



***Action Against Heartburn – Before it's too late
Charities promoting earlier diagnosis
of oesophageal and gastric cancer***

www.actionagaintheartburn.org.uk



@ActionHeartburn

2022-2023 ANNUAL REPORT

During 2023 we held three meetings and two presentations (see below) on Zoom. The membership of AAH continues to be stable although we have gained an additional member in Barrett's Essex. We have also decided to include the Less Survivable Cancer Taskforce (LSCT) and Cancer 52 as formal members. Our mailing list now includes almost 50 emailing addresses of campaigning organisations and individuals interested in defeating oesophageal cancer.

Research and Research Presentations

We have had two research presentations this year. The first was presented to us by Alice Guazelli who is the clinical trials manager for SARONG, (Surveillance After Resection of Oesophagus and Gastric Cancer), based in Oxford and led by Sheraz Markar. The study looks at whether additional surveillance leads to earlier detection of cancer returning after surgery in patients with oesophageal or gastric cancer – it aims to recruit 952 people from NHS hospitals across the country and is progressing well.

We were also given a presentation by Fiona Labrooy of Heartburn Cancer UK on developments in Capsule Sponge Technology (previously referred to as the cytosponge). Cytel, (the company behind Endosign (the commercial name for their capsule sponge technology) is taking the concept forward. AAH attends many of Cytel's promotional meetings and supports Cytel's activities.

The DELTA study has now concluded and its findings are published. AAH is grateful to Alan Moss for representing AAH in this study. DELTA was the background research conducted by Prof. Rebecca Fitzgerald into the feasibility of the cytosponge and the use of AI in pathology. Related to DELTA, AAH members participated in an on-line survey of a discrete choice experiment (DCE) questionnaire run by Kelly Seo of Cambridge University concerning preferences for screening technology. A workshop was also attended concerning issues relating to a risk tool for screening for oesophageal cancer.

Finally, AAH members participated in occasional and ad hoc online questionnaires such as the survey run by Kings College London (Jane Rigney) on acid reflux.

National Oesophago-Gastric Audit Patient Panel (NOGCA) www.nogca.org.uk

Jill Clark has been our representative on the NOGCA Patient Panel. The main Audit is produced every year under the auspices of the Royal College of Surgeons, and the Patient Audit is a shorter report designed for patients, and for lay people generally. The purpose of the main Audit is to establish a clinical survey of oesophago-gastric cancer services for England and Wales. A number of on-line meetings were held during the year drafting the

patients' version of the main Audit and the draft was sent around AAH's membership for input and commentary, finally being released in May.

Less Survivable Cancer Taskforce (LSCT) www.lesssurvivablecancers.org.uk

The LSCT, of which AAH was a founding member, represents the “less survivable cancers” i.e. those of the lung, liver, brain, oesophagus, pancreas and stomach, all with the poorest five year survival rates, of under 20%. The LSCT is professionally managed and financed and gives leverage to AAH's own campaigns. Their Awareness Day in January in which AAH plays an active part, was again very successful and attracted national press coverage. We again took part in the LSCT's “Drop-In” session at Westminster, at which parliamentarians “drop-in” and have their photos taken for social media showing their support for less survivable cancers. The photo below shows the LSCT campaigning members at the Westminster Drop-In for the LSCT Awareness Day on 11th January 2023.



Cancer 52 www.cancer52.org.uk

AAH is a member and supporter of Cancer 52 which campaigns for the 52% of cancers which are **not** the big four (breast, lung, prostate, bowel) and has over 100 members. AAH (and some of our own members) attends its monthly on-line meetings. It also occasionally holds meetings in person such as its recent conference at Canary Wharf in which AAH participated. Due to its lottery win improving Cancer 52's finances, AAH no longer has to pay its membership fee (£100) and is grateful to it for this gesture.

Primary Care Society for Gastroenterology (PCSG)

AAH, alongside Achalasia Action ran a stall at the AGM of the PCSG, displaying AAH's hard copy leaflets, posters and banners. We were particularly fortunate in making a number of contacts and personal links which we have been able to carry forward.

Finance

Our financial position is in good shape. We are grateful to GUTS UK for allowing us to use their banking facilities for our funds at no charge. We have been fortunate in securing small donations occasionally from members of the public and our supporters, especially Howard Soper. Our main outgoings remain membership fees to the LSCT, and payments for our website.

JMC 12/3/24