



AORTIC DISSECTION AWARENESS UK & IRELAND

Annual Report & Accounts

2018/19



Today is a Good Day!



aorticdissectionawareness.org thinkaorta.org



@AorticDissectUK @ThinkAorta



Aortic Dissection Awareness UK

ABOUT US

Aortic Dissection

Awareness UK & Ireland is

the patient association for people affected by Aortic Dissection and their families. We are the voice of Aortic Dissection patients in the UK & Ireland. Our work involves raising awareness of Aortic Dissection, its diagnosis and



treatment: providing vital friendship, support and advice for patients and family members; encouraging research into the condition; and working with healthcare providers to ensure that best practice diagnosis and care for Aortic Dissection are implemented consistently nationwide.

Membership of the Association is free to patients, relatives, carers and healthcare professionals with an interest in Aortic Dissection. As an unincorporated Patient Association, we rely on a team of dedicated volunteers, many of whom are Aortic Dissection survivors, to do our work. Our projects are funded entirely by donations from individuals, charities and corporations who share our vision for improving the diagnosis and treatment of Aortic Dissection patients in the UK and Ireland.

On 18th March 2018, Aortic Dissection Awareness UK & Ireland was formally constituted as a voluntary unincorporated association. This is our first Annual Report & Accounts, covering our first year of operation, up to 5th April 2019.

*"The secret of change is to focus all of your energy,
not on fighting the old, but on building the new."*

- Socrates

CHAIR'S REPORT



When I experienced an acute Aortic Dissection in 2016, I thought that my life was over. I never expected to become Chair of the Patient Association for Aortic Dissection in the UK & Ireland. The fact that I did is due to the amazing work of a large multidisciplinary team at Barts Health NHS Trust, led by Prof. Rakesh Uppal. They diagnosed me promptly, then performed two complex, major operations with incredible teamwork, skill and expertise, saving my life and giving me a great outcome from the same lethal disease that killed my father at the age of 49.

During those dark days in hospital, I formed a friendship with our Founder, Dan Burgess, who, as he drove his black cab around London every day, was helping other AD patients via a Facebook 'AD Buddies' group started by Brenda Grunwell. Dan carried me through my surgery and recovery. When his Aortic Dissection led to major surgery in 2018, I did my best to return the favour for my closest 'AD Buddy', including stepping-up to chair our fledgling Association. I agreed to take on the role of Chair on three conditions:

Firstly, that Catherine Fowler would serve as my Vice-Chair. I know no-one more dedicated to our cause. Motivated by the tragic loss of her father, Tim Fleming, in 2015 to a misdiagnosed Aortic Dissection, Catherine has become my trusted friend and partner in leading our Association. Catherine, thank you.



Secondly, that we would appoint a Committee to share responsibility for the work and take key decisions about the Association as it evolves. The Committee is an effective team of 12 lovely people, each of whom

contributes their particular talents and perspective to our work. I would like to thank the Committee for their time, efforts and advice, without which we would not have succeeded. I'm also very grateful to the understanding families of our Committee members, who allow them to participate in our work, indirectly helping many other families affected by Aortic Dissection.



Thirdly, that we would formally constitute ourselves as a Patient Association, to give us a loud, credible voice when asking for change in the diagnosis and treatment of Aortic Dissection. The Committee signed our Constitution on 18th March 2018 in Glasgow. You can read it here: [Our Constitution](#)

I am often asked how Aortic Dissection Awareness UK & Ireland has apparently come from nowhere, in a very short space of time, to be the powerful, national, patient voice and campaign that it is today. In my view, it is because we have patient leadership; a dedicated team of passionate individuals with real, lived experience of the disease; and a collaborative approach to achieving change in partnership with the healthcare professionals. As one eminent cardiac surgeon said to me recently:

"This national issue of Aortic Dissection that you have taken up has needed sorting out for the 25 years since I started my career in cardiac surgery".

In this, our first Annual Report, you can read about the progress we've made supporting patients and relatives affected by Aortic Dissection and changing the Aortic Dissection landscape for the better. I hope that reading it makes you feel as proud and as thankful as I do to be part of an Association dedicated to such an important cause. Thank you for your continued support of Aortic Dissection Awareness UK & Ireland. Today is a good day!

Gareth Owens, MSc. (Oxon), MBCS, CITP
Chair, Aortic Dissection Awareness UK & Ireland

MEDICAL ADVISOR REPORT



From its establishment, Aortic Dissection Awareness UK & Ireland appointed two professional Medical Advisors to the Committee: Mr. Graham Cooper, a Consultant Cardiac Surgeon at Northern General Hospital, Sheffield and a past-President of the Society for Cardiothoracic Surgery in Great Britain & Ireland; and Dr. Emma Redfern, a Consultant in Emergency Medicine at University Hospitals Bristol NHS Trust and a member of the Royal College of Emergency Medicine. We both feel very privileged to be appointed Medical Advisors to the Association and are proud of what we have all achieved together in the past year.



Emma took part in the Royal College of Emergency Medicine 'Think Aorta' podcast and in a Royal College of Radiologists webinar on 27th September 2018 about the importance of early CT imaging in the diagnosis of AD. Emma also provided evidence to a Health Service Investigation Branch investigation into the diagnosis and transfer of patients with acute aortic dissection.

Through the Coroners' Society, Graham contacted all Coroners and offered the Association's support to bereaved relatives who feel that we might help them. Graham also supported the Heart Research UK Aortic Masterclass at Keele University in November 2018 and attended the Irish College of Emergency Medicine conference in Dublin with Gareth and Catherine in October 2018, as well as meetings at the Royal College of Emergency Medicine and the Royal College of Radiologists.

We provided support to several patients with questions about the medical aspects of aortic dissection or the post-mortem reports of deceased relatives. We both also supported Aortic Dissection Awareness Day on 19th September.

Mr. Graham Cooper

Dr. Emma Redfern

Medical Advisors to the Association

MEMBERSHIP REPORT

ASSOCIATION MEMBERSHIP

On the 10th March 2019, we opened our online Membership registration at:

www.aorticdissectionawareness.org

...just in time to start signing-up new members at the Society for Cardiothoracic Surgery 2019 Annual Meeting in Westminster.

As of 28th June 2019, the Association had a total of **122** members. All of these members joined during our first year.



The Secretary has not been notified of any membership resignations.

One member, Mr. Mark Taylor, sadly died during a recent surgery. Our thoughts are with his family and with the team that cared for him.

The breakdown of Members by category is as follows:

- 67 Patients
- 38 Relatives/Carers
- 11 Healthcare Professionals
- 6 Other

The Association's membership is growing rapidly, as healthcare professionals refer patients and relatives to us and as we encourage those on our Facebook 'AD UK Buddies' group to sign-up as Members.

Anne Cotton

Secretary

Clare Payne

Assistant Secretary

AD UK BUDDIES GROUP MEMBERSHIP

Our private Facebook 'AD UK Buddies' group is the main place online where patients, relatives and carers connect to discuss their interest in Aortic Dissection and to support each other. It's a very active forum, with many interesting conversations and some great friendships being formed.



As of 1st August 2019, the AD UK Buddies Facebook group had 344 members, many of whom visit and interact on a daily basis. On average, there are 4,000 new posts, comments and reactions in the group every month. The group gained 150 new members during the year. Sadly, we also lost several AD Buddies to Aortic Dissection, including Dawn Walker and Mark Taylor.

We also operate a UK Genetic Buddies Facebook group for people with a particular interest in the genetics of Aortic Dissection; and an AD UK Buddies Bereaved Family & Friends group, where bereaved relatives can find friendship and advice and support each other.

The AD UK Buddies and our group administrators are always available online to listen and to offer advice and support to members with questions, concerns or just wanting someone to chat to.

Dan Burgess

Tony Larlham

Bridget Lawrence

'AD Buddies' Group Administrators

FINANCIAL REPORT

FINANCIAL REPORT FOR THE PERIOD: 18/03/2018 TO 31/03/2019.

The Association has opened a bank account with Yorkshire Bank.



Our activities are currently funded by small-scale donations from individuals, charities and corporations to specific projects, for which we are very grateful. If you would like to make a donation to our work, please contact our Secretary, Anne Cotton, via e-mail: hello@aorticdissectionawareness.org

The Association's summary accounts for the period are as follows:

Income - FY ending 31/03/2019	
Donations received	£1,761.50
Sponsorship received (AD Awareness Day UK 2018)	£6,000.00
TOTAL INCOME:	£7,761.50
Expenditure - FY ending 31/03/2019	
Sponsored event (AD Awareness Day UK 2018)	£6,114.19
Other expenditure	£92.68
TOTAL EXPENDITURE:	£6,206.87
Bank balance as of 31/03/2019	£1,554.63
BALANCE	£0.00

During the year, the Association purchased certain assets (a projector for AD Awareness Day and an Internet domain name for the Association's website) with a total value of £365.37.

The Association has raised sufficient funds to cover its costs and has managed its finances well during the first year of operation.

Eileen Haxby

Treasurer

Nicola McMeekin

Assistant Treasurer

PROJECTS REPORT

EXTERNAL CONFERENCES AND MEETINGS



During the year we used the power of the patient voice to tell our personal stories and outline our ambitions, in the belief that we will inspire and accelerate change. It's been an extraordinary year, visiting events that we never imagined and harnessing the support and drive of the medical community for our work. Conferences enabled our work to touch over 5,000 professionals in Cardiothoracic Surgery and Emergency Medicine across the UK, Ireland and Europe, including:

- Soc. for Cardiothoracic Surgery 2018 Annual Meeting in Glasgow
- European Soc. of Emergency Medicine Annual Congress in Glasgow
- Irish Association of Emergency Medicine Annual Meeting in Dublin
- Pathways to Progress Medico-Legal Congress in Sligo, Ireland
- UK Aortic Forum at the Belfry
- Brighton Aortic Symposium on the South Coast
- NHS England 'Voice of the Patient' Meeting in London
- Soc. for Cardiothoracic Surgery 2019 Annual Meeting in London

We continue to receive invitations to raise awareness of Aortic Dissection and present the patient case for change at many events.

AORTIC DISSECTION AWARENESS DAY 2018



Following successful events at the Royal Brompton Hospital in 2016 and at Liverpool Heart & Chest Hospital in 2017, we awarded the honour of hosting Aortic Dissection Awareness

Day UK 2018 to Barts Health NHS Trust, in recognition of the excellence of the Aortic service provided by their specialist multi-disciplinary team.

A record number of 160 patients, relatives and healthcare professionals attended from across the UK and Ireland. Our theme was 'Caring for the Whole Aorta' and the day featured patient stories and expert talks demonstrating 'what good looks like' in diagnosing, treating and caring for Aortic Dissection patients. We are very grateful to our fantastic hosts at Barts: Mr. Paul Flora, Mr. Sandip Sarkar and Prof. Aung Oo.

At the end of the day, we announced that the honour of hosting Aortic Dissection Awareness Day UK 2019 is awarded to the British Heart Foundation Cardiovascular Research Centre at the University of Leicester, led by Prof. Gavin Murphy, BHF Chair in Cardiac Surgery.



THINK AORTA

www.thinkaorta.org

Our patient-led **Think Aorta** campaign focuses on improving patient outcomes and ultimately saving lives, by improving the detection and early diagnosis of Aortic Dissection within the setting of Emergency Medicine.

Aortic Dissection is a medical emergency that is often fatal when missed. A diagnosis of Aortic Dissection is considered in less than half of the patients who present with the condition. A third of patients who present with an Aortic Dissection are initially treated for a different, incorrect diagnosis.

Think Aorta is a collaboration with The Royal College of Emergency Medicine, The Society for Cardiothoracic Surgery and Heart Research UK.

Together we created learning tools for Emergency physicians across the UK & Ireland, in the form of an educational podcast and a high-impact poster which has been distributed to every Emergency Department to increase awareness and early diagnosis of Aortic Dissection.



Think Aorta is driving awareness, education and change in Emergency Departments and receives much attention, including being featured on TV.

We are also supporting a US-based collaboration of The John Ritter Foundation, Aortic Bridge and Aortic Hope, who have joined forces to use our materials and create a national awareness campaign - **Think Aorta USA**.

EMERGENCY MEDICINE & PARAMEDIC EDUCATION

Two THINK AORTA education modules, for Emergency Medicine and Paramedics, have been developed. A half-day module has been delivered to over 100 Emergency Medicine clinicians in Norwich and in the North West region. A 3-hour Paramedic module has been accredited as part of two Paramedic degree courses at the University of East Anglia and has been delivered to 100 paramedics in the Norwich area.

Our objective is to build on these modules to provide a national educational program across the UK & Ireland, both face-to-face and via e-learning.



"Thanks to Aileen for a brave presentation. An excellent summary of Aortic Dissection from Dr. Crawford, much will be used in practice."

– ED Consultant, Norwich

AORTIC SURGERY MASTERCLASSES

We are delighted that our partner Heart Research UK is using funds donated by AD patients and their relatives to offer a programme of Aortic Surgery Masterclasses each year, which equip the next generation of Aortic surgeons with the skills they need to perform complex Aortic surgery.

To date, 70 surgeons from across the UK & Ireland have received expert coaching and training in surgical techniques, focusing on aortic dissection.



We would like to thank Miss Debbie Harrington, Consultant Cardiac Surgeon at Liverpool Heart & Chest Hospital, who leads the Aortic Surgery Masterclass programme and Helen Wilson, Head of Research at Heart Research UK, who co-ordinates the programme and ensures that all the monies donated are well-spent. We are very grateful to the AD patients and relatives who raise tens of thousands of pounds each year to fund the Heart Research UK Aortic Surgery Masterclass programme.

NHS ENGLAND SERVICE SPECIFICATION FOR THORACIC AORTIC DISEASE

We represented the patient voice on an NHS Working Group developing the new service specification for Thoracic Aortic Dissection. Working with NHS England and senior clinicians, we were part of the team led by Mr. Mark Field & Miss Rachel Bell that developed a new service model which, once commissioned, will improve Aortic surgery services nationally and will address the unwarranted clinical variation in care across the UK that currently exists. We look forward to NHS England publishing the new service specification before the end of 2019.

AORTIC DISSECTION: A UK STRATEGY

In March we launched our patient-led partnership to develop a national strategy to address the UK's challenges with Aortic Dissection, which claims almost 3,000 lives in this country every year – more than Road Traffic Accidents. We were disappointed that the new NHS Long-Term Plan did not mention the Aorta and we feel that this was a missed opportunity.



The available evidence suggests that a cohesive national strategy, in which stakeholders from different disciplines work together on awareness, education

service organization and research, will transform outcomes for Aortic Dissection patients and save 1,000 lives per year. In the spirit of patient leadership, we have partnered with the professions and with the following organizations to develop the first ever UK Strategy for Aortic Dissection.



We were also honoured to receive a letter of best wishes to the Strategy team from HM The Queen, whose ancestor King George II was the first documented case of a death from Aortic Dissection, in 1760. We will present our strategy to HM Secretary of State for Health later this year.

Catherine Fowler

Vice-Chair

Unexplained Severe Pain?

THINK AORTA

Aortic Dissection is an emergency
that is often fatal when missed

CT Scan for a definitive diagnosis

Symptoms

- Pain is the #1 symptom
- Neck, back, chest or abdomen
- Numbness or weakness in any limbs
- History of collapse

Pain characteristics can be:

- Maximal in seconds
- Migratory & transient
- Pain can be sharp, tearing, ripping

Patient Risk Factors

- Hypertension
- Aortic aneurysm
- Bicuspid aortic valve
- Familial aortic disease
- Marfans and other connective tissue disorders

Physical Examination

- Pulse deficit or vascular signs
- Neurological signs of stroke or paraplegia

Diagnostic Warning

- Chest x-ray, ECG, ultrasound & blood tests can be normal

Aortic Dissection Awareness UK in collaboration with:

Heart Research UK
Society for Cardiothoracic Surgery in Great Britain and Ireland
The Royal College of Emergency Medicine

www.thinkaorta.org

