



Trustees' Annual Report for the period

	Period start date				Period end date		
	Day 06	Month 04	Year 2022		Day 05	Month 04	Year 2023
From				To			

Section A Reference and administration details

Charity name GoPI3Ks (Genetic Overgrowth PI3K Support)

Other names charity is known by

Registered charity number (if any) 1176289

Charity's principal address 8 Bolton Avenue

Accrington

Lancashire

Postcode

BB5 6HN

Names of the charity trustees who manage the charity

	Trustee name	Office (if any)	Dates acted if not for whole year	Name of person (or body) entitled to appoint trustee (if any)
1	Mandy Sellars	Chairperson		
2	Susan Jane Harper	Treasurer		
3	Amanda Jane Kenyon	Secretary		
4	Katie Louise Kavannah	Trustee		
5	Yvonne Tierney-Neave	Secretary	Resigned 11/2019	
6				
7				
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Names of the trustees for the charity, if any, (for example, any custodian trustees)

Name	Dates acted if not for whole year
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Names and addresses of advisers (Optional information)

Type of adviser	Name	Address

Name of chief executive or names of senior staff members (Optional information)

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Section B Structure, governance and management

Description of the charity's trusts

Type of governing document
(eg. trust deed, constitution)

Constitution (December 2017)

How the charity is constituted
(eg. trust, association, company)

Charitable Incorporated Organisation (C.I.O)

Trustee selection methods
(eg. appointed by, elected by)

Trustees are appointed and/or reappointed at annual meetings by the current trustees.

Additional governance issues (Optional information)

You **may choose** to include additional information, where relevant, about:

- policies and procedures adopted for the induction and training of trustees;
- the charity's organisational structure and any wider network with which the charity works;
- relationship with any related parties;
- trustees' consideration of major risks and the system and procedures to manage them.

Apart from the very first trustees, every trustee must be appointed or reappointed by a resolution passed at a properly convened meeting of the existing charity trustees. This is always undertaken at an annual meeting.

In selecting individuals as trustees, the existing trustees must have regard to the skills, knowledge and experience needed for the effective administration of the C.I.O.

The current trustees will make available to each new trustee, on or before their first appointment:

- A copy of the current version of the constitution.
- A copy of the C.I.O's latest trustee annual report and statement of accounts.

All trustees give their time on a voluntarily basis and received no remuneration or other benefits, apart from reasonable expenses that are paid when having undertaken work for the charity.

Section C Objectives and activities

Summary of the objects of the charity set out in its governing document

To advance the education of the general public & those living with PROS by raising awareness, providing information & educational materials.

For the prevention & alleviation of poverty for the public benefit of those in need with PROS (PIK3CA Related Overgrowth Spectrum) by providing financial grants.

As always in the planning our activities during the financial period of 2023-2023, all trustees kept in mind the Charity Commission's guidance on public benefit. This places the focus on the general public as a whole as well as those living with the rare overgrowth condition that we support, PROS. (PIK3CA Related Overgrowth Spectrum)

Covid-19.

As the presence of Covid 19 was somewhat eased during this last financial year, it was easier, within reason to show our presence on a more face to face basis, whilst also taking care of ourselves and others during this time. The ease and popularity of alternative methods such as, Microsoft Teams and Zoom was also still implemented to continue to raise awareness and interact with the general public as well as PROS individuals and families.

Online awareness

Our online presence has always been a big focus for the charity, especially during the pandemic, but this has also continued as life has returned to some normality.

During this financial year we have created an Instagram account for the GoPI3Ks charity to raise awareness of PROS to our followers; those living with PROS, medical professionals and the general public.

As always our focus during our online fundraisers and the fundraisers that our supporters organise is that we are able to reach a significant number of people, through Facebook posts, Tweets and Instagram posts. During each post or Tweet we would provide links to the GoPI3Ks website which would explain to the viewer/reader what PROS is and how it can affect individuals. The website also explains what we (the GoPI3Ks charity) do to support those living with PROS, as well as providing links to our dedicated social media pages and contact details. This information will help anyone wanting to support us further through their own fundraising or maybe if they, a family member or they know someone living with PROS who may need support financially or psychologically.

Additionally, our online presence allows us to share relevant articles, research papers, interact with medical individuals and groups as well passing on news worthy information about PROS to the general public as well as the PROS community.

Attending events

With the easing of Covid, we were able to, where possible, attend

Summary of the main activities undertaken for the public benefit in relation to these objects (include within this section the statutory declaration that trustees have had regard to the guidance issued by the Charity Commission on public benefit)

events in person. Additionally, attending virtual online events also led to engagement between various rare disease groups, rare disease advocates, drug companies and the general public which enabled us to highlight PROS and the work we do at GoPI3Ks supporting those living with this rare overgrowth condition.

Grant making

Again through our fundraising and that of our supporters it has allowed us to offer financial grants to those living with PROS. Especially during this last financial year that saw many struggling with the general increase in the cost of living. This helped in some way to alleviate and/or prevent poverty that has occurred due to the extra costs of living with a rare medical condition. This also led to increasing the physical and psychological wellbeing of this individual and/or family.

Public awareness

Our charity trustees and supporters of the charity continued to raise awareness to friends, families and the wider population. Our continued presence online, particularly engaging with several rare groups, charities, as well the general public has allowed us to raise the awareness of PROS and the work we do at GoPI3ks. Additionally, we have shared information with international charities and companies to further their understanding of PROS, the physical as well as the psychological effects this can bring.

This has been achieved through the sharing of information via electronic means, through emails, online discussions and workshops, presentations and also sharing the website address to those with an interest.

We did on occasions still wear face masks printed with the GoPI3Ks logo and website which gave us the unique opportunity to spread the word about GoPI3Ks.

Additional details of objectives and activities (Optional information)

You **may choose** to include further statements, where relevant, about:

- policy on grantmaking;
- policy programme related investment;
- contribution made by volunteers.

Our grant making policy states that a copy of the medical evidence stating a diagnosis of PROS needs to be provided from a relevant medical professional and/or hospital, before an application can be processed.

We also ask for evidence of any relevant monetary quotes relating to the requested item, equipment or service that the funding is needed for. As a charity we may also undertake relevant searches to gauge if these can be sourced at a cheaper price. Where relevant and appropriate, we prefer to pay a company directly for any item or service we may be providing to the applicant.

Before an applicant receives funding, whether this be money, money for a service that is to be provided and/or equipment from the charity they are asked to sign a declaration of receiving charity funds.

This states as follows: I [insert name] confirm that any money / items I receive that are supplied and / or funded by the GoPI3Ks charity will not be sold or passed on to any other parties or used for any other purposes than what the grant has been designated for.

This declaration is not needed if we are reimbursing an applicant for the extra costs that they have already been paid for.

As always we owe a huge sense of gratitude to those that have given their time freely and helped the charity to continue their fundraising and raising awareness. Without their time & generosity we would not be able to achieve the charity goals that we set.

Section D

Achievements and performance

Section D

Achievements and performance

Summary of the main achievements of the charity during the year

Our main achievements during this last financial year saw the charity have a good balance between fundraising, grant making and a continued focus on raising awareness of PROS & GoPI3Ks alike.

Fundraising:

May 2022:

In May we received a donation of nearly £600 after our chairperson wrote an article on their experience of living with PROS and the impact this can have on someone's mental health.

We also received a donation from Amazon Smile for just over £15 from those that chose GoPI3Ks as their nominated charity when they shop with Amazon

May 2022:

Also in May, a face to face fundraiser meant we were able to raise over £150 for the charity as well as raising awareness to the general public about PROS and the work that we do as a charity to help those living with this rare condition.

In this month we also raised £100 when our chairperson gave a presentation on living with PROS.

August 2022:

We received a donation from Amazon Smile of just over £12

October 2022:

A donation from PayPal of £1

November 2022:

Donation again from Amazon Smile of over £12 from those who chose us as their nominated charity when shopping.

December 2022:

A grant of £250 from Co-Op making a difference locally.

January 2023:

Donation from Amazon Smile of nearly £15

February 2023:

Fundraiser from one of our supporters raised £209 for the charity.

The annual birthday fundraiser from our chairperson made just over £1,000

Grants provided:

May 2022:

In May we were able to help one of our families with the increasing

cost of their energy bills, which was a big help financially but also psychologically as the effects of the cold for her child living with PROS was a real struggle.

June 2022:

We were able to help a family to pay for the remaining cost of their once in a lifetime holiday that had been cancelled previously due to Covid. They received vouchers from the travel company but unfortunately this didn't cover the full cost of their holiday.

July 2022:

We paid for the accommodation so that one of our younger PROS members could take part in a short documentary, looking at how disabled people are represented and treated in today's society. This also gave her a chance to spend time with other young people with rare conditions, helping her to feel more included & accepted.

September 2022:

One of our younger members was in need of new shoes/trainers. However, due to how PROS affects his feet he needed two rather than one pair, so GoPI3Ks were happy to help the family with this.

October 2022:

We helped a family with payment to fill up their oil tank for the winter as the cost increase meant they would have been without heating for a significant part of the winter period. This was a real worry for the parent as their child really suffers physically with the cold weather due to how PROS affects them.

December 2022:

We helped one of our adult members with the cost of their increasing energy bills for the coming year. This would ease their financial worry but also the physical pain in their affected areas that is caused by the changes in temperatures.

January 2023:

We helped another of our adult members with the cost of accommodation needed for a hospital appointment in the London area.

Additional achievements:

April 2022:

Again as in previous years we had continued involvement with the All Stripes company to promote their research platform for rare diseases. Here patients can contribute to the acceleration of research and drug development of their rare disease, by allowing All Stripes to retrieve, access and structure their medical records all in one place. All Stripes work with top doctors in the medical

field of each rare disease which results in patients gaining access to various medical trials within their rare condition area.

April also saw another online Ambassador hour session held by All Stripes where we learn about their new projects as well as networking with other rare disease groups and advocates.

May 2022:

In May we hosted an online Zoom call for anyone in the GoPI3Ks community called 'Let's Chat' to boost the community engagement for parents, patients and those who support those living with and affected by PROS.

September 2022:

We became involved with a new project organised by doctors and professors at GOSH in their bid to establish a Rare Disease Collaborative Network (RDCN) for mosaic disorders.

The RDCN will be a more visible service for referring doctors, new patients/families and existing patients and families that need continued medical support, which should improve the patient access and ease the stress and worry of the patient/family journey.

An adult centre has also been set up with the RDCN, so that there will be, for the first time, somewhere for patients to either transition to from their child clinics (if they need ongoing specialist care), or be referred into as an adult if they have either never had their condition investigated or experience new clinical problems.

Also in September we became media partners to support RAREfest22, organised by the Cambridge Rare Disease Network (CRDN). We were able to raise awareness of PROS and GoPI3Ks by having our logo and website link on their website, as well as on their promotional leaflets that were handed to face to face attendees on the day.

Again in September we worked alongside All Stripes to create an informational video on the work/research All Stripes are doing to help the PROS community. This would encourage more community engagement and further understanding of the medical history of those living with PROS as well as the QOL – Quality Of Life.

Also in this month, working alongside a PROS specialist doctor and one of the GoPI3Ks parents to discuss the possibility of creating and setting up a PROS information day. This would be aimed at doctors (from G.P's to Professors) to highlight the need for a more joined up system so that the journey and pathway for patients and parents alike is easier and less stressful. We also focused on where to get funding from and a date in April 2023 to host the

meeting.

October 2022:

We worked with doctors to give them more understanding of the patient journey, of what it is like to have PROS in order to gain a patients perspective to help with grant applications for the RDCN (Rare Disease Collaborative Network)

February 2023:

On Rare Disease Day in February, we shared information slides online, on various social media platforms, with different contacts within the rare disease community, with doctors and also the general public. These contained various facts on PROS: symptoms, complications, treatment options, diagnosis & research updates. We also included our website address on these slides so people could get in touch and/or learn more about PROS and GoPI3Ks.

Also for Rare Disease Day we created some slides with quotes from those living with PROS which looked at the pros and cons of living with or having a loved one with this rare condition.

March 2023:

Continued work with a GoPI3Ks parent member organising the PROS Day by creating and distributing an online survey to gauge patients / parents and caregivers experiences of their medical care. The pros and cons of this and what could be improved, to be presented at the PROS Day meeting in April 2023.

Continued work throughout 2022-23

Our social media pages continue to be a source of communication between the families, these are also updated with any new medical developments that arise, as is the GoPI3Ks website. As well as information on such things as mental health awareness week/month, children's mental health awareness week, information on support for parents, teenagers and children. Whether this be workshops, Webinars or informal groups. Such information comes from continued contact with various medical professionals and scientific researchers as well as online information from other support groups as well as PROS charities from around the world.

We also keep people updated by emailing families and patients using our mailing list with any online or face to face conferences or workshops within the rare disease community that they may feel they would benefit from attending. As well as information on current research options that participants could take part in if they feel it

would be beneficial for them.

Our annual newsletter is another source that helps keep those living with PROS and their families up to date with what the charity is doing, how the charity can help them, but also what is new within the research of PROS.

Section E

Financial review

Brief statement of the charity's policy on reserves

We hold cash at the bank of £16,037.47 all of which is unrestricted funds. These funds are held to offer financial grants to individuals living with PROS, to relieve poverty and aid their independence and daily living. We are also looking to use some of this money for a family weekend this year which will cost around £5,000

The charity does not hold a policy on reserves.

Details of any funds materially in deficit

Not applicable.

Further financial review details (Optional information)

You **may choose** to include additional information, where relevant about:

- the charity's principal sources of funds (including any fundraising);
- how expenditure has supported the key objectives of the charity;
- investment policy and objectives including any ethical investment policy adopted.

Our main source of funding this financial year continues to be through generous donations, online fundraising by the trustees and supporters, face to face fundraising and other supporters raising money via online platforms such as the PayPal Giving Fund and Amazon Smile.

The income raised was used to help those living with PROS by giving grants to aid their daily living and alleviate any poverty that occurred due to living with this medical condition. Please refer to the achievements and performance section of this report under grants provided for more details.

Section F

Other optional information

Future plans:

Our future plans are always to continue to educate the public about PROS as well as those living with PROS and to raise the profile of GoPI3Ks and inform people how they can help raise funds. We will undertake this by making sure that despite any health restrictions we will remain visible online, on our social media pages and by attending relevant online events.

We are looking to attend more public events to engage with the general public as well as PROS individuals and families face to face.

Our plan is to host an information PROS Day for those within the medical profession to understand more about PROS and the journey/pathway that those living with PROS and affected by PROS go through.

We will continue to financially help PROS individuals and their families to aid their daily living and alleviate and/or prevent poverty that can develop due to the extra costs living with PROS can bring.

To reassess at regular periods, particularly during times of global changes, our way of fundraising and raising awareness and to develop ways to increase this within the general population and for those living with PROS.

We will continue to update the GoPI3Ks website with relevant information and contact details, which for many is their first port of call when researching PROS.


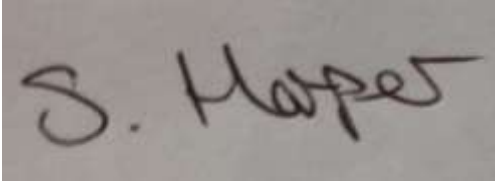
We are also hoping to host a face to face family weekend for PROS individuals and families. To bring these people together, along with doctors to present and speak at the weekend. We are also looking in include such things as mental health awareness, talks from possibly parents and an adult

living with this condition and a time for people to come together and spend time with like-minded people who have an understanding what they are going through.

Section G Declaration

The trustees declare that they have approved the trustees' report above.

Signed on behalf of the charity's trustees

Signature(s)		
Full name(s)	Mandy Sellars	Susan Jane Harper
Position (eg Secretary, Chair, etc)	Chairperson	Treasurer
Date	16/05/2023	



CHARITY COMMISSION
FOR ENGLAND AND WALES

GoPI3Ks

1176289

Receipts and payments accounts

CC16a

For the period
from

06/04/2022

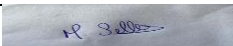
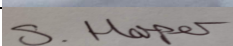
To

05/04/2023

Section A Receipts and payments

	Unrestricted funds	Restricted funds	Endowment funds	Total funds	Last year
	to the nearest £	to the nearest £	to the nearest £	to the nearest £	to the nearest £
A1 Receipts					
Donations	2,373	-	-	2,373	16,365
Fundraising events	1,153	-	-	1,153	-
Gift Aid (PayPal & Ebay)	1	-	-	1	-
Amazon Smile	55	-	-	55	-
Grants	250	-	-	250	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total (Gross income for AR)	3,832	-	-	3,832	16,365
A2 Asset and investment sales, (see table).					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	3,832	-	-	3,832	16,365
A3 Payments					
Individual Grants	3,964	-	-	3,964	-
Fundraising costs	196	-	-	196	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total	4,160	-	-	4,160	-
A4 Asset and investment purchases. (see table)					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total payments	4,160	-	-	4,160	-
Net of receipts/(payments)	- 328	-	-	- 328	16,365
A5 Transfers between funds					
A6 Cash funds last year end	16,365	-	-	16,365	-
Cash funds this year end	16,037	-	-	16,037	16,365

Section B Statement of assets and liabilities at the end of the period

Categories	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B1 Cash funds		-	-	-
		-	-	-
		-	-	-
	Total cash funds	16,037	-	-
	(agree balances with receipts and payments account(s))	OK	OK	OK
B2 Other monetary assets		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
B3 Investment assets			-	-
			-	-
			-	-
			-	-
			-	-
B4 Assets retained for the charity's own use			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
B5 Liabilities			-	
			-	
			-	
			-	
			-	
Signed by one or two trustees on behalf of all the trustees	Signature	Print Name	Date of approval	
		Mandy Sellars	16/05/2023	
		Susan Harper	16/05/2023	