



AORTIC DISSECTION AWARENESS UK & IRELAND

Annual Report & Accounts

2019/20



Today is a Good Day!



aorticdissectionawareness.org thinkaorta.org



@AorticDissectUK @ThinkAorta



Aortic Dissection Awareness UK

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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 across the UK & Ireland.

Our award-winning short film '**Today is a Good Day**' tells the story of the Association and our patient founders. It won the Peoples' Choice Award at the Rare Disease UK Film Festival 2020. You can watch the film [here](#).



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

Aortic Dissection Awareness UK & Ireland is formally constituted as a voluntary unincorporated association. This, our second Annual Report & Accounts, covers the financial year from 6th April 2019 to 5th April 2020.

"My husband had an acute Aortic Dissection in September 2019. He and our son now have a genetic diagnosis of Loeys-Dietz syndrome. You guys have actually saved both their lives so far. With the information I got from this group, I have been able to tackle everyone and get it sorted."

- Val Grainger

CHAIR'S REPORT



As one of the few who survive an Aortic Dissection, it is my privilege to chair our national Patient Association and help to improve care for other patients and families. With our supporters and partners in the NHS, Industry and Government, we have made huge strides this year. Four key developments stand out in particular:

- After meeting us in July, the **Secretary of State for Health and Social Care, Rt. Hon. Matt Hancock, MP**, made a public statement that not enough is being done about Aortic Dissection in the UK and committed himself to working with us to tackle the problem of diagnosis and commission more Aortic Dissection research. Watch Matt's video [here](#).
- In January, the **Healthcare Safety Investigation Branch** published a report highlighting that **lack of recognition and delayed diagnosis of acute Aortic Dissection is a national patient safety issue**. We are working with the Royal College of Emergency Medicine and the Royal College of Radiologists as they lead on the national response to this.
- For the first time in its history, the **NHS** is well on its way to having a formal **Service Specification for the delivery of Aortic Dissection surgery**. When implemented with the support of the Society for Cardiothoracic Surgery and the Vascular Society, this initiative will significantly improve care and outcomes for AD patients across the UK.
- **AD Awareness Day UK 2019**, hosted by Prof. Gavin Murphy and his team at the British Heart Foundation Cardiovascular Sciences Research Centre at the University of Leicester, has led to a new clinical trials project which we expect, in time, will **enable the UK to become the first country in the world to introduce targeted screening for AD risk**. This will prevent many Aortic Dissections before they occur.

Raising awareness of Aortic Dissection has started to create recognition of the problem and discussion at a national level. This is incredibly encouraging, but now it needs to lead to real change. **Aortic Dissection causes more deaths each year in the UK than Road Traffic Accidents.** Many people are dying unnecessarily. This is what motivates us, as we commit ourselves to the urgent challenge of implementing change that benefits AD patients.

This change can only be achieved through our network of influential partners and with the support of the **NHS** and **Government**. We are fortunate to have two senior NHS clinicians, one from Emergency Medicine and one from Cardiac Surgery, as our Medical Advisors. Their report is on page 5. Also, I'm delighted that our good friend **Pauline Latham, OBE, MP**, has written a report on page 7 about our Parliamentary campaign, which she leads.

The Association developed international links this year. We supported the team led by Carin Andersen of **Aortic Hope** in the USA, as they rolled out the **Think Aorta US** campaign to 6,000 Emergency Departments. It was also my great pleasure to welcome Dr. Dianne Milewicz and Amy Yasbeck of **The John Ritter Foundation for Aortic Health** as our guest speakers for AD Awareness Day UK.



The Committee, most of whom are themselves affected by AD, have done a sterling job again this year. We recently co-opted three AD survivors as our Country Representatives for Wales, Scotland and Ireland, to co-ordinate and develop our work in those nations. As ever, I could not have carried out my role without the support of the Committee and especially the friendship and support of my Vice-Chair, Catherine Fowler, for which I am very grateful.

I hope that this report informs and inspires you. Thank you for your ongoing 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 are both proud to have continued our work as Medical Advisors to Aortic Dissection Awareness UK and Ireland this year.

Although 2019/20 activities were curtailed by COVID-19, we have still been busy. We both attended the meeting with Matt Hancock, Secretary of State for Health and Social Care in July and of course we both supported Aortic Dissection Awareness Day UK on 19th September.

We provided input into the Association's submission to NICE requesting that a clinical Guideline is produced for Aortic Dissection. We also supported the work of Dr. Ter-Er Kusu-Orkar, an academic FY1 doctor in the East Midlands, in establishing the National Aortic Dissection Medical Education Committee (NADMEC), the first meeting of which has been postponed due to COVID-19.

Emma, with her colleagues Mark Callaway (Radiology), Marcus Brooks (Vascular Surgery) and Cha Rajakurana (Cardiothoracic Surgery), did a lot of work with the Association preparing to host AD Awareness Day UK 2020 in Bristol, until COVID-19 forced its postponement to 2021. She and Mark also made important contributions to the HSIB report on delayed diagnosis of AD.

On 19th September, Emma had the honour of giving the prestigious **Lilly Lecture** at the Royal College of Physicians, taking as her topic the medical leadership required in Aortic Dissection. You can watch her lecture [here](#).

Graham supported two **Heart Research UK Aortic Surgery Masterclasses** at Keele University and the national UK Aortic Surgery Forum at The Belfry. In February, with Gareth and Catherine, he met Dr. Katherine Henderson, President of the Royal College of Emergency Medicine to talk about the challenges of diagnosing AD in UK Emergency Departments. He was appointed as NHS England's National Clinical Advisor for Acute Aortic Dissection and has been working with the **NHS England Specialised Cardiac Improvement Programme**, with patient input from Gareth and Catherine, to introduce 24x7 rotas for acute Type A Aortic Dissection surgery across all NHS regions. We hope that this work will restart in the Autumn.

We have both provided support to several patients who had questions about medical aspects of Aortic Dissection or the post-mortem reports for their deceased relatives.

We hope that as the COVID-19 threat fades we will be able to resume our activities in the Autumn and we look forward to another year of advising and working with the Association.

Mr. Graham Cooper

Dr. Emma Redfern

Medical Advisors to the Association

PARLIAMENTARY REPORT



In a year which saw prorogation, a general election and four months of a pandemic lockdown interrupt the parliamentary calendar, I have still been actively campaigning to raise awareness of Aortic Dissection in Westminster.

Many MPs start from a position of knowing nothing about Aortic Dissection and I am continually reassured by the sincerity with which MPs, particularly my ministerial colleagues, are keen to learn more and discuss what they can do about it as policy-makers. I met with the Health Secretary, Matt Hancock, in June and July 2019 to discuss **a national Aortic Dissection strategy** and he was very receptive to the idea, releasing funding for further research. I am very hopeful that many of the recommendations contained in the **HSIB report** will form the basis of a future strategy.

I have also raised the issue publicly in Parliament, tabling questions to the Department of Health and Social Care, asking what steps are being taken to ensure the adequate diagnosis of Aortic Dissection at A&E departments. I was pleased to see in Jo Churchill MP's response that NHS Improvement's

Specialised Cardiac Improvement Programme has developed a guide and toolkit to support standardisation across A&Es from Spring this year.

Many of the new 2019 intake of MPs have also expressed an interest, particularly those with a medical background, like Dr Luke Evans MP. It is vital that we continue to convert this interest into action. One of the ways I will be doing that is by joining the **All Party Parliamentary Group on Rare Diseases**, a cross-party forum to help galvanise the debate in Parliament on diseases like Aortic Dissection.

I also hope to hold a **Westminster Hall debate on Aortic Dissection**, though this will have to be in Autumn 2020 given the delays the lockdown has caused. I had been looking forward to attending the Aortic Dissection Awareness Day in Bristol in September but sadly it has been postponed due to COVID-19, so I will try to attend future days. I remain committed to raising the profile of Aortic Dissection in Parliament and achieving a lasting legacy in improving patient outcomes through legislative change.

Pauline Latham, OBE, MP

Member of Parliament for Mid-Derbyshire

MEMBERSHIP REPORT

ASSOCIATION MEMBERSHIP

As of 5th April 2020, the Association had a total of **240** members who signed-up at our website www.aorticdissectionawareness.org and **456** members of our private AD Buddies Facebook support group, compared with figures of **122** and **344** respectively a year ago. This represents a very significant growth in our overall membership.

The Secretary has not been notified of any membership resignations.

Four members of the Association: Barbara Starkey, Barbara Suttle, Mark Taylor and Peter Naden sadly died during the year. Our thoughts are with their families and with the teams that cared for them. We value the opportunity that was ours to know and support them on their Aortic Dissection journey and we will continue our work in their memory.

The Association's membership is growing rapidly, as specialist Aortic centres and other healthcare professionals refer patients and relatives to us, in our unique role as the trusted organization where families in the UK & Ireland affected by Aortic Dissection can go to find advice, support and friendship.



The Association's Secretary, Anne Cotton, is also the direct contact to whom Coroners can refer bereaved relatives to access our support.

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. The most common post by new members is that they no longer feel alone and are happy that they found us. Some members have received life-saving advice.



As of 5th April 2020, the **AD UK Buddies** Facebook group had **456** members. On average, there are over 5,000 new posts, comments and reactions in the group every month. The group gained **112** new members during the year. This membership growth is driven by hospitals referring their patients to us and Coroners referring bereaved families to us for support. Sadly, we lost several of our AD Buddies to Aortic Dissection during the year, including our dear friends Mark Taylor, Barbara Starkey, Barbara Suttle and Peter Naden. We also operate an AD 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. The **AD UK Buddies** support network has proved invaluable during the COVID-19 lockdown. There is always someone online to help members with questions, concerns or just needing a chat.

Dan Burgess

Tony Larlham

Bridget Lawrence

AD UK Buddies Group Administrators

FINANCE REPORT

FINANCIAL REPORT FOR THE PERIOD: 06/04/2019 TO 05/04/2020.

The Association banks 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:

<i>Bank balance as of 06/04/2019</i>	<i>£1,554.63</i>
Income - FY ending 05/04/2020	
Donations received	£2,306.24
Sponsorship received (AD Awareness Day UK 2019)	£6,000.00
TOTAL INCOME:	£8,306.24
Expenditure - FY ending 05/04/2020	
Sponsored event (AD Awareness Day UK 2019)	£8,094.07
Other expenditure	£346.71
TOTAL EXPENDITURE:	£8,440.78
<i>Bank balance as of 05/04/2020</i>	<i>£1,420.09</i>
BALANCE	£0

The Association did not purchase any assets during the year. The total value of assets is unchanged at £365.37. The Association has no liabilities.

Expenditure for the year slightly exceeded income, by £134.54. This was covered by cash reserves. The Association has managed its finances well during its second year of operation.

Eileen Haxby

Treasurer

Nicola McMeekin

Assistant Treasurer

STRATEGY REPORT

Our strategy, launched in 2019, continues apace. Changing how national healthcare systems manage a complex disease like Aortic Dissection is challenging and takes time. Our strategic vision has attracted widespread support. We are pleased with the progress being made on the following initiatives, despite the challenge of creating change and the impact of COVID.

HSIB INVESTIGATION OF ACUTE AORTIC DISSECTION

Prompted by the tragic death of a 54-year old man due to a delayed diagnosis of Aortic Dissection, the Government's **Healthcare Safety Investigation Branch** conducted a full investigation into the issues surrounding accurate diagnosis, referral and transfer for treatment of patients with AD. We would like to thank HSIB and in particular Dr. Nick Toff, the investigator, for their detailed professional analysis and recommendations. As a result of the



investigation, HSIB produced two important patient safety reports (click the links to read): [Transfer of Critically-Ill Adults](#) and [Delayed Recognition of Acute Aortic Dissection](#).

The **Department of Health** and the **Association of Ambulance Chief Executives** have formally responded to the first report and are taking its recommendations forward. The **Royal College of Emergency Medicine** and the **Royal College of Radiologists** have been tasked with responding to the second report and we are working with them to ensure that the response reflects the best practice of our **Think Aorta** campaign. Implementing the HSIB safety recommendations is a key initiative which will reduce the number of people dying unnecessarily of Aortic Dissection in Emergency Departments and during transfer for surgery. We estimate that up to 1,000 lives a year could be saved if an effective response is delivered nationally.

AORTIC DISSECTION AWARENESS DAY UK 2019



The honour of hosting AD Awareness Day UK 2019 was awarded to the British Heart Foundation Cardiovascular Sciences Research Centre in the University of Leicester, at Glenfield Hospital. Our theme was 'AD Research' Led by our host Prof. Gavin Murphy and his team, 160 delegates participated in a collaborative research process which reached a consensus that **relatives of patients with thoracic aortic disease should receive imaging and genetics screening**. We are taking this project forward, with the aim of the UK becoming the first country in the world to introduce a targeted screening programme for Aortic Dissection risk. The results of our work were published recently in the international journal '*Trials*'. You can read the paper [here](#).

NHS NEW SERVICE SPECIFICATION FOR England THORACIC AORTIC DISEASE

Progress in converting the excellent work done by the Working Group of senior clinicians and patient representatives into an official NHS Service Specification has been slower than we would have liked. When trying to change things in the NHS, there are many bureaucratic hurdles to overcome. However, we are pleased that Ursula People, a senior Commissioner in **NHS England Specialised Commissioning**, has picked up the leadership of this initiative. It's also encouraging to see some forward-thinking Aortic specialist centres improving their services ahead of publication of the new service specification. The new service model, once commissioned, will improve Aortic surgery services nationally and will address the unwarranted regional variation in care and outcomes across the UK which currently exists.



Acute Type A Aortic Dissection is almost always fatal unless emergency surgery is undertaken. Outcomes for patients are improved if this surgery is undertaken by specialist surgeons. To enable access to specialist surgeons

requires specialist Aortic surgery centres to co-operate in providing a region-wide 24x7 rota. This need was recognized by the 'Getting It Right First Time' (GIRFT) recommendation 14 of the National Report on Cardiothoracic Surgery, which says that Acute Aortic Syndrome patients should only be operated on by rotas of Acute Aortic Syndrome specialist teams.

In addition, we know that about **one third of patients with acute Type A Aortic Dissection who should undergo surgery do not**. This is often due to a failure to diagnose the condition. This toolkit, developed by the NHS England Specialised Cardiac Improvement Programme (SCIP) in collaboration with patients and relatives from AD Awareness UK & Ireland, is an important step to improve outcomes for these patients. Launch of the toolkit was scheduled for April 2020, but has been delayed by COVID-19.

NADMEC

(NATIONAL AD MEDICAL EDUCATION COMMITTEE)

As Chair of the recently-established National Aortic Dissection Medical Education Committee (NADMEC), Dr. Ter-Er Kusu-Orkar is able to combine his passion for education with his interest in Cardiothoracic surgery, in particularly Aortic surgery. He founded NADMEC after realising the lack of attention Aortic Dissection received throughout his medical education and

work life; despite the profound effect that a better initial diagnosis can have on Aortic Dissection prognosis. He was excited to realise that AD Awareness UK & Ireland and its **Think Aorta** campaign had similar aims to educate younger medical students and doctors, but had not yet addressed this need.

With the support of the Association's Medical Advisor and Committee, Dr. Kusu-Orkar has launched this initiative and formed an Executive and an extended Committee. The aims of NADMEC are simple, but ambitious:

- *Educate junior doctors and medical students on aspects of diagnosing and initially managing an Aortic Dissection.*
- *Ultimately, liaise with Medical Schools and Foundation programmes to include Aortic Dissection teaching as a core part of their curriculum.*

Dr. Kusu-Orkar says that this will be a challenge, however he believes that the Aortic Dissection patients and their families who will benefit from NADMEC's efforts in the future make it all worthwhile.

NICE

(NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE)

The Association became an official NICE stakeholder during the year and commented on a number of draft NICE guidelines related to Aortic disease.



Hypertension in Adults - Diagnosis and Management (*Draft Guideline GID-NG10054*). We highlighted the need for urgent and effective blood pressure control in Aortic disease and requested that the guideline recommend a more urgent and proactive blood pressure management pathway for patients with such a high, short-term risk.

Medicines to Control Blood Pressure - Patient Decision Aid. This NICE tool helps patients understand their options and contribute to the process of selecting their blood pressure medicines. We liked the Patient Decision Aid, but highlighted that conditions like Aortic disease need more urgent and effective blood pressure control than normal. We requested inclusion of such a proviso and signposting within the document. NICE declined our request.

Workplace Health: Long-term Sickness Absence and Capability to Work (*Update to Guideline NG146*). We made comments on this guideline, which covers criteria for people on 'long-term' sickness returning to work in a managed way. A particular concern was the definition of 'long-term' illness as being more than 4 weeks. We argued that the guidance should differentiate between this situation and the needs of someone with 'extended' illness, such as the ongoing debility, often for years, that is many AD patients' experience

Chest Pain of Recent Onset (*Proposed Update of Guideline CG95*)

We reviewed this guideline and found that it does not adequately cover acute Aortic Dissection. AD is mentioned only peripherally, as something to consider once heart attack has been ruled out. This does not align with



best practice diagnosis or with the message of our **Think Aorta** campaign. NICE decided not to update the guidance, but suggested instead that we might propose acute Aortic Dissection as a topic for new guidance in its own right.

Acute Aortic Dissection: Diagnosis and Treatment (*Request for a new Guideline*). We were excited by the opportunity to make a strong case for official NICE Guidance on Aortic Dissection and we put a lot of work into our submission, highlighting the national problem and the need for NICE Guidance in order to raise awareness and save lives. After a technical review, NICE declined our request to produce such Guidance. We have written to Dr. Paul Chrisp, Director of the Centre for NICE Guidelines, requesting a meeting to discuss this decision.

Abdominal Aortic Aneurysm (*Guideline NG156*). We welcomed the modifications that NICE made to the controversial draft AAA guideline, about which we had commented in 2018. We felt that the guideline's strong bias towards open surgical repair ignored more recent evidence and established practice in the use of EVAR. We are pleased that NICE eventually decided not to deprive patients and their clinicians of the ability to choose the optimum treatment in each case.

Outcomes: We remain optimistic that our work and our status as a NICE stakeholder will, in due course, lead to Aortic Dissection being properly recognized and included within NICE clinical guidance. However, at present, NICE is the only national healthcare agency we have approached which is not aligned to or supporting our **Think Aorta** campaign. The Association's work with NICE, led by AD survivor Cliff Grover, will continue, because we believe that NICE has a key role to play in providing best practice clinical guidance to tackle the UK's national problem of Aortic Dissection.

Cliff Grover

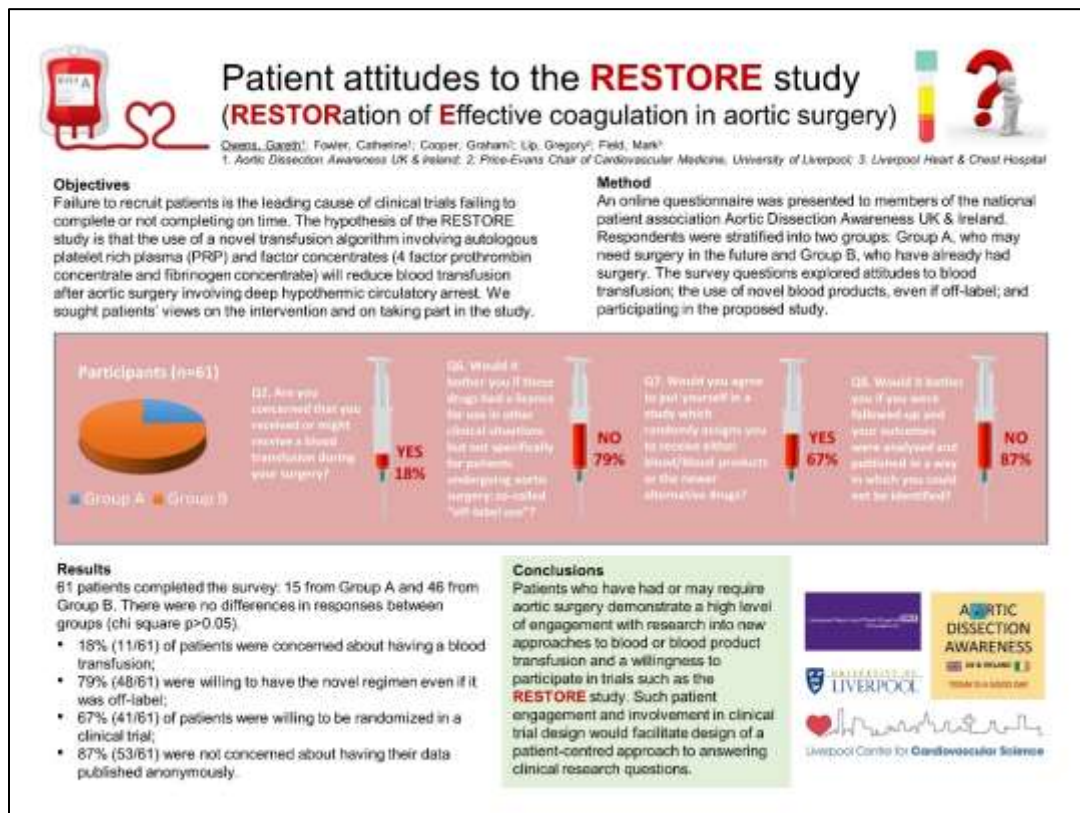
Scotland Rep & NICE Liaison

RESEARCH REPORT

As the voice of patients and families in the UK & Ireland, the Association receives many invitations to get involved with Aortic Dissection research. This can range from letters of support and patient input for a grant application; through providing patient representatives for a steering committee, undertaking Patient & Public Involvement work as part of a study and (in some cases) recruiting our members to take part; to full collaboration as part of the research team and co-authorship of the resulting papers.

This year, our collaborative research project with Prof. Gavin Murphy and his team at the University of Leicester delivered a consensus that **relatives of patients with thoracic aortic disease should receive imaging and genetics screening**. Our first paper from this project was recently published in the international journal 'Trials' and you can read it [here](#).

Our abstract for the **RESTORE** study, with the University of Liverpool and Liverpool Heart & Chest Hospital, is the first patient-led abstract accepted for presentation at the Society for Cardiothoracic Surgery Annual Meeting:



Research was a major topic of our discussion with Secretary of State for Health, Matt Hancock, who committed to holding a workshop to identify the gaps and priorities in UK Aortic Dissection research and making funding available to address them. The scheduled workshop had to be postponed due to COVID-19. We look forward to it re-convening as soon as possible.

We were disappointed that, despite a personal letter of support from the Secretary of State for Health, the **Healthcare Quality Improvement Partnership (HQIP)** rejected Dr. Emma Redfern's proposed **NCEPOD** study regarding the diagnosis of AD in Emergency Departments and transfer to specialist units. We believe that this study would go a long way towards understanding and resolving the national issues highlighted by the recent HSIB investigation report and we will be encouraging Emma to apply again.

Overall, we are pleased that the national issues associated with a complex disease like Aortic Dissection appear to be slowly moving up the research agenda. We need more research, in order to provide better care and outcomes for Aortic Dissection patients. We will work with any researchers who can clearly demonstrate that their proposed research benefits patients and moves us towards that goal.



PROJECTS REPORT

EXTERNAL CONFERENCES AND MEETINGS

The power of the patient voice remains at the heart of our campaign for change. We continue to tell our personal stories, sharing the successes and failures and our bold ambitions, in the belief that we will inspire and accelerate change across the AD patient pathway in the UK and Ireland. It has been a challenging year, with the unprecedented recent impact on people and the healthcare system from COVID-19.

Prior to the pandemic, our team attended many events in order to raise awareness and harness the support of the medical community for our work. This enabled us to reach thousands of professionals in Emergency Medicine and Aorto-Vascular Surgery. The events included:

- *Soc. for Cardiothoracic Surgery 2019 Annual Meeting - Westminster*
- *Royal College of Emergency Medicine Annual Congress - Newcastle*
- *UK Aortic Forum – The Belfry*
- *Barts Aortovascular Symposium - London*
- *London Aorta*
- *Liverpool Aortic Symposium*
- *Aorta: 'From Structure to Rupture' Research Meeting, Liverpool*
- *'Dissecting Dissections' Vascular Surgery Education Day - London*
- *RCEM Safety Meeting – York & Hull Medical School*
- *Pre-Hospital Educators Day – University of East Anglia*
- *FASSGEM Annual Conference – Liverpool*
- *MBRRACE Annual Conference and Report Launch – Birmingham*
- *Rare Disease Day UK Reception – Westminster*
- *Grand Round at Univ. Hospitals North Midlands NHS Trust - Stoke*

THINK AORTA www.thinkaorta.org

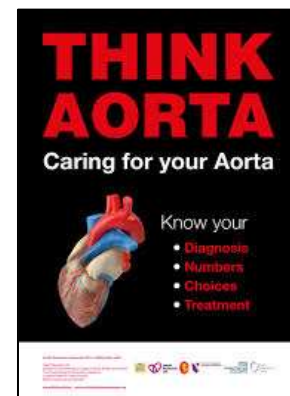
Our patient-led **Think Aorta** campaign continues to focus on improving patient outcomes and ultimately saving lives. By increasing awareness and education, we are improving the diagnosis of Aortic Dissection in the Emergency Medicine setting.

Think Aorta is the Association's collaboration with the Royal College of Emergency Medicine, the Society for Cardiothoracic Surgery and Heart Research UK. Together, we created a number of learning resources for Emergency Care practitioners in the UK & Ireland, which are freely available to download from our website www.thinkaorta.org.



We were delighted to be approached by a team from the USA who wanted to launch a **Think Aorta US** campaign. This has been successfully achieved through a collaboration with the **John Ritter Foundation, Aortic Hope** and **Aortic Bridge**, who joined forces to take our **Think Aorta** materials and tailor them to spread awareness across the USA.

In response to feedback from patients, relatives and the medical profession, we have created a patient education leaflet about the Aorta. The '*Caring for your Aorta*' leaflet was created with and is approved by Liverpool Heart and Chest Hospital; the Society for Cardiothoracic Surgery; the British Cardiovascular Society and the Royal College of Emergency Medicine. We are very grateful to **Heart Research UK** for funding it. Our distribution plan covers every UK Cardiac Surgery centre initially, with Vascular Surgery centres and ICC clinics to follow.



PARAMEDIC EDUCATION

Our **Think Aorta** education module for Paramedics continues to be delivered to East of England Ambulance Service by our



Paramedic Lead, Simon Rose and the University of East Anglia. Over 200 student Paramedics and 100 registered Paramedics have been trained to date. The module has also been rolled-out to regional Paramedic Educators in East Anglia. The module covers key information about acute Aortic Dissection and why diagnosis is commonly missed by both pre-hospital and in-hospital clinicians. Simon now has plans to deliver this module to the Yorkshire Ambulance Service. Our objective is to build on the success of this module and establish a national Paramedic education program in the UK and Ireland, using face-to-face sessions and e-learning.

THINK AORTA REGIONAL EDUCATION DAYS

Working in partnership with Mr. Geoff Tsang, Consultant Cardiothoracic Surgeon at University Hospital Southampton Foundation NHS Trust, we planned the first ever **Think Aorta** Regional Education Day, in the Wessex region. The event was scheduled for May, but will now be held in November as a virtual event, due to COVID-19. The day will cover the management of an acute Aortic Dissection, from initial involvement of healthcare professionals, through assessment and investigations for first responders, to diagnosis and transfer; then to surgical and medical management within the hospital setting and crucially, the impact of all of this on the patient and their relatives.

AORTIC SURGERY MASTERCLASSES

Aortic surgery is difficult to train for, because the operations are complex and highly-specialised, coupled with there being a relatively small number of patients. We are delighted that our partner **Heart Research UK** continues to use funds donated by AD patients and their families to offer, each year, a unique programme of Aortic Surgery Masterclasses, which equip the next generation of Aortic surgeons with the skills they need to perform complex Aortic surgery.

To date, 100 surgeons from across the UK and Ireland have received expert coaching and training in surgical techniques focusing on Aortic Dissection.



We would like to offer our continued thanks to Miss

Debbie Harrington, Consultant Cardiac Surgeon at **Liverpool Heart & Chest Hospital**, who leads the Aortic Surgery Masterclass programme; and to 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.

Catherine Fowler

Vice-Chair

CONTACT US



aorticdissectionawareness.org thinkaorta.org



@AorticDissectUK @ThinkAorta



Aortic Dissection Awareness UK



hello@aorticdissectionawareness.org

COMMITTEE OFFICERS



Chair

Gareth Owens
chair@aorticdissectionawareness.org



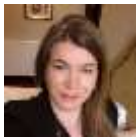
Secretary

Anne Cotton
secretary@...



Treasurer

Eileen Haxby
treasurer@...



Vice-Chair

Catherine Fowler
vicechair@aorticdissectionawareness.org



Assistant Secretary

Clare Payne



Assistant Treasurer

Nicola McMeekin

COMMITTEE MEMBERS



Founder

Dan Burgess



Medical Advisor

Graham Cooper



Medical Advisor

Emma Redfern



AD Buddies Group Administrator

Tony Larlham



Committee Member

Stefan Paudler



Committee Member

John Greenstreet



Country Rep – Wales

Alison Roberts-Pagent
wales@aorticdissectionawareness.org



Country Rep – Ireland

Steve Curry
ireland@...



Country Rep – Scotland

Cliff Grover
scotland@...

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

