



Note from the President

It is with great excitement that I pen my first “Note from the President” in this SADS Newsletter as the President of the Board of your Sudden Arrhythmia Death Syndromes (SADS) Foundation. It is with humility, honor, and tremendous excitement that I said yes to the request to carry on the torch held by SADS original torch-bearer Doctor Michael Vincent. I have said this to Dr. Vincent privately and now record this publicly, Dr. Vincent was and is an absolute giant in the field of long QT syndrome and sudden death. His role as the founder of SADS and president of the Board for the past 15 years has advanced the cause for the families that we serve tremendously and have undoubtedly resulted in saving many, many lives.

In February 2007, we held the first SADS Board meeting with the newly crafted board that included myself as SADS new board president, Dr. Susan Etheridge as our vice president, Ms. Nancy Adams as our board secretary/treasurer, Dr. Robert Campbell, Mrs. Marjorie Curry, Mrs. Denise Falzon, Mr. Ralph Hardy Jr.,



Mrs. Laurie Smith Hooper, Mrs. Katherine Timothy, and Dr. Martin Tristiani-Firouzi. (for information about our Board members: www.sads.org/about.html) This was a board retreat filled with tremendous gratitude for the achievements of the past and filled with tremendous optimism for what lies ahead. Clearly, the best days for SADS as a foundation and as an organization devoted to advancing the cause and saving lives for patients and families afflicted with genetic heart rhythm disorders like long QT syndrome, catecholaminergic polymorphic ventricular tachycardia (CPVT), short QT syndrome, and Brugada syndrome lie in front of us. As Albert Einstein once wrote, “If I have seen further it is from standing on the shoulders of giants”. As your new board and your new president, we fully expect to see further than we have in the past. We fully recognize that our extended vision and anticipated accomplishments on behalf of families affected with these conditions will be because of the shoulders of giants like Dr. Michael Vincent and the members of the original board have enabled us to see further.

President: Continued on next page

From the Executive Director



What a wonderful year SADS had in 2006! More than ever before, we appreciate the hard work of our volunteers around the world. As you read the list of donors in 2006, keep

in mind that many of these are also volunteers—giving countless hours to promote awareness of these conditions that can cause sudden death in young people.

While knowledge of SADS conditions has continued to grow, many are still not aware that their child may be at risk. And some of these children are part of the extended family of a diagnosed child. We need to do more work in expanding the family pedigrees of those who are diagnosed with a SADS condition and getting cousins, aunts, nephews, etc. tested. Parents of an affected child should be tested—not just siblings. And grandparents who are tested may lead to another group of people whose children

may be at risk. As an early SADS family discovered, one woman was able to contact 300 relatives who might have been at risk and many of them were diagnosed and treated.

Knowing your family health history, expanding your family pedigree and notifying—and testing—those who might be at risk will save lives. Helping you all with this task is a vital part of our plan 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.”

www.sads.org

- People from an average of 74 countries visited our website each month.
- More than 134,735 people visited our website last year and accessed over 269,401 pages of information. This represents over 11,000 visits each month.

SADS Goals

1. General Awareness/Prevention:

Proactively increase the general public’s knowledge of the warning signs that may identify the child or adult at risk for sudden cardiac death.

2. Family Support: To provide information, resources, and support to assist patients and families to make informed medical decisions and to live and thrive despite the challenges of these conditions.

3. Education-professionals: To facilitate early recognition and accurate diagnosis and treatment of heart rhythm abnormalities by implementing strategies to ensure that healthcare providers have all available current and relevant information.

4. Advocacy: To promote research by advocating for increased funding and patient participation and to support non-discriminatory treatment.

President: Continued from previous page

I do hope that each of you in whichever capacity that this newsletter finds you, whether it is an interested caregiver, an affect family member, or a loved one, that each of you will find this anticipation for our future together contagious and that you will want to partner with us to advance this great cause and to make sudden death associated with these potentially lethal syndromes a thing of the past. As a SADS organization, we have taken a detailed look as to our mission and our strategic plan. Our mission is clear. Our plan is clear. For years and years, SADS as an organization has operated on a relatively low budget (at or below \$200,000/year). In February, I set forth an ambitious position articulating that SADS must strive to become a \$400,000-\$500,000/year entity to continue to be a transformative organization and truly fulfill our mission statement. Recently many of you are aware of our first successful launch of what will certainly be one of our marquis events, The Climb to Conquer to SADS. Thanks to Doctor Chris Anderson, a pediatric heart rhythm specialist in Spokane, Washington, and now new board member, this vision of Climb to Conquer SADS was birthed. Plans were made, and the Climb happened. I would like to thank the members of the Climb to Conquer SADS committee for pulling this off. This was a heroic effort. Not only did the sentimental climb occur, but by all accounts it was a smashing success.

Every one of our objectives was met. We planted the seeds for future climbing events that will be even bigger and we will climb even higher. As the totals come in, I am delighted to report that the Climb to Conquer SADS with the climbing of Mount Rainier on June 23-25 resulted in nearly \$100,000 of essentially new money to SADS. As we cross the halfway point for the year 2007, it is very clear that the vision set forth in that February board meeting is already being fulfilled and we are optimistic that we will have increased the budget of the SADS Foundation by over 50 percent in just one year of the newly convened board. As Sister Generose from the Mayo Clinic and Saint Marys Hospital in Rochester, Minnesota has echoed on numerous occasions, "No money, no mission", that tenant is equally applicable to SADS. In closing, I would to thank each of you for your role advancing the cause and mission of SADS. Know that the board is absolutely dedicated and committed to this vital mission. Our mission is lifesaving and life-transforming, and it is a mission that needs you.

Sincerely,

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

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Christopher Nicholas Nesmith Memorial Service
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Jaime Miller Invitational
Jump-a-thon (Shelton School)
Octoberfest (Bill & Sally Layton)
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Awareness and Prevention Accomplishments 2006

- ABC Primetime Live featured SADS in April; over 39 volunteers participated in local media campaigns
- National SADS Awareness Month in September with 33 volunteers in 16 states
- Collected family stories throughout the year to use for national PR campaign
- More than 540 volunteers participated in awareness campaigns in 2006
- More than 10,400 SADS brochures, 5,196 posters, 3,068 LQTS brochures were distributed by volunteers

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Family Support Accomplishments 2006

- SADS Seminars in Atlanta and Boston—including a Long QTeen program, school nurse & EMT participants
- 326 individuals & families were networking through the SADS Networking program in 2006
- Quarterly literature review of newly published research (for members)
- Dallas Support Group held a bowling night for teens
- Kids/Teen Programming: SADSConnect
- 868 family members contacted SADS for the first time in 2006
 - 8% of them had a recent death that prompted their call
- 41% wanted a new family information packet mailed—the rest were OK with our Website
- 20% had specific medical questions for us to answer
- 11% wanted a referral to a physician
- We had 1,663 family members contact us (not including volunteer contacts) in 2006
 - 147 people wanted a referral to a physician
 - 459 people contacted us for a new family packet (28% more than in 2005)
 - 327 people asked us to answer specific medical questions (52% more than 2005)

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Medical Education Accomplishments 2006

- SADS participated in a Sudden Cardiac Death conference in Mississippi—more than 200 professionals attended
- School nurse campaign was conducted in the spring and fall with over 330 school-related contacts. Activities ranged from “presentations” to “adding the risk assessment questions to school physical forms” to “personally calling any parent of a student who I remember treating for an unexplained faint in the last couple of years”.
- More than 3,573 school nurse packets were distributed separately (not including those in new family packets) in 2006—that’s a 216% increase over 2005

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SADS Foundation Statement of Activities

Year Ended December 31, 2006

REVENUES AND SUPPORT	
Individuals	\$166,813.00
Foundations/Corporations	\$ 72,038.00
In-Kind Donations	\$ 6,950.00
Misc	\$ 163.00
Interest	\$ 496.00
Total revenues and Support	\$246,460.00

EXPENSES	
Personnel	\$117,825.00
Postage	\$ 11,337.00
Printing	\$ 21,091.00
Travel	\$ 8,578.00
Occupancy	\$ 8,406.00
Meetings/Conferences	\$ 792.00
Telephone	\$ 5,534.00
Equipment & Maintenance	\$ 5,838.00
Office Supplies	\$ 2,262.00
Professional Fees	\$ 3,243.00
Miscellaneous	\$ 1,868.00
Insurance	\$ 1,857.00
Dues/Membership	\$ 782.00
Training	\$ 587.00
Total Expenses before depreciation	\$190,000.00
Depreciation	\$ 73.00
Total Expenses	\$190,073.00

Expenses by Program		
Awareness	\$ 62,117	33%
Family Support	\$ 61,815	33%
Medical Professional Education	\$ 17,598	9%
Advocacy	\$ 3,616	2%
Volunteer	\$ 5,664	3%
Total Program Expenses	\$150,810.00	79%
Management	\$ 13,044	7%
Fund Raising	\$ 26,219	14%
Total Expenses	\$ 190,073	100%

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Advocacy & Research Accomplishments 2006

- Advocated for the Genetic Nondiscrimination Act (GINA), Rural AED Act, ADAM's Act (national clearinghouse), increase in NIH research funding and the Research Availability Rules
- Sent more than 4 Action Alerts (e.mailed) & included information in newsletters & e.newsletters—over 350 people responded & took action at some time during the year
- Participated as an agency in advocacy campaigns with Genetic Alliance, NORD, Sudden Cardiac Arrest Alliance, Coalition for Genetic Fairness, Alliance for Taxpayer Access and others

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Warning signs for every parent

Your child should be seen by a doctor if she/he has:

- Family history of unexpected, unexplained sudden death in a young person
- Fainting (syncope) or seizure during exercise, excitement or startle
- Consistent or unusual chest pain and/or shortness of breath during exercise

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 Miss Dorothy L. Schleichert, WI
 Denise and LeMont Schmid, IA
 Karen Schneller, IL
 Alan and Carol Lynn Schulman, NY
 Elizabeth Schutt and Abel Lushiku, NY
 Sally Schwarzlose, IL
 Lori Schwieger, CO
 Libby Sckenkman, CA

Ms. Gail Spedden, PA
 William and Denise Spence, PA
 Kathleen Spencer, FL
 Ben and Sarah Sprouse, VA
 Macel St. John, WI
 Stanley and Yvonne Stahl, CO
 Russel D. Stahl and Ann Moody, MI
 Joel B. and Marcele Starr, OR
 Barbara Staunton, PA
 Barbara Stettin R.N., WA
 Jacob and Rita Stevens, MO
 Stacy and Melissa Stevens, MO
 Joe and Carol Stevenson, IN
 Gail Marie Stewart, NY
 Anne Marie Stier, MI
 Corrine and Richard Stier, MI
 Joanne and Robert Stille, MI
 Eleanor and George Stine, CT