

ASPERGILLOSIS TRUST

England & Wales · Charity number 1194699

Details

Status Registered

Legal form CIO

Registered 2021-06-07

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

Contact

Address Aspergillosis Trust
PO Box 712
Preston
PR3 8DD

Email secretary@aspergillosistrust.org.uk

Website www.aspergillosistrust.org

Activities

Objects: 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. NOTHING IN THIS CONSTITUTION SHALL AUTHORISE AN APPLICATION OF THE PROPERTY OF THE CIO FOR THE PURPOSES WHICH ARE NOT CHARITABLE IN ACCORDANCE WITH [SECTION 7 OF THE CHARITIES AND TRUSTEE INVESTMENT (SCOTLAND) ACT 2005] AND [SECTION 2 OF THE CHARITIES ACT (NORTHERN IRELAND) 2008].THE CIO HAS POWER TO DO ANYTHING WHICH IS CALCULATED TO FURTHER ITS OBJECTS OR IS CONDUCIVE OR INCIDENTAL TO DOING SO. IN PARTICULAR, THE CIO HAS POWER TO:(1) BORROW MONEY AND TO CHARGE THE WHOLE OR ANY PART OF ITS PROPERTY AS SECURITY FOR THE REPAYMENT OF THE MONEY BORROWED. THE CIO MUST COMPLY AS APPROPRIATE WITH SECTIONS 124 AND 125 OF THE CHARITIES ACT 2011, IF IT WISHES TO MORTGAGE LAND;(2) BUY, TAKE ON LEASE OR IN EXCHANGE, HIRE OR OTHERWISE ACQUIRE ANY PROPERTY AND TO MAINTAIN AND EQUIP IT FOR USE;(3) SELL, LEASE OR OTHERWISE DISPOSE OF ALL OR ANY PART OF THE PROPERTY BELONGING TO THE CIO. IN EXERCISING THIS POWER, THE CIO MUST COMPLY AS APPROPRIATE WITH SECTIONS 117 AND 119-123 OF THE CHARITIES ACT 2011;(4) EMPLOY AND REMUNERATE SUCH STAFF AS ARE NECESSARY FOR CARRYING OUT THE WORK OF THE CIO. THE CIO MAY EMPLOY OR REMUNERATE A CHARITY TRUSTEE ONLY TO THE EXTENT THAT IT IS PERMITTED TO DO SO BY CLAUSE 6 (BENEFITS AND PAYMENTS TO CHARITY TRUSTEES ANDCONNECTED PERSONS) AND PROVIDED IT COMPLIES WITH THE CONDITIONS OF THAT CLAUSE;(5) DEPOSIT OR INVEST FUNDS, EMPLOY A PROFESSIONAL FUND-MANAGER, AND ARRANGE FOR THE INVESTMENTS OR OTHER PROPERTY OF THE CIO TO BE HELD IN THE NAME OF A NOMINEE, IN THE SAME MANNER AND SUBJECT TO THE SAME CONDITIONS AS THE TRUSTEES OF A TRUST AREPERMITTED TO DO BY THE TRUSTEE ACT 2000

Activities: We raise awareness and increase understanding of aspergillosis amongst patients, carers, medical professionals and the public at large. We support sufferers globally by providing information and creating real and virtual support networks. We also represent patients in various national and international lung health networks.

Classification

- **How:** Makes Grants To Individuals, Provides Advocacy/advice/information
- **What:** The Advancement Of Health Or Saving Of Lives
- **Who:** Other Defined Groups

Geography

- Throughout England And Wales

Finances

Period end	Income	Expenditure	Assets	Employees
2025-04-01	£18,140	£9,129	-	-
2024-04-01	£39,252	£24,930	-	-
2023-04-01	£10,594	£8,652	-	-
2022-04-01	£8,330	£7,291	-	-

Trustees

Name	Role	Appointed
Lisa McNeil	Chair	2021-01-01
Alison Redfern		2024-12-21
Jacqueline Ann Locker		2022-10-11
Katie Martin		2023-09-11
Sharon Gordon treasurer		2023-07-26

ASPERGILLOSIS TRUST

England & Wales - Charity number 1194699

Accounts



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)
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Principal address	Aspergillosis Trust PO Box 712 Preston Lancashire PR3 8DD
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Bankers	NatWest Blackpool 20 Corporation Street Blackpool Lancashire FY1 1EJ
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Registered Charity Number	1194699
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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.

Aspergillosis Trust Year ended 1st April 2025

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

Aspergillosis Trust Year ended 1st April 2025

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:

Aspergillosis Trust Year ended 1st April 2025

- 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

Aspergillosis Trust Year ended 1st April 2025

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

Aspergillosis Trust Year ended 1st April 2025

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
<u>Payments</u>		
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
Balances bfd	20,048	5,726
Balances cfd	29,059	20,048
STATEMENT OF ASSETS AND LIABILITIES		
Bank balances	29,059	20,048

Aspergillosis Trust Year ended 1st April 2025

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.

ASPERGILLOSIS TRUST

England & Wales - Charity number 1194699

Accounts



Aspergillosis Trust

Charity No. 1194699

Annual Report and Financial Statements

Year Ended 1st April 2024

Aspergillosis Trust

Year ended 1st April 2024

Reference and administrative details

Trustees	Lisa McNeil Katie Martin Sharon Gordon Jacqueline Ann Locker Bart Jozef Mariette Govaert (resigned in the year)
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Principal address	Aspergillosis Trust PO Box 712 Preston Lancashire PR3 8DD
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Bankers	NatWest Blackpool 20 Corporation Street Blackpool Lancashire FY1 1EJ
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Registered Charity Number	1194699
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Independent Examiner	M R Heaton FCCA FCIE DchA KM Chartered Accountants 1 st Floor, Block C The Wharf Manchester Road Burnley BB11 1JG
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Trustees Annual Report

This is our 3rd annual report and is for the period 2nd April 2023 to 1st April 2024.

During this year we have lost several people who have succumbed to aspergillosis, some of whom have been friends and supporters for many years. This report is dedicated to the memory of those we have lost, and with gratitude to those who have continued to support our work to remember them.

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.

This year we recruited a treasurer who is not a patient.

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 2024

World Aspergillosis Day is an important day in our calendar and this year was no different. Our theme was Aspergillosis Trust Needs You as we are trying to galvanise support for the charity amongst our support groups. With the help of our friends at GAAPP we designed several info graphs that we posted onto our socials in the weeks leading up to WAD. The messages these graphics were trying to get across were:

1. Improve the diagnostic journey
2. Call for new treatments
3. Improve access to specialists
4. Education is vital
5. Support for all patients
6. Airway clearance and access to physiotherapists.

GAAPP also created a reel for us which called for patients to wear something purple along with all the key messages from the info graphs. This reel was viewed over 1000 times on the day. We also attended the patient seminar hosted by the National Aspergillosis Centre in Manchester and our trustee Jacqueline Totterdell did a presentation about the charity and our aims for 2024. We invited patients in our support groups to wear purple and send in their pictures and we added these to our Facebook page. Our Chair, a trustee and our treasurer all spent the afternoon at Blackpool Victoria Hospital, handing out “What is Aspergillosis?” leaflets and speaking to both hospital staff and members of the public. In total over 200 leaflets were given away and a lot of very useful conversations took place. We also lit up Blackpool Tower and the Marine Hall in Fleetwood purple. Several of our patients held fundraising activities on the day to raise both awareness and money and one patient visited her GP with awareness materials.

Events

In April our trustee Katie Martin hosted a psychic night. She handed out leaflets and awareness wristbands and did a short talk on the charity and our aims. There was a raffle and a craft stall. 55 tickets were sold, and the event made £1040 for the charity.

World Lung Day – 25th September. This year we opened an art exhibition titled The Air that I breathe. The exhibition was opened by Tina Rothery an avid campaigner for clean air and anti-fracking. She is now a co-chair of the Green Party Women and a parliamentary candidate for Blackpool North. The exhibition was a huge success with over 50 works of art displayed. The exhibition was open for 2 weeks and during that time we also had an NHS Stop Smoking stall, a nurse practitioner offering free health checks and a talk on how to deal with mould in your home from a leading property specialist.

Social Media

Our website (www.aspergillosistrust.org) has been live for some time now and is a valuable source of information for people trying to find out about the illness.

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 long-term patients and those who are newly diagnosed to share their knowledge and experiences. We now have over 2000 members on the support group. We average around 40 posts per week.

This year we produced a new information video that we posted to our YouTube channel. The video was with Ras Kahai a dietician who works at the Royal Brompton Hospital in London and the topic was on managing your weight with aspergillosis and bronchiectasis. Our video's now cover subjects such as drug resistance, the importance of physiotherapy and airway clearance, introducing the charity, current and future therapeutics in ABPA, a conversation with Professor Denning and a Q&A session with Dr Anand Shah and Professor Darius Armstrong-Jones.

Aspergillosis Trust Year ended 1st April 2024

In addition, we have Twitter(@aspertrust) with 2413 followers, an Instagram account with 41.4k followers a Facebook page that relates to the charity and this year we also created a Facebook page for friends and family of patients.

Merchandising & Awareness Items

The Trust continues to produce awareness raising items such as key rings, t- shirts, etc. This year we have added many new items including mugs and tote bags. We have created several different slogans on our merchandise that we are promoting. We also purchased our own printer so we can print to order and save money. We are planning to start monthly give away competitions using our Facebook groups to help promote our merchandise and help to raise awareness.

We completed our plan to translate our leaflets into 30 different languages and these are now all stored on our website. They can be printed off by patients all around the world.

Other Activities

Throughout the year, we participated in several events organised by others. This typically involves sharing links and providing information to people to support their involvement. Examples include:

- World Lung Day in September – refer Events.
- Fungal Disease Awareness Week in October.
- Patient Organisation Day for the ERS Congress in September – this was attended virtually, and our chair facilitated a breakout session with other patients on mental health issues. Our aim is to attend the patient networking day in Vienna in 2024 in person.
- ELF Bronchiectasis Patient Conference in March – attended virtually.
- Writing regular pieces for ELF Patient Roundup.
- Rare Diseases Day
- Student Voice Prize with Medics4Rare and Rare Beacon
- Pfizer – We have been working with Pfizer on producing education material for GP's.

Fundraising

Completing a challenge to climb the 7 highest mountain summits in Northern Ireland, the Johnston family raised money to help create literature aimed at explaining aspergillosis to children. They raised their target of £1,500. We will be working on this project during 2024/25.

In April 2023 we had a runner in the London Marathon and a family running the Belfast Half Marathon in memory of their mum/wife, Lina Sweeney. The Sweeney family raised more than £16,000 for the charity which was an extraordinary amount of money. The charity used this money to get 5 of our leaflets translated into 30 different languages.

In September a team of 15 cyclists cycled from Blackpool Tower to the Eiffel Tower and raised in excess of £8000 for the charity, which was another extraordinary amount of money.

In October 2023 we had 5 people run the Royal Parks Half Marathon.

In April 2024 we had 5 people run the London Landmarks Half Marathon.

We are so grateful to all our fundraisers and those who contribute monthly payments to the charity.

Fundraising Plans

We have prepared a fundraising pack and have added this to our website. This can be downloaded from the website, or we can issue a pack if requested.

We have 5 runners secured for the Royal Parks Half Marathon in October 2024.

We will apply for 5 places for the London Landmarks Half Marathon in April 2025.

We have a runner in the Manchester marathon in April 2025.

We are hoping to secure some places for the London Marathon in 2026 (the first year we can be in the ballot).

Finance

The Trust has once again exceeded all our targets and expectations in terms of income, which has meant that we have met many of the things we set out to achieve.

During these dates money has been received via the following:

- Legacies and in memoriam donations
- Easy Fundraising
- Fundraisers
- One off and monthly donations
- Grant from GAAPP for the translation of leaflets project

Reserves

At the year end our reserves, being the amounts held in bank accounts, amounted to £20,048.

There is a donor commitment to produce a children's book to support children in the explanation of the illness when they have loved ones that have fallen ill. We expect this to cost in the region of £8,000 as has commenced in FY2025. We had an exceptional year of fund raising in FY24 with 2 main events that will not occur this financial year, on that basis we did not know how much funds would be raised in FY25 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

Risks are monitored by the trustees. Significant uncertainties include the trustees, as the main two trustees have the illness so there is focus in FY25 to recruit trustees that can contribute to the charity. Also sources of funds as the charity mainly relies on donations from fundraising raised by sufferers of the disease. In FY25 / FY26 the intention is to recruit/seek fund raising experience so that we can improve the level of funds being received into the charity.

Relationships

The charity works closely with Pfizer and GAAPP (Global Allergy's and Airways Patient Platform) in terms of grants and providing knowledge of the disease so that they can research medications.

This report was approved by the trustees on 29th January 2025 and signed on their behalf by:

Trustee

INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES OF ASPERGILLOSIS TRUST

I report to the charity trustees on my examination of the accounts of the charity for the year ended 1st April 2024

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 charity's accounts carried out under section 145 of the 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 matters have come to my attention in connection with the examination giving me cause to believe:

- (1) accounting records were not kept in respect of the charity as required by Section 130 of the Act; or
- (2) the accounts do not accord with those records.

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.

M R Heaton FCCA FCIE DChA
KM
Chartered Accountants
1st Floor, Block C,
The Wharf
Burnley
Lancashire
BB11 1JG

29th January 2025

Aspergillosis Trust Year ended 1st April 2024

RECEIPTS AND PAYMENTS ACCOUNT

All funds are unrestricted

	Year ended 1.4.24 £	Year ended 1.4..23 £
<u>Receipts</u>		
Sales	259	1,032
Just Giving	31,791	7,361
Amazon	45	62
Salary donations	170	460
Global Allergy & Airways Patient Platform grant	4,797	503
Easy fundraising	115	-
Will donations	310	137
Other Income	565	1038
Grant Income	1,200	-
Total Receipts	39,252	10,593
<u>Payments</u>		
JustGiving Fees	446	216
Leaflet translation	17,800	1,376
London Marathon	1,477	-
Tower2Tower	1,452	-
Hive Arts	300	-
Web hosting	1,681	-
Advertising and promotion	1,552	637
Postage	114	814
Other costs	108	-
Bank/finance charges	-	24
Telephone/internet	-	415
Public awareness items	-	3,870
Publicity	-	300
Research Grant	-	1,000
Total payments	24,930	8,652
Net receipts	14,322	1,941
Balances bfd	5,726	3,785
Balances cfd	20,048	5,726
STATEMENT OF ASSETS AND LIABILITIES		
Bank balances	20,048	5,726

Aspergillosis Trust Year ended 1st April 2024

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.

ASPERGILLOSIS TRUST

England & Wales - Charity number 1194699

Accounts



Aspergillosis Trust Annual Report 2022/23

This is our 2nd annual report and is for the period February 2022 to April 2023. During this year we have lost several people who have succumbed to aspergillosis, some of whom have been friends and supporters for many years. This report is dedicated to the memory of those we have lost, and with gratitude to those who have continued to support our work to remember them.

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 co-ordinators 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. This year we have recruited one such Trustee. Aspergillosis is a complex and highly dangerous disease. In consequence, the people who work to support our day-to-day endeavours 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.

Since April 2022 we have recruited 2 new trustees.

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 co-ordinated 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

WAD is probably the most important day in our calendar. This year, our theme was Think Fungus and Be Concerned. With the help of our friends at GoodWork we designed a poster that we could edit and we invited patients in our support groups to add some text that meant something to them and also include their photo if they wanted. We produced 20 different posters in total and shared them throughout the day on our various social media platforms. GoodWork also produced a video with us which was a call to arms and we posted this on our social media platforms. It is now on youtube and has been viewed over 300 times. GoodWork boosted the video on their platform for the day which had over 18,000 views. We had over 61K tweet impressions from all our posts on twitter for WAD. We also lit up Blackpool Tower purple and featured in the local paper and on local radio. A number of our patients held fundraising activities on the day to raise both awareness and money. A granddaughter got her school to all wear something purple and she even did a talk to her class about the condition that affected her Grandma all whilst raising £163 for the charity.

Social Media

Our website (www.aspergillosistrust.org) has been live for some time now and is a valuable source of information for people trying to find out about the illness.

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 long-term patients and those who are newly diagnosed to share their knowledge and experiences. We now have 1000 members on the support group. We average around 40 posts per week.

We produced 7 information video's that we posted to our youtube channel. These cover subjects such as drug resistance, the importance of physiotherapy, introducing the charity and the most popular was a frequently asked questions that we put to Dr Anand Shah and Professor Darius Armstrong-Jones which to date has had 352 views.

In addition, we have Twitter (@aspertrust) with 2429 followers, an instagram account with 133 followers and another facebook page that relates to the charity.

Merchandising & Awareness Items

The Trust continues to produce awareness raising items such as key rings, t-shirts, etc. This year we have also added drinking bottles to our range. These provide useful additional income for us.

We completed our plan to produce patient information leaflets and a medication leaflet. We now have 6 patient information leaflets on our website that can be downloaded and printed. We also post these out to patients upon request.

Other Activities

Throughout the year, we participated in several events organised by others. This typically involves sharing links and providing information to people to support their involvement. Examples include:

- World Lung Day in September
- Fungal Disease Awareness Week in October.
- Patient Organisation Day for the ERS Congress in September.
- ELF Bronchiectasis Patient Conference in March
- Writing regular pieces for ELF Patient Roundup.
- Rare Diseases Day
- Student Voice Prize with Medics4Rare and Rare Beacon
- Approximately 30 of our patients took part in a project with the University of London, benchmarking fungal levels in housing stock.
- A number of patients are also taking part in a research study to identify which medications work best with ABPA patients

Fundraising

In September 2022 we had one runner at the Great North Run.

In October 2022 we had 3 runners at the Royal Parks Half Marathon

During the World Aspergillosis Day campaign we had a number of fundraising activities.

Fundraising Plans

In April 2023 we have 1 person running the London Marathon.

In April 2023 we have a family from Belfast running the Belfast half marathon in memory of their mum/wife, Lina Sweeney.

In September 2023 we have 15 cyclists cycling from Blackpool Tower to the Eiffel Tower to raise money for us. One of the cyclists wife suffers from the condition.

We are holding an art exhibition in September 2023 to coincide with World Lung Day. We are hoping to raise awareness of the condition and a % of the sales will be donated to the charity.

We have 5 runners secured for the Royal Parks Half Marathon in October 2023.

Finance

The Trust has once again exceeded all our targets and expectations in terms of income, which has meant that we have met many of the things we set out to achieve.

During these dates money has been received via the following:

- Legacies and in memoriam donations
- Easy Fundraising
- Fundraisers
- One off and monthly donations
- Grant from Pfizer

Grants Provided by us

- We accepted a grant application for £1000 to help Dr Kuate Marius Paulin with his study into the assessment of environmental azoles in Africa. This study is still ongoing.

Profit & Loss
Aspergillosis Trust
Accounting Year 2022/23

	Debit	Credit
Turnover		10,594
Sales		1,032
JustGiving		7,361
Amazon Europe		62
Salary Donations		460
Global Allergy & Airways Donation		503
Easy Fundraising		137
Other Income		1,038
less Cost of Sales	1,592	
Purchase of Merchandise Materials	1,376	
JustGiving Fees	216	
less Administration Expenses	7,060	
Publicity	300	
Public Awareness Items & Activities	3,870	
Research Grant	1,000	
Internet & Telephone	415	
Advertising and Promotion	637	
Postage	814	
Bank/Finance Charges	24	
Operating Profit		£1,942
less Drawings		£0
less Profit & Loss journal entries		£0
Retained Profit this period:		£1,942
Retained Profit brought forward:		£3,785
Distributable Reserves / Retained Profit carried forward:		£5,727

ASPERGILLOSIS TRUST

England & Wales - Charity number 1194699

Accounts



Aspergillosis Trust Annual Report 2021/22

This is our very first report as an independent charity. During that year we have lost several people who have succumbed to aspergillosis, some of whom have been friends and supporters for many years. This report is dedicated to the memory of those we have lost, and with gratitude to those who have continued to support our work to remember them.

About Us

The Trust is a not-for-profit charity (reg. no. 1194699). We are patient-led and at the present time all of our trustees and co-ordinators are people who suffer with aspergillosis in one of its forms. Aspergillosis is a complex and highly dangerous disease. In consequence, the people who work to support our day-to-day endeavours 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.

The Trust was originally founded in 2018. Whilst other charities existed dealing with fungal-related issues generally, none focussed specifically on aspergillosis. Initially, the sole purpose of the Trust was to raise funds to pass on elsewhere, but in early 2021 a decision was taken by the founders of the Trust, Jill Fairweather and Cliff Whitefoot to establish ourselves as an independent charity. This would enable us to have direct control over all monies raised.

Following a process of recruiting new trustees, setting up all the legally required systems and going through a complex application process, we became a charity on 7 June 2021.

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 co-ordinated 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.

Finance

To date money from the above has been:

- Legacies and in memoriam donations
- Amazon Smile
- Easy Fundraising
- Fundraisers
- Donations – these are often paid anonymously through PayPal

We also wish to place on record our enormous gratitude to our friends at Pfizer UK who generously gave us a grant of £3240. The grant paid for six Patient Information Leaflets which cover:

- ABPA (Allergic Bronchopulmonary Aspergillosis)
- CPA (Chronic Pulmonary Aspergillosis)
- IA (Invasive Aspergillosis)
- AB (Aspergillus Bronchitis)
- SAFS (Severe Asthma with Fungal Sensitivities)
- Medications (How to take and side effects)

The leaflets are all available to download through our website and social media accounts. The grant also covered a poster for World Aspergillosis Day and funding for a pin badge.

One of trustees, Bart, worked to produce three video interviews. Two were with Dr Darius Armstrong-James and a third with Dr Anand Shah. These have been very popular on our Facebook groups, and likewise are available to view and download.

World Aspergillosis Day

WAD is probably the most important day in our calendar. This year, our friends at GoodWork designed a poster depicting the Road to the Correct Diagnosis and produced a video which has been viewed over 300 times. We also set up a page for medical blogs and vlogs and clinicians wrote short blogs on the research they are undertaking.

Social Media

One of the first things we wanted to do post-registration was to revamp our website & make it easier to update with new content as it becomes available. The new site (www.aspergillosistrust.org) went live earlier this year & is a valuable source of information for people trying to find out about the illness.

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 long-term patients and those who are newly diagnosed to share their knowledge and experiences. We average around 40 posts per week. In addition, we have Twitter (@aspertrust) and other Facebook groups that relate to the organisation.

We had over 53K tweet impressions from all our posts on twitter for WAD and another 30K impressions for Rare Disease Day. The patient stories had the highest impressions. GoodWork boosted the video on our public Facebook group for the day which had a reach of 9080 views.

GAAPP also helped on the day promoting our video and poster.

Merchandising & Awareness Items

The Trust continues to produce awareness raising items such as key rings, t-shirts, etc. These provide useful additional income for us. We have produced calendars for some years now, but unfortunately this year only 29 sold of the 50 produced, so we have taken the decision not to do a calendar for 2023.

Other Activities

Throughout the year, we participated in several events organised by others. This typically involves sharing links and providing information to people to support their involvement. Examples include:

- World Lung Day in September
- Fungal Disease Awareness Week in October.
- Patient Organisation Day for the ERS Congress in August.
- Writing regular pieces for ELF Patient Roundup.
- Rare Diseases Day

Future Plans

Three places have been secured for the Royal Parks Half Marathon in October and have already been filled. We also have another another runner doing the Great North Run in September who will be raising money for us.

It was agreed that we would offer grants to support people attending the European Respiratory Society Congress in Barcelona this September. One application has been received at the time of going to press.

Finances

The Trust exceeded all our initial targets and expectations in terms of income, which has meant that we have met many of the initial things we set out to achieve.

Profit & Loss

Aspergillosis Trust

07 Jun 21 - 01 Apr 22

	Debit	Credit
Turnover		8,330
Sales		3,852
Legacies		3,935
Donations		404
Online Fundraisers		140
add Other Income		3,642
Grant Income		3,642
less Cost of Sales	896	
Purchase of Merchandise Materials	896	
less Administration Expenses	7,291	
Public Awareness Items & Activities	5,640	
Web Hosting	752	
Advertising and Promotion	378	
Legal and Professional Fees	108	
Postage	396	
Bank/Finance Charges	18	
Operating Profit		£3,785
less Drawings		£0
less Profit & Loss journal entries		£0
Retained Profit this period:		£3,785
Retained Profit brought forward:		£0
Distributable Reserves / Retained Profit carried forward:		£3,785