



## Leading the Way to Save Lives

### VISION COMMITMENT ACTION

#### VISION—Sudden Arrhythmia Deaths Are Prevented Through Research and Medical Intervention

**Mission:** The Sudden Arrhythmia Death Syndromes (SADS) Foundation exists to save the lives and support the families of children and young adults who are genetically predisposed to sudden death due to heart rhythm abnormalities. SADS is a leader in education, research and advocacy for these families and individuals.

**Values:** It is important that values and beliefs be shared among the SADS families, medical professionals, researchers, educators, board members, management and staff. The values of passion and compassion are the underlying forces that carry us to fulfill our mission.

We believe in carrying out the mission of SADS with passion and compassion.

We believe in research—we will support increases in research funding.

We believe in sharing information. We will collaborate with other organizations in order to share our “expertise”, with the goal of making SADS the “go to” organization for expert opinions and dissemination of information related to sudden cardiac arrhythmia syndromes.

We believe in service.

We believe in being the umbrella organization that others can come to as a resource.

We are respected in the scientific community.

We believe in perseverance as we carry out our purpose.

#### COMMITMENT—Researchers, Medical Professionals and Families Working Together To Make a Difference

##### Living and Thriving with SADS!

*From the President -  
Michael J. Ackerman, MD, PhD*

Since becoming the President of SADS in 2007, I have counted it a blessing to be part of an organization with such a committed passion to matter in the lives of the individuals and families affected by the various inherited heart rhythm conditions comprised under the very sad sounding acronym of SADS (Sudden Arrhythmia Death Syndromes). Having just completed our annual Board retreat in Salt Lake City in February (details found throughout this newsletter), I want to assure you that your staff and your Board are committed to the life saving and life changing mission of SADS. As you will read, our organization had one of its most successful fundraising years, exceeding \$400,000 in 2007. Obviously, the money serves one purpose – to help the SADS Foundation fulfill its mission.

To this end, we have dedicated 2008 to the theme of Focus on the SADS Family. Although historically a long QT syndrome (LQTS)-centric family support and advocacy organization, “I want all individuals and families regardless of age who are affected with a SADS condition – whether it’s the most common one of LQTS or one of the less common forms such as Brugada syndrome, catecholaminergic polymorphic ventricular tachycardia (CPVT), or even short QT syndrome – to find sanctuary at the SADS Foundation.” Our organization wants to meet your needs as an individual and family with one of these conditions. Where we are doing it well, we will continue. Where we have missed the mark or have failed to devote enough attention, please let us know.



Check out our new website at [www.stopSADS.org](http://www.stopSADS.org) and you will see a fundamentally new look, feel, and attitude here at the SADS Foundation as you discover our new logo and cornerstone of STOPSADS which more actively captures our driving intent. As president of the SADS Foundation, I expect us to more accurately convey the hope and expectation that I and our Board have as we think of these conditions. I want you to know that we intend for you to live and thrive with your condition!

Although once viewed as extremely rare, highly lethal conditions where the “grim reaper” was standing around the corner, we must embrace the thankfully updated vantage point where these conditions are far more common than previously thought, but are also far less lethal. These conditions should now be viewed as potentially lethal, HIGHLY TREATABLE conditions. Unfortunately, awful tragedies of precious lives claimed far too prematurely because these genetic heart rhythm conditions continue. Consequently, we will continue our efforts to STOPSADS, to increase aware-

**Commitment: Continued from previous page**

ness of the warning signs so that people can be diagnosed before tragedy strikes enabling them to enter into my expected course of living and thriving with their condition.

For those individuals and families living with their SADS, are you living FULL or FEARFUL? At the SADS Foundation, we want to provide a valuable resource for you, your family, and your specialists to help you not only cope with your condition, but to live large, to indeed THRIVE despite your condition!

Won't you join us as we strive to take your organization to the next level? We can not do it without you. Check out our new website and let us know what you think. We would love to hear from you. Also, won't you consider joining me at our second annual Climb to Conquer SADS from July 9-12 as we partner together to make a difference, a real difference, a life saving and a life changing one!

Take care,

Mike



*Michael J. Ackerman, M.D., Ph.D.*

*Director, Long QT Syndrome/Inherited Arrhythmia Clinic, Mayo Clinic*

*Director, Mayo Clinic Windland Smith Rice Sudden Death Genomics Laboratory*

## **ACTION—Proactive Approaches Bring Results**

For more than sixteen years, the SADS Foundation has educated, supported and advocated on behalf of children and their families.



Since its inception, by Dr. Michael Vincent in 1992, the SADS Foundation has demonstrated its strong commitment to reducing sudden arrhythmia deaths by initiating programs to encourage continued research, raise awareness and provide ongoing support to affected families. We remain dedicated to informing individuals and communities about the risks and symptoms of cardiac arrhythmias.

The Foundation is proud of its record of accomplishments, last year addressing the needs of over 3,500 SADS families, providing materials to more than 157,000 people, sharing over 258,000 pages of information via our website and communicating with over 21,000 people through the SADS News publication and Enews. Almost 500 volunteers responded to calls to action, via e.news. Additionally, the Foundation was visible in local communities, at national conferences and in the halls of Congress increasing public awareness and calling for

research, diagnosis and treatments to save more young lives.

**Goals for 2008—developed by the Board at our annual retreat:**

**Enhance Patient and Family Support: Provide information, resources, and support to assist children and their families to make informed medical decisions and to live and thrive despite the challenges of these conditions. While we will continue to provide our SADS Hotline, physician referrals and networking support program, we plan to enhance our support to families by:**

Creating a needs assessment survey

Expanding the materials available for affected families on our new Website,

Adding an online discussion feature to help people “live and thrive” with SADS conditions,

Developing a family history/pedigree project.

Providing family educational seminars at the Climb to Conquer SADS

**Increase Awareness of SADS and SADS Warning Signs: Increase the general public's knowledge of the warning signs that may identify the child or adult at risk for sudden cardiac death.**

Continue leadership of SADS Awareness Month with a focus this year on keeping SADS kids safe in schools

Continue SADS School initiative, with presentations at school nurse conferences and literature distribution

Increase public awareness through expanded Climb to Conquer SADS media outreach.

**Expand Education to Health Professionals: Facilitate early recognition and accurate diagnosis and treatment of heart rhythm abnormalities by ensuring that healthcare providers have all available current and relevant information. New activities for 2008 include:**

Partnering with PACES on our newly redesigned website to provide physicians with appropriate materials for their patients and families,

Sponsoring the lecture at the Pediatric and Congenital Electrophysiology Society (PACES) dinner meeting yearly, this year it will be in honor of Katherine Timothy.

**Increase Advocacy for Research, Screening (Diagnosis) and Medical Treatment: Encourage increased arrhythmia research, nondiscriminatory treatment and efforts that will improve the quality of life for patients with heart rhythm abnormalities. In 2008 SADS will:**

Encourage medical emergency plans in all schools throughout the United States and promote CPR/AED training as a requirement for high school graduation.

Advocate for school health plans for all SADS kids to include automated external defibrillators (AEDs) in all school with SADS kids.

Develop a health insurance project to assist SADS families to get the care they need

Sponsor a SADS Young Investigator Award yearly through PACES

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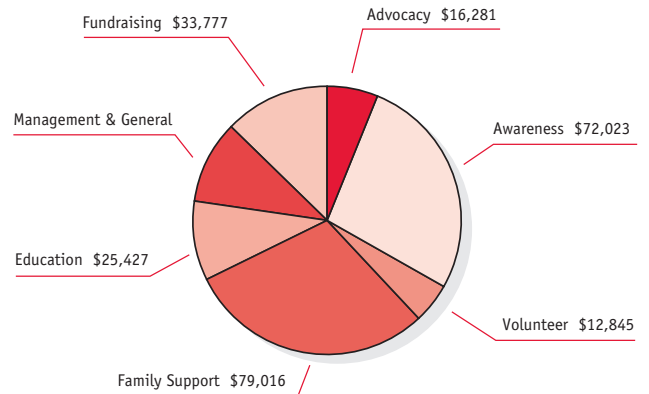
**SADS Foundation  
Statement of Activities**

*Year Ended December 31, 2007*

ASSETS	
Current assets	\$246,497
Net fixed assets	\$1,224
<b>Total assets</b>	<b>\$247,721</b>

LIABILITIES AND NET ASSETS	
Current liabilities	\$18,354
<b>Total net assets</b>	<b>\$229,367</b>

**Total liabilities and net assets \$247,721**



*For more financial information visit our web site at [StopSADS.org](http://StopSADS.org)*