

Working together with individuals, families and medical professionals to offer support and information on Syncope

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By Royal Appointment: STARS Founder and CEO awarded MBE

Trudie Lobban, Founder and CEO of STARS was made a Member of the British Empire (MBE) in the Queen's birthday honours list in 2009 for her work for STARS and services to healthcare.

Trudie has devoted the past seventeen years to running the charity, which was founded in March 1993 after her daughter, Francesca, was diagnosed with syncope.

Francesca herself has helped many of you over the years as she regularly posts on the STARS syncope message board.

Trudie's elder daughter, Charlotte, is studying to be a doctor in the UK and recently spent three months training in New York at Mount Sinai hospital. She also suffered, albeit mildly, with syncope. Charlotte works tirelessly

behind the scenes ensuring you all receive your monthly e-bulletins on time.

Although she is extremely honored and thrilled to receive this award, Trudie's happiness is tinged with sadness as her beloved late husband Charles, who passed away in 2008, was not there to share her honor.

As many of our long standing members know, Charles was an integral part of 'Team Lobban' and Trudie was the first to acknowledge this when the award was announced.



"I extend my warmest congratulations to Trudie on being appointed an MBE. Well done and keep up the important work!"

Sir Roger Moore KBE

A New Year message from Trudie...

Happy New Year everyone and welcome to our new members who are receiving this newsletter for the first time. I hope you will find it helpful and informative. Because of the Internet, I know we have many members who never contact us. Do not forget, we are still here to offer support during those periods of despair which we all experience at some point in our lives – you are never alone. Remember, 50% of adults will faint at some stage during their lifetime!

I am very excited to tell you that we have a great year scheduled for STARS US. A Syncope Awareness Day for patients and medical professionals to come together is planned for the summer of 2010. The aim of the awareness day is to provide more knowledge about syncopal conditions, reduce fears and advance the understanding of syncope in the young. A date for the conference will be coming soon.

New downloadable patient materials are soon to be launched on the STARS US web site on Reflex Syncope, Syncope in the Young and POTS. We hope also that 2010 will be the year when the medical professional will appreciate that POTS is a very real condition that can cause havoc in the lives of young and old alike.

And, finally please look out for the new STARS Blackouts Checklist coming soon (see pg 4), which has been written specifically to help patients and their doctors reach the correct diagnosis for unexplained loss of consciousness. I look forward to meeting many of you at our Syncope Awareness Days in the summer.

Syncope in the Young: The Most Frequently Asked Questions

We are going through a period when my daughter is having frequent syncopal attacks. Do syncopal attacks cause any damage to the brain in the long or short term?

No, there is a 'fail safe' mechanism in the brain that will restart the heart and breathing before the oxygen level is low enough to cause damage.

Ear piecing! My daughter wants to have her ears pierced, but I am worried she will have an attack.

Do not worry. It is usually unexpected pain or surprise that causes a syncopal attack.

My child keeps saying his legs hurt. Is this normal?

Unfortunately, yes! This is very common in children with syncope and some also complain of chest pains. Our STARS survey showed that 57% of children complain of leg pains and 26% of chest pains. We do not exactly know why but it is an accepted symptom of this condition. The reassurance of gently rubbing the legs will help when this happens.

My son has just been diagnosed with syncope. He is very pale and our Pediatrician thinks he might be anemic. Could this be due to syncope?

Syncope does not cause anemia but lack of iron in the blood can be the cause of some attacks. Some parents have found that the frequency of attacks is improved once a child's iron levels are normal.

My mum, who is a nurse, is not convinced my daughter has syncope. Why does she say this? I am waiting to see a Pediatrician for a diagnosis.

Unfortunately many medical professionals have not heard of syncope in the young, so it is frequently confused with epilepsy – in fact 39% of children and 30% of adults with epilepsy are actually misdiagnosed, which is a huge proportion. This is why it is so important to ensure a correct diagnosis is made. Syncope in the young can look a lot like epilepsy.

What is the difference between breath holding and syncope in the young?

Syncope is beyond the control of the child. Breath holding is within the control of the child. A syncopal attack can be triggered by unexpected stimuli such as unexpected pain, fear or fright, or fatigue and illness. Breath holding occurs when a child is upset and angry and starts screaming in the form of a temper tantrum. During this outburst they will stop and hold their breath until they pass out for a few seconds. Both syncope and breath holding attacks are very frightening to witness but they are not life threatening.

My daughter keeps holding her hands over her ears when her brother is playing music and recently she does not seem keen to go to parties. Do other children with syncope act like this?

Children who suffer with syncope are super-sensitive and everything seems twice as loud as it would to you or me. In fact it 'hurts' their ears. This is one of the reasons children with syncope are often quiet and prefer to play by themselves or with one friend.

Postural Tachycardia Syndrome (POTS)

The Most Frequently Asked Questions

My daughter has been diagnosed with POTS. What is POTS?

Postural Tachycardia Syndrome (POTS) is a manifestation of autonomic dysfunction and is defined as an increase in heart rate of over 30 beats per minute when standing upright but without a postural fall in blood pressure; this is often made worse by even modest physical exertion. Diagnosis is ideally made in an autonomic center.

My daughter who has been diagnosed with POTS experiences symptoms of light headedness and a feeling of weakness. Are these symptoms normal?

Yes, these symptoms are very normal. The main symptoms of POTS include: Increased heart rate (tachycardia), chronic dizziness, light headedness, insomnia, palpitations, blurred vision, weakness, pooling or discoloration of the ankles or feet and chest pain.

What treatments are out there for my sister with POTS?

Self help: Make sure that you are well hydrated (2 liters orally per day). It is recommended that a patient with POTS should have at least one glass or cup of fluids at meal times and at least two at other times during the day to obtain 2-2.5 liters per day. Increasing salt intake (10-20g of salt) can help.

Medication: Some specialists do prescribe medication and Midodrine is well known as a drug that can help sufferers lead a normal life.

Therapy: Cognitive Behavioral Therapy has had some success in helping patients come to terms with POTS and help manage their lives.

What causes POTS?

There are a number of factors or disorders causing or associated with POTS, therefore it is necessary to be evaluated by a center with such experience.

Hypermobility Joint Syndrome is sometimes associated with POTS. Depending on the results following investigation, treatment strategies can include self help measures as well as a range of drugs.

My doctor has never heard of POTS. Why is this?

POTS is a relatively new disorder, which is slowly being recognized by the medical profession. The condition is often under-appreciated by physicians, which can impact on the patient's quality of life through misdiagnosis or being told the symptoms are "all in their head".

Is it a fact that more often POTS seems to strike young adults from around 15 years to late twenties?

Most people with POTS are between 15 and 50 years of age, but it can occur in people younger and older than these ages. POTS is about five times more common in women than men. Some people with POTS have several days of intense symptoms, followed by periods of noticeable improvement. Other people may, on occasion, lose so much fluid (despite drinking a lot of water) that they have low blood pressure severe enough to require intravenous (IV) fluid replacement.

STARS *Events in 2010*

Syncope Trust And Reflex anoxic Seizures

First STARS-US Syncope Awareness Day!

The very first STARS-US Syncope Awareness Day will be held at the University of Michigan Cardiovascular Center in Ann Arbor, Michigan.

A date in June 2010 is being proposed for this program designed for sufferers of syncope, their families and medical professionals. The aim of the program is to provide more knowledge about syncopal conditions, reduce fears and stigma, and advance the understanding and awareness of syncope and the effects it has on both young and adults lives.

The morning session is designed for the medical professional with topics including: Syncope: An Overview, Cardiologist Perspective, Neurologist Perspective, Syncope And The Elderly, Research, Youth Medical Advances, and Treatment Options.

The afternoon session is designed for the patient, family member, and caregiver. It will offer the opportunity to gain more knowledge of syncope, causes and treatments, increase information sharing as well as networking opportunities with others who suffer.

Resources will be available for patients and medical professionals with allied professionals providing the latest technological advancements, vendors displaying innovative products, and medical literature provided by STARS-US.



Cindy Tobin

The program has been made possible with the help of STARS-US Board Member, Cindy Tobin, RN, MSN, NP-BC, from the University of Michigan Cardiovascular Center.

For more information and updates visit our web site: www.stars-us.org or contact Mary Rustic mary@stars-us.org



Heart Rhythm
Congress 2010
3 – 6 October
2010

Hilton Birmingham
Metropole Hotel,
Birmingham, UK

Our Annual **STARS International Patients Day** will be held on Sunday 3 October 2010 during the Heart Rhythm Congress.

There will be eminent international speakers, including the world expert on POTS and STARS Board of Trustees member, **Dr Blair Grubb**.

To register your early interest please email jenni@stars-us.org

New STARS Blackouts Checklist Coming Soon!

The new Blackouts Checklist, prepared under the guidance of the STARS' International expert Medical Advisory Committee is soon to be available in the US. Its principal aim will be to help you and your doctor reach the correct diagnosis for any unexplained loss of consciousness (blackout).

The Checklist will provide information and advice on the major reasons for experiencing a blackout, help you prepare for a doctor's appointment, and provide information on what to expect if you have to attend a hospital appointment.

