

ACHALASIA ACTION

Annual Report 2023-24

(Covering period 1 April 2023 – 31 March 2024)

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

Trustees

Silvia Davey

Chair from December 2023,
Trustee

Alan Moss

Chair until December 2023, Trustee

Majid Hashemi FRCS

Medical Chair, Trustee

Jayne Fitzgerald

Trustee, Secretary and Treasurer

Amanda Ladell

Trustee, Head of Patient Support

Neil Ham

Trustee

Gavin Nash

Trustee

Andrew Williams

Trustee

[Alan Moss was Chair until December 2023, and Silvia Davey took on the role of Chair from December 2023.](#)

As incoming Chair, Silvia shared the message below to Achalasia Action's supporters:

"Our founding Chair, Alan Moss, has had to step down due to unforeseen personal circumstances. I'd like to take this opportunity to thank him for his tireless work over the past four years in setting up and growing Achalasia Action, and in leading us with great diligence, compassion and integrity. As a volunteer-led charity without paid staff, Alan has spent countless hours completing a whole range of governance, operational and administrative tasks. We would not be where we are as a charity were it not for Alan's leadership and expertise.

As Achalasia Action's newly appointed Chair, I have very big shoes to fill. But I am committed to rising to the task. I developed achalasia in my late teens and have lived with the condition for many years. I know how painful it is to have food stuck in my oesophagus that just won't go down, or worse, to be woken up by unbearable chest spasms. I also remember how being misdiagnosed by GPs and experiencing difficulties in accessing the right care and information made me feel unheard and misunderstood.

But I also know how life-changing it is to be surrounded by a supportive community of people who are ready to share their achalasia stories alongside helpful information, tips and tricks. My personal experience of living with this rare condition inspires me to continue strengthening and growing Achalasia Action's activities, ensuring we continue supporting and positively impacting the lives of all those affected by achalasia."

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Volunteers

Achalasia Action has no paid staff and relies entirely on the hard work and dedication of volunteers.

We would like to thank the kindness of our volunteers this year, for everything they have done to make Achalasia Action's services and activities possible. In particular we'd like to thank:

Christine Hollywood

Patient Support (Writing Group)

Jack Eddy

Head of Policy and Campaigning

James Fitzgerald

Fundraising Support

Kelly Andrews

Patient Support
(Parents of Children with Achalasia)

Lewis Dickinson

Patient Support
(Young People with Achalasia)

We have also recently recruited a social media team consisting of Annie-Rose Tate and Ian Tuddenham.

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Medical Advisors

We would also like to thank the kindness of our collaborators from the healthcare profession, who have supported us in our specialist meetings over the past year, and who have helped deliver key achalasia research.

In particular, we'd like to thank our Medical advisory board:

Sacheen Kumar

Consultant in upper
gastrointestinal (GI) surgery

Anthony Hobson

Consultant GI clinical scientist

Ahmed Albusoda

Gastroenterologist

Melika Kalantari

Pharmacist and achalasia researcher

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Structure, Governance and Management

Achalasia Action's 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.

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Objectives and Activities

Achalasia Action's charitable objectives 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.
- To encourage and support research into achalasia.

To achieve these objectives, our activities include:

- **Support:** providing a friendly and well-informed community, education and guidance to support those with achalasia and their loved ones.
- **Inform:** raising awareness of the disease amongst patients, their families, the medical profession, policymakers and the wider public.
- **Research:** collaborating with the medical community and encouraging achalasia-related research.

Achievements and Performance

Achalasia Action's activities fall under three core pillars: support, inform and research. In the past year, we have achieved several big milestones under each pillar.

Support

Achalasia Action website

Our new Achalasia Action website was launched in August 2023. You can see our new and upgraded look here:

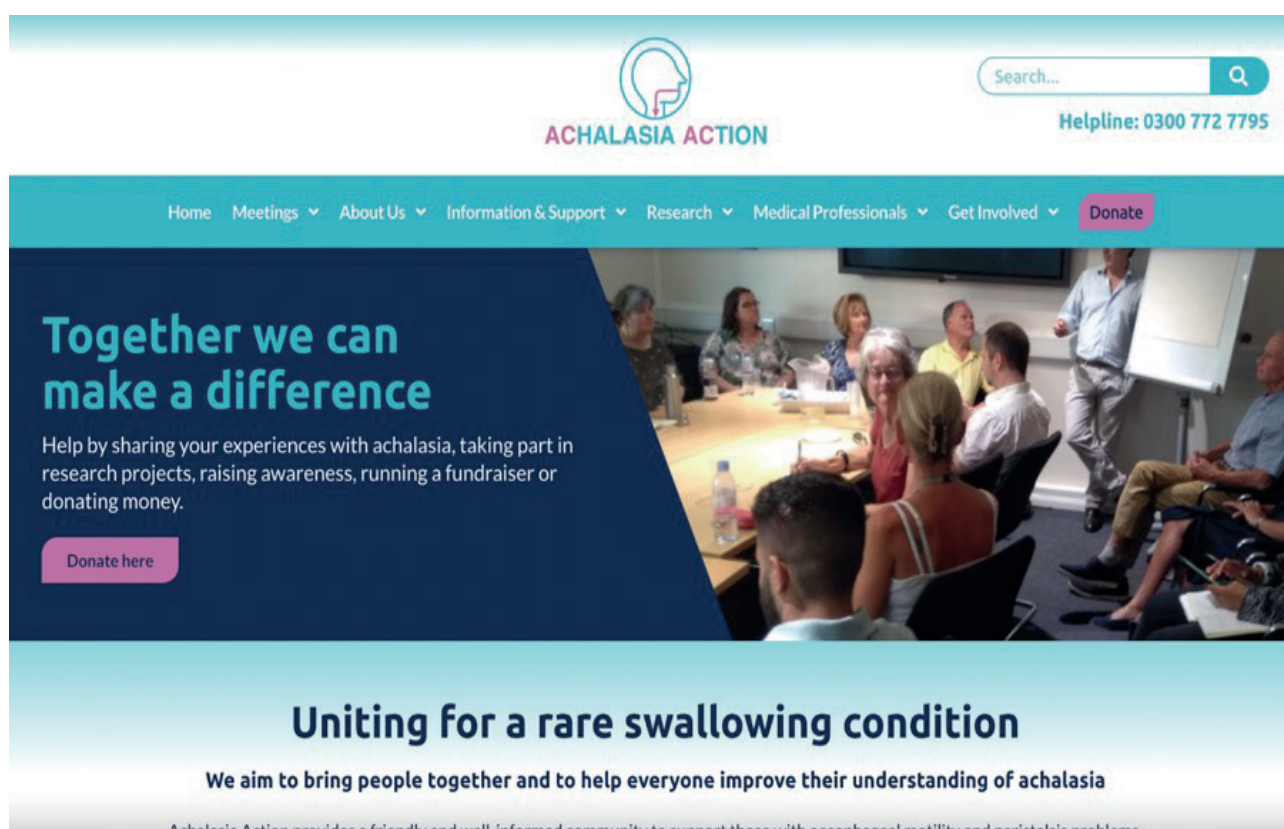
achalasia-action.org.

Our aim for the website was to ensure that our patient support information could be

easily accessed and navigated by patients and their loved ones, and to bring together in one place information on patient support meetings.

The website includes all the information that is in our booklets *Achalasia Explained* and *Living with Achalasia*, but we still provide paper copies of these booklets to those who do not have internet access. Our website is widely viewed as a reliable and credible information source on achalasia; for example, the NHS page on z links directly to our website.

Since our website was launched, it has been accessed by 17,283 new users.



New Achalasia Action website homepage

Patient support meetings

We also continue providing our core support services, including patient support meetings, patient meetings with healthcare specialists, and individual support sessions via email or the phone. The number of people we support continues to grow.

For example, in the past year:

We held two patient meetings with healthcare specialists, attended by 150 people:

- May 2023 - Keeping your Oesophagus as Healthy as Possible
- November 2023 - Achalasia Research Priorities and Patient Q&A

We held the following support meetings:

- 13x monthly support meetings attended by a total of 180 people
- 7x meetings for parents of children with achalasia attended by a total of 48 people
- 8x Writing Group meetings attended by a total of 47
- 2x Young People (18-35) with achalasia meeting attended by a total of 8 people

60 new people with achalasia have contacted us this year for help, either through our website, our helpline, or email.

In total, we have directly supported 342 people with achalasia; to put our reach into context, that equals approximately 5% of all people diagnosed with achalasia in the UK.

Other support services

We also held several small online meetings for people with specific achalasia problems and experiences who want to talk to others in a similar situation, or prefer a one-to-one or one-to-two meeting.

We also continue to provide information and support to people with achalasia on our social media platforms including Facebook and our recently launched Instagram page. For example, we regularly monitor and provide support on the Achalasia Action Facebook Group, which has grown by over 200 members in the past year, to a total of 715 members.

Inform

Rare Disease Day campaign

Achalasia Action was founded through the support groups that we continue to organise today. Those with achalasia can often experience feelings of isolation, frustration and discouragement when interacting with acquaintances, medical professionals, and even friends and family. We believe that sharing stories and experiences can be a powerful remedy to these problems, and a way to build confidence, wellbeing and knowledge.

We launched our “Shine a light on achalasia” campaign in February 2024, to raise awareness of achalasia and to offer support and community to patients with achalasia in the UK and around the world. Our objective was to build contact and momentum in the run up to Rare Disease Day, to maximise exposure and awareness.

We published and shared nine stories of people with achalasia and their loved ones, which you can read on our website: achalasia-action.org/news-and-blog/.

The stories focused on the impact that finding support, community and understanding had on people with achalasia.

These stories were widely read and shared, including by snooker player Ronnie O’Sullivan and actor Annie-Rose Tate. The stories also helped many people with achalasia feel less alone. For example, one person with achalasia commented: “Thank you for sharing your stories and informing people about the disease! This is really helpful”.



Nine achalasia stories for our Rare Disease Campaign.

Attendance at the British Society of Paediatric Gastroenterology, Hepatology and Nutrition

Continuing our efforts to raise awareness of achalasia amongst medical professionals, our trustee Amanda and volunteer Kelly attended the British Society of Paediatric Gastroenterology, Hepatology and Nutrition (BSPGHAN) 2024 meeting in Bristol.

The meeting gave them a great opportunity to meet many paediatric gastroenterologists and to distribute Achalasia Action literature, as well as information about the Achalasia Action website. Attendees were very interested to hear more about achalasia, especially from the perspective of living with the condition and the problems encountered by patients. After talking to us, one trainee is now very interested in making achalasia a specialism of his!



Kelly at BSPGHAN 2024

Achalasia Action's Prospective Parliamentary Candidates Campaign

The quality of care that people with achalasia receive is often very poor, with high rates of misdiagnoses, late intervention and inadequate aftercare. We believe that representation within the health system requires increased awareness and activity among policymakers. We are keen to raise the profile of achalasia amongst politicians, to ensure that people with achalasia are included in conversations and decisions on the future of the health and care system.

To achieve this, we have been targeting prospective parliamentary candidates (PPCs) in the run up to the General Election. This has involved providing a briefing, introducing the disease to PPCs, as well as highlighting issues experienced by people with achalasia and key asks for Parliament.

Research

Achalasia Action has helped support several research projects over the past year, by shaping the research focus and providing a network of people with achalasia who were willing to take part in the research. Below are two research projects which we supported in the past year.

Dr Kalantari's research on achalasia

We would like to congratulate Melika Kalantari on completing her PhD research project focused on understanding people's experiences of living with achalasia. Our medical chair Majid Hashemi was one of Melika's supervisors, and has noted that it is a rare achievement for a doctorate to focus solely on achalasia. Achalasia Action especially welcomes Melika's research, which directly helps people with achalasia to live better lives.

Achalasia Action supported Melika to recruit volunteers for her research project, and helped her shape the project. The project aimed to understand the most difficult eating behaviour for people living with achalasia and co-design a workbook to help people with achalasia when eating in a social or unfamiliar setting.

You can read a publication on the research project here:

<https://www.frontiersin.org/articles/10.3389/fmed.2024.1216209/full>

Management of painful symptoms of achalasia

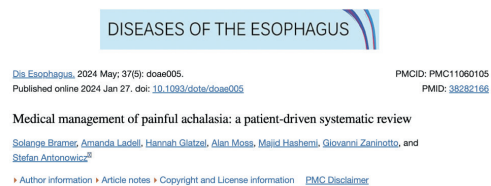
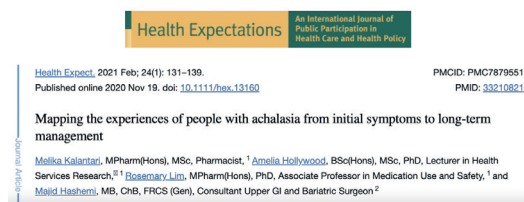
Achalasia Action are keen to support projects looking at chest spasms, and how the pain can be managed and treated. Chest spasms are one of the most recurrent themes raised in our patient meetings, and appear to be one of the most difficult symptoms to live with, and to diagnose and treat.

Achalasia Action shaped Stefan Antonowicz's and Solange Bramer's research looking into chest pains in people with achalasia. Informed by an Achalasia Action survey of 57 people who experienced chest spasms, which identified that chest spasms are common and difficult to manage, the researchers systematically reviewed all the written and published material on achalasia pain. They concluded that there was not much recent or relevant information available on chest spasms and achalasia, nor information on how to treat the pain.

The researchers also recommended the introduction of an international achalasia registry, from which appropriate clinical trials can be performed to expand our understanding of achalasia and chest spasms. We are currently working with the researchers to understand how we can make such a recommendation a reality.

You can read the researchers' full review here:

<https://academic.oup.com/dote/article/37/5/doi:10.1093/dote/37.5.533?login=false>.



Donations

Thanks to all those who have fundraised for us this year!

Our fundraisers have done walks, half marathons, marathons and even boxing matches to raise funds for us.

With special thanks to:

- Bonaventura Pacileo
- Claire Miller
- Gavin Nash
- Kenneth Boyle
- Tracey Bentley

	Notes	Unrestricted £	Restricted £	Total £
Income:				
Donations	1	10,549.03		10,549.03
Interest		240.16		240.16
Total		10,789.19	0.00	10,789.19
Expenses:				
Website	2	657.26		657.26
Conference fees	3	254.34		254.34
Helpline	4	77.96		77.96
Meeting Expenses	5	143.88		143.88
Postage & Packaging	6	75.13		75.13
Insurance	7	212.80		212.80
Subscriptions	8	60.00		60.00
Bank charges		60.00		60.00
Information Commissioner fees		40.00		40.00
Total		1,581.37	0.00	1,581.37
Net Surplus / (Deficit)		9,207.82	0.00	9,207.82
Opening Balance 1st Apr 2023		11,360.89	0.00	11,360.89
Cash Movement		9,207.82	0.00	9,207.82
Closing Balance 31st March 2024		20,568.71	0.00	20,568.71

Bank Balances as at 31 March 2024:

	Total £
CAF Gold Account	15,708.52
CAF Cash Account	4,860.19
Total	20,568.71

Bank Balances as at 1st April 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. Website maintenance and hosting costs
3. Attendance at BSPGHAN conference March 2024
4. The helpline is currently staffed by volunteers with costs limited to payment for telecom
5. Zoom fees for the Meetup patient meetings which have been held on Zoom since the Covid pandemic
6. For distribution of information and fundraising materials
7. Liability Insurance provided by Markel International Insurance Company Ltd
8. Subscription to Association of Chairs

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 authorised by at least two signatories.

Our long term reserves policy is to accumulate sufficient funds to allow for a reasonable period of operation during periods of financial uncertainty.

We are very grateful for the fundraising efforts and donations made by so many people to support our charity.

Authorised:



Jayne Fitzgerald
Treasurer



Silvia Davey
Chair

Declaration

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

Signed, on behalf of the charity's trustees:

Signed:



Silvia Davey
Chair
21 June 2024



Section A

Independent Examiner's Report

Report to the trustees/
members of

ACHALASIA ACTION

On accounts for the year
ended

31ST March 2024

Charity no
(if any)

1187367

Set out on pages

11-12

I report to the trustees on my examination of the accounts of the above charity ("the Trust") for the year ended 31/03/2024

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 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.

Signed:

Date:

24/9/24

Name:

Hasan Mustafa

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

Institute of Internal Auditors

Address:

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East Barnet

EN4 8EP