



Trustees' Annual Report for the period

From	Period start date			To	Period end date		
	Day 13	Month 04	Year 2022		Day 05	Month 04	Year 2023

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		Members
5	Eileen Haxby	Treasurer		Members
6	Peter Hill	Assistant Treasurer		Members
7	Dan Burgess	Founder		Members
8				
9				
10				
11				
12				
13				
14				
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 13th 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)

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 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 because of the COVID-19 pandemic and the economic recession. The Trustees took a cautious approach to expenditure during the year until the impact of this became clear. However, 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.
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. The Trustees adopted mitigation strategy of "buddying-up" two or more individuals around each role has proven successful in mitigating this risk whenever it has arisen.
3. That the activities of a competing charity set-up by three disaffected former members – the Aortic Dissection Charitable Trust – may confuse stakeholders and adversely affect the charity's income, activities, and reputation. The Trustees 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, rather than being drawn into unhelpful competition with another charity.
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.

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.
- 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.

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)

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 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.

Section D

Achievements and performance

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 35% during the year, to more than 1,000 members across the UK & Ireland. Our 'AD Buddies' peer support group for patients and their families saw a similar increase and the private online support group is busy every day with members asking and answering questions about Aortic Dissection. During the year, we established two additional peer support groups catering for the specific needs of bereaved relatives and caregivers.

The charity published the definitive handbook to the condition "Aortic Dissection: The Patient Guide" and made a charitable commitment to provide, in perpetuity, a free copy to every patient in the UK & Ireland via their treating hospital. More than 3,000 copies were distributed during the first year.

We also highlighted the underdiagnosed problem of Aortic Dissection during pregnancy and published a booklet "Planning Pregnancy with Aortic Disease", written by a patient who had survived this experience and a leading maternal cardiologist.

Disease Awareness

The Trustees awarded the hosting of our annual conference "Aortic Dissection Awareness Day UK" to the Wellcome Centre for Interventional Surgical Sciences at University College London, in recognition of their ground-breaking research in the field. More than 120 patients, relatives, clinicians, and researchers attended the conference, which was held at the Headquarters of the British Medical Association in central London.

The charity completed a post-COVID refresh of our THINK AORTA poster campaign, in partnership with Heart Research UK, which resulted in posters being sent to every A&E Department in the UK & Ireland. One of our speakers at the AD Awareness Day UK 2022 conference was a patient whose life was saved as a result of the charity's THINK AORTA campaign.

The charity also extended its reach into prevention of Aortic Dissection, with the launch of the public THINK AORTA, THINK FAMILY campaign, which addresses the often, genetic nature of the disease and highlighting the need for improvements in familial genetic testing.

Influencing/Improving Care

The charity provides the patient voice on the NHS England Acute Aortic Dissection Toolkit Working Group. Since the toolkit was launched for the NHS England Regions to implement in April 2022, we have supported each Region with the offer of a team of local patients and a tailored support package for improving the acute Aortic Dissection patient pathway. To date, five of the seven NHS England Regions have taken advantage of this support.

Section D

Achievements and performance

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

The charity made submissions proposing a focus on the prevention of Aortic Dissection as part of the UK Parliament Health & Social Care Committee Inquiry into Prevention in Healthcare.

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 completed its first phase. The initial results were presented at the Society for Cardiothoracic Surgery Annual Meeting in Birmingham. Papers are in preparation for publication in leading journals. 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 charity also completed its work with Barts Health NHS Trust on the CardiacCOVID study, which was published in the European Journal of Cardiovascular Nursing.

The charity also completed its work in a multi-centre, multidisciplinary research partnership led by the University of Bristol – the TRAVERSING study - which reached a consensus on the care of acute Aortic Dissection patients during transfer to specialist centres. Publication of the consensus guideline is expected during 2023.

Recognition

The charity was pleased to be invited to speak at several national events for medical professionals during the year, including the annual conferences of the Society for Cardiothoracic Surgery in Belfast, the Vascular Society in Brighton, and the British Cardiovascular Society in Manchester. We also put together a highly successful patient-interactive session for the prestigious London Aorta conference.

The work of the charity has also been recognised with the award of the title "Best Specialist Patient Support Charity – UK – 2023" in the international non-profit organisation awards.

Section E

Financial review

Brief statement of the charity's policy on reserves

The Charity set up without a reserves policy.

During the year, the trustees agreed to retain the unspent amount of the travel bursary funding set aside for Aortic Dissection Awareness Day 2022 as a designated reserve for future events. This balance is a Designated Fund as of 5th April 2023.

The trustees have also acknowledged that the policy may require further review to set aside the cost of reprinting current publications during the budgeting process.

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 2022.
- The cost of producing the publications "Aortic Dissection: The Patient Guide" and "Planning Pregnancy with Aortic Disease".
- Contribution towards the refresh of the THINK AORTA poster campaign.
- 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

Section G

Declaration

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

Signed on behalf of the charity's trustees

Signature(s)		
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Full name(s)	Gareth Owens	Clare Payne
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Position (e.g., Secretary, Chair, etc)	Chair	Secretary
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Date	05/01/24
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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 13th April 2022 To 5th April 2023

Section A Receipts and payments

	Unrestricted funds	Restricted funds	Endowment funds	Total funds	Last year
	to the nearest £	to the nearest £	to the nearest £	to the nearest £	to the nearest £
A1 Receipts					
Donations	32,982	-	-	32,982	-
AD Day 2022 Sponsorship etc.	15,000	3,800	-	18,800	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total (Gross income for AR)	47,982	3,800	-	51,782	-
A2 Asset and investment sales, (see table).					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	47,982	3,800	-	51,782	-
A3 Payments					
AD Day 2022	13,689	2,638	-	16,327	-
Publications	1,726	-	-	1,726	-
Other	7,106	-	-	7,106	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total	22,521	2,638	-	25,159	-
A4 Asset and investment purchases, (see table)					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total payments	22,521	2,638	-	25,159	-
Net of receipts/(payments)	25,461	1,162	-	26,623	-
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	1,663	-	-	1,663	-
Cash funds this year end	27,124	1,162	-	28,286	-

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 £
B1 Cash funds	Cash at Bank	27,124	1,162	-
		-	-	-
		-	-	-
	Total cash funds	27,124	1,162	-
	(agree balances with receipts and payments account(s))	OK	OK	OK
		Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B2 Other monetary assets		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		Fund to which asset belongs	Cost (optional)	Current value (optional)
B3 Investment assets			-	-
			-	-
			-	-
			-	-
			-	-
B4 Assets retained for the charity's own use			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
B5 Liabilities			-	
			-	
			-	
			-	
			-	
Signed by one or two trustees on behalf of all the trustees	Signature	Print Name		Date of approval
		Gareth Owens		31/10/2023
		Clare Payne		31/10/2023

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

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 2023.

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.

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

Previous FCCA membership, now lapsed.

Address: 7 Kilmardinny Grove, Bearsden, East Dunbartonshire, G61 3NY

Date: 2 February 2024