

## **PACE at Heart Rhythm Society Congress Denver 2010**

The American Heart Rhythm Society, HRS, held its 20<sup>th</sup> EP (Electrophysiology) Congress in Denver City, Colorado, USA from 12 to 15 May 2010. There were nearly 13 000 Medical and Allied Professionals and interested attendees and a large amount of scientific sessions.

Also attending and exhibiting were the Advocacy Organisations: SADS Canada [www.sads.ca](http://www.sads.ca), Sudden Cardiac Arrest Association [www.suddencardiacarrest.org](http://www.suddencardiacarrest.org), Parent Heart Watch [www.parentheartwatch.org](http://www.parentheartwatch.org), Hypertrophic Cardiomyopathy Association(HCM) [www.4hcm.org](http://www.4hcm.org), SADS [www.sads.org](http://www.sads.org), Arrhythmia Alliance [www.hearrhythmcharity.org.uk](http://www.hearrhythmcharity.org.uk) and others. It was great to see how much they were achieving and much was learnt with everyone willing to share and provide information.



The Heart Rhythm Society is the equivalent of South Africa's Cardiac Arrhythmia Society of Southern Africa - CASSA [www.cassa.org](http://www.cassa.org). They are medical professional organisations dealing with heart rhythm regulation, education, treatment, research and care.

This year, after PACE suggested International Advocacy Organisation participation, HRS introduced a session for Heart Rhythm Advocacy and Support Organisations. They have realised the enormous role that these organisations play in arrhythmia care and have thus invited a few organisations to participate in a session.

**The theme:** "Supporting the Patient: A Global Perspective" Saturday, May 15, 2010 10:30:00 AM - 12:00:00 PM

**Session Description:** With a growing number of arrhythmia patients around the world it is becoming more important that they have organizations to ensure they are well educated about their condition and well represented with a unified voice. This session will bring together patient organizations from around the world and the health care professionals that support them. During this time these groups will have an opportunity learn what type of organizations are out there, address major patient concerns, talk about support and advocacy groups, and share their successes.

**Learning Objectives:** 1. Illustrate the activities and resources available through international patient organizations that support arrhythmia patients and their caregivers. 2. Create a dialogue between healthcare professionals and advocacy organizations about the key issues affecting patients internationally. 3. Explain the best methods of creating and enhancing patient support groups.

**The Agenda was as follow:**

- 1. Introduction: International Perspective of the Need for Patient Support for SCA** by Chris Chiames, Executive Director Sudden Cardiac Arrest Association (SCAA), Washington, DC. [www.suddencardiacarrest.org](http://www.suddencardiacarrest.org). Sudden Cardiac Arrest (SCA) is the leading cause of death in the U.S and the SCAA is exclusively dedicated to preventing SCA. They have a network of local chapters and affiliates and involve survivors, patients, medical professionals, emergency responders and everyone touched by SCA in their mission. They actively promote awareness, CPR/AED training and placement and promote cardiac arrest month in October. Chris provided us with valuable and inspirational information on what can be done to save lives.
- 2. Addressing Major Patient Concerns** by Mary Jo Gordon, Executive Officer, Cardiac Arrhythmias Research and Education Foundation, Duvall, WA, <http://www.longqt.org/> Mary explained that their mission was to provide funding for research and to increase professional and public awareness of unexpected sudden

cardiac death due to acquired heart disease and inherited rhythm disorders. Mary Jo has a wealth of experience in patient concerns as she has an ICD herself! Patient concerns were certainly a global issue as travelling with an ICD requires an appropriate network of expertise.

**3. Support Groups and Advocacy Organizations: How Do They Work and Contribute?**

Lusan Luscombe, CEO, PACE Africa, Cape Town, South Africa. [www.paceafrica.org.za](http://www.paceafrica.org.za) Lusan explained that PACE was an Advocacy Organisation aiming to create awareness, initiate support groups and encourage research. She stressed that the success of PACE in South Africa is due to the partnership they have had with CASSA since PACE was started. CASSA has supported PACE at all times and promoted PACE at every opportunity.

Pam Husband. Sudden Arrhythmia Death Syndrome (SADS), Mississauga, ON, Canada [www.sads.ca](http://www.sads.ca) Pam gave an insightful presentation on her many years involvement in her SADS organisation. She highlighted that Advocacy and Support Groups are an integrate part of each other. Her family was affected and thus she has firsthand knowledge of the needs. Established in 1995, she has achieved and continues to achieve much in Canada for heart rhythm awareness and support. Pam also stressed the huge role that organisations play in reassuring patients and answering basic questions. This ultimately helps medical professionals work much more effectively.

**4. Sharing Experiences: Patient and Caregivers Success Stories Panel**

Aileen M. Ferrick, ACNP. NYU Medical Centre Heart Rhythm Centre, New York, NY  
Leonard I. Ganz, MD. University of Pittsburgh School of Medicine, Pittsburgh, PA  
Chris Chiames, Executive Director. Sudden Cardiac Arrest Association, DC  
Mary Jo Gordon, BA. Cardiac Arrhythmias Research and Education Foundation, Duvall, WA  
Lusan Luscombe, CEO. PACE Africa, Cape Town, South Africa  
Pam Husband. Sudden Arrhythmia Death Syndrome (SADS), Mississauga, ON, Canada  
Samuel F. Sears, Ph.D., Professor, East Carolina University, Departments of Psychology and Cardiovascular Sciences, Director of Health Psychology, NC  
Sylvia G. Priori, M.D., Ph.D., Associate Professor of Cardiology, Director of Molecular Cardiology, IRCCS Fondazione Salvatore Maugeri, Pavia, Italy

The session ended off with an interesting panel discussion about various issues but there was not nearly enough time to discuss all that we planned. It was realized that this session shared so much valuable information, that an earlier session is vital. This will inform and provide everyone interested in arrhythmia with a holistic approach to arrhythmia care.

Aileen Ferrick concluded that the Heart Rhythm Society appointed a task force and that we will definitively hear from them again in the future. We thus look forward to future developments!

Lusan Luscombe  
PACE