



# beatSCAD



## Annual Report 2022



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Registered charity number 1164066

## What is SCAD?

Spontaneous Coronary Artery Dissection (SCAD) is an under-diagnosed heart condition that cannot be predicted or prevented – yet. It affects people with few or none of the normal risk factors for heart disease.

SCAD affects mainly women, but men are affected too. It has associations with Fibromuscular Dysplasia (FMD), connective tissue disorders, female hormones, extreme stress and exercise, but the cause is unknown.

A bruise or tear develops in a coronary artery resulting in a blockage that prevents normal blood flow and can cause a heart attack or cardiac arrest.

Symptoms can include central chest pain, arm pain or numbness, pain in the jaw, back, shoulders, nausea, sweating/clamminess or breathing difficulties.

See [www.beatscad.org.uk](http://www.beatscad.org.uk) for more.

UK research project at the **NIHR Leicester Cardiovascular Biomedical Research Centre**  
[scad.lcbru.le.ac.uk](http://scad.lcbru.le.ac.uk)

# About Beat SCAD

Beat SCAD is a patient-led charity whose vision is a world that understands SCAD, where those affected are quickly and accurately diagnosed and never feel alone. Beat SCAD was established in 2015 by SCAD survivors whose mission is to:

- ❑ Raise awareness of SCAD.
- ❑ Provide support for SCAD patients, family and friends.
- ❑ Raise funds for research into SCAD.

Beat SCAD is run entirely by volunteers and is dependent on the generosity of our supporters offering their time, skills, knowledge and enthusiasm to continue pushing forward with our mission.



**Rebecca Breslin**



**Debbie Oliver**



**Sarah Coombes**

Beat SCAD's Trustees... **Rebecca** is a full-time Data Manager in the clinical research industry. **Sarah** worked in the City of London for almost 20 years and is now a full-time mum/carer/volunteer. **Harriet** is Co-Director of a digital marketing company, Assistant Practice Manager at a GP practice and mum to three teenagers. And **Debbie** has worked in the publishing industry for more than 30 years.

Read our stories at [beatscad.org.uk/scad-stories](https://beatscad.org.uk/scad-stories).



**Harriet Mulvaney**

# Welcome

Hello and welcome to the Beat SCAD Annual Report summarising the charity's seventh year of operation, from October 2021 to September 2022.

This year has been significant for the charity in terms of returning to in-person activities. We were delighted to host another walk and bring research news to the community (see page 8), as well as a return to raising awareness of SCAD to healthcare professionals (see page 9).

Next year, the trustees are excited to begin planning our return to hosting an in-person conference and, given the flurry of research publications which are delivering significant findings that are contributing to an increased understanding of SCAD (see page 10), there will be plenty of content to pack into the agenda.



Thanks to everyone who has supported us this year in raising awareness and funds. We'd love to hear from you if you're doing a fundraising event so we can help promote it. Email us at [contactus@beatscad.org.uk](mailto:contactus@beatscad.org.uk).

Together, we will Beat SCAD.

**Rebecca Breslin, Beat SCAD Chair**

The core values of Beat SCAD guide the decisions we make and the services we provide to fulfil our mission and work towards our vision.

## **PATIENT DRIVEN**

We understand the needs of the SCAD community and we push forward to find answers.

## **EMPOWERMENT**

We provide knowledge and support to enable SCAD patients to take control of their diagnosis.

## **COMMUNITY**

We bring together SCAD patients and families to benefit from sharing their experiences.

## **PARTNERSHIP**

We work collaboratively with our supporters and researchers to optimise outcomes.

# Fundraising & donations

Once again our wonderful fundraisers have done a fantastic job to raise much-needed money.

Just eight months after her SCAD in March 2021, aged 47, Jill Scaife ran her first ever 10K on 7 November!

Jill wasn't on her own when she completed the Middlesbrough 10K, though. Her two sisters, Debs and Kay, ran alongside her and they all crossed the finish line together, holding hands.

Jill's original fundraising target was £100 and she smashed it, raising £1,600! Jill also raised more than £4,800 in the summer at a garden party. She told us "I am determined to raise awareness of SCAD and hopefully help find some answers. The not knowing why it happens is one of the things I have really struggled with."

Other running challenges included Neil Richardson doing the London Marathon, raising more than £1,100, Louise Bellamy, whose sister Hayley had a SCAD in 2021, raised £2,520 by running



**Amy Porter ran the Great North Run**

the Manchester Marathon and Amy Porter running the Great North Run and raising £633.

Amy told us: "Completing an event like the Great North Run has always been on my bucket list, so when receiving a place in this year's event it gave me a great opportunity to run on behalf of Beat SCAD, as this charity means a lot to me and my family since my Mum unexpectedly had a SCAD in 2016. My hope and motivation are to raise funds and awareness, in order to help keep the research and conversation about SCAD going and saving lives."

A Santa Swim in December organised by T2 Events raised £550 for Beat SCAD. The 500m open water swim, held at the Capernwray Dive Centre in Carnforth, Lancashire, was well attended and swimmers got into the spirit of Christmas with their personalised Santa hats!

Other swimming challenges included Melanie Wiltshire's 50 open water swims,



**Jill Scaife and her sisters at their 10K**

which raised £500 and Richard Nightingale's Windermere 11 mile swim, which raised £456.

In August, Trustees Sarah Coombes and Debbie Oliver were honoured to attend a charity fundraising event by The PGA European Tour Group. It was held in memory of three PGA European Tour Group staff members who had passed away, including Clare Lipscombe, who sadly lost her life after having a SCAD and cardiac arrest, aged 43.

A phenomenal £135,579 was raised through golf and dinner packages, raffle items and live and silent auctions and this was split between three charities, Beat SCAD, Guts UK and the Royal Marsden Cancer Charity. We received a very generous donation of £45,193.

Other golfers raised funds too, with Fivehead Golf Society in Taunton raising £700, Prudhoe Golf Club Ladies section, led by Jenny Stewart, raising £337.

Sponsored walkers who raised money at our walk in June included Heather Slade (£520), Louise Baskeyfield (£240) and Celia Herrick (£265).

Facebook fundraisers brought in more than £1500, Elizabeth Allford's 60th



**Sarah Coombes at the PGA charity event**

birthday donations raised £300, Jonna Foote-Kortland's craft evening raised £33, Geri Moroney donated £1,000 and Trustee Harriet Mulvaney raised more than £280 at an open garden and afternoon tea event.

We only have room to highlight a few fundraisers, but we appreciate any and all fundraising – thanks to each and every one of you who have contributed!

### **Donation to research**

In April we awarded £106,000 to help fund a new Clinical Research Fellow for the SCAD research project in Leicester. The hope was that a Fellow would start in August 2022, however there was a delay, so the money has been retained by Beat SCAD until the Fellow starts in their new role.

Dr Adlam said: "This [award] is fantastic news. It has been relatively challenging to get funding outside of Beat SCAD and it is likely that things would have come to an end without Beat SCAD. Many thanks once again to the Beat SCAD Trustees and all your fundraisers for this amazing award."

Photo James Kirby



**A chilly but cheerful Santa swim**

# Support activities

Supporting SCAD patients, family and friends is an important part of our mission and we continued to provide our Buddy service ([beatscad.org.uk/buddy-service](https://beatscad.org.uk/buddy-service)) Our volunteer Buddies supported 24 SCAD patients this year. As well as providing information through our website, including via downloadable leaflets, we sent out more than 2,850 printed leaflets, 380 In Case of Emergency cards for patients and 450 for healthcare professionals.

In June, we held our first in-person event since before the Covid pandemic. 50 people including 20 SCAD patients gathered at the Bosworth Battlefield Heritage Centre and Country Park and we had glorious sunshine for our picnic and walk.

SCAD expert and research lead Dr David Adlam joined us, along with six members of his clinical and research teams.

Following the walk Dr Adlam updated us on some of the most recent research



**Dr David Adlam with some of his research and clinical teams and Rebecca Breslin**

papers and SCAD patients, families and friends asked questions on subjects including medication, hormones, stress, genetics and ongoing chest pain.

We are very lucky to have such dedicated and passionate people on the research and clinical teams and we presented three of the team members, Jay Moth, Jane Plume and Vanessa Hollings with some flowers as a gesture of our appreciation for their hard work and support for patients.



# Raising awareness

In March Beat SCAD exhibited live for the first time in over two years. Trustee Sarah Coombes and volunteer Charlotte Pearl staffed the Beat SCAD stand at the London Maternity and Midwifery Festival at the Royal National Hotel in London.

Charlotte and Sarah spoke to about 40 delegates and our leaflets and pregnancy-related SCAD (P-SCAD) case studies were snapped up.

Dr Abetehale Al-Hussaini, consultant cardiologist who specialises in SCAD, pre-recorded a 'meet the expert' session.

Sarah also continued her annual training of Advance Care Paramedics from the South East Coast Ambulance Service, which is always well received.

When Theresa Windsor, an Advanced Nurse Practitioner with the Cardiac Rehabilitation service at Milton Keynes University Hospital, began caring for a SCAD patient, she he found our website and downloaded some of the support leaflets for her patient.



**Volunteer Charlotte at the Midwifery event**



**Theresa Windsor and cardiac rehab colleagues at Milton Keynes Hospital**

She also asked Beat SCAD Co-Founder Karen Rockell to visit the Cardiac Nursing Team in May to give an educational talk.

Theresa said: "Your talk was very informative, I will be trying to improve the outcomes for our SCAD patients."

We were very excited that Beat SCAD's logo was put onto Ellington Football Club's football strip for the season.

The club, based in Northumberland, is managed by Benn Bulley, whose partner Claire Stark approached us for permission to use the logo. She said, "We thought this would be excellent publicity for SCAD and hopefully raise some awareness."

She added: "At Ellington FC's first match of the season, the new strip brought them luck and they won! We have educated the team on SCAD and they are sharing their knowledge and advertising the logo in our local area. Hopefully it gets more people talking and asking questions."

# Research update

Research papers released this year included Pregnancy and Spontaneous Coronary Artery Dissection: Lessons From Survivors and Nonsurvivors ([ahajournals.org/doi/epdf/10.1161/CIRCULATIONAHA.122.059635](https://ahajournals.org/doi/epdf/10.1161/CIRCULATIONAHA.122.059635)).

Using European SCAD registry data from 1984 to 2021, this research included 82 women with P-SCAD and 28 women who became pregnant after SCAD (37 pregnancies). Only five of the 82 P-SCAD cases occurred during pregnancy. Researchers also evaluated 13 fatal P-SCAD cases from a UK review of maternal deaths, 10 of which happened after pregnancy.

Another paper, Prevalence and Disease Spectrum of Extracoronary Arterial Abnormalities in Spontaneous Coronary Artery Dissection ([jamanetwork.com/journals/jamacardiology/fullarticle/2786555](https://jamanetwork.com/journals/jamacardiology/fullarticle/2786555)) investigated how common issues in non-coronary arteries are and their importance for SCAD patients.



**Dr Adlam updated us on the research and answered questions at our walk in June**



**Patients and families were able to ask Dr Adlam questions at the walk**

At our walk in June, Dr Adlam, UK SCAD Research Lead, Associate Professor of Acute and Interventional Cardiology & Honorary Consultant Interventional Cardiology, University of Leicester, said the most common condition is Fibromuscular Dysplasia (FMD) and occasional aneurysms and dissections in affected arteries. He said problems arising from these are very uncommon for SCAD patients.

In February, the NIHR Leicester Biomedical Research Centre highlighted the SCAD research being done by Dr Adlam and his team. Dr Adlam said that until a few years ago SCAD wasn't well-understood, but through the research team's efforts and by working with the patient group and Beat SCAD, a lot of progress has been made.

Trustees Rebecca Breslin, Sarah Coombes and SCAD patient Joan Errington shared their stories providing a patient perspective.

# Progress and future plans

This year saw the Trustees announce Beat SCAD's sixth funding award to Dr David Adlam and his SCAD research team in Leicester (see page 7). The £106,000 award will provide the majority salary funding for a new Clinical Research Fellow. This is the charity's largest single award to date and brings the total awarded to research since 2017 to £297,398.50. This incredible achievement has only been possible due to some herculean fundraising efforts by the SCAD community – read about some of this year's contributors on pages 6-7.

The details of the work to be conducted by the new Clinical Research Fellow have not yet been finalised. It is likely that the work of the previous Clinical Research Fellow, Dr Alice Wood, looking at SCAD in 'sub-groups' including men and recurrent SCADs will influence the next research focus. The Trustees will bring further updates to you in due course. We are excited and relieved that research efforts can continue in Leicester, with sincere thanks to the Beat SCAD supporters.

Global research collaborations are gradually revealing key information about the mechanism of SCAD and associated risk factors, but we still don't know why SCAD occurs in an individual on a given day. If an individual has a particular selection of genes that increases their risk of having a SCAD, what is the trigger that causes SCAD? It is essential that

fundraising efforts continue to enable the research team to continue investigating. Following the announcement of the £106K research award, Beat SCAD launched a new fundraising campaign\_ ([justgiving.com/campaign/beatSCAD-moreresearch](https://www.justgiving.com/campaign/beatSCAD-moreresearch)) to raise a further £25,000 to support the work of the new Clinical Research Fellow. The funds may be used for salary, laboratory work and/or imaging work (such as CT/MRI/MRA scans).

## In-person events

This year we were delighted to be able to return to in-person activities, hosting another walk and bringing research news to the community (see page 8). We were also able to attend events to raising awareness of SCAD with healthcare professionals (see page 9).

Next year, the trustees will be planning our first Conference for five years and, given the flurry of research findings that are contributing to an increased understanding of SCAD (see page 10), there will be plenty of content to pack into the agenda.

Thank you for continuing to support Beat SCAD. We'd love to hear from you if you have any feedback on our activities and plans, or would like to volunteer and help to progress our mission to raise awareness, provide support and fundraise for research. Email us at [contactus@beatscad.org.uk](mailto:contactus@beatscad.org.uk).

# Financial report

Beat SCAD fundraisers and donors once again made us immensely proud of the passion and dedication that the SCAD community has to support our mission, by raising an incredible £87,497 this year. A return to in-person activities saw you doing a variety of challenges and events, from running and swimming, to golfing and afternoon tea, that all contributed to this total (see p6-7).

Expenses this year were primarily research award payments totalling £19,000, related to the funding of the new Clinical Research Fellow.

Thanks to all who have continued to support Beat SCAD.

Year 7 financial report	
<b>Income</b>	
Fundraising & donations	£87,497
Other	£3,065
<b>Total income</b>	<b>£90,562</b>
<b>Expenses</b>	
Donations	£19,000
Events	£2,012
Merchandise	£4,428
Promotional expenses <sup>1</sup>	£130
Sundries <sup>2</sup>	£2,915
<b>Total expenses</b>	<b>£28,485</b>
<b>Surplus income<sup>4</sup></b>	<b>£62,077</b>
<b>Reserved funds</b>	
Awareness project <sup>3</sup>	£960
Wellbeing project	£2,400

	Platform	Year 6 (end 30.9.21)	Year 7 (end 30.9.22)
Regular donors	Standing order	20	20
	Total Giving – monthly	3	3
	Paypal	4	4
Amount raised (excluding Gift Aid)	Total Giving	£232	£203
	Facebook	£3,216	£4,553
Amount raised (including Gift Aid)	Just Giving	£11,232	£11,751
	Virgin Money Giving	£1,849	£1,657
	Enthuse	0	£247
Number of online shopping supporters	The Giving Machine	60	61
	Easyfundraising	82	87
Amount raised	The Giving Machine	£15	£17
	Easyfundraising	£436	£512
	Amazon Smile	£467	£447
	Giving Machine Lotto	£542	£641

**Notes:** **1** Includes printing of leaflets, pullups, posters and some filming costs. **2** Includes bank, insurance and fundraising expenses, website, postage and travel costs. **3** Remaining funds from Nationwide Grant to attend three Midwifery festivals (third festival postponed from July 2021 to March 2022). **4** At 30-Sep-22 £87,000 committed to research donations



We are a small charity and need your help to move forward...

### **Help us raise awareness**

Download or order printed leaflets ([tinyurl.com/3a43sf6j](https://tinyurl.com/3a43sf6j)) and give them to GPs, cardiologists, cardiac rehab nurses, SCAD patients and anyone who can help raise awareness.

### **Help us raise funds**

Every penny counts, so we appreciate all fundraising efforts. Here are some ideas:

- Hold a charity event.
- Run, walk or do other sponsored events.
- Ask your employer for match funding.
- Create a birthday fundraiser on Facebook.
- Use The Giving Machine and Easyfundraising when you shop

online ([thegivingmachine.co.uk/causes/beat-scad](https://thegivingmachine.co.uk/causes/beat-scad) and [bit.ly/2ix7mfG](https://bit.ly/2ix7mfG)).

### **Regular donations**

- Give As You Earn.
- Donate regularly by direct debit.
- Donate on our website ([beatscad.org.uk](https://beatscad.org.uk)).
- Don't forget to Gift Aid your donations!

### **Skills, time and contacts**

What skills can you offer?

- Fundraising, including grant writing and corporate donations.
- Film making and photography.
- Merchandising.
- Attending events on behalf of Beat SCAD or volunteering for us.
- Let us know of anyone who could sponsor our events or merchandise.



## Thank you for helping us to Beat SCAD!

Beat SCAD's Trustees would like to thank everyone who has supported us this year.

All the Trustees are volunteers, whose work for Beat SCAD is done in their spare time. We appreciate everything all our supporters do to help us achieve our aims, from distributing leaflets to healthcare staff to telling their stories in magazine and newspaper articles and volunteering their time and skills as Buddies. As more healthcare

professionals are made aware of SCAD, the journey for future SCAD patients will be easier.

As a result of your fundraising we are able to fund more research, raise more awareness and support more people affected by SCAD.

Thanks to Dr David Adlam's research team in Leicester and to Dr Abi Al-Hussaini, who continues to treat and support SCAD patients. You have all given us hope!

### Find us online



[beatscad.org.uk](http://beatscad.org.uk)



[facebook.com/beatscaduk](https://facebook.com/beatscaduk)



[@beatscaduk](https://twitter.com/beatscaduk)



[bit.ly/1TXhiLV](https://bit.ly/1TXhiLV)



[beatscad](https://www.instagram.com/beatscad)

### Contact us

Please get in touch if you have any questions, want to volunteer, fundraise or can help us achieve our aims in other ways.

[contactus@beatscad.org.uk](mailto:contactus@beatscad.org.uk)



beatSCAD





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Awareness | Support | Research