



beatSCAD



Annual Report 2021

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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 tear or a bruise 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 for more.

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

British Heart Foundation
bit.ly/1LaOgys

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.

		
Debbie Oliver	Harriet Mulvaney	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 volunteering for many local causes. **Harriet** is Co-Director of a digital marketing company, Assistant Practice Manager at a GP practice and mum to three teenagers. **Karen** is a Patient Research Ambassador and Organ Donation Campaigner. And **Debbie** has worked in the publishing industry for more than 30 years.

 **Karen Rockell**

You can read our stories on the website at beatscad.org.uk/scad-stories.

Welcome

Hello and welcome to the sixth Beat SCAD Annual Report, summarising another impressive and inspiring year of work by trustees, volunteers and supporters to further the charity mission of raising awareness of SCAD, providing support to people affected by SCAD, and fundraising for essential research.

The Covid-19 pandemic continued to have an adverse impact on the availability of opportunities and the way we carried out our activities but, despite these challenges, Beat SCAD continued to use online platforms to raise awareness and provide support. Our income this year was very similar to last year (£44,792 vs £47,073), which puts the charity in a good position to assess the possibilities for the next research donation.



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 for us. Email: 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.

SCAD stories

Patient stories can be powerful both for raising awareness and helping newer patients to feel less isolated. Thanks to those who have allowed us to publish their stories.

Polly

When Polly retired, she decided to return to college to study art. But in the summer of 2017 she became unwell with what she thought was a virus.

On her first day back at college in September, she felt a severe pain between her shoulder blades. She felt achy and nauseous as she had in the summer, but this time she also felt an overwhelming sense of dread.



Polly

Luckily, a tutor came into her studio, took one look at her and rang for the first aider who rang for an ambulance. At the hospital she was diagnosed with SCAD, which had caused a heart attack. "I was very lucky as the consultant knew about SCAD and my condition was managed medically.

Polly used to go on solo coastal walks to take photos for her course, but she no longer thinks it sensible to go alone, so she had to re-think her creative practice. She says: "I have found that my new practice, especially during Covid-19 'lockdown', has provided me with much needed peace, as I am able to sit and hand stitch and embroider; and I find that the steady rhythm of this type of work calms both my body and my mind.

Polly told us "At the age of 67 I have not only successfully completed my BA Hons Fine Art Textiles degree, but also been awarded a First! I have found both a new purpose and a life after SCAD."
beatscad.org.uk/pollys-story

Rebecca

After having a procedure to remove a kidney stone and then being put on the waiting list for a further operation, Rebecca went to bed early one evening as she wasn't feeling very well.

"All of a sudden I got a dizziness in my head and everything started to spin. I crawled into my partner's bedroom on my hands and knees and said I felt very

ill. I was bright red and hot on my face and chest. I crawled to the top of the landing and was violently sick."

Her partner called 111 and a doctor checked her over and gave her medication to stop the nausea and she was told to rest.

A few months later, she went into hospital for another routine operation. She was taken to the operating theatre and the next thing she remembers is waking up in her hospital bed.

"There were tubes coming out of my neck and my arms. My lovely eldest daughter, Holly, was by my side and Doug, my loyal partner, was there too.

"Holly and Doug told me that I had been put into an induced coma for the last two days as I had gone into cardiac arrest shortly after having the anaesthetic. I couldn't quite believe my ears. I was in so much shock and the tears ran down my face."

A doctor told her she'd had a SCAD and it took six minutes of CPR to get her heart to start again.

During many months of recovery both physically and mentally, Rebecca received a lot of love and care from close friends and family. "The SCAD group on Facebook helped a lot, especially in those early days," she said.

"My personal experience is that the emotional and mental scars take longer to heal than the physical. I felt like such a weak person and had so many mixed emotions. I was relieved that I had survived but also thought 'why has this happened to me?'"



Rebecca with her daughters

"The event did make me assess what's important in life. It also made me more anxious and lacking in self-confidence.

"But time is certainly a healer and I try my best to listen to my body but also not to get anxious. The best medicine I have found is to rest. I also try to go with the flow. It's good to feel in control of life, however sometimes life throws a curve ball and you have to go with it and overcome it the best you can."

beatscad.org.uk/rebeccas-story2

Tell us your story

SCAD stories both from patients and family members are a very powerful way of raising awareness of how SCAD can affect people, as well as helping those affected by SCAD to know they are not alone and others have experienced what they are going through. If you would like to tell us your story, please see beatscad.org.uk/scad-stories or email contactus@beatscad.org.uk.

Paying it forward

Two-time SCAD patient and doctor Giedre Calverley has been using art to maintain her health and wellbeing since her first SCAD in 2018. In February 2021, she decided to pay it forward and help other SCAD patients do the same.

She told us that after her second SCAD in January she attended a webinar about occupational stress in the caring professions and measures that have been proved to help prevent lasting negative effects on health.

“The idea of psychological PPE – having a plan that includes personally effective things for staying well, ready for possible stresses in the future, and peer-support groups – having a group of people who share the same experience and help each other with problem-solving and encouragement – gave me the idea to start a creative group with SCAD survivors,” Giedre explains.

She invited members of the SCAD UK & Ireland Survivors Facebook group to creative and conversation sessions. She said: “The purpose is to have a peer group where we could ‘make sense’ of changes in our lives caused by SCAD in a safe, facilitated creative space.”

The weekly online workshops started in early March and ran for eight weeks.

Giedre explained, “Each week we had a different theme and activities. We looked at making time to care for ourselves, being present and journaling. We explored our connections with



Some of the SCAD patients' artwork

others, looked at our strengths, explored our senses with a particular focus on touch (this session was beaming with laughter) and made drawings in response to our favourite text.”

One participant, Kay Deadman, said: “This really challenged me as I had lost confidence of who I was and what I wanted when I had the SCAD and, at first, thought I wouldn't be able to think of anything [to draw], but with Giedre's gentle nature and guidance I was amazed with what I had done. I really enjoyed engaging with the others while doing art and we chatted and talked about our experiences and worries of SCAD, which helped me immensely.”

Wellbeing and SCAD

In February we hosted an online event, where two-time SCAD patient Dr Colette Soan, who is an educational psychologist, talked about wellbeing after SCAD.

She started by saying it's normal to have an emotional or psychological reaction, such as anxiety, depression and post-traumatic stress, to a SCAD event and everyone responds differently.

Dr Soan and colleagues Zoe Capper, Lydia McTigue and Bethany Williams, reviewed research literature that discussed SCAD, mental health and psychological rehab for SCAD patients.

One research paper suggested there were higher scores of anxiety and depression closer to the point of SCAD, when the SCAD survivor was younger and when they were peripartum. A more recent study found there was no difference between P-SCAD (pregnancy-related) patients and other patients in terms of the level of anxiety and depression.

According to one study, 38.5% of SCAD patients had a history of depression or anxiety and around half experienced an intense emotional experience or stress prior to their SCAD event.

SCAD patients who attend cardiac rehab tend to have higher scores for anxiety and depression than non-SCAD patients prior to attending rehab. About 75% of patients indicated they experienced an emotional benefit from attending rehab.

The research tells us that things which help recovery include recommendations from primary care providers (eg cardiologist), SCAD-specific programmes, and online patient education and support groups.



Colette Soan

Colette also told her story and discussed how post-traumatic stress can lead to post-traumatic growth, where patients make positive changes following a trauma. She also reminded SCAD patients, with a lovely mnemonic (pictured below) to look after themselves!

Thank you Giedre and Colette for using your experience to help others!

- ❑ To see some of Giedre's art, have a look on Instagram [@giedr_art](#) and see [@Healing_scad_h_art](#) for some of the art created by the SCAD patient group.
- ❑ For more about Dr Soan's research see beatscad.org.uk/scad-and-wellbeing.



Buddy Service

Beat SCAD has long recognised that peer-to-peer support is an invaluable part of recovery, and one of our aims was to create a service linking newly diagnosed patients with more experienced ones, who could offer a helping hand along their recovery journey.

It all started back in 2019 when the Beat SCAD Trustees and other volunteers met with Dr Colette Soan, two-time SCAD survivor and educational psychologist, and her colleagues Sue Morris and Neil Hall to work out what kind of service we wanted to provide.

We are not medically trained and can't provide medical advice or mental health counselling services, but we are 'experts by lived experience of SCAD' and can identify with what newly diagnosed SCAD patients are going through. So, we decided our goals were going to be to:

- provide an empathetic service
- point patients in the right direction to get more information and help

□ try to help patients cope with their diagnosis and find ways to move forward.

Launching in November 2020, the Buddy Service has provided support to 21 people in this financial year.

Looking for a SCAD Buddy?

After applying (beatscad.org.uk/buddy-service) patients are matched with a suitable Buddy. They may live in the same part of the country or may have a similar health background, for instance have had a baby just before their SCAD or been diagnosed with an associated condition, such as FMD (Fibromuscular Dysplasia).

The importance of being heard

When the patient first talks to their Buddy, most start by sharing their SCAD story. The importance of telling their story, of being heard, understood and believed can't be underestimated. Many SCAD patients feel like the rug has been

pulled out from under them. They often feel immense shock at being an unexpected 'heart attack patient' and many will also have had a difficult time being believed and getting the hospital care they needed. Some will have had a diagnosis but have been told very little about SCAD. So, to speak

with someone who really 'gets' what they are going through, can be a real turning point and help patients feel less alone and isolated.

For quite a few service users, one call seems to be enough... particularly if they have also joined the Facebook patient support group. That said, Buddies will often follow up with 'checking in' messages and emails and may then arrange follow up calls – or just make sure the service user knows they can always get in touch if they want to chat again.

Some people prefer more regular contact with their Buddy over several months before moving towards a less frequent contact basis. The beauty of the Buddy Service is that it is up to the service user and their Buddy to work out what happens next.

One thing everyone can be sure of, though, is that anyone using the Buddy service will be listened to, treated with dignity and respect, supported and signposted to helpful sources of information and to other services that can help them on their road to recovery.

Being a Buddy

In addition to Trustees Rebecca, Karen, Debbie, Sarah and Harriet, Catherine, Laura, Nicki, Lucie and Amy have all been part of the team in its first year.

If you would like to volunteer as a Beat SCAD Buddy, please do email contactus@beatscad.org.uk as we will be looking to expand the number of Buddies in the coming years.

What our Buddies say...



Lucie

I volunteered to be a Buddy to give support to others who are struggling with any aspects of SCAD, knowing how I felt in the past. I have found that often an

objective listening ear, with someone who has experienced SCAD, is enough. Sometimes, just pointing people in the right direction and showing empathy is all that is needed.

I also know that often unexpected positives can come out of a difficult situation, and my own experience with SCAD has definitely resulted in many positives, including a lifestyle change for the better, as well as new friends and relationships. I hope that this has given hope and encouragement to people I have spoken with.



Catherine with her son, celebrating his birthday

I became a Buddy to enable those that had experienced SCAD to have the opportunity to talk about their experiences.

I had a P-SCAD and being able to provide empathy, reassurance and ideas on moving forward in my experience is humbling.

Fundraising and donations

Despite the Covid 19 pandemic, our fundraisers have been out in force raising money for us.

Isobelle, the daughter of SCAD patient Kelly Jones, raised more than £240 doing various challenges including handing out collection boxes for people to donate their loose change, and a sponsored cycle ride.

Another sponsored event, in July, saw the Henshaw Primary School Young Leaders raise more than £200 on a sponsored walk.

In August, SCAD patient Jill Scaife hosted a ladies-only garden party. Tickets were £10 and Jill laid on food, drink and live music. She raised £2,440 and her wonderful parents doubled that, donating a total of £4,880.

Thanks to all those who have set up birthday fundraisers on Facebook, including Charlie Forkes, Elaine Selkirk,



Rachel Heaton's beautiful bath bombs

Mel Furness, Maxine Joynson, Jane Morgan, Ander Alex, Joanna Duncan, Luke Royle, Shell George, Laura Crane, Chin Fisty, Emily Viller, Christna Allis, Jayne Morland, Gill Gould, Aimy Stevens, Ceri Brown, Sue Thomas, Rachael Bonner and Sarah Slade, who between them raised nearly £1,800.

Celia Herrick raised more than £1,100 with a retirement fundraiser – we hope you have a happy retirement Celia!

SCAD patient Rachel Heaton produced a some limited-edition bath bombs to sell in her online shop. She took inspiration from the Beat SCAD logo to design these beautiful products and her sales raised £245.

Talking of making things, Jo Moore raised more than £100 by selling flower posies she created.

Jo and SCAD patient Joan Errington were also kind enough to let us use their photos to expand our range of Christmas cards, raising funds from sales in our shop.

Two-time SCAD survivor Colette Soan and her colleagues at Sandwell Educational Psychology team decided to take on some personal challenges in September. She said "We work very hard and sometimes forget to look after ourselves too," so the team decided to do something for their wellbeing, including walking 10,000 steps a day, not eating chocolate, riding 250km, doing an Ironman triathlon. Thank you



Wheelock Primary School raised money in memory of their teacher, Katie Ratcliffe

Jas, Alison, Helen, Sarah, Julie, Grace, Tim, Roxy and Colette!

Marathons and half-marathon fundraisers raised nearly £1,800, with Dani Johnson running the virtual London Marathon in memory of her mum Carole, who died following a SCAD in 2016 and would have been 60 this year.

And Paul Hallas, who had a SCAD in 2019, ran a half marathon raising £785.

Although most people who have a

SCAD recover well, some sadly do not survive. This year we have received some very generous donations in memory of Katie Ratcliffe, who died aged 33 following a SCAD.

Anneka Field ran Tatton Park Marathon in April in memory of her friend Katie Ratcliffe, raising £685.

And Wheelock Primary School, where Katie taught, held fundraisers during the year in Katie's memory, raising £7,500 for Beat SCAD.

We were saddened to hear of the death of Rachel Armitage in July. Rachel had a SCAD in 2013 shortly after giving birth to her daughter Romilly. She suffered neurological damage but made a remarkable recovery. Rachel passed away suddenly aged 44. Her family asked for donations to be given to Beat SCAD and we are very grateful to receive more than £1,500.

We are always devastated to hear about these deaths and our thoughts are with the families and friends of those who have died following a SCAD.



One of the new Christmas card designs.

Raising awareness

The pandemic has not stopped us raising awareness and Trustee Sarah Coombes did some online educational sessions for paramedics this year. In January she and SCAD patients Rose, Zoe and Paul told their stories to paramedics from the South East Coast Ambulance Service and talked about their experience as SCAD patients.

Discussing the range of symptoms experienced by male and female patients, those who are perimenopausal, pregnant or post-partum, as well as those who had a cardiac arrest, illustrated clearly to the paramedics that there is no such thing as a 'typical' SCAD patient or 'typical' SCAD symptoms.

Alan Rice, Associate Professor Paramedic Practice at the School of Allied Health, Midwifery and Social Care at Kingston University and St George's, said: "Huge, huge thank you. One of the best patient-led sessions I've ever seen."



Critical Care Paramedic John, from Paddock Wood Ambulance Station, with our posters in the 'clinical corner'



Karen Rockell with the cardiac rehab team at Glenfield Hospital

In March, Sarah led CPD (continuing professional development) session with patients Rose, Zoe, Paul & Mag, this time talking to Senior Paramedics from the London and South East Coast Ambulance Services.

In April we were delighted to hear that some of the South East Coast Ambulance Service stations have put Beat SCAD posters in their 'clinical corner' areas to raise awareness among the station's staff.

Continuing our educational work, Dr David Adlam and Trustee Karen Rockell led a training event for the Cardiac Rehabilitation Team at University Hospitals of Leicester NHS Trust Glenfield site. Dr Adlam, lead UK SCAD researcher, discussed the latest understanding of the mechanism of SCAD and the best practice in terms of diagnosis and treatment. Karen then gave a talk on the impact of SCAD on patients and the

importance of cardiac rehab training being sympathetic to SCAD patients' needs, which are different to the usual cardiac rehab participants.

Raising awareness of SCAD at government levels with the aim of influencing how patients are diagnosed and treated is important. Beat SCAD submitted feedback for the Women's Health Strategy for England in June, covering issues such as conscious and unconscious bias in healthcare professionals that leads to misdiagnosis, barriers to specialist care and lack of NICE guidelines for SCAD.

June also saw the publication of an article in the Hospital Times where Lottie Moore talked to Trustee Sarah Coombes about her SCAD experience and discussed the inequalities in awareness, diagnosis and treatment of heart attacks that are resulting in a 'heart attack gap' where women are 50 per cent more likely to receive a wrong initial diagnosis.

Student filmmaker Aimy Stevens wanted to use her skills to make a film about SCAD in memory of her mum Anita, who died following a SCAD. We provided her with lots of information, she talked to Dr David Adlam and interviewed three patients, Caz, Elizabeth and Erica.

The film, This is SCAD, was launched on 21 September, the second anniversary of her mum's death. It is emotional and inspirational, so thank you Aimy and to everyone who contributed.

You can watch the film at [youtube.com/watch?v=I5CutFWMPfg](https://www.youtube.com/watch?v=I5CutFWMPfg).

To raise awareness of SCAD on World



M4RD podcast: Lucy McKay, Sarah Coombes, Dr David Adlam, Karen Rockell

Heart Day on 29 September, Beat SCAD collaborated with Medics for Rare Diseases (M4RD) to produce a podcast about SCAD. Lucy McKay, CEO of M4RD, was joined by Trustees Sarah Coombes and Karen Rockell, and Dr David Adlam.

The podcast (tinyurl.com/jpu86tnh) challenges medics to 'dare to think rare' and offers tips for diagnosing and managing SCAD. It also highlights challenges SCAD patients face accessing medical care, getting a diagnosis and appropriate aftercare.

Finding out if misdiagnosis has a negative impact on a SCAD patient's overall wellbeing was the theme of A-level student Ailsa Hamilton's Extended Project Qualification focusing on SCAD. Ailsa, whose mum, Anna, had a SCAD in 2019, reached out to Beat SCAD for help and we were very happy to promote her questionnaire to SCAD patients, so she could gather real-world, first-hand information about the impact SCAD has had on patients' lives.

As well as raising awareness, Ailsa achieved an A* for her 5,000-word essay – well done Ailsa!

Spotlight on...

Karen Rockell talked to Sarah Coombes about life as a Trustee.

Alongside Rebecca and Debbie, I started Beat SCAD nearly six years ago as the only way forward to achieve our aims: to raise awareness of SCAD, support patients and fund research. It's been a huge part of my life ever since.

During this year of Covid lockdown, as the recipient of a donated organ, I was deemed clinically vulnerable and had to stay at home, so online meeting platforms became an absolute lifeline for me – both for work and for socialising with family and friends.

Every day is different

While each day is different, most start in a similar way: with my morning walk and then sitting with a cup of tea to check my emails and messages. Invariably there will be a lot of them.

In a typical day I might look at what the Small Charities Commission is doing and see if they have any useful training sessions. There will be emails from colleagues and meetings to prepare for.

I check Twitter and Linked-In every day, looking for new people to link with who might be influential in our work.

Next, I could be preparing a presentation for a training session for paramedics or cardiac rehab teams – or getting ready for a support group meeting.



Karen at our last Conference in 2018

Beat SCAD moves online

We celebrated our fifth birthday as a charity in November with an online research update from UK SCAD experts, a review of our achievements over the past five years and looked ahead to our future plans. I was so proud of our celebration video (tinyurl.com/4346tcw8) that I put together with volunteer Adam Hacker. I spent hours looking through photos and annual reports, trying to pick out highlights – which was hard to do because there were so many! It was so moving and satisfying to see how much has been achieved. Sometimes, when we are focused on the day-to-day, we forget what we are achieving because we are so busy thinking ahead to the next item on the to-do list...

A few months later we hosted another online event 'Our wellbeing – what can we learn from research, pandemics and each other' (tinyurl.com/5h32hwct), which was very timely as we were still in the depths of the first lockdown.

What I love about being a Trustee is that I never know when a new opportunity will arrive and what shape it will take. A random email from someone who wants to learn more can lead to a major step forward with awareness raising.

I also get great satisfaction from knowing when I have made a difference to someone, for example in my role as a SCAD Buddy. For some people there is nothing like talking one-to-one to someone who has been through what you are going through.

Looking ahead...

I'm not getting any younger, so have decided that it will be time to step down once I complete my sixth year as Trustee in November 2021. I want to focus more



Karen participates in the Transplant Games and has won medals for swimming

on other interests, including doing more for the Fibromuscular Dysplasia (FMD) community, as well as allowing for fresh ideas to be brought into the leadership of the charity in due course.

I will continue to volunteer as well as remaining a Buddy. I am so proud of what we've achieved as a charity in our first six years. I now look at how the community has grown, how diverse it is, how supportive and caring it is. It never fails to motivate me to do more.

Karen's top tips

- ❑ Make time for yourself – I go for a daily walk before starting work.
- ❑ Help others – I'm a Health Walk Leader – part of a national scheme with my husband, Clive, leading local walks once a week. I'm passionate about the benefits of walking: exercise, companionship, improved mental wellbeing and a good cup of tea at the end. Each walk is 5k and we tailor them to the needs of participants, some of whom have gone on to get trained as walk leaders themselves.
- ❑ Stretch yourself – I'm a participant in the annual Transplant Games – though they were cancelled in 2020 and 2021, we hope they will go ahead in July 2022.
- ❑ Take stock – don't forget to look back and see what you have achieved.
- ❑ Be curious about everything – you never know where that curiosity might lead you!

Research update

We were pleased to see more research papers published during the year.

Connective tissue abnormalities, coronary inflammation and coronary artery Fibromuscular Dysplasia (FMD) have all been suggested as potential causes of SCAD, but had not previously been systematically assessed.

A study looking at this was published in May (*Vascular histopathology and connective tissue ultrastructure in spontaneous coronary artery dissection: pathophysiological and clinical implications*) and the findings suggest that any connective tissue abnormalities common to patients with SCAD who do not have hereditary connective tissue disorders are probably subtle, transient or localised to the coronary arteries.

Also in May, the first ever chapter dedicated to SCAD in any cardiology textbook was included in *PCR-EAPCI Textbook Percutaneous Interventional Cardiovascular Medicine*. Written by cardiologists and SCAD experts including Dr David Adlam, who is leading the SCAD

research in Leicester, the chapter defines SCAD, discusses conservative management and healing, risks and outcomes of stenting and bypass surgery, contraception, HRT and ongoing chest pain, recurrent SCAD and mental health.

In general, conservative management is preferred where possible, but some SCAD patients may need intervention to reduce the risk of greater heart injury. However, there is a higher risk of complications when PCI (invasive angiography and placing of stents) is used.

A study investigating the practice and complications of PCI in SCAD patients used data from patient registries in the UK, Netherlands and Spain. Co-written by Dr David Adlam and colleagues on the UK research project, *Risks and benefits of percutaneous coronary intervention in spontaneous coronary artery dissection* is the largest international observational study of PCI in SCAD. It looked at 215 SCAD patients who had undergone PCI and 221 who had been managed conservatively.

“While a conservative approach to revascularisation is favoured, SCAD cases with higher risk presentations may require PCI. SCAD-PCI is associated with longer stent lengths and a higher risk of complications but leads to overall improvements in coronary flow and good medium-term outcomes in patients,” said the study.

Exercise has been associated with some SCADs, but it is not yet known if exercise actually causes SCAD. However, this association has led to caution in terms of advising what kind of exercise can be done.

Written by SCAD experts, *Physical activity and exercise in patients with spontaneous coronary artery dissection and fibromuscular dysplasia* highlights that patients need to balance the theoretical risks of exercise after SCAD or FMD against the disadvantages of not exercising (both physical and mental) with all the known benefits exercise brings.

The authors say there is a lack of data to help identify specific exercise programmes, however in their experience looking after SCAD and FMD patients, they recommend SCAD patients follow most of the usual advice given to the general public. However, they should avoid extreme exercise, favouring regular repeated activities over exercising to exhaustion and should rest if they become uncomfortable.

In August, a ‘state of the art review’ was published providing an in-depth analysis and discussion about SCAD, use of angiography and intracoronary imaging



Dr Adlam explains SCAD at our virtual update

on SCAD patients and diagnosing and managing challenging cases. *Spontaneous Coronary Artery Dissection: Pitfalls of Angiographic Diagnosis and an Approach to Ambiguous Cases* was written by SCAD experts and researchers at the University of Leicester and the Mayo Clinic in the US.

At the end of our financial year we held a Research Update and talked to Dr Alice Wood, who finished her research fellowship on the SCAD research team in Leicester in July. Dr Wood researched SCAD in men and recurrent SCAD. She is currently analysing the results of the tests done on patients and healthy volunteers, after which she will write up her thesis and hopefully submit papers to journals.

Dr David Adlam discussed the various research papers that have been published over the last couple of years and answered questions from attendees.

For links to all the papers mentioned here please see p23. And for more research papers see [tinyurl.com/4daxzurf](https://www.beatscad.org.uk/tinyurl.com/4daxzurf).

Exercise and physical activity guidelines for SCAD patients

Recommended

- Cardiac rehabilitation
- Moderate aerobic exercise
- Interval training
- Weight training with low resistance/high repetitions

With caution

- Endurance aerobic training
- Muscle building exercises
- Yoga poses without extreme head and neck positions

Avoid

- Abrupt, high-intensity exercise
- Peak weights with prolonged Valsalva movements
- Contact sports
- Extreme head positions

Progress and future plans

We celebrated our fifth birthday on 7 November 2020 with a virtual event where UK SCAD experts Dr David Adlam, Dr Alice Wood and Dr Abi Al-Hussaini gave us insights into SCAD research, pregnancy-related SCAD and answered questions from the SCAD community.

Rebecca Breslin, Chair Trustee, shared highlights from our first five years, including the amazing fundraising by our supporters, who have raised nearly £260,000: a fantastic achievement. For every £1 spent by Beat SCAD, 84.4p has gone to research, which is much higher than our original commitment to donate at least 60% of funds.

To celebrate the achievements of the charity and its supporters, volunteer

Adam Hackers created a highlights film. All event videos can be accessed at tinyurl.com/2s3rjkw9.

Beat SCAD's aim for 2021 was to implement the first stages of our five-year strategic plan (Nov 2020 to Nov 2025), which was introduced during the fifth birthday celebrations (Looking to the future (tinyurl.com/47sm4p5p)).

Awareness

Campaigning for SCAD to be included in guidelines and training for healthcare professionals remains a top priority, as does general awareness raising.

We submitted comments to the National Institute for Health and Care Excellence (NICE) regarding their

Post-natal care guidelines, and these were included in the stakeholder section but no updates re SCAD were implemented at this time. During 2021, we also continued to educate healthcare professionals about SCAD (see p14).

Support

To support the SCAD community, a new 'Living with SCAD' section was added to our website (beatscad.org.uk/living-with-scad), a virtual wellbeing event was held (see p8), and our Buddy Service was launched (see p10). 21 buddy requests were received between November 2020 and September 2021.

Other projects are also continuing in relation to cardiac rehabilitation, as well as the psychological impact of SCAD.

Research & Fundraising

Beat SCAD funding has facilitated significant research efforts led by Dr David Adlam and publications continued to be released this year, including *Risks and benefits of percutaneous coronary intervention in SCAD*, *Physical activity and exercise in patients with SCAD and FMD* and *Pitfalls in the Angiographic Diagnosis of SCAD* (beatscad.org.uk/research-publications).

This year, we signed up to a new fundraising method: The Giving Machine Lottery (givinglottery.org.uk/support/beat-scad). Fundraising remains critical because we cannot guarantee other funding sources – and it is essential that we retain our research to continue advancing SCAD knowledge.



Get involved!

Help us spread the word about SCAD and raise funds so we can continue to fund the research.

Help us raise awareness

Download our leaflets or order printed ones at tinyurl.com/4mamjwbh and give them to GPs, cardiologists, cardiac rehab nurses and SCAD patients.

Donate regularly

Just £10 a month can help us support the SCAD research. Please consider setting up a standing order – and remember to Gift Aid your donations!

Help us raise funds

Do a sponsored event, Facebook fundraiser, or give free while you shop via Amazon Smile... there are many ways to help raise funds for us.

For more go to bit.ly/2dBtSUv.

Volunteer

We'd love to hear from you if you'd like to help us, so please email contactus@beatscad.org.uk.

Photo: Shutterstock

Beat SCAD Strategic Plan Nov 2020 – Nov 2025

OUR MISSION

Beat SCAD won't stop until the world understands SCAD, patients are quickly and accurately diagnosed and everyone affected feels supported and hopeful for their future

OUR OBJECTIVES

Campaign for SCAD to be included in Healthcare Professionals' guidelines and **educate** the general public

Support the SCAD community and drive the creation of fully funded **SCAD clinics** in each country of the UK

Fund, influence and **disseminate** SCAD research

OUR PLANS

- Attain appropriate **information** about SCAD in Healthcare Professionals' guidelines
- Educate** Healthcare Professionals about SCAD
- Raise awareness** of SCAD amongst general public

- Support** everyone affected by SCAD
- Champion **patient voice** in campaign for SCAD clinics

- Fund** research
- Influence** and collaborate with SCAD related research
- Disseminate** research

GOVERNANCE & OPERATIONS

- Continue to develop **policies** and **processes** to support our objectives and activities and comply with legal requirements
- Manage the daily **operational tasks** that help us deliver services to achieve our aims and objectives

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 £44,792 this year. Despite the continued impact of the Covid-19 pandemic, you managed an inspiring range of challenges and events to reach this grand total (see p12-13).

Expenses this year were primarily research award payments totalling £67,192 (93% of total expenses), related to the funding of clinical research fellow, Dr Alice Wood, and her PhD work.

Thanks to all who have continued to support Beat SCAD through the ongoing challenges of the global pandemic.

Year 6 financial report	
Income	
Fundraising & donations	£39,449
Other	£5,343
Total income	£44,792
Expenses	
Donations	£67,192
Merchandise	£2,370
Promotional expenses ¹	£575
Sundries ²	£2,255
Total expenses	£72,392
Deficit income	(£27,600)
Reserved funds	
Awareness project ³	£1,010
Wellbeing project	£2,400

	Platform	Year 5 (end 30.9.20)	Year 6 (end 30.9.21)
Regular donors	Standing order	15	20
	Total Giving – monthly	3	3
	Paypal	0	4
Amount raised (excluding Gift Aid)	Total Giving	£320	£232
	Facebook	£5,179	£3,216
Amount raised (including Gift Aid)	Just Giving	£7,299	£11,232
	Virgin Money Giving	£3,622	£1,849
Number of online shopping supporters	The Giving Machine	61	60
	Easyfundraising	66	82
Amount raised	The Giving Machine	£105	£15
	Easyfundraising	£343	£436
	Amazon Smile	£192	£467
	Giving Machine Lotto	N/A	£542

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).

Useful links

Research papers about SCAD

Vascular histopathology and connective tissue ultrastructure in spontaneous coronary artery dissection: pathophysiological and clinical implications
Paper: tinyurl.com/222jh4sv

News story: tinyurl.com/2p9cab3z

PCR-EAPCI Textbook Percutaneous Interventional Cardiovascular Medicine
Textbook: tinyurl.com/5xvdm33s
News story: tinyurl.com/3unpmtpj

Risks and benefits of percutaneous coronary intervention in spontaneous coronary artery dissection
Paper: tinyurl.com/2p8umz3y

News story: tinyurl.com/cx2kxbv2
Dr Adlam discusses the risks & benefits of PCI tinyurl.com/mtjv7a79

Physical activity and exercise in patients with spontaneous coronary artery dissection and fibromuscular dysplasia
Paper: tinyurl.com/2rvv7hap
News story: tinyurl.com/ywnwsft5

Spontaneous Coronary Artery Dissection: Pitfalls of Angiographic Diagnosis and an Approach to Ambiguous Cases
Paper: tinyurl.com/587xcrxu

List of research publications
tinyurl.com/396efbc5

Beat SCAD resources

Research update September 2021

Video of event:
tinyurl.com/2p85zw8r
News story:

tinyurl.com/4f87xvec
Dr Adlam discusses research papers:
tinyurl.com/2p8h4p9z
Interview with Dr Alice Wood:
tinyurl.com/33k9udz

SCAD research in Leicester

Get involved in the research
scad.lcbru.le.ac.uk

Leaflets & support

Download/order leaflets tinyurl.com/2jyhp72y

Information about living with SCAD
tinyurl.com/3nr8eenr

Beat SCAD Buddy Service
tinyurl.com/5hykx5re

Fundraising

Donate to Beat SCAD bit.ly/2dBtSUv.
Shop tinyurl.com/yb7485ec



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. As more healthcare professionals are made aware of SCAD,

the journey for future SCAD patients will be easier.

Despite Covid-19 your fundraising has continued, which means we can fund more research, raise more awareness and support more people affected by SCAD.

Thanks to Dr David Adlam's research team in Leicester, including Research Fellow Dr Alice Wood. Thanks also 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



facebook.com/beatscaduk



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



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





beatSCAD

Awareness | Support | Research