STARS and PoTS: our mission on your behalf

Trudie Lobban MBE FRCP (Edin)
Founder & CEO
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About me

Mrs Trudie Lobban MBE FRCP (Edin)

➢ Founder of STARS (Syncope Trust And Reflex anoxic Seizures) in 1993. In 2003, umbrella charity Arrhythmia Alliance and AF Association in 2007

➢ My daughter had RAS
➢ My husband died from cardiac arrest
➢ Both of my parents have AF

www.heartrhythmalliance.org
STARS (Syncope Trust And Reflex anoxic Seizures) was founded in 1993.

Founded at the request of Prof. John Stephenson, a paediatric neurologist who eventually diagnosed my daughter, Francesca with Reflex Anoxic Seizures (RAS).
In 1994 the very first STARS patients day was held, attracting 108 adults and 98 children. It was held in a small function room of a local hotel.

Few clinicians were aware of PoTS at this time.

1998 saw our first International syncope symposium for clinicians. We were breaking new ground but still no focus on PoTS.
25th Anniversary year

- 2018 STARS hosts our first ever dedicated PoTS meeting
- International PoTS experts have travelled across the world to share their knowledge
- Success will ensure this becomes an annual event

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Why a dedicated PoTS day?

➢ To acknowledge the despair, fear and struggle that PoTS patients endure

➢ To ensure each presentation is relevant to the condition

➢ To provide the opportunity to listen to international PoTS experts

➢ To be reassured that everyone is battling similar symptoms and you are not alone

www.heartrhythmalliance.org
PoTS symptoms are challenging and life changing

- Misdiagnosis of ME or chronic fatigue syndrome is common
- Being told you are struggling with stress is frustrating and hurtful

YOU KNOW THEY ARE WRONG, BUT WHY IS IT SUCH A COMMON OCCURRENCE?
PoTS is still a relatively newly identified condition

Could it be that not all medical schools include this in their curriculum?

GPs struggle to understand the symptoms and where to refer a patient

We understand your frustration
Our mission for 2019

➢ Our mission for the next 12 months is to raise awareness of PoTS

➢ We recognise that the weak link in referral to a PoTS specialist is the GP due to lack of awareness of the condition

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Cardiac update meetings will include a topic on PoTS.

GPs, local cardiologists and electrophysiologist will be invited to attend to listen to a PoTS specialist.

To increase the number of dedicated syncope/PoTS clinics because those already established are oversubscribed.
We all agree we need more PoTS and syncope clinics.

Do you attend such a clinic which addresses your needs and has time to provide support?

Please let us know so we can share with others not so fortunate.

You can help us achieve our mission

www.heartrhythmalliance.org
Clinics in your hospital

➢ If your hospital is considering establishing a syncope/PoTS clinic we have guidelines and information to help

➢ If your hospital already has such a clinic then please tell us so we can highlight it as GPs rarely know of these initiatives

➢ If clinics are not supported by GPs then funding can be withdrawn

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At the end of 2019 I would like to think that the number of heart rhythm specialists accepting referrals for PoTS patients will have doubled.

I would like to know that GPs are listening to their patients and referring when necessary.
What we do

We provide support through..

➢ Our patient helpline
➢ Our website www.stars-international.org
➢ Newsletters
➢ Educational videos
➢ Social media such as Twitter, Facebook, and Health unlocked forums
➢ Patient and professional meetings
➢ STARS patient days and regional meetings

www.heartrhythmalliance.org
How we reach the world

➢ A media tour of radio stations in November 2017 reached 14 million people across America

➢ World Stroke Day 2018 saw Trudie appear on TV reaching a further 23 million viewers!
A finger on the pulse of the world

We have reached over 45 million people worldwide,
And taken over 1.5 million pulses!

www.heartrhytmalliance.org
STARS resources

Cognitive Behavioural Therapy for chronic health conditions

Postural Tachycardia Syndrome (PoTS)

Reflex Anoxic Seizures (RAS)

Diagnostic tests for syncope

Living with low blood pressure

Identifying the undiagnosed person

Which ECG is Right for You?

Reflex Syncope (Vasovagal Syncope)

Jack has RAS

Bertie’s Pacemaker

Jane’s ILR

www.heartrhythmmalliance.org

www.afa-international.org

www.stars.org.uk
Dedicated PoTS Resources

Postural Tachycardia Syndrome (PoTS)

www.heartrhythmalliance.org
How can you help us?

Share your story

- Patient stories are an important way of providing reassurance, support and advice to others who have the same condition.

- This is where we need your help! Would you be willing to share your story?

- Please email info@stars.org.uk to share your story.
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.
As a registered charity, STARS relies on regular donations to continue to offer our valuable information and advice service.

Ask us for a donation form, or set up a monthly payment online.
STARS was born from my terror, confusion and frustration. I do not want anyone today or in the future to endure such emotions.

Remember, there is no such thing as a simple faint!
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