



# **Aspergillosis Trust**

**Charity No. 1194699**

## **Annual Report and Financial Statements**

**Year Ended 1<sup>st</sup> April 2024**

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#### **Reference and administrative details**

Trustees	Lisa McNeil Katie Martin Sharon Gordon Jacqueline Ann Locker Bart Jozef Mariette Govaert (resigned in the year)
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
Independent Examiner	M R Heaton FCCA FCIE DchA KM Chartered Accountants 1 <sup>st</sup> Floor, Block C The Wharf Manchester Road Burnley BB11 1JG

## **Trustees Annual Report**

This is our 3<sup>rd</sup> annual report and is for the period 2<sup>nd</sup> April 2023 to 1<sup>st</sup> 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 7<sup>th</sup> 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 – 1<sup>st</sup> 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 – 25<sup>th</sup> 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](http://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 1<sup>st</sup> 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 7<sup>th</sup> 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 1<sup>st</sup> 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  
1<sup>st</sup> Floor, Block C,  
The Wharf  
Burnley  
Lancashire  
BB11 1JG

**29<sup>th</sup> January 2025**

## RECEIPTS AND PAYMENTS ACCOUNT

All funds are unrestricted

	Year ended <b>1.4.24</b> £	Year ended <b>1.4..23</b> £
<b><u>Receipts</u></b>		
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	<b>39,252</b>	<b>10,593</b>
<b><u>Payments</u></b>		
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	<b>24,930</b>	<b>8,652</b>
Net receipts	<b>14,322</b>	<b>1,941</b>
Balances bfd	<b>5,726</b>	<b>3,785</b>
Balances cfd	<b>20,048</b>	<b>5,726</b>
<b>STATEMENT OF ASSETS AND LIABILITIES</b>		
Bank balances	<b>20,048</b>	<b>5,726</b>



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.