



Aspergillosis Trust

Charity No. 1194699

Annual Report and Financial Statements

Year Ended 1st April 2025

Aspergillosis Trust

Year ended 1st April 2025

Reference and administrative details

Trustees	Lisa McNeil Katie Martin Sharon Gordon Jacqueline Ann Locker Alison Redfern (joined December 2024)
Principal address	Aspergillosis Trust PO Box 712 Preston Lancashire PR3 8DD
Bankers	NatWest Blackpool 20 Corporation Street Blackpool Lancashire FY1 1EJ
Registered Charity Number	1194699

Trustees Annual Report

This is our 4th annual report and is for the period 2nd April 2024 to 1st April 2025.

As with every year, it has been one of both progress and profound challenge. During this period, we have again lost members of our community to aspergillosis. Some were long standing friends, advocates, and supporters of the Trust. We remember them with respect and gratitude, and we dedicate this report to their memory and to the families and friends who continue to walk alongside us.

This year we also remember, with deep affection and gratitude, our co-founder Jill Fairweather. Jill was a driving force behind the Aspergillosis Trust and a tireless advocate for patients and families. Her compassion, determination, and commitment continue to shape our work and values.

In December 2024 we were delighted to welcome Alison Redfern to the board of Trustees as a retired pharmacist, Alison brings a wealth of clinical knowledge and healthcare to the board. Living with aspergillus herself, she offers both professional insight alongside valuable lived experience, helping to strengthen the charity's patient centered approach and helping to ensure our work remains grounded in the real needs of those affected by fungal lung disease.

Despite the realities of living and working with a serious, life limiting illness, the Trust has continued to grow in reach, credibility, and impact. This has only been possible because of the commitment of our volunteers, trustees, supporters, fundraisers, and partner organisations.

Objects

The objects of the charity, as per its constitution dated 7th June 2021 are:

To preserve and protect good health for the public benefit of people suffering from aspergillosis by:

raising awareness of aspergillosis and increase the understanding of the condition amongst medical professionals and the public at large;

supporting sufferers globally by providing information and creating real and virtual support networks for sufferers of the most common forms of the disease;

circulating up-to-date information about the condition with all forms of aspergillosis and help them understand the disease and treatments;

raising funds for research, with the aim of making aspergillosis far more readily recognisable than at present;

via joint initiatives, educate healthcare professionals of the symptoms and treatment of aspergillosis as it is often missed and can take years to reach the correct diagnosis; and

represent aspergillosis patients in wider lung health networks.

Public Benefit

In accordance with their objectives for this year, and with due regard to the published Charity Commission guidance on the operation of the Public Benefit requirements of the Charities Act 2006, the trustees have undertaken appropriate activities in furtherance of these aims for the public benefit. This report explains how our activities achieve public benefit.

About Us

The Trust is a not-for-profit charity (reg. no. 1194699). We are patient-led and at the present time the majority of our trustees and coordinators are people who suffer with aspergillosis in one of its forms. To mitigate the risk of loss of key staff & volunteers through ill health we are trying to broaden the base of key people involved in the running of the Trust, in particular to involve specialist non-patient Trustees. Aspergillosis is a complex and highly dangerous disease. In consequence, the people who work to support our day-to-day endeavors can be prone to periods of illness, weakness, and hospitalisation. This creates constant challenges for us and it is only through the hard work of so many people that the work carries on. Our Treasurer continues in post as a non patient trustee, strengthening our governance and financial oversight.

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On a day-to-day basis, our main function is to ensure that anyone who is experiencing aspergillosis, or knows of someone who is, can obtain the best possible advice and information. We offer this to anyone who needs it, worldwide. This is primarily done through our social media accounts (particularly the Support Group on Facebook) as well as leaflets, videos, and other information that we widely circulate.

The day-to-day running of the Trust is coordinated by volunteers and trustees. The Trust has no paid staff, meaning that all income received can be used in the furtherance of our goals. We welcome any interest in supporting our work.

World Aspergillosis Day – 1st February 2025

World Aspergillosis Day (WAD) remains a cornerstone of our awareness raising activity. In 2025 our theme was “Together We Are Stronger”, reflecting the importance of community, collaboration, and shared voices in improving outcomes for people affected by aspergillosis.

Throughout the campaign we highlighted the value of patient support networks, the need for earlier diagnosis, improved access to specialist care, and better education for both patients and healthcare professionals. Patients and supporters were encouraged to wear purple, share their experiences, and amplify campaign messages across social media.

The theme strongly resonated with our community and partners, reinforcing that meaningful change can only happen when patients, clinicians, charities, and industry work together.

Events

Throughout 2024/25 we were involved in a range of in person and virtual events designed to raise awareness, reduce isolation, and promote lung health more broadly.

- ELF Patient Networking Day, Vienna: For the first time, the Trust attended the ELF Patient Networking Day in Vienna in person. This was a significant milestone for the charity, enabling direct engagement with European patient organisations, clinicians, and advocates, and strengthening our international collaborations.
- National Aspergillosis Webinar: We supported and participated in the National Aspergillosis Webinar, where we presented on the work of the Trust and how we support patients and their families. This provided an important opportunity to reach both patients and healthcare professionals.
- ELF Bronchiectasis Patient Conference – attended virtually
- Rare Disease Day – supported on social media
- World Lung Day – supported on social media
- Fungal Disease Awareness week – supported on social media
- AMR Awareness Week – supported on social media
- Global Allergy and Airways Patient Advocacy Summit, Amsterdam: In March 2025, we attended the Global Allergy and Airways Patient Advocacy Summit in Amsterdam in person for the first time. This summit provided valuable opportunities to connect with international patient advocates, share learning, and strengthen collaboration across allergy, airway, and respiratory disease communities.

These events not only raise awareness but also allow us to ensure the patient voice is represented in wider respiratory and fungal disease discussions.

Social Media

Our website (www.aspergillosistrust.org) continues to act as a central hub for information and downloadable resources.

Our Facebook support group (<https://www.facebook.com/groups/777282226382870>) is the main way that most people who want to discuss the illness come into contact with us. The group offers both

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long-term patients and those who are newly diagnosed to share their knowledge and experiences.

We continue to publish educational video content featuring clinicians and allied health professionals, covering topics such as airway clearance, nutrition, antifungal treatment, resistance, and living well with chronic lung disease.

Merchandising & Awareness Items

During this reporting period we continued to expand and diversify our educational and awareness resources.

- **Children's Book Project:** Work began on a children's book designed to help explain aspergillosis to younger audiences and families. We commissioned an author to work with the Trust on this project, and we aim to have the book completed by summer 2025.
- **Professional Education Campaign:** We worked in partnership with Pfizer to develop a UK wide awareness campaign for doctors titled "Danger in Disguise." As part of this campaign, posters were distributed to GP practices across the UK with a specialist interest in respiratory medicine. The campaign also ran for two months on LinkedIn, extending its reach to healthcare professionals nationwide.
- **Podcast Collaboration:** In collaboration with GSK, we produced a podcast focused on Respiratory Syncytial Virus (RSV), a condition that many people living with aspergillosis are also at increased risk of. This helped broaden awareness of overlapping respiratory risks and prevention.
- **Multilingual Resources:** Our multilingual leaflet library remains available online, allowing patients worldwide to access and print materials in their own language.

These resources play a crucial role in improving understanding, supporting informed conversations with healthcare professionals, and reducing anxiety around diagnosis.

Fundraising

We remain deeply grateful to everyone who has fundraised for or donated to the Trust during the year. Much of our income continues to be driven by personal stories, community generosity, and acts of remembrance.

Highlights:

- **London Landmarks Half Marathon (April 2024):** A team of runners took part in the London Landmarks Half Marathon, raising £2,725 in support of the Trust and helping to increase awareness of aspergillosis among the wider public.
- **Wedding Donations (May 2024):** In a wonderful act of generosity, our Treasurer Sharon Butler-Hughes and her husband Shaun Butler-Hughes chose to ask for donations to the Aspergillosis Trust in place of wedding gifts. This raised an incredible £2,700, demonstrating the strength of support for the charity within our own community.
- **In Memory of Jill Fairweather:** During the year we lost one of our co founders and a core member of the Trust, Jill Fairweather. Jill was instrumental in shaping the charity and supporting countless patients and families. In her memory, Johanna Rhodes and Dani Blackie both organised fundraising events to honour Jill's legacy and continue the work she cared so deeply about.

In addition to these highlights, income was generated through:

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- In memoriam and legacy donations
- One off and regular monthly donations
- Community led fundraising activities
- Online fundraising platforms and schemes

We are profoundly thankful to everyone who has supported the Trust financially during this reporting period.

Reserves

At the year end our reserves, being the amounts held in bank accounts, amounted to £29,059.

Production of the children's book has commenced and will be completed in FY2026. £1,500 has been spent in FY2025 and there is still a cost in the region of £8,000 to be expended in FY2026. As expected funds raised in FY2025 were not as high as FY2024, on that basis we do not know how much funds would be raised in FY2026 and therefore are preserving funds for essential patient awareness.

Structure, governance and management

The charity is a Foundation Charitable Incorporated Organisation and is governed by its constitution dated 7th June 2021.

We refer to recruitment of trustees earlier in the report.

Risks and uncertainties

The Trustees actively monitor and review the risks facing the charity on an ongoing basis to ensure appropriate safeguards and mitigation plans are in place.

As a small, patient led organisation, Trustees capacity remains a key area of focus. Three of the current trustees are living with aspergillosis, which brings valuable lived experience but can also present challenges in maintaining continuity and resilience within the Board. The charity therefore continues to prioritise the recruitment of additional Trustees who can contribute a broad range of skills, experience and capacity to support the charity's governance and strategic development.

The charity's funding base also represents an area of uncertainty, as we rely largely on voluntary donations and fundraising activities, many of which are led by individuals and families affected by the disease. While this demonstrates strong community commitment, it can also result in variability in income.

During FY2026, the Trustees intend to strengthen the charity's sustainability by recruiting or seeking access to fundraising expertise and exploring new income streams to improve and stabilise levels of funding.

Relationships

We continued to work collaboratively with a range of organisations across the respiratory, fungal disease, and rare disease communities. This included:

- Engagement with European and international respiratory and patient networks
- Contributions to patient focused publications and round ups
- Ongoing dialogue with healthcare professionals to highlight gaps in awareness, diagnosis, and access to specialist care

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Advocacy remains a growing area of our work, particularly around the patient voice in policy, research, and service design.

This report was approved by the trustees on 29th January 2026 and signed on their behalf by:

Lisa McNeil

Trustee

RECEIPTS AND PAYMENTS ACCOUNT

All funds are unrestricted

	Year ended 1.4.25 £	Year ended 1.4.24 £
<u>Receipts</u>		
Sales	224	259
Just Giving	10,533	31,791
Amazon	-	45
Salary donations	220	170
Global Allergy & Airways Patient Platform grant	2,209	4,797
Easy fundraising	124	115
Will donations	796	310
Other Income	4,034	565
Grant Income	-	1,200
Total Receipts	18,140	39,252

Payments

JustGiving Fees	562	446
Leaflet translation	-	17,800
London Marathon	2,753	1,477
Tower2Tower	-	1,452
Hive Arts	-	300
Production of Children's Book	1,500	-
Web hosting	934	1,681
Advertising and promotion	803	1,552
ELF Conference	943	-
Postage	505	114
Other costs	229	108
Bank/finance charges	-	-
Accountancy Fees	900	-
Public awareness items	-	-
Publicity	-	-
Total payments	9,129	24,930

Net receipts	9,011	14,322
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Balances bfd	20,048	5,726
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Balances cfd	29,059	20,048
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STATEMENT OF ASSETS AND LIABILITIES

Bank balances	29,059	20,048
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NOTES TO THE FINANCIAL STATEMENTS

- 1 Basis of preparation
These accounts have been prepared on the Receipts and Payments basis in accordance with the Charities Act 2011.
- 2 Fund Accounting
 - (a) Unrestricted funds are those that can be expended at the discretion of the trustees in the furtherance of the objects of the charity
 - (b) Restricted funds are those that may only be used for specific purposes. Restrictions arise when specified by the donor.
- 3 Taxation
The charity is not liable to tax on its charitable activities.
The charity is not registered for VAT. Irrecoverable VAT is included in the expense to which it relates.
- 4 Transactions with trustees
No remuneration nor expenses were paid to trustees or any persons connected with them during the year or previous year.