Sharing Can Save Lives
Remember, October is SADS Awareness Month

Join volunteers all over the world this October who are participating in SADS Awareness MONTH! Everyone is invited to participate in this event and to help spread the word that sudden death in young people from heart rhythm abnormalities can be prevented and that cardiac arrhythmias are treatable.

By sharing information about SADS and educating as many people as possible about the signs and symptoms of cardiac arrhythmias that can cause sudden death in children and youth, you can make a difference that literally saves lives!

So, how can you help, you ask? Working with SADS Foundation staff and other volunteers you can:

- contact your local media and tell them your story
- distribute materials in your community to schools, community centers, coaches, physicians, nurses, and others who work with children
- organize a local meeting for families
- give a personal gift to help cover the cost of materials, etc. for this special and important month
- hold a special event that will create public awareness AND benefit the ongoing mission of the SADS Foundation

The staff at the SADS Foundation has ideas, materials, and other resources. > continued on page 8

Louisiana Boy Shows Way to Spread Word

As a sixth-grader at Good Hope Middle School in West Monroe, LA, AJ Chase’s science fair project consisted of researching Long QT Syndrome. He also did a three-generation family history on our family to see how LQT has been passed down from person to person. He won first place at his school in the “Medicine and Health” division and took first place in his division at the Louisiana Region 3 Science & Engineering Fair.

Over 1,000 people saw this life-saving message at regional and state events. We are so proud of AJ. His aunt and uncle lost their lives due to Long QT. He and three brothers have, so far, tested negative for LQTS. I am the only surviving child of seven without an ICD, a blessing I credit to my Heavenly Father.

AJ’s desire is to spread information about Long QT Syndrome and, hopefully, to prevent at least one family from suffering the sudden losses we have. — Tiria Chase (AJ’s Mom)

Second Int’l Conference

ATLANTA, GEORGIA
OCTOBER 24-25, 2003

The 2nd International SADS Foundation Conference will be an event that you will not want to miss. On Saturday, October 25, experts will provide educational presentations and opportunities for interactive discussion on topics that include Automatic External Defibrillators (AEDs), Internal Cardiac Defibrillators (ICDs), the Medical Examiner’s Role, Living with Chronic Disease, and Genetic Research— all part of the agenda for families who attend. On the Physician Agenda, topics include Long QT and Brugada Syndromes, ARVD and Hypertrophic Cardiomyopathy, Sudden Death and Clinical Screening, Acquired Drug Induced LQTS, Genetic Testing, Medical Management, and Exercise and Sports Guidelines.

On Friday, October 24 topics for families will include a Family Support and Prevention Panel, as well as presentations on Getting Involved with SADS/How You Can Help; Increasing Awareness and Utilizing the Media to Spread the Word, Developing Resources, Fun and Productive Fund Raising Ideas that Help to Save Lives and Support Families, and an exciting brain-storming discussion on developing ideas for empowering and involving kids in the SADS Foundation.

Friday’s sessions will run from > continued on page 2

INSERT ➤ Annual Report for 2002
3 ➤ Drugs to Avoid: Web List Revised
4 ➤ Billy’s Story: Toddler’s Silent Killer
7 ➤ Raising Public Awareness of LQTS

> continued on page 8
Ruth Steed-Quintal, SADS’ New Program Director

Although I have only been here since the beginning of April, it is already apparent to me that everyone involved in the SADS Foundation has a passionate commitment to supporting families and saving lives. I have worked with a variety of non-profit organizations, in program development, education, advocacy, public awareness, youth and family support for the past fifteen years. It is a privilege for me to have the opportunity to work with you, as we strive to continue the SADS Foundation’s history of accomplishment in achieving the greatest form of success—positively impacting lives.

Thanks! – Ruth

Genetic Privacy

As most of you are aware, the conditions that lead to sudden cardiac death in the young are usually genetic—which means that the conditions can be passed on to your children. This also means that many families will be genotyped, both for research purposes and to determine the type of gene defect in their family. As a result of this genotyping, many people have lost their health or life insurance or even their jobs (or potential jobs). Even though most people with these heart conditions are not disabled and are clinically healthy.

The SADS Foundation has been working with the Genetic Alliance and the Genome Action Coalition to support legislation that would prohibit discrimination in health insurance and employment on the basis of genetic information and to fully protect the privacy of genetic information. The Genetic Information Nondiscrimination Act of 2003 has passed out of U.S. Congressional Committee in May. We will continue to follow this bill, to participate with these, and other, groups working to pass this bill and keep you up to date on progress. If you want more information about these issues, look at our website, www.sads.org or let me know (alice@sads.org). We must know that our personal genetic information will not be used in health insurance and employment decision-making. – Alice Lara, SADS Executive

VOLUNTEERS NEEDED TO MAKE CONFERENCE SUCCESSFUL

This major event is a huge undertaking! We would like to thank all of those who have generously been helping with the planning of this conference, and we welcome volunteers who would like to help in any of the following areas: Program Committee, Marketing and Media Committee, Hospitality Committee, Logistics Committee.

In other words, we need your talents and time, no matter what you have to give.

For more information on volunteering to help with the conference please contact Ruth Steed-Quintal, Program Director at ruth@sads.org or 1-800-STOP-SAD (786-7723)

For more information on the Conference, visit our web-site at www.sads.org 1-800-STOP SAD (786-7723). See you in Atlanta!
The list of drugs that prolong the QT Interval and/or Induce Torsades de Pointes posted on the web site www.torsades.org has gone through some changes recently.

The original list was based on whether or not prolonged QT or Torsades de Pointes (TdP) were listed in the drug labeling approved by the Food and Drug Administration. After the list was compiled, it became apparent that the list had two challenges: some drugs were not included on the list despite known risk, and it was hard to differentiate the risk associated with the listed drugs. Some drugs have clearly documented scientific studies to substantiate the risk while others might have only a case report of prolonged QT associated with an overdose. We decided to report drugs in 4 categories:

**Drug List 1:** Drugs that are generally accepted by authorities to have a risk of causing Torsades de Pointes.

**Drug List 2:** Drugs that in some reports may be associated with Torsades de Pointes but at this time lack substantial evidence for causing Torsades de Pointes.

**Drug List 3:** Drugs to be avoided for use in patients with diagnosed or suspected congenital long QT syndrome. (Drugs on Lists 1 and 2 are also included here.)

**Drug List 4:** Drugs that, in some reports, have been weakly associated with Torsades de Pointes but that, when used in usual dosages, are unlikely to be a risk for Torsades de Pointes.

Drugs are constantly being evaluated for inclusion in the lists. We go through a process that includes looking at the drug label, searching the literature, and searching the FDA Adverse Events Reporting system database for reported cases of prolonged QT and/or TdP.

If you are uncertain about the safety of a medication that is not on the list or if you would like to be placed on a listserv that will notify you of any changes to the drug list, please contact: arizonaCERT@ahsc.arizona.edu.

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**Some of the Conditions Which May Cause Sudden Death in the Young**

**Brugada Syndrome:** Another genetic condition which affects the electrical system of the heart and renders affected individuals susceptible to sudden cardiac death. In this condition the deaths tend to occur to adults between ages 20 and 40 years. It is usually evident on the electrocardiogram, but no abnormalities are detected at autopsy.

**Catacholaminergic ventricular tachycardia:** A genetic condition affecting the electrical system of the heart, with no specific abnormalities on the routine electrocardiogram, and none at autopsy, to assist in the diagnosis. Affected patients are prone to very fast heart rhythms and sudden death.

**Cardiomyopathies:** A cardiomyopathy is a disease of the heart muscle, and predisposes patients to sudden death from heart rhythm abnormalities. Cardiomyopathies are common causes of sudden cardiac death in the young as well as adults. The diagnosis is usually evident during life and at autopsy. There are a variety of causes. The most common form is known as hypertrophic cardiomyopathy, or HCM. This condition has been thought to be the most common cause of unexpected sudden death in young athletes.

**Inherited Long QT Syndrome:** A genetic condition affecting the electrical system of the heart, often abbreviated as LQTS. Individuals with this condition are at risk for serious heart rhythm abnormalities (arrhythmias) which can lead to loss of consciousness, cardiac arrest and sudden cardiac death. These events most commonly occur in children and young adults. It is a common cause of unexplained sudden death in the young. No abnormalities are evident at autopsy. It is usually recognized by an abnormality on the electrocardiogram known as a prolonged QT interval.

**Acquired Long QT syndrome:** A similar condition to Inherited Long QT syndrome, except the electrical abnormalities are not genetic, but caused by medications, strokes, and chemical imbalances in the body, among others. This condition caused the highly publicized withdrawal from the market the prominent drugs Seldane and Propulcid, among others.
My name is Sharon McClellan and I want to tell my family’s story to as many people as possible. You see, we recently lost our 17 month old son to a truly “silent killer”. It appears that he had what is called a fatal arrhythmia. A fatal arrhythmia is undetectable especially if you have no reason to look for it or suspect that there is a problem, as it is generally asymptomatic. Here’s our story:

On Good Friday, April 18, 2003, we had a very normal day—working, school and family time. A little after 5:00, I brought Billy in to put him in the tub. That was to be the last bath I ever gave my angel.

When you listen to our story, there is something you need to understand. Billy was what we referred to as our “miracle baby”. After Billy’s brother was born, I was told that I could have no more children. On November 1, 2001, William “Billy” Martin McClellan made his entrance into this world at 5lbs. 7oz. eight weeks early. We were ecstatic. My son was so thrilled at 5lbs. 7oz. eight weeks early. We were living the American dream.


Billy was in the tub, playing. All of a sudden Billy fell face first into the tub. It was the eeriest silence I’ll ever know. I pulled Billy from the tub. There was no breathing and no pulse. I was screaming and calling 911. My son, Michael, came in from the garage, picked up the phone and started talking to the 911 operators while I performed CPR on Billy. When the paramedics left our home with Billy in the ambulance, he was breathing on a mask. No mention of his heart. The next hours and days would become the worst of our lives.

At the hospital, they did everything possible to save Billy. Nothing worked. I would learn later that he was “gone before he hit the water”. As if this was not bad enough, I was told it was an accidental drowning. I thought to myself, “I could not have let anything happen to my baby. I let him down.”

Billy’s doctor felt that Billy had, in fact, not drowned. He wanted to know what happened to Billy in case it would have some impact on his brother or one of his cousins.

The doctor gathered as much information as he possibly could about what happened that fateful Friday night in April. He told me Billy had what is called a fatal arrhythmia.

I have found out that 1/3 of all SIDS deaths are, in fact, fatal arrhythmias. This is a heart condition that people don’t frequently look for unless there is a tragedy such as ours or a history of such an arrhythmia. It appears that arrhythmia is hereditary in our family. PLEASE know your family history and communicate with your family. It can be the difference between life and death. There are variations of fatal arrhythmias. If there is an abnormal cardiac test, and the problem is detected, it is treatable. The problem is even if you or your child had a “cardiac workup”, LQTS is NOT one of the things they are trying to rule out and my husband and I feel strongly that it should be.

I want to be able to help others out of our greatest sorrow. Please help me and my family to make others aware that there is a serious but not obvious, silent killer lurking only to take someone you love with no warning. Hug and kiss your children everyday. We have learned that each second is precious. Make good memories, because at any time that could be all you have to hold close to your heart.

Thank you for taking the time to read our story. We want to make as many people as possible aware of this condition.

— Sharon and Scott McClellan, parents and Michael McCray, brother.

Quilt Is Loving Tribute to Long QT Families

Shirley Gaster’s handmade quilt is not only a work of art — it is a tribute to all families who share the life-impacting experience of Long QT. Shirley proudly displayed the patchwork quilt that she has stitched with handprints of all sizes, representing Long QT families from all over the United States at the Pennsylvania Support Group.

Also detailed on the quilt are signatures from many of the adults, youth, and children whose hands are outlined on the artistic squares framed there. Shirley, who lost three children to Long QT, and whose daughter, Bernadette Driscoll is living with Long QT, said that she wanted to do something special for all of those whose lives have been impacted by Long QT, and to celebrate those who are courageously living with Long QT each day.

If you would like to send a tracing of your hands or your children’s hands, to stitch into the SADS Quilt—or if you want to help stitch—please contact Shirley at (610) 399-4822 or contact the SADS Foundation at (800) STOP SAD.
WHERE DO YOU WORK?

These employers will match your donation to the SADS Foundation. So will many others. Please talk to your Human Resources staff about the employee matching gifts program at your workplace.

Abbott Laboratories
ABN AMRO North America Inc.
ACF Industries, Inc.
Acuson
Adams Harkness & Hill, Inc.
Addison Wesley Longman
Adobe Systems, Inc.
Advanced Micro Devices
AEGON USA, Inc.
Aetna, Inc.
AG Communication Systems
AGL Resources, Inc.
Aid Association for Lutherans
AIM Management Group Inc.
Air Products and Chemicals, Inc.
Akzo Nobel
Albany International Corp.
Albemarle Corp.
Albertson’s, Inc.
Alexander & Baldwin, Inc.
Alexander Haas Martin & Partners
Allegheny Ludlum Corp.
Allegro MicroSystems W.G., Inc.
Allendale Mutual Insurance Co.
Allfirst Financial Inc.
Alliance Capital Management, LP
...and thousands of others!

No Ball At All
The Party of the Year!

By now, you should have received your invitation to this year’s No Ball At All. This grand non-event is taking on a fresh new look this year, by occurring in the summer rather than the winter. Not to worry, it is still a once a year event – you won’t need to rent a limo again in December!

This event is the SADS Foundation’s largest single fundraiser, generating thousands of dollars for awareness, family support and physician education programs.

Many thanks to this year’s No Ball Dinner Committee for ideas, names, stories, postage, and their personal touch. Most professional fund raisers will tell you that people give to individuals they know and trust, that’s why the No Ball Dinner Committee is so important. Last year, the Dinner Committee’s “guests” covered the costs of SADS’ phone, fax, and internet bill for the entire year.

2003 NO BALL DINNER COMMITTEE
Patti Androsko and Family
Denise and Christopher Falzon
Larry and Rona Greenstein
Jodi Wilinsky Hill and Frank Hill
Sharon and Jim Lentino
Dr. and Mrs. Carl Nathan
Darrell and Connie Ogden
Dorothy and Jim Renner
Dick Stafford and Family
Katherine Timothy
Mrs. Sue Wisniewski and daughters,
Sara and Jen Mihalek
Jon and Martha Zaborowski

This year the event will be held any evening this summer, in the privacy of your own home, with the family members you care most about. If you haven’t received an invitation, and have dinner dress you’re just dying to wear, please call 800/786-7723 to purchase your ticket to the best non-event of the year!

For more than ten years the Sudden Arrhythmia Death Syndromes Foundation has been saving the lives of young people afflicted with Long QT Syndrome and other hereditary arrhythmias. Over this time, hundreds if not thousand of lives have been saved through SADS work. None of this would have been possible without the financial support of thousands of people and institutions believing sincerely in the importance of this work and difference that is being made.

In order to better fulfill the mission of the SADS Foundation, and to appropriately acknowledge the financial generosity of those who make SADS’ efforts possible, the Foundation is establishing the SADS Legacy Circles program. Supporters may join the Legacy Circles by either donating or raising $1,000 in a calendar year.

LEGACY CIRCLES

BENEFITS OF CIRCLE MEMBERSHIP:
• Advanced invitation to SADS events occurring around the country and internationally.
• Semi-annual updates from the Executive Director and Board President.
• Exclusive invitations to annual Legacy Circles receptions.
Many Thanks!

Christine Badame We would like to express our thanks to Christine Badame and her family for their generous hospitality in hosting Alice Lara, Executive Director and Ruth Steed-Quintal, Program Director of the SADS Foundation at their home in Park Ridge, New Jersey on Monday, May 19 and Tuesday, May 20. Christine is a long-time SADS Foundation volunteer and she is President of H.O.P.E. (the Heart of Pediatric Electrophysiology). H.O.P.E. (www.rhythmsofthope.org) is a non-profit organization, whose primary goals are to help healthcare professionals provide comprehensive care in the area of pediatric cardiac arrhythmias through support, awareness, education, and research; and to help affected individuals and their families understand their conditions and cope with them in the best ways possible. While in New Jersey, Alice and Ruth met with Christine and with Lisa Salberg, Founder of the Hypertrophic Cardiomyopathy Association (www.hcm.org) to brainstorm ways to collaborate to increase awareness about sudden death in the young.

Cal and Bernadette Driscoll Special thanks to Cal and Bernadette Driscoll and their family for hosting Dr. Michael Vincent, Katherine Timothy, Alice Lara, and Ruth Steed-Quintal of the SADS Foundation for dinner at their home in West Chester, Pennsylvania on Saturday, May 17 and Sunday, May 18. Cal and Bernadette also worked tirelessly to make all the arrangements for the support group and educational presentation that was held at in West Chester, Pennsylvania on Saturday, May 17. For more information on becoming involved in ongoing SADS Foundation activities in the Pennsylvania area, you can contact SADS Foundation staff or e-mail Bernadette and Cal at bmDriscoll@hotmail.com

Carley Anne Tsaglos Our thanks go out to Carley Anne Tsaglos for scheduling a wonderfully productive day for Alice Lara and Ruth Steed-Quintal on Monday, May 19 at the Joseph M. Sanzari Children’s Hospital, Hackensack University Medical Center, in Hackensack, New Jersey. Through Carley’s efforts, Alice and Ruth met with many of the staff that serve children and families in programs that include Pediatric Social Work Services, Sudden Infant Death Syndrome (SIDS) Center, the CJ Foundation, Child Life Programs, Pediatric Cardiology, and Grief / Loss Support Services. Carley Anne is planning to start a SADS support group at Hackensack University Medical Center. Thank you for a delightfully informative and productive day Carley Anne!

A Free Summer Camp for Children with Heart Disease

Summer camp. Roasting marshmallows by the campfire. Sharing secrets with new friends after “lights out.” It’s something most of us took for granted as children. We were never told that it was too risky to send us away for a week without medical supervision.

For children with heart disease, Camp Del Corazon represents a vacation from their illnesses. When they are surrounded by other kids who’ve had heart surgeries, they don’t focus on their limitations. At Camp Del Corazon, being “different” is normal. Kids make friends with other children who share their fears and concerns, kids who can really understand them.

Campers enjoy all kinds of activities such as swimming, volleyball, rock climbing, kayaking, and hiking. And, for once, they don’t have to feel left behind, because all the kids at Camp Del Corazon are encouraged to perform at their own pace. Find out more at www.campdelcorazon.org.

Capture the Heart: Special Camp for Kids with ICDs

Children, teens and adults all have plenty to anticipate with the two-day Capture the Heart Young ICD Connection on October 10 and 11 at the Marriott Resort in Ypsilanti, Michigan.

The event seeks to inform, entertain and support families that deal with ICDs through workshops, programs, lectures and discussions. SADS and other organizations will provide informational booths for attendees.

Register before September 29 by calling Theresa Davidson, RN, BSN, at the University of Michigan hospital (734) 936-5544.

NEWS AND NOTES from SADS International Affiliates

SADS UK
Anne and John Jolly both received special awards recently—Anne received a civic award for her work with the Ashley Jolly SADS Trust (SADS UK) and John received the Jack Petchey Award for his work with young people. Congratulations!

SADS UK has been nominated for the Achievers of the Year Award 2003 (one of five charities to be nominated for this award).

Anne and John are also hard at work planning another SADS Conference for Spring 2004.

SADS CANADA
The Canadian SADS Foundation is planning a conference to be held in Toronto, October 3–4, 2003, entitled: Taking Awareness Information Making a difference At Cardiac Rhythm Disorders in the Young

Watch for details on our website at www.sads.org.

Many Thanks!
RAISING PUBLIC AWARENESS OF LQTS SYMPTOMS CAN SAVE LIVES: Spread the Word

Why do we want the public to be aware of LQTS and other cardiac arrhythmias that can lead to sudden death in the young? Because making the public aware of the symptoms of these conditions saves lives!

The SADS Foundation strongly encourages everyone to get involved in raising public awareness your community. Even if you don’t talk to the media, by informing and educating people who work with children and young people (coaches, teachers, recreation centers, church youth leaders, etc.) and with parents about the symptoms, children can be protected. Saturate your community with information. Anyone who comes into contact with young people should know:

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

Remember, in all your presentations, to make these points:
1. Children and young people who die from these conditions usually appear healthy, vital and normal.
2. These conditions are not rare: 1 in 4,000 people may have LQTS.
3. Though inherited, these conditions are absolutely treatable and treatment saves lives!

Please visit www.sads.org for more information and ideas for sharing.

Pennsylvania Support Group Members Make Valuable Connections at Meeting

On May 17, 2003, over 50 people attended a SADS Support Group held at the Westminster Presbyterian Church in West Chester, Pennsylvania. Thanks to SADS Volunteers, Cal and Bernadette Driscoll and Shirley Gastor, who worked hard arranging, coordinating, and facilitating everything, the event was a huge success!

An interactive discussion with G. Michael Vincent, M.D., founder and President of the SADS Foundation Board of Trustees, was followed by a presentation by Katherine Timothy, Clinical Coordinator for Cardiac Arrhythmia Genetic Research, Mark T. Keating, M.D. Genetic Laboratory at the University of Utah and Harvard University. A question and answer discussion period followed, giving all in attendance the opportunity to benefit from the extensive knowledge and vast expertise of Dr. Vincent and Ms. Timothy.

Alice Lara, Executive Director, and Ruth Steed-Quintal, Program Director for the SADS Foundation were both on hand to provide answers to questions regarding SADS Foundation programs, upcoming events, and volunteer opportunities.

For more information on becoming involved with upcoming events in the Pennsylvania area, contact Bernadette and Cal Driscoll at bmDriscoll@hotmail.com. For more information on events and activities in your area, or on how you can take advantage of opportunities as a SADS Volunteer, visit our website at www.sads.org. E-mail Ruth at ruth@sads.org or call us at 1-800-STOP SAD (786-7723).

Special Thanks To NASPE Volunteers

A very special thank you to volunteers Wendy Duncan, Matt Duncan, Luther Duncan, and Lauren Menzies for their help at the 2003 NASPE (North American Society of Pacing and Electrophysiology) Conference, held in Washington, D.C., May 14-17, 2003.

These volunteers helped to provide information about the SADS Foundation’s mission and programs, as well as increasing awareness about genetic cardiac arrhythmias and sudden unexpected death in the young to the many physicians and other medical professionals in attendance at the conference.

The dedicated volunteers’ efforts made a positive impact and lasting impression.

Katherine Timothy, SADS Board Member, and Lauren Menzies, a SADS volunteer, work the booth at the NASPE Conference.
October is SADS Awareness Month

available to help you start your efforts to reach out to families and save lives in your community. We can also put you in touch with others in your community who want to make the ultimate impact — saving lives. You just need to open your mouth and the information you share may reach someone who is not aware of arrhythmia dangers in his or her family.

Call 1-800-STOP SAD or e-mail dave@sads.org TODAY and let us know that you would like to be part of SADS Awareness Month. With your support we can make a LIFE-LONG DIFFERENCE for kids and their families!

The greatest gift we can give a family is the life of a loved one

Give Online at www.sads.org

It’s Easy! It’s Quick! It saves SADS staff time and money. Which means more of your gift goes to directly to saving lives.

October 24 & 25, 2003
Buckhead Sheraton Hotel
Atlanta, Georgia

Watch for more information on our website (www.sads.org) and in the mail. If you are interested in helping us with the conference, please e-mail us at sads@sads.org or phone 800-STOP-SAD.