



# Annual Report 2017



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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 pregnancy, menopause, connective tissue disorders, 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.

For further information go to:  
[www.beatscad.org.uk](http://www.beatscad.org.uk).

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

**British Heart Foundation**  
[bit.ly/1LaOgys](https://bit.ly/1LaOgys) & [bit.ly/1T345Aj](https://bit.ly/1T345Aj)

# About Beat SCAD

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

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

Beat SCAD 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.

<b>PATIENT DRIVEN</b>  We understand the needs of the SCAD community and we push forward to find answers.	<b>EMPOWERMENT</b>  We provide knowledge and support to enable SCAD patients to take control of their diagnosis.
<b>COMMUNITY</b>  We bring together SCAD patients and families to benefit from sharing their experiences.	<b>PARTNERSHIP</b>  We work collaboratively with our supporters and researchers to optimise outcomes.

# Welcome

I am excited to welcome you to our second Beat SCAD Annual Report to share further achievements of our small but growing community. Our second year has again been very busy, with the Trustees working hard to develop and implement our strategy to further our mission.

## Awareness

Raising awareness is an enormous task and requires great investment of time and energy – and sometimes a few pounds too. A key part of the Beat SCAD strategy is to establish relevant connections and pursue opportunities that offer the best platforms to share SCAD information – whether National, International or in smaller ‘bite-size’ pieces. For example, volunteers can help us focus on particular groups, such as local maternity services. Read about this year’s Promotional activities on page 14. **Would you be willing to help us progress further?**

## Support

Beat SCAD believes that patients, their families and caregivers require support and this may be needed at any time from the initial hospitalisation when the diagnosis is new and everything can feel overwhelming and frightening, to a year or more down the recovery road. Our strategy is to ensure that up-to-date information is readily available

and accessible, and peer support is provided to prevent isolation and aid adjustment. This year has seen a steady increase in patients and caregivers contacting the charity for advice and support – we are reaching the people who need us.

## Research

We are all looking for answers to our many questions about SCAD – and those answers will come from research, so our strategy is to promote the research and to raise funds to ensure the programme can continue. I strongly encourage all SCAD patients to sign up to the research, participate in questionnaires and generate valuable data for analysis.

Donating £25,000 to the research project on behalf of our fundraisers in July was an amazing achievement. Beat SCAD is entirely reliant on the generosity of our supporters – everyone who has donated time and money to our cause should feel proud of the progress made so far. But there is more to do and the next £25,000 is needed to keep the project moving.

I hope you feel inspired by our achievements so far and by our strategy. Please continue to support our mission.

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, Karen took early retirement and is a Patient Research Ambassador and Organ Donation Campaigner, and Debbie works as 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 served as a board member of the US NPO SCAD Research Inc for 18 months (2013-2015). This inspired her to establish a UK charity. Karen Rockell and Debbie Oliver had been instrumental in awareness raising and the push for UK research so were obvious choices as co-founders. The trio proudly launched Beat SCAD at the first UK SCAD conference in November 2015.

## **Highlight of Beat SCAD Year 2**

Receiving more messages from people saying Beat SCAD has helped them in some way – it makes the hard work so worthwhile. The charity is making a difference.

## **Hopes for next year**

To expand the team so we can achieve more!

## **Hopes for the research**

The publication of the initial findings from the Leicester team is hugely anticipated by the SCAD community. My main hope is the findings lead to new funding opportunities so the team can continue progressing towards a better understanding.



**Karen Rockell, Secretary**

Karen was 55 when she had her SCAD in 2010. She had a perfectly healthy heart (or so she thought) then out of the blue she had a heart attack. Nothing was known about SCAD at that time. Doctors had “no idea” how or why it had happened. She felt isolated and unsupported.

#### **Highlight of Beat SCAD Year 2**

Delivering another successful Beat SCAD conference. Supporting an increasing number of SCAD survivors and families.

#### **Hopes for next year**

That we can broaden our work to educate more professional disciplines about SCAD.

#### **Hopes for the research**

That the research gets more funding and that it will provide clear guidelines for post-SCAD care and surveillance.



**Debbie Oliver, Trustee**

Debbie had a SCAD aged 49 in 2011. After suffering chest pain at the gym, the pain subsided and, other than a numb left arm and hand, she had no further pain for a week. The following weekend she had chest pain again and was diagnosed with SCAD. At that time, information about SCAD and support for patients was sparse.

#### **Highlight of Beat SCAD Year 2**

Donating £25,000 to the research project on behalf of all our fantastic fundraisers.

#### **Hopes for next year**

That SCAD patients are diagnosed earlier and find the support they need quickly.

#### **Hopes for the research**

That more patients will be able to see a SCAD specialist. The more patients who are seen, the closer we get to answers.

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**Jackie Stopyra** served as Treasurer Trustee until September 2017. We would like to extend our thanks to Jackie for her valuable advice and support throughout the charity set-up process and our first two years of activity. Jackie will continue to volunteer her accountancy skills on an ad hoc basis, for which we are immensely grateful.



# Beat SCAD conference 2016

The Leicestershire County Cricket Club again hosted the Beat SCAD conference in November 2016 where the trustees were overjoyed to welcome 'old and new' SCAD survivors and supporters from around the country.

A new UK record for the number of SCAD survivors in one place was set: 61 this year versus 49 at the launch conference in 2015. Can we increase this again at the 2018 conference?

The 110 delegates heard about the charity's first year achievements (see our video at [bit.ly/2n00agv](http://bit.ly/2n00agv)) and were thanked by the Beat SCAD and research teams for their important contributions and support.

The research is a huge priority for the SCAD community and delegates heard from the Leicester team, Dr David Adlam and Dr Abi Al-Hussaini. Data analysis work is continuing but the team teased a few findings and thoughts of interest that made the delegates eager for the first research publication.

Some of the delegates kindly and bravely answered questions on camera about the importance of the research, the difficulties recovering from SCAD and the impact on families.

Videos of all the speakers' presentations are on our website at [beatscad.org.uk/conference-2016-2](http://beatscad.org.uk/conference-2016-2).





# SCAD stories



Every SCAD patient has a different experience and their events happen in varying circumstances, from post-partum and menopausal women to highly athletic men. Here are some of their stories. For more see [beatscad.org.uk/scad-stories](http://beatscad.org.uk/scad-stories).

## Cheryl

Cheryl had a SCAD while she was having dinner with her husband and friends. She said: "Feeling fragile and vulnerable, I had lost every confidence in my body and I grieved for the person I used to be. I was lucky to be alive but scared to live." [beatscad.org.uk/cheryls-story](http://beatscad.org.uk/cheryls-story)

## Robyn

Robyn was 27 when she had her SCAD two weeks after her third baby was born. Her family was told to prepare for the worst after she had a cardiac arrest. Her consultant said: "Robyn was extremely lucky to be in hospital when she collapsed where she had immediate, aggressive and persistent resuscitation." [beatscad.org.uk/robyns-story](http://beatscad.org.uk/robyns-story)

## James

James was 44 when he had crushing chest pains "as if someone were grinding their knuckles as hard as they could into the centre of my chest". [beatscad.org.uk/james-h-story](http://beatscad.org.uk/james-h-story)

## Tracey

Tracey was 38 when she had a SCAD and cardiac arrest. She then contracted a virus which damaged her heart further. She has had a heart transplant and has been given a new lease of life. [beatscad.org.uk/traceys-story](http://beatscad.org.uk/traceys-story)

## Carole

Sadly, not all SCAD patients survive. Matt Johnson told us about his beloved mum, Carole.

Carole died following a SCAD and cardiac arrest at 56, leaving behind a devastated husband and three children. [beatscad.org.uk/caroles-story](http://beatscad.org.uk/caroles-story)

*Pictured above (l to r), Robyn, Cheryl, Tracey and Carole.*

# Fundraising events

Like a musician's notorious difficult second album, the Beat SCAD team knew it was going to be a huge challenge for fundraising efforts in year two to match the incredible achievements of year one. Though the total amount raised this year is less, supporter engagement has increased.

It is always emotional to hear the stories that inspire people to support Beat SCAD, but each story helps to raise awareness and it is fantastic to see the varied fundraising events taking place – and the accompanying photos!

Highlights between October and June included:

❑ Magnus Alestrand, whose wife Andrea suffered a SCAD in 2016 ([beatscad.org.uk/andreas-story](http://beatscad.org.uk/andreas-story)), and his friend Markus challenged themselves to the Mud Masters Obstacle Race in Hamburg, Germany and raised over £600.

❑ SCAD survivor Helen McKellar celebrated February's Heart Month and Rare Disease Day by completing a Swim for SCAD which raised over £500, more than double her target.

❑ SCAD survivor Clare Swords hosted a Wine Tasting event and raised an incredible £830.

❑ After Colette Soan suffered a second SCAD event, her work colleagues rallied

together to support her and completed the Birmingham 10K raising an incredible £1,220 as well as looking stylish and helping to raise awareness by wearing their Beat SCAD running vests (pictured on page 11).



**Magnus and Helen gave themselves some tough challenges to raise money**



**Some of our Scones for SCAD fundraisers: Paula Leadbeater (top left), Rebecca Breslin's stand at Glenfield Hospital, and Martina Fletcher (bottom left)**

Just 7 months after her SCAD, Linda Purdon climbed the Sydney Harbour Bridge and raised over £600.

SCAD by completing a 30K sponsored walk at Goodwood racecourse, raising over £600.

Another group of work colleagues supported their friend Sophia after her

Scones for SCAD ran again through February, with Paula Leadbeater and her mother-in-law hosting an event which raised £500. Another SCAD survivor, Martina Fletcher, hosted a bake sale at work where funds raised were boosted by employer match funding to enable a donation of £250.

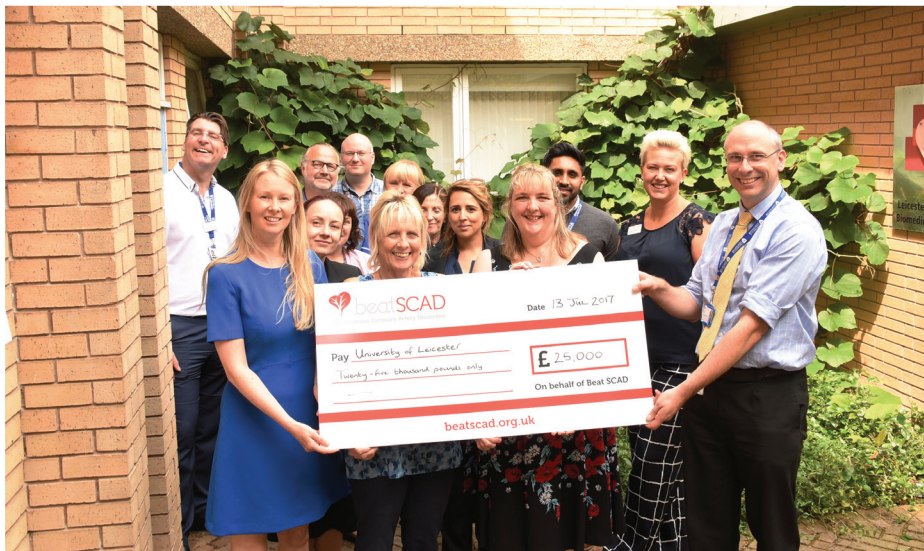


**Friends of Colette ran for Beat SCAD**

Beat SCAD Trustee Chair Rebecca Breslin held a scones event at Glenfield Hospital, Leicester on Rare Disease Day which raised £150 – read more about this under Promotional activities.



# Our first research donation



**The Beat SCAD Trustees present a cheque for £25,000 to the Leicester research team**

July brought a landmark day for Beat SCAD as the Trustees proudly presented a cheque for £25,000 to the research team in Leicester. Following a period of discussions and assessment of other funding applications, it was agreed for the donation to be used to support the salary of the new Clinical Research Fellow, Dr Alice Wood (pictured right with Dr David Adlam). Additional funding to keep the research ticking over is being provided by the NIHR Leicester Biomedical Research Unit.

After the presentation, the Trustees discussed the current status and future of the research project in more detail with Dr Adlam and his team. It is an

exciting time in the programme, with some potential leads and ideas worthy of further investigation. The Beat SCAD team affirmed their commitment to raise more funds and are keen to raise the next £25K as soon as possible.



# Further fundraising

Quarter four, July to September, enjoyed a boost of fundraising events including an impressive cycling challenge by David Wring whose wife Sarah suffered a series of heart attacks caused by SCAD. David used Just Giving to crowdfund his SCAD awareness cycle from Newquay to Nice – an incredible 1,300 miles in 18 days, wearing his specially designed Beat SCAD jersey. The challenge enabled David to donate £2,500 to Beat SCAD. Read more at [bit.ly/2vTZzMU](http://bit.ly/2vTZzMU).

Further highlights included:

❑ SCAD survivor Laura Needham gathered a team to take on the Color Obstacle Rush Race. Laura's family and friends joined forces with a further three SCADsters to tackle the inflatable obstacle course and raised over £500.

❑ David Selkirk took on the Yorkshire 3 Peaks challenge in support of wife Elaine who had a SCAD event in 2016. David's fabulous efforts raised over £500.



**Matt Johnson in the first of his 56 races**



**David Wring cycled from Newquay to Nice to raise money for Beat SCAD**

❑ Adam Vallance completed his first half marathon in August, raising over £400 – a very proud moment for his mum Fiona who suffered a SCAD in 2016.

❑ News of a fatal SCAD case is truly devastating. Matthew Johnson launched an inspiring challenge in response to the loss of his mum: 56 races before he's 56, hoping to raise £10K for research. Carole was only 56 when SCAD struck. Read more at [bit.ly/2EffzN4](http://bit.ly/2EffzN4).

❑ Beat SCAD's Walking to beat SCAD event took place in September at the Bosworth Battlefield. The walk was well attended and raised over £800. Dr David Adlam, lead SCAD researcher, walked with the group and delivered an update on the research status and answered questions from the audience ([bit.ly/2GNsYOG](http://bit.ly/2GNsYOG)).

Feeling inspired? For more details about fundraising or donating see [bit.ly/1XwiVPp](http://bit.ly/1XwiVPp).

# Promotional activities

One person CAN make a significant impact! SCAD survivor Sarah Coombes has taken great steps forward in raising awareness of SCAD among medics in her region by delivering a series of talks to groups of midwives and health visitors, student/junior/senior doctors, anaesthetists and cardiology consultants and registrars.

Sarah has been growing a network of important contacts, developed an informative presentation and helped to create a series of case studies to increase knowledge of pregnancy and post-partum SCAD – materials which are now available for others to utilise in a similar way and help to further spread the word around the country.

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

## TV appearances

We are reaching a wider audience through television appearances. Rare Disease Day on 28 February brought two fantastic TV appearances:

### SCAD survivors on the BBC

❑ Nicki Owen's pregnancy SCAD story was featured on the BBC website ([bbc.in/2lvDI8T](http://bbc.in/2lvDI8T)) and reached an estimated 1.9 million readers.

❑ Kate Alderton and Catherine Beck were interviewed for the Victoria



**Sam (left) and Alex (right) were interviewed by ITV News**

Derbyshire Show and spoke about the impact of SCAD.

## Research project on ITV and BBC

❑ Samantha Roberts and Alex Mortimer were in Leicester for their research assessments and spoke to the ITV News crew about their experience and hopes for the future. Dr Adlam and Dr Abi Al-Hussaini also featured. Read more at [bit.ly/2ntsnXt](http://bit.ly/2ntsnXt).

❑ Another TV opportunity arose with BBC East Midlands News on 29 September, the day before the Beat SCAD walk, with Rebecca Breslin featuring with Dr David Adlam. Watch 'Becks on a mission' at [bit.ly/2nCA0xv](http://bit.ly/2nCA0xv).



# Progress and future plans

The Beat SCAD Trustees and supporters have big ambitions and many ideas for fulfilling our mission – the main hurdle encountered is TIME!

Some plans for 2017 have been realised, some have made great progress, and some had to be reprioritised.

## Awareness

Raising awareness remains a key focus of the Beat SCAD team.

- More patient stories have been added to our website and shared via our social media channels.

- The charity registered as a stakeholder with the National Institute for Health and Care Excellence (NICE) to participate in guideline consultations.

- Thank you to everybody who has taken copies of our leaflets to your doctors – this all helps to spread the word. With the publication of initial research findings, Beat SCAD will be updating the information materials and aiming for wider distribution.

## Support

- The launch of the support system was planned for 2017 but has been delayed into 2018. The training course is being finalised and volunteers have expressed their interest to join the team of ‘buddies’

who will provide a support network to our growing community.

- The Trustees have developed an Information pack for patients that can be downloaded from our website ([beatscad.org.uk/useful-documents](http://beatscad.org.uk/useful-documents)) and is full of up-to-date information and answers to frequently asked questions.

## Fundraising

- One of our fundraising goals for this year was to increase the number of people using the online shopping platforms which generate FREE donations – thank you to everybody who has signed up to The Giving Machine and/or Easyfundraising. We hope more of you will join – every penny counts!

- Following the first £25K research donation, the Beat SCAD team set about raising the next £25K and launched a Prize Draw in September with high hopes of a successful fundraiser.

- Regular Beat SCAD events will run again and we hope to see our SCAD community members joining in and making each year more successful than the previous.

- The Trustees are also seeking funding opportunities to develop or support various projects and will apply for grants where eligible.

# 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](http://bit.ly/1VHnYxb)) and give them to GPs, cardiologists, cardiac rehab nurses, SCAD patients and anyone who can help raise awareness.

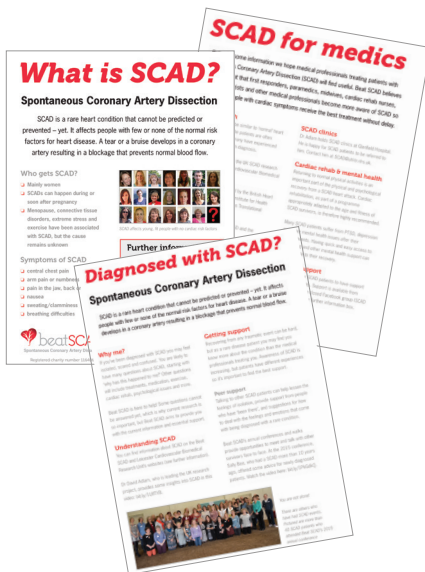
## Raise funds

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

- ❑ Place one of our collection boxes in a local shop, school or leisure centre.
- ❑ Drop your spare change into one of our home collection boxes.
- ❑ Use The Giving Machine when you shop online ([bit.ly/2dbmH2b](http://bit.ly/2dbmH2b)) – and install the Shop and Give Reminder on your web browser.
- ❑ Use Easyfundraising when you shop online ([bit.ly/2ix7mfG](http://bit.ly/2ix7mfG)) and install the Donation Reminder on your browser.
- ❑ Choose Beat SCAD as a charity when you sell on Ebay ([charity.ebay.co.uk](http://charity.ebay.co.uk)).
- ❑ Run, walk or do other sponsored events.
- ❑ Ask your employer for match funding.

## Regular donations

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



## Skills, time and contacts

What skills can you offer?

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

For further information or to offer help, please contact [contactus@beatscad.org.uk](mailto:contactus@beatscad.org.uk).

# Financial report

Beat SCAD fundraisers and donors have again done a fantastic amount of fundraising, raising £20,095.

Individual and team fundraising events were held throughout the year (see pages 10, 11 and 13), with a 100% increase in the number of supporter fundraising pages on Total Giving and Just Giving. The number of regular donations through standing orders, The Giving Machine and Easy Fundraising has also increased.

Your fundraising efforts during 2016 and 2017 enabled us to donate £25,000 to the SCAD research project in Leicester (see page 12).

Income	
Fundraising	£20,095
Other	£1,488
<b>Total income</b>	<b>£21,583</b>
Expenses	
Promotional expenses	£1,141
Admin	£1,308
Donation	£25,000
<b>Total expenses</b>	<b>£27,449</b>
<b>Deficit income</b>	<b>(£5,886)</b>

	Platform	Year 1 (end 30.9.16)	Year 2 (end 30.9.17)
Regular donors	Standing order	0	3
	Total Giving – monthly	0	3
	Total Giving – annual	0	1
Number of charity fundraising pages	Total Giving	1	2
Number of supporter fundraising pages	Total Giving	5	11
	Just Giving	N/A	2
Amount raised (excluding Gift Aid)	Total Giving	£14,055.85	£6,150.84
	Just Giving	N/A	£285
Number of online shopping supporters	The Giving Machine	20	46
	Easyfundraising	N/A	19
Amount raised	The Giving Machine	£68.16	£146.73
	Easyfundraising	N/A	£72.49



## Thank you for helping us to Beat SCAD!

The Trustees of Beat SCAD 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 radio and television interviews plus 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 into

SCAD, so a big thank you to everyone who has held events, set themselves challenges and donated. We couldn't have made such a large donation to the research project without your help.

Thanks to the staff and researchers at the Leicester SCAD research project, led by Dr David Adlam. You have given us hope! And thanks to the National Institute for Health Research for continuing to fund the project.

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

### Find us online



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



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



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



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

### Contact us

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



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