

GOPI3KS (GENETIC OVERGROWTH PI3K SUPPORT)

England & Wales · Charity number 1176289

Details

Status Registered

Legal form CIO

Registered 2017-12-14

Register [View on the Charity Commission register](#)

Contact

Address 8 Bolton Avenue
Accrington
BB5 6HN

Phone 07742849012

Email gopi3ks@yahoo.com

Website <https://gopi3ks.com/>

Activities

Objects: THE OBJECTS OF THE CIO ARE 1. THE PREVENTION OR RELIEF OF POVERTY FOR THE PUBLIC BENEFIT OF PERSONS IN NEED WITH PIK RELATED OVERGROWTH SPECTRUM (PROS) IN PARTICULAR BY MAKING GRANTS TO THEM. 2. TO ADVANCE THE EDUCATION OF THE GENERAL PUBLIC AND PERSONS WITH PROS IN ANY PART OF THE WORLD RELATING TO PROS IN PARTICULAR BUT NOT EXCLUSIVELY BY RAISING AWARENESS, PROVIDING INFORMATION AND EDUCATIONAL MATERIALS.

Activities: 1. The prevention or relief of poverty for the public benefit of persons in need with PIK Related Overgrowth Spectrum (PROS) worldwide in particular by making grants to them. 2. To advance the education of the general public and persons with PROS in any part of the world relating to PROS in particular but not exclusively by raising awareness, providing information and education materials.

Classification

- **How:** Makes Grants To Individuals, Provides Advocacy/advice/information
- **What:** Disability
- **Who:** Other Defined Groups

Geography

- Australia
- Denmark
- India
- Scotland
- Sweden
- Turkey
- United States
- Throughout England And Wales

Finances

| Period end | Income | Expenditure | Assets | Employees |
|------------|---------|-------------|--------|-----------|
| 2025-04-05 | £31,022 | £26,167 | - | - |
| 2024-04-05 | £7,247 | £11,408 | - | - |
| 2023-04-05 | £3,832 | £4,160 | - | - |
| 2022-04-05 | £4,010 | £1,722 | - | - |
| 2021-04-05 | £3,911 | £1,516 | - | - |

Trustees

| Name | Role | Appointed |
|-----------------------|-------|------------|
| MANDY SELLARS | Chair | 2017-12-14 |
| Amanda Jane Kenyon | | 2019-11-13 |
| Katie Louise Kavannah | | 2019-11-13 |
| SUSAN JANE HARPER | | 2017-12-14 |

GOPI3KS (GENETIC OVERGROWTH PI3K SUPPORT)

England & Wales - Charity number 1176289

Accounts



Trustees' Annual Report for the period

| | | | | | | | |
|-------------|-------------------|-------------|--------------|-----------|-----------------|-------------|--------------|
| From | Period start date | | | To | Period end date | | |
| | Day 06 | Month 04 | Year 2024 | | Day 05 | Month 04 | Year 2025 |

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 | | | | |
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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 those currently holding roles as trustees |

Additional governance issues (Optional information)

| | |
|--|--|
| <p>You may choose to include additional information, where relevant, about:</p> <ul style="list-style-type: none"> • 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. | <p>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.</p> <p>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.</p> <p>The current trustees will make available to each new trustee, on or before their first appointment:</p> <ul style="list-style-type: none"> • 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. <p>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.</p> |
|--|--|

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 2024-2025, 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 was as always a big focus for the charity during the last financial year. The ease and popularity of using social media platforms such as X, Facebook & Instagram as well as applications like Microsoft Teams and Zoom allowed us to continue to raise awareness of PIK3CA Related Overgrowth Spectrum and interact with the general public as well as PROS individuals and families. Using such media breaks down barriers that can occur 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 organised by our supporters we are able to reach a significant number of people. These can be through Facebook posts, posts on X and Instagram posts as well as sending emails to our mailing list. During each post we 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 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

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)

condition.

Attending events

During this financial period. We were able to attend a face to face fundraiser that allowed us to raise funds for GoPI3Ks as well as raising awareness of PROS to the general public attending this event.

During this year we collaborated with PIPgen who are a consortium of over 11 universities, research institutes and companies across 8 countries from Europe & the UK which came together to host and train 15 PhD Candidates in the field of PI3K basic and translational research. Together with an art school of Cambridge (CSVPA), PIPgen developed an Art-Science exchange programme: PIPgenerating Art, their aim was to disseminate science from the perspective of artists. As a charity we worked closely with the organisers, scientists and artists to educate them on what PROS is, what it is like to live with to enable them to produce their final art pieces. We attended the event where we were able to mingle with scientists, artists and the general public as well as take part in a Q and A session to again raise awareness of PROS and what we do at the charity.

Grant making

Again through our fundraising and that of our supporters it has allowed us to offer financial grants to those living with PROS. During this last financial year we were able to help several families with travel costs to attend hospital appointments, funding specialised mental health support, as well as equipment to help one of our younger members. Help with making a garden safe and secure, funds towards a much needed short break away and also helping a family pay for tests and doctors consultations that wasn't covered by their insurance. Finally during the Christmas period we were able to help some of our members with a small grant to make the festive period a little easier for them.

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 and collaborative events has led to an increased awareness of PROS and also the charity and what we do to support those with this rare overgrowth condition.

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: Throughout this financial year we received several donations from PayPal, from those that chose GoPI3Ks as their nominated charity when they shop, as well as when gift aid was ticked during fundraisers.

Also during this financial period we are grateful to an individual donor who uses Charitable Giving Fund to donate £25 to GoPI3Ks every month.

We are also grateful to one of our GoPI3Ks families who also donates monthly to us.

April 2024:

In April one of our GoPI3Ks members ran the Brighton marathon in aid of GoPI3Ks and raised over £1,000.

Also in this month we attended a ghost hunt organised by a friend of our chairperson where we could raise awareness of PROS and also raised over £370 during our ghostly evening.

May 2024:

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.

September 2024:

One of our members who lives with PROS took on a challenge to ride her horse 50 miles during September to raise money for us and she raised over £200.

Also one of the mums of a little girl who lives with PROS organised a raffle at her daughters school and raised over £299

December 2024:

We received a research grant from the VTCT foundation (*VTCT Foundation seeks to invest in all forms of research and services that help people living with a visible difference and their families and carers to overcome any social, physical, psychological, emotional or other disadvantage*). The grant will allow us to carry out a year-long research project in 2025 alongside researchers at the Centre for Appearance Research at the University of the West of England.

Our aim is to look in to the psychological burden of living with PROS with the goal of understanding this aspect of living with this rare condition as well as developing resources that can be widely used and distributed to those living with PROS, parents of a child with PROS, medical professionals, educational settings and the general public.

January 2025:

We received a donation following our collaboration with PIPGen in September of last year.

February 2025:

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

We received an amazing donation of £500 from someone who lives with PROS and came across the work we are doing within the PROS community.

Also in February we had a donation of £50 from a nursery who had nominated us as their charity to support.

March 2025:

Also one of our members and her son who lives with PROS, along with his friends organised an auction for GoPI3Ks and raised over an amazing £650.

Grants provided:

April 2024:

In April we were able to help out a family with the travel costs to their hospital appointment.

June 2024:

We were able to help by funding some specialist mental health support to help one of our members

August 2024:

We funded a short break for one of our families before the new school term begin in September.

September 2024:

We were able to help out one of our families whose young daughter has a suppressed immune system due to medication she takes to help her condition. Their garden wasn't secure or safe for her to play in so we contributed towards this enabling her to have a safe and secure place to spend time outside.

October 2024:

During October we were able to help several families, one with

travel expenses to their hospital appointment and another young member where we provided equipment to help them during their long wait and travel to and from hospital appointments.

December 2024:

During this month we helped out a family who's insurance didn't cover a series of blood tests and doctor consultations they needed, so we were able to cover this for them.

Also in December we gave a number of grants to some of our members/families to make their Christmas a little easier.

Additional achievements:

April 2024:

Following on from the previous financial year, we continued our 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 was and is to look in to the psychological burden of living with PROS (Parents of children, teenagers & adults) We recognise through other work/surveys that there is a huge psychological effect for those living and affected by PROS that is not addressed within the traditional medical setting.

We worked together to devise a short survey on how living with PROS effects their life, from the physical, financial, psychological to their mental health. This was sent to our mailing list and posted on several social media groups. The responses we received highlighted several areas that individuals and families struggle with and showed that there is a huge need for further research to be undertaken.

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.

Also during this month we added more vital information to our website focusing on the RDCN (Rare Disease Collaborative Network) This included the contact details for the Segmental Overgrowth and Vascular Malformations clinic, which includes 6 centres around the U.K.

The purpose of the RDCN is that it will become 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.

In April 2024 we signed up with the “I am number 17” campaign and their next stage to raise awareness and hopefully make changes for those living with rare conditions. The awareness amongst the public and healthcare professionals of those with rare conditions is very low, which often results in people with rare diseases often being misdiagnosed and experience care inequity. So, in 2024, the “I am number 17” campaign were calling on Members of Parliament (MPs) to represent all their constituents and Elevate Care for Rare.

Their aim consisted of three steps:

Reducing variation in services

Improving coordination of care

Strengthening awareness of a rare disease

This involved meetings with other rare disease groups and the “I am number 17” team to discuss the best ways to achieve this the objective and push for awareness of rare patients and their families.

Also in April we attended a workshop with the Appearance Collective focusing on social media and appearance-altering conditions. They shared the findings of a recent qualitative research into the experiences of adults and young people with visible differences who use social media. The workshop also included interactive discussions about experiences of using social media as a charity and the key needs of your members. We also had an opportunity to directly inform the social media resources that were being developed by the VTCT Foundation team at CAR, which will be freely available to Appearance Collective members.

May 2024:

Along with one of our volunteers who is a parent to a child with PROS we were invited to give a presentation on: what is PROS, our journeys as an adult growing up with PROS and a parent to a child living with this condition. These presentations were given to the members of the PIPgen team (a consortium of over 11 universities, research institutes and companies across 8 countries from Europe & the UK which has come together to host & train 15 PhD Candidates in the field of PI3K basic and translational

research). The presentation was also delivered to students at the art school of Cambridge (CSVPA) who together with the PIPgen team developed an Art-Science exchange programme. The aim was to disseminate science from the perspective of artists. All 15 projects within the PIPgen network were transformed into unique pieces of Art. These projects were focused on the PI3K pathway and culminated with an in-person, open-door, art exhibition where all 15 art and science students presented their works and interact with scientists and a lay audience.

August 2024:

The charity signed up for Dazzle4Rare24, 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.

September 2024:

We attended the open art exhibition from the collaboration between ourselves, PIPgen and art school of Cambridge (CSVPA). Here we got to meet the artists and scientists involved in this project and took part in an open round table to answer any questions they had about PROS. We also had merchandise at the event that featured a QR code link to our website donation page. This was a good networking opportunity and led to good relationships with some of the scientists in the area as well as fermenting our relationship with the PIPgen team which may lead to further projects in the future.

December 2024:

Working alongside a senior researcher at the Centre for Appearance Research (CAR) we were successful in our grant application from the VTCT Foundation. We have funding for a year-long project which focuses on the impact of the psychological burden living with PROS can bring. As stated earlier, the purpose of this project is to gain a better understanding of 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. We will also be developing physical and online resources to help patients, doctors and family and friends as well as the general public have a better understanding of how PROS can affect someone's mental health and how they/we can help.

February 2025:

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 about 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, the 28th of February, 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 was your first thought when you/your child was diagnosed with PROS?" Also "What is your thought/s now living with or having a child with PROS?"

March 2025:

We met with some of those within the PROS community, from various countries around the world and two researchers from University of West England and the CAR (Centre for Appearance Research) to start the project in to psychological burden of living with PROS. Here the focus group discussed what the main causes and burdens people / families live with, this brought up several categories which gave us a lot of material to work with to help design the main survey.

April 2025: we attended an online meeting, comprising of a number of worldwide patient organisations who have an interest in Vascular conditions. Here we discussed a Proposal for the Establishment of a Patient Committee within ISSVA (International Society Study Vascular Anomilies) A proposal was written to be presented at the annual conference in April 2025.

Continued work throughout 2024-25

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 £16,731.22. 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.

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 the Charitable Giving Fund.

We have also received a grant this financial year from the VTCT foundation that has enabled us to begin our mental health / psychological project in to the psychological burden of living with PROS.

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 as always is 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 and 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 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.

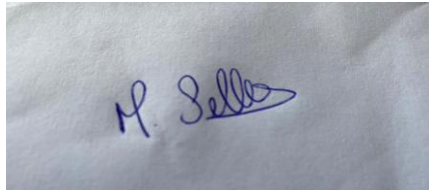
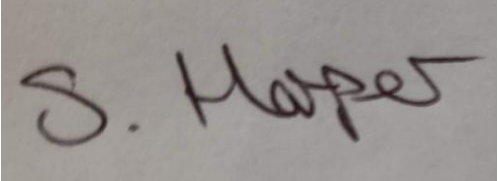
We will continue to work closely with the Senior Research Fellow at the Centre for Appearance Research (CAR) University of the West of England to look further in to the psychological burden of

living with PROS, along with those within the PROS community, from different backgrounds, ethnicity, gender and sexuality. We will develop a larger scale survey to gauge more of an understanding of how PROS effects all aspects of an individual and family life. The resources that we develop following this year-long project will be used and distributed to those within the medical field, healthcare professionals, educational settings and even friends and family, to further their understand PROS and the effect it can have on various aspects of a person/families life.

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 | 30/07/2025 | |



CHARITY COMMISSION
FOR ENGLAND AND WALES

GoPI3Ks

1176289

Receipts and payments accounts

CC16a

For the period
from

06/04/2024

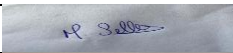
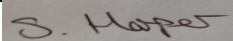
To

05/04/2025

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 | 1,555 | | - | 1,555 | 11,876 |
| Fundraising events | 3,993 | - | - | 3,993 | |
| Gift Aid (PayPal & Ebay) | 604 | - | - | 604 | - |
| Grants | 24,870 | - | - | 24,870 | - |
| | | - | - | - | - |
| | | - | - | - | - |
| | | - | - | - | - |
| | | - | - | - | - |
| Sub total (Gross income for AR) | 31,022 | - | - | 31,022 | |
| A2 Asset and investment sales, (see table). | | | | | |
| | - | - | - | - | |
| | - | - | - | - | - |
| Sub total | - | - | - | - | - |
| Total receipts | 31,022 | - | - | 31,002 | 11,876 |
| A3 Payments | | | | | |
| Individual grants | 4,050 | - | - | 4,050 | - |
| Fundraising & expenses costs | 146 | - | - | 146 | - |
| Public Liability Insurance | 101 | - | - | 101 | - |
| Money to UWE for research project | 21,870 | - | - | 21,870 | - |
| | | - | - | - | - |
| | | - | - | - | - |
| | | - | - | - | - |
| | | - | - | - | - |
| Sub total | 26,167 | - | - | 26,167 | |
| A4 Asset and investment purchases. (see table) | | | | | |
| | - | - | - | - | |
| | - | - | - | - | - |
| Sub total | - | - | - | - | - |
| Total payments | 26,167 | - | - | 26,167 | - |
| Net of receipts/(payments) | 4,855 | | - | 4,855 | 11,876 |
| A5 Transfers between funds | | - | - | | - |
| A6 Cash funds last year end | 11,876 | - | - | 11,876 | - |
| Cash funds this year end | 16,731 | | - | 16,731 | 11,876 |

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 | | 15,189 | 1,542 | - |
| | | - | - | - |
| | | - | - | - |
| | Total cash funds | 15,189 | 1,542 | - |
| | (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 | 30/07/2025 | |
| |  | Susan Harper | 30/07/2025 | |



Section A

Independent Examiner's Report

Report to the trustees

Charity Name
GoPI3Ks (Genetic Overgrowth PI3K Support)

On accounts for the year ended

05/04/2025

**Charity no
(if any)**

1176289

Set out on pages

1-2

1-(remember to include the page numbers of additional sheets)

I report to the trustees on my examination of the accounts of the above charity ("the Trust") for the year ended 05/04/2025.

Responsibilities and basis of report

As the charity's trustees, you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ("the Act").

I report in respect of my examination of the Trust's accounts carried out under section 145 of the 2011 Act and in carrying out my examination, I have followed all the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

**Independent
examiner's statement**

I have completed my examination. I confirm that no material matters have come to my attention in connection with the examination which gives me cause to believe that in, any material respect:

- the accounting records were not kept in accordance with section 130 of the Charities Act; or
- the accounts did not accord with the accounting records; or
- the accounts did not comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the accounts give a 'true and fair' view which is not a matter considered as part of an independent examination.

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.

Signed:

Date:

18 October 2025

Name:

Sean Hegarty

Relevant professional qualification(s) or body (if any):

The Institute of Chartered Accountants in England and Wales
ACA 8468485

Address: Chartered Accountants' Hall, Moorgate Place, London EC2R 6EA

| |
|--|
| |
| |

Section B Disclosure

Only complete if the examiner needs to highlight material matters of concern (see CC32, Independent examination of charity accounts: directions and guidance for examiners).

Give here brief details of any items that the examiner wishes to disclose.

No matters of concern

GOPI3KS (GENETIC OVERGROWTH PI3K SUPPORT)

England & Wales - Charity number 1176289

Accounts



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 | | |
| 5 | | | | |
| 6 | | | | |
| 7 | | | | |
| 8 | | | | |
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| 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 |
|------|-----------------------------------|
| | |

| | |
|--|--|
| | |
| | |

Names and addresses of advisers (Optional information)

| Type of adviser | Name | Address |
|-----------------|------|---------|
| | | |
| | | |
| | | |
| | | |

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

| |
|--|
| |
|--|

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)

| | |
|--|--|
| <p>You may choose to include additional information, where relevant, about:</p> <ul style="list-style-type: none"> • 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. | <p>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.</p> <p>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.</p> <p>The current trustees will make available to each new trustee, on or before their first appointment:</p> <ul style="list-style-type: none"> • 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. <p>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.</p> |
|--|--|

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

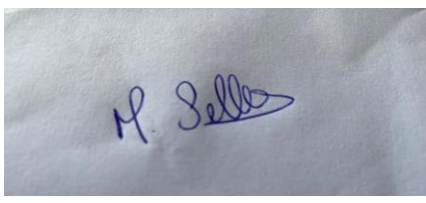
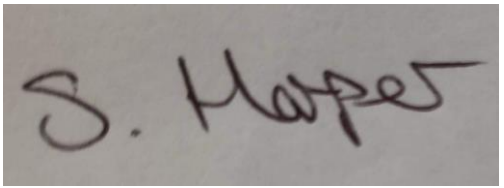
will be stored securely, help patients/families and the medical profession moving forward.

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

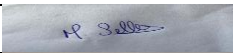
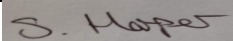
To

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 | - | - | - |
| | | - | - | - |
| | | - | - | - |
| | | - | - | - |
| | | - | - | - |
| | | - | - | - |
| B3 Investment assets | Details | - | - | - |
| | | - | - | - |
| | | - | - | - |
| | | - | - | - |
| | | - | - | - |
| B4 Assets retained for the charity's own use | Details | - | - | - |
| | | - | - | - |
| | | - | - | - |
| | | - | - | - |
| | | - | - | - |
| | | - | - | - |
| | | - | - | - |
| | | - | - | - |
| B5 Liabilities | Details | - | - | - |
| | | - | - | - |
| | | - | - | - |
| | | - | - | - |
| | | - | - | - |
| 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 | |

GOPI3KS (GENETIC OVERGROWTH PI3K SUPPORT)

England & Wales - Charity number 1176289

Accounts



Trustees' Annual Report for the period

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

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 | | | | |
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| 20 | | | | |

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)

| |
|--|
| |
|--|

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)

| | |
|--|---|
| <p>You may choose to include additional information, where relevant, about:</p> <ul style="list-style-type: none"> • 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. | <p>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.</p> <p>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.</p> <p>The current trustees will make available to each new trustee, on or before their first appointment:</p> <ul style="list-style-type: none"> • 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. <p>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.</p> |
|--|---|

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.

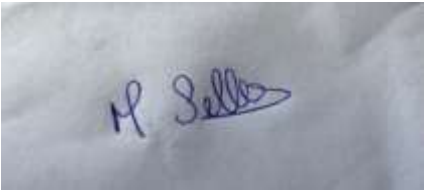
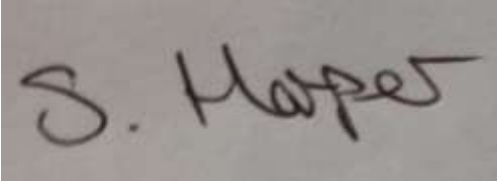
We are also hoping to host a face to face family weekend for PROS individuals and families. To bring these people together, along with doctors to present and speak at the weekend. We are also looking in include such things as mental health awareness, talks from possibly parents and an adult

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

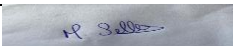
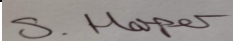
To

05/04/2023

Section A Receipts and payments

| | Unrestricted funds 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 | 2,373 | - | - | 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 | 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 | 16/05/2023 | |
| |  | Susan Harper | 16/05/2023 | |

GOPI3KS (GENETIC OVERGROWTH PI3K SUPPORT)

England & Wales - Charity number 1176289

Accounts



| Trustees' Annual Report for the period | | | | | | | |
|---|-------------------|-------|------|-----------|-----------------|-------|------|
| | Period start date | | | | Period end date | | |
| | Day | Month | Year | | Day | Month | Year |
| From | 06 | 04 | 2021 | To | 05 | 04 | 2022 |

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 | | | | |
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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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| | |
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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)

| |
|--|
| |
|--|

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)

| | |
|--|--|
| <p>You may choose to include additional information, where relevant, about:</p> <ul style="list-style-type: none"> • 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. | <p>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.</p> <p>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.</p> <p>The current trustees will make available to each new trustee, on or before their first appointment:</p> <ul style="list-style-type: none"> • 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. <p>All trustees give their time voluntarily and received no remuneration or other benefits, apart from reasonable expenses.</p> |
|--|--|

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 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

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)

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

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.

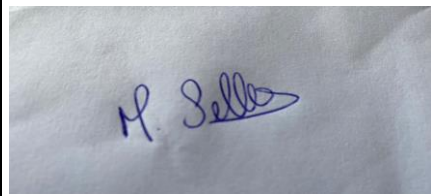
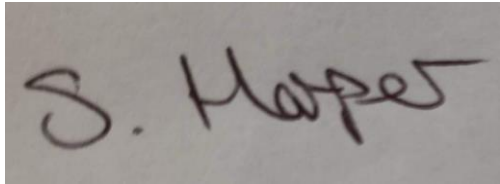
We will continue to update the GoPI3Ks website with relevant information & contact details, which for many is their first port of call when researching PROS.

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 |

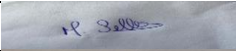
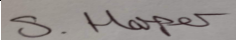
| | Details | Unrestricted funds to nearest £ | Restricted funds to nearest £ | Endowment funds to nearest £ |
|---------------------------------|---------|---------------------------------|-------------------------------|------------------------------|
| B2 Other monetary assets | | - | - | - |
| | | - | - | - |
| | | - | - | - |
| | | - | - | - |
| | | - | - | - |
| | | - | - | - |

| | Details | Fund to which asset belongs | Cost (optional) | Current value (optional) |
|-----------------------------|---------|-----------------------------|-----------------|--------------------------|
| 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 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 | 07/06/2022 |
|  | Susan Harper | 07/06/2022 |

GOPI3KS (GENETIC OVERGROWTH PI3K SUPPORT)

England & Wales - Charity number 1176289

Accounts



Trustees' Annual Report for the period

| | | | | | | | |
|-------------|-------------------|-------------|--------------|-----------|-----------------|-------------|--------------|
| From | Period start date | | | To | Period end date | | |
| | Day 06 | Month 04 | Year 2020 | | Day 05 | Month 04 | Year 2021 |

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 | | | | |
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| 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 |
|------|-----------------------------------|
|------|-----------------------------------|

| | |
|--|--|
| | |
| | |
| | |

Names and addresses of advisers (Optional information)

| Type of adviser | Name | Address |
|-----------------|------|---------|
| | | |
| | | |
| | | |

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

| |
|--|
| |
|--|

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.

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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.

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

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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.

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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.

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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.

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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

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)

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

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.

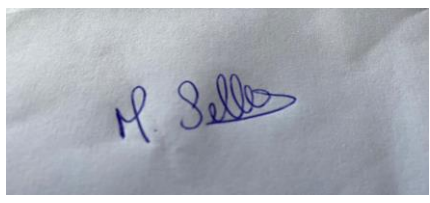
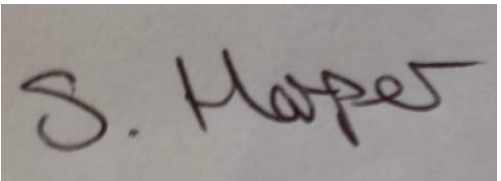
The success of the first family weekend in 2018 for both patients & their families on a psychological & medical knowledge level demonstrates the need to look into doing this again in 2022, so Covid-19 allowing this is something we can help to fund.

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 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 | 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 |

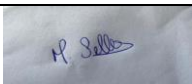
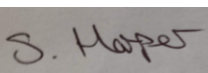
| | Details | Unrestricted funds to nearest £ | Restricted funds to nearest £ | Endowment funds to nearest £ |
|---------------------------------|---------|---------------------------------|-------------------------------|------------------------------|
| B2 Other monetary assets | | - | - | - |
| | | - | - | - |
| | | - | - | - |
| | | - | - | - |
| | | - | - | - |
| | | - | - | - |

| | Details | Fund to which asset belongs | Cost (optional) | Current value (optional) |
|-----------------------------|---------|-----------------------------|-----------------|--------------------------|
| 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 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 |