

**D**ick Stafford, a National Contact living in Phoenix, Arizona, is one of SADS' most committed and most effective volunteers. His success in increasing Long QT awareness demonstrates what a difference one person's initiative can make. We are often surprised by his ingenuity. He is full of new ideas and sound suggestions. Most importantly, he possesses a natural empathy and has an ability to identify needs in others, and, in his community.

Most recently, an article in the Arizona Republic inspired Dick to organize a SADS information booth at a citywide health-fair. The article highlighted Carrie McDevitt, whose daughter, Faith, died, on Dec. 1, at 20 months old. Carrie marshaled the resources of the community members affected by heart disease to call attention to heart-related illnesses. Dick seized the opportunity and spent the day distributing brochures, information sheets and posters to the many curious participants. He was also able to network with

several Pediatric Cardiologists and other professionals in the "heart" community who are interested in working with SADS.

Dick has been working with our foundation almost since its inception in 1992.

He talked about the sense of futility that accompanies a child's death, "we provide our children with the very best medical care possible, and when something happens in spite of that, you feel so helpless—and you have to do something to combat that grief."



Dick's experience with LQTS was eerily familiar to Cathy Coleman, who met him for the first time at his health-fair table. She recently lost her own teenage son, and said of Dick, "he was just very comforting, very helpful. He shared his story and after I talked with him I felt so much better. He told me what to do now. When you're going through this all-consuming grief, you can't see the next step. But now I do. Now I have a plan for my other children."

Watch for new developments in Dick's work with citywide high schools. He has been

improving the process of team physical examinations. Last year, Phoenix school districts offered voluntary EKG's to all ath-

After the death of his 15-year-old son Andrew, he feels few things are more important than spreading awareness about the symptoms and facts of Long QT Syndrome. When asked why he devotes so much time to educating his community, he answered simply, "I guess if I can do anything to provide people with information that could prevent the loss of a child, that's motivation enough. You just have to keep talking about it. It's not always going to be a first contact, but eventually someone knows someone whose child fainted."

letes. Abnormal findings were referred to a physician for follow-up. Dick provided families with information about Long QT in cooperation with the Physicians and Coaches.

**"...eventually someone knows someone whose child fainted."**

“ On February 13, 2001, our son Caleb was found dead in his bed. The cause of death was reported as “undetermined.” Caleb was sixteen years old at the time of his death and had always been a healthy child. I had never heard of SADS until his passing. ”

*Leslie Wuerzburger*

## FINANCIALS

| <b>ASSETS</b>  | 2001            | 2000            |
|--|-----------------|-----------------|
| Cash and cash equivalents  | \$60,021        | \$75,754        |
| Receivable from former employee  | \$1,084         | \$4,956         |
| Inventory - promotional pins   | \$1,645         | \$1,645         |
| Prepaid expenses   | \$1,314         | \$1,087         |
| Investments  | \$12,511        | \$9,783         |
| Property and equipment, net of accumulated depreciation of \$29,017 and \$27,956 for 2001 and 2000, respectively | \$1,755         | \$1,491         |
| <b>Total Assets</b>  | <b>\$78,330</b> | <b>\$94,716</b> |

| <b>STATEMENTS OF ACTIVITIES</b>            | 2001            | 2000            |
|--|-----------------|-----------------|
| <b>PUBLIC SUPPORT</b>                      |                 |                 |
| Contributions                              | \$132,838       | \$121,949       |
| Special events, net of expenses of \$5,672 | ---             | 4,242           |
| <b>Total Public Support</b>                | <b>132,838</b>  | <b>126,191</b>  |
| <b>REVENUE</b>                             |                 |                 |
| Interest and dividend income               | 1,561           | 2,257           |
| Promotional pin sales                      | ---             | 80              |
| Other income                               | 301             | 92              |
| <b>Total Revenue</b>                       | <b>1,862</b>    | <b>2,629</b>    |
| <b>Total Public Support and Revenue</b>    | <b>134,700</b>  | <b>128,820</b>  |
| <b>EXPENSES</b>                            |                 |                 |
| <b>Program Services:</b>                   |                 |                 |
| Awareness                                  | 40,931          | 28,595          |
| Chapter                                    | 3,902           | ---             |
| Education                                  | 27,289          | 22,420          |
| Patient and Family Support                 | 39,517          | 21,340          |
| Research / Advocacy                        | 5,787           | 5,308           |
| <b>Total Program Services</b>              | <b>117,426</b>  | <b>77,663</b>   |
| <b>Support Services:</b>                   |                 |                 |
| Management and general                     | 15,255          | 9,724           |
| Fundraising                                | 19,204          | 18,152          |
| <b>Total Support Services</b>              | <b>34,459</b>   | <b>27,876</b>   |
| <b>Total Expenses</b>                      | <b>151,885</b>  | <b>105,539</b>  |
| <b>OTHER INCOME (EXPENSES)</b>             |                 |                 |
| Unrealized gain (loss) on investments      | 2,728           | 2,107           |
| <b>CHANGE IN UNRESTRICTED NET ASSETS</b>   |                 |                 |
|  | (14,457)        | 25,388          |
| <b>NET ASSETS AT BEGINNING OF YEAR</b>     | <b>88,870</b>   | <b>63,482</b>   |
| <b>NET ASSETS AT END OF YEAR</b>           | <b>\$74,413</b> | <b>\$88,870</b> |



Dear Friends,

This year, SADS will celebrate its 10th year anniversary. Notably, we will begin a new, worldwide educational effort on genetic, cardiac causes of sudden death in the young. The inaugural event will be the 1st International SADS conference on this topic, in London, in October 2002. Subsequent annual conferences will be held in different metropolitan areas of the world. When I helped start the Foundation nearly 10 years ago, we were concerned about unnecessary deaths due to uninformed medical professionals, and misdiagnoses and failure to treat. The SADS Foundation was established with the principal goals of medical professional education, general public education, family support services, patient support services, and the encouragement and support of research.

The subsequent years have been exciting, productive, and rewarding. The SADS Foundation has played a pivotal role in medical and lay public education, and a significant role in genetic research focused on the long QT syndrome. SADS' scientific advisors are national and international researchers and physicians in LQTS.

SADS has been remarkably effective. Many people have contributed to this exceptional effort, and many lives have been touched and saved. Words do not adequately convey the appreciation that I, and the others who are intimately involved with SADS have for the tremendous contributions that so many people have made.

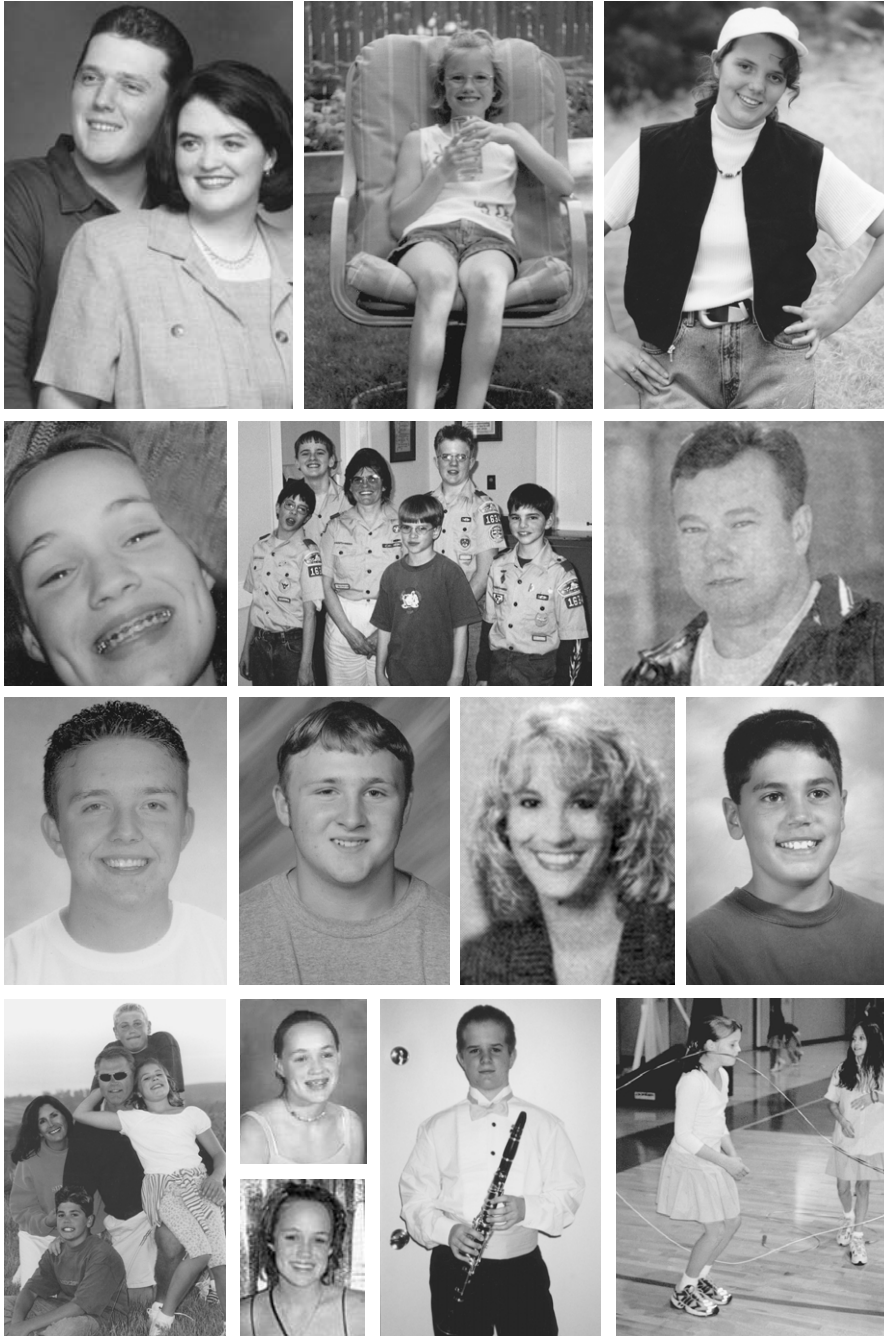
However, much remains to be done. There are still many physicians who are unfamiliar with the inherited Long QT syndrome, Brugada syndrome and other emerging genetic arrhythmias causing sudden death. Furthermore, SADS is progressively involved in cardiomyopathies and drug induced Long QT syndrome. Unfortunately, tragedies such as cardiac arrests and sudden death in young people still occur. These events are largely preventable, and thus our education and clinical care programs are still very much in need.

The SADS Foundation's success is based on thousands of individuals and families who share their stories, strength and financial resources. Physicians and researchers contribute their knowledge, clinical care and time. I thank you all, and invite your participation and support of the SADS Foundation and its life-saving programs.

With best wishes and great appreciation for your efforts,

G. Michael Vincent, M.D.

President & Medical Director



## What We Do

### Support Services

Our Patient and Family Support Services improve people's ability to make informed decisions about the diagnosis and treatment of LQTS, and other life-threatening arrhythmias. We work with families and community collaborators to prevent the unnecessary loss of life. In the last year we distributed more than **12,000 information packets** to newly diagnosed patients and their family members. More than **10,000 educational brochures** were mailed. **Thousands of phone calls** and emails are answered. We facilitate a nation-wide support network for people who have lost loved-ones to sudden death. And, of course, work always to provide people with life-saving resources.

### Awareness

We are dedicated to informing individuals and communities about the risks and symptoms of cardiac arrhythmias. If patients are diagnosed early, if they receive preventative precautions, medication and information, they are much less likely to die. We are currently organizing national affiliates so that volunteers can work more effectively within their own communities to spread awareness about Long QT. Our website receives an average of 5,421 visits a month— last year more than 65,000 people found LQTS information and materials about their disease. 160 media kits were mailed to newsrooms and reporters who wanted to know more about this condition. As more people learn the facts about Long QT treatment, fewer people will die.

### Education

It is difficult to educate people about dangerous disorders that have ordinary symptoms, but we are committed to informing both the general public, and medical professionals about how best to recognize and treat LQTS. While it is one of the most frequently diagnosed cardiac arrhythmias, it is still one of the least understood. With the help of researchers and specialists throughout the world, we provide physicians with the most recent breakthroughs and clinical updates about diagnosing and treating Long QT Syndrome.

“ I still remember the kindness from everyone at the SADS Foundation. To go on after the death of a child is so difficult. In daily activities I functioned in a zombie-like state. It seemed life was a downward spiral. Now we have adopted a 14 month-old boy from Vietnam. He is beautiful inside and out, and helps us to go on. But, I am so very grateful to you for your help in my time of need. ”

*Sharon Cramer*

## National Contact Volunteers

Sylvia Allen  
Keron Bailey  
Gail Bartok  
Suebeth Brown  
David Brown  
Mary Campbell  
Bernadette Carithers  
Rena Carr  
Toni DeBilzan  
Frankie Deeds  
Terri Dorendorf  
Claire Doyle  
Merla Duncan  
Wendy Duncan  
Denise Falzon  
Allison Finkelstein  
Sara Francello  
Michaela Gagne  
Shirley Gaster  
Larry Greenstein  
Janet Hackleman  
Cheri Hines

Stephanie Hooper  
Judson Hyatt  
Blair Jones  
Colleen Kausak  
Evelyn Manning  
Arlene Mastanduno  
Kori McGartland  
Jennifer McKenna  
Jaime Miller  
Ellen Mitchell  
Teresa Moore  
Carol Mulligan  
Chris Nieuwenhuis  
Jan Nordsiek  
Connie Ogden  
Leonor Olivero  
Susie Penagaricano  
Erica Perry  
Marsha Peterson  
Debbie Purvis  
Trudy Redding  
Pamela Reich

Dorothy Renner  
Laurie Robinson  
Marsha Schmidt  
Kerri Sheets  
Dick Stafford  
Sara Staley  
Linda Sullivan  
Traci Tatarzewski  
Brenda Tiffan  
Cynthia Tracy  
Melissa Trout  
Janece Vathauer  
Denise Wieman  
Beth Wiley  
Sue Wisniewski

**59 Contact Volunteers  
worked with SADS in 2001—  
39% more than 2000.**

This is the hardest story for me to tell, the story of my family—and our mysterious history of sudden death. My brother died at 25. My sister, the mother of two sons died at 24. My nephew died at age 13, while running to catch the school bus. Jason, another nephew, died when he was just 3 years old. My niece, Florence, died twelve weeks after the birth of her first child. She was twenty-two.

The losses we suffered left us feeling angry, helpless, hurt, and empty. There are no words to tell you how much I miss them all. But now we must face the future with resolve.

Support of the SADS Foundation advances research in the genetics, evaluation and treatment of Long QT Syndrome. The fact that there is increasing awareness about this disease, in both the public and the medical community, means there is a better chance of early detection and intervention. Hopefully, together, we can prevent tragic outcomes like mine.

*Patti Androsko*

I wish I had known about your organization before. We lost our nineteen-year-old daughter last September. The doctors testing her gave us the impression there was nothing to worry about. I see now how naïve I was to think her condition would go away by itself. I will live with the regret of not pursuing more answers for the rest of my life. I thank the creator your group exists and is helping others to cope with this condition, and to educate those who are unaware of its dangers.

*Anonymous*

“Over the years I’ve seen the value of the research and the exposure to the media that SADS has initiated. You look at the difference it’s making and you know someone is in there, slugging away at the problem.”

*Dick Stafford*

### Supporting Families • Saving Lives

**Mission:** To save the lives of children and young adults who are genetically predisposed or otherwise susceptible to sudden death due to cardiac arrhythmias and to provide education and support to families and the medical community who are dealing with these disorders.

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Robin Brown, *Bookkeeper*  
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