



## **Aspergillosis Trust Annual Report 2022/23**

This is our 2<sup>nd</sup> 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 – 1<sup>st</sup> 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](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 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

	<b>Debit</b>	<b>Credit</b>
<b>Turnover</b>		<b>10,594</b>
Sales		1,032
JustGiving		7,361
Amazon Europe		62
Salary Donations		460
Global Allergy & Airways Donation		503
Easy Fundraising		137
Other Income		1,038
<b>less Cost of Sales</b>	<b>1,592</b>	
Purchase of Merchandise Materials	1,376	
JustGiving Fees	216	
<b>less Administration Expenses</b>	<b>7,060</b>	
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	
<b>Operating Profit</b>		<b>£1,942</b>
<b>less Drawings</b>		<b>£0</b>
<b>less Profit &amp; Loss journal entries</b>		<b>£0</b>
<b>Retained Profit this period:</b>		<b>£1,942</b>
<b>Retained Profit brought forward:</b>		<b>£3,785</b>
<b>Distributable Reserves / Retained Profit carried forward:</b>		<b>£5,727</b>