

ACTION FOR BPAN

Trustees' Annual Report

For the period 17 October 2024 to 30 September 2025

Registered Charity Number: 1210529

Principal Office: Westfield Lodge, Old Mill Lane, Bray, Maidenhead,
SL6 2BG

1. Objectives and Activities

Action for BPAN is a Charitable Incorporated Organisation (CIO) established to improve the lives of individuals and families affected by Beta-propeller Protein-Associated Neurodegeneration (BPAN), an ultra-rare, progressive neurological disorder that causes developmental delay, epilepsy, movement disorders and progressive neurodegeneration.

The charity exists to:

- Advance scientific and medical research into BPAN and potential treatments, including gene therapy.
- Raise awareness of BPAN amongst healthcare professionals, researchers, policymakers and the wider public.
- Support individuals and families affected by BPAN through information, connection and community.
- Promote collaboration between clinicians, researchers, charities and families to accelerate progress towards effective treatments.

The charity was founded by Kelly Sayers and Nicole Harper following the diagnoses of their daughters, Emily and Isabella, with BPAN. At the time there was no UK charity dedicated exclusively to BPAN, leaving families with limited support and researchers without a dedicated organisation to

coordinate fundraising for potential treatments. Action for BPAN was established to address both of these unmet needs.

Prior to the charity's formation, Kelly Sayers led significant fundraising efforts as a private individual, helping to provide the initial seed funding that enabled researchers at Great Ormond Street Hospital and University College London to begin developing a pre-clinical BPAN gene therapy programme. Action for BPAN was then established by Kelly Sayers and Nicole Harper to build on those foundations by creating a sustainable organisation capable of funding research, raising awareness and supporting families affected by BPAN over the long term.

In planning the charity's activities, the trustees have had due regard to the Charity Commission's guidance on public benefit.

2. Activities and Achievements

Although this represented the charity's first reporting period, significant progress was made in establishing Action for BPAN as the UK's first charity dedicated exclusively to BPAN. The trustees focused on building a sustainable organisation capable of accelerating research, raising awareness and supporting families, while laying strong foundations for future growth through fundraising, governance, partnerships and community engagement.

Fundraising

The charity established multiple fundraising channels including online giving platforms, community fundraising campaigns, individual giving, corporate support and organised fundraising events. Income was generated primarily through community fundraising and individual supporters, demonstrating strong public engagement with the charity's mission. Early relationships with corporate supporters and charitable organisations were also established, providing important foundations for future growth.

During its first reporting period, the charity generated income of £118.116, reflecting the exceptional commitment of its supporters, volunteers, corporate partners and the wider community.

Highlights from the reporting period included the charity's **first Founders' Snowdon Challenge on 20 June 2025**, which brought together **55 climbers** to raise funds and awareness for BPAN, and the charity's **inaugural Golf Day on 8 September 2025**, which welcomed **over 50 participants** for a day of fundraising, networking and awareness. These events not only generated valuable income but also strengthened community engagement, introduced new supporters to the charity's work and laid the foundations for future flagship fundraising events.

Supporting Research

Throughout the reporting period, the charity has built a good working relationship with leading BPAN clinicians and researchers at Great Ormond Street and University College London to help progress the development of a pre-clinical gene therapy programme for BPAN and ensure accuracy of Charity information. The trustees remained committed to building the financial resources required to accelerate this work and ultimately support progression towards future clinical trials.

Building on the initial seed funding secured prior to the charity's formation, Action for BPAN's first year focused on creating a sustainable fundraising and awareness platform capable of supporting this long-term research programme. By the end of the reporting period, the charity had established itself as the UK's principal charity dedicated exclusively to BPAN, providing an important foundation for continued investment into research, increased national awareness and long-term support for families affected by the condition.

The charity has established itself as a trusted partner for clinicians, researchers and families affected by BPAN, helping to bring these groups

together around a shared ambition of accelerating the development of effective treatments for this ultra-rare condition.

Raising Awareness

During its first year, the charity significantly increased awareness of BPAN through the launch of the Action for BPAN website, social media, digital communications, community engagement, fundraising events and public outreach. As the UK's first charity dedicated solely to BPAN, Action for BPAN began establishing itself as a recognised voice for families affected by this ultra-rare condition, helping to increase understanding amongst the public, healthcare professionals and potential supporters.

Supporting Families

The charity has developed a growing network of families living with BPAN, providing opportunities for connection, shared experiences and peer support. This work helped reduce isolation for families navigating an exceptionally rare diagnosis while strengthening collaboration across the BPAN community. The charity has also had commitment from the National Institute of Child Health to hold a patient day at Great Ormond Street Hospital in 2026 to bring together families and researchers for a day of exciting updates and family connection.

Building a Sustainable Charity

Alongside its charitable activities, the trustees focused on establishing robust governance, financial systems, fundraising platforms, policies, digital infrastructure and operational processes necessary to support the charity's long-term growth.

This included implementing appropriate financial controls, securing insurance, developing the charity's digital presence, establishing fundraising infrastructure, delivering successful fundraising events and building

relationships with researchers, clinicians, families, supporters and corporate partners.

The charity's achievements during its first year would not have been possible without the dedication of volunteers, fundraisers, families, ambassadors and supporters who freely gave their time, skills and expertise in support of the charity's mission.

Through the dedication of its trustees, volunteers, supporters and families, Action for BPAN established strong foundations during its first year of operation, creating the infrastructure, partnerships and momentum required to accelerate research whilst building a lasting source of support for those affected by BPAN.

3. Financial Review

This was the charity's first financial reporting period.

Income for the period totalled **£118.116**.

Expenditure for the period totalled **£18.278**.

Income was generated through individual donations, community fundraising initiatives, online giving platforms, corporate support and fundraising events. The trustees were encouraged by the strong level of public support received during the charity's first year of operation.

Expenditure was carefully managed and directed towards furthering the charity's charitable objectives. The principal areas of expenditure included fundraising event delivery, website and digital infrastructure, insurance, governance, financial management systems and other essential operating costs associated with establishing the charity.

The trustees sought to minimise administrative expenditure wherever possible, ensuring that resources were used efficiently and that the maximum possible proportion of funds raised could be directed towards achieving the charity's objectives.

The charity concluded the reporting period with total funds of **£99.838**, providing a strong financial platform from which to continue pursuing its charitable objectives. Throughout the period, the trustees remained committed to prudent financial stewardship, ensuring that donations were managed responsibly and applied in support of the charity's mission. This approach has enabled the charity to enter its second year in a secure financial position with the capacity to further expand its impact.

Reserves Policy

As this was the charity's first reporting period, the trustees' priority was to establish sufficient unrestricted reserves to support the charity's ongoing operations and provide financial stability whilst continuing to invest in its charitable objectives. The trustees recognise the importance of maintaining appropriate reserves to manage unforeseen circumstances whilst ensuring that funds are applied effectively in pursuit of the charity's mission.

The Trustees have set a policy reserve of £5.000 for core running costs. At 30 September 2025, unrestricted reserves totalled **£99.838**

The trustees will review the reserves policy annually as the charity continues to grow.

In addition to its unrestricted reserves, the charity holds funds that have been raised to support the BPAN gene therapy research programme being undertaken by Great Ormond Street Hospital and University College London. These funds are held securely, including in an interest-bearing savings account where appropriate, until they are required to meet the agreed research funding commitments. The trustees monitor these funds regularly to ensure they remain available to support the charity's long-term charitable objectives.

4. Structure, Governance and Management

Action for BPAN is a Charitable Incorporated Organisation (CIO) governed by its Constitution.

The trustees are responsible for the overall governance, strategic direction and financial stewardship of the charity. They ensure that the charity's resources are applied solely in furtherance of its charitable purposes and that appropriate governance arrangements are maintained.

Trustees are appointed in accordance with the charity's governing document and meet regularly to oversee the charity's activities, finances, strategy and risk management.

The trustees serving during the reporting period were:

- Kelly Sayers - CEO
- Nicole Harper - secretary
- Schalk Visser - treasurer
- Susannah Kemmis - legal advisor

All trustees serve on a voluntary basis and bring a combination of lived experience, professional expertise and governance oversight to the strategic development of the charity.

Trustee Remuneration

No trustee received any remuneration or financial benefit from the charity during the reporting period. Trustees were entitled to reimbursement of reasonable out-of-pocket expenses incurred in carrying out their duties. £0 was reimbursed during the reporting period.

5. Risk Management

The trustees regularly reviewed the principal risks facing the charity and implemented appropriate measures to mitigate them.

During the reporting period, the principal risks identified included:

- Maintaining sustainable fundraising income.

- Ensuring appropriate governance and financial oversight during a period of rapid growth.
- Managing the charity's reliance on volunteers.
- Maintaining sufficient resources to support both research and charitable activities.

To mitigate these risks, the trustees established appropriate financial controls, adopted governance policies, held regular trustee meetings and maintained close oversight of financial performance and strategic priorities. Risk management will continue to be reviewed and developed as the charity grows.

6. Plans for Future Periods

The trustees intend to build on the strong foundations established during the charity's first year by:

- Continuing to grow sustainable fundraising income through community fundraising, corporate partnerships, trusts and foundations, and major fundraising events.
- Increasing investment in research aimed at developing effective treatments and, ultimately, a cure for BPAN.
- Supporting the progression of the BPAN gene therapy programme towards future clinical trials.
- Expanding national and international awareness of BPAN through education, advocacy and media engagement.
- Strengthening support for individuals and families affected by BPAN by developing opportunities for connection, information sharing and collaboration.
- Building new partnerships with researchers, clinicians, charitable organisations and industry to accelerate progress for those living with BPAN.

The trustees remain committed to ensuring that Action for BPAN continues to grow responsibly whilst maximising the impact of every pound raised in pursuit of its charitable objectives.

7. Public Benefit Statement

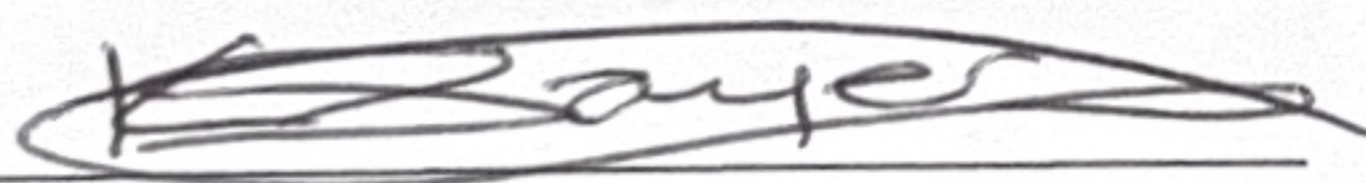
The trustees confirm that they have complied with their duties under the Charities Act 2011 to have due regard to the Charity Commission's guidance on public benefit when planning and carrying out the charity's activities.

Action for BPAN provides public benefit by advancing medical research into an ultra-rare neurological condition, raising awareness of BPAN amongst healthcare professionals and the wider public, supporting families affected by the condition, and fostering collaboration between researchers, clinicians and the BPAN community to accelerate the development of future treatments.

8. Approval and Declaration

This Trustees' Annual Report was approved by the Board of Trustees on 22.07.26 and signed on its behalf by:

Kelly Sayers
Chair of Trustees

Signature: 

Date: 22.07.26



CHARITY COMMISSION
FOR ENGLAND AND WALES

Charity Name
Action for BPAN

No (if any)
1210529

Receipts and payments accounts

CC16a

For the period
from

Period start date
17/10/2024

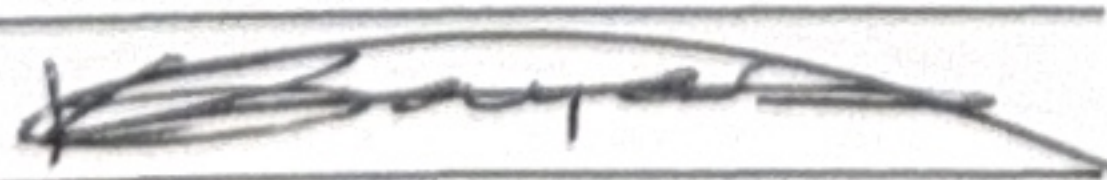
To

Period end date
30/09/2025

Section A Receipts and payments

	Unrestricted funds to the nearest £	Restricted funds to the nearest £	Endowment funds to the nearest £	Total funds to the nearest £	Last year to the nearest £
A1 Receipts					
Donations	96,296	-	-	96,296	-
Grants	500	-	-	500	-
Fundraising events	10,908	-	-	10,908	-
Sponsorship	10,412	-	-	10,412	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total(Gross income for AR)	118,116	-	-	118,116	-
A2 Asset and investment sales, (see table).					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	118,116	-	-	118,116	-
A3 Payments					
Cost of fundraising events	17,676	-	-	17,676	-
Advertising and marketing	224	-	-	224	-
Insurance	99	-	-	99	-
IT software and consumables	154	-	-	154	-
Accountancy and software subscriptions	25	-	-	25	-
Administration and set-up costs	100	-	-	100	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total	18,278	-	-	18,278	-
A4 Asset and investment purchases. (see table)					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total payments	18,278	-	-	18,278	-
Net of receipts/(payments)	99,838	-	-	99,838	-
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	-	-	-	-	-
Cash funds this year end	99,838	-	-	99,838	-

Section B Statement of assets and liabilities at the end of the period

Categories	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B1 Cash funds	Bank current account	29,838	-	-
	Bank savings account	70,000	-	-
		-	-	-
	Total cash funds	99,838	-	-
	(agree balances with receipts and payments account(s))	OK	OK	OK
		Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B2 Other monetary assets	Details	-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
B3 Investment assets	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
			-	-
			-	-
			-	-
			-	-
			-	-
B4 Assets retained for the charity's own use	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
B5 Liabilities	Details	Fund to which liability relates	Amount due (optional)	When due (optional)
			-	
			-	
			-	
			-	
Signed by one or two trustees on behalf of all the trustees		Signature	Print Name	Date of approval
			Kelly Sayers	21/07/2026



Section A

Independent Examiner's Report

Report to the trustees

Charity Name
Action for BPAN

On accounts for the year
ended

30 September 2025

Charity no
(if any)

1210529

Set out on pages

1 and 2

I report to the trustees on my examination of the accounts of the above charity ("the Trust") for the year ended 31 / 09 / 2025.

Responsibilities and
basis of report

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

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

- the accounting records were not kept in accordance with section 130 of the Charities Act; or
- the accounts did not accord with the accounting records; or
- the accounts did 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.

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

** Please delete the words in the brackets if they do not apply.*

Signed:

Jason Smith

Date:

21/07/2026

Name:

Jason Smith

Relevant professional
qualification(s) or body
(if any):

ICAEW

Address:

5 Moat Close

Sevenoaks

TN13 2HZ