



Giving thanks for 2008 successes Looking forward to 2009

A Season of Thanks and Giving

As we celebrate our upcoming holidays – Thanksgiving, Hanukkah, and Christmas, and prepare for the New Year, the SADS Foundation wants to express our sincere thanks to all who are part of the SADS family – parents, children, physicians, volunteers and supporters. Without your efforts, we would not be able to help families and communities to save more young lives. 2008 has been a banner year for the SADS Foundation and our volunteers!

The Foundation is proud of our many successes - addressing the needs of 1,000 new families, providing materials

to almost 135,000 people via our website and communicating with over 13,000 US households through the SADS News. We are visible in local communities, at national

conferences and in the halls of Congress increasing public awareness and calling for research, diagnosis and treatments to save more young lives.



The SADS Foundation has set ambitious goals for 2009: to enhance our ability to serve more families, to ensure that at-risk children are diagnosed and treated and that more people recognize the warning signs and symptoms and know what to do when faced with an emergency. We are hopeful that with our collective efforts, we will reduce the number of sudden cardiac deaths and see more children and young adults who are able to “live and thrive” with their conditions.

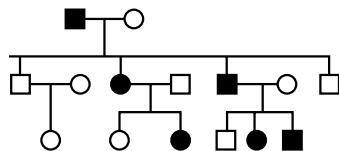
What Has SADS Done This Year?

Increased SADS Awareness

Our second annual Climb to Conquer SADS included seminars, media outreach and onsite activities to highlight our cause. SADS Awareness Month provided opportunities around the country for SADS volunteers to reach out to schools and the public to increase knowledge of the signs and symptoms of SADS. And, in 2008, SADS Foundation leadership helped create a second national focus on saving lives – SCA Awareness Month in October. All these activities extended our reach to provide life-saving information and materials.

Launched Pedigree Program

We know that SADS conditions are hereditary and that more than one family member may be at risk. Our Family Pedigree Project was begun this year to provide tools to help you map out your family history. SADS staff has begun contacting families by phone to offer individual assistance. SADS hired Joanne Robinson to lead this program and to enhance our ability to serve more families. Contact Joanne if we can help your family.



Promoted SADS Safe Schools in Every State

This year the SADS Foundation aimed to provide SADS Safe Schools and communities for kids in every state. Thanks to our wonderful volunteers, we have expanded our program greatly. By focusing on schools – nurses, teachers, coaches and parents, our goal was to increase awareness of signs and symptoms and importance of school emergency plans.

With your help, together we can save MORE lives!

Our work depends on the generosity of people around the country - you, your relatives and friends. We are grateful for whatever charitable contribution you can give. And, please let others know about the SADS Foundation. Our promise to you is that all donations will be used wisely and focused on advancing our mission. Please consider making a gift to the SADS Foundation this holiday season. You may donate through our website, mail or phone. You may also establish a memorial fund to remember a special child. We would be pleased to discuss all of our giving options – call us toll-free at 800-STOP SAD.

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.

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Sudden Arrhythmia Death Syndrome (SADS) Foundation
508 East South Temple Suite 20
Salt Lake City, Utah 84102
800-STOP-SAD or 801-531-0937
Fax: 801-531-0945
www.sads.org

Awareness and Fundraising (at the same time!) the Combined Federal Campaign (CFC)

This year was the first year SADS has participated in the national Combined Federal Campaign, which is the federal employees' workplace giving campaign. The campaign runs from September to November. In an effort to have the full experience, (and thereby know what we are asking you to do!), I jumped in and here is what I have learned:

1. The most valuable reason for attending a Kick Off event is to hand out flyers that offer a SADS guest speaker to talk at the individual worksites.

2. You don't have to be an expert to share your story and follow a power point presentation to educate others. This is a great awareness month activity because the campaign occurs during awareness month. In addition, it has the potential of raising money!

There will be a Speaker's Bureau Job Description in the new volunteer program coming out in January. Sign up then or email me at Joanne@sads.org and let me know if you would like to help next year. Take it from me—it's lots of fun!

SADS Board Member Attends Michigan Conference

SADS board member, Denise Falzon, attended the Sudden Cardiac Death (SCD) in the Young in Michigan: A Call to Action conference on September 18th. This was a follow-up meeting to report on the activities since the previous conference two years ago (in which Denise, Alice Lara and Dr. Vincent were active participants).

In Michigan 300 individuals die each year from SCA. The conference developed action steps for patient, provider, and public health systems to prevent future deaths. We congratulate the state of Michigan and the Health Department on this ground-breaking work and hope to continue to participate in the future.

Needs Assessments Recommendations (Have you sent yours in?)

We have had 38 Needs Assessment surveys returned so we only need 3,962 more from our SADS families! However, even though the number is small, the recommendations are great, and there seems to be a consensus on many ideas.

New Volunteer Program Recommendations: For the new volunteer structure next year the top services recommended were local telephone or email support, and the ability to meet locally for an educational seminar, and/or recreational activity. Remember we will be posting volunteer's contact information directly on the website next year so let me know if you are interested!

Get Connected! SADS Discussion Board:

With the unveiling of our new website, the SADS Foundation is excited to offer you our new discussion board! Ask questions and chat with other SADS affected people and with experts; topics include: ICDs, Insurance, Medical Questions, Parent to Parent, and Teen Chat. The discussion board gives you the opportunity to "meet" other SADS families and share your experiences together. Do you need some advice about what activities are OK for your son? Or maybe you've learned some tips to getting better health insurance coverage? www.StopSADS.org

National Conference: Most respondents agreed that a national conference that is held regularly and well-attended by SADS members can help advance awareness and advocacy for the disease.

Materials: Information on exercise, nutrition, children and teen-specific materials, and tips for domestic and international travel all rated high on the survey. Individual recommendations included: local family support groups, more stories about people living and thriving to support those living with the disease (OK EVERYONE SEND IN YOUR STORIES!), exercise and diet charts for fridge.....

Please send in form (or fill out online at www.StopSADS.org)! Thanks for participating!

2008 SADS Awareness Month a Success!

Because November is a time for showing gratitude, and because we could not be successful without the efforts of our friends and supporters, we at the SADS Foundation want to give thanks to you, our volunteers, for your hard work in promoting SADS Safe Schools and communities for kids and young people living with heart conditions. September was our annual SADS Awareness Month and we also participated in Sudden Cardiac Arrest Awareness Month in October. We received emails from volunteers all over the United States sharing their personal stories and relating their progress in promoting SADS Awareness.

Trisha Rohloff, a Long QT patient from Wisconsin and the mother of 2 young children with Long QT shared a particularly tender experience when she had an RN come to her home to give her family a CPR/AED lesson. She wrote:

Not only were the Grandma's & Grandpa's trained, Brooklyn (9



at the time) and Quinten (6 at the time) were also trained since Mom (me!) also has LQTS! It was definitely one of my prouder moments when I tucked the kids in that night and they both said, "Don't worry Mommy, we would save you if something ever happened to you!"

Suebeth Brown, an RN at Massachusetts General Hospital sent a letter telling us her experiences sharing information about Long QT with schools and nurses in and around her community. As a mother of children with Long QT, and having witnessed several frightening, close calls with her youngest daughter Zeena, Suebeth has been dedicated to getting the word out and has created and presented a Long QT program to 55 nurses at Mass. General Hospital, with 3 more requests for her presentation in the near future.

The SADS Foundation was pleased to be a part of the **Abington School District's Health and Wellness Fair** in Pennsylvania this October with over 500 children and parents attending. In a recent letter to SADS, Abington School District wrote, "Your organization is one of an elite group that significantly helped to make it successful—we are so glad you came!"

Thanks again for your dedication. Your efforts truly help save lives and we look forward to working with you again next September!

SADS Works to Keep Children Safe at School

The Sudden Arrhythmia Death Syndromes (SADS) Foundation recommends that every child with a SADS condition have a personalized care plan, a school Medical Emergency Plan and an AED in place. We want to ensure that school officials are aware of the implications of SADS and are prepared to respond to an emergency immediately.

For the past four years, the SADS Foundation has had a focus on schools. We have worked with school nurses, teachers, coaches and others to spread awareness of Sudden Arrhythmia Death Syndromes in their schools. Now, we want to do more. New tools and resources can help expand our reach into more schools and provide guidance on how to implement SADS Safe Schools.

What the SADS Foundation Recommends:

1. Every child have a risk assessment history at regular intervals: preschool, before/during middle school, before/during high school and before participation in organized sports
2. Every school should have a medical emergency response plan in place, which includes a plan for cardiopulmonary resuscitation (CPR) and an automated external defibrillator (AED).
3. Every school child with a SADS condition should have an individualized care plan in place.



4. Every school with a child who has a diagnosed SADS condition should have an AED program.
5. All high school students should be trained in CPR and AED protocol as a requirement for graduation.

6. Everyone should be aware of the warning signs that may indicate a child at risk of a sudden cardiac arrest.

It's never too late to make sure that your school—or community center—is SADS Safe! You can download the above materials and forms from our website (www.StopSADS.org) or order them online or by calling Michelle (1-800-STOP SAD)

A young boy is given a miraculous second chance at life.

At 7:11 AM on the morning of March 26, the burglar alarm in the home of Mark and Becky Knowles was accidentally activated. At that precise moment, the heart of their 7-year-old son Cameron stopped.

Cameron was still in bed. Mark (his dad) touched him gently to wake him up, but Cameron didn't respond. Mark looked closely at his son and realized he wasn't breathing. Mark yelled to Becky (his mom), who rushed into the room. Becky pulled Cameron onto the floor and started performing chest compressions.

The fire department was at their house in two minutes, and they administered a shock to Cameron. The EMTs gave Cameron two more shocks as well as a shot of epinephrine. Cameron now had a pulse and was just barely breathing on his own. A call was put in to the Pediatric Intensive Care Unit at Strong Memorial Hospital, part of the University of Rochester Medical Center.

Cameron once at the hospital was put into a medically induced coma and his body would be cooled to 92° F. This would



decrease swelling and bring the body's functions to a near-halt, helping prevent the cascade of events that can lead to irreversible brain damage. The EKG revealed that Cameron had Long QT Syndrome. Cameron had an ICD implanted on April 4th.

Becky was certain that Cameron had survived for a reason. Four weeks to the day after Cameron had nearly died, that reason would become very clear: A report from the American Heart Association suggested that there was link between medications used to treat Attention Deficit Hyperactivity

Disorder (ADHD) and sudden death from conditions like Long QT. Cameron has ADHD, and had been on three medications to help control it. New guidelines now recommend giving children EKG exams prior to and during use of certain medications for ADHD.

We don't ever want any other family to go through what we did, so that is why we are trying to get Cameron's story out. He, and we, were given another chance at life and as a result, we have developed informational seminars to parents to teach them about LQTS and signs/symptoms to look for. I have also been an advocate for insurance companies to pay for the Familion testing. I didn't stop when we were denied twice. I made it my mission to have the insurance company know how important this test is and by the determination of our family we have paved the way for us and others. Never stop being an advocate, that's what I have learned as well.

Heart Beaters:

Liz Oldham

In the spring of 2005, after many trips to the doctor, Liz was finally diagnosed with LQT while attending Portland State University and completing a double major in Theater Arts and English. The months following her diagnosis included various treatments and minor surgeries, but she continued her studies and managed to graduate *summa cum laude*.

In her upbeat way, Liz treated her health issues as another learning experience.



rience. "I had to set my priorities differently," she reflected. "I had become a perfectionist, and I discovered it was all right to let some things go."

Liz Oldham is poised at the beginning of her career as a teacher with a bright future ahead.

Teresa Bencie

Schools in Sarasota, FL have AED's now, thanks to Teresa Bencie's efforts. And about 300 district employees were trained by Oct. 17 on how to use them. Teresa spear-headed the effort with her "Mother's Letter" to the state legislature explaining why AED's in schools and proper training on their use is so necessary to saving young lives.

Dozens of parents contacted school officials after an article about the AEDs appeared in the local newspaper.

Julie Backlar

When Julie's son, Dylan, was diagnosed with WPW, she had a lot of questions about kids with heart arrhythmias. SADS adapted our Long QT Care Plan and helped her tailor it specifically to her son's needs. After long hours and major efforts from Julie to get a good care plan approved by Dylan's doctor, Julie says "now I feel comfortable going to my son's school and asking them for the protection he needs."

Cyndie Baker

Cyndie jumped right in and adapted the information she used at her kids' school to our Care Plan format—resulting in plans for kids with Brugada Syndrome and kids with an ICD.



Two SADS Runners Participate in Medtronic Global Heroes Race

Glenda McDonald and Catherine Silva

The Medtronic Foundation recently donated \$2,000 to Sudden Arrhythmia Death Syndromes (SADS) on behalf of Medtronic Global Heroes Glenda McDonald and Catherine Silva. Avid runners, they are living full and active lives with the help of medical technology. Both women have an ICD. And both were chosen by the Medtronic Twin Cities Marathon to be part of its 2008 class of 25 Global Heroes.

Glenda was diagnosed with Long QT in 1995. "I blacked out driving to work" says Glenda. She didn't understand how she could have run 6 miles one day and been in the hospital with heart problems the next day. She was sure that her life as an athlete was over. But in 2001, at age 53, she received an ICD and in the ensuing years began to run again. Earlier this year, her ICD fired while she was on a training run, shocking her heart out of a dangerous rhythm. After the episode, her doctor gave her the clear to



continue running. "I realize how lucky I am to be alive and that my ICD allows me to live a normal life."

Catherine was diagnosed with Long QT at age 16. She was a competitive swimmer and received her first ICD in 2002. "While I was grateful for the lifesaving technology, I became depressed with the feeling that my life would never be the same," she states. She eventually decided that "I would no longer let this condition or my device limit my life and my dreams" and since January of 2003, Catherine has completed in 3 marathons and a half-Ironman triathlon. "Living through this as a young person

brings even more challenges to the table. I want to inspire those around me who find themselves in a similar position."

For more information on how to apply or nominate someone to be a Medtronic Twin Cities Marathon Global Hero, visit www.StopSADS.com. All runners with medical devices are welcome to apply with no restriction on manufacturer.

Volunteer Events Help the Foundation.

Here's a few stories:

Metoyer Run for Rosanna

On July 26th Bryan and Remy Metoyer held the first annual *Run For Rosanna* 5K Run/Walk at Lake Balboa Park in Van Nuys, CA. Bryan was inspired to put the event together as the tenth anniversary memorial of his first wife Rosanna's passing due to LQT.



The Metoyer's started planning the event six months in advance using the SADS Fun Run Kit located on our website which, Bryan says, "was very informative and great help."

Bryan says "sponsors are key to being able to put the event together without having to cover costs prior to the event and collect all fees from participants." Donations and sponsors allowed the Metoyer's to have a successful event and donate over \$4,000 to SADS.

Ask Your Company ...

The SADS Foundation encourages its supporters to ask their employers to make a matching charitable gift. Most companies are good corporate citizens that regularly give to charities. Let your company know of the important work of the SADS Foundation and ask them to match your contribution.

Individuals and businesses, together saving lives!

Tolosky-Christie's HeartOberfest

Craig and Barbara Tolosky host an annual fundraiser, Christie's Heartoberfest, in memory of their daughter Christie Tolosky who passed away in June of 2005. This was their third year doing the fundraiser. About 130 people attended this year's event.

The party included a silent auction, a table raffle, travel packages to Montreal, Lake Placid and Saratoga, and general donations from the Tolosky family and friends to make this year's grand fundraising total about \$12,000. Guests at the party were also given Forget-Me-Not & Butterfly flower seeds with this thought: "We hope that these flowers and the butterflies they attract bring light in to your life and a smile to your face, as Christie did to everyone who knew her. We invite you to plant these seeds in celebration of Christie's life."

Melissa Tolosky contacted the local CBS station about running a story on Christies Heartoberfest. They interviewed Melissa and her cousin, both of whom have an ICD and aired the story a few weeks after the event.

Layton Octoberfest

Bill and Sally Layton have been hosting their annual Octoberfest fundraising event for 11 years now and each year's event is an even greater success than the year before. This year they held the event on Saturday, September 27th at their home in Colorado Springs, CO.



Olivia's Story

Do you remember the saying "Life is like a box of chocolates, you never know what you're going to get" from the movie *Forrest Gump*? Forrest's mother, tells this to her son.

At the time, I never thought much about this or how it would or could be connected to life. Unfortunately, after April 12, 2004, I understood the connection. Our 14 year-old daughter Olivia Corrine Hoff passed away. Olivia was born with previously undetected Long QT Syndrome. Of course, I never knew my daughter was sick, as she was so active and energetic. Just a normal, curious little girl and the typical, boy crazy, always on the phone, teenager Olivia started to complain about severe headaches and feeling faint, especially after exercising. She would feel very dizzy and weak after running. About 3 weeks before Olivia died, she came running out of her bedroom. She couldn't breathe and



her chest was hurting. I held her, calmed her down until she felt better. I then followed up with a doctor's visit. The doctor's diagnosis was stress. I, not even knowing anything about LQTS, accepted this diagnosis. Olivia went into cardiac arrest some

time during the night of April 12, 2004. I went to wake her for school and she was not breathing. My daughter was on a breathing machine for 10 days with no brain activity. We had to make the decision to let our beautiful Olivia go to her home in Heaven. As I look back now, I get very upset that I was uneducated and not aware of this condition.

It has now been four years and my life is changed. I still cry every day, and miss my Olivia so much but I know she is always with me in Spirit. I see life through different eyes. I truly appreciate and enjoy each new season. I have developed a passion for garden-

ing. My garden, which is lovingly named Olivia's garden, is filled with beautiful flowers, birds and butterflies. I find such peace when I work in my garden.

Since Olivia's passing, I have become more involved with various organizations such as SADS and Parent Heart Watch. I have found that by sharing Olivia's story, I am reaching out to other parents, mostly moms, regarding LQTS.

I have found that we all have a strength, deep within us, to survive the most painful and difficult times in our lives. I didn't plan to be in this situation; however, this is my box of chocolates.

SADS New Volunteer Program

Sign up for our E.newsletter and receive advance notice of our new volunteer program (support groups, etc.) in 2009. To sign up, email Michelle@sads.org or www.StopSADS.org.

Submit Your Stories, Photos

You can now submit your own stories—with pictures—of your family, your children, yourself. Telling your story is often a great help to others experiencing similar things. We would love to publish any stories on our new website: www.StopSADS.org

Would You Like a Local Support Group?

We have had a lot of inquiries about Support Groups and are happy to help anyone start a group. We are currently working with families in the following states who have approached us to start groups: Phoenix, Arizona; Cleveland, Ohio, and Salt Lake City, Utah. We will also most likely have at least one group in New York City. If you live in those areas and would like more information here are the contacts for your area:

Cleveland, Ohio:
Karen Dobbs at 440-638-4396
hm, 440-334-7031 cell, or email
kdobbs@wowway.com;

Phoenix, Arizona:
Ann Willingham at 602-686-3441
or email ann14500@yahoo.com.

Salt Lake City, Utah:
Joanne Robinson 800-786-7723
or email Joanne@sads.org

SUPPORT GROUPS CAN:

- Organize recreational activities
- Report on research articles
- Conduct awareness activities as a group
- Arrange for an educational seminar with a guest speaker
- Share coping methods for living and thriving with SADS!
- Whatever you want!

Advocacy Corner

SADS Visits the Senate

Scott Dailard (SADS Board member) and Alice Lara visited the Senate in September to ask Sen. Lieberman and Sen. Dodd to send a letter to Blue Cross/Blue Shield in Connecticut supporting coverage of genetic testing for LQTS. Their lack of coverage affects 1.1 million people in the area.

Genetic Counselors and SADS

Alice Lara spoke at the National Society of Genetic Counselor's Annual Meeting in Los Angeles this October at a special pre-conference on Genetics and the Heart. SADS is a member of the Cardiac Special

Interest Group and will be working with them on several educational projects in 2009.

Educating Local MD's

This year SADS has coordinated and supported several educational meetings of adult and pediatric electrophysiologists, cardiologists, primary care physicians, nurse practitioners and other medical professionals to increase knowledge of SADS conditions. We plan to continue and expand this program in 2009—watch for news about how to participate!

SADS to Collaborate with UCSF

Dr. Melvin Scheinman has initiated a new Comprehensive Genetic Arrhythmia Program at the University of California at San Francisco. UCSF recently received a private 4-year grant for the study of cardiac arrhythmias and sudden cardiac death, and will soon be looking to recruit eligible subjects. Contact Michelle@sads.org or 1-800-Stop SAD if interested.

New Driving Recommendations for Patients with Primary Prevention ICDs

Anne B. Curtis, MD, FHRS, FACC, FAHA, Professor of Medicine, Chief, Division of Cardiovascular Disease, University of South Florida, Tampa, Florida

In 1996, the American Heart Association and the North American Society of Pacing and Electrophysiology (NASPE, now the Heart Rhythm Society) published a scientific statement on Personal and Public Safety Issues Related to Arrhythmias That May Affect Consciousness: Implications for Regulation and Physician Recommendations. Recently, an addendum was developed to this document with the major recommendation being that patients who receive ICDs for primary prevention (SADS patients) should be restricted from driving for only one week after implantation to allow for recovery from the surgical procedure and a short period of observation in case any immediate complications, such as lead instability or inappropriate shocks, were to occur. Thereafter, there is no need to restrict patients who are asymptomatic from an arrhythmia standpoint from driving a private automobile.

Long QT Syndrome in the Young: Diagnostic and Therapeutic Update

*HRS - San Francisco - May 14-17, 2008
Long QT Syndrome in the Young: Diagnostic and Therapeutic Update*

Making the Diagnosis: Beyond the 12 Leads and Without the Genotype

Emanuela T. Locati, MD, PhD

*Cardio-Vascular Department "Angelo De Gasperi"
Niguarda Hospital - Milan - Italy*

At the Heart Rhythm Society's Annual Scientific Sessions this May, Emanuela T. Locati, MD, PhD presented an interesting—and possibly more effective—way to evaluate patients with suspected LQTS. For the complete chart outlining the progression of steps in the diagnosis of LQTS, visit www.StopSADS.org or email your request to sads@sads.org.

Calling all Long QT Type 2 families

The Gladstone Institute of Cardiovascular Disease in California is looking for families to participate in research. The project is a publicly funded program to establish stem cell lines from LQTS, type 2 (LQT2) patients with the hope of developing a disease model for research and drug screening. If successful, this would allow us to really know which drugs are OK for LQTS folks to use. Essentially, they would like to obtain small skin punch biopsies from families with LQT2 to isolate skin cells that will be reprogrammed into stem cells.

If you have LQTS 2 and are interested in participating in this study, contact michelle@sads.org or 1-800-Stop SAD.

Make a Last Minute Donation Online

The SADS Foundation receives almost 70 percent of its total support from individuals like you, your families and friends. Your charitable contributions make our efforts possible. It's not too late to make a tax-deductible contribution via the SADS website – www.StopSADS.org. We are hopeful that with our collective efforts, we will reduce the number of sudden cardiac deaths and see more children and young adults who are able to "live and thrive" with their conditions.

With your help, together we can save lives!

Donate Now!

Upcoming Events

SADS Family Seminar:

Sudden Death in the Young: Is it Written in the Genes, An Educational Program for Patients and Families

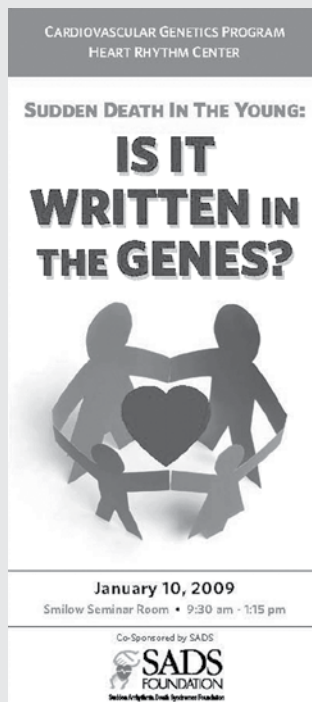
New York City, NY
Saturday, January 10, 2009
9:30 AM – 1:15 PM (includes lunch)

Cardiac Arrhythmias 2009: The Emerging Role of Genetics, a CME-Sponsored Program for Cardiovascular Specialists

New York City, NY
Friday, January 9, 2009
8:00 AM – 3:15 PM

Parent Heart Watch 4th Annual Conference

Orlando, FL
January 16-19, 2009



American College of Cardiology Scientific Sessions

Orlando, FL
March 29-31, 2009

Heart Rhythm Society Scientific Sessions

Denver, CO
May 13-16, 2009

3rd Annual Climb to Conquer SADS, Presented by PGx Health

Mt. Rainier, WA
July 10-12, 2009

Information on all events at www.StopSADS.org or call Michelle at 1-800-Stop SAD. Check back often or watch for e-mails with new events added for 2009.

