Coronary arteries have three layers. A dissection is when one or more inner layers tears away from the outer layer. The torn flap of arterial wall creates a hematoma or blockage in blood flow to the heart, leading to angina, a heart attack, or sudden cardiac arrest.

SCAD is not the usual heart disease. 80% of heart disease is preventable but SCAD is in the 20% that is not. Many cardiologists have not treated it. The medication given is based on treatment of the normal type of heart attack. As with any heart attack cardiac rehabilitation is necessary. SCAD has been linked to female hormones or extreme physical exertion.

Otherwise healthy people can suddenly find themselves with chest pain, unconscious, being told they have had a heart attack, waking up with the realisation of having gone through bypass surgery (any or all of the above) and currently Spontaneous Coronary Artery Dissection is free to strike again.

We have only met through online support groups and out of frustration at being told it is so rare and wanting to see if it really is!

SCAD UK and Europe research portal: http://scad.lcbru.le.ac.uk

This poster is compiled by SCAD survivors based on their own experience. It is not intended to take the place of medical advice from a clinical professional, and if you are in any doubt about any aspect of your condition or treatment, you are recommended to consult your own doctor appropriately.
Our lives will not be the same again and indeed a whole chain of events have made sure of that from the day we fell ill, but we are thankful that we may one day have answers. Rebecca will tell the story...

When I experienced a heart attack in March 2012 I was diagnosed with SCAD during my 3 weeks in hospital. I found limited information online, e.g. the BHF website. I kept searching while still in hospital and found out more from on-line communities.

In April 2012 I joined a closed group of survivors on Facebook with about 80 members but only 5 were from the UK and Ireland with most being American. Then I posted my story on Inspire (the Women’s Heart Support Community) and had my first contact with someone from the UK, Catherine.

I emailed Mayo Clinic to express my interest in participating in their SCAD Registry and genetic studies. Over the following months, the Mayo clinic found it difficult to gain access to UK medical records.

Once I had made contact with the American Non-Profit Organisation, SCAD Research, who help to fund the Mayo Clinic research, I organised a fundraising walk in May 2012, which is where I first met Catherine. Face to face with another SCAD survivor, something many others were told would never happen! Two ‘flukes’ together!

7 UK SCAD Survivors met up in July 2012 after getting involved in a discussion on Inspire.

I met Dr Adlam to discuss SCAD in August 2012 and he told me he had seen other SCAD patients.

By March 2013, the time of my one year follow-up appointment with Dr Adlam I knew of 55 SCAD survivors in the UK and Ireland with 34 of which I was in contact with. Dr Adlam indicated he may be able to begin some collaborative research using the UK group I was in contact with. And so it began!

April 2013 saw the BRU discussing research with the Mayo Clinic. A walk to raise funds for SCAD Research was enjoyed by 14 SCAD survivors at Bradgate Park.

In June 2013 LCBRU begin designing the web portal and in July 2013 they host a meeting to discuss the plan for UK/EU research and 6 UK SCAD survivors attend.

August 2013 was a landmark month for SCAD as the portal is launched and a group of 14 SCAD patients met at the BRU to discuss the research collaboration with a presentation from Dr Gulati from Mayo Clinic.

Today the poll on the portal stands at 99 so do check it out yourself and spread the word.

SCAD UK and Europe research portal:
http://scad.lcbru.le.ac.uk

This poster is compiled by SCAD survivors based on their own experience. It is not intended to take the place of medical advice from a clinical professional, and if you are in any doubt about any aspect of your condition or treatment, you are recommended to consult your own doctor appropriately.
Debbie

I was 49 when I had my SCAD heart attack in 2011. I had a pain in my chest and a numb left arm while I was exercising at the gym. The pain disappeared once I stopped exercising but reappeared a week later. I called the ambulance after a few hours as the pain wouldn’t go away and, to my surprise, the paramedics told me I was having a heart attack.

I was taken to hospital and had an angioplasty and was told the heart attack had been caused by spontaneous cardiac artery dissection, something I’d never heard of.

The first few weeks of recovery were scary and it was frustrating not being able to find information on SCAD. Cardiac rehab was very beneficial in helping me learn my new exercise limits.

Two years on I’m fit and healthy… but there are still questions that I hope the research at Leicester BRU will go some way to answering. The possibility of another SCAD event is always in the back of my mind, but it doesn’t rule my life or stop me doing anything.

Louise

I was 37 when I noticed for the second day running a pain in my chest and down my left arm. Something made me phone 999 and while at Accident and Emergency the pain became much worse and the medics told me it was stress. Almost 24 hours later I was visited by a doctor and told I had had a heart attack. An angiogram confirmed SCAD and having no reason for that event in my life causes me fear at times, even 2 years on. I have now given up my wish to have a family as I know it would be risky and I am happy to be alive. My recovery to full strength took over 2 years and while I don’t know the future, I do know that the BRU is giving me hope that one day SCAD patients will have more accurate information to draw from.

Catherine

My SCAD occurred on the longest day of the year, June 21st 1999. I was 9 months pregnant. The pregnancy was my fourth; I had had three previous miscarriages with no known cause. On June 21st I was due to visit hospital to receive an induction date. That morning I woke feeling thirsty, as I got up I felt chest pain and I began shaking my left arm as it felt numb. I told my husband we needed to go to the hospital.

At the hospital I clearly remember looking into my husband’s eyes and saying ‘I feel like I am having a heart attack’. After having my obs checked and an ECG, I was becoming more unstable and in and out of consciousness. At one stage, my husband tells me I went grey and he thought I was dead. Doctors surrounded me, giving me drugs and a crash trolley was pulled to the side of the bed. The decision was taken to transfer me to Southampton General Hospital, 50 miles away. I was moved under a blue light with two doctors and my husband in the ambulance. It was decided that I should have a General Anaesthetic and a Caesarean that same day. Our son was born fit and healthy in a Cardiac Theatre with a maternity team from the Princess Anne Hospital in attendance.

An angiogram five days later confirmed I had had a SCAD. The following 3 years were an emotional rollercoaster; Post Traumatic Stress, in hindsight, was what I was experiencing. I returned to work after 1 year and had many years of good health since. I did not see a Cardiologist for many years; however now have a few issues. I have a fantastic Cardiologist, take my daily medication and live a healthy lifestyle.

Finally, it is worth noting that in 1999, it took me 2 years to even hear of another SCAD patient and she lived in America.
Spontaneous Coronary Artery Dissection

SCAD...

be educated

Facebook group has grown from 80 members in April 2012 to 370 in October 2013, 37 are UK/Ireland.
The target for the LCBRU study is 100

SCAD patients:
Are between the ages of 19 to 64 years old
Are 80% Female
Have few, if any, cardiac risk factors
30% are peripartum - 3rd trimester or after delivery
Can have associated conditions: Fibromuscular Dysplasia (FMD) and connective tissue disorders
Can have similar risk factors associated with hormonal therapy or extreme physical exertion
Sometimes live with no explanation at all

SCAD UK and Europe research portal: http://scad.lcbru.le.ac.uk
SCAD overview and animation: http://tinyurl.com/c9f7r64

This poster is compiled by SCAD survivors based on their own experience. It is not intended to take the place of medical advice from a clinical professional, and if you are in any doubt about any aspect of your condition or treatment, you are recommended to consult your own doctor appropriately.