



Trustees' Annual Report for the period

From	Period start date			To	Period end date		
	Day 06	Month 04	Year 2023		Day 05	Month 04	Year 2024

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		
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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

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 those currently holding roles as 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 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.

In the planning our activities during the financial period of 2023-2024, 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, PROS. (PIK3CA Related Overgrowth Spectrum) that the charity was set up to support.

Online awareness

Our online presence has always been a big focus for the charity and 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. Using such media allowed the charity to be able to organise group chats between the members, which isn't always possible face to face due to location, financial costs, time and health factors.

During this financial year we have continued to interact, share information and raise the profile of the GoPI3Ks charity. The aim is to raise awareness of PROS to our followers; those living with PROS, medical professionals and the general public.

During the charities online fundraisers and those fundraisers that our supporters organise is that they/we are able to reach a significant number of people, through Facebook posts, Tweets and Instagram posts and sending emails to our mailing list. 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) does to support those living with PROS, as well as providing links to our dedicated social media pages and contact details. We also share links to our funding application form as well as our new GoPI3Ks You Tube channel. 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, current 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 virtual online events also led to engagement between various rare disease groups, rare disease advocates 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.

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)

Attending events

With life returning back to normal, face to face meetings and conferences was possible during this financial period. We were able to attend a face to face fundraiser as well as organise a medical conference in collaboration with Great Ormond Street hospital. This was aimed at those currently working in the medical field who may come in to contact with someone with PROS. The aim was to provide updates of what treatment is currently available as well as looking to make the patient pathway easier, quicker and less stressful. In order to understand more about the patient pathway, the charity also conducted an online google form survey to understand how patients and families felt about their past and current medical care.

On the 18th of November we held our first ever dedicated PROS family weekend at the Holiday Inn at Heathrow in London. This was a chance for adults, children and families to come together and meet others with the same/similar conditions. In attendance was also various medical professionals who's area of expertise is PROS, this included the first ever presentation on mental health and living with PROS. The positive feedback from those who attended showed how beneficial a family weekend is for those living with and affected by this rare overgrowth condition and how isolation plays a huge role in their lives.

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, especially for some families to attend our family weekend. So we were able to help with travel and accommodation costs which allowed families and individuals be part of the first ever PROS family weekend. This led to increasing the physical and psychological wellbeing of this individual and/or family. We were also able to help with the extra costs of living with this condition by funding breathing equipment, clothing and specialised mental health counselling.

Public awareness

Our charity trustees and supporters of the charity continue to raise awareness of PROS 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. This has been achieved through the sharing of information via electronic means, through emails, online discussions and workshops and also sharing the website address to those with an interest.

Additionally, our attendance in person at fundraisers, conferences and our family weekend helped to raise awareness to the general public. This year we took part in scheme in which we were paired

with a medical student/doctor where we were able share information about PROS and its effect on someone and their life.

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 supporting 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 financial 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.

If we are unable to pay the company directly for said item or service and the applicant is to receive the funds, 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 long as receipts are provided.

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 donations, fundraising, grant making and a continued focus on raising awareness of PROS and GoPI3Ks alike.

Donations:

We are continually grateful for those who have donated funds over this last financial year, without their support we wouldn't be able to achieve the goals we set as a charity.

Fundraising:

April 2023:

In April one of our GoPI3Ks members, mum to a little girl with PROS and volunteer with the charity raised an amazing £2,111 to help us pay for the PROS medical conference we held in collaboration with GOSH (Great Ormond Street hospital)

We also received donations from Amazon Smile and PayPal from those that chose GoPI3Ks as their nominated charity when they shop.

May 2023:

Also in May, a face to face fundraiser meant we were able to raise over £140 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 are grateful to an individual who uses Charitable Giving Fund to donate £25 to GoPI3Ks every month.

We also received further donations from Amazon Smile and PayPal.

July 2023:

We received a donation from PayPal of just over £380 following an online fundraiser to help us pay for the family weekend.

August 2023:

A Gift Aid donation of just over £126 as well as another donation from PayPal.

September 2023:

We received a further donation from PayPal.

December 2023:

An online fundraiser to recoup some of the money spent for the family weekend raised over £590

January 2024:

A further donation from PayPal.

February 2024:

The annual birthday fundraiser from our chairperson made just over £830

March 2024:

Also one of our members and volunteer with the charity created an online fundraiser for Rare Disease Day and raised over an amazing: £1,500.

Grants provided:May 2023:

In May we were able to help one of our younger members who needs to use breathing equipment due to how PROS affects their airways. The family were struggling with the heaviness of the old equipment he had, so we were able to provide a more lightweight version making it easier for the younger member to be more independent.

August 2023:

We were able to help a family with the expenses incurred to come to the family weekend set for November 2023. This consisted of flights, bus fares and overnight accommodation and meals.

September 2023:

We paid for one of our younger members' footwear which requires buying more than one size to fit.

We also paid travel expenses for some of the doctors to attend the up and coming family weekend in November 2023.

October 2023:

We paid the final sum for the hotel in London that we were using to host the family weekend. This included: hire of rooms and presentation equipment, meals, accommodation and child care for the younger children attending the weekend.

November 2023:

Payment was made to help some of the families with their travel and extra accommodation costs so they were able to attend the family weekend.

We also paid the mental health charity for their presentation at the family weekend.

February-April 2024:

We helped a family with specialised mental health counselling, with both parent and younger member being helped.

Additional achievements:April 2023:

During April we collaborated with a doctor at GOSH (Great Ormond Street hospital) along with one of our volunteers to organise a PROS day at GOSH: Updates & advances in MDT care for PROS. Here we hosted various doctors who specialise in different areas such as orthopaedic and plastic surgery to highlight advances in medical care in their field. We also conducted an online survey asking those living with PROS (adults and families) how they feel about their medical care, which we went on to present to the doctors. This highlighted four main areas, surgery, mental health, coordination of care and access to care. This enabled doctors attending the meeting to understand a little more the issues that patients and families face so that we can look at making the patient pathway more accessible, useful and easier for all involved.

Also in this month we worked with the Cambridge Rare Disease Network on their “This Is Me” rare disease Patient passport. The premise of this is that the patient carries with them information about themselves, their medical history, their diagnosis and how this affects them. Other information includes how the patient needs to be moved, their current medication and their next of kin. The aim is to make any hospital visit more streamlined and easier for both medical professional and patient so time isn’t taken away by not knowing about the condition as the majority of the information will be found on the Patient Passport.

May 2023:

We continued working with GOSH to share information about the Rare Disease Collaborative Network and the work they are doing to ease the transition from child to adult service, the adult clinic and this information was added to our website which includes contact details.

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.

Since then we have also become aware of a RDCN that focuses on Segmental Overgrowth and Vascular Malformations. This information is now on our website with contact details due soon.

July 2023:

As in previous years we became media partners to support RAREfest23, 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.

August 2023:

The charity signed up for Dazzle4Rare23, this online campaign is designed to raise awareness of rare groups and charities as they share each other's information and websites, thus reaching a greater audience.

November 2023:

On the 18th of November we held our first ever dedicated PROS family weekend at the Holiday Inn at Heathrow in London. This was a chance for adults, children and families to come together & meet others with the same/similar conditions. Some of who had never met anyone living with the same condition. We had people from Ireland, the Netherlands & all across the U.K attending the weekend.

As well as listening to various talks from those with expertise in PROS, from research, current drug trials, an overview of PROS, management of PROS, as well as a talk on the Rare Disease Collaborative Network for mosaic conditions. Also for the first time a dedicated talk on mental health & living with PROS.

We also hired a child care company to entertain the younger children to allow the parents/carers to give their full attention to the talks. We also offered overnight accommodation and meals for attendees so the families did not have to worry about any financial cost over the weekend.

The positive feedback from the weekend highlighted how important weekends like this are for those living with and affected by this rare condition:

- I really enjoyed Saturday, all the specialist Drs talks on new medication and treatments. It's so nice to know there is help for the children who are born with PROS.
- I benefited by meeting up with people with the same condition as me, it helped me feel less alone.
- This was the first time we had spoken to doctors that knew about the condition and met other people who had similar experiences. I'm 24 and would have loved this as a child, to see others like myself and to know it was okay. We learnt more in one weekend then we had my whole life living with this. I feel like we now have a support network which is

wonderful.

- “We were” unaware of multidisciplinary clinic at GOSH, can now be referred in.
- I feel this event has helped my mental health so much.
- Meeting people and seeing my little boy running round happy.

Also in this month the charity signed up to continue the work with the: I am number 17 campaign (phase 4). The phase four policy will be asking the following: recognition of the need for equity in access to high quality care. More specifically, reducing the variation in services, improving coordination of care and strengthening awareness of rare conditions.

January 2024:

We held an online chat with various members and those living with PROS, this meant that anyone around the world could attend and virtually meet others with the same/similar condition.

Also this in month we took part in Student Voice Prize to raise awareness of PROS. This involves being paired with a student doctor, this can be in any part of the world. The student interviews the individual about their condition and then writes an essay on the condition they have learnt about, thus raising awareness about a condition not many doctors would be aware of.

February 2024:

Throughout Rare Disease Month 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 rare diseases in general and on the actual Rare Disease Day 29th we dedicated that day to sharing information on PROS: symptoms, complications, treatment options, diagnosis and research updates. We also included our website address on these slides so people could get in touch and learn more about PROS and GoPI3Ks.

Also for Rare Disease Day we created some slides with quotes from those living with PROS which we called “Voices of the PROS community” This year we asked individuals living with PROS and parents of children with PROS what one piece of advice would you give either your younger self, or as parent of a newly diagnosed child.

Also in February along with our volunteer (mum of a child with PROS) we looked in to the possibility of setting up a patient registry for those living with PROS. A patient registry is a collection of data related to patients with a specific diagnosis or condition. One of the main benefits of patient registries is **their ability to improve patient care**. By collecting and studying data from many patients, it

can help healthcare providers gain valuable insights into the effectiveness of different treatment plans.

March 2024:

In this month we started a collaboration between GoPI3Ks, a paediatric consultant at GOSH (Great Ormond Street hospital) and a researcher (VTCT Foundation Senior Research Fellow, Chartered Psychologist (BPS) & Registered Health Psychologist (HCPC) at the Centre for Appearance Research (CAR) University of the West of England).

Our aim is to look in to the psychological burden of living with PROS (Parents of children, children & adults) We recognise through other work/surveys that there is a huge psychological effect of those living and affected by PROS that is not addressed within the traditional medical setting.

We hope through funding, we can carry out research to understand this in more detail in the hope to make positive changes in the future to integrate mental health services as a regular option for those living with and affected by PROS. As well as developing physical and online resources to help patients, doctors and family and friends have a better understanding of how PROS can affect someone's mental health and how they/we can help.

Continued work throughout 2023-24

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 £11,875.64. The majority of our funds are unrestricted and are considered reserves that are freely available to spend on any of the charity's purposes. This being to offer financial grants to individuals living with PROS, to relieve poverty and aid their independence and daily living.

However, we do hold a small amount of funds that are restricted as of March 2024 that have been set aside for a particular project, setting up of a patient registry, totalling: £1,541.60.

The charity does hold a policy on reserves which can be viewed on our website under the section: privacy, safeguarding, terms and conditions and 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, Amazon Smile and the Charitable Giving Fund.

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 we will remain visible online, on our social media pages and by attending relevant online events as well as face to face events/fundraisers.

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.

Our plan is to continue to research and look in to the possibility of setting up a patient registry for those living with PROS. The cost of this, how this will evolve, who can help and how the information

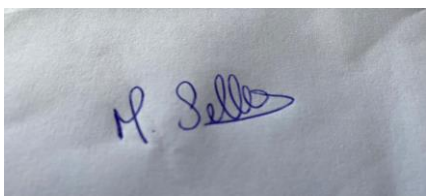
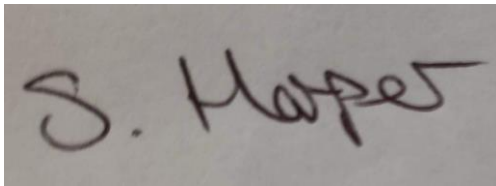
will be stored securely, help patients/families and the medical profession moving forward.

We will also be working closely with GOSH and Senior Research Fellow at the Centre for Appearance Research (CAR) University of the West of England to look further in to the psychological burden of living with PROS. How we can secure funding, design and distribute surveys, involve GoPI3Ks members to set up a steering group to drive this project forward in the hope of making changes to mental health services going forward. As well as producing resources that can help those living with and affected by PROS that can be distributed online, be found on our website, sent to our mailing list as well as producing a paper/leaflet version that can be used to pass along to doctors/healthcare professionals.

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	21/08/2023	



CHARITY COMMISSION
FOR ENGLAND AND WALES

GoPI3Ks

1176289

Receipts and payments accounts

CC16a

For the period
from

06/04/2023

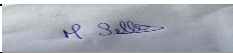
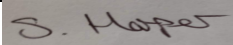
To

05/04/2024

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	1,550	1,542	-	3,092	16,037
Fundraising events	3,146	-	-	3,146	-
Gift Aid (PayPal & Ebay)	844	-	-	844	-
HMRC	127	-	-	127	-
Amazon Smile	38	-	-	38	-
	-	-	-	-	-
	-	-	-	-	-
Sub total (Gross income for AR)	5,705	1,542	-	7,247	
A2 Asset and investment sales, (see table).					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	5,705	1,542	-	7,247	16,037
A3 Payments					
Individual grants	1,973	-	-	1,973	-
Fundraising & expenses costs	398	-	-	398	-
Family weekend costs	8,261	-	-	8,261	-
PROS medical conference costs	675	-	-	675	-
Public Liability Insurance	101	-	-	101	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total	11,408	-	-	11,408	-
A4 Asset and investment purchases. (see table)					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total payments	11,408	-	-	11,408	-
Net of receipts/(payments)	- 5,703	1,542	-	- 4,161	16,037
A5 Transfers between funds					
A6 Cash funds last year end	16,037	-	-	16,037	-
Cash funds this year end	10,334	1,542	-	11,876	16,037

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	-	-	-
	(agree balances with receipts and payments account(s))	Agreement Error	Agreement Error	OK
B2 Other monetary assets	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
B3 Investment assets	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
			-	-
			-	-
			-	-
			-	-
B4 Assets retained for the charity's own use	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
B5 Liabilities	Details	Fund to which liability relates	Amount due (optional)	When due (optional)
			-	
			-	
			-	
			-	
Signed by one or two trustees on behalf of all the trustees	Signature	Print Name	Date of approval	
		Mandy Sellars	21/08/2024	
		Susan Harper	21/08/2024	