

| Trustees' Annual Report for the period |                   |       |      |    |                 |       |
|--|-------------------|-------|------|----|-----------------|-------|
| From                                   | Period start date |       |      | To | Period end date |       |
|  | 01st              | April | 2023 |    | 31              | March |

## Section A Reference and administration details

|   |   |
|---|---|
| <b>Charity name</b>                       | Alpha-1 UK Support Group                    |
| <b>Other names charity is known by</b>    | Alpha-1 UK (since 1997)<br>Alpha-1 Alliance |
| <b>Registered charity number (if any)</b> | 1146330                                     |
| <b>Charity's principal address</b>        | 24 Pelham Road                              |
|   | Droitwich                                   |
|   | Worcestershire                              |
| <b>Postcode</b>                           | WR9 8NT                                     |

### Names of the charity trustees who manage the charity

|    | Trustee name           | Office (if any)                        | Dates acted if not for whole year | Name of person (or body) entitled to appoint trustee (if any) |
|----|------------------------|--|-----------------------------------|---|
| 1  | Karen O'Hara           | Chairman / Treasurer                   |                                   | Alpha-1 UK Support Group                                      |
| 2  | Beverley Burroughs     | Secretary                              |                                   | Alpha-1 UK Support Group                                      |
| 3  | Dr Sandra Nestler-Parr | Strategy and External Relations        |                                   | Alpha-1 UK Support Group                                      |
| 4  | Jemma Coad             | Parent Support                         |                                   | Alpha-1 UK Support Group                                      |
| 5  | Tanya Jones            | Social Media / Data Protection Officer |                                   | Alpha-1 UK Support Group                                      |
| 6  |                        |  |                                   |   |
| 7  |                        |  |                                   |   |
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| 22 |                        |  |                                   |   |

**Names of the trustees for the charity, if any, (for example, any custodian trustees)**

| Name | Dates acted if not for whole year |
|------|-----------------------------------|
|      |                                   |
|      |                                   |
|      |                                   |

**Names and addresses of advisers (Optional information)**

| Type of adviser | Name | Address |
|-----------------|------|---------|
|                 |      |         |
|                 |      |         |
|                 |      |         |
|                 |      |         |

**Name of chief executive or names of senior staff members (Optional information)**

|  |
|--|
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## Section B Structure, governance and management

**Description of the charity's trusts**

|   |  |
|---|--|
| Type of governing document<br>(eg. trust deed, constitution)        | Constitution adopted 16 <sup>th</sup> February 2012 / Amended 24 <sup>th</sup> September 2017<br>Registered Charity Scotland SC043177 23 May 2012.<br>Previously small charity registered with HMRC 19 <sup>th</sup> March 2010<br>Reference XT23971 |
| How the charity is constituted<br>(eg. trust, association, company) | Association  |
| Trustee selection methods<br>(eg. appointed by, elected by)         | Trustees are appointed/re-appointed annually by members using<br>electronic poll voting.   |

**Additional governance issues (Optional information)**

You **may choose** to include additional information, where relevant, about:

- policies and procedures adopted for the induction and training of trustees;
- the charity's organisational structure and any wider network with which the charity works;
- relationship with any related parties;
- trustees' consideration of major risks and the system and procedures to manage them.

All trustees give their time voluntarily and receive no remuneration or other benefits.

## Section C

## Objectives and activities

### Summary of the objects of the charity set out in its governing document

To relieve the needs of individuals suffering from the genetic condition Alpha-1 Antitrypsin Deficiency their families, carers and friends, in particular but not exclusively by:-

- A) Providing advice, practical support, communication and equipment with a view to improving the quality of life of those suffering with the condition, their families, carers and friends, and
- B) Advancing awareness and knowledge of AATD, in particular among affected patients, medical professionals, and healthcare providers including information relating to genetic implications, treatment and lifestyle choices.

### Summary of the main activities undertaken for the public benefit in relation to these objects (include within this section the statutory declaration that trustees have had regard to the guidance issued by the Charity Commission on public benefit)

In planning our activities for the year we the Trustees acknowledged the Charity Commission guidance on public benefit and the focus of our activities are as follows:-

- Providing support and education for patients, families, carers and friends who are affected directly or indirectly by Alpha-1 Antitrypsin Deficiency.
- Growing a social network for patients, by providing a website and discussion group focusing on news, events, information which benefits patients how better to cope with Alpha-1 Antitrypsin Deficiency aiming towards improving quality of life.
- Informing and educating the medical community and general public through producing, publishing and distributing information booklets to advance the understanding and awareness of alpha-1 antitrypsin deficiency genetic lung, liver and skin disease.
- Organising annual social gatherings to educate and unite the Alpha-1 community.
- Profiling the burden of unmet needs of patients in the UK amongst relevant stakeholders. Actively engaging with healthcare professionals, NHS decision makers and politicians.
- Actively supporting the establishment of a nationally commission highly specialised service for Alpha-1 to ensure equal access for patients to optimal integrated clinical care.
- Supporting research initiatives.

### Additional details of objectives and activities (Optional information)

You **may choose** to include further statements, where relevant, about:

- policy on grantmaking;
- policy programme related investment;
- contribution made by volunteers.

A great contribution is made by our members, families, carers and friends in supporting and advising newly diagnosed members through our Social Network Group for which we are very grateful. Without this valuable contribution of time, energy and expertise we would not have been able to achieve so much.

Member's financial donations and fundraising events throughout the year continue for which we are very grateful, as it is a crucial part of the success of the charity.

Any surplus funds which are not likely to be needed to pay for activities and promotional material are placed on deposit to earn interest.

## Section D

## Achievements and performance

### Summary of the main achievements of the charity during the year

We have continued throughout the year to raise the profile of the unmet medical needs of Alpha-1 patients in the UK and the wider alpha-1 community in Europe. Our campaign for the establishment of nationally commissioned highly specialised services and treatment for Alpha-1 and to ensure equal access for patients to optimal integrated clinical care for this complex condition is ongoing.

Many of our members continued to be cautious of attending large events due to the risk of COVID. Many meetings and events were still conducted virtually via Zoom or Teams platforms. However, we are delighted that we were able to host our first face-to-face Annual Social Gathering & Information Day in September 2023 although attendance was reduced due to the risk to our most vulnerable members of COVID.

### Achievements and Performance included

- Chair attended EARCO Steering Committee Virtual meetings throughout the year. EARCO is a pan-European network committed to promoting clinical research and education in alpha-1 antitrypsin deficiency (AATD). EARCO have also commenced work on a long awaited and much needed AATD clinical guideline.
- Monthly meeting of European Patient Group leaders continued throughout the reporting period. The Core Team, of which our Chair is a member, conducted a survey of European AATD associations. Work subsequently commenced on establishing an official European organisation. In January 2023 a “co-ordinator” was employed and Working Groups were established and commenced activities. Meetings with pharma and relevant stakeholders conducted throughout the reporting period.
- October 2023 – Alpha-1 Europe Alliance asbl formally established in Belgium giving a united and collective voice representing the national organisations of individuals living with Alpha-1 Antitrypsin Deficiency across Europe. Our Chair is also on the Board.
- Chair attended various ERN-LUNG and associated ePAG virtual meetings throughout the reporting period. Chair also joined the ERN-LUNG Function Committee “Patient Recorded Outcomes and Quality of Life”
- Weekly Pulmonary Rehabilitation classes continued throughout the reporting period, led by a qualified instructor. The classes are self-funding with attendees paying a nominal fee weekly fee
- Trustees continued work on rebranding of charity to include website redesign, new merchandise & information materials and other resources
- April 2023 – Trustees attended Alpha-1 Patient & Research

## Section D

## Achievements and performance

conferences in Dublin

- April 2023 – Trustee attended Alpha-1 Alliance meeting in Dublin
- September 2023 – hosted our first post COVID face to face conference. Partial launch of the new charity branding via new merchandise and graphics.
- November 2023 –social media awareness campaign comprising of daily posts related to AATD
- Trustees attended various virtual meetings and AATD related conferences
- Throughout the year our Trustees attended several meetings with pharmaceutical/biotech companies that undertake clinical research in AATD

### General Achievements and Performance throughout the year

- Facebook Membership continues to increase worldwide with membership increased from 4183 to 4470
- Twitter Followers increased from 511 to 534
- Linked-In Account created in November 2023
- Instagram account created in August 2022 – 204 followers
- Provided equipment and grants to members to improve day to day living and quality of life.
- Continue to increase awareness through Brochures/Posters/Flyers Social Networking Sites/Fundraising Events and inclusion of our website link wherever possible on medical and related websites.
- Continued to offer support and advice through Social Networking Sites
- Supported Fundraising events throughout the year.

## Section E

## Financial review

### Brief statement of the charity's policy on reserves

We hold total cash funds at bank of £250,301  
Of which £122,216 is currently invested with immediate access  
£59,995 is reserved for Alpha-1 Alliance campaign activities.

### Details of any funds materially in deficit

Not Applicable

### Further financial review details (Optional information)

You **may choose** to include additional information, where relevant about:

- the charity's principal sources of funds (including any fundraising);
- how expenditure has supported the key objectives of the charity;
- investment policy and objectives including any ethical investment policy adopted.

We received donations from the pharmaceutical industry this year in support of our annual meeting and rebranding activities, expenditure on the rebranding activities is ongoing into the next reporting period as we redesign our website and information materials and other resources. We will continue to rely upon our historic main source of funding from private donations, fundraising events and the bonus ball syndicate. We rely on the Alpha community and the medical profession for their continuing support for which we are very grateful.

## Section F Other optional information

## Section G Declaration

The trustees declare that they have approved the trustees' report above.

Signed on behalf of the charity's trustees

Signature(s)

*Karen O'Hara*

*Tanya Jones*

Full name(s)

Karen O'Hara

Tanya Jones

Position (eg Secretary, Chair, etc)

Chairman/Trustee

Date

6<sup>th</sup> December 2024

6<sup>th</sup> December 2024



# Alpha-1 UK Support Group

## Financial Statements for the Year ended

### 31 March 2024

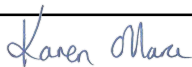
Alpha-1 UK Support Group  
Statement of Financial Position  
31 March 2024


|   | 31 Mar 2024       | 31 Mar 2023       |
|---|-------------------|-------------------|
|   | £                 | £                 |
| <b>Fixed Assets</b>                               |                   |                   |
| Office Equipment                                  | 793.00            | 793.00            |
| Less Accumulated Depreciation on Office Equipment | (463.00)          |                   |
| <b>Total Assets</b>                               | <b>330.00</b>     | <b>793.00</b>     |
| <b>Current Assets</b>                             |                   |                   |
| <b>Cash at bank and in hand</b>                   |                   |                   |
| Alpha-1 UK Support Group - Treasurers Account     | 121,053.00        | 97,630.00         |
| Alpha-1 UK Support Group - Savings Account        | 122,216.00        | 120,928.00        |
| Co-Op   | 1.00              | 0.00              |
| PayPal  | 7,031.00          | 6,843.00          |
| <b>Total Cash at bank and in hand</b>             | <b>250,301.00</b> | <b>225,401.00</b> |
| Accounts Receivable                               | 640.00            | 0.00              |
| <b>Total Current Assets</b>                       | <b>250,941.00</b> | <b>225,401.00</b> |
| <b>Creditors</b>                                  |                   |                   |
| Accounts Payable                                  | 100.00            | 0.00              |
| Alpha-1 Alliance Activities                       | 59,995.00         | 59,995.00         |
| <b>Total Creditors</b>                            | <b>60,095.00</b>  | <b>59,995.00</b>  |
| <b>Net Current Assets</b>                         | <b>190,846.00</b> | <b>165,406.00</b> |
| <b>Net Assets</b>                                 | <b>191,176.00</b> | <b>166,199.00</b> |
| <b>Capital and Reserves</b>                       |                   |                   |
| Current Year Earnings                             | 25,290.00         | 16,264.00         |
| Retained Earnings                                 | 165,886.00        | 149,935.00        |
| <b>Total Capital and Reserves</b>                 | <b>191,176.00</b> | <b>166,199.00</b> |

**Alpha-1 UK Support Group**  
**Income Statement**  
For the year from 1 April 2023 to 31 March 2024

|   | <b>2024</b>      | <b>2023</b>      |
|---|------------------|------------------|
|   | £                | £                |
| <b>Receipts</b>                                     |                  |                  |
| Bonus Ball Subs                                     | 2,826.00         | 2,397.00         |
| Donations/Fundraising Donations                     | 5,170.00         | 4,132.00         |
| Income from PR & Yoga                               | 2,062.00         | 0.00             |
| Income from Social/Fundraising Events               | 0.00             | 1,195.00         |
| Interest Income                                     | 1,288.00         | 0.00             |
| Revenue from sales (badges, promo goods, cards etc) | 174.00           | 18.00            |
| JustGiving/Easyssearch/Easyfundraising              | 6,482.00         | 11,274.00        |
| Pharma Income/Donations                             | 20,683.00        | 0.00             |
| <b>Total Receipts</b>                               | <b>38,685.00</b> | <b>19,016.00</b> |
| <b>Expenditure</b>                                  |                  |                  |
| Annual Meeting                                      | 7,001.00         | 0.00             |
| Bonus Ball Winnings                                 | 820.00           | 631.00           |
| Donations/grants                                    | 0.00             | 400.00           |
| Expenditure for PR & Yoga                           | 1,125.00         | 0.00             |
| Expenditure for social events                       | 0.00             | 1,391.00         |
| Fundraising Expenditure                             | 300.00           | 339.00           |
| Membership Fees                                     | 50.00            | 0.00             |
| Bank Fees   | 0.00             | 0.00             |
| Depreciation Expense                                | 159.00           | 0.00             |
| General Expenses                                    | 832.00           | 0.00             |
| Gifts , Flowers and Cards                           | 100.00           | 206.00           |
| IT Software and Consumables                         | 2,426.00         | 0.00             |
| Office supplies                                     | 254.00           | 123.00           |
| Travel - National                                   | 328.00           | 0.00             |
| <b>Total Expenditure</b>                            | <b>13,395.00</b> | <b>3,090.00</b>  |
| <b>Profit for the year</b>                          | <b>25,290.00</b> | <b>15,926.00</b> |

Signed by two trustees on behalf of all the trustees

|   |               |
|---|---------------|
|  | Signature 1   |
| 6 December 2024   | Date Approved |
| Karen O'Hara  | Print Name    |

|   |               |
|---|---------------|
|  | Signature 2   |
| 6 December 2024   | Date Approved |
| Tanya Jones   | Print Name    |



# Independent Examiner's Report on the Accounts

## Section A

## Independent Examiner's Report

Report to the trustees/members of

Charity Name

Alpha-1 UK Support Group.

On accounts for the year ended

3 1 0 3 2 4

Charity no (if any)

1 1 4 6 3 3 0

Set out on pages

(remember to include the page numbers of additional sheets)

### Respective responsibilities of trustees and examiner

The charity's trustees are responsible for the preparation of the accounts. The charity's trustees consider that an audit is not required for this year under section 144 of the Charities Act 2011 (the Charities Act) and that an independent examination is needed.

It is my responsibility to:

- examine the accounts under section 145 of the Charities Act,
- to follow the procedures laid down in the general Directions given by the Charity Commission (under section 145(5)(b) of the Charities Act), and
- to state whether particular matters have come to my attention.

### Basis of independent examiner's statement

My examination was carried out in accordance with general Directions given by the Charity Commission. An examination includes a review of the accounting records kept by the charity and a comparison of the accounts presented with those records. It also includes consideration of any unusual items or disclosures in the accounts, and seeking explanations from the trustees concerning any such matters. The procedures undertaken do not provide all the evidence that would be required in an audit, and consequently no opinion is given as to whether the accounts present a 'true and fair' view and the report is limited to those matters set out in the statement below.

### Independent examiner's statement

In connection with my examination, no matter has come to my attention ~~(other than that disclosed below)~~:

(1) which gives me reasonable cause to believe that in, any material respect, the requirements:

- to keep accounting records in accordance with section 130 of the Charities Act;
- to prepare accounts which accord with the accounting records and comply with the accounting requirements of the Charities Act have not been met; or

(2) to which, in my opinion, attention should be drawn in order to enable a proper understanding of the accounts to be reached.

\* Please delete the words in the brackets if they do not apply.

Signed

M. A. Woolfen

Date

13/12/2024

Name

MICHELLE WOOLLEN

Relevant professional qualification(s) or body (if any)

FCCA

Address

Gladstones

Selby Rd.

Wistow.

Selby, N. Yorkshire, YO8 3UT