



**Annual Report 2018** 

## Contents

About Boat SCAD

About Beat SCAD	7
Welcome	5
Meet the Trustees	6
2018 in review	
European Position Paper	9
SCAD stories	10
Research donations	12
Fundraising events	14
Conference 2018	17
Promotional activities	18
Progress and future plans	19
How you can help	20
Financial report	21
Thank you!	22



© Beat SCAD Registered charity number 1164066

## What is SCAD?

Spontaneous Coronary Artery
Dissection (SCAD) is an underdiagnosed 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

www.beatscad.org.uk 3

## **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.

#### **COMMUNITY**

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

#### **EMPOWERMENT**

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

#### **PARTNERSHIP**

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

## Welcome

Firstly, a big thank you to everybody who has supported Beat SCAD this year to help us further our mission to raise awareness of SCAD, provide support to those affected by SCAD, and to fund research. Without you, the incredible achievements summarised within this report would not have been possible.

Year 3 has been the charity's most successful financial year to date. We have been overwhelmed by your fundraising efforts which enabled Beat SCAD's largest research donation so far to be presented at our conference in June (see pages 12 & 17).

In addition to your fantastic fundraising, I am delighted that our third year included the realisation of the hopes of Trustees, which we shared in last year's annual report:

- □ I hoped to expand the team, which we did by recruiting two new trustees (see page 7) and by receiving more support from volunteers who helped at our conference and participated in awareness-raising events (see page 18).
- □ Karen hoped to broaden our work to educate more professional disciplines. This is a huge ongoing task, but we are making great progress in the midwifery field (see page 18) which is so important because P-SCAD (pregnancy SCAD) has been identified as a particularly high-risk group.

□ Debbie hoped for SCAD patients to be diagnosed earlier and find support quickly. We are seeing new patients join the online communities sooner after diagnosis and it is great when they report that their doctor told them about Beat SCAD and/or the research.

Perhaps you will be able to help us fulfil our hopes for next year? We'd love to hear from you if you'd like to support our work (see page 20 for ideas).

Year 3 concluded in September with our 'Design a Christmas card' competition (see bit.ly/2ELh22o). SCAD patient and one of the winners, Cheryl, explained why she entered the competition: "I found it a wonderful way to express my appreciation and gratitude for your unreserved support and advice. I want you to know how much you meant to me in those first desperate, frightening weeks and months and how much you will always mean. You are an incredible team and I thank you wholeheartedly."

I extend Cheryl's kind words to the wider SCAD community who provide so much support to one another and show a wonderful spirit of 'giving back' which is pushing both our charity and the research forward.

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 supporting many local causes, Harriet is Director of a Digital Marketing agency, Karen took early retirement and is a Patient Research Ambassador and Organ Donation Campaigner, and Debbie is a Production Editor in the Publishing industry.

#### Rebecca Breslin, Chair

Becks was 34 when SCAD struck in her sleep in March 2012. Thanks to her career in clinical research, Becks had enough knowledge of the symptoms to suspect that she was having a heart attack, even though she didn't fit any of the criteria

of the patients who usually participated in the cardiovascular trials she worked on.

When doctors explained that very little is known about SCAD, Becks' experience in her job also told her that more could be done to answer those unknowns.

After finding other survivors online, Becks approached her cardiologist in 2013 to demand a UK research project. Dr David Adlam agreed and the project launched in 2014 and exceeded all expectations for recruitment, thanks to the impressive engagement of the SCAD community.

Becks proudly launched the Beat SCAD charity with Karen Rockell and Debbie Oliver at the first UK SCAD conference in



November 2015. The trio are thrilled by how much the charity has grown in its first three years and are keen to maintain momentum.

Away from full-time work and SCAD-related volunteering, Becks loves spending time with her two whippets who help to keep her active.

### **Highlight of Beat SCAD Year 3**

Doubling our previous research donation to £50K at the conference this year is a stand-out achievement by the community.

### Hopes for next year

To develop the website to ensure we are providing optimum resources.

## Hopes for the research

The collaboration between SCAD and Fibromuscular Dysplasia (FMD) research is an exciting development and brings great hope of a better understanding of these associated conditions.



**Sarah Coombes** 

Sarah had her SCAD in 2014, age 46. She has also been diagnosed with Fibromuscular Dysplasia (FMD). She found her mental recovery took far longer than her physical one, so is now giving back by supporting SCAD survivors.

Before becoming a Trustee, Sarah was an active volunteer, organising both our second and third conferences, and raising awareness of the condition by giving talks to all kinds of medical professionals. As a Trustee, she is continuing this work.

#### Highlight of Beat SCAD Year 3

Bringing together 68 SCAD survivors at our third conference – having been told in 2014 I would never meet another patient!

### Hopes for next year

That we can encourage more longerterm survivors to become even more active in their support for Beat SCAD.

### **Hopes for the research**

That more will be found out about the link between SCAD and FMD.



**Harriet Mulvaney** 

Harriet had her SCAD in 2014. She is a Director of a Digital Marketing agency working alongside her husband, Steve. Prior to this, Harriet was a Senior Human Resources professional, with a career spanning nearly 20 years.

Before becoming a Trustee, Harriet was an active volunteer, raising awareness at conferences in Wales and working to improve access to SCAD experts for patients located in Wales.

### **Highlight of Beat SCAD Year 3**

The honour of becoming a Trustee and feeling the 'buzz' in the room when survivors came together at our third conference this year.

#### Hopes for next year

That we can continue to improve access to SCAD specialists for patients in Wales.

## Hopes for the research

That we continue to peel back the layers of the SCAD onion and that we draw in more experts to help in the discovery.



#### **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 3**

All the fantastic fundraising events our supporters have held, from sponsored swims and walks to retirement donations and cake sales

#### Hopes for next year

That more cardiologists commit to providing SCAD-specific care.

### Hopes for the research

That collaboration across the world continues so we can find answers faster.



Karen Rockell

Karen had a SCAD in 2010. Eight years on she feels 'normal' again and is leading a busy life both as a Trustee of Beat SCAD and as a Patient Research Ambassador. Her Beat SCAD interests focus on the ongoing physical, mental health and wellbeing of the SCAD community.

#### **Highlight of Beat SCAD Year 3**

Facilitating meet-ups around the country. SCAD survivors say meeting another person who understands what they have gone through is enormously beneficial.

#### Hopes for next year

To work with medical professionals to facilitate more SCAD clinics around the UK and Ireland. Also to further our work with patient groups supporting those with conditions associated with SCAD.

#### Hopes for the research

That the Position Paper on SCAD will lead to NICE guidelines to identify SCAD swiftly, treat patients appropriately and implement recommended monitoring.

# European Position Paper

A major milestone for the SCAD community was reached on 22 February 2018 with the publication of the first Position Paper on SCAD by the European Society of Cardiology, Acute Cardiovascular Care Association, SCAD study group. Members of the group are SCAD researchers and clinicians from across Europe, including UK SCAD specialist Dr David Adlam.

The Paper, aimed at healthcare professionals, is a consensus of current SCAD knowledge. As well as a definition of SCAD, the paper covers risk factors and associations, such as hormones, Fibromuscular Dysplasia (FMD), exercise and connective tissue disorders; symptoms; diagnostic techniques; treatment options; prognosis and aftercare recommendations.

Rebecca Breslin, Chair Trustee of Beat SCAD, said: "The release of this eagerly awaited Position Paper is a hugely significant step in the understanding of SCAD. This isn't formal guidelines that make their way into the NHS and general practice, but it is certainly progress towards that goal."

Key messages in the paper include:

SCAD is a frequent cause of acute coronary syndrome (ACS) in young to middle-aged women and patients with heart attack in pregnancy or post-partum.

Pregnancy-associated SCAD accounts for a minority of cases.

- Male SCAD patients may be slightly younger and exercise may be more of a trigger for them than for women.
- ☐ The causes of SCAD are unknown but there are indicators that female sex hormones have a role, as do conditions such as FMD.
- ☐ There is no strong indicator that SCAD is an inherited condition.
- □ Delayed diagnosis is common because SCAD patients usually fall into the lowest risk groups for ACS based on traditional risk scores.

The paper outlines the current thinking about managing SCAD, including the risks of repeat angiograms, and the prognosis, including the likelihood of recurrent SCADs.

Dr Adlam said: "The Position Paper is an important document for doctors and for the recognition of SCAD because currently neither the European nor American guidelines for heart attacks mention SCAD but, as we are learning, the considerations for managing SCAD differ from atherosclerotic heart attacks It is also important for this paper to reach other medical disciplines such as obstetricians because, ultimately, we need SCAD to be mentioned within their guidelines. The paper gives us a starting point and as more data comes out we will then update the paper over the course of time."

For more see bit.ly/2PmFTxX.

## **SCAD** stories

We hear so many stories from SCAD patients, many of whom have similar experiences of delayed diagnosis and feeling alone and isolated due to lack of information. However, awareness is increasing and we are now often approached by patients within a few days of their SCADs – some are even still in hospital when they make contact.

We know finding others who have been diagnosed with the same condition is invaluable in terms of recovery and reading other patients' stories helps them know they are not alone.

Here are some of their stories...

#### Debbie

A former ice skater, Debbie had her SCAD aged 55 in March 2018.

She said: "I was getting ready to go to a meeting and I felt the most intense crushing pain in the middle of my chest,



Debbie returned to skating after her SCAD

could not breathe and felt pain in my left arm and left-hand side of my neck, I became very clammy. My first-aid experience helped me realise I had classic heart attack symptoms, I tried to keep calm while I called 999."

When the paramedics arrived, there was nothing concerning on the ECG, but

### Men with SCAD

Dr Alice Wood, research fellow at the UK SCAD research project, is researching sub-groups, including men as they may hold the key to what causes SCAD. Here are some of the men's stories...

Ben was at work when he had his SCAD and, looking back, he feels he was very stressed. He was shocked when the doctors in A&E told him he had had a heart attack.

beatscad.org.uk/bens-story

James' SCAD happened at home and after a couple of hours of pain he called 111. They told him they would send a paramedic. "Are you sure that's really necessary?" he asked. He was 44 at the time, had never smoked, drank moderately, maintained a healthy weight and was fairly active.

#### beatscad.org.uk/james-h-story

For more on Dr Wood's research see bit.ly/2Cy5fUd.



Jenny was no stranger to long cycle rides before her SCAD

they took her to hospital as a precaution. However, after troponin tests, the doctors confirmed a heart attack.

Her recovery was a bit of a rollercoaster, but she said: "Reading stories from SCAD patients, online forums, Facebook groups and information sheets has been a rock; without this I feel I would be very alone and still in the dark about my condition." beatscad.org.uk/debbies-story

#### Jenny

A keen cyclist and triathlete, Jenny was certainly not a typical heart attack candidate. Despite that, when she had a SCAD, her cardiologist insisted that her artery was furred up and would not budge from that diagnosis, even though Jenny had found information about SCAD and told him her symptoms fitted.

When she had another SCAD, the doctors insisted the first diagnosis was correct... until they did an angiogram. "I can still hear his words when he exclaimed 'Wow, the artery is clear – it's



Margaret raised awareness with her cardiac rehab nurses

absolutely clear'," said Jenny. "Then he looked at me and said 'you're right – it was a SCAD as was your last one!"" beatscad.org.uk/jennys-story

#### Margaret

Margaret had a SCAD in May 2018. Shocked, she searched for information online and found Beat SCAD and the UK & Ireland SCAD Survivors Facebook group.

"Finding the Beat SCAD community was a real turning point. It wasn't just the practical advice, it was the sense of not being alone with this any more," she said.

Prior to her SCAD she did boxercise at a professional boxing gym three times a week, yoga, and hillwalking. But when she went to her first cardiac rehab session, she said "I was frightened to move. I was shocked that I couldn't run for one minute when I used to run just for fun."

The rehab process was a very positive one for Margaret and her nurses were keen to find out more about SCAD so they could help her recover.

beatscad.org.uk/margarets-story

## Research donations



Beat SCAD presented a cheque for £50,000, our largest donation yet, to the Leicester research team at our conference in June

Beat SCAD made two donations to the University of Leicester during the charity's third financial year and these funds have proved to be essential to the SCAD research project led by Dr David Adlam at Glenfield Hospital, Leicester.

#### **Blood sampling**

In January 2018, a donation of £3,000 was awarded following the Beat SCAD Prize Draw that ran between September and November 2017 (see bit.ly/2D7sXpO). These funds were used to purchase and distribute blood sample tubes to SCAD patients who were registered for the research but had not participated in any research assessments.

SCAD patients took the blood tubes to their GP or local hospital for samples to be taken and shipped to Leicester. Almost 400 patient samples plus a further 50 samples from relatives were returned, which was a fantastic return rate and was hugely appreciated by the research team.

Dr Adlam said: "The blood samples have led directly to the identification of the first genetic risk locus associated with SCAD. This should not be considered as an indication that SCAD is strongly inherited as the evidence suggests SCAD does not usually run in families, but it provides international research groups with the first opening

into understanding how our genes affect the risk of SCAD."

The first SCAD genetics paper was published in January 2019 in the prestigious Journal of the American College of Cardiology (JACC) was published and the funding support of Beat SCAD is acknowledged in the manuscript.

The blood samples are now undergoing gene sequencing and will soon provide a valuable dataset for the research team to investigate, including looking for known genes for connective tissue disorders.

The blood samples are also enabling important laboratory work to be conducted which aims to investigate some of the underlying 'why' questions about SCAD.

Samples from SCAD patients and healthy volunteers are being used for a proteomics study in which the structure and function of proteins are being analysed. The expression of proteins by cells and tissues can change in relation to disease so this study is looking for any patterns that may be linked to SCAD.

#### **Clinical Research Fellow**

The second donation was made in June 2018 at the third Beat SCAD Conference (see page 17) and was for an enormous £50,000 – what an achievement, well done everybody!

The £50K donation has been vital in ensuring the important work of Clinical Research Fellow, Dr Alice Wood, can progress. Dr Wood joined the research team in September 2017 and quickly set



Dr Alice Wood, Clinical Research Fellow

to work co-ordinating research activities and running SCAD clinic appointments alongside Dr Adlam.

Thanks to the Beat SCAD funds, Dr Wood has embarked on her PhD, studying SCAD sub-groups including male survivors and those who have had a recurrence. Sub-groups may hold key findings to help us better understand SCAD.

#### **European Position Paper**

"The funding support from Beat SCAD has also led to the first international guideline-type documents being published on SCAD," Dr Adlam said. The European Position Paper and American Consensus Statements were released in February 2018 (see page 9). The support of Beat SCAD is acknowledged in the Position Paper.

#### Your donations in action

The Beat SCAD donations, and the advancement of key research activities, were only possible because of the tremendous fundraising efforts of the SCAD community: thank you for all you do.

# Fundraising events

It was hard to keep up with all the fundraising events supporters held during our third year! They ranged from sponsored walks, runs and swims, to golfing events and donations from retirement, birthday and Christmas collections. Here is a selection of some of the fantastic fundraising that has been done this year.

□ Kicking off events were two marathon runners. Tim Roone, whose colleague Colette Soan has had two SCADs, ran the Birmingham Marathon in October, raising more than £570. Liam Breslin, whose wife Becks is Chair of Beat SCAD, ran the Leicester marathon in October, raising more than £400.



Liam and Becks Breslin

- □ Denise Wilson-Pink, who had her SCAD in 2016, did a 'marathon swim' at the London Aquatic Centre in November, raising more than £740. She said: "I couldn't have believed at the time of my SCAD, that I would make a full recovery and be back to normal, (albeit a new and more cautious normal!) After the first few months of rest I regained my fitness and some confidence, in part due to regular swimming and moderate exercise."
- □ Another SCAD patient, who had her SCAD in 2016, Cheryl Sivell, created a fundraising page and raised a massive £4,600. She said: "When I had my SCAD I was told that I was lucky to be alive and that I would probably never meet another SCAD survivor. I hope that with fundraising efforts from the SCAD community on behalf of BeatSCAD we can enable the crucial research to continue." Read more about Cheryl's SCAD at beatscad.org.uk/cheryls-story.
- □ Colleagues at the school Cheryl works at, Welwyn St Mary's, were so struck by her story that they chose Beat SCAD as the charity to receive the proceeds of the retiring collection at their Christmas production more than £1,200.
- ☐ In November, Beat SCAD launched a Prize Draw to raise funds. We were very pleased to receive lots of donated



Dr Adlam and Dr Wood (second left) draw the winning Prize Draw tickets

prizes, including holiday accommodation, beautiful quilts and a sterling silver necklace. We raised £3,000, which we donated to the research project to purchase and distribute blood sample tubes to SCAD patients to further genetic research (see page 12).

- □ SCAD patient Carol Massey donated her February commission from the sale of Tropic products and held an online raffle, raising more than £570.
- □ Dani Johnson, whose mother Carole sadly died following a SCAD (see beatscad.org.uk/caroles-story), ran the Retford Half Marathon in March on Mother's Day, raising more than £1,000. Her brother, Matt, continued his quest to achieve 56 races before he is 56, the age his mother died, and ran the Retford race alongside Dani. He also ran the Huddersfield Half Marathon in June and the Great North Run in September. The Huddersfield run was a special race for Matt as his mum was born in



Beat SCAD trustees and volunteers with some of the intrepid One Community team

Huddersfield. He has so far raised more than £1,500 for Beat SCAD. Matt's employer, Covance, also donated £250 match funding.

- May saw a beyy of fundraising events. A team of 30 cyclists from the One Community group took on a massive challenge in May by cycling from Barcelona to Beziers. The 289-mile route across the Pyrenees Mountains was the longest and hardest route the One Community cyclists have attempted (see bit.ly/2Km3PPn). Beat SCAD is a cause very close to one team member's heart. John Worsfold, who drove one of the support vehicles during the three-day challenge, has seen his wife, Danielle, suffer two SCADs. The team raised more than £21.000, which enabled us to double our intended donation to the research (see page 13).
- □ Paul Bone, whose wife Robyn suffered a SCAD after the birth of her third child (see beatscad.org.uk/robyns-story), and



Victoria Warnes-Elgie and 20 friends walked the Jurassic Coast path in one day

his sister Loren Keighley, ran the Milton Keynes marathon, raising over £1,900.

- ☐ To celebrate the second anniversary of her SCAD, Magda Lenka walked 50km from London to Henley, raising over £560.
- Ellie Jones, mother of SCAD patient Eva Rees, hosted a fundraiser in May. Rather than having a retirement party, Ellie asked for donations to Beat SCAD and raised £500.
- □ Also in May, we were the recipient of funds raised by golfers at the REPS golf day (see repsltd.co.uk/golf-day). The REPS (Real Estate Project Solutions) Charity Golf Day was held in association with Women in Property and more than £1.100 was raised for Beat SCAD.
- □ In the heat of the summer Victoria Warnes-Elgie, whose SCAD was in 2017, and 20 friends took on a marathon challenge and walked 26 miles along the Jurassic Coast path in one day. Together



Paul Bone (left) with the winner of the competition at the Charity Golf Day

with match funding from her husband Richard's company, Salesforce, and Gatwick Airport, where their friend, Tony Embling, works, they raised £8,000 (see more at bit.ly/2wCcog9).

- □ Also battling the stifling heat of the summer, were twins Jennifer Heenan, who had her SCAD in 2013 at the age of 40 (beatscad.org.uk/jennifers-story), and her twin sister Karen, who walked the 96-mile West Highland Way over a week at the start of July, raising £1,695.
- □ Finishing off the year in style, Paul Bone organised the first Beat SCAD Charity Golf Tournament in September in Northampton. 22 golfers played 18 holes of golf and enjoyed a dinner, followed by an auction. The event raised more than £1,220.

We appreciate all donations, no matter how large or small, so thanks to everyone who organised events and to their supporters for their generosity.

## **Beat SCAD Conference 2018**

Beat SCAD's third conference in June in Birmingham, was our biggest one yet, attended by 116 delegates, 68 of whom were SCAD survivors.

SCAD experts Dr David Adlam, Dr Alice Wood and Dr Abi Al-Hussaini talked about best practice in the diagnosis, treatment and management of SCAD, SCAD research, and the links between SCAD and Fibromuscular Dysplasia (FMD). Sally Bee, two-time SCAD survivor gave an inspirational talk about life after SCAD and Beat SCAD Chair, Rebecca Breslin

updated delegates on the charity's mission and future plans.

Delegates told us the presentations were informative and reassuring. They also appreciated the opportunities to network during the day.

More than 20 delegates continued networking the next morning, on a walk around the University of Birmingham's campus and the local canal waterways organised by SCAD survivor Colette Soan and her colleagues.

For more see bit.ly/2DkK5sj.











# Promotional activities

Beat SCAD has been busy this year raising awareness among midwives, other medical professionals and the general public.

In December 2017, trustees Karen Rockell and Sarah Coombes attended a meeting of consultant midwives at the Royal College of Obstetricians and Gynaecologists in London.

Of the 21 consultant midwives present, three had heard of SCAD, one having had a SCAD patient in her hospital at 26 weeks pregnant.

They listened closely to our presentation and had lots of questions and committed to sharing Beat SCAD materials with their colleagues.

In April we talked to 40 Lead Midwives for Education at London's King's College about SCAD in pregnancy (P-SCAD). The event was organised by Nicky Clark, Lead Midwife for Education at the School of Health and Social Work, University of Hull.

Dr Abtehale Al-Hussaini, formerly the SCAD Research Fellow on the Leicester research project and now a Consultant Cardiologist at the Chelsea & Westminster Hospital, discussed some of the latest research findings about SCAD and its possible causes as well as symptoms of P-SCAD. She provided information for the educators to give to their students about best practice in diagnosing and managing the condition.



(I to r) Sarah Coombes, Nicky Clark Victoria Warnes-Elgie and Dr Al-Hussaini at the Lead Midwife Educators meeting

Pregnancy after SCAD is considered high risk and Dr Al-Hussaini discussed the P-SCAD and post-SCAD pregnancy clinic that she has set up to help and advise patients – and the successful pregnancy outcomes already recorded at the clinic (see bit.ly/2EEAxVI). Giving the patients' perspective, Sarah Coombes and Victoria Warnes-Elgie, who had her SCAD after giving birth (see bit.ly/2JcBtnN), told their stories. For more on this event see bit.ly/2jqbyNa.

Spreading the word among other healthcare professionals and the public, Sarah and SCAD patients including Guy Huxtable and Emerita Briones, attended a very busy Research Awareness day at the Royal Brompton in July.

If you're interested in helping to raise awareness, send us a message: contactus@beatscad.org.uk.

# Progress and future plans

There have been many achievements during our third year thanks to the efforts of trustees, volunteers and supporters.

#### Governance

Numerous governance matters keep the Beat SCAD Trustees busy each year, and this year included an additional requirement to transition from the Data Protection Act to the General Data Protection Regulation (GDPR).

Trustee Debbie Oliver, Data Protection Officer, led the smooth transition to our new contacts database and 'keep in touch' forms (beatscad.org.uk/keep-in-touch) to ensure GDPR compliance.

□ Aim for 2019: As well as asking people to give us their details so we can keep in touch with them about our activities and the research, we would like all UK SCAD patients to 'sign up' and share their event details to help us establish community statistics and measure change.

#### **Awareness**

New and improved promotional collateral was produced, including our own graphics to demonstrate SCAD types (tear vs bruise).

☐ Aim for 2019: To attend more medical conferences to raise awareness.

## Support

We have made progress this year in encouraging, attending and assisting with regional SCAD patient group get-togethers.



We updated our promotional collateral to help raise awareness of SCAD

Trustees Harriet Mulvaney and Karen Rockell led the development of connections with medical professionals in Wales to support patients denied referrals to the Leicester/London clinics.

☐ Aim for 2019: To facilitate an increase in the number of SCAD clinics available.

#### **Fundraising**

We have added more fundraising methods

- why not try them out?
- ☐ Raise free donations by shopping at Amazon Smile
- ☐ Hold a Facebook fundraiser
- ☐ Donate the cost of a card/postage using Don't send me a card
- Buy products from our online shop (beat-scad-shop.myshopify.com), including clothing, ceramic hearts, pens and more. See all our fundraising options at beatscad. org.uk/how-to-donate-to-beat-scad
- ☐ **Aim for 2019:** To expand our merchandise range.

# How you can help

As a small charity we have few resources but big ideas. 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. If you would like printed copies of these leaflets, email contactus@beatscad.org.uk.

#### Raise funds

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

- ☐ Hold a charity pub quiz, wine-tasting event, raffle or 'bake off' get creative!
- ☐ Run, walk or do other sponsored events.
- Ask your employer for match funding.
- ☐ Create a birthday fundraiser on Facebook.
- ☐ 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 and Easyfundraising when you shop online (thegivingmachine.co.uk/causes/beat-scad & bit.ly/2ix7mfG) and install the Shop and Give/Donation Reminder on your web browser.
- □ Send e-cards using Don't send me a card and donate the cost of a printed card to Beat SCAD (bit.ly/2NYdB8a).
- □ Choose Beat SCAD as a charity when you sell on Ebay (bit.ly/2V3fHls).



### 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.
- Let us know of anyone who could sponsor our events or merchandise.
- Let us know of venues we could use for local events or training sessions. For further information or to offer help, please contactus@beatscad.org.uk.

# Financial report

Fundraisers and donors have excelled this year, raising an astonishing £60,215. Lots of individual and team fundraising events were held (see pages 14-16) and the number of regular donations through standing orders and shoppers using The Giving Machine and Easy Fundraising has increased again.

Your incredible efforts enabled us to make two important research donations (see pages 12-13).

Income	
Fundraising	£60,215
Other	£9,067
Total income	£69,282
Expenses	
Promotional expenses	£3,224
Admin	£3,318
Donations	£53,000
Total expenses	£59,542
Surplus income	£9,740

	Platform	Year 2 (end 30.9.17)	Year 3 (end 30.9.18)
Regular donors	Standing order	3	9
	Total Giving – monthly	3	2
	Total Giving – annual	1	0
Number of charity fundraising pages	Total Giving	2	0
Number of supporter	Total Giving	11	4
fundraising pages	Just Giving	2	11
	BT MyDonate	N/A	1
	Virgin Money Giving	N/A	3
Amount raised (excl Gift Aid)	Total Giving	£6,150.84	£3,961.70
Amount raised	Just Giving	£285	£11,836.16
(including Gift Aid)	BT MyDonate*	N/A	£825.23
	Virgin Money Giving*	N/A	£12,612.31
Number of online shopping supporters	The Giving Machine	46	57
	Easyfundraising	19	35
Amount raised	The Giving Machine	£146.73	£242.43
	Easyfundraising	£72.49	£225.12
	Amazon Smile*	N/A	£12.27

<sup>\*</sup> New fundraising/donation method added during Year 3.



## Thank you for helping us to Beat SCAD!

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

SCAD patients, families and friends have raised awareness in many ways, from distributing leaflets about SCAD to GPs, cardiologists, maternity staff, paramedics, cardiac rehab nurses and many others, to magazine and newspaper articles telling their stories.

As a small charity run by volunteers in their spare time, we rely on supporters to help raise money for research, so a big thank you to everyone who has held events,

set themselves challenges and donated. Without you we couldn't have made such a large donation to the research.

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!

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



#### Contact us

Please get in touch if you have any questions or can help us achieve our aims. contactus@beatscad.org.uk



