

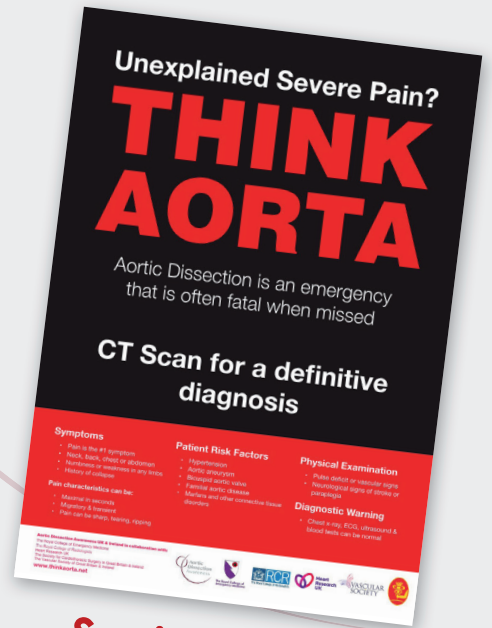
2023 IMPACT REPORT

Aortic Dissection Awareness

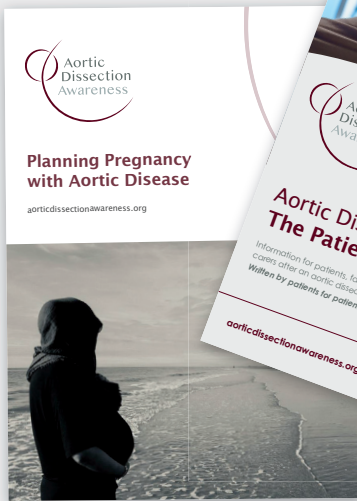
The Patient Charity



Supporting Patients



Saving Lives



Improving Care



Enabling Research



Aortic Dissection Awareness UK & Ireland

Best Specialist Patient Support Charity 2023 - UK

aorticdissectionawareness.org



Aortic
Dissection
Awareness

The Patient Charity

**“You helped
save my life!
Imagine where
I would be now
if you hadn’t
told me that I
needed to see
a specialist
Aortic surgeon.”**

2023 IMPACT REPORT

Supporting Patients – Saving Lives – Improving Care – Enabling Research



Emma, 32, (2nd from right) was discharged from her local hospital with an extensive Type B Aortic Dissection, then had genetic testing and a successful open surgical repair of her Aorta after we arranged her referral to a specialist Aortic centre.

Supporting Patients & Families – Building Community

Online Support: Provided 24x7 support to members of our private, moderated [AD Buddies](#) online peer support group – sustaining and growing our engaged, empowered and resilient community of around **1,000 individuals affected by Aortic Dissection**.

Community Engagement: Organised well-attended AD Buddy social meets in the North, the South, the Midlands & Ireland. Sponsored and jointly organised the **Barts 900 AD Patient Day** in London. Face-to-face engagement, connecting patients and families.

Patient Empowerment: Distributed over **3,000 copies** of our acclaimed patient handbook [Aortic Dissection: The Patient Guide](#), now endorsed by three professional societies.

Global Reach: Published the [US edition of Aortic Dissection: The Patient Guide](#) and began work on Spanish and German translations, extending the reach and benefits of our work.

Awareness Days: Organised two national Aortic Dissection Awareness Days on 19th September: the UK event hosted by [Royal Papworth Hospital, Cambridge](#) and the Ireland event hosted by [St. James's Hospital, Dublin](#). Over 150 delegates attended the two days.

Tailored Support: Provided individualised support to Aortic Dissection patients in extreme circumstances - see **Emma** and **Paige's** testimonials as examples.

Recognition: Named “[Best Specialist Patient Support Charity, UK, 2023](#)” in the international Non-Profit Organization Awards.

www.aorticdissectionawareness.org



Aortic Dissection Awareness UK & Ireland

Best Specialist Patient Support Charity 2023 - UK



2023 IMPACT REPORT

Supporting Patients – Saving Lives – Improving Care – Enabling Research

The Patient Charity

“My brother goes for his surgery tomorrow at 8am. I want to say a massive thank you to Aortic Dissection Awareness UK & Ireland for helping us get here. Our family will never be able to repay you for the hope you have given us.”



Paige, whose brother Richard, 42 (right) was given 48 hours to live due to an inoperable Type A Aortic Dissection in August, then had successful life-saving surgery in December at a specialist centre after we secured a medical re-evaluation of his case.

Improving Care – Advocating for Better Outcomes

Implementing the NHS AAD Toolkit: Our patient teams supported the implementation of the [NHS England Acute Aortic Dissection Toolkit](#) across the English regions, ensuring that the patient voice is central to improving standards in Aortic Dissection care.

National Policymaking: Our Chair, Gareth Owens, was invited to be the expert patient voice on the national [Aortic Dissection Steering Group](#) convened by the Secretary of State for Health, Steve Barclay. In this role he influences policy at the highest level.

Patient Advocacy: We provided AD patient speakers for medical events in London, Cambridge, York, Birmingham, Bristol, Nottingham, Derby, Lincoln, and Leicester.

For the **Cambridge Aorta** conference in November, we fielded a team of three patient speakers - all Cambridge graduates & acute Type A Aortic Dissection survivors. From left to right they are **Dr. Christopher Stewart**, **Prof. Rob Sneyd**, and **Dr. Gordon McManus**.



www.aorticdissectionawareness.org



2023 IMPACT REPORT

Supporting Patients – Saving Lives – Improving Care – Enabling Research

The Patient Charity

“I just want to give my story away, so that it helps the medical profession to THINK AORTA and save the lives of others like me.”



Tony's harrowing [video](#) of surviving a Type A Aortic Dissection while at home alone includes a recording of his actual 999 call, followed by a short ambulance journey to hospital and a 10-hour delay in the ED, before transfer to a specialist Aortic centre.

Saving Lives - THINK AORTA

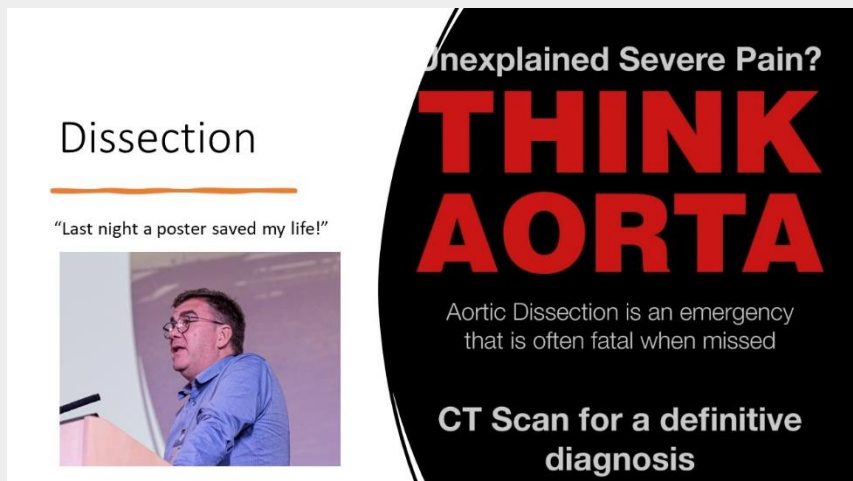
Impactful Presentations: Presented [THINK AORTA](#) in the Grand Round at Derby Hospitals NHS Trust, promoting Aortic Dissection awareness among healthcare professionals.

Patient Safety: Released our high-impact video, [Tony's Story](#), for World Patient Safety Day.

Screening Relatives: Launched the [THINK AORTA, THINK FAMILY](#) campaign at the SCTS 2023 Annual Meeting, advocating for **family screening for Thoracic Aortic Disease**.

Education: Delivered an extensive [THINK AORTA](#) education program in the Midlands, honouring [Andrew Stevenson's](#) memory and teaching clinicians to **THINK AORTA**.

Publications: Contributed an article to [Medico-Legal Magazine](#) about Aortic Dissection and Inquests, raising awareness among 37,000 medico-legal professionals.



Simon Jones shared the story of how a [THINK AORTA](#) poster saved his life with delegates attending the **London Aorta** conference in September.



The Patient Charity

“In the next 20 years we will turn Aortic Dissection from a cardiovascular catastrophe into a preventable disease.”

2023 IMPACT REPORT

Supporting Patients – Saving Lives – Improving Care – Enabling Research



Our Chair, **Mr. Gareth Owens** and co-lead **Prof. Gavin Murphy** present a keynote lecture about our collaborative research at the Society for Cardiothoracic Surgery 2023 Annual Meeting

Enabling Research – Defining the Future of Aortic Dissection Care

National Research Programme: Successfully completed phase 1 of our NIHR-funded DECIDE-TAD research programme in partnership with the University of Leicester.

Keynote Lecture: Presented the initial results of our DECIDE-TAD research as a keynote lecture at the SCTS Annual Meeting, sharing new insights into Thoracic Aortic Disease.

Tackling Misdiagnosis: Collaborated with Barts Health NHS Trust on a [THINK AORTA research project](#) which won 'Best Poster' at the **Barts 900 Aortovascular Symposium**.

Expert Consensus: Published results of the multi-disciplinary TRAVERSING study, delivering a national consensus on transfer of acute aortic dissection patients to specialist centres.

Charity Matters

We welcomed to our Leadership Team [Mr. Geoff Tsang](#) as Medical Advisor (Cardiac Surgery); [Deirdre Clinch](#) and [Stuart Garvie](#) as Ireland Reps; and [Dr. Gordon McManus](#), who joins the Committee after two years as our **Head of Research**. We also thanked retiring Committee member **Bernadette Nolan** for her service as an Ireland Rep and [Haleema Saadia](#), who relinquished her role as Vice-Chair while remaining a Trustee.

Finally, we launched our [new charity website](#) where you can find lots more detail about our work. Thank you to our many members, partners, supporters and friends for enabling us to make 2023 the best year yet for our **national patient charity** and the people we help.

www.aorticdissectionawareness.org