

**PTEN UK and Ireland Patient Group**

**Charity Number:1172205**

**Trustees' Annual Report & Financial Statements**

**Year ended 31 December 2024**

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## **Trustees' Annual Report**

The Trustees present their report with the financial statements of the charity for the year ended 31<sup>st</sup> December 2024. 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**

In 2024 our focus was on continuing to provide vital emotional, practical, and financial support to our community while also raising awareness of PTEN.

Due to the economic climate we decided to award a "Cost of Living" grant to our community in February 2024, which allowed us to distribute 25 individual grants of £150 each to families most in need. These grants supported essential equipment in the home, mental health days such as family trips, and technology such as iPads to help with learning and communication.

Our PTEN Counselling Service remained a cornerstone of support, and thanks to a new National Lottery grant of £20,000 over two years (August 2024 - August 2026), we are able to ensure its continuation. Alongside this, we launched our online PTENUKI One Lotto, enabling supporters to purchase tickets to help raise funds for our work in an accessible and sustainable way.

We also continued to host our monthly PTEN Power Hours, providing a platform for medical professionals to connect with our community and share expertise on topics such as thyroid health, immune deficiencies, and the wider impact of PTEN. We extended this support to siblings of patients by collaborating with the charity Sibs, recognising the importance of including the whole family in our care. We hosted 11 online workshops in total across the year.

Awareness remained a key priority. The *Pipgen Art Project* combined science and creativity to highlight the impact of rare genetic conditions. Our Charity Manager, Kelly Kearley, represented the PTEN community on the *Medics 4 Rare*, *Rareminds*, and *On One Condition* podcasts, ensuring the PTEN voice reached wider audiences. Kelly also co-authored the *Positively Rare* book, which PTEN UK & Ireland



was proud to support. The book brought together stories from across the rare disease community, giving a powerful platform to lived experiences and helping raise awareness of the challenges faced by families with rare conditions.

We were also delighted to become members of NORD (National Organization for Rare Disorders). Joining NORD strengthens our international connections, allows us to share knowledge and resources with other rare disease groups, and ensures that the PTEN community in the UK and Ireland has a voice within a wider global network advocating for research, policy change, and improved support for those affected by rare conditions.

We are proud of the progress made in 2024 and remain committed to supporting families living with PTEN through financial help, counselling, advocacy, and awareness initiatives. As always, we extend our thanks to our trustees, volunteers, members, medical professionals, and research partners who make this work possible.

## **FINANCIAL REVIEW**

### **Financial Position**

This year we saw the fruits of our labour in terms of fundraising. We were successful in our application for further support for our PTEN counselling service from the National Lottery with a two year grant (£20,000) which will help us run the service until August 2026. In total, our donations plus the fundraising efforts has given us income of £47,904 which is an extra £16,000 from the previous year. These funds enabled us as a charity to provide more support for our community, resulting in total expenditure of £29,236.

We generated an overall surplus of £18,668 for the year (2023: £6,672 surplus). This surplus is split £10,653 in our unrestricted funds and £8,015 in our restricted funds (2023: £1,187 unrestricted and £5,485 restricted funds). The grant from The National Lottery was for the specific purpose of counselling and has been accounted for within our restricted funds.

Our total funds as at 31 December 2024 stand at £36,704 (2023: £18,036) and is split £23,204 in unrestricted funds and £13,500 in restricted funds (2023: £12,551 unrestricted and £5,458 restricted). The detailed financial statements are included on pages 8 to 13.

### **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 2024, with unrestricted, undesignated funds of £23,204 (2023: £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 2024, the trustees met four times (every quarter). This year brought new leadership and expertise to our trustee board. We welcomed Pete Welch as our new Chair in July 2024, bringing both professional insight and personal passion as a PTEN parent, and Eleanor Welsh, a clinical geneticist, as our new Care and Support Trustee.

### **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)

Peter Welch (appointed 24 July 2024)

Ellie Collins – Marketing and Communications

Colette Knight – Care & Support

Eleanor Welsh – Care and Support (appointed 24 July 2024)

Priyanka Tibarewal – Research

Dr Katherine Lachlan – Medical Advisor

John Pemberton- Technology (resigned January 19th 2024)

Kelly Kearley – Administration & Fundraising

## 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 21 October 2025

Signed on behalf of the charity's trustees by:



Full name: Peter Welch

Position: Chair of Trustees

Date: 21 October 2025

**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 2024 which are set out on pages 8 to 13.

**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: 23.10.2025



**Statement of Financial Activities**

	2024 Unrestricted Funds £	2024 Restricted Funds £	2024 Total Funds £	2023 Total Funds £
<b>Income and Endowments from :</b>				
Direct Donations	13,059	-	<b>13,059</b>	9,739
Gift Aid Recoverable	289	-	<b>289</b>	-
Fundraising Donations	13,392	-	<b>13,392</b>	7,266
Fundraising Lottery	414	-	<b>414</b>	-
Grants receivable	750	20,000	<b>20,750</b>	14,376
Sundry income	-	-	<b>-</b>	30
<b>Total Income</b>	<b>27,904</b>	<b>20,000</b>	<b>47,904</b>	<b>31,411</b>
<b>Expenditure on :</b>				
<i>Raising Funds</i>	766		<b>766</b>	2,517
<i>Charitable Activities:</i>				
Awareness Raising	2,058	-	<b>2,058</b>	-
Care & Support	4,393	11,985	<b>16,378</b>	10,215
Patient Day costs	0	-	<b>-</b>	4,537
Conferences & Training	259	-	<b>259</b>	662
Charity Management	8,000	-	<b>8,000</b>	5,333
Insurance	213	-	<b>213</b>	213
Bank & Just Giving Costs	294	-	<b>294</b>	282
Subscriptions	266	-	<b>266</b>	192
Independent Examination	400	-	<b>400</b>	500
Depreciation	185	-	<b>185</b>	-
Sundry expenditure	417	-	<b>417</b>	288
<b>Total Expenditure</b>	<b>17,251</b>	<b>11,985</b>	<b>29,236</b>	<b>24,739</b>
<b>Net Income/(Expenditure)</b>	<b>10,653</b>	<b>8,015</b>	<b>18,668</b>	<b>6,672</b>
Transfers between funds	-	-	<b>-</b>	-
<b>Net movement in funds</b>	<b>10,653</b>	<b>8,015</b>	<b>18,668</b>	<b>(758)</b>
Total funds brought forward	<b>12,551</b>	<b>5,485</b>	<b>18,036</b>	<b>11,364</b>
<b>Total funds carried forward</b>	<b>23,204</b>	<b>13,500</b>	<b>36,704</b>	<b>18,036</b>

## Balance Sheet

	Note	2024 £	2023 £
Tangible Fixed Assets	6	369	-
Debtors	7	289	1,727
Cash at bank		42,041	23,271
Creditors : amounts falling due within one year	7	(5,995)	(400)
<b>Total Net Assets</b>		<b>36,704</b>	<b>18,036</b>
<i>Represented by:</i>			
Unrestricted Funds	8	23,204	12,551
Restricted Funds	8	13,500	5,485
<b>Total Funds</b>		<b>36,704</b>	<b>18,036</b>

The notes 1 to 10 form part of these financial statements.  
The financial statements were approved by the trustees on 21  
October 2025 and signed by:



NAME Peter Welch (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 2021, 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. Tangible fixed assets

Tangible fixed assets are initially recognised at cost, or for donated assets, at a reasonable estimate of their value on receipt.

Depreciation is provided on all fixed assets, to write off the cost on a straight line basis over their expected useful life. For computer equipment this is at the rate of 33% per annum.

	Equipment £
<b>Cost:</b>	
At 1.1.2024	-
Addition in year	554
<b>At 31.12.2024</b>	<b>554</b>
<b>Accumulated Depreciation:</b>	
At 1.1.2024	-
Charge for year	(185)
<b>At 31.12.2024</b>	<b>(185)</b>
<b>Net Book Value at 31.12.2024</b>	<b>369</b>
Net Book Value at 31.12.2023	-

## 7. Debtors and Creditors

	2024 £	2023 £
<b>Debtors:</b>		
HMRC Gift Aid Recoverable	289	-
Grants receivable	-	1,727
	<b>289</b>	<b>1,727</b>
<b>Creditors:</b>		
Accruals	995	1,962
Deferred grant income	5,000	5,000
	<b>5,995</b>	<b>6,962</b>

## 8.Movement in Funds

	Balance at 1.1.2024 £	Income £	Expenditure £	Transfer £	Balance at 31.12.2024 £
<b>Restricted Funds:</b>					
National Lottery -Counselling Service	5,485	20,000	(11,985)	-	13,500
	5,485	20,000	(11,985)	-	13,500
<b>Unrestricted Funds:</b>					
General	12,551	27,904	(17,251)	-	23,204
<b>Total Funds</b>	<b>18,036</b>	<b>47,904</b>	<b>(29,236)</b>	<b>-</b>	<b>36,704</b>

### Prior year figures:

	Balance at 1.1.2023 £	Income £	Expenditure £	Transfer £	Balance at 31.12.2023 £
<b>Restricted Funds:</b>					
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
<b>Unrestricted Funds:</b>					
General	11,364	17,035	(14,524)	(1,324)	12,551
<b>Total Funds</b>	<b>11,364</b>	<b>31,411</b>	<b>(24,739)</b>	<b>0</b>	<b>18,036</b>

### 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.

## 9.Trustees and Related Party Transactions

The charity maintained insurance for the trustees throughout the financial year ended 31 December 2024 and such indemnity insurance was in place at the date of approval of these financial statements. For the year ended 31 December 2024, the premium cost for indemnity insurance was £213 and the cover was £250,000.

During the year, no Trustees received remuneration for their role as Trustee (2023:£nil). Trustees were reimbursed for out of pocket expenses, totalling £1,221 for 2 trustees (2023: £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 £8,000 ( 2023: £4,667. An amount of £nil was outstanding as the 31 December 2024 (2023:£666).

Also during the year, as allowed under the constitution, a Trustee (E Collins) undertook social media and communications duties by contractual arrangement. The amount chargeable under this arrangement was £330 and no amount was outstanding at 31 December 2024.

#### 10.Comparative Statement of Financial Activities

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



