



Trustees' Annual Report for the period

	Period start date				Period end date		
	Day 06	Month 04	Year 2021		Day 05	Month 04	Year 2022
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				
8				
9				
10				
11				
12				
13				
14				
15				
16				
17				
18				
19				
20				

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 voluntarily and received no remuneration or other benefits, apart from reasonable expenses.

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.

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)

As always in the planning our activities during the financial period of 2021-2022, all trustees kept in mind the Charity Commission's guidance on public benefit. This focuses 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.

With the continued presence of COVID-19 during this financial period, this did again limit our ability to be face to face with the public, as well as PROS individuals, so as not to risk possible transmission of the virus. However, by using alternative methods such as Zoom, Microsoft Teams & social media we have been able to continue to raise awareness & interact with the general public as well as PROS individuals & families.

Online awareness

We were very aware, again especially due to the current pandemic that an online presence was even more vital to connect with the public & those living with PROS.

As always our focus during our online fundraisers & those fundraisers that our supporters organise is that we are able with numerous posts/Tweets to reach a significant number of people. During each post or Tweet we would provide links to the GoPI3Ks website which would explain to the viewer what PROS is & how it can affect individuals. The website also explains what we (the GoPI3Ks charity) do to support those living with PROS, as well providing links to our dedicated social media pages & contact details. This information enables anyone who may want 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 & news worthy information about PROS with the general public as well as the PROS community.

Attending events

Again during this financial year & the continued presence of Covid meant attending events in person was very restricted. However, attending virtual online events that sees an engagement between various rare disease groups, rare disease advocates, drug companies & the general public has allowed us to highlight PROS & GoPI3Ks alike. Also we were able to share with others how we as a charity continued to fundraise successfully during the global

pandemic & highlight PROS & the work we do at GoPI3Ks supporting those living with this rare overgrowth condition.

Grant making

Again through our fundraising & that of our supporters it has allowed us to offer financial grants to those living with PROS, thus helping to alleviate &/or prevent poverty that has occurred due to the extra costs of living with a rare medical condition. This also leads to a knock on effect of promoting the physical & psychological wellbeing of this individual &/or family.

Public awareness

Alongside our charity trustees continuing to raise awareness to friends, families & the wider population. Our continued presence online, particularly engaging with several rare groups & charities as well as pharmaceutical companies has allowed us to raise the awareness of PROS & the work we do at GoPI3ks. Plus how we may be able to work with pharmaceutical companies to help further research in to PROS. Additionally, we have worked with international charities & 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 & workshops, presentations & also sharing the website address to those with an interest.

With face masks until very recently still being worn this gave us the continued unique opportunity to spread the word about GoPI3Ks through bespoke face masks advertising the charity along with the website address.

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 &/or hospital, before an application can be processed.

We also ask for evidence of any relevant monetary quotes relating to said 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 & appropriate, we prefer to pay a company directly for any item or service they may be providing to the applicant.

Before an applicant receives funding, whether this be money, money for a service that is to be provided &/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 paid.

As always we would like to take this opportunity to thank those that have given their time freely. Without their time & generosity we would not be able to achieve our charity goals.

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 the last financial year, despite the global pandemic, saw the charity have a balance between fundraising, grant making & a continued focus on raising awareness of PROS & GoPI3Ks.

Fundraising:

May 2021:

In May we received a donation of £5.65 from Amazon Smile. This is from those generous people that have nominated us as their chosen charity to receive donations when they shop online.

Also in May we received a donation of £28.75 from the members of the general public who through PayPal Giving Fund nominated us as their chosen charity to receive donations when they shop using their PayPal account.

August 2021:

Again we received another donation from those who shopped at Amazon Smile of £12.11.

Also during this month we received an extremely kind donation of just over £2,000 to help us to continue supporting individuals with PROS.

February 2022:

In February we received a donation of £18.80 through Amazon Smile.

Again in February our chairperson created an online birthday fundraiser using personal social media pages on Facebook & Twitter as well as advertising this on the respective GoPI3Ks social media pages. Every time any supporter donated to the fundraiser they were put in to a raffle draw to win one of two vouchers, these were 2 £25 Amazon vouchers. This proved very successful raising over £1,100 for the charity.

Grants provided:

May 2021:

In May we were able to help one of our members with hospital costs, travel & parking costs to enable them to attend a much needed appointment.

August 2021:

In August we were asked by one of our members who has a love for horse riding if we could help with the cost of a specialised saddle, this would enable her to take part in dressage competitions. This has been something that over the years has been of great help to her mental health as living with PROS has caused many health complications, including hospitalisations &

surgeries. Being able to provide her with this equipment has made such a huge difference to her physical & mental wellbeing & she has continued to progress & has entered a number of dressage competitions with good success.

Additional achievements:

April 2021

Continued involvement with the All Stripes company to promote their research platform for rare diseases. Here patients can contribute to the acceleration of research & drug development of their rare disease, by allowing All Stripes to retrieve, access & 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 trials within their rare condition.

May 2021

This collaboration has allowed GoPI3Ks to offer our families & individuals the opportunity to become involved in this program. A recent All Stripes' partnership with the drug company Novartis has led to a QOL study of PROS that we (GoPI3Ks) have been able to share with our members to help further the research & understanding in to PROS.

Also our continued work with All Stripes has led to our chairperson becoming an ambassador & writing an article that was widely shared online describing living with PROS as well as mentioning GoPI3Ks, again sharing what we do & how we can help those living with PROS worldwide.

Every month an online Ambassador hour session is held by All Stripes where we learn about their new projects as well as networking with other rare disease groups & advocates.

Also in May, our chairperson was interviewed for an international podcast, again to talk about what PROS is, what it is like living with such a rare overgrowth condition & how this can affect someone's life. As well as highlighting the work that GoPI3Ks does to help those living with PROS. Again our website link appeared on the podcast website.

May also saw us take part in the Cambridge Rare Disease Network's inaugural Patient Group & Industry Partnering event. This event involved 10-12 rare disease patient groups & those pharmaceutical companies working in an orphan drug area. The aim was for the collaboration to focus on possible developments of new treatments. As well as to raise awareness of PROS & the

effect this condition has on the individual & the wider family network so that the companies have better insight in to this rare condition.

Again in May we circulated information of & attended a Webinar on Rare disease and the lessons learned from the COVID-19 pandemic. The focus on 3 areas of concern & the effect this had on those with rare conditions: diagnostic delay, health & social care coordination & research, drug development & access to treatment.

June 2021:

Our chairperson took part in Find A Cures', now "Beacon for rare disease," Drug Repurposing Conference, with a focus on Segmental Overgrowth. Speaking at the Drug Repurposing for Rare Diseases Conference, she shared her personal story of living with PROS & the use of the repurposed drug Sirolimus in the small clinical trial run by Professor Rob Semple. This was attended by medical professionals as well as being open to the general public to learn more about PROS & GoPI3Ks. This was shared on personal social media & GoPI3Ks social media pages too.

July 2021:

Find A Cure held a Webinar that was attended with the focus on Health Economics, looking to further our understanding of the following subjects:

- **What is health economics?**
- **How is health economics used in the UK?**
- **Why do we need health economics?**
- **Who are the decision makers in the UK and Ireland?**
- **How are treatments compared when their benefits can be so different?**
- **What else is considered in health economic decision making?**
- **What is an economic model?**
- **When is an economic model useful in healthcare?**
- **What are the different types of model available?**
- **What do you have to consider when making an economic model?**
- **What is the purpose of the model?**
- **Who is the model for?**

- What is the perspective of the model?
- Particular considerations for rare diseases
- How is economic modelling relevant for rare disease organisations?
- What help is available for economic modelling for rare diseases?

September 2021:

Attended Find A Cure's community fundraising workshop where we gave a presentation to a number of rare disease patients & groups about online fundraising that was done for GoPI3Ks during the pandemic & how successful this can be despite limitations due to Covid. Here we shared our website link so people could learn more about us & the rare overgrowth condition.

Also in September we became part of Find A Cure/Beacon's patient engagement team. The aim is to help formulate & develop courses / webinars / workshops for the rare disease community.

October 2021:

We attended the Cambridge Rare Disease Network's RAREsummit21. We displayed a poster explaining about what PROS is & how it can affect someone as well as details of GoPI3Ks. This was attended online by 350 individuals from 24 countries and 138 cities around the world, with people attending from the UK, Europe, USA, Australia, India, Pakistan, Colombia, Mexico, Oman & South Korea.

Also in October we hosted a zoom call with Professor Robert Semple & Dr Ralitsa Madsen who are both experts within the field of PROS. This gave the GoPI3Ks members the chance to speak directly with these doctors with questions that were submitted in advance, but also asked on the evening. This proved very popular with attendees from the U.K, Europe, South America as well as Kenya.

In October, working alongside other groups & charities supporting PROS individuals & families, we co-organised & hosted online the first International Scientific Meeting for PIK3CA Related Overgrowth Conditions. This involved around 225 people worldwide, including patients, caregivers, basic scientists, researchers & pharmaceutical companies. GoPI3Ks members also

contributed by sharing personal stories of themselves & their children, as well as networking with other attendees on both days of the conference.

December 2021:

Our chairperson gave a presentation on PROS & GoPI3Ks to workers within the NHS in the Lincolnshire area. This was organised by the Lincolnshire equality team within the NHS for Disability Awareness Month which takes place every December.

January 2022:

GoPI3Ks took part in Mystery Disease Monday run by M4RD (Medics 4 Rare Diseases) This is a way for patient groups & charities to raise awareness of the medical condition they support with the medical community. Throughout the day, M4RD share stories on Instagram highlighting: signs & symptoms, diagnosis, who is affected & with links to support groups & charities.

February 2022:

We attending the online International Rare Disease Showcase: This is an event which highlights the best examples of rare disease progress around the UK & beyond, through interesting talks & presentations. Here we were able to networking with various patient groups, pharmaceutical companies & doctors.

Also in February, we became involved with the “I am Number 17” campaign. This is a project that has been running for 3 years to raise awareness that 1 in 17 people within the U.K will be affected by a rare disease at some point in their life. This next phase as well as educating the general public is to raise awareness amongst health care professionals. We shared various materials on social media, through electronic newsletters & via the website. Additionally, M4RD would place our logo & website details on their campaign website to encourage viewers to learn more about GoPI3Ks & PROS.

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. 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 &/or learn more about PROS & GoPI3Ks.

Also on this day, our chairperson also shared a #RareSnapshot of living with the rare condition PROS via All Stripes, who organised this Rare Snapshot hashtag for Rare Disease Day.

Also in February on Rare Disease Day we gave a PVP (Patient Voice Publication) update shared via Prime Global PEP (Patient Engagement Practices). This was following on from a previous poster we had designed with this company to highlight what PROS is, how it affects people, the unmet needs of the patient population & how Pharmaceutical companies can help. This was shared with patients groups, doctors, & pharmaceutical companies on social media with links to the GoPI3Ks website.

Again in February we attended the Westminster Virtual Rare Disease Day 2022 Reception. Here we could listen to talks on rare disease & followed this with a chance to network with MP's & other patient representatives to highlight PROS & GoPI3Ks.

March 2022:

In March our chairperson wrote a blog for All Stripes focusing on how someone's mental health can be affected by living with a rare medical condition that changes your appearance. This was shared online via social media, websites & newsletters, as well as giving details of how to contact us at GoPI3Ks should we reach someone or a family that have a PROS diagnosis.

Continued work throughout 2021

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 & children. Whether this be workshops, Webinars or informal groups. Such information comes from continued contact with various medical professionals & scientific researchers as well as online information from other support groups as well as PROS charities.

We also keep people updated by emailing families & 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 is something they would benefit from.

Our annual newsletter is another source that helps keep those living with PROS & 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 £16,365 all of which is unrestricted funds. These funds are held to offer financial grants to individuals living with PROS, to relieve poverty & aid their independence & daily living.

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 has been through generous donations, online fundraising by the trustees & other supporters raising money via online platforms such as the PayPal Giving Fund & Amazon Smile.

The income raised was used to help those living with PROS by giving grants to aid their daily living & alleviate any poverty that occurred due to living with this medical condition. Please refer to the achievements & 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 & to raise the profile of GoPI3Ks & 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 & by attending relevant online events. As the Covid-19 situation dies down we are looking at attending public events to engage with the general public as well as PROS individuals & families face to face. At the time of writing, we are soon to be attending our first face to face fundraiser & awareness event post COVID-19.

We will continue to financially help PROS individuals & their families to aid their daily living & alleviate &/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 & raising awareness & to develop ways to increase this within the general population & for those living with PROS.

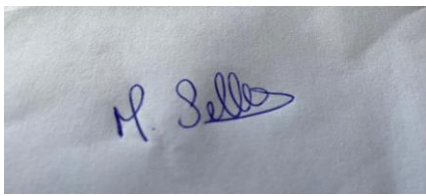
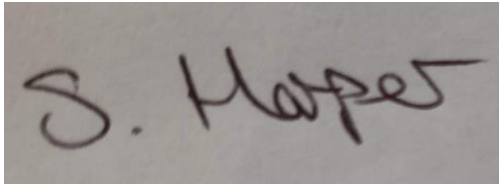
We will continue to update the GoPI3Ks website with relevant information & contact details, which for many is their first port of call when researching PROS.

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	07/06/2022	



CHARITY COMMISSION
FOR ENGLAND AND WALES

GoPI3Ks

1176289

Receipts and payments accounts

CC16a

For the period
from

06/04/2021

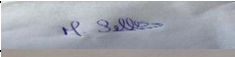
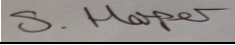
To

05/04/2022

Section A Receipts and payments

	Unrestricted funds to the nearest £	Restricted funds to the nearest £	Endowment funds to the nearest £	Total funds to the nearest £	Last year to the nearest £
A1 Receipts					
Donations	2,777	-	-	2,777	14,077
Fundraising events	1,159	-	-	1,159	-
Gift Aid (PayPal & Ebay)	28	-	-	28	-
Amazon Smile	46	-	-	46	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total (Gross income for AR)	4,010	-	-	4,010	14,077
A2 Asset and investment sales, (see table).					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	4,010	-	-	4,010	14,077
A3 Payments					
Individual Grants	1,722	-	-	1,722	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total	1,722	-	-	1,722	-
A4 Asset and investment purchases. (see table)					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total payments	1,722	-	-	1,722	-
Net of receipts/(payments)	2,288	-	-	2,288	14,077
A5 Transfers between funds					
A6 Cash funds last year end	14,077	-	-	14,077	-
Cash funds this year end	16,365	-	-	16,365	14,077

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	16,365	-	-
	(agree balances with receipts and payments account(s))	OK	OK	OK
B2 Other monetary assets		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
B3 Investment assets			Cost (optional)	Current value (optional)
			-	-
			-	-
			-	-
			-	-
			-	-
B4 Assets retained for the charity's own use			Cost (optional)	Current value (optional)
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
B5 Liabilities			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	07/06/2022	
		Susan Harper	07/06/2022	