



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

www.actionagaintheartburn.org.uk



@ActionHeartburn

ANNUAL REPORT 2019-20

UK Barrett's Oesophagus Registry

During the twelve months from 1 October 2019 we held three meetings, in one of which we heard a presentation from Christine Caygill about the work of UK Barrett's Oesophagus Registry whose primary aim is to identify those with Barrett's Oesophagus (BO) most likely to progress to adenocarcinoma. Men with rhesus negative blood groups are a small group three times more likely to progress to cancer, the effect of nitric oxide being a relevant factor. The research has not been replicated, however, partly because the registry, the largest in the world, has been unable to secure its funding for the future, notwithstanding heroic efforts made by the trustees of Barrett's Oesophagus UK. Blood groups are not always recorded by other bodies.

Research from the registry has shown that the second least deprived group on the Government's index of deprivation were most likely to be diagnosed with Barrett's, and another group at more risk were manual workers from Group IIIM, perhaps because of heavy and repetitive lifting and bending.

The population with BO carried a risk of death from oesophageal adenocarcinoma that was twenty times greater than the general population, according to a UKBOR-based study.

The registry had been dealt an enormous blow by the requirement for informed consent to be obtained from patients, whereas consent for cancer research is assumed unless people opt out. The future of the registry, despite its valuable research potential, looks bleak.

February Awareness Month and COVID19

We undertook our February Awareness month activities again in 2020, but on a much-reduced scale because of lack of resources. The COVID19 pandemic was becoming a major health emergency and started having a devastating effect on the country with a formal 'lockdown commencing 23 March. Because the virus is spread through aerosol infection, endoscopy workloads were affected dramatically, meaning that the route towards cancer diagnosis was severely curtailed. Hard-pressed NHS staff recovered much of the backlog by the autumn of 2020, but cancer services, along with much other normal work of the NHS, were adversely affected.

World Barrett's Oesophagus Day

The first World Barrett's Oesophagus Day was held on 16 May and was well supported on an international basis, with great credit being due to Barretts Wessex and Chris Robinson for their role in organising it.

The organisations supporting *Action Against Heartburn* are: AUGIS – Association of Upper GI Surgeons; Barrett's Oesophagus UK; Barrett's Wessex; BSG – British Society of Gastroenterology; Cancer Research UK; CARD – Campaign Against Reflux Disease; GUTS UK (formerly CORE) – Funding research into diseases of the gut, liver and pancreas; GOSH - Gastro-Oesophageal Support & Help, Bristol; Gutsy Group; Heartburn Cancer UK; Northern Oesophago-Gastric Cancer Fund; OOSO – Oxfordshire Oesophageal and Stomach Organisation; OCHRE charity (Scotland); OG Cancer NI (Northern Ireland); PCSG - Primary Care Society for Gastroenterology; UKBOR – UK Barrett's Oesophagus Registry

Medical Advisor to *Action Against Heartburn* – Dr Jason Dunn MB BS PhD MRCP BSc, St Thomas' hospital
Pharmaceutical Advisor: Ash Soni OBE

Cytosponge

The results of the BEST3 clinical trial were published during the year, clearly indicating that the Cytosponge device is much more effective at identifying Barrett's Oesophagus than conventional primary care methods. Action Against Heartburn is represented on the Delta project that aims to develop the best methods of introducing it into clinical practice. The laboratory analysis of Cytosponge samples are geared towards identifying the TFF3 protein that is a signature of Barrett's Oesophagus; hopefully the process will also be able to identify signs of dysplasia, adenocarcinoma and squamous cell carcinoma in due course.

Less Survivable cancers Taskforce

Action Against Heartburn are founding members of the Less Survivable Cancers Taskforce that held a Parliamentary Drop In on 4 February, World Cancer Day. The pictures include some of the 57 MPs who attended:



The Scottish government has committed to using Cytosponge in hospitals as a triage device to improve the process of endoscopy and to respond to the extra problems created by COVID19 after meetings with the Less Survivable Cancers Taskforce (LSCT).

The LSCT produced reports on *Barriers to Research* and *Early Diagnosis* during the year, both of which are very relevant to the oesophageal cancer.

The LSCT ran a campaign to Close the #DeadlyCancerGap

Our Supporters

We are sorry to report that three of the charities that supported us have closed, Fighting Oesophagus Reflux Together (FORT), Humberside Oesophageal Support group (HOSG), and the Michael Blake Foundation. We remain deeply appreciative of their support for the cause of promoting better outcomes for oesophageal cancer patients, and were extremely grateful for the Michael Blake Foundation's decisions to donate to us the residue of their funds, nearly £3000.

We record our appreciation of the supportive role played by our treasurer, Jonathon Holt of Cloke & Co, and the trustees of Barrett's Oesophagus UK. We ended the financial year with £4,754.65 in our account and are very grateful for the financial donations made to support our aims.

We undertook a review of our role and activities during the year, which has been very difficult for many charities, and envisage continuing our commitment to a role that supports and communicates with other charities active in the field. It is a regrettable fact that there is no one single charitable body representing patients with oesophageal cancer. We will continue to make specific contributions to delivering impactful messages about the importance of improving outcomes for the 9,200 people who are diagnosed with oesophageal cancer in the UK each year.

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