

PTENUKI 2020 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.

2020 has been a tough year worldwide due to the Coronavirus pandemic, limiting a number of things we could do as a charity and putting additional pressures on patients, families and the NHS. That said, PTENUKI adapted as well as possible, focusing on adding more information to the website such as our 'Autism & Developmental Delays' page, supporting our community online and giving back to patients through our Covid Kindness Grant.

The size and impact of the group is still growing, our social media group now totalling over 250 members. A big thank you to Sarah Plummer for taking on the role for promotion and awareness of the charity, and putting in so much effort coordinating our social media activity, keeping the Facebook community alive and engaging.

Due to lockdown restrictions, we wanted to still promote wellness and feelings of positivity to our community, in what was a very challenging year for everyone. This year we launched our Covid Kindness Grant which replaced our annual face-to-face event, with the aim that it helped to promote the sense of community that we love to create. Although we could not meet in person, we were still there to help and support patients through the challenging time. It was a huge success and many thanks goes to Kelly Kearley in helping run the process. We awarded 15 grants to patients and families, enabling them to purchase educational tablets to help with speech and language, household appliances, family days out, games consoles for kids, and even a hospital bed for a young boy to be able to sleep in his own bedroom. We are very proud of how we were able to help in this way.

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.

PTEN UK and Ireland Group - 1172205

Statement of Financial Activities

For the period from 01 January 2020 to 31 December 2020

	Unrestricted funds	Restricted funds	Endowment funds	Total funds	Prior year total funds
<i>Income and endowments from:</i>					
Donations and legacies	9,298	—	—	9,298	975
Income from charitable activities	—	—	—	—	—
Investments	—	—	—	—	—
Total income	9,298	—	—	9,298	975
<i>Expenditure on:</i>					
Raising funds	—	—	—	—	394
Expenditure on charitable activities	3,000	—	—	3,000	504
Other expenditure	445	—	—	445	134
Total expenditure	3,446	—	—	3,446	1,033
Net income / (expenditure) resources before transfer	5,851	—	—	5,851	(57)
<i>Transfers</i>					
Gross transfers between funds - in	—	—	—	—	—
Gross transfers between funds - out	—	—	—	—	—
<i>Other recognised gains / losses</i>					
Gains / losses on investment assets	—	—	—	—	—
Gains on revaluation, fixed assets, charity's own use	—	—	—	—	—
Net movement in funds	5,851	—	—	5,851	(57)
<i>Reconciliation of funds</i>					
Total funds brought forward	6,403	—	—	6,403	6,460
Total funds carried forward	12,254	—	—	12,254	6,403

There may be minor discrepancies in the totals if the pence are not being shown