



## First Annual Climb to Conquer SADS

The First Annual Climb to Conquer SADS was a fantastic success—even more spectacular than we hoped. Of course, the setting is beautiful. About an hour and a half from Seattle, the wilderness unfolds you and, as Dr. Ackerman remarked, “makes you instantly relaxed.”

The Alta Crystal Resort, which was the headquarters for Board members, volunteers and staff attending the event, was even more wonderful than their website promised. Combining the rustic “cabin and wilderness” look with the practicalities of a full kitchen and the luxury of a TV/DVD/video in every room, the resort had something for everyone. We got to explore the mountain on hikes and drives to look-out points throughout the park. After some full days of exploring we were able to soak in the pool and the hot tub, join other resort guests for barbecues and campfires, or head into Enumclaw.

We were glad to see so many families attend the seminar this year. We filled the meeting hall to capacity, and each family still got individual attention from Dr. Ackerman and Dr. Etheridge. After the seminar, some of the board, staff, and families went on a hike led by Dr. Etheridge.

It was so moving to see the climbers gear up and start up the mountain. It was even more moving to see them come back down the mountain safe and sound—though tired. What an effort on their part!

Our steering committee worked hard all year to plan all the little details that made

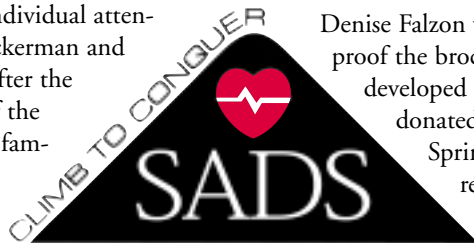
the First Annual Climb to Conquer SADS such a success. Not only raising money for the Climb, but working on the publicity, getting equipment and food donated, coordinating the facility needs—there was more than enough work for our steering committee! We especially want to thank



Nancy Adam’s sister, Patty Nolan, for obtaining all the fantastic food! And to Nancy for her decadent lasagna. We all ate extremely well! Nancy also got some great TV coverage in Seattle, announcing the event & the warning signs. And, she did a fundraising web page that raised lots more than she had expected.

Denise Falzon worked from Michigan to proof the brochure (her daughter, Nicole, developed our logo) and obtain a donated AED for the Climb.

Spring Faussett was a super resource in the PR part of Climb and also coordinated the production of the banners, t-shirts and the caps for the climbers. We had some super professional help getting our message to the media from Medtronic, Mayo Clinic and PGx Health. Kathy Conlin was tireless in planning the details “on the ground,” obtaining the supplies for the first aid kit, and promoting the seminar in Spokane.



Presented by  
**PGx HEALTH**  
A DIVISION OF CLINICAL OXY

And of course, without Chris Anderson, the Climb would not have happened. Not only did he “attend” every steering committee meeting, but he raised money (LOTS!), recruited the Climb leader and climbers, trained hard for the climb, etc. He worked day and night for over a year to make sure this event was a success. We thank him—and his family—for his dedication to saving lives of people affected with SADS!

### Thanks to Our Top Sponsors

**Summit Sponsor - \$40,000**  
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**Camp Schurman Sponsor - \$2,500**  
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**White River Sponsor - \$1000**  
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Chris: Anderson, M.D.  
Mr. Jim Bosler  
Susan Etheridge, M.D.  
Hrair Garabedian, M.D.  
Lene Righheimer  
Spokane Mountaineers

### Thanks To Everyone & Join Us on July 9, 2008!

A great big thanks to everyone who donated their time or money to this great cause—including the fantastic Alta Crystal Resort staff and Brian Gates who designed our brochure. We hope to see all of you on Mt. Rainier on the morning of July 9, 2008!

## New SADS Board Members

### Chris Anderson, M.D.

Charles Christian (“Chris”) Anderson, MD was born in Omaha, Nebraska and moved to Texas during his late childhood. In 1993, he married Dr. Seiko Miki, whom he met in medical school.



Chris' clinical interests include arrhythmia management, Wolff-Parkinson-White syndrome, congenital Long QT syndrome, and management of cardiomyopathy. Dr. Anderson is board certified in both Pediatrics and Pediatric Cardiology. His extracurricular interests include skiing, hiking, mountaineering, reading, movies, dining out, and spending time with his wife Seiko, and sons Alex and Luke.

And, of course, Chris is the heart and soul of the Climb to Conquer SADS!



### Laurie Smith Hooper

*Public Relations & Government Affairs  
Nashville, TN*



Most recently Laurie was a principal at the Ingram Group in Nashville, a public relations and government affairs firm where she tackled a wide variety of client work, including public and media relations, event management, materials production, fundraising and grassroots community campaigns.

Laurie is an active board member of the Nashville Zoo at Grassmere and of Trustees of St. Mary's Episcopal School in Memphis.

In May 2005 Laurie suddenly and tragically lost her sister Wendy to Long QT Type 2 after being misdiagnosed for 18 years with a mild seizure disorder. At the young age of 35, Wendy was a loving and wonderful daughter, sister, wife and mother. Since this tragedy Laurie and her family have discovered through genetic testing that Laurie, her children, a nephew and two siblings also have LQT2. As her family has been so deeply impacted, Laurie's goal along with her entire family is to work to make a real difference – to help increase awareness nationally and educate the public to encourage prevention and ultimately to save lives.

### Marjorie Currey

*Educator, Lecturer;  
Free-lance Writer  
Dallas, Texas*



Marjorie has been an educator of both children and adults for over thirty years. She has also been a consultant to a private foundation and to private businesses in Dallas. She has served on numerous boards in Dallas—most recently for the Callier Center for Communication Disorders, the Meadows Museum Executive Committee, and LIFT (Literacy Instruction for Texas).

Marjorie lost her first husband and her son to Long QT Syndrome and has been a dedicated volunteer for the SADS Foundation for many years. She would particularly like to help the SADS Foundation communicate the importance of the foundation's work to its natural constituencies – primarily the affected families and the associated medical community.

### Carla Haglund

*Family Support  
Coordinator, SADS*



Carla is a lifelong Minnesotan. She has been a secretary at the Mayo Clinic for 11 years and has worked along side Dr.

*Continued from page 7: see STAFF*

## Staff Updates

### Chris Ferguson

*V.P. of Development*



Chris comes to us from the University of Utah, where he served as a Director of Development. He has been in the development field for over six years, representing a number of nonprofits including the Huntsman Cancer Institute, American Diabetes Association, and the American Lung Association to name a few. Chris has a degree in biology and a background as a cancer researcher prior to moving into the

development field. His interests are working with nonprofits, social & justice groups, catamaran sailing, and diving.

### Jenny Marinovich

*Development Projects*

In January, Jenny Marinovich moved to Virginia, where her husband will be attending graduate school. On June 2nd they welcomed their first child, a healthy baby boy named Mateo John Marinovich. Jenny will continue working for SADS on a part-time basis on special development projects such as the Climb to Conquer SADS. She has greatly enjoyed her past two years with SADS and is excited to continue working with us!

### Michelle Hoon

*Program Associate, SADS*



Michelle is the new Program Associate for SADS. She graduated from Brigham Young University with a BA in History and Spanish. In college she was afforded the opportunity to travel to Spain and study language, culture, history, and art. After college she was able to spend one year in Washington DC, working as an intern for one of Arizona's congressional representatives. She is excited to work with the volunteers and families of the SADS Foundation to promote awareness of LQT.

# SADS Awareness MONTH

October 2007

SADS Awareness Month is our annual effort to increase the public's awareness of conditions that can cause sudden cardiac death in young people. We have made great progress alerting the school community in our country—and especially school nurses—to these heart conditions and their warning signs. As you know, these conditions are treatable and children can live happy, productive lives if they are diagnosed and treated.

This year we plan to continue our focus on the school community—nurses, teachers, coaches and parents. With your help, we can expand our reach to schools in every state—with articles in school papers, posters and materials distributed to schools and presentations to school nurses.

And, we have a new event—National Sudden Cardiac Arrest Awareness week which will begin October 7th. As a mem-

ber of the SCA Coalition, SADS will be participating in events in Washington, D.C. during that week.

### How can I help?

1. Distribute SADS materials (packets and posters) in your community's schools
2. Publish an article in your school(s) newspaper or distribute (mail) a hand out to parents (SADS has samples)
3. Organize a SADS presentation for school health professionals—we will help!
4. Recruit your school district to implement our model program for school-based awareness

If you would like to participate in SADS Awareness Month this October, please let us know by filling out the form at [www.sads.org/awareness07.htm](http://www.sads.org/awareness07.htm) or by calling 800-786-7723.



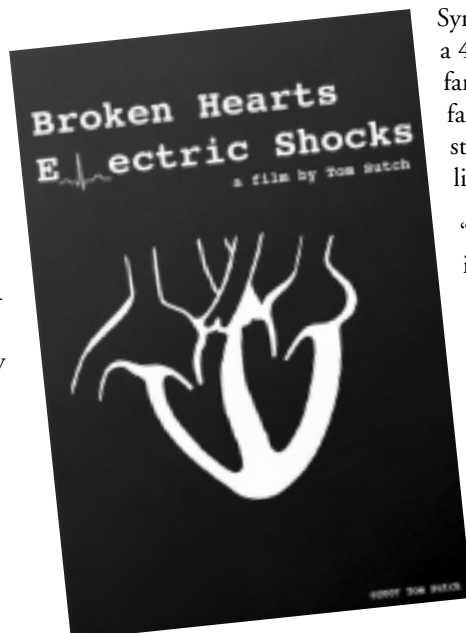
You can make a difference and save lives through your participation in SADS Awareness Month! Thank you!

*SADS Awareness Month is sponsored by Boston Scientific*

## Film on LQTS Wins Award

Local filmmaker Tom Sutch was honored with the Best First Film award at the 2007 Long Island International Film Expo for his documentary, "Broken Hearts, Electric Shocks."

Sutch, 23, a lifelong resident of Levittown, NY, wrote and directed the award-winning film on a budget of under \$200. Originally created as his senior project at Binghamton University, "Broken Hearts, Electric Shocks," is an intimate telling of his family's decades-long struggle with a rare heart condition called Long QT



Syndrome. In the film, Tom narrates a 40-minute journey through his family's tragic past, while other family members share their own stories of losing loved ones and living with the disease.

"It was such a great experience; it's very rewarding to have my family's story recognized by the festival," Sutch stated. "I hope it shows how one can do something constructive after suffering a loss, and above all I hope someone can view this and catch Long QT Syndrome before it is too late, and know they are not alone."



*For more information on the film, visit our website at [www.sads.org](http://www.sads.org).*



## Cynthia Dailard

1968 – Dec. 2006



Cynthia Dailard, a beloved wife and mother of 2 daughters, and a senior public policy associate at the Guttmacher Institute passed away on December 24, 2006 after suffering cardiac arrest as a result of previously undetected Long QT Syndrome. She was 38 years old. Cynthia collapsed at work during an emotional moment in a meeting and never regained consciousness. A co-worker administered CPR at the scene, but sadly, she suffered an irreversible ischemic brain injury before paramedics arrived with an AED. She had experienced no symptoms of Long QT syndrome prior to the catastrophic cardiac event that tragically claimed her life.

Since 1998, Cynthia worked at the Guttmacher Institute, a nonprofit research and advocacy group devoted to women's

sexual and reproductive health issues, in the Washington office where she wrote articles and spoke out on matters of family planning, adolescent sexual behavior and favoring insurance coverage for contraception. Before joining Guttmacher, Mrs. Dailard was associate director for domestic policy for President Bill Clinton, legislative assistant and counsel for Sen. Olympia J. Snowe (R-Maine), and a fellow at the National Women's Law Center. In a resolution passed by the Senate, Sen. Clinton said, "I remain touched by the ways Cynthia made a difference in people's lives as a wife and a mother, as a lawyer and a writer, and as an advocate and a friend. I had the pleasure of working with Cynthia on numerous occasions and was always impressed with her intellect, knowledge and passion for women's health." "All of us who

were touched by Cynthia's life are greatly saddened—she will be forever missed but always remembered", said Senator Snowe.

Cynthia was a native of Syosset, N.Y., and a graduate of Harvard University and the University of California at Berkeley's Boalt Hall School of Law. She lived in

Washington, DC and is survived by her husband of 14 years, Scott Dailard, and their two daughters, Miranda Dailard (age 5) and Julia Dailard (age 3); her mother, Ellen Boles; her sister, Sandra Boles; and a grandmother. Mrs. Dailard's daughters and her sister Sandra are currently undergoing genetic testing to screen for the presence of Long QT Syndrome. Her husband Scott has been working with SADS to



secure federal funding for a research program designed to develop reliable and cost-effective protocols for diagnosing Long QT and other congenital arrhythmia disorders in young people.

## Mike Monell a Heartsaver Hero

*Courier News, Suburban Chicago*

Mike Monell of Elgin, Illinois was among the 35 Illinois State citizens praised by the Illinois governor for making life-saving Automated External Defibrillators as common as fire extinguishers in Illinois establishments as part of a grass-roots effort known as Heartsaver Heroes. Monell, manager of the Elgin Sports Complex, says all sporting sites statewide need to have at least one AED on hand. "There is funding now available, so there is no excuse not to have one," Monell said. "They are so easy to use...a voice walks you through it at a sixth-grade level of difficulty."

Monell, whose grandfather, mother and sister all died of Long QT Syndrome, said



heart conditions are often misdiagnosed—especially in the teen population. "My main focus is awareness of sudden cardiac events in teenagers," Monell said. "It's not an easy diagnosis, but a child dying of

sudden cardiac death is more common than leukemia." Monell has promoted sudden cardiac death awareness since 1991 as a member of the Sudden Arrhythmia Death Syndrome (SADS) foundation, to help educate the public and health-care providers about early diagnosis and treatment of cardiac conditions. "I know what the symptoms are...but today many people's symptoms are still being misdiagnosed as anything but heart disease," Monell said. "People are fainting, and they are still looking at other syndromes, such as epilepsy, rather than checking cardiac things."

## Brugada Syndrome Families Want to Connect

If your family has been diagnosed with Brugada Syndrome, please let us know. We are working with a mom who wants to put together a support group for Brugada Syndrome. At this early stage, we're not sure if this will be online only but would love to have your input and participation. If interested, call or email Michelle ([michelle@sads.org](mailto:michelle@sads.org) or 1-800-STOP SAD).

## Volunteer organized events

Who knew SADS Foundation volunteers were such creative, organized, and committed people? Actually, staff had suspected it for years. But here's proof! Volunteer organized events are taking off. Contact [Chris@sads.org](mailto:Chris@sads.org) for the scoop on upcoming events near you:

- Octoberfest (Bill & Sally Layton)— October 13, 2007 Colorado
- Christmas Tree Candyland (In Memory of Brittany Valene)—December 2007 Illinois

Please let Chris know if you are planning an event for SADS.

2007 Events you may have missed include:

- Heartoberfest (Barbara & Craig Tolosky) – October 2007 New York
- Jump-a-thon (Shelton School-Brian Price)
- Denver Starry Night Gala (Brianna Badger)
- Tommy Marren Beef & Beer
- Jamie Miller Invitational Swim Meet
- Ryan Weidler Memorial Golf Tournament
- Bessler Baseball Tournament



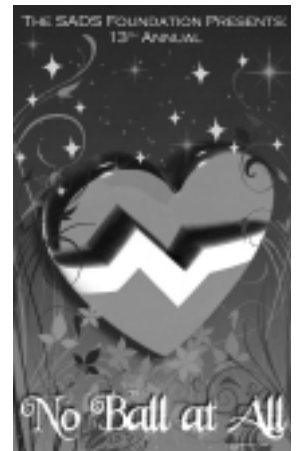
*Donnor Jaime Miller Invitational Swim Meet: (left to right) Chantele Brown, Teryn Miller, Melissa Dondlinger, & Brittany Miller*

## No Ball At All

In the SADS Foundation's tradition of (almost) painless fundraising, a capital crew of No Ball Dinner Committee members have joined staff to stamp and label invitations, cajoling their family and friends into buying tickets to No Ball XIII – the most not-happening event of the summer. Results are starting to add up: more than \$20,585 has arrived thus far, all to fund family support, nurse and physician education, and community awareness programs. Please join us in a standing ovation for Committee members:

Tammy Adrian  
Cyndie Baker  
Kathi Blum  
Tracy Curtis  
Molly deGroh  
Karen Doust  
Denise Falzon  
Carla Haglund  
Shawna Hatch  
Laurie Hooper

Colleen Kausak  
Joan Lamar  
Denise Larivee  
Vanessa Leone  
Deborah Meissner  
Connie Ogden  
Pam Osterhout  
Marsha Peterson  
Lene Righeimer  
Barbara Schardt



Marsha Schmidt  
Maureen Schulman  
Netie Simpson  
Michael Sirchio  
Karen Smith  
Alice Smith  
Denise Tindall  
Lori White  
Shelly Wright

*Thanks to Brian Gates for the design of the No Ball at All artwork*

## Matchmaking!

Watch your donation double...

Please speak with your manager or human resources department about matching your donations with a corporate contribution. The list of companies that have recently matched employees' donations to SADS keeps on growing. Visit our webpage to see if your company matches. [www.sads.org/Development/match.htm](http://www.sads.org/Development/match.htm)



*SADS accepts check from the Brianna Badger Memorial Gala: Michelle Hoon, Bill Badger, Alice Lara, Cheryl Badger, Liam.*



*Nicole Falzon & Robert Locke donated to SADS instead of wedding favors for their guests. A card was placed on each table indicating this gift.*

## ICD Sports Registry

The ICD Sports Registry is an exciting new registry, whose goal is to determine the safety of sports for individuals with implantable cardioverter-defibrillators (ICDs). Whether sports are safe for individuals with ICDs is currently unknown. Current guidelines recommend that ICD patients refrain from participation in competitive sports more vigorous than golf or bowling.

A recent survey of heart rhythm cardiologists suggests that some individuals with ICDs, do participate in vigorous and even competitive sports, despite these guidelines. The ICD Sports Registry is currently enrolling individuals, age 10-60 years old, who have made the deci-



sion to participate in competitive sports at any level. The ICD Sports Registry does not endorse competitive sports for ICD patients. Rather, we want to obtain information to determine the safety and/or risks of sports participation by following those individuals who have made this decision and are participating in sports, over a two year period.

A phone interview is done at the time of enrollment in the registry, and then every 6 months. The interview consists of questions regarding the individual's medical history and details about the sports he or she is playing. The registry has just recently started enrolling,

but individuals participating in the registry so far are playing soccer, basketball, baseball, volleyball, softball, skiing, speed skating, and running (5K, 10K, and marathons). The overall goal is to enroll about 800 individuals. Since the interviews are done by phone, there are no geographic limitations to participation. All information is kept strictly confidential.

The Registry is made possible by support from Boston Scientific Corporation, Medtronic, and St. Jude Medical. For more information, please call the ICD Sports Registry coordinating center at 1-866-207-9813 or email [ICDsports.registry@yale.edu](mailto:ICDsports.registry@yale.edu).

**View Parent Heart Watch's first public service announcement at <http://www.youtube.com/JPLinterns>. It is designed to raise awareness about these undetected heart conditions.**

## Health Insurance Tips:

### Handling a claim denial or refusal to cover a prescribed service

It is not unusual for particular claims to be denied or for insurers to say they will not cover a test, procedure, or service that your doctor orders. If this occurs it is important to have a working relationship with a customer service representative or case manager at your insurance company with whom the situation can be discussed. This is your insurance—even if your employer pays for it—and you are the best person to get your company to pay for needed tests or services. Your doctor can help with a letter and/or recoding the claim, but you are still the best one to put it all together and get it done. Many companies (those that make ICDs or AEDs, for example) have staff the help you get coverage for their products.

A first step should be to resubmit the claim, sent with a copy of the denial letter. It may be necessary for the patient's doctor to explain or justify what has been done or is being requested. Sometimes the test or

service only will need to be "coded" differently. If questioning or challenging the denial in these ways is not successful, then you may need to:

- Postpone payment until the matter is resolved.
- Resubmit the claim a third time and request a review.
- Ask to speak with a supervisor who may have authority to reverse a decision.
- Formally appeal the denial in writing, explaining why you think the claim should be paid. SADS may be able to help with this.
- Request a written response.
- Keep all originals of correspondence in your possession
- Keep a record of dates, names, and conversations you have about the denial.

- Seek help from the consumer services division of your state insurance department or commission.
- Be persistent in trying to resolve the matter.
- Consider legal action.

#### SADS Insurance Help.

In addition to the links on our website ([www.sads.org/Links/insurance.html](http://www.sads.org/Links/insurance.html)), we are planning to develop information for the three issues we hear about most:

1. Getting insurance coverage (especially young adults),
2. Coverage for genetic testing and
3. Coverage for devices. If you would like to help—or tell us about your experience—please let Alice know ([alice@sads.org](mailto:alice@sads.org)).

# SADS Screening Research Legislation

The SADS Foundation had an opportunity to add \$5 million to the NIH budget to begin research projects to determine the best screening method(s) to use to screen young people for their risk of sudden cardiac death. We hope that this research will tell us which test(s) are the most effective and when and how we can use them to screen kids.

We requested a \$5 million appropriation to design and pilot cost-effective strategies for nationwide screening of children for diseases

that can cause sudden cardiac death. Many families in New York state wrote to their Senator and signed on to our letter but it was just too late for this year.

We plan to continue this campaign—which has been included in an Omnibus bill to be introduced by the the SCA Coalition. We know will be needing your help in this effort. If you would like to participate in this effort, please email Michelle at michelle@sads.org or call 1-800-STOP SAD.

## New Practice Guidelines Issued for the Prevention of Sudden Cardiac Death

This is a great compilation of the “state of the art” recommendations for the management of patients with ventricular arrhythmias and the prevention of SCD from the American Heart Association, the American College of Cardiology and the European Society of Cardiology. It includes discussions about exercise, ICDs, fainting and all the various conditions. It also includes statements endorsing the role of genetic testing in the diagnostic evaluation and management of patients and families suspected of having congenital long QT syndrome. “Genetic analysis is very important for identifying all mutation carriers within an LQTS family. In patients affected by LQTS, genetic analysis is useful for risk stratification (199) and for making therapeutic decisions. (204).” For a summary, wallet card or complete guidelines, visit <http://sads.org/services.html#articles>.

## New Guidelines for Managing Sudden Cardiac Arrest During School Athletics

These new guidelines were established by an interdisciplinary team of experts to assist high school and college athletic programs to prepare for and respond to a sudden cardiac arrest (SCA). This consensus statement summarizes the current understanding of SCA in young athletes, defines the necessary elements for emergency preparedness, and establishes uniform treatment protocols for the management of SCA.

Among other things, it recommends a structured emergency plan specific to sports, AED access and yearly training/practice. For more information you can access the complete article on our website: <http://sads.org/services.html#Articles>.

## Sudden Cardiac Arrest in the Young Symposium

The Sudden Cardiac in the Young Symposium was an official pre-conference at the Scientific Sessions of the Heart Rhythm Society in Denver this May. Developed in collaboration with the Pediatric and Congenital Electrophysiology Society (PACES),

The Children’s Hospital Heart Institute, and several advocacy groups, this meeting was the culmination of years of planning and organizing and, we hope, the beginning of some coordinated research into these conditions that can cause sudden death in the young. As our materials said, “without up to date knowledge of the scope of the problem, future research and education is without structure and guidance.”

The conference presented the current state of the art on topics related to the diagnosis, therapy and prevention of cardiac arrest in young people. Topics included clinical syndromes associated with risk of sudden death, use of implantable defibrillators in the young, screening, public access defibrillation, and the role of advocacy groups, with an emphasis on defining levels of evidence and areas of controversy in management decisions. Alice Lara presented “The Psychology of Sudden Death Syndromes and the Role of Patient Advocacy.” A summary of this meeting will be published soon and SADS will have copies available if you are interested.

**Watch for more information on SADS advocacy activities (some may begin in Oct.) and give us your email address so you can receive our Action Alerts!**

*STAFF: continued from page 2*

Michael Ackerman (current President of SADS) since 1999. Currently, she coordinates the activities of both Mayo’s Long QT Syndrome Clinic and the Mayo Clinic Windland Smith Rice

Sudden Death Genomics Laboratory. She was hired recently as the Support Programs Coordinator for the SADS Foundation. Carla is grateful to be part of this life changing and life saving Foundation. In her spare time, Carla enjoys coaching her daughter’s 6th grade traveling basketball team, taking in a sporting event, golfing, camping, or spending time with her family.



## Don't Miss the Special PBS Documentary and the Chance to Spread the Word During SADS Awareness Month

A new, groundbreaking PBS documentary "The Mysterious Human Heart" will air publicly beginning October 15th. This is a great chance to get the word out in your local community – on one of your local TV stations. If you want to tell your story to the media, please let Michelle know ([michelle@sads.org](mailto:michelle@sads.org) or 1-800-STOP-SAD) and she can send you tips and help you make the connections.

*This newsletter was made possible by generous funding from the Medtronic Foundation*

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SADS News/Fall 2007  
[www.sads.org](http://www.sads.org)



— July 9, 2008 —

Join us to walk a ways with the climbers on the morning of July 9th and to have fun, learn about SADS conditions and network with other families until the party for the climbers on July 12th. Watch for more details emailed soon (email [Jenifer@sads.org](mailto:Jenifer@sads.org) so you won't miss a thing!) and volunteer to help plan the parties.

## October is SADS Awareness Month

It's not too late to volunteer!  
Call 1-800-STOP SAD or  
e-mail: [Alyson@sads.org](mailto:Alyson@sads.org)

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