

ACHALASIA ACTION

England & Wales · Charity number 1187367

Details

Other names ACAC, ACHALASIA LONDON MEET UP

Status Registered

Legal form CIO

Registered 2020-01-15

Register [View on the Charity Commission register](#)

Contact

Address 40 Orpington Road
London
N21 3PG

Phone 0300 772 7795

Email info@achalasia-action.org

Website www.achalasia-action.org

Activities

Objects: THE OBJECTS OF THE CIO ARE: A) TO ADVANCE EDUCATION FOR THE PUBLIC BENEFIT OF ACHALASIA AND ASSOCIATED CONDITIONS B) TO PRESERVE AND PROTECT THE PHYSICAL AND MENTAL HEALTH OF PERSONS WITH ACHALASIA INCLUDING THEIR FRIENDS AND FAMILIES BY SUPPORTING RESEARCH INTO ACHALASIA. NOTHING IN THIS CONSTITUTION SHALL AUTHORISE AN APPLICATION OF THE PROPERTY OF THE CIO FOR THE PURPOSES WHICH ARE NOT CHARITABLE IN ACCORDANCE WITH SECTION 7 OF THE CHARITIES AND TRUSTEE INVESTMENT (SCOTLAND) ACT 2005 AND SECTION 2 OF THE CHARITIES ACT (NORTHERN IRELAND) 2008.

Activities: Holding support meetings for those living with achalasia. Giving information and support to those interested in achalasia Supporting those involved in research into achalasia

Classification

- **How:** Provides Services, Sponsors Or Undertakes Research
- **What:** Education/training, The Advancement Of Health Or Saving Of Lives, Disability
- **Who:** People With Disabilities, The General Public/mankind

Geography

- Throughout England And Wales

Finances

Period end	Income	Expenditure	Assets	Employees
2025-03-31	£12,200	£8,835	-	-
2024-03-31	£10,789	£1,581	-	-
2023-03-31	£4,473	£7,752	-	-
2022-03-31	£3,563	£3,444	-	-
2021-03-31	£22,057	£8,137	-	-

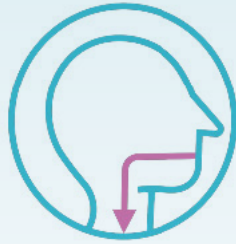
Trustees

Name	Role	Appointed
Silvia Davey	Chair	2020-01-14
AMANDA LADELL		2020-01-14
Andrew Williams		2020-01-14
Annie-Rose Williams		2025-09-24
Gavin Nash		2020-01-14
Jack Eddy		2024-06-18
Jayne Elizabeth Fitzgerald		2021-12-07
Majid Hashemi FRCS		2020-01-14
Neil Ham		2020-01-14

ACHALASIA ACTION

England & Wales - Charity number 1187367

Accounts



ACHALASIA ACTION

Annual Report 2024-25

Covering period 1 April 2024 – 31 March 2025

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

Chair's remarks

Dear Achalasia Action supporters,

2024-25 was an exciting year of growth and increased confidence for our charity. Across all our work, we have remained focused on our core purpose: supporting people affected by achalasia, raising awareness of the condition, and driving change through research and advocacy.

One of the most encouraging aspects of the past year has been seeing the growing awareness of achalasia and the expanding reach of Achalasia Action. More people who need our support are finding us, more conversations are happening, and more doors are opening. This growth brings challenges for a small volunteer-led charity like ours, but it also brings great opportunity for positive change.

Supporting people with achalasia remains the cornerstone of Achalasia Action. Throughout 2024-25, we continued to deliver a wide range of support services, including patient support meetings, specialist-led patient events, and individual one-to-one support by phone and email.

We created spaces for people at different stages of their achalasia journey, from those newly seeking a diagnosis to those who have lived with the condition for many years. It is so powerful and transformative for people with achalasia to meet others who truly understand what living with this condition means.

This year we placed significant emphasis on awareness-raising and campaigning. We worked hard to ensure that achalasia is better understood and taken more seriously within the healthcare system and amongst policymakers.

One of the most significant moments of the past financial year was seeing achalasia mentioned in Parliament for the first time, following our campaign with prospective parliamentary candidates ahead of the General Election. This was a historic and encouraging step for our community, and it demonstrated the impact that sustained, focused advocacy can have.

None of this would be possible without our volunteers, trustees, healthcare partners, supporters, and the achalasia community itself. Thank you for your commitment, your trust and your voices. I look forward to everything we will achieve together in the year ahead.

Yours truly,

Silvia Davey

Chair, Achalasia Action

2

Trustees

Silvia Davey

Chair

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

Jack Eddy

Head of Policy and Campaigning, Trustee from June 2024

Annie-Rose Williams

Head of Marketing and Social Media, Trustee from October 2025

3

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)

Kelly Andrews

Patient Support
(Parents of Children with Achalasia)

James Fitzgerald

Fundraising Support

Lewis Dickinson

Patient Support
(Young People with Achalasia)

4

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

5

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.

6

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

We continue providing our core support services, including patient support meetings, patient meetings with healthcare specialists, and individual support sessions via email or phone. The number of people we support continues to grow (see growth from 2023-24 in brackets). For example, in the past year:

We held two patient meetings with healthcare specialists, attended by 180 people (20% growth):

- July 2024 - Nutrition and Long Term Management of Achalasia
- February 2025 - Diagnosis of Achalasia - Meeting with Achalasia Experts

We held the following support meetings:

- 16x online support meetings attended by 207 people (50% growth)
- 8x meetings for parents of children with achalasia attended by 56 people
- 12x Writing Group meetings attended by 57 people
- 4x Young People (18-35) with achalasia meeting attended by 28 people

111 new people (85% growth) with achalasia contacted us this year for help. 63 of these were new enquiries via email, and 48 were phone calls, many of which were followed up with subsequent calls.

Supporting people via social media

Our social media audience continues to grow. We are reaching increasing numbers of people with information and support about achalasia that we post on Facebook and Instagram. For example, our Instagram page has grown in reach and interactions, and it now has 817 followers. Our Facebook presence also continues to grow, and we now have 1.3k followers on our Facebook page. We continue to regularly monitor and provide support on the Achalasia Action Facebook Group, which has grown by over 1.5k members in the past year, to a total of 2.2k members.

Developing our support services and training peer supporters

Our one-to-one and peer support services provide vital support to people with achalasia and their families. People who seek support include those who are in the process of getting a diagnosis or who are newly diagnosed, and people who have had achalasia for many years but wish to meet others with similar symptoms and going through shared experiences.

Our support services are the cornerstone of our charity, and over the past financial year we have developed a peer support training programme to ensure that the service is sustainable in the long-term, and can meet the continued growth in need we have experienced. We are aiming to deliver a pilot peer-support training programme in April 2026.

Inform

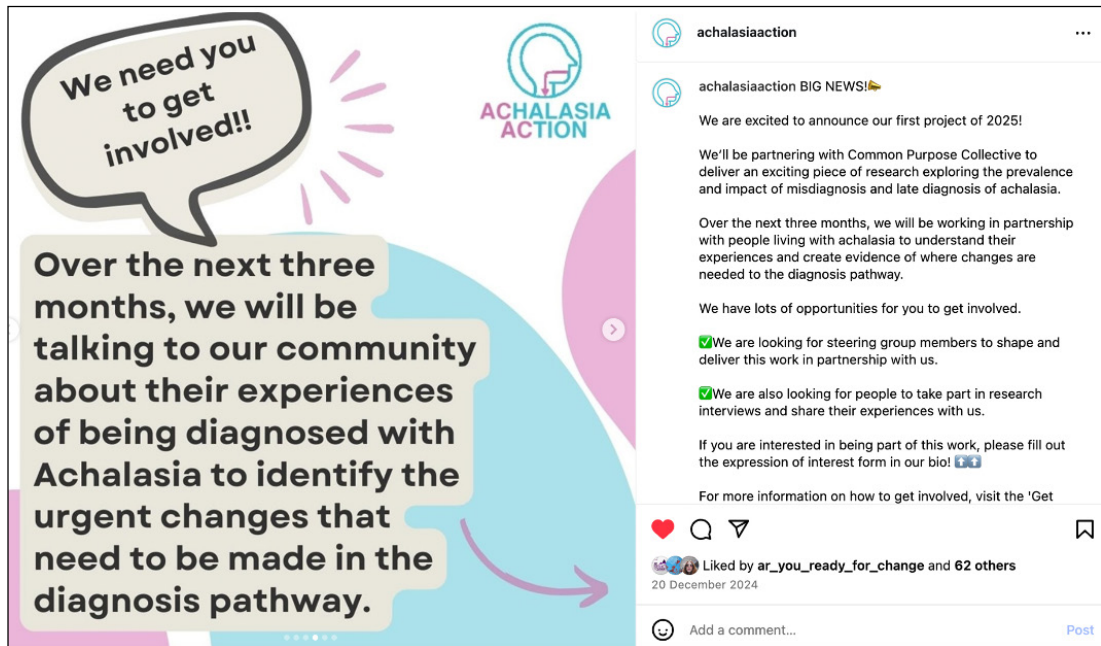
We have put a lot of focus, effort and energy into our inform and campaigning activities, to raise awareness of achalasia and change the healthcare landscape for those with the condition. These activities have resulted in some very positive successes.

Achalasia Action's Prospective Parliamentary Candidates Campaign

In last year's annual report, we outlined that we had targeted prospective parliamentary candidates (PPCs) in the run up to the General Election. Our campaigning activities resulted in a historic moment for the achalasia community: Vikki Slade MP mentioned achalasia for the first time ever in parliament, via an oral question. Other MPs have submitted written questions on achalasia.



Vikki Slade MP asking the first ever verbal question on achalasia in Parliament



Misdiagnosis and late diagnosis policy research report

Achalasia Action launched its first policy research project in misdiagnosis and late diagnosis of achalasia in the UK, and the results were published in September 2025. The research involved collecting survey data from hundreds of people with achalasia across the UK and conducting interviews and focus groups with people with the condition. The research was co-produced by the achalasia community, with a steering group shaping and conducting every step of the research process.

Rare Disease Day campaign 2025

Following the success of our Rare Disease Day campaign in 2024, we continued raising awareness of achalasia on Rare Disease Day 2025 (28 February).

For our campaign this year, we focused on the topic of misdiagnosis and late diagnosis of achalasia, mirroring the topic of our policy research project. Throughout the month we shared content and information related to achalasia diagnosis and misdiagnosis, including information on our research project on the topic.

Our Chair Silvia talked about achalasia and Achalasia Action's work on [national TV \(GB News\)](#), [regional radio \(BBC London\)](#) and a specialist health radio channel.



[Home](#) > [Pilot and Feasibility Studies](#) > [Article](#)

A co-designed intervention to support people living with achalasia to eat in a social setting: a feasibility study

Research | [Open access](#) | Published: 19 December 2024

Volume 10, article number 152, (2024) [Cite this article](#)

✓ You have full access to this [open access](#) article

Dr Sacheen Kumar's systematic review on Endoscopic functional luminal imaging probe (EndoFLIP)

[Download PDF](#) ↓

[Melika Kalantari](#), [Amelia Hollywood](#) ✉, [Rosemary Lim](#) & [Majid Hashemi](#)

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 achalasia research projects which we supported in the past year.

[Dr Melika Kalantari's research on achalasia](#)

Dr Melika Kalantari published a second publication on her doctoral research project, which Achalasia Action supported by recruiting volunteers. In this research, Dr Kalantari explored whether a new, co-designed workbook could help people with achalasia feel more confident and

supported when eating in social situations, which many find particularly challenging. Those who completed the study said the workbook was clear, easy to use and helpful, and many reported feeling better able to manage their symptoms and more supported when eating with others. The findings highlight the value of involving people with lived experience in developing support tools and suggest that this kind of intervention could be a promising way to improve social eating and quality of life for people living with achalasia. You can read a publication on the research project here: <https://link.springer.com/article/10.1186/s40814-024-01574-5>

Dr Sacheen Kumar's systematic review on Endoscopic functional luminal imaging probe (EndoFLIP)


Dr Sacheen Kumar systematically reviewed existing research to see how a tool called EndoFLIP is used during procedures to treat achalasia. EndoFLIP measures how well the lower part of the oesophagus opens during treatment, giving doctors real-time feedback while they are operating. The review found that using EndoFLIP helps guide treatment more accurately and is linked to improved swallowing symptoms

after procedures. Overall, the research suggests that EndoFLIP can help doctors tailor achalasia treatment more precisely, although the authors note that clearer, standardised guidance is still needed to ensure it is used consistently in practice. You can read the full review here:

https://journals.lww.com/international-journal-of-surgery/fulltext/2025/07000/endoscopic_functional_luminal_imaging_probe_for.2.aspx

INVITED SPECIAL PAPER

Endoscopic functional luminal imaging probe for intraprocedural guidance of achalasia treatment: a systematic review and meta-analysis

Fehervari, Matyas PhD, FRCS^{a,b}; Middleton, Isla MBBS^c; McGlone, Emma Rose PhD, FRCS^{b,c}; Fadel, Michael G. MRCS^{b,c}; Brewer, James FRCS^c; Patel, Pranav PhD, FRCS^{d,e}; Hashemi, Majid MD, FRCS^f; Fakh-Gomez, Naim FRCS^g;  Kumar, Sacheen PhD, FRCS^{d,e,g,*}

[Author Information](#) 

International Journal of Surgery 111(7):p 4165-4176, July 2025. | DOI: 10.1097/JIS9.0000000000002397 

Donations

Thanks to all those who have fundraised for us this year! Our fundraisers have undertaken walks, half marathons, marathons and even boxing matches to raise funds for us.

With special thanks to our fundraisers who raised significant funds for Achalasia Action between April 2024 and March 2025:

- Bonaventura Pacileo
- Claire Miller
- Giacomo Malandrino
- Jessica Pearcey
- Lamberto Lamberti
- Lewis Dickinson
- Lorien Schipperus and friends
Noortje & Sena
- Tim Sewell

	Notes	Unrestricted £	Restricted £	Total £
Income:				
Donations	1	11,730.58		11,730.58
Interest		469.87		469.87
Total		12,200.45	0.00	12,200.45
Expenses:				
Website	2	2,017.58		2,017.58
Helpline	3	82.60		82.60
Postage & Packaging	4	26.04		26.04
Insurance	5	212.80		212.80
Subscriptions	6	72.50		72.50
Bank charges		60.00		60.00
Information Commissioner fees		52.00		52.00
TShirts		441.15		441.15
PRCampaign	7	4,000.00		4,000.00
Diagnosis Project	8	1,390.00		1,390.00
Marathon Entry Fee	9	480.00		480.00
Total		8,834.67	0.00	8,834.67
Net Surplus / (Deficit)				
Opening Balance 1st Apr 2024		20,568.71	0.00	20,568.71
Cash Movement		3,365.78	0.00	3,365.78
Closing Balance 31st March 2025		23,934.49	0.00	23,934.49

Bank Balances as at 31 March 2025:

	Total £
CAF Gold Account	21,170.13
CAF Cash Account	2,764.36
Total	23,934.49

Bank Balances as at 1st April 2024:

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

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. The helpline is currently staffed by volunteers with costs limited to payment for telecom
4. For distribution of information and fundraising materials
5. Liability Insurance provided by Markel International Insurance Company Ltd
6. Subscriptions to Association of Chairs and Genetic Alliance UK
7. PR Campaign was run by Relations Group around Rare Disease Day
8. Research Project into Diagnosis of Achalasia
9. One marathon place secured via 2026 Charity ballot

Authorised:



Jayne Fitzgerald
Treasurer



Silvia Davey
Chair

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.

Declaration

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

Signed, on behalf of the charity's trustees:

Signed:



Silvia Davey

Chair

Friday 23 January 2026



**Report to the trustees/
members of**

ACHALASIA ACTION

**On accounts for the year
ended**

31ST MARCH 2025

**Charity no
(if any)**

1187367

Set out on pages

11 and 12

I report to the trustees on my examination of the accounts of the above charity ("the Trust") for the year ended 31/03/2025.

**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:

H Mustafa

Date:

13/7/25

Name:

Hasan Mustafa

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

Institute of Internal Auditors

Address:

114, Gallant's Farm Road

East Barnet

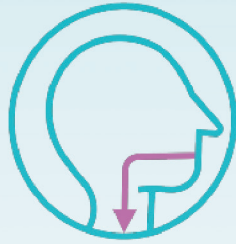
Herts

EN4 8EP

ACHALASIA ACTION

England & Wales - Charity number 1187367

Accounts



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."

2

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.

3

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

4

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:

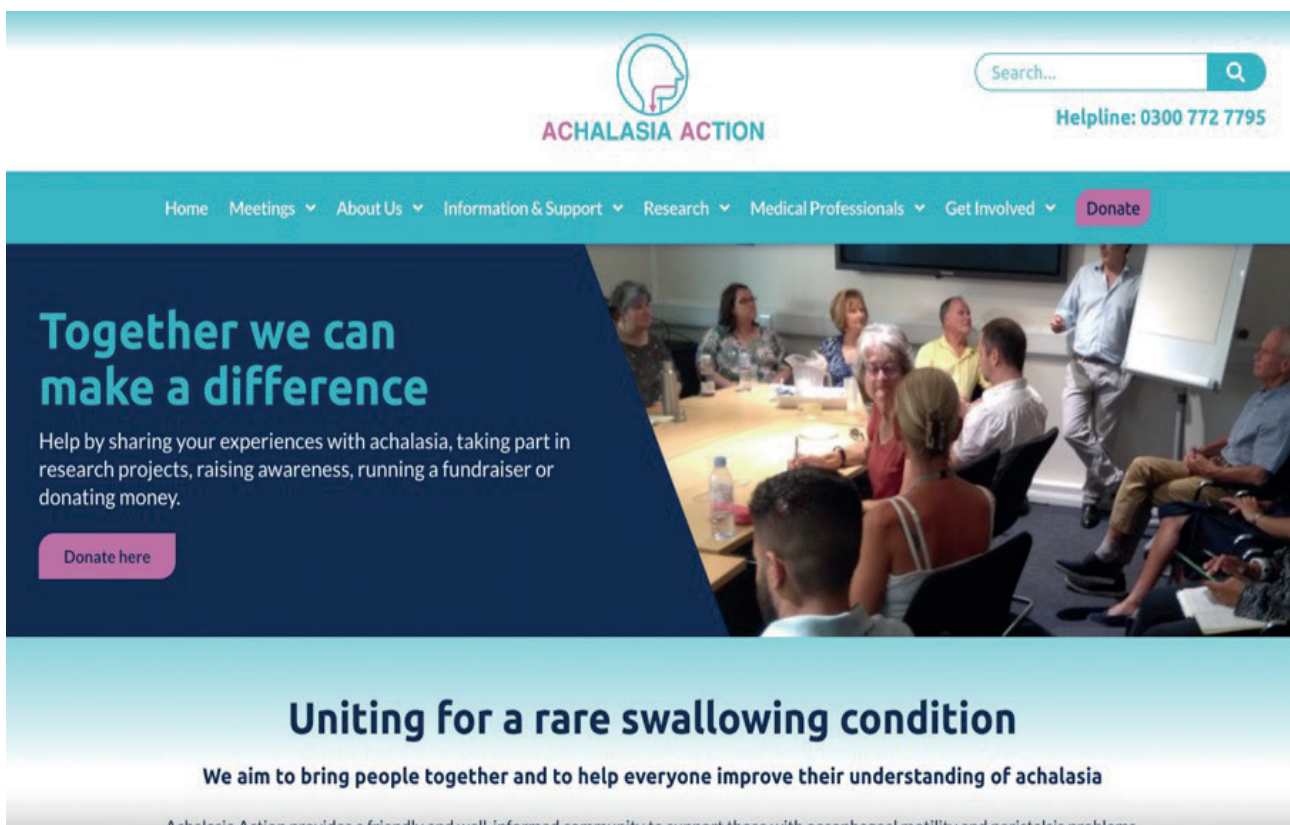
achalasia-action.org.

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.

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:

H. Mustafa

Date:

24/9/24

Name:

Hasan Mustafa

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

Institute of Internal Auditors

Address:

114, Gallants Farm Road

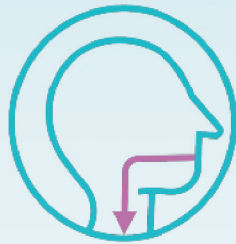
East Barnet

EN4 8EP

ACHALASIA ACTION

England & Wales - Charity number 1187367

Accounts



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

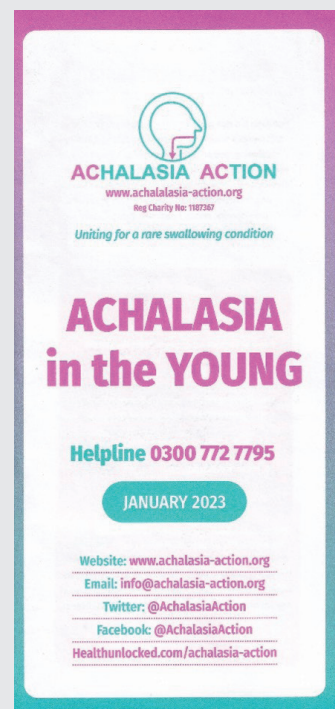
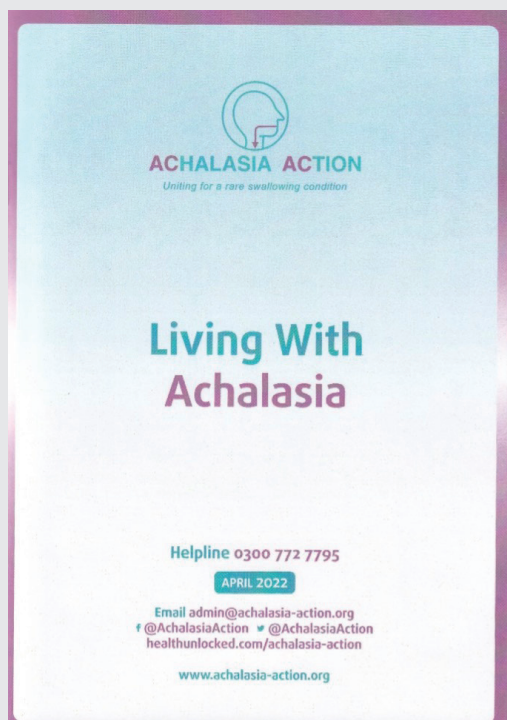
We published a booklet *Living with Achalasia* that contains information on many different aspects of this condition such as food that people find problematic, dietary issues, helpful hints, painful spasms and medication.

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

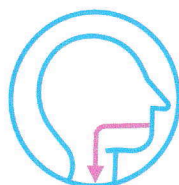
East Barnet

Herts EN4 8EP

ACHALASIA ACTION

England & Wales - Charity number 1187367

Accounts



ACHALASIA ACTION

www.achalasia-action.org

Reg Charity no 1187367

Uniting for a rare swallowing condition

40 Orpington Road, Winchmore Hill, London, England N21 3PG

Helpline: 0300 772 7795

ANNUAL REPORT 2021 -22

(Covering period 1 April 2021 – 31 March 2022)

A Trustees:

Alan Moss	<i>Chair</i>	Neil Ham	<i>Webmaster</i>
Majid Hashemi FRCS	<i>Medical Chair</i>	Silvia Davey	<i>Fundraising</i>
Amanda Ladell	<i>Patient Support Co-ordinator</i>	Gavin Nash	<i>Helpline administrator</i>
Andrew Williams	<i>Treasurer</i>	Jayne Fitzgerald	<i>(From 7-Dec-2021) Secretary</i>
David Holden	<i>Resigned 7-Dec-2021</i>		

B Structure, Governance and Management

Achalasia Action was registered by the Charity Commission of England and Wales as a Charitable Incorporated Organisation on 14 January 2020 (no 1187367). We are governed by a foundation model constitution in which our charity trustees are our only voting members. We are the only UK registered charity specialising in achalasia, a medical condition affecting around 6,000 people that prevents food properly reaching the stomach because of problems with nerve endings controlling the muscles in the oesophagus.

We are also known as the 'London Achalasia Meetup'

We have no paid employees or advisors. We do not occupy dedicated premises.

In December 2021 we were delighted to appoint Consultant Upper GI surgeon Mr Sacheen Kumar PhD MRSC (Chem) FRCS (Gen Surg) from Royal Marsden hospital as an honorary medical advisor. We especially value Mr Kumar's experience of treating benign oesophageal conditions including achalasia and his role as honorary clinical senior lecturer in the Division of Surgery at Imperial College, London.

C Objectives and Activities

During the year we began an exercise to clarify our strategic aims, summarised as:

To provide help and support within a friendly and well informed community to those with achalasia, oesophageal motility and peristalsis problems.

We identified three main strategic pillars that will guide our activities:

Support Providing information and a network of support for people with achalasia, their families and loved ones to ensure they can effectively manage the condition and how it affects their lives.

- Information videos, booklets and posters
- Peer Support Networks
- Support Meetings
- Helpline
- Directory of treatment centres

Research Supporting research efforts into understanding the causes of achalasia, and into the development of treatments and healthcare management strategies, and ultimately a cure, for achalasia.

- Continuing to develop and maintain a log of research projects with emphasis on topics that are of greatest priority to those with achalasia
- Utilising the services of clinical research fellows for projects that can make the best short term impact on quality of life issues
- Building and maintaining our ability to contact people with achalasia to contribute to research studies
- Influencing major funders and institutions to support research that will make progress towards the long term goal of finding a cure for achalasia.

Inform Raising awareness of achalasia amongst the general public, and especially with relevant professionals within the medical community.

- Developing and maintaining our contacts with achalasia treatment centres
- Developing and maintaining research partnerships
- Maintaining relationships with dietitians, food psychologists, occupational therapists and other relevant health professionals including paediatricians
- Awareness raising for GPs, gastroenterologists and eating disorder specialists
- Developing appropriate education and training on achalasia for healthcare professionals
- Providing appropriate information for relevant government policy makers

Supporting these activities are some important programmes to improve our website, database and fundraising, also ensuring that we have appropriate training and governance policies in place.

D Achievements and Performance

One of the highlights of the year was the publication on YouTube of a set of animated videos, entitled *Understanding Achalasia* (www.youtube.com/watch?v=LHWFGdKINpE&t=190s), *Diagnosing Achalasia* (www.youtube.com/watch?v=MvfK03fmOkw&t=232s), *Treatments for Achalasia* (www.youtube.com/watch?v=JXLJE4ezKfY&t=450s), and *About Achalasia Action* (www.youtube.com/watch?v=vuVh2A4O6vI). These were produced with the assistance of generous grants from Foyle Foundation and the National Lottery Fund. They are recorded as having been viewed on more than 6,800 occasions, and represent a valuable source of education and information free of any potential vested interest, particularly when the constraints of COVID have prevented us from holding physical meetings.

We published a leaflet *Achalasia and Education* at the request of a group of parents of children with achalasia that explains the condition for the benefit of schools and colleges so that children and young people have a good source of information to explain their symptoms and difficulties.

We attended a conference of the Primary Care Society of Gastroenterology in November 2021 and organised a stall as part of our aim to raise awareness amongst the medical profession.



Our monthly support meetings have continued throughout the year in an online format. Being able to take part through the zoom facility has continued to reduce the travelling time involved, and has improved access for many patients, but at the expense of the ability to take part in the valuable, quiet conversations that take place in the margins of physical meetings. Holding meetings online has also affected the development and status of regional meetings because geographical proximity no longer has the same advantage. Some individuals do meet up together having been introduced at these meetings however.

In November 2021 we held a meeting on pain and spasms with valuable contributions from Dr Ahmed Albusoda, Consultant Gastroenterologist from Barts & Royal London, our medical advisor, Mr Sacheen Kumar and our medical chair Mr Majid Hashemi.

During the year we started a creative writing group organised by Christine Hollywood to enable people to describe their experiences in the format of their choice. This can be valuable therapy.

In relation to social media, we have 225 followers on Twitter (@AchalasiaAction), 377 members of our Achalasia Action Facebook group and 124 members in our HealthUnlocked community. Some people will participate in more than one forum, and some will be from other countries. This reflects the modern world and how people communicate with charities. It can be a very valuable method of people seeking information and reassurance from fellow sufferers from a source complementary to their medically-qualified health practitioners, particularly in a period when the National Health Service is under so much pressure, but we have a firm policy of emphasising the primacy of the advice they receive from their own doctor.

One other aspect of communication through the internet is that we receive income from donations from people who generously support us through sites like Justgiving or Facebook fund raisers, but we sometimes do not know the full details of these valuable supporters so that we can write and thank them. Many donations reach our account from these third party fundraising organisations in a form that does not facilitate easy calculation of the total that individuals have raised apart from what is shown on their fundraising page.

We do receive donations direct, however, and are greatly encouraged by our donors' comments, such as:

"Thanks Amanda, for all you are doing to support families and raise awareness "

"Thank you so much for today's meeting. So informative!"

"Keep up the amazing work, I was diagnosed last year and charities like this are so needed for support and advice. Let's hope the future is bright for people with achalasia "

E Financial Review

ACCOUNTS for the period 1 April 2021 to 31st March 2022 (based on payments and receipts)

	Notes	Unrestricted	Restricted	Total
		£	£	£
INCOME:				
Donations	1	3,563.87	0	3,563.87
Total		3,563.87	0	3,563.87
EXPENSES:				
Meeting Expenses		287.76	0	287.76
Computer Costs & Database		40.00	0	40.00
Animated video	2	0	1,669.55	1,669.55
Helpline	3	0	73.68	73.68
Printing & Stationery	4	0	855.67	855.67
Postage & Packaging		0	93.89	93.89
Insurance		0	212.80	212.80
Bank charges		88.00	0	88.00
Miscellaneous		122.90	0	122.90
Total		538.66	2,905.59	3,444.25
NET SURPLUS / (DEFICIT)		3,025.21	(2,905.59)	119.62
OPENING BALANCE		5,993.00	8,527.00	14,520.00
CASH MOVEMENT		3,025.21	(2,905.59)	119.62
CLOSING BALANCE as at 31 March 2021	5	9,018.21	5,621.41	14,639.62

Bank balances as at March 31st 2022:

CAF Cash Account = £4,587.33

Gold Account = £10,052.29

CAFbank Total = £14,639.62

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 Animated video costs began to be paid in 2020-21 but due to delays in filming because of Covid 19, the remaining costs were paid in 2021-22
- 3 The helpline is currently staffed by volunteers with costs currently paid for by Trustees
- 4 Printing & Stationery includes the design and production of new posters, leaflets and booklets on achalasia with further expenditure anticipated in 2022-23
- 5 Closing balance includes £600 Loans from trustees which are expected to be repaid in 2022-23.

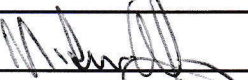
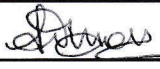
There were no items of income or expenditure outside the United Kingdom.

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, and Trustees have been active in providing resources, including financial loans, to enable the charity to start its life so well.

Our long term reserves policy is to aim to accumulate sufficient funds to allow for a reasonable period of operation during periods of financial uncertainty, particularly when conventional fundraising methods have been severely constrained.

We are also most grateful for the fundraising efforts and donations made by so many people to support our charity, including Kirsty Howe who ran the London marathon.

Authorised: 	
M. PEN-COCCHINI	ALAN MOSS Chair
Independent Examiners	pp Andrew Williams, Treasurer


F Other Optional Information

None

G Declaration

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

Signed, on behalf of the charity's trustees:

Signature	
Name	ALAN MOSS
Position	Chair
Date	5 July 2022



Section A Independent Examiner's Report

Report to the trustees/ members of	Charity Name Achalasia Action		
On accounts for the year ended	31 March 2022	Charity no (if any)	1187367
Set out on pages	6 pages <small>(remember to include the page numbers of additional sheets)</small>		

I report to the trustees on my examination of the accounts of the above charity ("the Trust") for the year ended DD / MM / YYYY.

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.

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

Signed:  **Date:** 13/09/2022

Name: Mr Michael Pen-Collings

Relevant professional qualification(s) or body (if any): CIMA (PQ) Chartered Institute of Management Accountants (1-14TJ)

Address: 22 Sheffield Close, Pangbourne, Reading, Berkshire, RG8 7GD

Section B Disclosure

Only complete if the examiner needs to highlight matters of concern (see CC32, Independent examination of charity accounts: directions and guidance for examiners).

Give here brief details of any items that the examiner wishes to disclose.

A large, empty rectangular box with a thin black border, occupying the right two-thirds of the page. It is intended for the user to provide details of items for disclosure as requested in the text to its left.

ACHALASIA ACTION

England & Wales - Charity number 1187367

Accounts



ACHALASIA ACTION

www.achalasia-action.org
Reg Charity no 1187367

Uniting for a rare swallowing condition

40 Orpington Road, Winchmore Hill, London, England N21 3PG

Helpline: 0300 772 7795

ANNUAL REPORT 2020 -21

(Covering period 14 January 2020 – 31 March 2021)

A Trustees (all of whom served for the whole period covered by this report):

Alan Moss	<i>Chair</i>	Neil Ham	<i>Webmaster</i>
Majid Hashemi FRCS	<i>Medical Chair</i>	Silvia Davey	<i>Fundraising</i>
Amanda Ladell	<i>Patient Support Co-ordinator</i>	Gavin Nash	<i>Helpline administrator</i>
David Holden	<i>Treasurer</i>	Andrew Williams	<i>Assistant Treasurer</i>

B Structure, Governance and Management

Achalasia Action was registered by the Charity Commission of England and Wales as a Charitable Incorporated Organisation on 14 January 2020 (no 1187367). We are governed by a foundation model constitution in which only voting members are our charity trustees.

We are also known as the 'London Achalasia Meetup'

We have no paid employees or advisors. We do not occupy dedicated premises.

C Objectives and Activities

Our charitable objects are:

- a) To advance education for the public benefit of achalasia and associated conditions
- b) To preserve and protect the physical and mental health of persons with achalasia including their friends and families by supporting research into achalasia.

Our Trustees have regard to the Charity Commission guidance on public benefit and aim to provide information to assist those affected by achalasia through patient support meetings, answering questions by telephone and online, through written publications, by our website and by means of an animated video.

Achalasia is a rare swallowing condition that prevents food from reaching your stomach properly. It affects the muscles in the oesophagus, the food pipe that runs from your throat to your stomach. In a normal oesophagus, muscles squeeze the food down towards your stomach in a coordinated sequence called peristalsis. At the lower end of the oesophagus, a valve-like ring of muscle (the lower oesophageal sphincter) should automatically relax to allow food through into the stomach, but with achalasia this fails to occur. The problem appears to involve the nerve endings controlling the muscles rather than the muscles themselves. There is no cure for achalasia at present, but symptoms can be relieved by medical procedures to allow food to move into the stomach by gravity.

D Achievements and Performance

In a difficult year overshadowed by COVID19 we were forced to cancel our physical meetings for patient support but have continued with equivalent online zoom meetings. These have enabled people to participate regardless of geographical distance, but with the disadvantage of missing quiet personal conversations.



In addition to our London Meetup group, we have been pleased to support the development of regional meetings in the South West, Leicester and Manchester, as well as our young adults group. During the life to date of the London Achalasia Meetup and of Achalasia Action we estimate that we have talked to approximately 1,000 people with achalasia. It is a natural part of a patient support group that many people stay in contact for a period, but then withdraw, perhaps until they have a need to contact us again. In our first year, we have been in contact with 194 people who follow our

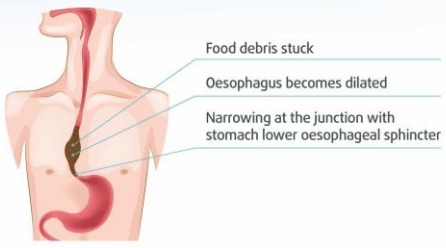
Facebook page, 123 who follow our Twitter feed, 85 members of our HealthUnlocked community, 534 on our Meetup system and 120 who have signed up for our Newsletters.

For some years, including before our registration as a charity, we have held meetings at the Hospital of St John and St Elizabeth in St John's Wood, London and have been grateful for the hospital's generous hospitality. We have covered subjects that include diagnostic tests, manometry, dietary issues, psychological aspects of eating, breath tests, spasms, children's issues, as well as some general question and answer sessions. We have conducted informal surveys about food that causes difficulties, and have heard presentations on relevant research projects relating to stem cells, breath tests and the I-PASS patient outcome measurement. We have been able to put researchers into contact with numbers of people with achalasia to help the development of research. We anticipate this aspect of our work continuing to develop as we identify areas of research that would be of benefit to those with achalasia.

We are most grateful for the support given by medical practitioners who have been visiting speakers, or supported our charity in other ways, including Stephen Attwood, Matthew Banks, Osvaldo Borrelli, Nick Carter, Claire Donnelly, Yan Mei Goh, Rehan Haidry, Anthony Hobson, Amelia Hollywood, Melika Kalantari, Sacheen Kumar, Sheraz Markar, Conor McCann, Kenneth Park, Raj Parmar, Rami Sweis, Nigel Trugdill and Giovanni Zaninotto.

We have produced a clinic poster and designed a leaflet *An Introduction to Achalasia* for gastroenterological units, and have started distributing pens and notepads to raise awareness of our charity's existence to the medical profession and to patients. We also have restaurant cards to help those with achalasia with the process of ordering smaller portions.


**Food not going down properly?
Painful chest spasms?
Ask your Doctor about Achalasia**




Information | Support | Encouraging Research

Achalasia is a rare, sometimes painful medical condition experienced by around 6,000 people in the UK that affects swallowing and the ability of food to pass through the oesophagus and into the stomach. Achalasia Action is here to help you.



Helpline 0300 772 7795
Email admin@achalasia-action.org


**ACHALASIA ACTION**
Uniting for a rare swallowing condition

Achalasia Action Charity
Registered Number 1187367
(England & Wales)
www.achalasia-action.org



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Funded by  HM Government |  in partnership with THE NATIONAL LOTTERY COMMUNITY FUND



ACHALASIA ACTION
Uniting for a rare swallowing condition

**An introduction to
Achalasia**

Helpline 0300 772 7795

FEBRUARY 2021

Email admin@achalasia-action.org
f [@AchalasiaAction](https://www.facebook.com/AchalasiaAction) v [@AchalasiaAction](https://www.youtube.com/channel/UC...)
healthunlocked.com/achalasia-action

www.achalasia-action.org

With generous financial support from Foyle Foundation and from the National Lottery Community Fund we have commissioned an animated video that aims to explain achalasia to the public, in terms that will especially benefit those recently diagnosed with the condition. We look forward to its publication later in 2021.

E Financial Review

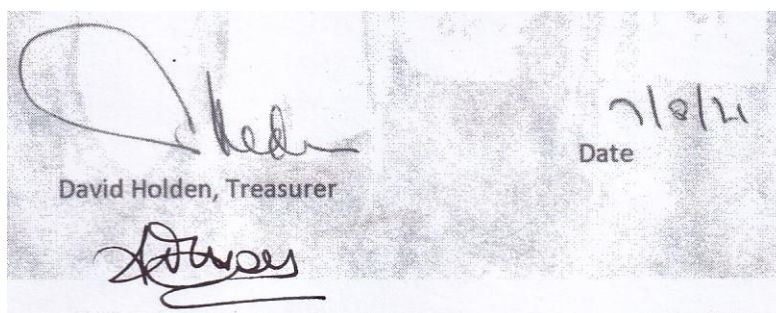
ACCOUNTS for the period 14 January 2020 (date of incorporation) to 31st March 2021 (based on payments and receipts)

	Notes	Unrestricted	Restricted	Total
		£	£	£
INCOME:				
Grants	1	0	15,900	15,900
Meeting Revenue	2	100	0	100
Donations	3	6006	0	6,006
Legacies		0	0	0
Other		51	0	51
Total		6,157	15,900	22,057
EXPENSES:				
Meeting Expenses	4	100	0	100
Conferences	5	0	0	0
Research	6	0	0	0
Computer Costs & Database	7	55	0	55
Website	8	0	0	0
Animated video	9	0	6,109	6,109
Helpline	10	8	0	8
Printing & Stationery	11	29	1,053	1,082
Merchandise	12	246	0	246
Postage & Packaging		78	211	289
Travel & Subsistence		0	0	0
Insurance		0	0	0
Bank charges		82	0	82
Miscellaneous		166	0	166
Total		764	7373	8137
NET SURPLUS / (DEFICIT)		5,393	8,527	13,920
OPENING BALANCE		0	0	0
CASH MOVEMENT		5,393	8,527	13,920
Loans from trustees		600	0	600
CLOSING BALANCE as at 31 March 2021		5,993	8,527	14,520

Notes to Accounts:

- 1 Over the period grants were received from The National Lottery and The Foyle Foundation
- 2 Meeting Revenue was generated at physical meetings which were then postponed until after Covid 19
- 3 Donations include individual fund raising initiatives and money received from online platforms that also collect gift aid on the charity's behalf.
- 4 A donation was made to the Hospital of St Johns & St Elizabeth for use of their facilities
- 5-6 Conferences and contributions to research projects have yet to be funded
- 7-8 Costs towards computers and website had been met by the Trustees.
- 9 Animated video costs began to be paid in 2021 but due to delays in filming because of Covid 19, the remaining costs will be paid in 2021/22
- 10 The helpline was started in 2021. The line is currently manned by volunteers with costs currently paid for by Trustees
- 11 Printing & Stationery includes the design and production of new posters, leaflets and booklets on achalasia with further expenditure anticipated in 2021-22
- 12 Merchandise began to be purchased in 2021 and will be paid for in 2021/22

Authorised:

A photograph of a document showing two handwritten signatures. The first signature is in dark ink and is written over the printed name 'David Holden, Treasurer'. To the right of this signature, the date '7/10/21' is handwritten above the printed word 'Date'. Below the first signature is a second signature in dark ink, which is written over the printed name 'Alan Moss, Chairman'.

Alan Moss, Chairman

This is our first year of operation as a registered charity and we are most grateful for the valuable support given to us by The National Lottery and Foyles Foundation whose grants have enabled us to produce an animated video about achalasia and to develop, other educational material relevant to this distressing medical condition, and to build other resources essential for our work.

We have introduced online support and information 'Zoom' sessions to replace physical support and education meetings because of COVID19 and have been pleased to welcome a number of people from other countries to those sessions as a result. We have formed links with similar groups with an interest in achalasia in other countries, so our charity is becoming known internationally because of these communications. 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, and Trustees have been active in providing resources, including financial loans, to enable the charity to start its life so well.

Our long term reserves policy is to aim to accumulate sufficient funds to allow for a reasonable period of operation during periods of financial uncertainty, particularly when conventional fundraising methods have been severely constrained.

We are also most grateful for the fundraising efforts and donations made by so many people to support us, including Maria-Chiara Borelli, Olimpia Lamberti, Billy Moss, Beth Payne and the Winton branch of Messrs Waitrose and Partners.



Achalasia Action runners at the Gravesend Marathon event on 5 September 2020

F Other Optional Information

None

G Declaration

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

Signed, on behalf of the charity's trustees:

Signature	
Name	ALAN MOSS
Position	Chair
Date	12 August 2021