



Annual Report 2016



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What is SCAD?

Spontaneous Coronary Artery Dissection (SCAD) is a rare or 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.

A tear or a bruise develops in a coronary artery resulting in a blockage that prevents normal blood flow.

SCAD affects mainly women and can happen during or soon after pregnancy. Menopause, connective tissue disorders, extreme stress and exercise have been associated with SCAD, but the cause is unknown.

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

For further information go to:
www.beatscad.org.uk.

UK research project at the
**Leicester Cardiovascular
Biomedical Research Unit**
scad.lcbru.le.ac.uk

British Heart Foundation
bit.ly/1LaOgys
bit.ly/1T345Aj

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 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 Trustees



Rebecca Breslin, Chair

Rebecca had a SCAD heart attack in 2012 and helped to initiate the UK SCAD research programme. She is a member of the Patient Advisory Group at the National Institute for Health Research Rare Diseases Translation Research Collaboration.



Karen Rockell, Secretary

In 2010 Karen had a successful liver transplant after developing liver cancer due to an autoimmune condition. Six weeks later she had a SCAD heart attack. Finding no support in the UK, she turned to Facebook and found other SCAD survivors.



Debbie Oliver, Trustee

At the time of Debbie's SCAD event in 2011 at the age of 49, information about the condition was scarce. It was six months before she found any other SCAD survivors on social media. Debbie works at a London-based publishing company in the editorial, production and design field.



Jackie Stopyra, Treasurer

Jackie is a qualified accountant running her own practice. She has gained a lot of experience over the years working with local and national charities. As Debbie's sister, she has first-hand experience of being a family member of someone who has had a SCAD event.

Welcome

Beat SCAD launched in November 2015 and our first year has been packed full of incredible successes. We're finding our feet in the charity world and have been working very hard to develop and implement our strategy to achieve our vision of a world which understands SCAD, where those affected are quickly and accurately diagnosed and never feel alone.

When I suffered my SCAD heart attack in March 2012, I found very little information other than frightening statistics in medical journals so I took to social media searching for other SCAD survivors. Over the next year I started to build a SCAD network, noting details of our SCAD events and theories – all of us looking for answers.

As I heard more SCAD stories, I recognised some important factors influencing our outcomes:

Knowledge of heart attack symptoms

I knew the symptoms through my job in clinical research, even though it made no sense why I would be having a heart attack aged 34 with no risk factors. This meant I called for help quickly. I heard many describe delays seeking help because they expected a 'Hollywood' heart attack.

Being taken seriously by medics

I heard a recurring theme of people being sent away with a diagnosis of indigestion or panic attack.

Diagnosis via angiogram

After some initial delay, a heart issue was suspected and I was transferred to Glenfield hospital and underwent an emergency angiogram where the medic had a high suspicion of a dissection. I heard so many stories of delays getting to the cath lab – missed opportunities to prevent or reduce heart damage.

Medic knowledge of SCAD

Whilst a patient in Glenfield, I met Dr David Adlam, a consultant who had seen SCAD before. I came to understand this was as rare as the SCAD itself!

I knew more could and needed to be done to change the outcomes for SCAD patients – a strong view held by all in our group. This pushed me to ask Dr Adlam for UK research and to establish Beat SCAD with fellow survivors Karen Rockell and Debbie Oliver who share my drive and passion for this cause.

I would like to extend an enormous thank you to my fellow trustees and all our supporters who have very generously volunteered and donated to Beat SCAD. We are immensely proud of your achievements and hope you continue to support our cause and inspire others to join our mission.

Together, we will Beat SCAD.

Rebecca Breslin, Beat SCAD Chair

Beat SCAD conference 2015

Our first annual conference in November 2015 was also the official launch of Beat SCAD.

The conference, held at the Leicestershire County Cricket Club, was attended by 90 people, almost half of whom were SCAD patients.

Lead researcher at the Leicester Cardiovascular Biomedical Research Unit, Dr David Adlam, explained what SCAD is, as well as its diagnosis and treatment. Dr Abteahle Al-Hussaini

updated the delegates on the progress of the research.

Sally Bee, SCAD survivor, heart healthy cook and TV presenter, gave an inspirational talk for newly diagnosed patients. And Beat SCAD Trustees explained the charity's mission and plans.

The event was also a great opportunity for SCAD patients and their families and friends to meet each other. For many patients it was the first time they had met anyone with the same diagnosis.



SCAD stories

Patient stories are a powerful way to help people understand not only what SCAD is, but the effect it can have.

Beat SCAD has heard many stories, all of them different, but there are overriding themes: Why me? What caused it? Can it be prevented? When will I get back to normal?

This year we launched the SCAD stories section of our website with three incredible people: Charlotte, James and Jennifer.

Charlotte's SCAD, in 2010, happened when she was picking up her three-year-old son at nursery. She had emergency bypass surgery to restore blood flow. In 2015 she had another SCAD that was medically managed.

James, a runner, who was achieving some great times in high-level competitions, had a SCAD while running in 2015. Many SCAD patients who previously did a lot of exercise find it hard to adjust to not doing it to such a high level and this was true for James. He has, however, returned to the sport he loves and is slowly achieving better times.

Jennifer's SCAD was in 2013 at the age of 40. One question many SCAD patients have is 'is it genetic?' and this is an important question for both Jennifer and her twin sister Karen.

Read their stories here:
beatscad.org.uk/charlottes-story
beatscad.org.uk/jennifers-story
beatscad.org.uk/james-story



Charlotte and her son Samuel



James doing what he loves



Jennifer (right) and her twin Karen

Fundraising events

Fundraising efforts during our first year exceeded all our expectations.

Our first official fundraising event was a raffle at our conference, where the delegates raised more than £400.

To coincide with Rare Disease Day and Heart Month, February saw supporters taking part in our Scones for SCAD events, raising nearly £5,000.

We baked scones, cakes and biscuits and held tea parties and bake sales at homes, in schools and offices. For the full story go to bit.ly/1095YdW.

In June we had our first annual walk

attended by 50 people, including 19 SCAD survivors. For some, this was the first time they had met another SCAD patient in person. The walk was held in the beautiful surroundings of Beacon Hill Country Park near Loughborough.

As well as a great opportunity to meet others affected by SCAD, walkers raised money for Beat SCAD. More than £9,000 was raised – a fantastic total. Read more here: bit.ly/1rw2Xtv.

Scones for SCAD events raised almost £5,000 for Beat SCAD





Andrew Armitage, David Lamont and Lizzie Tulip (l to r) took on cycling and running challenges to raise money for Beat SCAD

Two husbands of SCAD patients took on cycling challenges to raise money. David Lamont, whose wife Michelle had two SCADs, took on a gruelling London to Paris cycle ride and raised over £6,000. And Andrew Armitage, whose wife Rachel had a SCAD three weeks after her baby was born, cycled 100 miles to raise over £1,500.

In September Lizzie Tulip took part in the Great North Run and raised more than £900.

Beat SCAD was pleased to be chosen



SCAD survivors walking to Beat SCAD

as the Melton & District Model Club's charity for its annual open weekend. We were given some fantastic prizes and many people showed a lot of interest in SCAD. Dr Adlam, lead researcher at the Leicester research programme, made an appearance too! We raised a fantastic £1,000 over the weekend. Read more at bit.ly/2ezEdwB.

Beat SCAD would like to say a massive thank you to everyone who has held, taken part in and supported fundraising events – you have raised much-needed money to further our mission to raise awareness, support those affected by SCAD and contribute to research.



Beat SCAD spreading the word at the Melton & District Model Club weekend

Promotional activities

Beat SCAD trustees and supporters have been involved in many promotional activities this year. Here are just a few highlights.

On the rarest day, 29 February, as part of Heart Month, the British Heart Foundation (BHF) published a story about SCAD. It detailed how the UK research was initiated by a group of patients led by Rebecca Breslin, Chair of Beat SCAD (bit.ly/2a2PJkh). Rebecca, together with her consultant and lead SCAD researcher at the Leicester Cardiovascular Biomedical Unit (LCBRU), were featured in the video published with the story.

Karen Rockell, Beat SCAD Secretary (pictured below left), went through a rigorous audition process to become an approved speaker for the Oxford region Women's Institute (WI). Since then, she has told her SCAD story to many WI groups.



Karen (left) raising awareness of SCAD at the Gilmorton Women's Institute



Rebecca being filmed for a BHF video

In April, Beat SCAD collaborated with the LCBRU to enter a video for the National Institute for Health Research's New Media Competition (bit.ly/2ayEvkK). Unfortunately we didn't win, but had fun making it and, more importantly, raised more awareness of SCAD.

SCAD survivor Harriet Mulvaney was asked to speak at the BHF Wales Supporter Conference in July. She was joined by Dr Adlam and their presentations were very well received.

One of our target audiences in terms of raising awareness is first responders and paramedics, so we were pleased to be asked to write an article for the June issue of the College of Paramedics magazine.

Supporters and SCAD survivors have also been raising awareness among GPs, cardiologists, cardiac rehab nurses and more.

Thanks to everyone who has raised awareness of SCAD and Beat SCAD – keep up the good work!

Plans for 2017

Beat SCAD will be building on our great start and continuing to further our mission:

Awareness

It is vital that medical staff who see patients with potential cardiac symptoms but who do not fit the normal profile of a heart attack patient, consider SCAD as a possible cause. We aim to:

- ❑ Increase the distribution of our information materials.
- ❑ Attend events to discuss SCAD with medical professionals such as GPs, cardiologists, midwives and more.
- ❑ Conduct surveys and develop statistics.

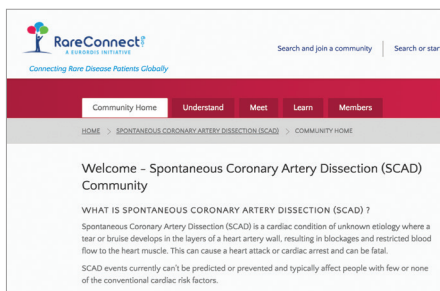


Attending events to raise awareness

Support

Many SCAD patients find the emotional and psychological effects of SCAD harder to cope with than the physical after effects. Family members and friends can also be faced with life-changing circumstances and need help to understand and adapt. We aim to:

- ❑ Launch a support system to help



Building the community via Rare Connect

- people cope with life after SCAD.
- ❑ Build the SCAD community on Rare Connect (rareconnect.org) so non-English speakers or those who don't use social media can find support.
- ❑ Host events to bring together SCAD patients, families and friends.

Fundraising

Funds raised will be used to fulfil our aims. We will continue to work with the Leicester Cardiovascular Biomedical Research Unit to determine how Beat SCAD can help to fund aspects of the research programme. We aim to:

- ❑ Beat 2016's Scones for SCAD participation and total (bit.ly/1095YdW).
 - ❑ Increase the number of venues and people attending our walk.
 - ❑ Increase the number of people using the Giving Machine to generate free donations when shopping online.
- We look forward to making further progress to achieve our mission in 2017.

How you can help

As a small charity we have limited resources but big ideas. In order to make sure those ideas become reality we need your help!

Raise awareness

Download our leaflets (bit.ly/1VHnYxb) and give them to GPs, cardiologists, cardiac rehab nurses, SCAD patients and anyone who can help raise awareness.

Raise funds

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

- ❑ Place one of our collection boxes in a local shop, school or leisure centre.
- ❑ Drop your spare change into one of our home collection boxes.
- ❑ Use The Giving Machine when you shop online (bit.ly/2dbmH2b) – and install the Shop and Give Reminder on your web browser.
- ❑ Choose Beat SCAD as a charity when you sell on Ebay (charity.ebay.co.uk).
- ❑ Run, walk or do other sponsored events to raise money.
- ❑ Approach your employer for match funding.

Regular donations

- ❑ Give As You Earn.
- ❑ Donate regularly by Standing Order.
- ❑ Donate on our website (bit.ly/2dBtSUv).
- ❑ Don't forget to Gift Aid your donations!



Skills, time and contacts

What skills can you offer?

- ❑ Fundraising, including grant writing and corporate donations.
- ❑ Marketing.
- ❑ Web development.
- ❑ Film making and photography.
- ❑ Merchandising.
- ❑ Attending events on behalf of Beat SCAD or volunteering for us.
- ❑ Do you know anyone who would sponsor our events or merchandise?
- ❑ Does anyone have a venue we could use for local events or training sessions?

For further information or to offer help, please contactus@beatscad.org.uk.

Financial report

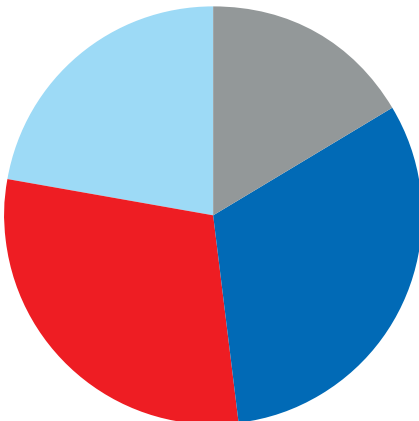
Beat SCAD fundraisers and donors have been very busy this year, raising a massive £29,056.

Individual fundraisers (two bike rides and a run) raised more than £8,600, which is a fantastic achievement. Beat SCAD events, Scones for SCAD and the Beat SCAD walk raised £4,816 and £9,152 respectively. The latter included two individual fundraisers, who raised over £6,700, including £2,250 of match funding from companies. More than £3,000 will also be claimed in Gift Aid.

We plan to split the funds three ways to support our three missions: Awareness, Support and Research. We will be donating up to 60% to the Leicester Cardiovascular Biomedical Research Unit's SCAD project. We are in discussions about how best to use this money and will post details on our website.

The other 40% will be split between raising awareness, including attending events, and supporting SCAD patients, families and friends through initiatives such as a support system to help people cope with life after SCAD.

Income	
Fundraising	£29,056
Other	£157
Total income	£29,213
Expenses	
Promotional expenses	£2,993
Admin	£427
Total expenses	£3,420
Surplus income	£25,793



Fundraising breakdown

Donations & other	£6,412
Individual fundraising events	£8,676
Beat SCAD Walk	£9,152
Scones for SCAD	£4,816



Thank you for helping us to Beat SCAD!

The trustees of Beat SCAD would like to thank everyone who has supported us throughout the year.

Thanks to all the SCAD patients, families and friends, who have raised awareness in many ways, from distributing leaflets about SCAD to GPs, cardiologists, cardiac rehab nurses and many others, to radio interviews telling their stories.

Thanks to everyone who has raised such an incredible amount of money through events, challenges and

donations – you have been so generous and exceeded our expectations.

Thanks to the staff and researchers at the Leicester Cardiovascular Biomedical Research Unit SCAD research project, led by Dr David Adlam and Dr Abtehale Al-Hussaini (Abi). You have given us hope!

Thanks to the funders of the research, including the BHF and National Institute for Health Research Rare Diseases Translational Research Collaboration.

Thanks to all our supporters who have given time and skills to help us beat SCAD.

Find us online



beatscad.org.uk



facebook.com/beatscaduk



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



bit.ly/1TXhiLV

Contact us

Please get in touch if you have any questions or can help us achieve our aims. [**contactus@beatscad.org.uk**](mailto:contactus@beatscad.org.uk)



beatSCAD



