



Annual Report 2020

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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.



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.

Welcome

Hello and welcome to the fifth Beat SCAD Annual Report, summarising the charity's continued efforts to raise awareness of SCAD, support people affected by SCAD, and fundraise for essential research.

The charity's fifth year of operation ran from 1st October 2019 to 30th September 2020 and was certainly a year of two distinct halves, with significant differences from March 2020 due to the start of the Covid-19 global pandemic.

The first half of the year was packed full of awareness-raising activities, with multiple talks delivered to some of Beat SCAD's target audience, including paramedics and cardiac rehabilitation teams. Following the onset of the pandemic, a small number of virtual talks were delivered, but the demands on the NHS have been so great that it has not always been possible to continue with planned awareness activities. Read more on pages 16-17.

The pandemic has, along with many other charities, affected our income this year, but thanks to the success of Year 4 fundraising, Beat SCAD awarded more than £113,000 to the UK SCAD research project in 2020 (see pages 12-13), which brings the overall total for the charity's first five years to more than £191,000. A truly wonderful achievement – thank you to all who contributed to this.

As a small charity led entirely by volunteers, the Trustees are thankful that the charity was not placed in the difficult situation of furloughing staff – there are no paid employees at Beat SCAD. On the flip side of this, many of our volunteers have not had their usual amount of time or resources available to dedicate to the charity, so this of course has impacted the work of Beat SCAD during this challenging year. Time will tell how the pandemic impacts the funds we can donate to subsequent research projects.

However, resilience is in our nature! Beat SCAD advocates for wellbeing, self-care, and post-traumatic growth as part of the SCAD recovery process and many of the tools, tips and tricks recommended to the SCAD community are also of great benefit in managing the anxiety that these challenging circumstances may have brought into our lives. The Trustees collaborated with the UK Research Team to share relevant information and advice in response to the pandemic (beatscad.org.uk/covid-19).

All things considered, it has been a busy, productive and successful year. Thank you for continuing to support Beat SCAD. Email contactus@beatscad.org.uk if you'd like to help in any way.

Together, we will Beat SCAD.

Rebecca Breslin, Beat SCAD Chair

Meet the Trustees

All the Trustees are volunteers, doing Beat SCAD work in their spare time. **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 local GP practice and mum to three teenagers. **Karen** took early retirement and is a Patient Research Ambassador and Organ Donation Campaigner. And **Debbie** has worked in the publishing industry for more than 30 years.

Rebecca Breslin

Becks had her SCAD in 2012, age 34. At the time, she was the Data Manager for a clinical trial researching treatment of Acute Coronary Syndrome. When she awoke frightened by a crushing sensation on her chest which moved to her jaw and left arm, she suddenly thought about the hospital reports she read every day at work – these were symptoms of a heart attack, but...?! It was a huge shock when doctors confirmed a heart attack, and Becks had never heard of SCAD. She felt at a loss over the limited information available.

Becks found other SCAD patients via social media and subsequently worked with Dr David Adlam to launch the first UK SCAD research project in 2014.

Away from full-time employment and SCAD-related volunteering, Becks loves



spending time with her two whippets who help to keep her active as well as relaxed as they love a lazy sofa day watching a film.

Highlight of Beat SCAD Year 5

Seeing the progress being made in raising awareness by reaching wider audiences (Myles Textbook for Midwives, see p16) and attending events such as the Maternity & Midwifery festivals.

Hopes for next year

To resume/reschedule fundraising activities impacted by the pandemic and advance towards the next research donation.

Hopes for the research

For more publications to be released to help with raising awareness in the medical community and open more research opportunities.



Sarah Coombes

Sarah had her SCAD in 2014, age 46 and was diagnosed with Fibromuscular Dysplasia (FMD) in 2015. Finding that her mental recovery was far harder and took far longer than her physical one, these days Sarah spends a lot of time supporting more recently diagnosed SCAD survivors.

Highlight of Beat SCAD Year 5

Educating advanced paramedic practitioners at the South East Coast Ambulance Service about SCAD and being invited to update the content of the NHS Mum & Baby app with information about heart health, including SCAD.

Hopes for next year

Developing the Buddy support service and training more Buddies.

Hopes for the research

That more will be found out about the link between SCAD, FMD and migraine following the PHACTR1 gene findings first published in 2019.



Harriet Mulvaney

Harriet had her SCAD in 2014, age 44. At the time she was a Senior HR professional. Harriet focuses on raising awareness of SCAD in Wales, working to improve access to SCAD experts for patients in Wales, and advising SCAD patients on work-related issues.

Highlight of Beat SCAD Year 5

Continuing to build connections with BHF Wales, paramedics, cardiac rehab teams and more, to raise awareness of SCAD and its management.

Hopes for next year

To push for the ever-growing Welsh SCAD patient population to be able to access specialist SCAD care either across the border in England or in Wales itself.

Hopes for the research

That the research papers that continue to be published lead to more widespread understanding of SCAD, which translates into guidelines for patient care.



Debbie Oliver

Debbie had a SCAD aged 49 in 2011. Researching online, all she could find were very scary statistics that most cases were diagnosed on the autopsy table.

Support and information for patients was non-existent and being treated like a 'classic' heart attack patient was frustrating. It took six months to find other patients online. Finally meeting Becks and other patients in 2012 was a turning point – there's nothing like talking to others who have 'been there'!

Highlight of Beat SCAD Year 5

Donating such a large amount to the research project to enable the team to continue searching for answers.

Hopes for next year

That we can create and offer more wellbeing resources for SCAD patients, families and friends.

Hopes for the research

That we are able to secure further funding to keep the momentum going.



Karen Rockell

Karen had a SCAD in 2010 and was appalled with the lack of knowledge about SCAD across the NHS. She is an NIHR Research Champion, and during 2020 was a public reviewer for the NIHR Covid-19 Urgent Public Health studies. Karen is also on the Executive Board of the UK Organ Donation and Transplantation Research Network.

Highlight of Beat SCAD Year 5

Our ability to continue to virtually support SCAD patients and their families during the challenging Covid pandemic.

Hopes for next year

Successful campaigning for NICE guidelines and SCAD guidelines for specific groups of healthcare professionals, including paramedics, midwives, A&E staff, and improved post-SCAD services for SCAD patients

Hopes for the research

A better understanding of the role hormones play in causing a SCAD.

Research update

The UK SCAD research project has continued its excellent work this year, studying sub-groups including male and recurrent SCADs. As with many things this year, the study was affected by Covid-19 as Dr Alice Wood, Research Fellow, was reassigned to clinical duties for a few months.

Dr Wood chose to study men because although there are suspicions that there are hormonal influences in SCAD, there are other factors and, as men don't have female sex hormones, studying them may reveal useful information.

For recurrent SCADs, studying a small number of people may help identify subtle differences or changes.

After pausing recruitment for the research due to Covid-19, her priority now is to see more patients and healthy volunteers and then analyse the data.

Research across the world has made important steps forward including on the genetics front, with the identification of the first common variant genes to be associated with SCAD, as well as more uncommon genes such as those associated with Loeys-Dietz Syndrome.

One paper published this year looked at the size of heart injury after SCAD and found that in the majority of cases, the damage is small. This helps clinicians to understand the consequences of SCAD and how it should be managed.



Dr Alice Wood

The research and global collaboration on SCAD has helped raise its profile and in August, the European Society of Cardiology published updated Guidelines for the management of acute coronary syndromes in patients presenting without persistent ST-segment elevation and included a section on SCAD for the first time. This is a welcome addition as it highlights the importance of recognising SCAD and that the way it is diagnosed and managed is different to atherosclerotic heart attacks.

For a list of some of the research papers that have been published over the past few years see beatscad.org.uk/research-publications.

Read more...

Sub-group study beatscad.org.uk/research-update-male-and-recurrent-scads

European Heart Journal, chronic infarct size after SCAD

beatscad.org.uk/study-reveals-majority-of-scad-patients-have-little-lasting-damage-to-their-heart and tiny.cc/jn77tz

European Society of Cardiology Guidelines

beatscad.org.uk/scad-included-in-european-clinical-practice-guidelines

SCAD stories

Everyone's road to recovery is different but time and time again, we hear stories from SCAD patients who, although their lives have changed, find something positive in their lives after SCAD.

Sarah

In 2016 Sarah woke up feeling groggy and had a pain at the back of her neck and a headache. She ignored it and rushed about as normal. However, she then had chest pain, a tingling sensation in her left arm and was finding it difficult to breathe.

She called her GP and was told to go to A&E, where she was diagnosed with SCAD. As luck would have it, her GP knew Beat SCAD Trustee Harriet Mulvaney and put them in contact. Sarah said: "The part that sticks in my mind is that Harriet said that she couldn't honestly say that now, several years on, life was any worse because of her SCAD. To see her and others with the condition



Sarah's SCAD was part of a new chapter



Linn with her cardiac rehab team

looking so well, some of them many years after their SCAD, made me realise that this wasn't the end but rather the start of a new chapter."

She added: "Harriet was right. I couldn't honestly say that life has been made worse by my SCAD. My life is the same as it was before except that I am now in tune with my body and I have learnt to listen very carefully to what it tells me."

beatscad.org.uk/sarahs-story

Linn

While she was at work in August 2019, Linn felt her chest tightening and she was having trouble breathing. A colleague called an ambulance and, once in hospital, she was diagnosed with SCAD.

Linn said: "I was forever changed. My life was changed. There was a before and after, and I could not pretend that SCAD did not happen and had not

affected me. I had changed, and I had to work through what this meant.

"This is where the cardiac rehabilitation came in. It ended up being such a blessing to me; both the gym sessions and CBT (cognitive behavioural therapy). I have grown so much because of this. It took me time to be able to see this, but SCAD ended up being a blessing in disguise and a new chance at life. In the end I could say this about myself: I am a survivor. I am a SCAD survivor!"

beatscad.org.uk/linns-story

Debbie

After having her SCAD in 2018, Debbie was having recurrent chest pain and was frustrated that her recovery was not going as fast as she'd hoped.

As a skater, her goal was to compete at the International Adult Ice Skating Competition in Oberstdorf in 2019.

In March 2020, she updated her story, saying: "The last two years have been the most difficult of my life, full of highs and lows and learning to live with the fear of it happening again. Yet, I feel it has made me a better person and I feel so much stronger than ever before. I have learnt so much about myself and how to make the most of life."

She shared some coping strategies that have helped her through the past two years, and said her psychiatrist introduced her to the phrase "Is what your doing right now going to make your life richer, fuller and more meaningful?"

She added: "I live by this now and for me, ice skating is my happy place. This



Debbie (centre) at a skating competition

has led to me not only taking part in the Oberstdorf Adult Skating Championships but also The Australian Master Games, The Juna Cup in Tallinn, Estonia and the Winter World Masters Games in Innsbruck. I've had the most amazing experiences and hope to do more in future."

Well done, Debbie, for chasing your dreams. Your story gives hope for other SCAD patients who are at the beginning of their journey.

beatscad.org.uk/debbies-story

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.

Our donations to research

Thanks to your amazing fundraising, Beat SCAD has donated more than £113,000 to the UK SCAD research project this year.

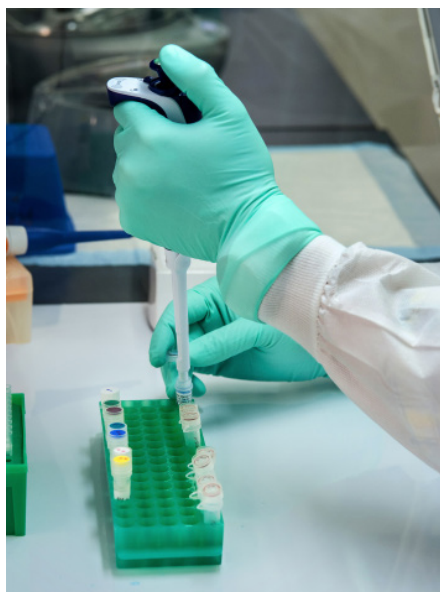
In July we donated £64,000 to fund a further year of research for Clinical Research Fellow Dr Alice Wood.

And in late September we awarded almost £50,000 to the research project, transferring just over £30,000 that month and the remainder ring-fenced for subsequent transfer in accordance with project timelines.

It's important that funds raised by you are used in ways that move the research forward, so following discussions with Dr David Adlam, Associate Professor of Acute and Interventional Cardiology at the University of Leicester and Honorary Consultant Interventional Cardiologist at University Hospitals Leicester, who is leading the SCAD research project, we agreed to fund the following:

❑ 42 cardiac MRI scans – £23.1K

These scans are being done as part of Dr Wood's phenotyping study into male and recurrent SCADs. Scans cost £550 each and they allow the researchers to look at the cardiac structure and function. The scan data are provided to Dr Wood in a blinded manner, which means she will not know if the scan belongs to a SCAD patient or a healthy volunteer, which aids unbiased review of the images. Dr Wood is also looking at



CDC/Unsplash

Funds you have raised are helping pay for vital laboratory work and consumables

responses to pharmacological stress, to see whether there is any difference in perfusion (the passage of fluid through the circulatory system) in SCAD patients.

We know that a proportion of SCAD cases happen after psychological stress and that some SCAD survivors have chest pain when under emotional stress, so she is investigating this too. "I am interested to see both whether SCAD survivors have more marked responses to psychological stress (in terms of blood pressure and heart rate) and also whether this affects myocardial perfusion," said Dr Wood.

❑ Transcriptomics (analysis of RNA) on skin fibroblasts – £15.6K

Fibroblasts are cells found in connective tissue. Skin biopsies have been taken from 50 SCAD patients and 35 healthy volunteers during the study. The aim of this work is to investigate if there are any differences between the RNA of SCAD patients and healthy volunteers. This will feed into and help further genetics studies into SCAD.

❑ Proteomics – £7.6K

Dr Ania Baranowski has been doing proteomics laboratory work as part of her PhD. This is a study of proteins and looks at blood plasma to identify which proteins are present in SCAD patients' blood. Dr Baranowski has already looked at one cohort of patients and healthy volunteers and will now study a second cohort of 50 SCAD patients and 50 healthy volunteers to confirm the findings of the first set of results. We are providing £7.6K for a six-month extension to Dr Baranowski's PhD.

❑ Laboratory consumables – £3K

We are funding lab consumables for Dr Baranowski's work, such as antibodies, gels and reagents.

Five-year donation total

These donations bring the total we have donated to the UK SCAD research project since 2017 to more than £190,000!

Dr Adlam said: "It has been relatively challenging to get funding outside of Beat SCAD. Without Beat SCAD, things would



Dr David Adlam

have come to an end. We would have made some progress but I'm not sure we would have been able to continue at the same level of ongoing research we have. Beat SCAD has been utterly instrumental in allowing us to continue."

Chair of Beat SCAD, Rebecca Breslin, said: "Throughout Beat SCAD's first five years, the SCAD community has demonstrated an incredible drive to fulfil the charity mission to raise awareness, provide support and fund research. Each year has seen impressive fundraising efforts, which have enabled these important donations to be awarded to Dr Adlam's research work in Leicester. The impact of these donations is being seen in the publications of research findings, which are steadily being released and are contributing to improved knowledge of SCAD. I extend a heartfelt thank you to all our supporters – the Beat SCAD Trustees appreciate all that you do and we continue to be inspired by you."

Fundraising and donations

In common with many charities, Covid-19 has affected our income this year, as fundraising activities were cancelled or postponed. However, our fantastic community of supporters still managed to achieve some great fundraising targets.

Kicking off the year was the Eye2i cycle ride. Long-time friends Paul Sorensen, Chris Dowdeswell and Clive Rockell, husband of Beat SCAD Trustee Karen, came up with a 'ridiculous' plan to cycle from the London Eye to Istanbul. Dubbing themselves 'Three old men on bikes,' they started in mid-September 2019 and arrived in Istanbul a month later. Their home for the month was a campervan, aka the Mothership, and their adventures were charted on their Facebook page www.facebook.com/eye2i. The 'Three old men' raised more than £6,800.

In November, Kirsty Buckwell and Greg Cox organised a Ladies' night and, together with donations from Masons meetings, raised more than £1,300.



Claire's bake sale was a great success



Paul, Chris and Clive with the 'Mothership' their home for the Eye2i trip

Claire Church, whose mum had a SCAD, had a bake sale and raffle, raising more than £1,500. Martina Fletcher and Angela Cox also held bake sales in February, raising more than £500.

Selling other things raised funds, too. Kathy Griffiths, sold a family history book raising £90. And Philip Bleasdale donated more than £500 from an auction and raffle of golfing items.

SCAD patient Sylvia Bowen and a group of ladies who had also had SCADs, held a charity ball and raised £140 for Beat SCAD, as well as fundraising for a new treadmill for cardiac rehab at the Cumberland Infirmary Carlisle.

Talking of dancing, Elizabeth Allford organised a charity barn dance and raised more than £1,700.

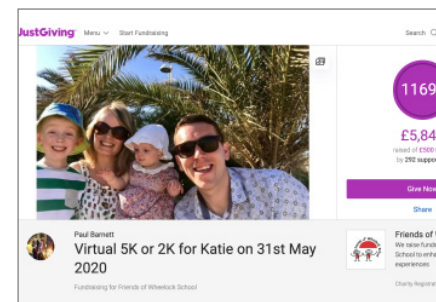
And Susannah Mitchell and her colleagues in ITU raised £1,000 at a charity night.

Diana Walker, who had a SCAD in 2016, pledged to run a 10K every month in 2019 to raise money for Beat SCAD and the BHF. Not being a runner before her SCAD, she did a zero to 5K nine-week challenge in 2017 and worked up to running 10K races. Despite injuries along the way, she completed all her races, raising £750 for Beat SCAD.

Many of you will have heard of Katie Ratcliffe, who died following a SCAD in 2019. Her family and friends have raised an amazing amount of money for Beat SCAD, starting with her husband, John Ratcliffe's fundraising page, which raised nearly £10,000. Family and friends also had a fundraising dinner in March.

Katie's cousin, Robin Barnett, entered the 2020 London Marathon and, before it was postponed due to Covid-19, raised more than £700. He will be running the 2021 race – hopefully in fancy dress!

And during Covid lockdown, Katie's brother organised a virtual fundraising walk to raise money for us and Wheelock Primary School, where Katie taught, raising more than £3,300 for us.



Paul Barnett organised a virtual walk to raise money in memory of his sister, Katie



Marcia Fotheringham, High Sheriff of Cumbria, at the charity ball organised by four SCAD patients

We are very grateful to families and friends who have donated nearly £4,000 to Beat SCAD in memory of their loved ones who died during the year, including Shauna Holmes, JE Lane and Peter Stribling.

There have been many other donations and fundraising activities this year, too numerous to mention here, but no matter how large or small, all donations are very much appreciated and, as you can see from our research donations (see page 12), the money is being put to good use.



Diana (left) with running buddies Tracey Cable and Julie Lockwood

Raising awareness

During this challenging year, we have continued raising awareness with both in-person and virtual events.

Trustees Karen Rockell and Sarah Coombes attended the London Maternity & Midwifery Festival in January and volunteers in Scotland attended a similar event in Edinburgh the previous month. The London event attracted more than 600 maternity and midwifery staff and we handed out hundreds of leaflets.

Sarah said “The emotional response by midwifery professionals to our pregnancy-related SCAD (P-SCAD) case studies was moving and sincere. Photographs and stories stick in hearts and minds far better than dry words and statistics ever could. Beat SCAD is so grateful to our survivor community who are willing to tell their stories to raise awareness of SCAD.”

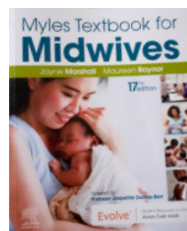
At this event, we were asked by Fiona Ghalustians, Senior Project Manager, Maternity Transformation Programme, North West London Collaboration of CCGs, if we could provide information about heart health and pregnancy, including SCAD, for the Mum & Baby app, produced by the NHS Central London (Westminster) CCG (Clinical Commissioning Group). The app is for pregnant or post-partum women and helps them navigate their maternity care choices in England.

We were very pleased to have this opportunity and SCAD is now included in the updated app.



Karen at the London Midwifery event

This year also saw SCAD information included in the Myles Textbook for Midwives (tinyurl.com/z4368nvs). Beat SCAD was approached two years ago by the book's publisher Elsevier and asked



to contribute a section on SCAD for the 17th edition. The book is used by student midwives in more than 75 countries, so will increase awareness among student

midwives and hopefully lead to earlier diagnosis of SCAD.

As well as P-SCAD work, Sarah has presented talks about SCAD to paramedics. In January she and SCAD patient Mag Davis talked to the Greenwich University Paramedics Society, raising awareness among student paramedics. When Covid-19 prevented face-to-face meetings, Sarah did an online training session in March attended by qualified paramedics and advanced paramedics as

part of the South East Coast Ambulance Service's post-qualification paramedic education programme.

Following the session, Phill Richardson, Critical Care Paramedic for South East Coast Ambulance and Senior Lecturer for St George's University of London, told us: “Our critical care paramedic clinical management plans (South East Coast Ambulance Service) have been updated to include awareness surrounding SCAD, so thank you for your help in educating us.”

Trustee, Harriet Mulvaney, met with the BHF in Wales to discuss how Beat SCAD could work with them to help raise the profile of SCAD patients and their treatment in Wales.

BHF Cymru are currently building their long-term strategy to influence politicians. One of the key aspects of this work is bringing attention to the gender gap that exists when treating heart patients. Research has shown that women are treated differently, and often with poorer outcomes.



The winning Christmas card designs



Sarah with paramedics at Greenwich Uni

Harriet was asked by BHF Cymru's Policy and Communications teams to contribute to an article on this topic, to appear in an influential publication by the think tank, the Institute of Welsh Affairs.

Karen also did an online talk to cardiac and chest pain nurses and cardiac rehab staff. Delegates committed to giving each new SCAD patient a Beat SCAD information pack.

In November 2019 Dr Alice Wood delivered a comprehensive overview of SCAD at a Scottish Cardiac Rehab Conference in Edinburgh. Beat SCAD had a stand at the conference and volunteers handed out leaflets to delegates and talked about their cardiac rehab experiences.

Over the summer, our supporters got involved in raising awareness when we ran a competition to design a Christmas card. We had some lovely entries and choosing the four winners was tough. The winning cards (left) were printed, with information about SCAD on the back, and sold in our shop.

Thanks to everyone who has helped raise awareness of SCAD!

Progress and future plans

Beat SCAD's aim for 2020 was to gather more momentum to push projects forward and continue working towards a better understanding of SCAD. The charity and our supporters can certainly be proud of achievements made this past year but, of course, Covid-19 brought some adverse effects.

Awareness

Significant awareness activities were achieved with talks given to our target healthcare professional groups, and a highlight being the publication of a SCAD section in the Myles Textbook for Midwives. As Covid-19 forced changes, Beat SCAD took advantage of online opportunities. Read more on pages 16-17.

We submitted feedback to the National Institute for Health and Care Excellence (NICE) regarding their guidelines for Acute Coronary Syndromes (ACS), aiming to get information about SCAD added. Unfortunately, this was not successful, but we will continue pushing to get SCAD into healthcare guidelines. We also submitted comments to a BHF consultation regarding a National Heart Disease Plan for Scotland.

Support

As Covid-19 began to dominate the news, Beat SCAD received questions from concerned SCAD patients. Trustees consulted with the UK SCAD experts to compile helpful resources on our website (beatscad.org.uk/covid-19).

Covid-19 contributed to the delayed launch of our Buddy Support Service (which went live in November 2020). Buddies are trained volunteers, who are longer term SCAD survivors and 'experts by experience', who will support newer patients and help them navigate the challenges presented by having a SCAD.

Research

Beat SCAD aim to collect patient data to derive statistics that can be used to make changes for the SCAD community. We ran our Cardiac Rehabilitation survey this year and will publish results once fully analysed. So far, 418 UK-based SCAD survivors are registered with Beat SCAD but this is estimated to be less than half of known UK cases.

Please sign up at tinyurl.com/yejwnr8x

Fundraising

Your continued fundraising efforts enabled us to award donations of more than £113K to keep research progressing (see pages 12-13). We look forward to hearing results from these studies.

Governance

The Trustees worked on our strategic plan to prioritise objectives and plans for the next five years.

Aim for 2021

Implement the first stages of our five-year strategic plan.

How you can help

Help us raise awareness

Download our leaflets (bit.ly/1VHnYxb) or order printed ones at tiny.cc/5jvokz 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.

Volunteer stories

We rely on help from volunteers to help us achieve our aims, and here we highlight just three of them.

Rosie Wood helped us make data entry into our database faster and more efficient.

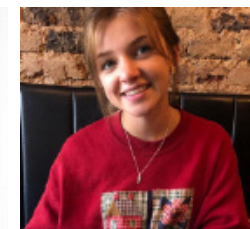
Entering the data collected via our Keep in Touch form manually was time-consuming and automating this freed up time to focus on other work. We were very pleased with the solution Rosie came up with, which has made this process simpler.

Victoria Warnes, who had a SCAD in 2017, helped us develop our cardiac rehab survey. The aim of the survey is to discover SCAD patients' experiences of rehab so we can identify areas where we can campaign for improvements, such as a more tailored offering.

Psychotherapist and coach Vicky



Victoria



Rosie

Bailey volunteered to run some webinars for fellow SCAD patients in the spring. Covid and lockdowns affected everyone in different ways and her 'Healthy mind platter' webinars discussed seven daily essentials that help us balance our lives, including sleep and gratitude. You can watch the webinars here tinyurl.com/hpscsc4j.

Thanks to all our volunteers!

beatscad.org.uk/volunteer-case-study-database-project

beatscad.org.uk/beat-scad-launches-cardiac-rehab-survey

Five-year financial review

After Beat SCAD's financial year concluded on 30 September 2020, the Trustees looked back at the charity's first five years and the exceptional achievements of our supporters.

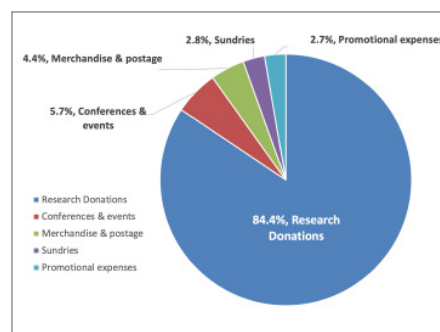
Chair of Beat SCAD, Rebecca Breslin said: "The Trustees are truly in awe of everything the SCAD community has achieved throughout our first five years. We cannot thank you enough for all that you do to progress our mission."

Your amazing efforts resulted in Beat SCAD's total income for the first five years reaching over £258,700, which averages at more than £51.7K per year. This is such an incredible achievement!

Year 1 fundraising was such a heart-warming endorsement for establishing the charity. The Trustees were impressed by large amounts raised by individuals who sought sponsorship for various running and cycling events, as well as the community efforts from participating in the charity's own events 'Scones for SCAD' and the first Beat SCAD walk.

Year 2 fundraising had a lot to live up to after the success of Year 1 and while the total income was less, it was still an impressive amount and we were able to award our first research donation of £25K.

Year 3 fundraising raced off to a fantastic start and within seven months the income had beaten the Year 2 total income. The Trustees were planning to award the next £25K research donation at the July conference when we received



How we spent your donations

a fundraising boost by the incredible One Community cycle challenge, which enabled us to double the donation to £50K.

Year 4 fundraising resulted in our most successful year. One of the new platforms we used this year was Facebook Giving Tools and many of you created Facebook Fundraisers, raising over £12K.

Year 5 fundraising got off to a great start. The total income has been impacted by the Covid-19 pandemic but is still an incredible achievement. Approximately three-quarters of Year 5 income was raised during the first six months, to March 2020. In common with other charities, Beat SCAD and our supporters were forced to cancel an array of fundraising plans.

In 2016, the Trustees committed to donating 60% of funds to research and for the majority of the remaining 40% to be split between awareness and support projects and running costs.

Due to your incredible fundraising, in

combination with the Trustees' efforts to minimise and optimise other charity spending, Beat SCAD surpassed the initial commitment and has donated a massive 84.4% of funds spent during our first five years to research.

For every £1 spent by Beat SCAD, 84.4p has been donated to research, 2.8p has been used to run the charity and 12.8p has been used for other charitable activities which largely fall under the awareness and support mission areas, such as costs to run our conferences, and attend external conferences as well as merchandise and promotional expenses.

Thank you for continuing to support Beat SCAD throughout this difficult time. We are so appreciative of the regular donations and fundraisers you have held.

Year 5 financial report	
Income	
Fundraising & donations	£44,848
Other	£2,225
Total income	£47,073
Expenses	
Conferences & events	£2,323
Donations ¹	£46,206
Merchandise	£488
Promotional expenses ²	£1,108
Sundries ³	£1,788
Total expenses	£51,913
Deficit income	(£4,840)
Reserved funds	
Donations ¹	£67,192.50
Awareness project	£1,010
Wellbeing project	£2,400

	Platform	Year 4 (end 30.9.19)	Year 5 (end 30.9.20)
Regular donors	Standing order	12	15
	Total Giving – monthly	2	3
Amount raised (excluding Gift Aid)	Total Giving	£1,033	£320
	Facebook	£12,118	£5,179
Amount raised (including Gift Aid)	Just Giving	£30,574	£7,299
	Virgin Money Giving	£2,918	£3,622
Number of online shopping supporters	The Giving Machine	60	61
	Easyfundraising	62	66
Amount raised	The Giving Machine	£84	£105
	Easyfundraising	£279	£343
	Amazon Smile	£95	£192

Notes: **1** Research donations awarded in 2020 total £113,398.50. £46,206 was transferred to the University of Leicester in July and September 2020. The remaining balance will be transferred per an agreed schedule according to when funds are required. **2** Includes printing of leaflets, pullups, posters and some filming costs. **3** Includes bank, insurance and fundraising expenses, website, postage and travel costs.



Thank you for helping us to Beat SCAD!

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

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. And to the National Institute for Health Research for continuing to fund the project. Thanks also to Dr Abi Al-Hussaini, who continues to treat and support SCAD patients. You have all given us hope!

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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



