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Draft Programme

Aortic Dissection Awareness Day UK

18th September 2025

BOOK NOW!
Patients and Family

BOOK NOW!
Healthcare Professionals



Conference Venue
St Martin's House
7 Peacock Lane,
Leicester, LE1 5PZ

Tickets—there are some rules, please read them before booking

This is a **fully ticketed event** and is reserved for **eligible participants only**. Admission only by an original, valid Eventbrite® ticket. No copies, scans or duplicates. Tickets are not transferrable. One ticket per person. Eligibility is at the sole discretion of the organisers.

Please **ONLY book for yourself (+/- family member or supporter)**. No third-party or block bookings.

Patient eligibility: Thoracic Aorta Disease patient (i.e. Thoracic Aortic Dissection or Aneurysm or syndrome). Each Patient may be accompanied by ONE Family member or supporter. This requires TWO tickets.

Healthcare workers eligibility. Employed in healthcare (i.e. not students) and interested in Thoracic Aortic Dissection or Aneurysms or syndromes). AFTER 1st May 2025

Medical students who would like to attend, should inquire by email only, to hello@aorticdissectionawareness.org AFTER 1st July 2025.

Researchers. We welcome researchers with relevant interests. Please inquire by email only, to hello@aorticdissectionawareness.org no date restriction.

Cost of tickets

There is no charge for attending and participating in this event. The actual cost (venue, catering, other costs) is somewhat over £50 per person... So, please try to avoid late cancellation or (still worse), simply not turning up. This event is usually fully booked. Casual 'no-show' = thoughtless, expensive, rude and denies a place to somebody else who would like to participate...

Badges

All delegates and guests will receive a name badge at the registration desk. Please wear your badge at all times.

Catering facilities

The catering stations for the coffee and lunch breaks are located in the Main Hall. Coffee breaks and lunch buffets are included in your registration.

Venue

St Martin's House
7 Peacock Lane
Leicester LE1 5PZ

Disclaimer

The organisers cannot be held liable for any hindrance or disruption of congress proceedings arising from political, social or economic events or any other unforeseen incidents beyond their control. The organisers will accept no liability for any personal injuries sustained or for loss or damage to property belonging to congress participants, either during or as a result of the congress or during all events. Registration of a participant entails acceptance of these conditions.

Helpful telephone numbers

Police: (national) 999

Fire: (national) 999

Ambulance: (national) 999

Uber services are available

How to get to St Martin's House

www.stmartinshouse.com/contact-us/how-to-find-us

Accommodation

www.stmartinshouse.com/our-venue/bedrooms

Please use the code 'Aortic Dissection Awareness Day' when booking. Your booking and contract is solely with St. Martin's House and subject to their terms and conditions including cancellation.

A SPECIAL YEAR

Most of us will be aware, often through personal experience, that Thoracic Aorta Disease often runs in families – it has, at least for some, a strong genetic background.

As we learn more about genetics in general, and the genetics of Thoracic Aorta Disease in particular, we turn up some important, and complicated, questions.

Who should be offered genetic testing? Who should have screening scans? Should we screen siblings? Children? Other relatives? Everyone? What are the implications and pitfalls of doing this?

Aortic Dissection Family Screening: The DECIDE-TAD Programme

DECIDE-TAD is our NIHR-funded strategic research partnership with the University of Leicester, looking at preventing Aortic Dissection through the screening of 1st and 2nd degree relatives of people who have the disease.

The aims of the programme are to design a tool to help people at risk of Thoracic Aortic Disease decide if they want to participate in screening; to develop a screening, monitoring and treatment pathway for those who do; to evaluate this pathway to provide evidence that it works; then to implement it as a part of standard NHS care.

The programme evolved from our 2019 Aortic Dissection Awareness Day UK conference, held in Leicester, which was a large-scale Patient & Public Involvement event attended by 160 patients, relatives, clinicians and researchers. Our Chair, aortic dissection survivor Gareth Owens, co-leads the programme with Prof. Gavin Murphy, BHF Chair of Cardiac Surgery at the University of Leicester. This is a true research partnership. A team of patients and relatives from our national patient charity contributes to every aspect of the research, co-creating all plans, designs and outputs, advising on PPI and EDI matters, conducting some of the research and disseminating the results. The DECIDE-TAD programme is supported by our THINK AORTA, THINK FAMILY campaign.

The first phase of the programme received an NIHR Programme Development Grant and completed in mid-2023. We are delighted as a result of this work to have been shortlisted and invited by NIHR to submit an application for a Phase 2 Programme Grant for Applied Research (PGfAR) for the full DECIDE-TAD programme. To date, 24 of the 29 cardiac surgery centres in the UK have expressed interest in being a part of DECIDE-TAD. Together with the partnership between researchers and our national patient charity, this means that the DECIDE-TAD programme is well-placed to deliver national change in care pathways which benefits TAD patients and their family members at risk of the disease.

Over 200 of our members have been involved in the DECIDE-TAD research to date. Our charity's patient engagement in the programme is led by a core team of five PPI partners: Gareth Owens, Haleema Saadia, Mark Lewis, Lisa Skinner and Anne Cotton, supported by our Head of Research, Gordon McManus.

This year, genetics in general and the DECIDE-TAD research project are an important part of our conference.

Our researchers need your help...

---- everybody, not just patients...

We aren't going to use you for experiments

We aren't going to collect your personal medical history, your blood or your data...

We are going to ask you to help – by thinking about how you feel about genetic testing and screening for patients and their families. We'll do this in some workshops which are built into the programme.

Not just genetics—don't worry, there's plenty of other stuff in the programme as well.

So, book your place and join us in September....

PROVISIONAL PROGRAMME

09:00-09:30 30min	Registration & Coffee	
	Welcome & Introductions	Grand Hall
09:30-09:37 7min	Mrs Anne Cotton, Chair, Aortic Dissection Awareness UK & Ireland	Grand Hall
09:37-09:40 3min	Professor Nilesh Semani, Professor of Cardiology, University of Leicester	Grand Hall
	Let's get clinical...	Grand Hall
09:40-09:55 15min	Patient story, tbc, tbc ??with surgeon??,	Grand Hall
09:55-10:15 20min	Genetics 101 - Boy meets girl and beyond, tbc tbc	Grand Hall
10:15-10:45 30min	New genetics in a changing NHS – 100,000 genomes and beyond, Professor Julian Barwell , Professor in Genomic Medicine, University of Leicester	Grand Hall
	Your charity in action	Grand Hall
10:45-10:55 10min	ADAUK&I update, Various from Committee/Trustees	Grand Hall
10:55-11:00 5min	Think Aorta® international programme, Robert Glass , International lead for Think Aorta®	Grand Hall
11:00-11:30 30min	Coffee Break	Atrium
11:30-11:45 15min	My aorta - How I learned to stop worrying & love the bomb..., Mr Robert Glass , Patient story	Grand Hall
	Decide-DAD Project	Grand Hall
11:45-12:35 50min	Introduction, Professor Gavin Murphy & Marie ?? , Professor of Cardiac Surgery, University of Leicester	Grand Hall
	Cascade screening in the UK	Grand-Hall
	Making sense of workshops	Grand Hall
12:35-12:45	Remembering those who have died of Aortic Dissection, Bereavement Team	Grand-Hall
12:45-13:45 60min	Lunch Break	Atrium
	Decide-DAD Project	Grand-Hall
13:45-15:00 75min	Workshop A	Room A tbc
	Workshop B	Room B tbc
	Workshop C	Room C tbc
	Workshop D	Room tbc D
15:00-15:30 30min	Tea Break	Atrium
15:30-15:55 25min	Queries, comments & themes from workshops. Roundup on genetics research. Gavin Murphy & Maria	Grand Hall
	Patient originated topics	Grand Hall
15:55-16:20 25min	"Am I losing my marbles?" Science, realities & remedies..., Prof Rob Sneyd, Vice- Chair & Mrs Emma Hope, Aortic Nurse Specialist, Aortic Dissection Awareness UK & Ireland	Grand Hall
16:20-16:50 30min	Open Mic... Open House, ?? Benefits and driving??. Trustees and Guests , Topical free for all..	Grand Hall
16:50-17:00 10min	Closing Remarks, Announcement & Preview/Handover of AD Awareness Day UK 2026, Chair & Vice-Chair , Wrap up & look ahead	Grand Hall
17:00	Close	