



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	(2905.59)	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:	

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	
Position	
Date	