

geriatricians, paediatricians, cardiologists and psychologists. It also incorporated neurologists because, as I mentioned earlier, many people are misdiagnosed with epilepsy when in fact, the cause is an underlying arrhythmia.

A lot of the elderly people who fall, break their hip and end up in care homes have an underlying arrhythmia which, if properly treated, would mean they would still be able to live an independent life. Bringing this multi-disciplinary committee together, representing patients of all ages from around the world, was the crème de la crème – the best of the best!

**Could you tell us about STARS' main campaigns and how they meet their objectives?**

In 2004, we launched the STARS Blackout Checklist with Sir Roger Moore, who sadly passed away recently. This is a checklist for undiagnosed people with a history of unexplained loss of consciousness, or diagnosed people who can go into their appointment with the checklist ready-prepared.

For the clinicians, it prompts them to ask: "Is there any history of sudden cardiac death in the family?" Because all too often, the only history you have with people that suddenly 'drop dead' is: "Oh, they used to faint." That is a clear indication they had a potential fatal arrhythmia, and this checklist has gone on to save lives. By asking the same history questions as based on our checklist, diagnosis is sped up and potentially fatal arrhythmias can be identified. It is improving outcomes for those at risk of sudden cardiac death and making people aware that there is no such thing as a simple faint – there is always a reason behind it. It might be because you are dehydrated or overheated, but you still need to know the reason.

As part of our recent World Heart Rhythm Week, our aim was to make at least one million people heart rhythm aware, and take 10,000 pulse checks. We ended up doing far more than that, so that is fantastic. People never used to know what leukaemia was, or AIDS, or diabetes, or Alzheimer's, or dementia – but all those conditions are widely known now. We need to make syncope and arrhythmia a household name, and then people will be aware of their heart rhythm. You do not need to buy a piece of machinery to know that, but understanding how to take your pulse could save your life or someone you know.

**How do you make sure this oversight does not continue?**

We go into schools and teach children how to take their pulse. The biology teachers love it because you are teaching them about the heart and the electrics of the heart, and the maths teachers love it because you are teaching young children to count, and slightly older children their times tables – as you multiply your pulse to get your heart rate as well as heart rhythm per minute. In fact, the children's homework is to go home and take the pulse of their parents, grandparents or neighbours – and, because of this, we once had a nine-year-old who found that her father had an irregular pulse rhythm, he went on to receive a diagnosis.

**Trudie, you have received great recognition by Her Majesty the Queen. What impact has this had on you and the organisation overall?**

The Queen's recognition came through a year after my husband passed away and his final words to me were: "Trudie, I'm going to faint." So, when the Queen's award came it was a shock – it was an honour but it was very emotional because my husband had obviously gone through everything with me, with my daughters and the charity itself.

For STARS, the recognition was huge. We represent people with conditions that need to be recognised – they need help, support, information and education and this is what we are striving to provide. It was fantastic for STARS to be recognised for doing something so important.

**STARS have some amazing, high-profile medical and celebrity patrons. How have these ambassadors contributed to your success, especially in terms of getting recognised?**

Having these patrons is fantastic, especially if they have had experience of the problem themselves in the past as they can talk about it from the heart – excuse the pun. For example, with Sir Roger Moore, when I was talking to him he was saying that both his father and one of his children used to often pass out, but he had never put two and two together. So, he could talk passionately and openly about it – even when he wrote his autobiography he mentioned STARS and me by name, which I thought was fantastic. Right up to the end he was so supportive and he even got Sir Elton John to come on board as a patron as well. Once you have one person, it starts this chain reaction and they reach out to others.

**It's STARS' 25<sup>th</sup> anniversary and that must be a tremendous achievement. What does the future hold?**

I will only feel that I have been successful once everyone is diagnosed after their first or second faint, and able to get all the information and support they require. Sadly, we are a long way from that yet judging by the number of enquiries we still get. It does not matter whether you are rich and famous, or not – one of our patrons is the American actress Selma Blair and she struggled to get a diagnosis for her son, until she came across STARS. We have since helped her find a doctor in California where she lives.

There is still a long way to go. We must continue with awareness, information, support and, above all, education. We need to educate medical professionals who dismiss the condition as "only a faint" – they still have so much to learn.

**How can people get involved with STARS and help raise awareness?**

Please contact me directly. Even if it is through the simple action of taking one of our leaflets to your doctor and saying, "Do you know about this organisation?" – you are helping spread the word. You can do as little or as much as you would like – whether it be putting a poster up in your office, or helping fundraise – you are raising awareness and spreading the word.

• For more information on how you can get involved with and become a friend of STARS, or for further details on syncope and arrhythmias, please visit [www.hearhythmalliance.org](http://www.hearhythmalliance.org)

# STARS

Syncope Trust And Reflex anoxic Seizures™

[www.stars-international.org](http://www.stars-international.org)

## Getting to the HEART of fainting



# STARS

Syncope Trust And Reflex anoxic Seizures

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# STARS: Getting to the heart of fainting

There is no such thing as a simple faint – there is always an explanation and, if the work of Syncope Trust And Reflex anoxic Seizures (STARS) is anything to go by, that explanation could be because of an underlying arrhythmia (heart rhythm disorder). For **Trudie Lobban MBE**, CEO of STARS, she understands this better than anyone, with syncope (fainting) a condition that has affected her family for many years. After seeing her daughter randomly losing consciousness from the age of ten months, and with seemingly no explanation as to why, she founded STARS to build a collaboration of patients, carers, healthcare professionals and policy makers – aiming to spread the word and reduce misdiagnosis.

If you have ever fainted and thought it was nothing, you could be mistaken, you could have an underlying arrhythmia (heart rhythm disorder) called 'Syncope'. Trudie Lobban MBE, Founder and CEO of Syncope Trust And Reflex anoxic Seizures (STARS), understands this better than anyone, as syncope is a condition that has affected her family for many years.

Fortunately, through the tireless work of Trudie Lobban MBE and her team of medical experts at STARS, these disorders are becoming more and more recognised and diagnosed thereby saving countless lives.

Starting at Trudie's kitchen table back in 1993, STARS has grown from strength to strength over the years and, with the likes of Sir Elton John and the late Sir Roger Moore

acting as celebrity patrons, that success looks set to continue. We spoke to Trudie about STARS' recent accomplishments and discussed why commonly-missed arrhythmias was an issue so close to her heart.

*Hi Trudie! Can you tell us about how your personal experience with your daughter as a sufferer with syncope initiated the foundation of STARS?*

When my daughter was ten months old, she passed out in front of me at playgroup. I rushed her to the doctors, but they said it was nothing to worry about. However, her loss of consciousness started to happen regularly, even up to eight times a day, where she would go deathly white and blue around the lips. She honestly looked like she was dead but no one could tell me what was wrong with her – she

**39% of children and 30% of adults with epilepsy are wrongly diagnosed. They are not epileptic – they frequently have an underlying arrhythmia (heart rhythm disorder)**



had several tests in hospital but everything came back as 'normal'.

I am the sort of person who would rather know the worst and work up from that – not knowing what was wrong was far worse. I started writing to paediatric neurologists at different hospitals – not just in this country, but around the world – and I eventually received a call from who turned out to be the world expert.

My daughter was three and a quarter when she was finally diagnosed. Professor Stephenson performed a test which showed me that her heart – not even during a real attack – had stopped for 28 seconds, I was horrified. He asked if I would consider talking to other parents in similar situations and, as there were no treatment options available, I thought other parents would be able to help me. Prof Stephenson put them in contact with me and, in fact, they all thought I was going to help them – so that was the birth of STARS (Syncope Trust And Reflex anoxic Seizures).

*When was the charity first set up?*

I established STARS in 1993 on the understanding that Prof Stephenson would always review and approve anything that I produced. I did not want to give misleading or inaccurate information, and I have stood by that to this day. I have a medical advisory board and all our publications are reviewed by them. So, while it is a patient-led organisation, we work in partnership with numerous medical experts.

*What has changed since STARS was first established?*

I now run three charities all focusing on various arrhythmias. In 2003, I realised that the National Service Framework on Coronary Heart Disease only mentioned the word 'arrhythmia' (heart rhythm disorder) once. So, I invited other organisations and doctors to join forces, asking for plans to be put in place to improve arrhythmia services. We then organised the very first Arrhythmia Awareness Week (now known as the World Heart Rhythm Week) where we launched the Arrhythmia Alliance – a second charity which provides collaboration between patient carers, patient organisations, healthcare professionals, organisations, allied professionals, industry, government and all those affected by or interested in cardiac arrhythmias.

*STARS has had a great impact politically and internationally in raising awareness into*



Trudie Lobban  
MBE, Founder and  
CEO of STARS

**We need to encourage medical professionals not to dismiss the condition as "only a faint" – there is still so much to learn**



*syncope and helping with diagnosis. What kind of a reception has STARS had, from both patients and medical professionals?*

We have heard from thousands of patients globally, not just in the UK. When I first started STARS, I thought it was for children, because of my daughter. I was told syncope was a childhood condition which she would grow out of over time. However, as time

went on, she continued to have syncopal episodes, although they did become less frequent. However, I started hearing from elderly patients as well as people of all ages. I soon realised that geriatricians and paediatricians were not communicating with each other. So, I established the first STARS Medical Advisory Committee to do just that, building a collaboration between