

**ACHALASIA ACTION**

# Annual Report 2024-25

Covering period 1 April 2024 – 31 March 2025

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[www.achalasia-action.org](http://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

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## 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

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## 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)

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## 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

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## 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.

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## 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

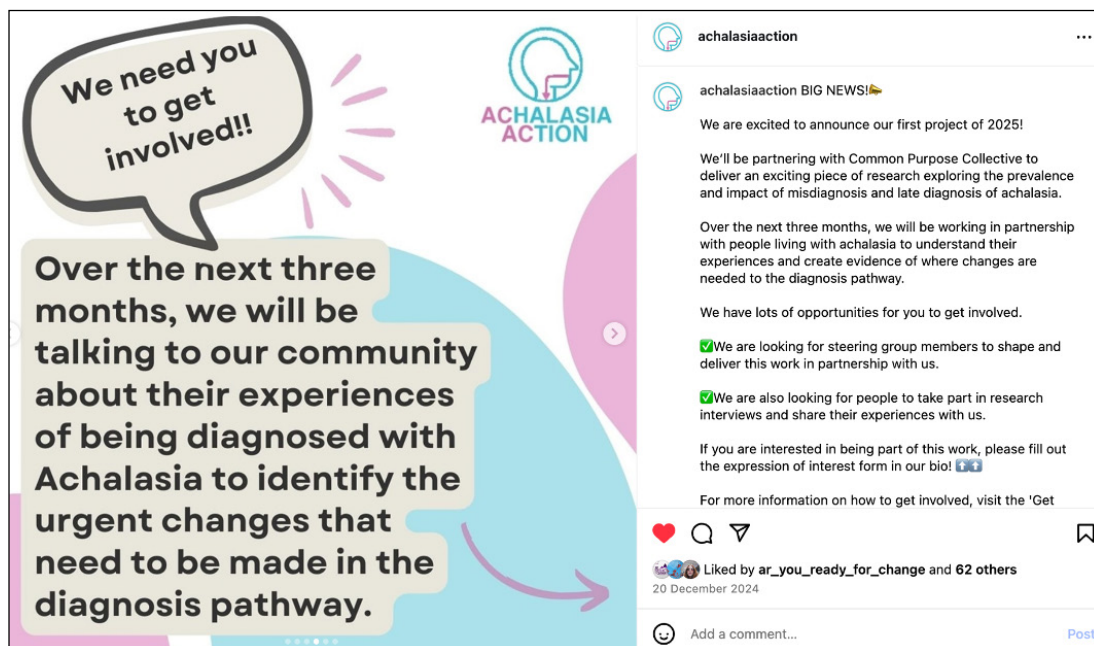
We have put a lot of focus, effort and energy into our inform and campaigning activities, to raise awareness of achalasia and change the healthcare landscape for those with the condition. These activities have resulted in some very positive successes.

### 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

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

[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](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<sup>a,b</sup>; Middleton, Isla MBBS<sup>c</sup>; McGlone, Emma Rose PhD, FRCS<sup>b,c</sup>; Fadel, Michael G. MRCS<sup>b,c</sup>; Brewer, James FRCS<sup>c</sup>; Patel, Pranav PhD, FRCS<sup>d,e</sup>; Hashemi, Majid MD, FRCS<sup>f</sup>; Fakihi-Gomez, Naim FRCS<sup>c</sup>;  Kumar, Sacheen PhD, FRCS<sup>d,e,g,\*</sup>

[Author Information](#) 

*International Journal of Surgery* 111(7):p 4165-4176, July 2025. | DOI: 10.1097/JJS9.0000000000002397 

## 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 £
<b>Income:</b>				
Donations	1	11,730.58		11,730.58
Interest		469.87		469.87
<b>Total</b>		<b>12,200.45</b>	<b>0.00</b>	<b>12,200.45</b>
<b>Expenses:</b>				
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
<b>Total</b>		<b>8,834.67</b>	<b>0.00</b>	<b>8,834.67</b>
<b>Net Surplus / (Deficit)</b>		<b>3,365.78</b>	<b>0.00</b>	<b>3,365.78</b>
Opening Balance 1st Apr 2024		20,568.71	0.00	20,568.71
Cash Movement		3,365.78	0.00	3,365.78
<b>Closing Balance 31st March 2025</b>		<b>23,934.49</b>	<b>0.00</b>	<b>23,934.49</b>

## Bank Balances as at 31 March 2025:

	Total £
CAF Gold Account	21,170.13
CAF Cash Account	2,764.36
<b>Total</b>	<b>23,934.49</b>

## Bank Balances as at 1st April 2024:

	Total £
CAF Gold Account	15,708.52
CAF Cash Account	4,860.19
<b>Total</b>	<b>20,568.71</b>

## 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

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

Friday 23 January 2026



**Section A**

**Independent Examiner's Report**

**Report to the trustees/  
members of**

ACHALASIA ACTION

**On accounts for the year  
ended**

31<sup>ST</sup> 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