

PTEN UK AND IRELAND PATIENT GROUP

England & Wales · Charity number 1172205

Details

Status Registered

Legal form CIO

Registered 2017-03-22

Register [View on the Charity Commission register](#)

Contact

Address 11 Whinchat Close
Hartley Wintney
Hook
RG27 8TT

Phone 07768864667

Email info@ptenuki.org

Website www.ptenuki.org

Activities

Objects: A) TO PROMOTE AND PROTECT THE HEALTH OF PERSONS AFFECTED BY PTEN HAMARTOMA TUMOUR SYNDROME AND RELATED SYNDROMES IN THE UK AND IRELAND BY THE PROVISION OF SUPPORT, INFORMATION AND PRACTICAL ADVICE FOR SUCH PERSONS, THEIR FAMILIES AND CARERS. B) TO IMPROVE THE HEALTHCARE OF PERSONS AFFECTED BY PTEN HAMARTOMA TUMOUR SYNDROME AND RELATED SYNDROMES IN THE UK AND IRELAND THROUGH ADVANCING THE EDUCATION AND AWARENESS OF MEDICAL PROFESSIONALS AND THE GENERAL PUBLIC. C) TO SUPPORT AND PROMOTE RESEARCH, ESPECIALLY BUT NOT EXCLUSIVELY INTO THE DIAGNOSIS, TREATMENT AND PREVENTION OF PTEN HAMARTOMA TUMOUR SYNDROME AND RELATED SYNDROMES IN THE UK AND IRELAND.

Activities: Promote, protect and improve healthcare of persons affected by PTEN Hamatoma Tumour Syndrome Support and promote research into the Syndrome

Classification

- **How:** Provides Advocacy/advice/information, Sponsors Or Undertakes Research
- **What:** The Advancement Of Health Or Saving Of Lives, Disability
- **Who:** Children/young People, Elderly/old People, People With Disabilities

Geography

- Ireland
- Northern Ireland
- Scotland
- Throughout England And Wales

Finances

Period end	Income	Expenditure	Assets	Employees
2024-12-31	£47,904	£29,236	-	-
2023-12-31	£31,411	£24,739	-	-
2022-12-31	£9,454	£10,212	-	-
2021-12-31	£1,776	£1,908	-	-
2020-12-31	£9,298	£3,446	-	-

Trustees

Name	Role	Appointed
Clare Thurlow		2025-10-01
Dr KATHERINE LACHLAN		2017-03-22
ELLEN CHALLIS		2017-03-22
Eleanor Welsh		2024-10-10
IAN STOCK		2017-03-22
Kelly Kearley		2017-06-25
Priyanka Tibarewal		2024-01-01

PTEN UK AND IRELAND PATIENT GROUP

England & Wales - Charity number 1172205

Accounts

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

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)
Total Net Assets		36,704	18,036
<i>Represented by:</i>			
Unrestricted Funds	8	23,204	12,551
Restricted Funds	8	13,500	5,485
Total Funds		36,704	18,036

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

7. Debtors and Creditors

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

8.Movement in Funds

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

Prior year figures:

	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.

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 £
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

PTEN UK AND IRELAND PATIENT GROUP

England & Wales - Charity number 1172205

Accounts

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

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OBJECTIVES AND ACTIVITIES

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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.

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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

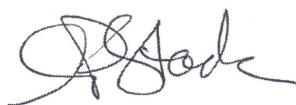
Statement of Financial Activities

	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	<u>1,727</u>	<u>0</u>
Creditors:		
Accruals	1,962	400
Deferred grant income	<u>5,000</u>	
	<u>6,962</u>	<u>400</u>

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	<u>11,364</u>	<u>31,411</u>	<u>(24,739)</u>	<u>0</u>	<u>18,036</u>

Transfers between funds were as follows

	Unrestricted General	Restricted
	£	£
General fund to Global Genes fund	<u>(1,324)</u>	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).

PTEN UK AND IRELAND PATIENT GROUP

England & Wales - Charity number 1172205

Accounts

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

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

PTEN UK AND IRELAND PATIENT GROUP

England & Wales - Charity number 1172205

Accounts

PTENUKI 2021 Annual Report

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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

PTEN UK AND IRELAND PATIENT GROUP

England & Wales - Charity number 1172205

Accounts

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