

SADS UK Manifesto



Stride to STOP SADS

SADS UK

– Manifesto –

Working in Prevention

For over 20 years the national cardiac charity SADS UK has been working in the community to save lives. A lot of work has been carried out by the charity over this time including involvement in Department for Health Guidelines, chapter 8 Arrhythmias and Sudden Cardiac death being brought into the National Service Framework; ensuring people affected receive appropriate treatment. SADS UK works with SADS International and together with eminent cardiologists and electrophysiologists have developed 'The Warning Signs'. These are signs and symptoms people should be aware of that indicate they should seek medical advice for a possible inherited or underlying cardiac condition. People who contact the charity are directed to appropriate care.

SADS UK continues to urge Government to legislate for defibrillators to be made available in all school. SADS UK also works with the Welsh Government initiative Save a Life Cymru to create a life-saving chain of survival across Wales.

Heart Monitors and Event Recorders

Early identification of a potentially dangerous cardiac arrhythmia is important. SADS UK has donated over 2,000 heart monitors and recorders to medical establishments to enable the rapid assessment of people who are experiencing arrhythmias, so that people with a life-threatening arrhythmia may be quickly referred to a Electrophysiologist and people with arrhythmias that are more benign may be quickly reassured.

Research

Thanks to research we now know about many of the faulty genes that cause an inherited heart condition. By finding these genes, researchers can produce genetic tests to help find family members also affected by an inherited condition. But more still needs to be done. SADS UK works with major Heart Hospitals around the country, providing funding for projects that deepen the understanding of cardiac arrhythmia and genetic conditions that can cause SADS, sudden cardiac death.

Defibrillators in all Schools

The SADS UK Big Shock Campaign. SADS UK has enabled over 5,000 defibrillators to be placed in schools, together with CPR and defibrillator training. SADS UK set up a e-petition urging Government to bring in legislation to make it compulsory for all schools to have defibrillators on the premises. 10,000 signatures in favour of making defibrillators compulsory was taken by SADS UK to No. 10 Downing Street, together with the West Midlands and London Ambulance Services. The launch of the SADS UK Big Shock Campaign was viewed by over 25 million people.

Anne Jolly, MBE, the Founder and CEO of the charity spoke with Policymakers at the Department for Education and subsequently guidelines were sent to schools advising them of the lifesaving potential of putting a defibrillator on their premises. SADS UK continues to urge Government to legislate to make defibrillators compulsory in all schools to save young lives.

The evidence in favour of defibrillators in schools and public places is overwhelming. The International Liaison Committee on Resuscitation (ILCOR) have stated for many years now that early CPR coupled with the use of the defibrillator is the most powerful combination in saving lives.

Taking action has always been the philosophy of the charity. SADS UK and our members are proud to have helped so many schools in the community put defibrillators and training in place. Every year teachers and staff are honoured at the Annual SADS UK National Lifesaver Awards for using CPR and their school defibrillator to save a pupil's life.

Community Public Access Defibrillators (CPADs)

SADS UK designed and organised production of defibrillator cabinets to make them more affordable to localities around the country, with over 4,000 being installed to date. CPADs are being installed in schools, at park runs, recreational grounds, leisure centres, workplaces, telephone boxes, rural areas and even on the Summit of Snowdon! Lives are being saved because CPR and defibrillators are being administered when a cardiac arrest emergency happens anywhere in the community.

Support for the Bereaved

SADS UK provides qualified counsellors and support contacts throughout the country to assist individuals with their grief. Formal counselling is organised for people struggling with their grief after a SADS death. SADS UK holds an annual Retreat where qualified counsellors are available. The Retreat provides solace and comfort to the bereaved.

Support for people who have been diagnosed with a cardiac condition of the electrics of the heart

Being diagnosed with a condition that affects the electrics of the heart, quite often at an early age can be daunting. It is especially harrowing if there has been a sudden cardiac death in the family. The charity offers information and support to people who have been affected in this way, together with their families.

Support for people who have suffered a Sudden Cardiac Arrest

Life after experiencing a sudden cardiac arrest can bring about an enormous psychological burden on the patient and their family. The anxiety and depression, that understandably can follow such a traumatic event, are often not adequately acknowledged and the Consultant treating the patient doesn't have the resources available to deal with the psychological impact. A cardiac arrest is a life changing experience; the patient can be left feeling too nervous to go back to work and everyone impacted by the traumatic incident can be left feeling in a very anxious and vulnerable state. SADS UK organises counselling for cardiac arrest survivors and family members who are feeling overwhelmed. SADS UK is providing funding to Essex Cardiothoracic Centre to work with patients to provide expert follow-up care. The aim is that the care provided for the patients at the centre will be used as a model and emulated in cardiac centres around the country.

Networking and Sharing Resources

SADS UK backed the British Heart Foundation and Resuscitation Council (UK) call for lifesaving to be included in the core curriculum in schools. SADS UK was delighted to see a recent statement from Secretary of State for Health Damien Hind intending to bring this to fruition in January 2020.

Working with the Genetic Alliance UK, SADS UK provided evidence to the Human Fertilisation and Embryo Authority that made Pre-implantation Genetic Diagnosis possible so that embryos could be screened for the LQT syndromes 1,2,3,5 & 6 and Brugada 1 to prevent the birth of a baby with the condition.

With the support of SADS UK members, supporters and the general public we will persuade policymakers that sudden cardiac death in young people who lead healthy lifestyles is unacceptable. The Department of Health needs to allocate more funding into researching into SADS conditions and sudden cardiac death. More funding for genetic testing must be made available.

Defibrillators and training on school premises is saving lives. The Automated External Defibrillator (AED) can be used by anyone. SADS UK urges the Dept. of Health and Social Care to lead on a national TV Campaign advising the public that in a cardiac arrest emergency anyone can use a defibrillator. No-one knows when or where a sudden cardiac arrest emergency may occur, having defibrillators in schools and widely in the community, together with people willing to carry out CPR and use the defibrillator will save many more lives.

SADS UK Manifesto commits to:

- ♥ Continuing to work to prevent SADS
- ♥ Highlighting the Warning Signs
- ♥ Providing Heart Monitors and Event Recorders
- ♥ Supporting research into SADS to prevent tragic young deaths
- ♥ Installing defibrillators in schools and other establishments
- ♥ Installing Community Public Access Defibrillators (CPADs)
- ♥ Ensuring more people in the community will confidently carry out CPR and have access to a defibrillator
- ♥ Supporting the Bereaved and those who have been diagnosed with a cardiac condition
- ♥ Supporting individuals who have suffered a cardiac arrest
- ♥ Networking and sharing resources
- ♥ Enabling cardiac Arrest Survivors and people newly diagnosed with a condition to have access to improved services and the support they deserve
- ♥ Urging Government to legislate for defibrillators to be compulsory in all schools

HOW YOU CAN GET INVOLVED

Stride with SADS UK to STOP SADS

A SADS UK Campaign Event to keep SADS highlighted
A day to unite in our common aim to **STOP SADS**
Show your solidarity by Striding with SADS UK in London

**When we walk and talk together
amazing things happen!**



The SADS UK Manifesto

Sign and show your support of the SADS UK Manifesto

Ask MPs, dignitaries, celebrities and other prominent people within your community to sign and complete the Manifesto to show their support

Return your completed Manifesto Support Form to SADS UK at the address below

To receive further information about the Stride with SADS UK event, charity updates and ways in which you can get involved and support SADS UK in their aims to STOP SADS

Email: info@sadsuk.org with the words “STOP SADS” in the subject line