



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.

