



SADS
FOUNDATION

NEWSLETTER

Supporting Families ♥ Saving Lives

Spring Issue 2002



Automatic External Defibrillators (AED) in Schools

Colleen Kausak says she feels the country is at a turning point, “it seems like this year there’s finally increased awareness about defibrillators and why they’re so important. The things I’ve been talking about for years, well now people are finally listening.”

One of the things Colleen has been talking about is the need for AEDs

in schools, on buses, and in other central community locations. When her son Adam was diagnosed with Long QT Syndrome in 1997, she felt, “there was so

much we needed to do to protect him when he wasn’t at home.”

“Initially it was an uphill battle,” she says. “There wasn’t any support. We had to educate ourselves, and others at the same time.” Her local representative in Illinois put her in touch with a lobbyist, and together they worked on



“...well now people are finally listening.”

an agenda to present to the legislature. Key points included EKGs for all athletes, an improved procedure for school physicals, LQTS materials provided to teachers and school nurses—but first and foremost, AEDs in the schools.

The administration and staff in her district were very helpful. They immediately obtained two AEDs for the large high school Adam attended. Currently the district has two more on order. They are working on a state grant, in partnership with Medtronics, to purchase AEDs for all remaining schools in the area.

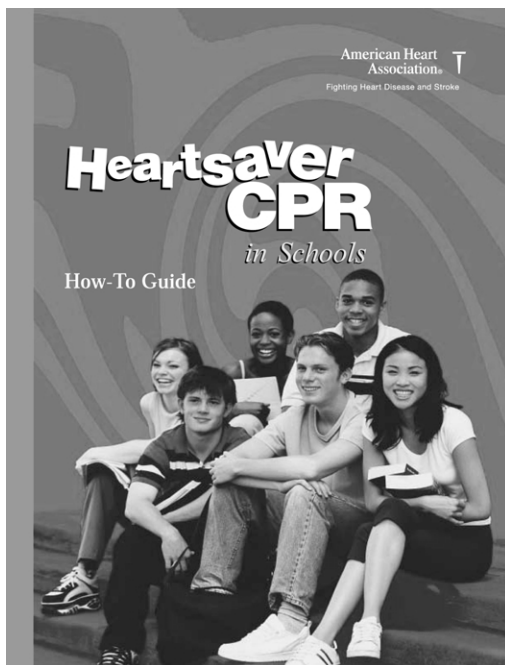
Look for stories about other SADS volunteers and AED Programs on our web site www.sads.org

See page 6 for AED resources

AED Funding News

February 6, 2002 - The US Senate approved the “Access to Emergency Defibrillation Act,” which provides state funds to expand the availability of automated heart defibrillators that treat patients in cardiac arrest. The defibrillator bill will authorize \$30 million over the next six years for community grants to help purchase and place automated external defibrillators (AEDs) in schools, community centers and other public places. Funds can also be used to set up training programs for the public and to develop systems to coordinate with emergency medical personnel.

In October 2001 the Senate Health, Education, Labor and Pensions committee approved legislation called the “Teaching Children to Save Lives Act.” This bill encourages schools to apply for funding to train students in CPR. Schools that already offer CPR courses are eligible to apply for grants which extend their training to include the use of AEDs. Children in grades 6 through 12 are eligible for this funding.



IN THIS ISSUE

- What’s Up at SADSpg. 2
- Volunteer/Affiliate Newspg. 3
- Blue Ribbon Award.....pg. 4
- Birthday Tribute.....pg. 5
- Research.....pg. 6
- In Loving Memory.....pg. 7
- Annual Report 2001center

From the Executive Director

The support all of you give our programs is very exciting! We at SADS really want to get to know you better. Many of you filled out the survey (www.sads/survey.org) included in our last newsletter—thank you very much. We will use this information to update your record in our new database. In this way, we hope to strengthen programs, such as Networking, and develop new programs to meet your needs. We also want to create a means to keep in touch with you on a more regular basis—and for you to keep in touch with us and with others throughout the country and around the world. We want to use all the talents, experience and knowledge available in our quest to save kid's lives.

To make sharing and communication easier, we plan on using e-mail much more extensively—to send out short news bulletins, updates for people interested in a particular area or project, etc. Please let us know your e-mail address (and any interests you may have).
SADS@sads.org

We also added some new features to our web site—including materials about LQT Syndrome, the SADS Foundation, etc. which you can print and copy for your local community. We get many comments from people new to SADS about how useful our web site was to them—but we would like to know if it is useful to you, and what we can add or change that will help you in your work.



What's Up at SADS?

About Rachel Day

I am happy to join the SADS Foundation. This organization provides invaluable services to families, patients and health care professionals, which, as Development Director I am excited to promote. After working as a journalist for several years, I missed the sense of fulfillment present in the non-profit world. I wanted to work with people, for a cause that mattered. I found that sense of purpose at SADS.

I have already learned so much from the committed staff and many volunteers of this organization. This is an exciting time for the foundation. We have lots of goals, many programs to develop, as well as talented new individuals to work with. I feel lucky to work for, and with you.

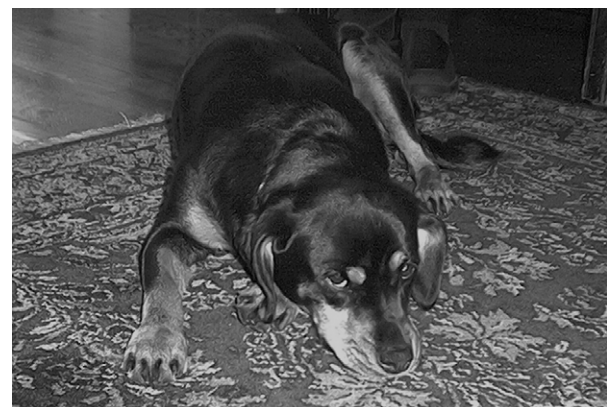


SADS is pleased to welcome **Denise Falzon** to our Board of Directors. Denise has worked with SADS Foundation since she contacted us in 1993 after losing her 19-year-old son, Brian. Her volunteer efforts are tireless—in both fund raising and awareness initiatives. Though she is a full time Realtor, Denise describes herself as “an activist.” She is a member of numerous professional, educational, charitable and social organizations.



“Eight years ago, my life as I knew it crumbled when my ‘healthy’ nineteen year old son, Brian, suddenly collapsed and died. The cause of death was inconclusive, but a sudden arrhythmia due to LQTS was suggested because of a fainting episode that was misdiagnosed a year earlier. I have dedicated myself to SADS, because I truly believe my son, Brian, would be here with us now if he had been diagnosed correctly. I do this in my son's name so that he may never be forgotten. I pray and hope that by educating the public and medical professionals about the symptoms and warning signs of LQTS, we will be able to stop the senseless deaths of other young people.”

Christie Machan, a tireless SADS staff member for the past 2 years, has left the Foundation to pursue other career goals. The Board, staff and the many volunteers of the SADS Foundation would like to give Christie our heartfelt thanks! Her generosity of spirit, patience, and dedication to the people of SADS inspired us all. We wish her well in her new work!



Christie, Genevieve really misses your puppy, Mabel!

The Heart and Hands Award

Each year our country recognizes the vital role of philanthropy in our communities, and in our lives, with National Philanthropy Day. On this day we honor organizations and individuals who contribute time, talent and money in an effort to improve the circumstance of others.

In observance of Philanthropy Day, the Utah Nonprofits Association and the Utah Society of Fund Raisers present a special award, acknowledging the impact individuals have made to their respective causes.

We are pleased to announce that in 2001, our Board member, Katherine Timothy, received The Heart and Hands Award at an honorary luncheon in Salt Lake City.

Katherine is one of the original founders of the SADS Foundation. In 1990 she was working with Dr. Vincent as the Long QT research coordinator, when a critical breakthrough was made. After expanding the principal genetic pedigree for LQTS research, Katherine worked closely with Dr. Mark Keating to identify the linkage between the Christenson pedigree and the affected genetic location. Their work was published in Science in 1991.

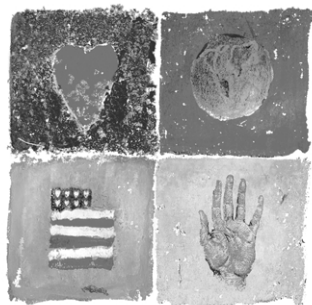
The reputation and success of SADS is built largely on the credibility and vision of its founders. We work to realize their dream of saving lives.

Katherine has given her time, expertise and love to this foundation for more than ten years. She

reminds us of how far we have come, and in her continued partnership with Dr. Keating, how much work we still have to do. We join the state of Utah in honoring her accomplishments and generosity.



National Philanthropy Day



Celebrating Utah's Philanthropists

SADS Australia

As director of SADS Australia, July Foley has made great progress in formalizing the structure and purpose of the organization. Long QT awareness is spreading rapidly in Australia. With that awareness comes a growing need for support and information, which Julie and her volunteers are working to meet.



Julie is also working on a nation LQTS support network. In an effort to connect her newly formed group with Long QT patients around the world, she is sending a stuffed kangaroo, "Kanga," on a global tour. She hopes individuals and families dealing with LQTS will invite Kanga into their homes and offices and then write letters of introduction, detailing their experience of living well with this syndrome.

Contact Julie and her staff at www.sads.org.au

With a new Board of Trustees and committed members, SADS Australia is designing LQTS poster to be distributed to doctors and clinics around the country.

SADS UK News

It has been a very busy time for SADS UK. We are happy to say there's been a lot of recent media interest in Sudden Arrhythmia Death Syndrome.

The British Broadcasting Company (BBC) compiled a documentary about The Gorry family. After a Long QT diagnosis in one family member, researchers theorized the mysterious deaths of many young people throughout the family could probably be attributed to this condition. The film traces the family's history and documents their efforts to reach all living members to talk about the risks, symptoms and treatment of LQTS.

After the show, people phoned our hotline non-stop for the rest of the evening and through the following week. We sent dozens of information packets out, and many people went on to seek specialist medical advice.

Tragically one of our SADS members,



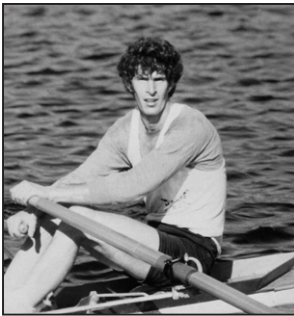
Susie, experienced a second family death. Her 21-year-old daughter was found in bed—another devastating victim of Long QT. The incident was reported in the National Press and our SADS UK support group was featured in the article. Susie vowed to try and prevent needless deaths like that of her sister and beautiful daughter Nadine. SADS members throughout the country are working extremely hard to raise awareness about these tragic deaths.

Ashley Jolly
sad
Sudden Adult Death Trust

Joel Augenblick

January 6th, 2002 was a red-letter day on the Augenblick calendar. It was the 80th birthday of David—my husband of 55 years and the devoted father of our four children. It was the perfect occasion to gather the family and celebrate this milestone. Preparations had begun six months before, therefore all the children, grandchildren, sundry relatives and many friends were able to gather and toast his health and vigor.

The only sad note was the absence of our son Joel, who almost four years ago at the age of 46, just did



not wake up one morning. No symptoms, no warning, just sudden arrhythmia death syndrome. The unexpected loss of a vibrant, healthy athlete—a sculler, a kayaker, a Macabee gold medallist—was overwhelming. He had recently seen the birth of his first child. She would not remember him at all. At age four, she now says “she has no daddy.”

Time has softened the edges of grief, though Joel lives on in our daily thoughts. What better way to honor his memory than to turn to this happy occasion into an opportunity to ask our guests to forgo the usual gifts and instead, make a contribution to SADS. Its valuable research may some day help other parents avoid a similar tragic loss.

One of the most rewarding aspects of our work at the SADS Foundation is the opportunity to learn from the educational and fundraising initiatives, individuals and families undertake to spread awareness about Long QT Syndrome. We hope this story of the party held in Florida by Helen and David Augenblick inspires you as much as it did our staff. Please think about what you could do in your own community.

SADS Wish List

- **Computers**- we badly need 2 computers to replace old, inoperable machines.
- **Frequent Flyer Miles**- staff needs to travel to affiliate groups around the country
- **Mailing Service**- We do 4-6 bulk mailings each year through a professional mailing house. If anyone has connections for a possible donation of postage or mailing services, we need your help! We can ship materials to your vendor for processing.
- **Printing**-we want to print all our materials for the year. We can use any printer in the country.

Another Great No Ball At All!

We want to thank everyone who participated in our Seventh Annual No Ball at All. It was a great success because of the commitment, time and money, so many of you contributed. This event is the cornerstone of our fundraising efforts, and the money we raise sustains the programs and staff of the SADS Foundation through much of the year. Your generosity fuels our research, support, advocacy and awareness initiatives.

We extend special appreciation to our dinner committee. Their willingness to share personal experience with friends, neighbors and colleagues, made the importance of this syndrome, and our immediate need clear. So, with much gratitude we acknowledge each of you.

Patti Androsko
Jerald and Sherrie Boseman
David and Julie Brown
Peg and Tim Bruen
Richard and Penny Cline
Frankie Deeds
Suzanne Doleman Shirley Gaster
Stacy and Richard Hunt
Colleen Kausak
Denise Larivee

Jennifer McKenna
Constance and Paul Nigro
Debbie Purvis
Pam Reich
Beth Respass
Maureen Schulman
Elmer and Esther Skoegard
Blair, Gun Maria & Rick Swanson
Martha Zaborowski
Marsha LeGrand Lentz

If you would like to participate in our No-Ball-At-All in 2002, please contact Rachel Day at (801) 531-0937 or write to Rachel@SADS.org

Matching Grant

We have a success story to share about an employment perk many of you may not be aware of. Last October we received \$150 from a certain, anonymous, donor. A month later, a check arrived from an unnamed corporation, for three times more than the original contribution. A letter attached to the contribution explained the organization's matching grants program. Many employers are willing to match, and even increase the charitable contributions of their employees. We were so impressed by the ease and net reward of this single example! We hope each of you will ask your employer if a matching grants program is available in your company.



Jenna Aaland

The Blue Ribbon Award

Strong spirit, kind heart and possessing a clear vision of the future are three phrases I would use to describe my oldest daughter, Jenna. Her strong spirit was not shaken when she was diagnosed with LQT syndrome in the fall of 2001, and it was her clear vision of the future that allowed her to participate in the decision to have the AICD implant. Jenna has never let her diagnosis of LQTS or her implanted defibrillator slow her down. At the tender age of 16, she is a beautiful young woman who experiences a heightened awareness of

the world around her, the feelings of others and the strength of her determination. She has accepted the changes in her life with poise, creativity and maturity beyond her years.

One important aspect in the life of any teenager is their access to activities like sports. Although Jenna's thoughts of playing high school sports have been revised, she plays an active role in things, like managing the girls basketball team or participating in non contact sports like golf. Her openness with her limitations has endeared her to the team.

Holding steadfast to her dreams, she plans on attending medical school and is contemplating pursuing a career in pediatric cardiology. Rather than be a victim of the disorder, Jenna has chosen to turn it into a chance for personal growth and has emerged a victor. She is a true source of inspiration to every member of our family, her school and community. It is with great pride and respect that I call her my daughter. She is truly amazing!

The Blue Ribbon Award:

We love to hear about children who are thriving—the kids who live well and grow-up with LQTS. These stories give hope to other parents and families. Tell us more about your kids, their lives, successes and accomplishments.

Karla Aaland' Story

In today's busy lives we have to be open to the unexpected, and rise to the challenges that come our way. I can assure you that my overflowing calendar had no room for the news of a LQTS diagnosis in June of 2000. As a mother of two teenager daughters, newly enrolled in an MBA program and an executive in a thriving manufacturing business, I was already too busy. From dawn to dusk I was on the go....



Having lost my mother in 1971 to Long QT Syndrome, I resolved to make sure that my children grew up with a mother, and took on the mission of spreading the word about a silent killer—Long QT Syndrome.

In the Fall of 2000, I had a Guidant AICD implanted, which has lifted the fear that many LQT carriers live under.

It has virtually given me a new lease on life. My family's story will be featured in their 2001 Annual Report. This worldwide exposure will bring LQTS to the forefront and serves as a solid kick-off for future speaking opportunities.

Back in the real world of day-to-day life my schedule is still full and the appointments are back to back—but my passion for spreading the news about LQTS takes top priority. Through speaking engagements and other press opportunities I hope to reach others who are unsuspectingly inflicted by the genetic disorder.

“I resolved to make sure that my children grew up with a mother”

Volunteer Task Force

Recently, seven volunteers from around the country “met” in a conference call with Alice Lara. It is a wonderful milestone for SADS that some of us from throughout the country are coming together to plan for greater local involvement for individuals (National Contact Volunteer, etc.) and Local Affiliate Groups in partnership with SADS. While individuals have been working to support SADS in myriad ways for a long time, we are hoping that this increased structure will encourage and provide more structure for this critical volunteerism. Working together on national initiatives will greatly increase SADS impact in the community.

Jodi Hill, moderator
Karla Aalund
Patti Androsko
David Brown

Claire Doyle (via e-mail)
Allison Finkelstein
Dick Stafford

AED Resources

Please keep SADS up to date—let us know if you are interested in, or working on any AED project. We will use this information to keep volunteers informed and share ideas, successes, etc. sads@sads.org

National Center for Early Defibrillation

www.early-defib.org

A fantastic site launched by the Medtronic Foundation and the University of Pittsburgh in November 2000. The Center provides information, resources and support for those wanting to start early defibrillation programs in their communities.

HeartCenterOnline

www.heartcenteronline.com & go the arrhythmia section. This site has many simple explanations about arrhythmias, Long QT Syndrome, AEDs and more. There is also a section entitled “An Arrhythmia Resource Center” sponsored by Guidant.

Others

http://www.cpr-ecc.org/Cpr_aed/cpr_aed_menu.htm#padprograms

American Heart Association’s information about AEDs, public access programs, training and much more. Also includes sample documents to use in an AED program.

<http://www.citizencpr.org/>

Citizen’s CPR Foundation publishes Currents, a magazine with important ideas and new development about CPR. Also holds a large national conference each year.

<http://www.aedusa.com>

This site was founded by one of SADS’ volunteers, Blair Jones, to help prevent further deaths Blair’s son, Graeme, died when he was 12 years old.

www.padl.org

This site is devoted to educating the public about AEDs and the need for early defibrillation. You can check out your state’s laws (as they relate to AEDs), find a trainer, or request a grant to purchase an AED.

Detecting LQTS Earlier—Preventing More Deaths

In the December issue of the Journal of Medical Screening there are two articles about the difficulties of making the diagnosis of LQTS. The articles rely on clinical information made available to the authors by Dr. Michael Vincent and Katherine Timothy – two individuals at the heart of the SADS Foundation who are also co-authors of the papers. Here is a brief description of the papers:

was based on children from families who have had DNA testing. The authors found that only 30% of children with LQTS would be found with screening at birth and that DNA analysis would not do much better even if it could be made available.

Long QT syndrome in children: the value of rate corrected QT interval and DNA analysis as screening tests in the general population
W C Allan, K Timothy, G M Vincent, G E Palomaki, L M Neveux, J E Haddow
J Med Screen 2001;8:173–177

When a child faints, test for LQTS

This first paper concludes that general population screening for LQTS (i.e. all newborns) will not work right now. This conclusion was based on frequency curves for the corrected QT interval and on known results of DNA testing in research labs. Frequency curves show how often a QT interval of any specific length is found in children with and without LQTS. For the first time this information

In the second paper, evaluating children who faint is considered. This approach seems to be more likely to help. Many fewer normal children will be tested since fainting only occurs in about 1 in 14 normal children, whereas 1 in 2 children with LQTS have an episode of fainting from which they recover. In addition, this paper suggests QT interval testing in the parents of children with borderline prolonged QT intervals can be used to increase the detection of LQTS. Overall, about a third of children with LQTS could be detected if the QT interval was evaluated after fainting with very few false positives.

Long QT syndrome in children: the value of the rate corrected QT interval in children who present with fainting
W C Allan, K Timothy, G M Vincent, G E Palomaki, L M Neveux, J E Haddow
J Med Screen 2001;8:178–182



Research Study

The University of Kentucky is conducting a research study of a new treatment for Long QT Syndrome. They want to speak to people already diagnosed with Long QT Syndrome and those who may have LQTS. The study involves the administration of potassium, wearing a Holter event monitor, four times and medications. If you are interested in participating, or to obtain more information, please contact Tonya Shepperd, RN, Nurse Clinician at (859) 323-4738.

Are you or your family members participating in any research studies? If so, SADS would like to know about them. Please e-mail us with the information (sads@sads.org) or call (1-800-STOP SADS) so that we can let other LQTS patients participate in research.

In Memoriam



Samuel Robert Mitchell

Sept 23, 1996-Jan 5, 2000

Sammy was a late-life fulfillment of my dream of having three wonderful children. We were thrilled when we found out I was pregnant. The age range was perfect for the older kids to enjoy their little brother and they took an active role in his care. They absolutely delighted in each other.

On Sammy's 3rd birthday he lost consciousness while swimming. We couldn't find a pulse and performed CPR. He spontaneously recovered before the ambulance arrived. The doctors at the ER were baffled and sent him to a children's hospital for evaluation. We had many other tests and specialist consultations, but nothing was found. No one suggested a cardiac work-up. I was uneasy without a medical explanation but found an outlet for my fear by trusting in God.

Three months later Sammy went into a quick convulsion and lost consciousness. We called 911 and did CPR until they arrived, but little Sammy's heart never started again. Our precious son was dead. Anguished, we waited for the autopsy results to find out why. The phone call came; they found nothing wrong with him.

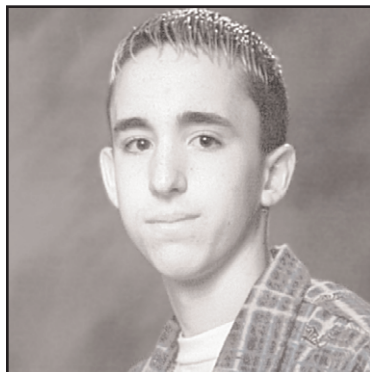
Our other children were tested with a resting EKG and sonogram, which also showed nothing. Months later our doctor insisted that we all have stress tests. These

showed possible LQTS for both children. The kids were put on beta-blockers and removed from their competitive sports activities with regret and uncertainty. Just last month, my mother had a stress EKG for an unrelated reason and it showed LQTS. This result identified the genetic carrier for Long QT Syndrome.

“Other lives will be saved through his story”

We know that Sammy's legacy is twofold. Other lives will be saved through his story, including possibly his own brother and sister. Two TV stations have spread his story to promote awareness and my cardiologist has lectured local physicians. Secondly, my walk with my Comforter and Lord has survived and been strengthened.

*Submitted by Wendy Mitchell,
Sammy's mother*



Adam John Kausak

July 26, 1986 – January 17, 2002

On January 17, 2002 after completing the first semester of sophomore year, our loving fifteen-year-old son, Adam, an honor student at Grayslake Community High School in Illinois, died of a heart condition called LQT Syndrome. Around 4:00 P.M., his mother, Colleen, went out with our son Andy. When she returned an hour later, she found Adam lying on his

bedroom floor. She immediately called 911, started CPR, and administered our home defibrillator paddles. Every effort to save his life failed.

Over 500 loving family and friends attended his wake and funeral. It was evident Adam impacted many lives in the 15 years that God gave him to us. He will always be remembered for his openness and acceptance of everyone.

In August 1997 Adam experienced his first episode. Colleen, returning from a short errand, discovered him unconscious on his bedroom floor. Fortunately, she was able to bring him back. After numerous tests, an ECG revealed he had prolonged QT rhythm. He was placed on Beta Blockers and prevented from participating in sports.

When Adam was diagnosed with LQTS, little did we know, it would change our lives forever. Our entire family was tested and my son, Andy, and I were both diagnosed with Long QT syndrome. Colleen went into action to get awareness about this life threatening condition out. She still says: “Living with LQTS is like living with ticking time bombs.”

After Adam's untimely death, Andy had a pacemaker defibrillator implanted on February 11, 2002. Our other nine-year-old son, Alex, who thus far is asymptomatic, will be going for additional testing.

Although we are grieving the loss of our son to this deadly condition, it is our family's mission to make people aware of this manageable but potentially devastating syndrome. We are continuing to work with schools to obtain defibrillators and lobbying public officials to change sports physicals and to establish mandatory ECG testing on newborns.

*Submitted by Donald J. Kausak
Adam's father*

If you want to submit a tribute to a lost loved one, send us a letter and a photograph. We will include them in upcoming issues.

First ever!
**Annual International
SADS Conference**

**Unexpected Sudden Cardiac Death in the Young:
A Focus on Genetic Causes of Arrhythmia's,
Syncope and Sudden Death**

Where: The Royal College of Physicians
London, England

When: October 12 & 13, 2002

Who should attend: Families, primary
care physicians, pediatricians, and other
health professionals. There will be separate
sessions just for families.

Watch for more information (or let us
know to put you on the mailing list)!



Help SADS Keep in Touch!

Our last newsletter mailing included asking the post office to correct our addresses. We have lost over 880 people and do not have their new addresses! So...if you know anyone who would like to receive our newsletter, please let us know. And, if you use e-mail, please let us know your e-mail address so that we can keep in closer touch without the costs of postage and mailing. sads@sads.org

Send Photos

People respond to stories and pictures. When conducting awareness campaigns, our volunteers and staff need materials from you. We want to know more about you, your families and activities, hobbies and work. We want to keep a visual record of people living healthy, happy lives. We would like to see children growing-up. If you have pictures you want to share with us, and other members of the SADS community please email them to Rachel@SADS.org. If you don't have digital images, send photographs. Please!

Now on www.sads.org

National Contact Volunteers: If you need to talk with someone in your state, please give us a call or look at our website for information.

The Drugs to Avoid List: You can find the list on our website or at www.torsades.org

If you would like a copy of either of these lists mailed or faxed to you, contact us at sads@sads.org, by mail or at 1-800-STOPSAD.

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