

ACHALASIA ACTION

Annual Report 2022-23

(Covering period 1 April 2022 – 31 March 2023)

40 Orpington Road,
Winchmore Hill,
London N21 3PG

Helpline: 0300 772 7795

www.achalasia-action.org
Reg Charity no 1187367

Uniting for a rare swallowing condition

A

Trustees

Alan Moss
Chair

Majid Hashemi FRCS
Medical Chair

Amanda Ladell
Patient Support Co-ordinator

Andrew Williams
Treasurer until October 2022

Neil Ham
Webmaster

Silvia Davey
Fundraising & Database

Gavin Nash
Helpline Administrator

Jayne Fitzgerald
Secretary & Interim Treasurer
from October 2022

B

Structure, Governance and Management

Our structure, governance and management arrangements remain unchanged having adopted a foundation model constitution of a Charitable Incorporated Organisation on our registration as a charity on 14 January 2020 (number 1187367 in England & Wales). We are the only UK-registered charity specialising in achalasia. We have no paid employees or advisors, and do not occupy dedicated premises.

We were pleased to appoint Professor Anthony Hobson MPhil PhD and Dr Ahmed Albusoda MD PhD as medical advisors and were grateful for the services of Dr Mark Fellows BMedSci (Hons) BM MRCP MRCGP to bring some GP experience to our panel until he had to resign owing to pressure of work and other commitments.

C

Objectives and Activities

Our charitable aims remain unchanged, and include:

- To advance education about achalasia and associated conditions
- To preserve and protect the health of people with achalasia, including their friends and families, and
- To encourage and support research into achalasia.

D

Achievements and Performance

Support

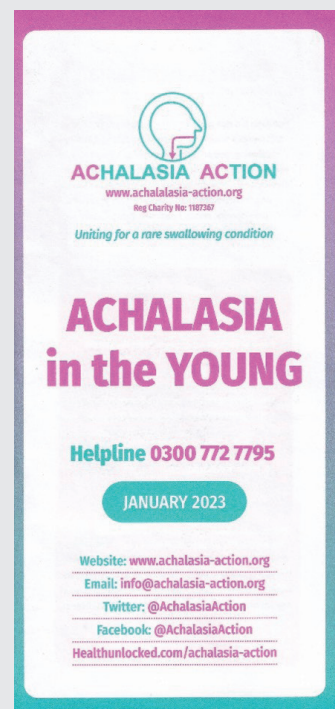
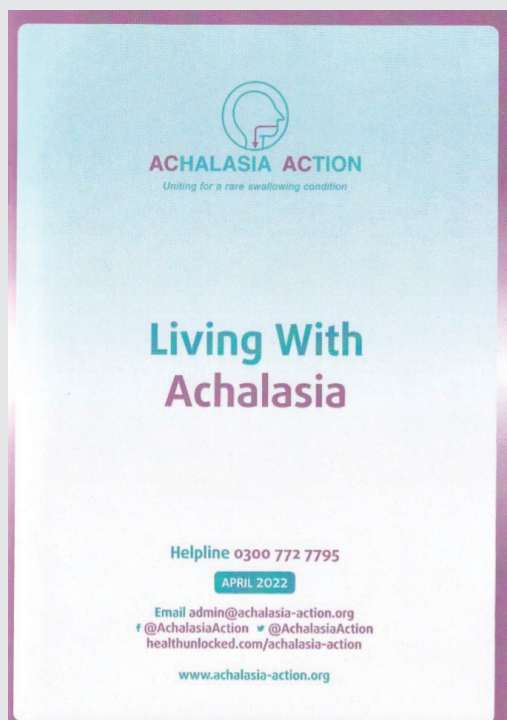
We published a booklet *Living with Achalasia* that contains information on many different aspects of this condition such as food that people find problematic, dietary issues, helpful hints, painful spasms and medication.

This is a companion booklet for our *Achalasia Explained*.

We also produced a leaflet *Achalasia in the Young* for the benefit of those being treated at children's hospitals and attended the conference of BSPGHAN (British Society of Paediatric Gastroenterology Hepatology and Nutrition).

We ran two larger-scale online support meetings in June and November, both of whom attracted an attendance of 65-70 people. Our smaller Meet Ups continued on a monthly basis, again online, and our creative writing group also continued.

We made much progress on planning a reorganisation of our website www.achalasia-action.org and aim to be publishing the new version in mid-2023. The new website will be organised so that we regularly update it with the information and helpful tips that are generated in our patient support meetings.



Research

We held a number of research planning meetings.

Currently we are pleased to see a literature review being conducted by Stefan Antonowicz and Solange Bramer from Imperial College.

We hope to initiate a more comprehensive survey into the experience of people suffering spasms related to achalasia, and a comparative study into medical treatment for these spasms, something very much related to the priorities set by those suffering from achalasia.

The patient experience workbook project by Melika Kalantari has proved to be a valuable exercise in providing insights into the daily lives of those with achalasia.

The I-PASS study being led by Professor Giovanni Zaninotto aims to track the treatment pathways and experiences of achalasia patients. There is a pressing need for better, more standardised approaches to treatment pathways.

We have also helped with the OPERA (Outcomes in Paediatric Achalasia) study being run by the Paediatric Surgery Trainee Research Network (PSTRN).

ERNICA is a Europe-based study that initially is concentrating on the experiences of children with achalasia.

Information:

We have circulated a briefing note about achalasia to a number of politicians. The Government's initiative on Rare Conditions has emphasised the problems of timely diagnosis and suitable research activity that

is shared amongst many of these conditions including achalasia. The criterion for being qualified for this policy is 1-in-2,000, a benchmark that achalasia meets by virtue of about 1-in-100,000 being diagnosed annually and a prevalence of about 1 in 10,000.

We attended a meeting of the All Party Parliamentary Group on Health in March 2023 to discuss the Government's initiative on Major Conditions, and made our representations that chronic, lifelong conditions such as achalasia can be a significant drain on NHS resources needing higher priority, especially when there is no outright cure for the disease.



Alan Moss and Majid Hashemi at Parliament

	Notes	Unrestricted £	Restricted £	Total £
Income:				
Donations	1	4,410.15	0.00	4,410.15
Interest		62.70		62.70
Total		4,472.85	0.00	4,472.85
Expenses:				
Repayment of Trustee loans	2	600.00		600.00
Website Development	3		5,220.00	5,220.00
Conference fees	4	78.00		78.00
Helpline	5	74.28		74.28
Meeting Expenses	6	143.88		143.88
Printing	7	405.83		405.83
Publications	8	48.59	401.41	450.00
Merchandise	9	274.80		274.80
Postage & Packaging		179.99		179.99
Insurance		212.80		212.80
Bank charges		72.00		72.00
Information Commissioner fees		40.00		40.00
Total		2,130.17	5,621.41	7,751.58
Net Surplus / (Deficit)		2,342.68	(5,621.41)	(3,278.73)
Opening Balance 1st Apr 2022		9,018.21	5,621.41	14,639.62
Cash Movement		2,342.68	(5,621.41)	(3,278.73)
Closing Balance 31st March 2023		11,360.89	0.00	11,360.89

Bank Balances as at 31 March 2023:

	Total £
CAF Gold Account	8,895.63
CAF Cash Account	2,465.26
Total	11,360.89

Notes to Accounts

1. Donations include individual fundraising initiatives and money received from online platforms that also collect gift aid on the charity's behalf.
2. All trustee loans, which were made on the instigation of the charity, were repaid during 2022/23.
3. Payment for the development of a new website during 2022/23. Website will be launched in Summer 2023.
4. Attendance at BSPGHAN conference.
5. The helpline is currently staffed by volunteers with costs limited to payment for telecom.
6. Zoom fees for the Meetup patient meetings which have been held on Zoom since the Covid pandemic.
7. Printing of information booklets and leaflets including two new booklets "Living with Achalasia" and "Children with Achalasia".
8. Graphic Design fees for new booklets.
9. Purchase of items used for fundraising and events including T-shirts, running vests, and tablecloth.

There were no items of income or expenditure outside the United Kingdom.

All financial transactions have taken place through the regulated banking system. The Trustees are satisfied that the Treasurer has established and kept under review the financial controls and systems appropriate for the size of the Charitable Incorporated Organisation we represent.

No Trustee has received any payment other than reimbursement for proper expenses duly authorised by at least two signatories.

We are most grateful for the fundraising efforts and donations made by so many people to support our charity. As examples of the range of contributions we have received, George Collet ran the Worthing Half Marathon on behalf of his sister, Hayley Woolley organised an awareness week at the premises of Curry's in Mansfield, and we received many donations in memory of Vivien Walker.

Authorised:



Jayne Fitzgerald
Treasurer



Alan Moss
Chair



The display at Curry's Mansfield for achalasia awareness week

F

Other Optional Information

As a charity we are always grateful to receive feedback from those we have helped. After a recent meeting, we had the following comments:

Rosie: Brilliant first meeting for me. Thank you.

Merle: Extremely informative session. Thank you Majid and James for your time.

Clare: Thank you so much. This has been massively informative and interesting

Corine: ...I am so grateful for all I have been able to learn from the wealth of knowledge shared tonight

G

Declaration

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

Signed, on behalf of the charity's trustees:

Signed:

Alan moss
Chair
21 June 2023



Section A

Independent Examiner's Report

**Report to the trustees/
members of**

Charity Name
Achalasia Action

**On accounts for the year
ended**

31/03/2023

**Charity no
(if any)**

1187367

Set out on pages

5 and 6

I report to the trustees on my examination of the accounts of the above charity ("the Trust") for the year ended 31/03/2023.

**Responsibilities and
basis of report**

As the charity trustees of the Trust, 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 Trust's accounts carried out under section 145 of the 2011 Act and in carrying out my examination, I have followed 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 material matters have come to my attention (other than that disclosed below *) in connection with the examination which gives me cause to believe that in, any material respect:

- accounting records were not kept in accordance with section 130 of the Act or
- the accounts do not accord with the accounting records

I have no concerns and have come across no other matters in connection with the examination to which 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:

H. Mustafa

Date:

31/3/2023

Name:

Hasan Mustafa

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

Institute of Internal Auditors

Address:

114 Gallants Farm Road

East Barnet

Herts EN4 8EP