £3,486 are attributable to the continued operation of the charity.



Governance includes basic operational costs, accounting fees, insurance, postage, professional memberships, and costs associated with training and supporting trustees and staff.



## Achievements

### 2019 Jeannie Peeper International Leadership Award



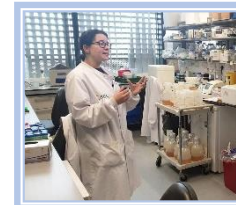
Helen and Chris were honoured to receive this award for Outstanding International Leadership, in recognition of their contribution to the FOP community both in the UK, but also on an international stage. As well as being Chairman of FOP Friends, Chris is on the Board of the IFOPA and is the Chair of the International President's Committee. Helen also serves as a volunteer on several non-elected committees for the IFOPA, working with other FOP community representatives to improve the information and support for people affected by FOP.

### Regeneron: Clinical Trials App



Helen has worked closely with Regeneron to assist them with the creation and development of an App which will support children who are participating in clinical trials. The App hopes to offer a practical tracking of the trial, in a fun way, with a vision to reduce the stress of participation in a trial by adding in a gaming element which is so popular and powerful with young people these days. Helen has liaised between Regeneron and the patient families, and also assisted with the organisation of a workshop for collaboration between the App developers and the patients. The App is now in its final stages of development. We look forward to seeing the finished product and using it as an effective tool with our young people as they embark on potentially life-changing clinical trials.

### Providing funding to Oxford FOP Research



Year on year, FOP Friends and its supporters have successfully funded the FOP



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

### Oxford Vice Chancellor's Circle

Helen and Chris were pleased to represent FOP Friends at the University of Oxford's Vice Chancellor's Dinner, in recognition of the charity's ongoing financial support for the FOP research team at the University.



### International FOP involvement

Chris Bedford-Gay (Chairman of FOP Friends) continues his role on the board of the International FOP



Association (IFOPA) working on international FOP projects and meeting annually with researchers at the University of Pennsylvania and other board members for his 7th year.



Additionally, as part of his role as Chair of the IFOPA International Presidents Council (IPC), Chris has also attended many international FOP meetings and works to bring together national FOP leaders to tackle the search for a treatment/cure for FOP and to share challenges faced by FOP families the world over.

Helen worked on a committee with the IFOPA, to help to create an information video/cartoon which explains FOP to a young audience, whilst celebrating all our differences.

### EURORDIS



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

EURORDIS seeks to achieve this through advocacy at the European level, support for research and medicines development, facilitating networking amongst patient groups, raising awareness, and many other actions designed to reduce the impact of rare diseases on the lives of patients and family.

### Fundraising Regulator



FOP Friends is voluntarily registered with the Fundraising. The Fundraising Regulator is the independent self-regulatory body for UK fundraising. The Fundraising Regulator works with member charities, suppliers, and the wider charity sector to encourage commitment to and compliance with best practices in fundraising.

### A Young Leader is Emerging



Following on from the success of his previous presentation, Oliver travelled with Helen and Chris to the IPSEN Head Office, Slough, to give a presentation on his life with FOP.

Another young person with FOP also attended. Oliver spoke to over 200 employees from the company and answered questions as part of a patient panel. Chris also gave a presentation, and Helen and Chris also took part in the patient panel. Oliver's speech was incredibly well received and was very powerful for those who are working on the development of palovarotene.

### Social Media Activity



FOP Friends continues to be proactive on social media, increasing its followers year on year. It proves to be a useful communication tool to raise awareness of the condition as well as celebrate the contributions and achievements of our fundraisers who tirelessly fundraise to support us.

## New Website Launched

In January 2020, FOP Friends was delighted to launch its new and improved website. A huge thank you to the team at AND Digital, Manchester, who donated a team of staff to develop and build the website. We needed a new website, to ensure that we provided relevant and useful information to our families and supporters. The new website is host to information about FOP as a medical condition, as well as introducing us as an organisation. It is also a celebration of our achievements. There is information about what to do in an emergency, as well as quick access to the International Clinical Council of FOP's medical guidelines.



Based on the success of our first Christmas Card campaign, we released a new design for the 2019 Christmas Card. This made a profit for the charity, but also helped to raise awareness of FOP and the charity through branding and a brief explanation of the condition on the reverse of the card.

## Supporting a child with FOP: a practical guide to their learning journey



We were thrilled to launch our first publication, a practical school guidebook, for families and professionals working with a child with FOP. The project was made possible thanks to a grant from Regeneron. We felt very privileged to have the foreword written by Stephen Fry.

We worked with families, teachers, an SEN consultant, parents, and medical experts to produce the book. We were most pleased to be able to use many photos of children living with FOP in the guide to illustrate the possibilities and potential for young people living with FOP.

A copy of the book was given, free of charge, to the family and an additional copy was sent to the child's school. A poster, with an inspirational quote from one of our FOP mums, was also sent with

the book. The book was also made available as a pdf to download. The book was very well received, and families from countries other than the UK also requested copies. Such was the interest in the guide, we are now looking into adapting the book to address the different requirements of the education systems around the world. We hope to be able to work with patient organisations and parents around the world, including the IFOPA, in a collaborative effort.

## FOP Family Weekend



We hosted our second family respite weekend at Center Parcs, Sherwood Forest in May 2019. The event was made possible thanks to grants from Genetic Disorders UK, The Adamson Trust, Bruce Wake Charitable Trust, and The Hedley Foundation. Thirteen of our FOP families attended the weekend and it was a great success.







The bonds of friendship developing between the young people but also their parents and carers, was clear to see. We were also able to welcome the family of newly diagnosed little girl. This gave the mum a lifeline to knowing she was not going to be alone. The impact of this weekend on all the families was clear to see. “[We loved] making memories with the FOP families that hold a very special place in our hearts and make this journey so much easier and brighter,” FOP parent.

### #FunFeet4FOP – Fire Walking!



In April, to celebrate the fourth #FunFeet4FOP campaign, we held one of our biggest and most ambitious fundraising events yet: a fire walk! We had 22 supporters who literally walked over hot



coals to raise the much-needed funds for FOP research. We had three different FOP families attend, along with two local councillors, and an FOP medical specialist. There was also a raffle which included a signed Manchester United football.



## Impact and value



FOP Friends continues to work with the FOP community in the UK, but also the wider international community and is recognised as an influential organisation in all fields, from patients and families, to pharmaceutical companies and medical professionals.

FOP Friends continues to benefit from the fantastic ongoing efforts of FOP families, friends and the wider public. The funding FOP Friends receives allows the search for a treatment and a cure for FOP to continue within the UK. The income generated has

allowed the charity to continue its financing of the University of Oxford FOP Research team, supporting international research, as well as providing increased support and resources for families touched by FOP.

We continue to benefit from our charitable status with success with grants, trusts, and corporate sponsorship. However, nothing would be possible without the phenomenal support of the communities in which those touched by FOP live; those communities who have gone out of their way to aid the small number of FOP families. It is only through their generosity, willingness to help with fundraising, and their direct donations, that the search for a cure can continue.

The FOP community may be small, but it makes a big difference.

### Supporting Families

To continue to offer support to our families and the medical professionals who work with them, we have produced several free to download resources including a simple leaflet, *Fibrodysplasia Ossificans Progressiva: the essential facts*, a leaflet which outlines the key points of the condition and is written in a simple to



access Q&A style. The leaflet was medically endorsed by Dr Richard Keen.

Other resources include a list of support guides and support groups available to people living with FOP; information about how we can help people as a charity; directories of the FOP specialists, both in the UK and international; and dental advice for patients with FOP.

We also collated the information from all the UK's Ambulance Trusts, to advise our families how to place a marker on their homes to ensure they receive the appropriate medical care from the paramedic team in the event of an emergency.

We provide free, ongoing support for families. We liaise with different agencies; support families with writing documents such as ECHPs; and advocate for patients with educational and medical agencies.

### Finding the undiagnosed: Tin Soldiers Documentary



Chairman Chris and trustee Nicky took part in filming for the 'Tin Soldiers' documentary which provides a personal perspective on living with FOP from diagnosis. Chris also assisted the production team in filming at the University of Oxford, accessing our FOP research teams labs and interviewing Professor Alex Bullock who leads the team and Dr Ellie Williams.



The Tin Soldiers documentary, and the follow-on global outreach campaign, aims to find the undiagnosed FOP patients across the globe of which there are approximately 7000 (Based on 1 in 1,000,000 incidence and a global population of 7.8 Billion).

### Working with students

We were pleased to be able to offer student placements to a student from the University of Chester, as well as a student from the University of Manchester.



As part of our goal to raise awareness of FOP within the medical community to prevent misdiagnosis, we were pleased to

have the opportunity to work with the organisation Medics4RareDiseases, and to be paired with a student as part of their FindACure Student Essay competition. We were paired with final year student Sandy Ayoub, who wrote her essay on "Dual Deprivation: Dual Deprivation: Understanding the Psychological Burden that Coexists with the Physical Struggles in Individuals with Rare Diseases and their Caregivers". We paired her with a family of a young person with FOP, as well as discussing the challenges many people who are living with FOP face. We were



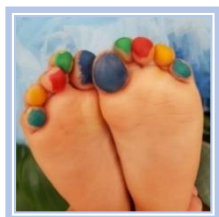




delighted when Sandy placed runner up in the competition, which is open to medical students from all around the world. Sandy qualified as a doctor in Summer 2019, and as a part of the essay competition, was invited to present her essay in February to Findacure's Drug Repurposing for Rare Diseases Conference, thus introducing a number of the next generation of medical professionals to FOP. We hope to have the opportunity to work with another student for next year's competition as we recognise the value being able to educate the next generation of medical professionals.

### Fundraising events

#### #FunFeet4FOP & FOP Awareness Day



The fourth #FunFeet4FOP campaign was a huge success. Why feet? Because the first sign of FOP is malformed big toes. This classic sign is seldom recognized because of a lack of awareness of FOP, and this leads to FOP being misdiagnosed in many cases (often as cancer).

People from around the world shared pics of their decorated feet or flamboyant footwear.

#### Skydive for FOP

The brother of one of our adults with FOP chose to take part in a skydive to raise money and awareness of FOP. Whilst the adult lives in the UK, his brother took the 12,000ft leap of faith on the other side of the world in his hometown of Queenstown, New Zealand.



#### Charity Badge for Brownies



Four Brownies decided to raise awareness of FOP by creating a presentation for their Brownie pack to teach them about FOP. They also baked and sold cakes and made their own leaflets to teach people about FOP.

### Express Solicitors

We were pleased to be chosen as a charity of the month at a local solicitor's office.

### London Marathon 2020

We were delighted when we were successful in the London Marathon Charity ballot, being awarded a place for the April 2020 event.

### Great North Run

Five years after our first Team FOP Friends for the Great North Run, we were thrilled to have another team of twelve fabulous runners taking part in support of us. Of note, one of the runners was an FOP specialist doctor who travelled up from London to don the white shirt for us and raise much needed money for research. She dedicated her run to all the children she cares for who are living with FOP and reflected on a different child for every mile.



### Lambrook School

The staff and pupils at Lambrook school continue to be some of our longest serving supporters, in honour of Isla whose aunt works at the school. Isla's cousin gave a presentation to the school in an assembly, and wrist bands were handed out to raise awareness.



## Freemasons

We were thankful to the Masonic Hall who held a Gala Dinner, including a presentation about FOP as a condition, to its guests. The event raised over £2500.

## Future plans

Going global with our recently released “Supporting a child with FOP: a practical guide to their learning journey” is one of our biggest plans for 2020 through 2021. We are aiming to secure additional funding to translate the school guidebook into multiple languages and with country specific adaptations. Expanding our support of the global FOP community following the success of the UK focused first edition.

In addition to this, we are hoping to begin development of the “FOP and Me” journal for children. With professional illustrations, honest information, practical tips, and space to reflect and celebrate, this book aims to support not only children with FOP, but their siblings and friends too.

Plans are underway to gain funding and support to run subsequent Family Weekends. These are weekends where families dealing with FOP can step-away and enjoy a relaxed atmosphere with others in the same situation. After the success of our first and second weekends away in 2017 and 2019, we plan round three for 2021 after our 2020 family gathering.

This leads us on to our plans to hold our 2020 FOP Conference and Family Gathering, currently scheduled for May 2020. However, the writing may already be on the wall for this. As we compile this annual return, the world appears to be entering a difficult period with the appearance of COVID-19, we shall see.

Finally, continued awareness and fundraising is planned to ensure research at the University of Oxford continues to be funded and the level of family support FOP Friends offers can continue.

We aim to move further towards being a sustainable organisation whose day-to-day operation is not entirely dependent upon the time and commitment of the founders and their families (who run the organisation alongside full time jobs and family commitments).

## Ambition & long-term plans

### Charity objectives

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



abreast of the work that FOP Friends undertakes, progress with research and to thank those who fundraise for us

### Preventing misdiagnosis

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

### Fundraising

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

### Family support

- To continue to provide support and advice to existing and recently diagnosed FOP families

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

### Medical support

- To reach out to health professionals and professional bodies to create interest and awareness of FOP to help prevent misdiagnosis and to increase the available support for those with FOP
- To help establish UK specialist centres for the care and treatment of FOP patients
- To strengthen the reliability of our information sources by engaging medical professional as advisors



## 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.

FOP Friends registered with The Scottish Charity Regulator (OSCR) in November 2016, SC046950.

### Organisational Structure

Ultimate responsibility for the governance of FOP Friends is with the trustees. The trustees are appointed by the founding trustees as detailed within the Trust Deed dated March 2012. The trustees meet in-person (defined as physically or via video conference) at least twice each year. Interim meetings are also held throughout the year. Trustee duties include ensuring compliance with all relevant laws and ensuring that its activities are in accordance with its charitable objectives and operation for the public benefit. Certain functions are delegated to individual trustees and it is expected in the future there will be several committees with specific responsibilities for the charity. Any change to the Trust Deed including the appointment of trustees is subject to 10 days’ notice of the intention to discuss prior to any meeting.

### Employment

FOP Friends continues moving towards being a sustainable and professional organisation through employment of appropriate staff.

#### Hannah

Hannah left FOP Friends in November 2019 to pursue her career as a psychologist. She completed her Masters degree whilst working part time for the charity.

Hannah’s departure means there is now one part time employee supporting the charities operation and objects with all other activity being undertaken by its trustees and additional volunteers.



### 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.



## Statement of responsibilities of the trustees

Under the Charities Act 2011 and the Companies Act 2006, the Trustees are required to prepare a report and financial statements in accordance with applicable law and United Kingdom Generally Accepted Accounting Practice. Company law requires the Trustees to prepare financial statements for each financial year which give a true and fair view of FOP Friends and of its incoming resources and application of resources, including its income and expenditure, that period. In preparing those accounts, the Trustees are required to:

- Select suitable accounting policies and then apply them consistently
- Observe the methods and principles in the Charities SORP
- Make judgements and estimates that are reasonable and prudent
- State whether applicable accounting standards and statements of recommended practice have been followed, subject to any material departures disclosed and explained in the financial statements
- Prepare the accounts on the going concern basis unless it is inappropriate to presume that the charity will continue its operations

The trustees are responsible for keeping proper accounting records, which disclose with reasonable accuracy at any time the financial position of FOP Friends and enable them to ensure that the financial statements comply with the Charities Act 2011, the Charity (Accounts and Reports) Regulations 2008 and the provisions of the trust deed. They are also responsible for safeguarding the assets of FOP Friends and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

For the purposes of charity law, the trustees who served during the year and up to the date of this report are set out on page 2. The trustees are responsible for the maintenance and integrity of FOP Friends and financial information included on the charity's website.

This report was approved by the trustees on 30th November 2020 and signed on their behalf by

Chris Bedford-Gay.

Founding Trustee and Chairman





## Financial review

### Summary

Gross income totalled £141,339 with £221,092 to be carried forward to next charity year. Of the amount carried forward £125,000 is designated to research and £15,000 to operating reserves. The charity has no long-term investments. Cash reserves are held in bank deposit accounts.

### Income

Income for the year totalled £141,339 made up of unrestricted funds from fundraising and voluntary donations together with income from successful grant and trust applications, conference fees and a small amount of interest on savings.

### Grants, trusts, and corporate sponsorship

The charity received £31,061 in grants. A 119% increase on the previous charity year. This is in part due to crossover of grants towards events within the next (2020/21) charity year.

### Charitable expenditure

Through the charity year, £60,500 was spent on funding FOP research. This was entirely directed towards the University of Oxford FOP Research team. Operating costs of £55,974 include costs associated with fundraising of £5,030 (t-shirts, event places, and support of fundraisers), staff salaries of £40,002, £3,486 in governance costs and £3,484 costs associated with projects.

Governance costs of £3,486 include accounting fees, insurance, postage, professional memberships, and costs associated in employing staff. £3,253 was spent on the 2020 FOP Family Weekend, 2020 Conference, and StopFOP stakeholder meetings. These costs largely being covered by grants.

### Gains and losses

Income from fundraising, voluntary income and fundraising activities increased by 30% from £94,284 to a total of £122,690.

### Policy on reserves

The Trustees aim is to maintain reserves in unrestricted funds of £15,000 to cover operational, support, governance costs and unforeseen expenditure over at least a 3-month period.

### Designated Funds

£125,000 is designated towards future funding of FOP research with £15,000 held in reserve as an operating fund as detailed in our “Policy on reserves” above.

### Future commitments

FOP Friends remains committed to funding FOP research internationally. The trustees decide where disbursements are made to achieve the aims and objects of the charity. Presently £125,000 is designated from funds carried over towards FOP research.

Ongoing projects such as the “FOP Friends Together” newsletter is recognised as a future financial



commitment being funded through restricted grants and trust awards.

### Restricted Funds

A total of £87,471 in funding received in this reporting year has been restricted towards research (£36,170 from international FOP organisations) and several projects including the “FOP Friends Awareness Leaflet”, the FOP Friends ‘Together’ quarterly newsletter. It also includes £29,949 in fees associated with the 2020 FOP Conference and Family Gathering and £7,256 in funding towards the FOP Family Weekend.

### Investments

Presently FOP Friends has no investments.



## Independent examiner's report

I report on the accounts of the charity for the year ended 1st March 2017 which are set out on pages 27 to 32.

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

Respective responsibilities of the trustees and examiner

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

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

### Basis of independent examiner's report

My examination was carried out in accordance with General Directions given by the Charity Commission. An examination includes a review of the accounting records kept by the charity and a comparison of the accounts presented with those records. It also includes consideration of any unusual items or disclosures in the accounts and seeking explanations from you as trustees

concerning any such matters. The procedures undertaken do not provide all the evidence that would be required in an audit, and consequently no opinion is given as to whether the accounts present a 'true and fair' view and the report is limited to those matters set out in the statement below.

### Independent examiner's statement

During my examination, no matter has come to my attention:

1. which gives me reasonable cause to believe that, in any material respect, the requirements:
  - a. to keep accounting records in accordance with section 130 of the Act; and
  - b. to prepare accounts which accord with the accounting records and comply with the accounting requirements of the Act; have not been met; or
2. to which, in my opinion, attention should be drawn 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	2020	2019
<b>Incoming resources</b>					
<b>From generated funds</b>					
Voluntary income	2	£ 73,802	£ 26,163	£ 99,965	£ 87,089
Activities for generating funds	3	£ -	£ 22,725	£ 22,725	£ 7,195
Investment income		£ -	£ 494	£ 494	£ 382
<b>Other incoming resources</b>	4	£ 13,669	£ 4,486	£ 18,155	£ 28,819
<b>Total incoming resources</b>		£ 87,471	£ 53,868	£ 141,339	£ 123,485
<b>Resources expended</b>					
<b>Costs of generating funds</b>					
Fundraising costs	5	£ -	£ 5,030	£ 5,030	£ 4,608
Advertising and marketing	5	£ -	£ 52	£ 52	£ -
Salaries	5	£ 35,632	£ 4,370	£ 40,002	£ 42,277
Project costs	5	£ 3,484	£ -	£ 3,484	£ 2,888
<b>Charitable activities</b>					
Research	6	£ 30,500	£ 30,000	£ 60,500	£ 78,012
Events	7	£ 3,019	£ 234	£ 3,253	£ 32,638
Salaries	5	£ -	£ -	£ -	£ -
Awareness		£ -	£ 667	£ 667	£ -
<b>Governance costs</b>	8	£ -	£ 3,486	£ 3,486	£ 2,475
<b>Total resources expended</b>		£ 72,635	£ 43,839	£ 116,474	£ 162,898
<b>Net incoming/(outgoing) resources</b>		£ 14,836	£ 10,029	£ 24,865	-£ 39,413
<b>Reconciliation of funds</b>					
Total funds brought forward		£ 31,424	£ 164,803	£ 196,227	£ 235,640
<b>Total funds carried forward</b>		£ 46,260	£ 174,832	£ 221,092	£ 196,227



## Balance sheet

	-	Notes	2020		2019	
<b>Fixed assets</b>	9		£	137	£	114
<b>Current assets</b>						
<b>Cash at bank</b>			£	223,980	£	200,434
<b>Debtors</b>	10		£	1,953	£	-
			£	223,980	£	200,434
<b>Creditors: amounts falling due within one year</b>	11		-£	3,025	-£	4,321
<b>Net current assets</b>			£	220,955	£	196,113
<b>Net assets</b>			£	221,092	£	196,227
<b>Funds</b>						
<b>Restricted</b>	12		£	46,260	£	31,424
<b>Designated</b>	13		£	140,000	£	140,000
<b>Unrestricted</b>			£	34,832	£	24,803
			£	221,092	£	196,227

Approved by the trustees on 30th November 2020 and signed on their behalf by

Alison Acosta Bedford, Founding Trustee.





## Notes to 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 comprises those funds which are free to use for any purpose in line with the charitable objects. Unrestricted funds include designated funds where the trustees, at their discretion, have set aside resources for a specific purpose.

#### *INCOMING RESOURCES*

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

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

Investment income is included as 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

		2020	2019
Donations	£	68,904	£ 72,924
Grants	£	31,061	£ 14,165
	£	99,965	£ 87,089

### 3. ACTIVITIES FOR GENERATING FUNDS

		2020	2019
Fundraising events	£	22,725	£ 7,195
	£	22,725	£ 7,195



#### 4. OTHER INCOMING RESOURCES

	2020		2019	
Conference fees	£	11,169	£	19,976
Family getaway	£	2,500	£	6,500
Sales	£	4,486	£	2,343
	£	18,155	£	28,819

#### 5. FUNDRAISING COSTS

	2020		2019	
Salaries	£	40,002	£	42,277
Advertising & promotional items	£	52	£	-
Entry fees	£	-	£	-
Fundraising costs	£	3,647	£	4,608
Project costs	£	3,484	£	2,888
Operational costs	£	1,383	£	-
	£	47,185	£	49,773

#### 6. RESEARCH

	2020		2019	
UK research	£	60,500	£	66,146
International research	£	-	£	11,866
	£	60,500	£	78,012

#### 7. EVENTS

	2020		2019	
Conference meeting costs	£	554	£	25,797
Family weekend (Center Parcs)	£	2,465	£	6,841
Stakeholder meeting	£	234	£	-
	£	3,253	£	32,638

#### 8. GOVERNANCE

	2020		2019	
Accountancy charges	£	100	£	90
Insurance	£	420	£	364
Subscriptions	£	1,160	£	1,129
Bank charges	£	58	£	246

Computer costs	£	943	£	517
Staff training	£	-	£	517
Depreciation	£	160	£	129
General expenses	£	645	£	-
	£	3,486	£	2,992

#### 9. FIXED ASSETS

		Office equipment	
<b>Cost</b>			
At 2nd March 2019		£	1,221
Additions		£	183
Disposals		£	-
As at 1st March 2020		£	1,404
<b>Depreciation</b>			
At 2nd March 2019		£	1,107
On disposals		£	-
Charge for year		£	160
As at 1st March 2020		£	1,267
<b>Net book value</b>			
As at 1st March 2020		£	137
At 1st March 2019		£	114

#### 10. DEBTORS

	2017		2016	
Accounts receivable	£	1,953	£	-
	£	1,953	£	-

#### 11. CREDITORS

	2020		2019	
Amounts falling due within one year:				
HSBC mortgage	£	-		-
Accounts payable	£	3,033	£	4,521
PAYE and NI	£	149	£	288
VAT	-£	252	-£	668
Accrued expenses	£	95	£	180
	£	3,025	£	4,321



## 12. RESTRICTED FUNDS

	Balance b.fwd	Incoming resources	Resources expended	Balance c.fwd
Research fund	£ -	£ 36,170	-£ 30,500	£ 5,670
Conference fees fund	£ 19,334	£ 11,169	-£ 554	£29,949
Family getaway	£ 7,221	£ 2,500	-£ 2,465	£ 7,256
Support fund	£ -	£ -	£ -	£ -
Operational	£ -	£ 28,632	-£ 28,632	£ -
Be Safe at School Handbook fund	£ 194	£ -	-£ 194	£ -
FOP 'Together' Newsletter fund	£ 3,183	£ 8,500	-£ 9,156	£ 2,527
Charity leaflet	£ 1,492	£ -	-£ 1,134	£ 358
Home improvement grant handling	£ -	£ 500	£ -	£ 500
	£ 31,424	£ 87,471	-£ 72,635	£46,260

Key items within restricted funding include:

- Research fund describes funding toward FOP research from other international FOP organisations.
- The Conference fees fund represents donations and delegates deposits received in respect of the FOP Conference in May 2020.
- Family getaway fund is associated with grants to assist in running future family weekend where the charity takes all FOP families with children away for a respite / break.
- The FOP 'Together' Newsletter fund represents grants awarded to fund the production of a quarterly print/online newsletter to inform the FOP community and to support fundraising.

- Charity leaflet funds were provided to allow for update and re-print of FOP Friends awareness leaflets used at events and fundraisers.
- The “Home improvement grant handling” line is associated with a patient who was awarded a grant personally for home-improvements, but the awardees required the funding to be handled via a recognised entity “on their behalf”.

## 13. DESIGNATED FUNDS

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

The Charity will sometimes raise funds to meet specific objectives, but the donor chooses not to restrict the Charity in how the funds are to be used. These funds are legally unrestricted, but the Trustees choose to designate the purpose for which the funds are to be used as follows:

The Research fund represents monies received which the Trustees have designated to be used to fund research in future years.

The Operating fund represents the higher of £15,000- or 3-months operating costs which is the safe minimum reserve level as determined by the charity's Reserves Policy.

## Our history (to 1st March 2019)

### March 2008

Oliver Peter Bedford-Gay born; all the medical professionals just think he has “funny toes”.

### November 2008

Oliver has mysterious lump removed from the back of his head.

### April 2009

Bedford-Gay family receive devastating diagnosis of FOP.

### 2010

Family and friends begin fundraising to support the research team at Oxford.

### 2011



Friends of Oliver website created to celebrate and thank those who are supporting Oliver and the research team at Oxford.

FOP Friends chairman and founder Chris Bedford-Gay elected to the Board of the IFOPA.

### April 2011

First of many line dancing evenings held, which have been one of our biggest fundraisers, raising £16,000 to date.

### January 2012

FOP Friends of Oliver website goes ‘live’ together with “What is FOP?” animation, narrated by Stephen Fry.



### June 2012

FOP Friends of Oliver becomes a registered charity # 1147704.

### December 2012



Chris becomes an ‘informal’ member of University of Pennsylvania FOP research team to collaborate on the International FOP Flare-up survey.

First donation to the University of Oxford to support its research team: £10,000.

### March 2013

First newsletter is published to celebrate the many different fundraising events being held across the country.

FOP Friends is awarded a grant for £16,000 from GDUK to fund a Charity Administrative Assistant.



### December 2013

FOP Friends is awarded a grant to employ a Senior Drug Developer at the University of Oxford.





## December 2013

Annual donation to the University of Oxford's research team, this time £20,000.

## March 2014

£65,000 in funding is provided by FOP Friends to employ a full-time medicinal chemist within the University of Oxford's FOP Research team.

## May 2014



FOP Friends organizes a family gathering in Manchester, uniting UK FOP families for the first time in 12 years. The world's experts in FOP are also in attendance, including Prof. Kaplan.

## June 2014

Friends of Oliver proudly becomes FOP Friends® to reflect the growing number of UK families now raising money together to support FOP research.

## August 2014

FOP Friends' Drug Developer begins work at the University of Oxford, alongside the excellent existing team.

## August 2014

FOP Friends is adopted by companies PwC Manchester and Avaya as their "Charity of the Year".

## September 2014



Two teams of FOP Friends' runners take part in the Great North Run and the Windsor Half Marathon, raising £21,000 in total.

## October 2014

FOP Friends makes an incredible donation of £70,000 to help maintain the research team at the University of Oxford for another year.

## November 2014

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



FOP Friends Founder and chairman Chris attends the IFOPA Drug Development Forum in Boston, with over 100 researchers and interested pharmaceutical companies in attendance. A milestone in the search for a treatment and cure for FOP.

## December 2014

FOP Friends decorates their annual Christmas Tree at St. Alban's Church, Cheshire, with photos of FOP patients from around the country.



CBBC's Katie Thistleton appears on Celebrity Mastermind and her chosen charity is...FOP Friends!

## January 2015

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



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

## February 2015



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

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

## March 2015

Chris is honoured to be invited to, and attend, the 1st UK Genetic Disorders Leadership Symposium in London.



An update meeting at Oxford with the excellent FOP research team. Chris, Rachel, Nicky, George and Marian all attend.

Chris visits Rome for the FOP Italia conference: twelve countries coming together to find a cure for FOP.

## June 2015

Chris flies to Boston for the first IFOPA Strategic Planning meeting. He visits the FOP research team and laboratory at Harvard University, who are collaborating with the team at Oxford to find a treatment. Next, he visits Blueprint Pharmaceuticals to learn of their progress and then goes on to Regeneron Pharmaceuticals in Tarrytown, New York. Chris finishes his whistle-stop tour with a quick visit to the FOP lab at the University of Pennsylvania.

PushOn adopt FOP Friends as their Charity of the Year.



## August 2015



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



## September 2015

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



## October 2015



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

FOP Friends is selected as Avaya's Charity of the Year, and many exciting fundraising activities are planned.

## November 2015



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

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

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

Chris flies out to Amsterdam for the Dutch FOP Symposium.

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



## December 2015

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

## January 2016

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



FOP Friends is excited to announce the award of a grant from The Big Lottery Fund to help fund the UK FOP Conference and Family Gathering 2016.

FOP Friends supports IFOPA competitive research grant programme which saw FOP Friends providing 25% of the funding towards the "Allosteric inhibitors of ALK2 for FOP therapy" project at the University of Oxford.



## February 2016



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

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

Adobe chooses FOP Friends as beneficiary of their Charity of the Year.





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



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

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

### March 2016

Rachel Winnard appears on ITV's 'Emergency Room with Jeremy Kyle' to raise awareness.

Trustee Rachel Almeida is proud to attend at the Genetic Disorders UK Conference, London, on behalf of FOP Friends.

The Hospital Saturday Fund awards FOP Friends a grant that will fund a new microscope for the FOP research team at Oxford.

Chris attends his second FOP Italia meeting in Livorno. A very positive conference with lots of exciting developments in the field of research, from all around the world.

### April 2016

FOP Friends launch the #FunFeet4FOP campaign in celebration of FOP Awareness Day.



Our first national (now international) campaign, encouraging supporters to wear #FunFeet4FOP.

The weekend is an incredible success with many people posting photos of their weird and wonderful footwear.

### May 2016

Savills take part in a 100k bike ride to raise funds and awareness for FOP Friends and the charity Dreams Come True.

The second 'FOP Friends Family Gathering' is a great success; Dr Keen sees patients in the morning before going to run the Manchester 10k to support FOP Friends, then is back to see more patients after!

### June 2016

The NERDOC guys ride an amazing 270-mile round trip from one UK coast to another for the second time.

Dr Keen presents on the International FOP Association (IFOPA) FOP Connection Registry at Bone Research Society meeting.

FOP Australia holds an official launch, marking one year since the organization was established by Lara Boniface, mum of Jarvis with FOP.

### July 2016

Kevin Gordon completes a sponsored cycle from Lands' End to John O'Groats in 15 days, helping to raise awareness of FOP.





## August 2016

The eBay Charity UK sale for FOP Friends proves a great success.

## September 2016

Several FOP Friends champions take part in the Great North Run and London to Brighton cycle.



## October 2016

Organized by Margot Charlton for the third year in a row, the charity gig for Isla is held on the Isle of Wight. The L&M Band play 60's tunes to dance the night away with attitude.



Chris attends the 2nd IFOPA Drug Development Forum in Boston. FOP Friends provides \$15,000 towards the event generating a total \$30,000 thanks to fund matching.

Helen and the boys visit Centre Parcs to check out the facilities for the FOP Family Weekend.

## December 2016

FOP Friends decorates a Christmas tree at the annual event at St. Albans, with decorations made by the FOP families at the Family Gathering in May.

The "Don't send me a card" appeal proves an effective way of saving the trees and raising some £s for FOP Friends.

## January 2017

Chris, Oliver, and FOP Friends received an exciting acknowledgement in Fiona Cummins' debut novel 'Rattle'. Chris consulted on the book as one of the main characters suffers from FOP. One to look out for in the cinemas soon!

## February 2017

Anoushka, 16, from Azerbaijan, arranges for five groups of swimmers from the Baku sharks to swim the equivalent of the English Channel over two weeks.

Each group swam 32km, and together they raised £360 for FOP friends.



Chris attends the Eurordis Black Pearl Rare Disease Gala in Brussels.

## March 2017

Fun in the Forest for FOP Families - In March, over a dozen FOP families were able to enjoy a weekend at Centre Parcs Sherwood Forest thanks to funding from Children in Need.

## April 2017



The second #FunFeet4FOP event takes place on International FOP Awareness Day, with some fab feet (including a farm animal or two) helping to boost the profile of FOP.

Jo and Jack take on a marathon each, with Jo running in London and Jack in Southampton.

May 2017



Enjoying the University of Oxford Vice-Chancellors Circle evening. An invite extended to us thanks to all the support we as a community have been able to give to our FOP Research team at Oxford.

June 2017

FOP Friends partner with Genetic Disorders UK.

Savills continue their support by holding a Golf Day and raising over £165.

July 2017

Sophie, Becky and friends host a Garden Fundraiser and raise £670 taking FOP Friend Isla's fundraising page to over £40,000

Stewart and friends cycle over 500 miles across Scotland to raise awareness for FOP.

August 2017

Trekking an impressive 800 miles, Rebecca completes her Appalachian Trail journey, raising an incredible £2,000 along the way.



September 2017

8 runners took on the Great North Run, raising over £5,000 for FOP research, with special support from 6 different Nationwide branches.

October 2017

Chris attends the 3rd IFOPA Drug Development Forum in Sardinia, Italy, and opens the event with his inspirational 'Along for the Ride' speech.

FOP Friends is proud to be listed and recognised in the 2016/17 The Oxford Thinking - The Campaign for the University of Oxford report, as one of their valued donors.



The charity is awarded Runner-Up as Charity of the Year at the Altrincham & Sale Chamber of Commerce Awards.

November 2017

Bex completed a 61-day dryathlon, raising a sparkling £500 in the process. While Amy celebrated her 50th Birthday in style by jumping 855ft from the top of Las Vegas' Stratosphere Tower and raising over an incredible £2,100.

FOP Friends feature on the University of Manchester's Volunteer Hub, to help raise awareness and recruit student volunteers.

The charity also awarded Charity of the Week in the "The Week" magazine.

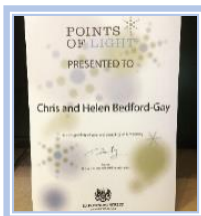
December 2017



FOP Friends present their tree of thanks for Children in Need at the annual St. Alban's Church Tree Festival. Oliver's little brother, Leo, contributed his own 'Little FOPer's trees.



## January 2018



Chris and Helen are named the UK's 883rd and 884th Points of Light. The Points of Light programme recognises outstanding volunteers who are making a real difference in their communities.

## February 2018

Chris attends the 7th edition of the EURORDIS Black Pearl Awards alongside other FOP leaders from Italy, Germany, and France.



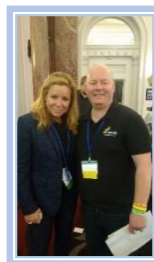
## March 2018



FOP Friends were pleased to announce that we had been awarded a grant from the Big Lottery Fund to help fund our 2018 UK FOP Conference and Family Gathering.

University of Manchester Boat Club take on a 24hr row in aid of FOP, raising £1023.77. While Natalie completed the inaugural London Landmarks Half Marathon, raising £350.

Chris presents at the Genetic Disorders UK 2018 Leadership Symposium. His 'In it to win it! Changing the future for children born with fibrodysplasia ossificans progressiva (FOP)' presentation focused on building a sustainable, small charity, supporting patients and families and punching above your wright in pursuit of your charity's ultimate goals.



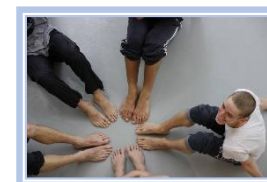
## April 2018

Jane Deane took on the Manchester Marathon raising £1,180, while DAC Beachcroft LLP held a dress down day at work to raise FOP awareness and collected £185.



T-UK Stockport Taekwon-Do chose FOP Friends as their Charity of the Year and Chris was thrilled to attend their evening dinner and accept a cheque of £613.

Chris was honoured to receive a letter from Oxford Thinking, which thanked FOP Friends for the generous funding of FOP research at Oxford University.



#FunFeet4FOP was a great success for the third time, with lots of fun feet making an appearance. We were



so grateful and honoured to see that the BalletBoyz chose to help raise awareness for FOP! Hummingbird Bakery in Guildford supplied cakes for #FunFeet4FOP bake sale, which raised over £230.

Mick Henry ran the Connemara Marathon for Friends of Rion, while Sharon Moore took on the Newport Marathon for Friends of Annalese.

## May 2018



William Jones, 11, has supported FOP Friends through lots of different fundraisers and decided to hold another sweet stall to raise funds and awareness for FOP.





Manchester University Boat Club decided to fundraise for us again, the team taking on the Manchester 10K.



Our third Conference and Family Gathering took place



and was a resounding success! With talks from the world leading FOP experts, workshops and clinical consultations – everyone in attendance had a wonderful time connecting with one another.

## June 2018

FOP Friends received a grant from Jeans for Genes to help fund the 2019 FOP Family Respite Weekend.

Julian cycled over 100 miles, from Wolverhampton to Aberdovey, to raise funds and awareness for FOP. While Belinda Davis and our wonderful friends at Dell Park Farm Windsor provided parking at the Royal Wedding in aid of FOP Friends & raised £644!



## July 2018

The wonderful Melissa and Freya both took a 'Chop for FOP', raising funds for FOP and donating their hair to the Little Princess Trust.

We were thrilled to unveil our new FOP Friends leaflet.



## August 2018

Alexis who completed the 3-peaks challenge for FOP Friends

## September 2018

Harry, Jack, Judith, Alistair and one of our FOP specialists Dr Bubbear all took on half marathons across the country.



Twelve runners headed to Newcastle to take on the Great North Run this year, while Josie Heade ran an impressive 100k to raise awareness and funds for FOP.

Manchester Round Table & Cheadle & Gatley Ladies Circle hosted the first ever Cheadle Big Charity Pub event, with 25% of the profits going towards FOP Friends.

Wonderful members of Team Isla organised a charity ball exceeding £2500!



## October 2018

Gig for Isla 5 was another success - the dedicated community on the Isle of Wight dancing the night away to the fabulous L & M Band and raising thousands of pounds for FOP research.

We drummed up some local support in Manchester with Slater Heelis holding a Dress Down Day; Altspace Coworking Office holding a brilliant bake-off; and COS Bookkeeping holding a charity raffle.



## November 2018

Chris has arrived safely in Baltimore for the International FOP Association (IFOPA)'s 30th Family Gathering.

Our first-ever Christmas card campaign was launched.



Oliver visited Sale Grammar School, where he spoke to sixth form students for an hour about FOP.

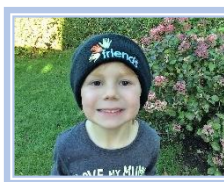


FOP Friends was acknowledged by the University of Oxford as one of their most committed supporters.

## December 2018

We launched our FOP Friends beanie hats.

Oliver gave an amazing presentation talking about FOP & Me, to the colleagues of Regeneron UK at their Christmas conference.



Boxing Day saw a wonderful group get dressed up and visit 35 pubs, Irish dancing whilst raising money for charity. A whopping £973 was raised for FOP Friends.

## January 2019

Launched Supporter Spotlight programme. We are thrilled to be able to celebrate the many people who have joined us on our journey to find a treatment and a cure for FOP.

#Swap4FOP. Simply take a bunch of friends each bringing a few unwanted items/gifts, add an entry fee, a raffle and some fizz = fun night, recycles, take away some treasure and raise much needed funds for #FOPFriends. Isla's godmother did just that but with 20 friends and raised a whopping £800!

## February 2019

Launched Facebook Fundraiser – supporters can now raise money and awareness for FOP on Facebook for their special celebrations.



Helen receives acknowledgement from The Duke and Duchess of Sussex, coincidentally on Rare Disease Day.

FOP Friends donate \$15,000 towards the IFOPA ACT for FOP Grant program helping to fund novel FOP research.

## March 2019

FOP Friends runs its second FOP Family Weekend v2. Taking all children with FOP and their families for a weekend together at Center Parcs.



## April 2019



#FunFeet4FOP and #FireWalkforFOP. 22 Fundraising firewalkers including 2 FOP families, 2 local councillors from Trafford, Manchester (Amy Whyte & Steve Longden) and FOP Nurse Jackie all burn their toes to raise awareness for FOP.

## May 2019

FOP Friends releases “Supporting a Child with FOP: a practical guide to their learning experience” This book was made possible thanks to a generous grant from Regeneron Pharmaceuticals. This book is an essential and informative guide for anyone supporting a child with FOP, offering clear information and advice to parents and teachers to help a child with FOP navigate their school journey as well as their life beyond the classroom.



Helen and Chris were delighted to represent FOP Friends at Oxford University's Vice-Chancellor's Dinner in May. They received the prestigious invitation in recognition of the charity's contribution to their excellent FOP research team, led by Dr Alex Bullock.

## June 2019

Helen and Chris were delighted to win the 2019 Jeannie Peeper Award for “Outstanding International Leadership”. The award recognised their exceptional commitment to the FOP community through their leadership, service, family support, fundraising and awareness-building, both in the UK and world-wide.



## July 2019



In July, Oliver's family were devastated when Grandma Ann passed away suddenly. Ann was well-known and well-loved in the North-East where she held monthly line dancing social events to raise both money and awareness. Over the years, Ann's line-dance fundraisers raised over £40,000 for FOP Friends. She is sadly missed.



## Sept 2019

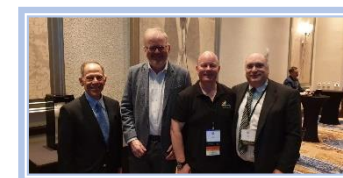
FOP Friends have another team of fundraisers take part in the Great North Run including FOP specialist, Doctor Bubbear.



## November 2019



IFOPA Drug Development Forum in Florida. Whilst attending the Drug Development Forum, Chris also ran meetings for the national FOP leaders from around the world followed by taking the stage as part of a panel of patients and parents talking about FOP and answering questions.



Hannah, who first worked at FOP Friends in 2015 said farewell as she moved to pastures new to pursue a career in psychology.



## December 2019



Amish Patel saw 2019 out in style when he took part in a skydive for his brother Hamish, who has FOP. Amish, who lives in Queenstown, New Zealand took a leap of faith and completed a 12,000 ft tandem skydive for Hamish who lives in the UK.

## January 2020

We are most thankful to the amazing team at “And Digital” in Manchester, led by Jamie and Mike, who



donated their time and skills for free. The new website has all the information you need about FOP as a condition, and all about FOP Friends as a charity.



There are downloadable resources to support fundraisers as well as information for people who are coming to terms with a new diagnosis. Perhaps most importantly, there is information for people living with FOP in the case of an emergency including the latest ICC medical guidelines.

## February 2020

Chris attended IFOPA in-person board meeting in Philadelphia as part of his role at the IFOPA. Whilst there he attended an early screening of the Tin Soldiers documentary in which he, Oliver, and FOP Friends’ trustee Nicky with her daughter Isla all feature.



During his visit Chris and his fellow IFOPA board members had a guided tour of the Mütter Museum where two FOP skeletons are now displayed. Harry Eastlack a resident since 1973 and Carol Orzel who joined Harry in May 2018. It was Carol’s wish to donate her body to be displayed next to Harry, along with her jewellery collection, and studied by researchers.





## Thank you to (March 2019 – March 2020)

FOP Friends would like to acknowledge our ever-growing supporters.

### Trusts / Grants

Albert Hunt Trust	Big Lottery Fund
Bruce Wake Trust	Duchy Fund
Fitton Trust	Genetic Disorders UK
Marsh Christian Trust	Manchester Guardian Society CT
Sobell Foundation	The February Foundation

### Corporate Supporters

Ipsen Pharmaceuticals	Regeneron Pharmaceuticals
Skillsarena Ltd	

### Donors of time and resources

Clarity Comms: FOP Animation
Stephen Fry: FOP Animation Narration; foreword
Keith Hopwood (Herman's Hermits): FOP Animation Music
Skillsarena Ltd: Director's time
Foliozine: Logo design

### Community / Clubs & Associations











Gloriana Freemasons Lodge	Manchester Round Table
Royal Northumberland Yacht Club	Uxbridge Rotary Club

### Fundraisers

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

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

### Contact Details

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	<a href="https://www.facebook.com/fopfriends">/fopfriends</a>		<a href="https://wiki.fopfriends.com/wiki/FOP_Friends">/wiki/FOP_Friends</a>
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	<a href="https://www.youtube.com/channel/UCkr4gz62-K3baYkyxCjIqbg">channel/UCkr4gz62-K3baYkyxCjIqbg</a>		
	<a href="https://www.pinterest.com/fopfriends">FOP Friends</a>		