



Trustees' Annual Report for the period

	Period start date				Period end date		
	Day 06	Month 04	Year 2020		Day 05	Month 04	Year 2021
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	
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7				
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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 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 voluntarily and received no remuneration or other benefits.

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 and those living with PROS by raising awareness, providing information and educational materials.

For the prevention and 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 2020-2021, all trustees kept in mind the Charity Commission's guidance on public benefit. This is aimed at 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 emergence of the global pandemic during this financial period, it did limit our ability to be face to face with the public, as well as PROS individuals. However, by using alternative methods such as Zoom & social media we have been able to raise awareness & interact with the general public & as well as PROS individuals & families.

Online awareness

We were very aware, especially during this year that an online presence was even more vital to connect with the public & those living with PROS.

During our online fundraisers & also any fundraisers that our supporters organised we were aware that the numerous posts/Tweets could 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 should anyone want to support us further through their own fundraising or if they (a family member or someone they know living with PROS) needs any 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

This financial year has meant attending events in person was simply not possible. However, attending virtual online events that sees an engagement between various rare disease groups, drug companies & the general public has allowed us to highlight PROS & GoPI3Ks alike.

Grant making

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 has a knock on effect to 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. We have also had members of the public wanting to know more about the charity as well as wanting to understand more about the rare condition PROS. This has been achieved through the sharing of information via electronic means, through emails, online discussions & also sharing the website address to those with an interest.

With the introduction of face mask wearing, this gave us the 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 we prefer to pay a company directly for any item or service they may be providing to the applicant.

We also require a signature on the application form stating that the applicant is not able to self-fund the item, equipment or service that is needed.

Before an applicant receives funding, whether this be money &/or equipment from the charity they are asked to sign a declaration of receiving charity funded goods form. 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 does not need to be signed if we are reimbursing an applicant for the extra costs that they have already

paid.

A great contribution was made by several volunteers over this period, from their invaluable fundraising to raising the public profile of PROS & GoPI3Ks.

Without their time & generosity we would not have been able to achieve so much.

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 good balance between fundraising, grant making & a continued focus on raising awareness of PROS & GoPI3Ks.

Fundraising:

July 2020:

In July we received a donation of £95 through the PayPal giving fund. This is thanks to the generosity of our supporters who nominated GoPI3Ks as their preferred charity to donate to whilst they shop online.

August 2020:

One of our members held an online fundraiser for GoPI3Ks & raised £111.

September 2020:

A family member of one of our trustees held an online fundraiser for her birthday & nominated GoPI3Ks as her charity of choice, she raised £90.

November 2020:

During this month the partner of one of our trustees held a unique fundraising event to raise money for us. At this time 'I'm a celebrity get me out of here' was airing on TV, so our fundraiser decided she wanted to take part in a bug eating challenge & stream this online. As the money rose so did the number & type of bugs she would have to consume. She did amazingly well eating everything she was asked to & raised £760.

February 2021:

In February we received a donation of £50 through the PayPal Giving Fund UK. This is thanks to the generosity of our supporters who nominated GoPI3Ks as their preferred charity to donate to whilst they shop online.

Also in February after signing up with Amazon Smile we received a donation of £6.47. Again this is thanks to our supporters who nominated GoPI3Ks as their charity to donate to.

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 draw to win one of two vouchers, these were 2 £20 Amazon vouchers. This proved very successful raising over £1,280.00 for the charity.

Grants provided:May 2020:

In May we were able to pay for puppy training classes for one of our PROS families who wanted to train their new puppy to become an assistance dog for their daughter who lives with PROS. With the hope that this would help with the anxiety she lives with but also during hospital visits that have become increasingly stressful for all the family.

June 2020:

In June we were also happy to pay for the vaccinations for the puppy that was in training to become an assistance dog. This took away a lot of the worries for the family of being able to, when Covid-19 allowed them, to attend the training classes in person.

August 2020:

In August we were able to help one of our members who lives with overgrowth in his lower limbs. This often means that he cannot buy just one pair of trousers, he often needs two, which then need to be altered to fit. So GoPI3Ks paid for the cost of the trousers as well as the charge to cover the alterations.

Again in August we were able to help one of our families with their travel & parking costs so that they were able to attend hospital & receive the treatment/surgery that was required.

October 2020:

In October we were able to help one of our younger members who had recently undergone surgery on her leg. The young girl is a very promising dancer & to enable her to get back to full fitness & the range of movements she needed, she required specialist physio. We were happy to be able to fund this & pleased to report that she is now back dancing having recovered from her surgery.

Additional achievements:July 2020

Making use of video conferencing we were able to offer our GoPI3Ks families the unique chance to chat and ask questions with two of leading experts & scientific researchers within the medical field of PROS. Here we all gained knowledge of what the current research looks like, what treatments could be available in the future & more personal questions about individual patients were also discussed.

September 2020

We invited the Proteus Syndrome Foundation UK charity founder Tracey Whitewood-Neal and mum to an adult with a rare

overgrowth condition to join us in two Zoom calls with GoPI3Ks families & patients. Here PROS individuals & families were able to chat with Tracey & understand more what it is like to have a child with a rare overgrowth condition and discuss the problems she faced.

Also during this month we engaged with the drug company Novartis & RWS Life Sciences to help with a QOL questionnaire. This was distributed to all our GoPI3Ks members to aid Novartis in their forthcoming research & potential future treatment for PROS.

November 2020

We attended an online event named Rarefest 2020, organised by the Cambridge Rare Disease Network, this was advertised on our online platforms to everyone from patients, medical students, pharmaceutical companies, charities, to doctors & the general public. Here we saw a number of presentations, posters, exhibitions highlighting the rare community, helping to engage & aid learning in to rare disease, from diagnosis & how this is found, to how research is undertaken, how treatment is developed & how patients become involved in trials, compassionate use of drugs & drug repurposing.

February 2020

GoPI3Ks were actively involved in Rare Disease Day 2021 online event by becoming their media supporter. Here we engaged with a number of different people online via social media, from the general public, rare disease support groups as well as our own PROS community. We created various slides that explained PROS: its definition, what conditions fall within PROS, what the complications are, the management & finally what treatment there currently is.

During this month we also organised a Zoom video call between GoPI3Ks members & Jordan Whitewood-Neal who lives with a rare overgrowth condition which is very similar to PROS. Here people could ask questions to gain a better understanding of what it is like to live with this condition. It also gave parents of a child with PROS more insight in to what it is like from their child's point of view.

Also during this month we partnered with All Stripes who developed a 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. Following our collaboration with All Stripes, we have been able to offer our GoPI3Ks families the opportunity to become involved in this program.

Continued work throughout 2020

Collaborating with other PROS support groups & registered charities, GoPI3Ks helped to develop a patient registry for those living with PROS. The aim is to generate a data base of medical information from PROS patients to describe their experiences of living with this rare condition. This is then used to help with research & possible future treatment & drug trials.

We are also working with a larger number of PROS groups to organise an International Scientific Meeting for October 2021. The aim is to bring together patients, support groups, scientific researchers, PROS experts & those just starting out in the medical field. This will involve presentations from those in the medical field, enabling patients/families, support groups & other doctors to learn more about where the research is within PROS. As well as audio, video & poster presentations from PROS patients about their lives with PROS to enable those within the medical field a better understanding of the people they are trying to help.

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. Such information comes from continued contact with various medical professionals & scientific researchers.

We also keep families updated via our social media pages & 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.

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 £14,077 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.

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 online fundraising by the trustees & their families & other supporters of the charity.

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.

Other small expenditures included the buying of vouchers that would hopefully encourage people to donate during online fundraising events.

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 and inform people how they can help raise vital funds. We will undertake this by making sure that despite any restrictions we will remain visible online, on our social media pages & by attending relevant online events. Where we can, we will look at attending public events to engage with the general public as well as PROS individuals & families face to face.

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

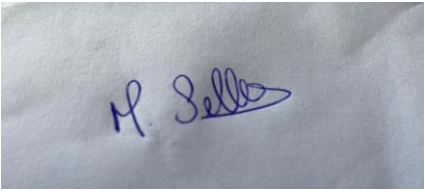
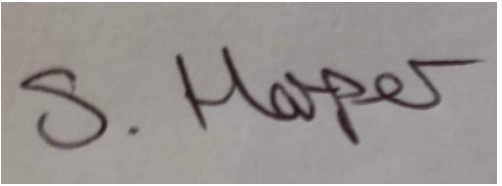
The success of the first family weekend in 2018 for both patients & their families on a psychological & medical knowledge level demonstrates the need to look into doing this again in 2022, so Covid-19 allowing this is something we can help to fund.

To continue to update the GoPI3Ks website with relevant information and 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	15/07/2021	



CHARITY COMMISSION
FOR ENGLAND AND WALES

GoPI3Ks

1176289

Receipts and payments accounts

CC16a

For the period
from

06/04/2020

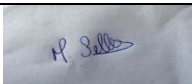
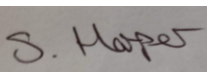
To

05/04/2021

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	1,201	-	-	1,201	11,682
Fundraising events	2,559	-	-	2,559	-
Gift Aid (PayPal & Ebay)	151	-	-	151	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total (Gross income for AR)	3,911	-	-	3,911	11,682
A2 Asset and investment sales, (see table).					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	3,911	-	-	3,911	11,682
A3 Payments					
Fundraising costs	40	-	-	40	-
Individual Grants	1,476	-	-	1,476	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total	1,516	-	-	1,516	-
A4 Asset and investment purchases. (see table)					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total payments	1,516	-	-	1,516	-
Net of receipts/(payments)	2,395	-	-	2,395	11,682
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	11,682	-	-	11,682	-
Cash funds this year end	14,077	-	-	14,077	11,682

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	14,077	-	-
	(agree balances with receipts and payments account(s))	OK	OK	OK
		Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B2 Other monetary assets		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		Fund to which asset belongs	Cost (optional)	Current value (optional)
B3 Investment assets			-	-
			-	-
			-	-
			-	-
			-	-
		Fund to which asset belongs	Cost (optional)	Current value (optional)
B4 Assets retained for the charity's own use			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
		Fund to which liability relates	Amount due (optional)	When due (optional)
B5 Liabilities			-	
			-	
			-	
			-	
			-	
Signed by one or two trustees on behalf of all the trustees	Signature	Print Name	Date of approval	
		Mandy Sellars	15/07/2021	
		Susan Harper	15/07/2021	