STARS Patients Day

Trudie Lobban MBE FRCP (Edin)
Founder & CEO
1 October 2017 (10.00-10.30)
"It was years of going from one appointment to another before my daughter was finally given a correct diagnosis of RAS – it was such a relief"

1948: The NHS is there for us from the moment we are born. It takes care of us and our family members when we need it most
Factors affecting patient experience

- Accurate and comprehensive information
- Advice about all options available
- Access to treatments not denied by local directive
- More streamlined care
- More choice
- Services that fit around the patient and not the patient fitting around the service
Patient engagement

21st century Vision is partnership

Between professionals (who can be scary)

and patients (who can feel unsure, scared... and unwell)

2012: The NHS Constitution
“No decision about me, without me”
The National Institute for Health and Care Excellence (NICE)

NICE is responsible for providing national guidance on the promotion of good health and the prevention and treatment of ill health.

- Join a committee
- Attend a meeting
- Take part in focus groups
- Join the public involvement programme
Discuss your treatment options

Discussing your treatment options will help you to understand why one option may be beneficial over another.

If at any time you have questions or concerns, do not hesitate to contact your doctor.
Share your story

Patient stories are an important way of providing great reassurance, support and advice to others who have the same condition. This is where we really need your help.

Would you be willing to share your story?

Please speak to Rachel or Zoe from STARS if you are happy to be interviewed or filmed today.
Fundraise or volunteer

There are a wide range of opportunities for volunteers across STARS. Whatever your motivation you will find that volunteering for STARS is both challenging and rewarding.
Join World Heart Rhythm Week

➢ Just through our Social Media sources alone, we made more than ONE MILLION people Pulse Rhythm Aware.
➢ Over 10,000 pulse checks were taken!
➢ We distributed over 600 Arrhythmia Alliance information and event packs to Healthcare Professionals in the UK plus many more internationally.
➢ More than 15 countries participated in World Heart Rhythm Week.
➢ Over 200 'Know Your Pulse' events have taken place in UK hospitals and GP practices.
➢ Our media reached 8.7 million+ (That’s more than the population of Scotland, Wales & N.Ireland put together!)
How can we help you?

- Cognitive Behavioural Therapy for chronic health conditions
- Reflex Syncope (Vasovagal Syncope)
- Postural Tachycardia Syndrome (PoTS)
- Diagnostic tests for syncope
- Reflex Anoxic Seizures (RAS)
- Living with low blood pressure
- Which ECG is Right for You?
- Identifying the undiagnosed person
- Jack has RAS
- Bertie’s Pacemaker
- Jane’s ILR

www.stars.org.uk
Brand new booklets

Identifying the undiagnosed person
How mobile devices can make a difference

Which ECG is Right for You?
You have already helped...

Patient Surveys

Implanted Devices - Infection

- 5.4% of those surveyed had their devices removed and re-implanted in another position.
- 28.5% of those had an infection after their second implant.

Mobile ECG Devices

- Just 8% were provided the device by their cardiologist or other specialist at the hospital.
- And 83% purchased the device themselves.
- 3 out of 4 doctors used the results to make a diagnosis.
Getting to the heart of fainting

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 Reflexic Seizures (STARS) is anything to go by, that explanation could be because of an underlying arrhythmia (heart rhythm disorder). For Trudie Lobbie 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 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 Lobbie MBE, Founder and CEO of Syncope Trust And Reflexic Seizures (STARS), undertook this better than anyone, even though it is a condition that has affected her family for many years.

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

Starting in Trudie’s kitchen table back in 1995, STARS has grown from strength to strength over the years and, with the likes of Sir Elton John and the late Dr Roger Moore acting as celebrity patrons, the success has only been upwards. We spoke to Trudie about STARS most recent accomplishments and discussed why common sense arrhythmias remain so close to her heart.

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

When my daughter was ten months old, she passed out in front of me, as a young girl and I 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 dead as a doornail and blue around the lips. The honestly fainted like she was deader and no one could tell me what was wrong with her – she was in pain and suffering.

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)."

www.stars.org.uk
…and this is why there is no such thing as a simple faint…

The astonishing moment a man suddenly collapses and flips off a station platform and onto the tracks - before hero commuters rush to save him from an oncoming train.

- The man stumbled toward Sydney's Wynyard station and appeared to faint.
- A customer service officer signalled for the train to stop as it approached.
- Six members of the public rushed to the unconscious man's aid.
- Sydney trains discourages running to help because a live track is dangerous.
My word is my Bond

& there is no such thing as a simple faint

Sir Roger Moore
1927-2017