

PTENUKI 2021 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.

2021 has been another challenging year with the Coronavirus pandemic. The UK went into its third nationwide lockdown post-christmas, the first vaccine rollout started early January, lockdown restrictions began to ease through spring, lifted fully in summer, and then went back to mandatory facemasks in the winter. As such our focus remained on maintaining the charity and doing what we could remotely and digitally for the patients and families in our community during these challenging times.

Our online community and following continues to grow and is the main source of interaction and support for the patients. It is the main channel of communication for the charity and we regularly post new information, features and questions. We now have over 300 people in our Facebook group with a good mix of patients and family members from across the UK and Ireland, including a number of people from overseas. We finished awarding all of our Covid Kindness Grants, fifteen in total, which was immensely rewarding to be able to give back to those in our community that needed help the most. We made several updates to the website (ptenuki.org) over the year, including a new page with information and links about Pre-implantation Genetic Diagnosis (PGD) and Pre-implantation Genetic Testing (PGT), another page for the new PHTS Patient Registry that has been set up in the UK, and we revamped our fundraising pages to include lots of great ideas and materials to help with raising money for our cause. Thanks once again goes to Sarah Plummer as this year she set up our very own PTEN Podcast (<https://ptenuki.org/podcasts/>). She has had several guests on the show, bringing some great insights and stories to our ever widening audience.

After seven years of working to create and drive the charity to a position where it can be sustained for the long-term, Ian Stock announced that he will be stepping down as Chair of Trustees as soon as a replacement is found. PTENUKI is still a passion of his, so he will continue to be a trustee, and provide support and guidance where needed.

We all owe our gratitude to Kelly Kearley who has stepped up to take on the role of Charity Manager, and is already doing a fantastic job driving the day to day operations of the charity.

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. Long may it continue.

PTENUK&I

Statement of Financial Activities

Y/e 31/12/21

Income

£

Donations

1,776

Less Expenditure

Finance Charges

23

Insurance

145

Emoluments

750

Care and Support

972

Donations

18

1,908

**Excess of expenditure over income
(132)**

Statement of Assets and Liabilities

Assets

Bank balance

12,122

Represented by

Opening funds

12,254

**Less excess of expenditure
(132)**

Closing funds

12,122

M. Collins - Treasurer

