



President's message

It is a delight to greet you all again. From my perspective, the work to prevent cardiac events in children and young adults who are genetically predisposed to arrhythmias is going well. An important advance this last year was the introduction by Genaisance Pharmaceuticals of the Familion commercial genetic test for mutations causing Long QT and Brugada syndromes. The SADS conferences and seminars, noted elsewhere in the newsletter, also provided important opportunities for families to meet with knowledgeable physicians in their geographic area, to learn about new thoughts and technologies, and to have questions answered. SADS has a number of similar programs scheduled for this year. Thanks to all for the terrific work of spreading the word and developing contacts and resources!



There remains a lot of interest and activity in the medical community regarding the genetic cardiac arrhythmias. As an example, at the annual meeting of the cardiologists who are particularly interested in the cardiac electrical system and arrhythmias, held in New Orleans May 3-7, 2005, there were approximately 50 presentations on Long QT, Brugada and related syndromes during that meeting to help educate and update these physicians on these disorders and their diagnosis and management.

There do remain important gaps in our knowledge about LQTS and, thus, uncertainties about the most appropriate care for patients. The false negative results of genetic testing and the limited ability to predict risk of serious cardiac events in asymptomatic patients, particularly children, cause confusion about treatment options, particularly beta-blockers versus ICD implantation. Both of these topics will be discussed in some of the presentations I mentioned above. While no definitive answers to these complexities are yet available, work continues to progress and more information will be forthcoming in the not too distant future. There are a number of outstanding investigators and clinicians working on the genetically caused arrhythmias, and SADS plans to help keep you informed about the results as they become available.

I very much appreciate the opportunity to participate in the SADS Foundation activities and to work with many of you on our mutual goals. It is a great privilege. Again, I thank you all for your many contributions and encourage your continued support.

G. Michael Vincent, M.D.

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Mission: To save the lives and support the families of children & young adults who are genetically predisposed to sudden death due to heart rhythm abnormalities.

Awareness/Prevention, Family Support, Medical Education, Advocacy

SADS provides Family Support, Awareness & Prevention, Medical Education, & Advocacy/Research. To give you a bit of an idea of what we do, last year:

Awareness & Prevention

Family stories were published around the country, including in Arizona, California, Oregon, Texas, Utah, Georgia, Massachusetts, Nebraska, North Carolina, Washington and West Virginia.

2,010 posters distributed (168/month)

Family Support

Over 6,800 people visit our website every month

12 lively and energetic young people attended the 1st ever session for kids at our 3rd International SADS Foundation Conference-this summer.

SADS staff refer 12 families to physicians each month

Over 1,142 people contacted SADS in 2004 with questions, requests for materials, etc.; we

received notice of 7 deaths each month

SADS held three family seminars around the country last year

Medical Education

SADS volunteers educated school nurses all over the country. We mailed over 700 packets of information, numerous presentations and gave a formal session at the Arizona School Nurses Association.

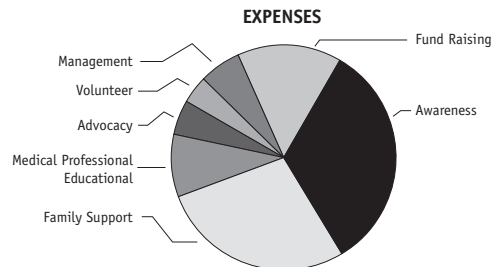
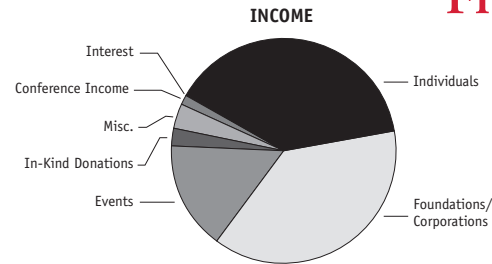
We attended 9 conferences to educate medical professionals and others about the warning signs of SADS, and distributed over 450 medical packets.

Advocacy/Research

A new condition that includes Long QT Syndrome—called Timothy's Syndrome—was found this year by Katherine Timothy and Dr. Mark Keating's lab.

Volunteer support

284 volunteers help us raise community awareness, educate medical professionals support families and advocate.



SERVICES

Costs for some SADS services last year:

Support Seminars	\$17,985.00	
HotLine	\$21,136.00	(\$1,761 each month)
SADS International Conference	\$35,209.00	
Networking	\$2,000.00	
Heart Rhythm Conference.....	\$6,624.00	
Newsletter	\$25,842.00	(\$8,614 each issue)
Website	\$15,674.00	(\$1,306 each month)

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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