



# NEWSLETTER

Genetic Overgrowth PI3K Support

[www.gopi3ks.com](http://www.gopi3ks.com)

**December 2021**

Welcome to the newsletter for GoPI3Ks – Genetic Overgrowth PI3K Support. Here we will share updates from PROS medical experts, information on fundraising, how we have helped those living with PROS, as well as rare events.



A huge thank you to Professor Rob Semple for his input in to this years newsletter. Thank you for your continued dedication, research & support of the PROS community.


Thank you also to Ralitsa Madsen for your tireless work in the scientific research of PROS.

You both give hope to all of us living with & affected by this condition.

## **Research and Treatment Update – Robert Semple**

Unbelievably, it is now coming up to a decade since changes in the *PIK3CA* gene were found to cause some tissues in the body to grow too much, and about 6 years since the name PROS was suggested for the wide range of different types of problems that are caused by these changes. So what progress is currently being made in the research world and in the clinic that might help people with PROS to live the best lives they can?

First of all, I have been very pleased to see that PROS is very much on the radar of the research world, as showcased in an excellent meeting I attended on different types of blood vessel malformation and overgrowth, where PROS was much discussed. Many excellent scientists are now working on how PROS develops, and are being creative in trying to devise new ways to stop the growth in its tracks. This is really good news, although it is also fair to warn that it usually takes several years from making scientific discoveries to changing treatment.



In the clinic, more experience of the use of the medicine Alpelisib has been revealed this year in a conference presentation of the results of the EPIK-P1 study. This is not actually a proper trial of Alpelisib (where it is compared against a dummy tablet). Instead, it is the description of how 57 patients (39 adults and 18 children) from 5 countries did who were given Alpelisib because of severe complications of PROS. About 40% of people who were given Alpelisib showed some reduction in overgrowth on scans, averaging about one seventh in size of the extra growth. There was also encouraging evidence that symptoms such as pain and tiredness improved even more. About 40% of patients also reported side effects such as diabetes or mouth ulcers, but these were not severe. Overall this study continues to suggest that Alpelisib has benefits for a significant number of people with PROS, but it also shows that not everyone benefits, and that it can cause side effects.

In other words, results are really encouraging, but Alpelisib is not a “wonder drug”. The big caution is that this was not actually a controlled trial, so the placebo effect may have exaggerated results. We really need to have a proper trial now to be sure exactly what the risks and benefits of Alpelisib are. I’m very pleased to say that such a trial is now recruiting volunteers with PROS across several different countries (UK very soon!), and will run for the next few years, so at last we will have clear answers about the benefits of Alpelisib. The trial will be very strict in only including people where an obvious area of extra growth that can be measured in scans, and where a PIK3CA change has been found. This sort of evidence is always needed before the NHS agrees to fund a new medicine. In the meantime people who are really severely affected by PROS can still work with their doctors to apply to the company who makes Alpelisib for early access to the medicine.

Also in the last year, I was part of a large group of experts in different aspects of PROS who gathered to discuss the best current approach to treatment. Although there are many aspects of treating PROS that are not yet proven by formal trials, there are also many things that experts do believe based on extensive experience. A lot of doctors seeing patients with PROS will not have the same experience, however, or may be experts in only some types of overgrowth. The expert PROS group have published a paper summarising their opinion of the best current approach to diagnosing and treating PROS. This covers a lot of ground and only some bits of the paper are relevant to any particular person with PROS. The paper is not supposed to be the last word on this – we expect information and guidance to improve as trials come through in due course. Finally the paper is not written for patients and families – it is very much written in technical and medical language. However the hope is that it will be very useful for any person seeing a doctor who is not a PROS expert. The paper should help describe all the key issues, what is known and what is not known, and also where to get help.

The free pdf of this paper can be downloaded from here:  
<https://onlinelibrary.wiley.com/doi/10.1111/cge.14027>.

So, nearly 10 years on, good progress is being made. Although everyone is impatient for improvements to come faster, some things are very difficult to hurry. Nevertheless every year we are learning more and more, so there is lots of hope of good things to come. Let’s all keep the pressure on to get there quickly!



## OUR 2021 FUNDRAISING FOR GOPI3KS

As always we want to say a big THANK YOU to everyone who donated during this year. No matter how big or small every donation is really appreciated.



### FEBURARY 2021

Mandy held an online fundraiser on Facebook & Twitter for her birthday.

Everyone who donated any amount was entered in to a draw to win 1 of 2 £20 Amazon vouchers that we could then email directly to the winner.

This year totally blew us away as we raised an amazing 1,172.34

Thank  
you



### AMAZON SMILE DONATIONS

**amazon**smile  
You shop. Amazon gives.

For those who shopped at Amazon you have donated £24.23. THANK YOU, every little helps.

### PAYPAL JUST GIVING FUND

A huge thank you to those who nominated GoPI3Ks as their charity to support through PayPal Just Giving

You helped to  
raise a fantastic  
£78.75

Thank  
you!

**AUGUST 2021**

We would like to say a huge thank you to AllStripes for their support of GoPI3Ks. This will enable us to keep on working with those within the PROS community. If you would like to know more about the work AllStripes does then please click on the following link: <http://www.allstripes.com>



**Power to the patients**

#### **HOW THE GoPI3Ks CHARITY HAS HELPED IN 2021**

**THANK YOU** to everyone that has donated, this is how **YOUR** money is helping & making a difference to people's lives.

**Remember, we are always here to help, please email:**  
[gopi3ks@yahoo.com](mailto:gopi3ks@yahoo.com) **for more information.**

**MAY 2021**



In May 2021 we received an application to help one of our members who had to take her little boy to a London hospital for some tests. However, this can prove very expensive with the cost of petrol and the congestion charge. So GoPI3Ks were happy to help with this for the family.





**JULY 2021**

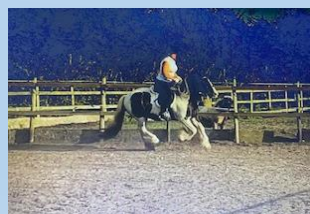
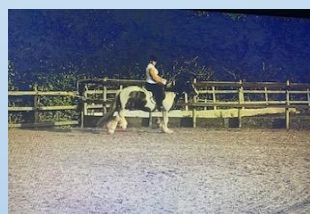
In July we were contacted by Jess who was really struggling to safely ride her horse Blue

Being born with several rare conditions has made life challenging in more ways than one, my life has been full of ups and downs with over 300 hospital admissions and surgeries which is still on going. I've always had a passion for horses, at the age of 39 my mum and dad purchased my first horse for me, he was a rescue and was still a stallion, but the bond between us was there, now gelded and with all the hard work we've put in, we are definitely a fantastic duo, Being disabled, funds are tight, I'm lucky to have a wonderful yard owner and husband who helps on the day to day upkeep, however saddles have been a bit of an issue, due to (PROS) Pik3ca related overgrowth spectrum my balance and leg stability in a saddle wasn't great. I'd heard of chunky monkey



Saddles who specialised in para riding saddles but unfortunately it was way out of my budget! I approached the GoPI3Ks charity and asked for their help. My application was awarded and after a consultation with Sam at Chunky Monkey she knew exactly what I wanted and needed. We are now the proud owner of a brand new saddle and what a difference it has made not only to my riding and stability but also for Blue my horse The saddle that Sam has made me is the most comfortable and helps get me in the best position possible. My saddler Samantha Rhodes did a fantastic job at measuring Blue out , so it also is

the best fit for him. She really took the time to analyse me when I rode and then to liaise with Sam about what we needed. They were so helpful to do whatever we needed, and the saddle is just perfect. I have Front and back knee and thigh blocks to help stop my legs from bouncing off the saddle, but it also helps to keep my hips and legs in the correct position. My balance is so much better which is great for both me and Blue as I'm not bouncing about on his back causing pain and other issues, the saddle is a perfect fit for us both. I can't thank the people who made this happen enough, it really is a game changer, so much so I can now plan away events, we are aiming to enter para rider dressage next year!



**A video of Jess using her new saddle will be on our website soon**

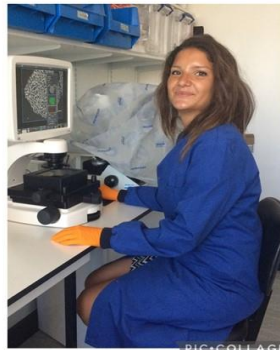


**OCTOBER 2021**

# zoom

In October due to Covid restrictions we held another virtual Zoom call with Professor Rob Semple & Dr Ralitsa Madsen & some of the PROS community. Some questions were submitted prior to the meeting & some were asked on the evening. This year we had more people attending & we had attendees from several different countries.

## Zoom call with Professor Semple, Dr Madsen & some PROS community members 20<sup>th</sup> October 2021



For anyone who would like to watch the zoom chat, here is a link to the You Tube video, this can only be viewed by following the link & isn't searchable on You Tube:

<https://youtu.be/3HHfsPvskT0>



## COLLABORATION WITH OTHER PIK3CA GROUPS & RESEARCH COMPANIES

2021 has again led to GoPI3Ks working on various projects with a number of other PROS groups. Please click on the links for more info:

	<a href="https://www.m-cm.net/">https://www.m-cm.net/</a>
	<a href="https://www.associazione-nazionale-macrodatilia.org/">https://www.associazione-nazionale-macrodatilia.org/</a>
	<a href="https://wonderfilmsmiles.com/">https://wonderfilmsmiles.com/</a>
	<a href="https://www.clovessyndrome.org/">https://www.clovessyndrome.org/</a>
	<a href="https://k-t.org/">https://k-t.org/</a>
	<a href="https://www.projectfava.org/">https://www.projectfava.org/</a>
	<a href="https://www.lgdalliance.org/">https://www.lgdalliance.org/</a>





## ALL STRIPES

GoPI3Ks and AllStripes are partnering to create a database that will enable new PIK3CA-related overgrowth spectrum (PROS) research projects!

*We're looking for patients/families willing to contribute their de-identified medical records to make this effort as strong as possible.*

AllStripes is a platform that makes it easy for rare disease patients and caregivers to contribute to treatment research from home. Participate by signing up at [allstripes.com/pros](https://allstripes.com/pros) and the AllStripes team will collect the records on your behalf, at no cost, and extract insights to power research. The more we know about PROS, the more we can do for PROS patients.



 AllStripes ×  ×  × 

### Sharing your journey with PROS can advance new treatments

Because PIK3CA-related overgrowth spectrum (PROS) is rare, researchers need more information directly from patients and their families to understand the condition.

Your progression, symptoms and health challenges are all important clues to help researchers develop new treatments.

#### How you can help


Join other PROS patients and families on AllStripes to contribute to multiple research efforts:

- 1 **Go to [allstripes.com/pros](https://allstripes.com/pros)**
- 2 **Create your account**  
Our team collects and de-identifies your medical records. No appointments, no cost.
- 3 **Success — you're a hero for PROS!**  
You'll receive exclusive research updates and all your records in your private, secure account.

#### What is AllStripes?

As the first and only research platform dedicated to rare diseases, AllStripes makes it easy for patients to contribute to new treatment studies from home. We do the work to collect and analyze your de-identified medical records to help power faster, better drug development for your condition.

To learn more contact us at [community@allstripes.com](mailto:community@allstripes.com) or visit [allstripes.com](https://allstripes.com).



By joining AllStripes, you can contribute your (or your child's) de-identified medical records to power multiple research efforts.



Victor & Jenny (left), and James AllStripes PROS Ambassadors



"GoPI3Ks, CLOVES Syndrome Community, and WonderFIL Smiles have partnered with AllStripes to advance treatments for PROS. Check out this video: <https://gopi3ks.com/> to learn more about why we're working with AllStripes and how you can contribute to research from home by signing up for the PROS research program."



In February 2021 we took part in Rare Disease Day by sharing information cards on rare disease statistics & PROS



## DID YOU KNOW?



- RARE DISEASE AFFECTS 3.5 MILLION PEOPLE IN THE UK.



ARE PROUD FRIENDS & SUPPORTERS OF RARE DISEASE DAY FEBRUARY 28<sup>TH</sup> 2021



Check out their website at: [RareDisease.Org](http://RareDisease.Org)

## DID YOU KNOW?



- THE NUMBER OF PEOPLE DIRECTLY AFFECTED BY A RARE DISEASE IS EQUIVALENT TO THE POPULATION OF THE WORLD'S 3<sup>RD</sup> LARGEST COUNTRY.



ARE PROUD FRIENDS & SUPPORTERS OF RARE DISEASE DAY FEBRUARY 28<sup>TH</sup> 2021



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## DEFINITION OF PROS



- PROS IS A BROAD-RANGING SPECTRUM OF OVERGROWTH DISORDERS CAUSED BY PIK3CA MUTATIONS
- PROS WAS ESTABLISHED BY THE NIH IN 2015 TO UNITE A GROUP OF OVERGROWTH DISORDERS BASED ON THEIR SHARED GENOMIC CAUSE.



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## WHAT IS PROS?



- (PIK3CA-RELATED OVERGROWTH SPECTRUM)
- CLINICAL HALLMARKS OF PROS:
  - CONGENITAL OR EARLY CHILDHOOD ONSET
  - SPORADIC OR MOSAIC OVERGROWTH PATTERN
  - PROGRESSIVE NATURE



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## WHAT IS PROS?



- PROS FEATURES BROADLY INCLUDE:
  - OVERGROWTH OF ADIPOSE, MUSCLE, NERVE OR SKELETAL TISSUE
  - VASCULAR MALFORMATIONS, INCLUDING CAPILLARY, VENUS, ARTERIOVENUS, OR LYMPHATIC EFFECTS
  - SKIN LESIONS



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## WHAT OVERGROWTH DISORDERS ARE FOUND IN PROS?



- CLOVES SYNDROME (Congenital Lipomatous Overgrowth, Vascular malformations, Epidermal nevi, Scoliosis)
- KTS (Klippel-Trenaunay Syndrome)
- FIL (Facial Infiltrating Lipomatosis)



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## WHAT OVERGROWTH DISORDERS ARE FOUND IN PROS?



- MCAP or MCM (Megalencephaly-Capillary Malformation)
- ILM (Isolated Lymphatic Malformations)
- HHML (HemiHyperplasia-Multiple Lipomatosis)
- FAVA (FibroAdipose Vascular Anomaly)



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## WHAT OVERGROWTH DISORDERS ARE FOUND IN PROS?



- CLAPO SYNDROME (Capillary malformation of the lower lip, Lymphatic malformation of the face & neck, Asymmetry of the face & limbs & partial or generalized Overgrowth)
- FAO (FibroAdipose hyperplasia or Overgrowth)
  - MUSCULAR HH (HemiHyperplasia)
  - Macroductyly



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## SELECT COMPLICATIONS OF PROS



- **LYMPHATIC MALFORMATIONS CAN CAUSE:**
  - CELLULITIS



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Check out their website  
at: [RareDisease.Org](http://RareDisease.Org)

## SELECT COMPLICATIONS OF PROS



- **ABNORMAL GROWTH CAN CAUSE:**
  - SPINAL COMPRESSION
  - REDUCED MOBILITY
  - SCOLIOSIS
  - PAIN



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Check out their website  
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## SELECT COMPLICATIONS OF PROS



- **VASCULAR MALFORMATIONS CAN CAUSE:**
  - BLOOD CLOTS (EG, DVT OR PE)
  - INTERNAL BLEEDING
  - VARICOSE VEINS



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Check out their website  
at: [RareDisease.Org](http://RareDisease.Org)

## MANAGEMENT OF PROS



- This varies dependent on the individual
  - **COMPRESSION & ELEVATION:** Raising limbs to reduce inflammation & swelling caused by lymphedema. As well as applying pressure to control vascular bleeding & venous insufficiency.



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DISEASE DAY FEBRUARY 28<sup>TH</sup> 2021



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## MANAGEMENT OF PROS



- This varies dependent on the individual
  - **MONITORING:** Monitoring of your symptoms maybe the most appropriate way forward for yourself & the medical team.



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DISEASE DAY FEBRUARY 28<sup>TH</sup> 2021



Check out their website  
at: [RareDisease.Org](http://RareDisease.Org)

## MANAGEMENT OF PROS



- This varies dependent on the individual
  - **SURGERY:** Removing areas of overgrowth. Having this type of de-bulking surgery can cause regrowth in the same area, meaning the procedure needs repeating.



ARE PROUD FRIENDS & SUPPORTERS OF RARE  
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## MANAGEMENT OF PROS



- This varies dependent on the individual
  - **INTERVENTIONAL RADIOLOGY:** Used for those with vascular malformations by applying various techniques that cut off blood flow from the vessels & surrounding tissue so affected cells die.



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DISEASE DAY FEBRUARY 28<sup>TH</sup> 2021



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## IS THERE A TREATMENT FOR PROS? Alpelisib



- **RECENT RESEARCH IN TO CANCER HAS LED TO A PROMISING BREAKTHROUGH WITH A DRUG CALLED APELISIB**



ARE PROUD FRIENDS & SUPPORTERS OF RARE  
DISEASE DAY FEBRUARY 28<sup>TH</sup> 2021



Check out their website  
at: [RareDisease.Org](http://RareDisease.Org)

## February 2021

As part of Rare Disease Day 2021 we held a zoom call with Jordan Whitewood-Neal where he spoke openly & honestly about what it is like to live with a rare overgrowth condition.

### GOPI3KS RARE DISEASE DAY EVENT



#### CHAT WITH JORDAN WHITEWOOD-NEAL



- Jordan lives with the rare overgrowth condition Proteus Syndrome. Come along & chat on zoom with Jordan about what his life has been like living with Proteus.

SUNDAY 28<sup>TH</sup> FEB – 7PM



ARE PROUD FRIENDS & SUPPORTERS OF RARE  
DISEASE DAY FEBRUARY 28<sup>TH</sup> 2021



Check out their website  
at: [RareDisease.Org](http://RareDisease.Org)



# Cambridge Rare Disease Network inaugural Patient Group and Industry Partnering event May 2021

For this event we worked alongside Kristen Davis the Executive Director of the CLOVES Syndrome Community. This event brought together 10-12 rare disease patient groups and a similar number of companies working in the orphan drug space. The main goal was to look at finding new ways to collaborate between individual companies and patient groups, towards the development of new treatments. This also gave us the chance to raise awareness of PROS and the challenges those affected face.

## PRESENTATION ON PROS – PIK3CA RELATED OVERGROWTH SPECTRUM



The PIK3CA gene gives instructions for the production of a protein called PI3K. This protein is involved in a cell's life cycle by making sure it behaves correctly & dies in the right way. A mutation in this PIK3CA gene causes the PI3K protein to become damaged resulting in cells dividing & growing abnormally, leading to the various types of symptoms & severity in PROS patients.

CLOVES Syndrome: Congenital Lipomatous Overgrowth, Vascular malformations, Epidermal nevi, Scoliosis/skeletal and spinal challenges



Facial Infiltrating Lipomatosis (FIL)



PROS is a heterogeneous condition that impacts patients in many different ways.

Visually from face to fingers and from legs to feet.

And internally affecting organs, blood vessels, spinal column and more.



### Amputation



### Hip dysplasia surgery



### Spinal surgery



Success of Sirolimus – Mandy lost 31.8KG in 5 years until her body became resistant to the drug



## Some of the unmet needs of those living with PROS.

### Medical concerns

A lack of joined up medical services – leading to duplicate tests.

No single point of contact for care.

Lack of consistency of funding for compassionate use of drugs.

### Physical concerns

Finding shoes & clothes to fit.

Living with severe pain.

Slowing down disease progression.

De-bulking surgery may provide more harm than good.

### Emotional concerns

Being bullied both physically & psychologically.

Living with anxiety & depression.

Living with the fear of the unknown & emotional exhaustion that comes with answering questions like "What happened to you.?"

### Healthcare concerns

Including: access to genetic testing.

To treatment options that work.

Transition from paediatric to adult care.

### Financial concerns

The cost of care.

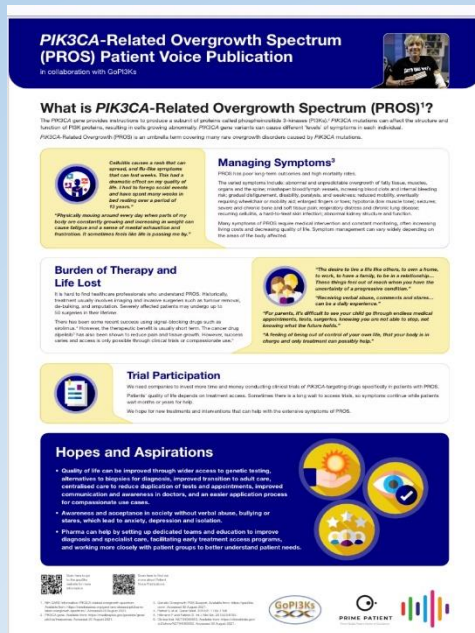
The cost of medical travel expenses.

The extra costs related to living with a long term progressive disease.



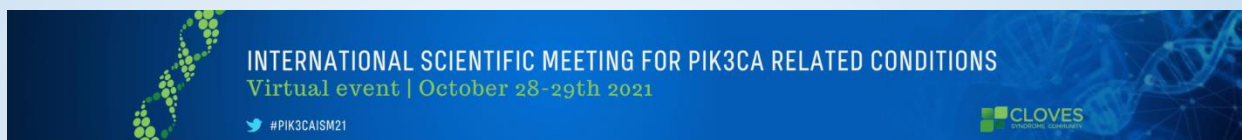
October 2021

We took part in the  
RAREsummit21 event organised  
by the CRDN – Cambridge Rare  
Disease Network.

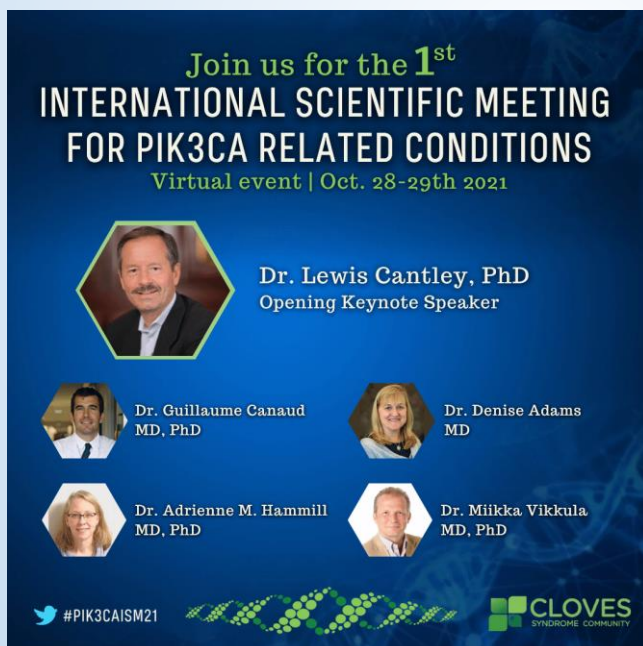


GoPI3Ks worked with Prime Global to create a PATIENT VOICE PUBLICATION poster to highlight just what PROS is; managing the symptoms, the burden of therapy & life lost. Trial participation as well as hopes & aspirations.

To read the poster you can either right click on the image to the left & open in a new window & zoom in. Alternatively if you click this link to open a new window to see the poster: <https://gopi3ks.com/wp-content/uploads/2021/11/PVP-PROS-1.pdf>



GoPI3Ks were proud to be part of the organising committee for this event.



The goals for this meeting were:

- To bring together the experts in the PIK3CA pathway including clinicians, clinical researchers and basic scientists to allow opportunities to present new information, share data, foster collaboration and encourage networking
- To stimulate new ideas
- To encourage new researchers to enter the field, to collaborate with others in the field and to collaborate with our patient organizations.
- To identify the gaps and unmet needs for our heterogenous patient populations.

I was honoured to asked by the CLOVES Syndrome Community to give a short presentation on living with PROS



## \*FUNDRAISING, COULD YOU HELP?\*

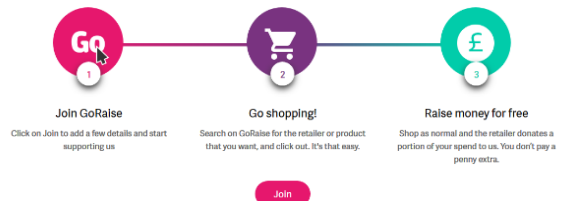
Here are 3 ways you can shop & raise money for GoPI3Ks.

# GO RAISE

You can help raise funds for GoPI3Ks by simply shopping online with Go Raise. Click on the link:

[www.goraise.co.uk/gopi3ks-genetic-overgrowth-pi3k-support](http://www.goraise.co.uk/gopi3ks-genetic-overgrowth-pi3k-support) & follow the instructions provided.

### SHOP AND EARN DONATIONS FOR FREE



# Amazon Smile

**amazon**smile  
You shop. Amazon gives.

Here's how to sign up for AmazonSmile

<https://smile.amazon.co.uk/ch/1176289-0>

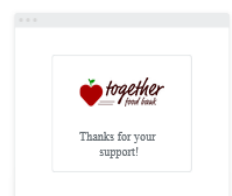
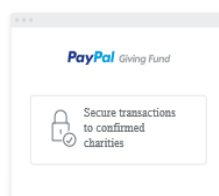
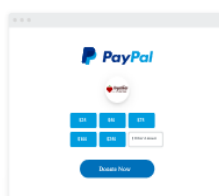
Download or update to the latest version of the **Amazon Shopping app** on your phone. You **can** find it in the **App Store** for iOS or Google Play for **Android**. Tap on '**AmazonSmile**' and follow the on-screen instructions to turn on **AmazonSmile** on your phone.

1. Visit **smile.amazon.com**.
2. Sign in with your **Amazon.com** credentials.
3. Choose a charitable organization to receive donations, or search for the charity of your choice.
4. Select your charity.

# PayPal Giving Fund

How can I support GoPI3Ks using PayPal  
Please click this link: <https://www.paypal.com/gb/fundraiser/hub>

### How donating to PayPal Giving Fund works



- 1** Find a charity you'd like to help. Your gift goes to PayPal Giving Fund, a registered charity (No. 1110538). PayPal will take care of all transaction fees.
- 2** We'll give 100% of the donation to your chosen charity, or in rare cases, a similar charity if necessary. Please read our [Donation Delivery Policy](#) for details.
- 3** PayPal Giving Fund will issue your donation receipt, with the option to [add Gift Aid](#). You can ask us to share your name and email with the charity you help so they can contact you or you can donate anonymously, if you prefer.



# YOUR GOPI3KS CHARITY TRUSTEES.

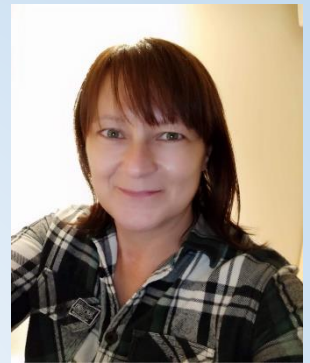


## MANDY SELLARS - CHAIRPERSON

As we come to the end of yet another year, one that again saw us all impacted in some way by Covid. I hope that this finds you all well & looking forward to some festive celebrations. Thank you to everyone who has supported us during this year, we truly appreciate your help. Here is hoping that 2022 brings happiness, better health, more research & treatment options for all of us affected by PROS. Remember, we are always here to help you in any way we can with those extra costs.  
#Stronger Together xx

## SUE HARPER - TREASURER

I would like to use this Christmas message to say a big thank you to Mandy for setting up this charity. By creating this community of people living with PROS and related conditions, she has created both a support network and a valuable resource to share experiences and medical advances and treatments with regards to the condition, as well as providing funding to assist with the additional costs of living with PROS. Despite the last year being incredibly hard for fundraising, Mandy has put in many hours networking with other rare condition groups and organisations which can provide useful resources to the PROS community. She has also given a number of presentations. All Mandy's hard work has resulted in a number of donations, allowing the charity to continue to provide funding to members in these difficult times. So well done and thank you Mandy for everything you do for the charity. To all the PROS community wishing you a happy, healthy and peaceful Christmas and New Year, Sue



## AMANDA KENYON - SECRETARY

So it's that time of year again! The weather is definitely changing and hot chocolate and mince pies have become part of my staple diet (any excuse!).

It has been another challenging year for many and we haven't been able to make the plans we wanted. Hopefully, we are all well and safe. Please know if you are struggling, we are always on hand to help where we can.



There are other organisations out there to help too:

The Samaritans <tel:116123>

Shelter [https://england.shelter.org.uk/get\\_help](https://england.shelter.org.uk/get_help)

Mind <tel:+44-300-123-3393>

Refuge <tel:08082000247>

Dottie, the pug and I, would like to wish you a very Merry Christmas and a wonderful New Year.

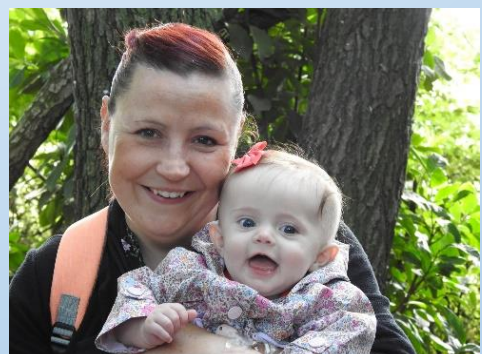
## KATIE KAVANNAH - TRUSTEE

We all started 2021 with optimism that it would be a better year than 2020. Whilst it hasn't quite been the year we expected, safe to say it has still been better than last, and we all live in hope that 2022 will be better still.

But we all have to be grateful for the love we have around us and treasure the family and

friends supporting us. Remember to smile daily and laugh lots and enjoy each and every day. I also want to take this opportunity to thank each and every one of you who has donated or helped the charity over the last 12 months. I hope we can help more people next year.

Wishing you all a wonderful Christmas surrounded by love.



**Merry Christmas**