



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

Agreement 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 t @AchalasiaAction
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

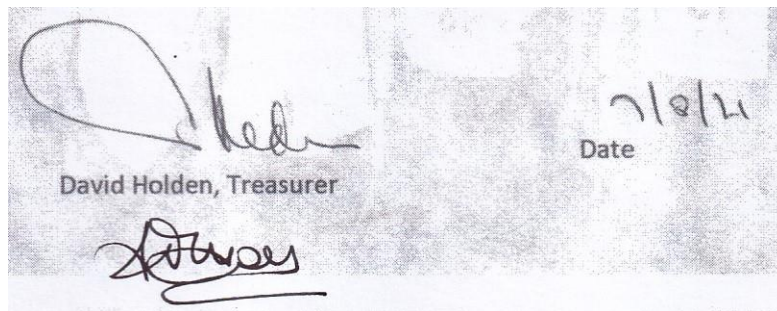
ACCOUNTS for the period 14 January 2020 (date of incorporation) to 31st March 2021 (based on payments and receipts)

	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'. The second signature is in red ink and is written over the printed name 'Alan Moss, Chairman'. To the right of the signatures, the date '2/8/21' is handwritten, with the word 'Date' printed below it.

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

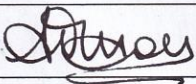
F Other Optional Information

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