

PACE – Prevent Arrhythmic Cardiac Events

This report was compiled by A Okreglicki, Lusan Luscombe and Paul Brink.

Sudden Cardiac Deaths or Arrests (SCD or SCA) are not just random events or a cruel “luck of the draw”. In fact, they may be predictable, and in that case usually preventable; and the event itself may be reversible.⁽¹⁾ This, therefore, deserves our attention and awareness. Armed with this knowledge, intervention may not only protect those who have experienced and survived an SCD or SCA event from a repeat episode but may also identify those, often apparently well, who are at risk from dying suddenly.

With the realization that many of the conditions that lead to SCD in young persons are hereditary, a death in the family is not just a passing life event but should trigger off careful evaluation of the surviving family members, which may be life-saving.

This all needs awareness; awareness amongst the affected survivor or family of the victim, amongst the general public and amongst medical professionals and doctors.

Affected families are often desperate for answers, especially if other members may be discovered to also be at risk, and hungry for knowledge. In such times, they need support: a source of information, advice and guidance.

Advocacy to spread the awareness at all levels is needed: whether that be knowledge and training in CardioPulmonary Resuscitation (CPR), providing information about Automatic External Defibrillators (AEDs), medical or genetic screening of potentially affected individuals and even sportspersons at risk, understanding amongst patients with implantable cardioverter defibrillators (ICDs), or identifying doctors and units specializing and providing expertise in arrhythmias and SCD / SCA.

Clearly, research in this field may be life-saving.

With these needs in mind, Lusan Luscombe, an affected parent, Prof Paul Brink from the Department of Internal Medicine at Tygerberg Hospital and Prof A. Okreglicki from the Cardiac Clinic at Groote Schuur Hospital, founded PACE - Prevent Arrhythmic Cardiac Events, an organization with the goals of:

- Facilitating a support system and counselling for patients and families

- Raising awareness through information distribution and education of the public and medical professionals

- Ultimately creating a communication network and promoting research.

This project has received international support and a grant from the Medtronic Foundation.

Being a lay-persons' organization and guided by interested medical experts, it is perfectly positioned to assume the public and general medical “face”, interaction and mediation of CASSA, the Cardiac Arrhythmia Society of Southern Africa, the special interest group of the SA Heart Association, for medical professionals.

PACE, based in Cape Town, is establishing branches nationwide. Awareness meetings and/or branches have been set up in Gauteng, Durban, Bloemfontein and Port Elizabeth. In October 2008, PACE is being re-launched at the Arrhythmia Clinic at eThekweni Hospital, Durban. PACE will be represented at the SA Heart Congress in November and will hold a breakfast session.

PACE was instrumental in South Africa's participation in the World Heart Rhythm Day, 13 June, started by the Arrhythmia Alliance of over 20 similar organizations internationally and with which PACE is affiliated and whose founder, Trudie Lobban, has been invited to speak at the SA Heart Congress on: “The Team Approach - an Arrhythmia Alliance”, as well as at a number of centres in South Africa.

PACE members have participated in many events, often sporting, to gain publicity and create awareness.

The PACE website: www.paceafrica.org.za provides information about arrhythmias, support, contact, events and involvement.

¹Okreglicki A. Sudden Cardiac Death in children and young adults. SA Heart 2005;2(2):46-58.