

PTEN UK and Ireland Patient Group

Charity Number:1172205

Trustees' Annual Report & Financial Statements

Year ended 31 December 2023

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Trustees' Annual Report

The Trustees present their report with the financial statements of the charity for the year ended 31st December 2023. The trustees have adopted the provisions of Accounting and Reporting by Charities: Statements of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102).

OBJECTIVES AND ACTIVITIES

Aims and charitable objectives

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.

Public Benefit

In planning our activities, we keep in mind the Charity Commission guidance on Public Benefit. We do this by our accessible awareness resources to the general public and the design of our support activities to ensure that all beneficiaries are able to access support no matter their age, location and economic circumstances to support our charitable objectives.

ACHIEVEMENTS AND PERFORMANCE

Our main focus of support in 2023 was on the mental health of our community, as this had been an important theme that came out of our 2022 patient day.

A National Lottery grant was awarded to help fund our PTEN Counselling Service (<https://ptenuki.org/counselling-service/>). We were also successful in being awarded a Global Genes grant to run 6 online group wellbeing sessions. These sessions proved popular and concentrated on a PTEN patient's journey and the impact of living with a rare condition, such as emotions after diagnosis and the impact of having multiple hospital appointments, tests and scans. The wellbeing clinics also focused on the mental strain for family members who become carers to disabled children and how to tell your child about their rare condition. Both the counselling service and the wellness clinics were brought to the PTEN community in collaboration with Rareminds (www.rareminds.org) and have made a very positive impact on the wellbeing of our community.

We held another PTEN patient family day in June 2023 in Oxford. This year we decided to make it more about face-to-face support, getting PTEN families together, rather than have the day medically focused. With this in mind we booked a children's entertainer and also put on a lovely BBQ. The patient day was a huge success with over 100 people attending the day.

As a charity we also assisted medical research studies conducted by the PTEN Research Foundation and genetic counsellors. We are waiting for the results to be published.

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.

FINANCIAL REVIEW

Financial Position

This year we saw the fruits of our labour in terms of fundraising. We were successful in our application for a National Lottery grant (£10,000) and we also were granted £4,500 by Global Genes. Our 6 runners in the London Landmark half marathon in April also raised just over £6,000 between them. In total, our donations plus the fundraising efforts has given us income of £31,411, which is more than triple the previous year. These funds enabled us as a charity to provide more support for our community, resulting in total expenditure of £24,739.

We generated an overall surplus of £6,672 for the year (2022: (£758)deficit). This surplus is split £1,187 in our unrestricted funds and £5,485 in our restricted funds. The grants from The National Lottery and Global Genes were for specific purposes and have been accounted for within our restricted funds.

Our total funds as at 31 December 2023 stand at £18,036 (2022:£ 11,364) and is split £12,551 in unrestricted funds and £5,485 in restricted funds. The detailed financial statements are included on pages 8 to 12.

Reserves Policy

The trustees are mindful of their responsibility towards the charity, the resources they manage and how they have been accumulated. It is the trustees' policy to hold unrestricted general reserves amounting to £2,000 to reflect budgeted and unexpected calls upon resources within the coming year. The reserves target amount is reviewed on an annual basis. This target was achieved as at 31 December 2023, with unrestricted, undesignated funds of £12,551.

We prepare a carefully considered budget and cash flow for the year, which are based on historical performance and prudent estimates. We also produce a profit and loss forecast for each major support activity and carefully monitor actual performance versus forecast.

STRUCTURE, GOVERNANCE AND MANAGEMENT

Constitution and Governing Document

We are constituted as Charitable Incorporated Organisation (CIO) and our constitution governs our operation as a charity. We were registered as a CIO with the Charity Commission on 22 March 20217.

Board of Trustees

The Board of Trustees has independent control over, and legal responsibility for the charity's management and administration. The Board's decision making process is informed by charity law and its constitution. Our constitution requires a minimum of three trustees.

During 2023, the trustees met four times. At the start of the year, Ian Stock, our charity founder, stepped down as charity chair after 6 years. We thank Ian for his incredible contribution to our community by both founding the charity and leading us for so many years. We have not said goodbye to Ian as he continues to be part of the charity as a trustee. The Chair role was during 2023 undertaken by Jack Donnelly and this passed to Peter Welch in July 2024.

Appointment term

In selecting individuals for appointment as trustees, the trustees must have regard to the skills, knowledge and experience needed for the effective administration of the charity. In accordance with the constitution appointments are for an initial term of three years. A trustee who has served for three consecutive terms may not be reappointed for a fourth consecutive term but may be reappointed after an interval of at least one year.

Trustee Induction

All trustees complete an induction programme designed to inform them about the charity's structure, objectives, finances and decision making framework and ensure that they are fully aware of the responsibilities of being a trustee. The induction process takes the form of a combination of meetings and the provision of appropriate reading material including our constitution, annual report and accounts and guidance from the Charity Commission.

The Trustees and their areas of focus for the year and up to the date of approval of the Annual Report & Financial Statements were:-

Ian Stock – Founder trustee

Jack Donnelly (appointed 19 January 2023, resigned 22 July 2024 – Chair during period of office)

Peter Welch (appointed 24 July 2024 as Chair Designate)

Ellie Collins – Marketing

Ellie Welsh – Communications (appointed 24 July 2024)

Pryanka Tibarewal – Research

Colette Knight – Care & Support

Dr Katherine Lachlan – Medical Advisor

John Pemberton- Technology

Kelly Kearley – Administration & Fundraising

Mike Collins – Finance (until 31 December 2023)

REFERENCE AND ADMINISTRATION DETAILS

Principal Address

11 Whinchat Close
Hartley Whitney
Hook
RG18

Bankers

HSBC UK

Independent Examiner

Melanie Crooks Associates Limited
Bellfield House
33 Stafford Road
Bloxwich
WS3 3NJ

Declaration

The trustees declare that they have approved the trustees' report above on 10 October 2024

Signed on behalf of the charity's trustees by:

A handwritten signature in black ink, appearing to read 'I Stock', written in a cursive style.

Full name: Ian Stock

Position: Trustee

Date: 10 October 2024

Independent Examiners Report to the Trustees of PTEN UK and Ireland Patient Group - Charity number 1172205 ("the Charity")

I report to the Charity trustees on my examination of the accounts for the Charity for the year ended 31 December 2023 which are set out on pages 8 to 12.

Responsibilities and basis of report

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

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

- Accounting records were not kept in accordance with section 130 of the 2011 Act: or.
- The accounts do not accord with the accounting records.
- The accounts do 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.
- The trustee's annual report is not consistent with the accounts

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



Melanie Crooks
Melanie Crooks Associates Limited
Bellfield House
33 Stafford Road
Bloxwich
West Midlands
WS3 3NJ

Date: 16.10.2024

Statement of Financial Activities

	2023 Unrestricted Funds £	2023 Restricted Funds £	2023 Total Funds £	2022 Total Funds £
Income and Endowments from :				
Direct Donations	9,739	0	9,739	1,123
Fundraising Donations	7,266	0	7,266	820
Grants receivable	0	14,376	14,376	7,415
Sundry income	30	0	30	96
Total Income	17,035	14,376	31,411	9,454
Expenditure on :				
<i>Raising Funds</i>	2,517	0	2,517	1,164
<i>Charitable Activities:</i>	0	0		
Care & Support	0	10,215	10,215	0
Patient Day costs	4,537	0	4,537	4,643
Conferences & Training	662	0	662	199
Charity Management	5,333	0	5,333	4,000
Insurance	213	0	213	146
Bank & Just Giving Costs	282	0	282	60
Subscriptions	192	0	192	0
Independent Examination	500	0	500	
Sundry expenditure	288	0	288	0
Total Expenditure	14,524	10,215	24,739	10,212
Net Income/(Expenditure)	2,511	4,161	6,672	(758)
Transfers between funds	(1,324)	1,324	0	0
Net movement in funds	1,187	5,485	6,672	(758)
Total funds brought forward	11,364	0	11,364	12,122
Total funds carried forward	12,551	5,485	18,036	11,364

Balance Sheet

	Note	2023 £	2022 £
Debtors	6	1,727	0
Cash at bank		23,271	11,764
Creditors : amounts falling due within one year	6	<u>(6,962)</u>	<u>(400)</u>
Total Net Assets		<u>18,036</u>	<u>11,364</u>
<i>Represented by:</i>			
Unrestricted Funds	7	12,551	11,364
Restricted Funds	7	<u>5,485</u>	<u>0</u>
Total Funds		<u>18,036</u>	<u>11,364</u>

The notes 1 to 9 form part of these financial statements. The financial statements were approved by the trustees on 10 October 2024 and signed by:



Ian Stock (Trustee)

Kelly Kearley (Trustee)

Notes to the Financial Statements

1. Basis of Accounting

The financial statements have been prepared in accordance with the Charities Act 2011, applicable accounting standards (FRS102) and Charities SORP and under historical cost accounting.

The financial statements comprise of the Statement of Financial Activities, Balance Sheet and associated Notes. The Charitable Incorporated Organisation meets the definition of a public benefit entity under FRS102.

2. Going Concern

The financial statements have been prepared on a going concern basis as the trustees believe that no material uncertainties exist.

The trustees have considered the level of funds held and the expected level of income and expenditure for 12 months from authorising these financial statements.

3. Income

Income is included in the Statement of Financial Activities when the charity is legally entitled to it, ultimate receipt is probable and the amount to be recognised can be quantified with reasonable accuracy.

Voluntary income in the form of donations and fundraising is recognised when the cash is received or the financial year that the income is stated to relate to.

Grants are recognised on a receivable basis when the charity has probable and measurable entitlement to the income (i.e. The conditions for its award have been satisfied).

Where the use of the income has been restricted in accordance with the donor/grantee wishes the income is credited to an appropriate fund until it can be spent for the purposes for which it is given.

4. Expenditure

Liabilities are recognised as soon as there is a legal or constructive obligation committing the charity to pay our resources.

5. Funds

General Fund

The general fund is the charity's unrestricted, undesignated fund available for any the charity's purposes without restriction.

Designated Funds

Designated funds are unrestricted in nature and created by the charity's Trustees for a specific purpose.

Designated funds may be un designated at any time by the charity's Trustees.

Restricted Funds

Restricted funds relate to income received which are restricted by the donor or grantee for specific purposes within the overall aims of the organisation.

These funds are used in accordance with the specific purposes.

6. Debtors and Creditors

	2023 £	2022 £
Debtors:		
Grants receivable	1,727	0
Creditors:		
Accruals	1,962	400
Deferred grant income	5,000	
	6,962	400

7. Movement in Funds

	Balance at 1.1.2023 £	Income £	Expenditure £	Transfer £	Balance at 31.12.2023 £
Restricted Funds:					
National Lottery -Counselling Service	0	10,000	(4,515)		5,485
Global Genes - Mental Health Support	0	4,376	(5,700)	1,324	0
	0	14,376	(10,215)	1,324	5,485
Unrestricted Funds:					
General	11,364	17,035	(14,524)	(1,324)	12,551
Total Funds	11,364	31,411	(24,739)	0	18,036

Transfers between funds were as follows

	Unrestricted General £	Restricted £
General fund to Global Genes fund	(1,324)	1,324

This represents the transfer of funds to support the Mental Health Support programme.

8. Comparative Statement of Financial Activities

As the only fund in use during the year ended 31 December 2022, was the general unrestricted fund, a comparative Statement of Financial Activities in addition to that within the 2023 Statement of Financial Activities has not been reproduced in the notes to the financial statements.

9. Trustees and Related Party Transactions

The charity maintained insurance for the trustees throughout the financial year ended 31 December 2023 and such indemnity insurance was in place at the date of approval of these financial statements. For the year ended 31 December 2023, the premium cost for indemnity insurance was £ 36 and the cover was £250,000.

During the year, no Trustees received remuneration for their role as Trustee (2022:£nil). Trustees were reimbursed for out of pocket expenses, totalling £1,700 for 3 trustees.

During the year, as allowed under the constitution, a Trustee (K Kearley) undertook the duties of the charity manager under a contractual agreement.

The amount chargeable under this contractual agreement was £4,667 (2022: £4,000). An amount of £666 was outstanding as the 31 December 2023 (2022:£400).