

## **PTENUKI 2022 Annual Report**

The purpose of our patient group is to improve the lives of patients, parents and carers of all ages, in the United Kingdom and Ireland, who are affected by rare PTEN genetic alterations, PTEN Hamartoma Tumour Syndrome (PHTS), Cowden Syndrome (CS), or Bannayan-Riley-Ruvalcaba Syndrome (BRRS) through better patient support, increased awareness, more accurate and accessible information, earlier diagnosis and intervention, greater research into treatment and prevention, and improved coordination of care.

2022 was a busy year for the charity, getting back on track after the Covid-19 pandemic. We had a lot of ideas in mind of how we wanted to support the community and for this we needed funding, so in March we sent Kelly, the charity manager, on a grant applications writing course to help the charity's cause.

In July we hosted our first face-to-face meet up since the pandemic, which was very well received. The community loved coming together and it was an opportunity for medical and research professionals to give an update about what is happening in the PTEN world of science and research. It was also a chance for the patient community to meet each other and speak about what support they needed for the future. One of the biggest areas of need that arose from the meeting was that of mental health support. With this learning, along with the grant application course that Kelly had previously attended, we started to apply for grants to help our community with their mental health. The results will be given to us in 2023.

Also, at the patient day, we signed up 6 runners to take part in the London Landmark half marathon to help raise funds for the charity to put towards our new wellness and mental health initiative. The run will take place in April 2023, but fundraising is going well.

We have worked well alongside PTEN Research Foundation this year and we have been working hard to build up our international relations within the PTEN world. We have set up an International PTEN facebook group so we can communicate with other PTEN patient groups from across the globe. We also invited the manager of the Netherlands patient group to join us at our PTEN patient day which was very interesting. We were able to offer a children's story book to our community that the Netherlands patient group has written that is all about a child with PTEN. This is to help our child patients understand what is happening to them in an age appropriate way. The parents and children loved the book and we have ordered more!

In October 2022, we also welcomed a new Research Trustee to the committee, Priyanka Tibarewal, who is a researcher at UCL focusing on understanding the science behind the various symptoms in PHTS and repurposing drugs for PTEN therapy. Priyanka takes on the role to try and communicate the ongoing research on PHTS to the PTENUKI family and bridge the gap between research and the patient community. We believe she will be an asset to the team and welcome her onboard.

Thanks again, as per every year, goes to all our trustees, volunteers, members, medical professionals and researchers who continue to make the PTENUKI patient group and wider community such a success. By working together, we are making a real difference and positive impact on people's lives.

**PTENUK&I**

**Statement of Financial Activities**

**Y/e 31/12/22**

<b><u>Income</u></b>	<b>£</b>
Donations	1,123
Fund-raising	820
Grants	7,415
Care and Support	<u>96</u>
	9,454

**Less Expenditure**

Finance Charges	60	
Insurance	146	
Emoluments	4,000	
Fund-raising	1,164	
Care and Support	4,643	
Training	<u>199</u>	<u>10,212</u>
Excess of expenditure over income		(758)

**Statement of Assets and Liabilities**

**Assets**

Bank balance	11,764
Less Creditors due within 12 months	<u>400</u>
	11,364

**Represented by**

Opening funds	12,122
Less excess of expenditure	<u>(758)</u>
Closing funds	11,364

**M. Collins - Treasurer**

