



## Trustees' Annual Report for the period

From	Period start date			To	Period end date		
	Day	Month	Year		Day	Month	Year
	06	04	2023		05	04	2024

### Section A

### Reference and administration details

Charity name

Aortic Dissection Awareness UK & Ireland

Other names charity is known by

THINK AORTA is a registered trademark of the charity

Registered charity number (if any)

1198617

Charity's principal address

5 Newsham Road

WOKING

Surrey

Postcode

GU21 3LA

### Names of the charity trustees who manage the charity

	Trustee name	Office (if any)	Dates acted if not for whole year	Name of person (or body) entitled to appoint trustee (if any)
1	Gareth Owens	Chair		Members
2	Haleema Saadia	Vice-Chair		Members
3	Clare Payne	Secretary		Members
4	Karen Cunningham	Assistant Secretary	Resigned 08/02/2024	Members
5	Peter Hill	Treasurer		Members
6	Eileen Haxby	Assistant Treasurer		Members
7	Dan Burgess	Founder		Members
8				
9				
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15				
16				
17				
18				
19				
20				

### Names of the trustees for the charity, if any, (for example, any custodian trustees)

Name	Dates acted if not for whole year

**Names and addresses of advisers (Optional information)**

Type of adviser	Name	Address
Medical Advisor	Dr. Emma Redfern	Emergency Department, Bristol Royal Infirmary, Upper Maudlin St, Bristol BS2 8HW
Medical Advisor	Mr. Geoff Tsang	Cardiothoracic Surgery, Southampton General Hospital, Tremona Rd, Southampton SO16 6YD

**Name of chief executive or names of senior staff members (Optional information)**

No staff

## Section B Structure, governance and management

**Description of the charity's trusts**

Type of governing document (eg. trust deed, constitution)	Constitution adopted on 13 <sup>th</sup> April 2022
How the charity is constituted (eg. trust, association, company)	Charitable Incorporated Organisation
Trustee selection methods (eg. appointed by, elected by)	Trustees require nomination by two members and are elected by a vote of members at the AGM

**Additional governance issues (Optional information)**

You **may choose** to include additional information, where relevant, about:

- policies and procedures adopted for the induction and training of trustees;
- the charity's organisational structure and any wider network with which the charity works;
- relationship with any related parties;
- trustees' consideration of major risks and the system and procedures to manage them.

**Strategic relationships:**

The charity enjoys strong, mutually beneficial working relationships with the following third-party organisations:

The Royal College of Emergency Medicine (RCEM)  
 The Royal College of Radiologists (RCR)  
 The Society for Cardiothoracic Surgery in Great Britain & Ireland (SCTS)  
 The Vascular Society of Great Britain & Ireland (VSGBI)  
 The Intensive Care Society (ICS)  
 Heart Research UK (HRUK)  
 The University of Leicester Cardiovascular Sciences Research Centre

RCEM, RCR, SCTS, VSGBI and HRUK all partner with and endorse the charity's lifesaving THINK AORTA campaign and materials.

SCTS, VSGBI and ICS all endorse the charity's patient handbook 'Aortic Dissection: The Patient Guide'.

The University of Leicester is our partner in the NIHR-funded strategic, national research programme, DECIDE-TAD, investigating family screening in Thoracic Aortic Disease.

The charity also partners with a leading manufacturer of Aortic grafts, Terumo Aortic (Vascutek Ltd), who sponsor our annual conference 'Aortic Dissection Awareness Day UK' and distribute our handbook 'Aortic Dissection: The Patient Guide'.

## Risks

The Trustees identified the following strategic risks and established mitigation plans for them:

1. That the charity may be affected by a general drop in charitable giving due to economic conditions following the COVID-19 pandemic. This risk has not materialised. The charity's income continues an upward trend, enabling the Trustees to commission and fund more activities and projects for the direct benefit of patients. Increased income enabled the Trustees to increase the charity's expenditure by 68% compared with the prior year.
2. That the charity's reliance on Aortic Dissection patients and relatives to lead the charity and to undertake its work may result in resourcing challenges, due to Trustees and volunteers having to focus on personal health or family issues at short notice. While there is some turnover of volunteers due to health issues, the Trustees adopted mitigation strategy of "buddying-up" two or more individuals around each role and the growth in the available pool of resources in the charity's membership has proven successful in mitigating this risk.
3. Other charities with a focus on aortic dissection have similar names and objects and there is a risk that this could confuse stakeholders and adversely affect this charity's income, activities, and reputation. The Trustees have adopted a mitigation strategy of clear differentiation as 'The Patient Charity'; regular communication with stakeholders about The Patient Charity's unique aims, values, and patient leadership; and a focus on The Patient Charity's own objectives and mission.
4. That information provided by the charity may be the subject of a legal challenge by a patient or relative. This risk has not materialised. The charity's support group does not provide medical advice and makes this clear in all its interactions with the public. Further mitigation of this risk is provided by the charity having a board of appointed professional Medical Advisors and a network of relationships with the medical and surgical Royal Colleges and professional societies, who review and endorse all the charity's publications. The Trustees also have appropriate expert legal advice and insurance to cover any legal challenges in place.

## Section C

## Objectives and activities

### Summary of the objects of the charity set out in its governing document

In summary, the objects of the charity are, for the public benefit:

- To preserve and protect those suffering from or at risk of Aortic Dissection or associated conditions.
- To provide the voice for patients, survivors, their families (including bereaved families) and those at risk of Aortic Dissection within the UK and Ireland.
- To campaign and raise awareness of Aortic Dissection, its diagnosis and treatment and work with the medical profession to improve patient outcomes.

**Summary of the main activities undertaken for the public benefit in relation to these objects (include within this section the statutory declaration that trustees have had regard to the guidance issued by the Charity Commission on public benefit)**

- To provide support to patients, survivors, their families (including bereaved families) and those at risk of Aortic Dissection.
- To encourage and support research into Aortic Dissection, including but not limited to causes, treatment, and the dissemination of results.
- To provide practical support to and collaborate with charitable and non-charitable organisations supporting patients, their families (including bereaved families) and those at risk of Aortic Dissection, and the medical and research professions, in other countries.

In planning and carrying out the charity's activities for the year, the Trustees kept in mind the Charity Commission's guidance on public benefit and had regard to this guidance in our decision-making, especially in decisions about where to spend the charity's money. The charity's main activities are as follows:

- Supporting patients and families affected by Aortic Dissection.
- Raising awareness of Aortic Dissection generally.
- Influencing the healthcare system to improve patient care.
- Partnering in research to improve care and outcomes.

These activities benefit everyone affected by Aortic Dissection in the past, present, and future, by providing a supportive, informative community to which they can belong; increasing awareness of the disease among the public at risk and in the medical profession; improving diagnosis and care within the healthcare system; and enabling high-quality, patient-centred research to improve care and outcomes in the future. We welcome as members everyone who is affected by or interested in Aortic Dissection in the UK & Ireland, regardless of personal background, faith, gender, politics, or personal circumstances.

The actions undertaken to support these activities are detailed in "Section D – Achievements and performance" of this report.

**Additional details of objectives and activities (Optional information)**

You **may choose** to include further statements, where relevant, about:

- policy on grantmaking;
- policy programme related investment;
- contribution made by volunteers.

## Volunteering

The totality of the charity's work is undertaken by volunteers. Our volunteer resourcing model enables people affected by Aortic Dissection to fulfil meaningful roles and 'give back' to the community by helping others. Our bereaved volunteers tell us that involvement in the charity's work helps them to feel that something positive is happening following their loved one's death. Our professional Medical Advisors also give their time voluntarily and tell us that it is a privilege to work with our patients.

## Investment in Charitable Aims

In prior years, the Trustees have committed the charity to two notable charitable acts involving significant investment in perpetuity:

1. Publishing and printing our highly successful patient handbook Aortic Dissection: The Patient Guide and distributing it nationally, with the aim that every patient who has an Aortic Dissection receives a copy before they leave hospital.
2. Organising two major conferences in September each year: Aortic Dissection Awareness Day UK and Aortic Dissection Awareness Day Ireland, to provide a unique opportunity for patients, relatives and healthcare professionals to meet and learn about Aortic Dissection.

In the current year, the Trustees further committed the charity to a third charitable act in perpetuity:

3. Creating, publishing and printing a Guide to Bereavement due to Aortic Dissection for bereaved families and distributing it nationally, with the aim that every family bereaved due to Aortic Dissection receives a copy.

This new charitable act extends the reach and support of the charity to everyone in the UK & Ireland affected by Aortic Dissection, whether the patient survives or not. It is a key plank in delivering our public benefit.

## Section D

## Achievements and performance

**Summary of the main achievements of the charity during the year**

**Patient/Family Support**

Membership of the charity grew by 40% during the year, to more than 1,400 members across the UK & Ireland. Our 'AD Buddies' peer support group for patients and their families saw a similar increase, with the 1,000<sup>th</sup> member joining in February 2024. The private online support group is busy every day with members asking and answering questions about Aortic Dissection. During the year, we continued to grow our two new peer support groups catering for the specific needs of bereaved relatives and caregivers and appointed a Bereavement Support Lead.

The charity published a third impression of its definitive handbook to the condition "Aortic Dissection: The Patient Guide", printing and distributing 5,000 copies to meet the demand from hospitals treating these patients.

We also continued to invest in our project to produce a similar guide for bereaved relatives and expect to publish this in late 2024.

During the year, the Trustees appointed Emma Hope as the charity's Aortic Specialist Nurse. Emma will join the charity in September 2024 and provide direct support to our patient members. Emma pioneered the concept of Aortic Specialist Nursing in the NHS at Southampton General Hospital 10 years ago. A number of NHS Aortic centres have now implemented the model she established. The Trustees are delighted that Emma is joining the national patient charity as our Aortic Specialist Nurse, now that she has retired from the NHS.

**Disease Awareness**

The charity held a very successful 9<sup>th</sup> annual **Aortic Dissection Awareness Day UK** conference, with the hosting this year awarded to Royal Papworth Hospital, in recognition of the excellence of this specialist Aortic centre. 120 patients, relatives and clinicians attended.

The Trustees announced the award of hosting of Aortic Dissection Awareness Day UK 2024 to the Royal College of Surgeons of Edinburgh, in recognition of their excellent work developing Aortic surgery around the world. This will be the first time the event has been held in Scotland, further extending the charity's reach and influence.

The 2<sup>nd</sup> annual **Aortic Dissection Awareness Day Ireland** was also held at St. James's Hospital, Dublin, with patients and relatives joining our host, Consultant Aortic Surgeon Mr. Saleem Jahangeer, for a very successful day. Hosting of the 3<sup>rd</sup> annual Aortic Dissection Awareness Day Ireland in 2024 was once again awarded to St. James's, in recognition of the developing all-Ireland Aortic service there.

The charity also continued to promote prevention of Aortic Dissection through the public-facing THINK AORTA, THINK FAMILY campaign, which was the centrepiece of the charity's presence at the Society for Cardiothoracic Surgery annual meeting in Wales this year.

During the year a team of volunteers led by professional website developer and Aortic Dissection survivor Stephen McIver created a new website for the charity. This has proven very popular and is regularly visited by members of the public looking for support or wanting to download some of the charity's excellent online resources.

## Section D

## Achievements and performance

### Influencing/Improving Care

The charity was invited by the Secretary of State for Health to join a National Steering Group led by NHS England to recommend improvements in Aortic Dissection care. Our Chair, Mr. Gareth Owens, represented the charity in this important forum.

As a result of our work with NHS England on the Acute Aortic Dissection Toolkit, the SW/SE Regions produced a Supraregional Acute Aortic Syndromes Standard Operating Procedure, which will improve diagnosis and care for a population of 15 million people. This became the first such regional document to be endorsed by the national patient charity and is now recommended to other regions by the UK Aortic Society.

The charity also provided a Patient & Public Voice Partner to sit on the NHS England Vascular Clinical Reference Group, which advises on the provision of vascular services nationally.

### Research

The charity's Research Team met every second month to discuss proposals and partnerships in the field of Aortic Dissection and consider and respond to requests for patient involvement and advice.

The strategic DECIDE-TAD research partnership that the charity co-leads with the BHF Cardiovascular Sciences Research Centre at the University of Leicester developed its grant application for the next phase – a 5-year applied research programme including a national clinical trial. This is expected to be funded in the 2024/25 financial year. This multi-year research programme is leading towards Decision Support Tools and professional guidance/pathways that will enable screening of the first- and second-degree relatives of people who have an Aortic Dissection.

The TRAVERSING study - a multidisciplinary research project in which the charity is a partner, was published in the Emergency Medicine Journal in December 2023. The study delivered for the first time a national consensus on the care of acute Aortic Dissection patients during transfer to specialist centres.

### Recognition

The charity was pleased to be represented at national events for medical professionals during the year, including the annual conferences of the Society for Cardiothoracic Surgery in Wales and the UK Aortic Society at The Belfry. We also once again put together a highly successful patient-interactive session for the prestigious London Aorta conference.

## Section E

## Financial review

### Brief statement of the charity's policy on reserves

During the previous financial period, the trustees created a "Travel Bursary Fund" as a Designated Reserve to provide financial assistance to members towards their travel costs for attendance at Aortic Dissection Awareness Day. The value allocated to this fund will be determined each year.

All other funds are retained as "General Fund".

**Details of any funds materially in deficit**

None

**Further financial review details (Optional information)**

You **may choose** to include additional information, where relevant about:

- the charity's principal sources of funds (including any fundraising);
- how expenditure has supported the key objectives of the charity;
- investment policy and objectives including any ethical investment policy adopted.

The principal sources of income for the period under review are:

- Direct donations from members of the charity or the public through a variety of means.
- Sponsorship support towards the costs of the annual Aortic Dissection Awareness Day UK conference from Terumo Aortic (Vascutek Limited).

Expenditure supports the key objectives of the charity, primarily covering the following:

- Cost of Aortic Dissection Awareness Day UK 2024.
- The cost of reprinting "Aortic Dissection: The Patient Guide".
- Travel and other expenses associated with attendance at various supported events.
- A limited range of merchandise to support and promote the charity.
- Charity running costs, including IT costs, registration fees etc.

**Section F**

**Other optional information**

The original annual report document dated 5<sup>th</sup> December 2024 has been amended for minor corrections on 25<sup>th</sup> April 2025.

**Section G**

**Declaration**

The trustees declare that they have approved the trustees' report above.

Signed on behalf of the charity's trustees

<b>Signature(s)</b>		
<b>Full name(s)</b>	Anne Cotton	Clare Payne
<b>Position (e.g., Secretary, Chair, etc)</b>	Chair (w.e.f. 9th January 2025)	Secretary
<b>Date</b>	25/04/25	25/04/25



CHARITY COMMISSION  
FOR ENGLAND AND WALES

Charity Name  
Aortic Dissection Awareness UK & Ireland

No (if any)  
1198617

CC16a

## Receipts and payments accounts

For the period from	Period start date 6th April 2023	To	Period end date 5th April 2024
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### Section A Receipts and payments

	Unrestricted funds to the nearest £	Restricted funds to the nearest £	Endowment funds to the nearest £	Total funds to the nearest £	Last year to the nearest £
<b>A1 Receipts</b>					
Donations	36,848	-	-	36,848	-
AD Day 2023 Sponsorship etc.	12,000	-	-	12,000	-
Contribution to publications	7,858	-	-	7,858	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
<b>Sub total (Gross income for AR)</b>	<b>56,706</b>	<b>-</b>	<b>-</b>	<b>56,706</b>	<b>-</b>
<b>A2 Asset and investment sales, (see table).</b>					
	-	-	-	-	-
	-	-	-	-	-
<b>Sub total</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>
<b>Total receipts</b>	<b>56,706</b>	<b>-</b>	<b>-</b>	<b>56,706</b>	<b>-</b>
<b>A3 Payments</b>					
AD Day 2023	16,220	833	-	17,053	-
Publications	7,858	-	-	7,858	-
Other	18,519	-	-	18,519	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
<b>Sub total</b>	<b>42,597</b>	<b>833</b>	<b>-</b>	<b>43,430</b>	<b>-</b>
<b>A4 Asset and investment purchases, (see table)</b>					
	-	-	-	-	-
	-	-	-	-	-
<b>Sub total</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>
<b>Total payments</b>	<b>42,597</b>	<b>833</b>	<b>-</b>	<b>43,430</b>	<b>-</b>
<b>Net of receipts/(payments)</b>	<b>14,109</b>	<b>- 833</b>	<b>-</b>	<b>13,276</b>	<b>-</b>
A5 Transfers between funds	- 2,000	2,000	-	-	-
A6 Cash funds last year end	27,123	1,162	-	28,285	-
<b>Cash funds this year end</b>	<b>39,232</b>	<b>2,329</b>	<b>-</b>	<b>41,561</b>	<b>-</b>

## Section B Statement of assets and liabilities at the end of the period

Categories	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
<b>B1 Cash funds</b>	Cash at Bank	39,231	2,330	-
		-	-	-
		-	-	-
	<b>Total cash funds</b>	<b>39,231</b>	<b>2,330</b>	<b>-</b>
	(agree balances with receipts and payments account(s))	Agreement Error	Agreement Error	OK
<b>B2 Other monetary assets</b>	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
<b>B3 Investment assets</b>	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
			-	-
			-	-
			-	-
			-	-
<b>B4 Assets retained for the charity's own use</b>	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
<b>B5 Liabilities</b>	Details	Fund to which liability relates	Amount due (optional)	When due (optional)
			-	
			-	
			-	
			-	
Signed by one or two trustees on behalf of all the trustees	Signature	Print Name	Date of approval	
		G Owens	10/10/2024	
		C Payne	10/10/2024	

**Independent examiner's report to the trustees of Aortic Dissection Awareness UK & Ireland (registered charity number**

**Independent examiner's statement**

I report to the trustees on my examination of the accounts of Aortic Dissection Awareness UK & Ireland (the Trust) for the year ended 5<sup>th</sup> April 2024.

**Responsibilities and basis of report**

As the charity trustees of the Trust you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ('the Act').

I report in respect of my examination of the Trust's accounts carried out under section 145 of the 2011 Act and in carrying out my examination I have followed all the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

**Independent examiner's statement**

I have completed my examination. I confirm that no material matters have come to my attention in connection with the examination giving me cause to believe that in any material respect:

1. accounting records were not kept in respect of the Trust as required by section 130 of the Act; or
2. the accounts do not accord with those records; or
3. the accounts do not comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the accounts give a 'true and fair view which is not a matter considered as part of an independent examination.

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.

Signed:

Name: Nicola McMeekin

Address: 7 Kilmardinny Grove, Bearsden, East Dumbartonshire. G61 3NY.

Date: 23<sup>rd</sup> October 2024

# **Independent examiner's report to the trustees of Aortic Dissection Awareness UK & Ireland (registered charity number 1198617 England and Wales)**

## **Independent examiner's statement**

I report to the trustees on my examination of the accounts of Aortic Dissection Awareness UK & Ireland (the Trust) for the year ended 5th April 2024.

## **Responsibilities and basis of report**

As the charity trustees of the Trust you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ('the Act').

I report in respect of my examination of the Trust's accounts carried out under section 145 of the 2011 Act and in carrying out my examination I have followed all the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

## **Independent examiner's statement**

I have completed my examination. I confirm that no material matters have come to my attention in connection with the examination giving me cause to believe that in any material respect:

1. accounting records were not kept in respect of the Trust as required by section 130 of the Act; or
2. the accounts do not accord with those records; or
3. the accounts do not comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the accounts give a 'true and fair view which is not a matter considered as part of an independent examination.

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.

Signed:

Name: Nicola McMeekin

Address: 7 Kilmardinny Grove, Bearsden, East Dumbartonshire. G61 3NY.

Date: 23rd October 2024