



## Support Your Local Climber— or a Favorite Climber

SADS needs your help to fundraise for climbers! Climbers will be coming from all over the country. Each climber will have a profile and fundraising goal on the SADS Website. Or, you can build your own personal/family fundraising Webpage and use e.mail to tell friends and family about the climb. We are also asking volunteers in climber's local communities to help fundraise for them locally.

We hope  
you will  
support a  
climber

## Climb to Conquer SADS

We are excited to announce the first annual Climb to Conquer SADS! It will be held on June 23, 2007 at Mt. Rainier in Washington State. Dr. Chris Anderson, Harry Hoops and friends will be hiking to the top of Mt. Rainier to raise money and awareness for SADS' programs and to help save numerous lives from a sudden cardiac death.

We are almost at our limit of climbers—so sign up soon if you want to participate. Dr. Anderson and Harry Hoops, the climb leader, will screen anyone interested in climbing to ensure that they are able to make the climb. Please see <http://sads.org/Climb/index.htm> for forms to participate in the climb.

### Family Gathering

We invite families to come to the park to cheer on the climbers. It will be a great opportunity to meet SADS staff and other SADS families—and to have a great time in this beautiful country. Climbers will be

leaving from the White River campsite in Mt. Rainier National Park. You can camp in the area or stay in nearby lodges, etc. SADS will headquarter at the Alta Crystal Resort. For more information on Mt. Rainier and accommodations in the area, please see <http://www.nps.gov/mora>. Stay tuned to the SADS website (<http://sads.org/Climb/index.htm>) for information on planned activities and a post-climb celebration!



Fundraising information will be available for anyone interested and we will be happy to help you build your Webpage. We hope you will support a climber and help us reach our goal!

## Corporate Sponsorship Opportunities

Sponsorship opportunities are available for the climb. Please help us recruit companies to sponsor this great event. If you are an employee of an organization that might be interested in sponsoring our event, please contact us. Sponsorship levels are available at <http://sads.org/Climb/index.htm>.

The SADS Foundation is committed to supporting families and saving lives through awareness, prevention, family support, medical education, advocacy and research.



## New Leadership of SADS Board of Trustees

The new officers of the Board were unanimously elected last month. We are very excited to have these talented people directing our efforts: Dr. Michael Ackerman, President; Dr. Susan Etheridge, Vice President; Nancy Adams, Secretary/Treasurer.

Dr. Ackerman is an associate professor of medicine, pediatrics, and molecular pharmacology at the Mayo Clinic College of Medicine. He is also the director of the Long QT Syndrome/Inherited Arrhythmia Clinic and the Sudden Death Genomics Laboratory at the Mayo Clinic.

Dr. Ackerman has an M.D./Ph.D. from the Mayo Clinic College of Medicine, the Mayo Medical School, and the Mayo Graduate School in Rochester, Minnesota. He completed fellowship training in pediatric cardiology, and postdoctoral training in molecular genetics at the Mayo Graduate School of Medicine. He joined the Mayo Clinic faculty in 2000. He has an avid interest in sudden infant death syndrome, hypertrophic cardiomyopathy, and congenital long QT syndrome.



Dr. Etheridge is an Associate Professor in the Department of Pediatric at the University of Utah Division of Pediatric Cardiology and Pediatric Electrophysiology and she is the Director of the Electrocardiography Laboratory at Primary Children's Medical Center. Nancy Adams is the Chief Financial Officer and provides finance operations, business planning & analysis and accounting services to The Hope Heart Institute, a non-profit organization located in Seattle.

Dr. Ackerman and our new officers and Trustees will be meeting in February in Salt Lake City to develop SADS' priorities for the next few years—and the road map we will follow to reach our goals. We are looking forward to working with the new officers and Trustees in the coming year.

Finally, David Salisbury, a founding SADS board member and attorney, has resigned from active board membership. We will miss his business and legal insight and wish him well in his travels.



### SADS Welcomes Two New Trustees

Robert Campbell, M.D. has served on our Scientific Advisory Committee for several years and has hosted the SADS International Conference in Atlanta and a SADS Seminar this past year. He is the founder of Project S.A.V.E., an organization concerned with preventing the sudden death of young people in Georgia. Robert is the Chief Medical Officer, Children's Healthcare of Atlanta Sibley Heart Center, the Director of Sibley Heart Center Cardiology and the Division Director of Cardiology, Department of Pediatrics, Emory University School of Medicine.



Martin Tristani-Firouzi, M.D. is an Associate Professor of Pediatric Cardiology at the University of Utah. His laboratory is interested in the structural basis of K<sup>+</sup> channel function and the cellular mechanisms that underlie susceptibility to arrhythmia. A second major area of interest is inherited arrhythmia syndromes that predispose affected individuals to lethal arrhythmias.

### SADS Founder and Guiding Light Resigns

Our founder, Medical Director and Board Chair, Dr. Michael Vincent, is retiring. After 15 years of giving his time, expertise and money to the SADS Foundation, he has resigned from his position as Board President. He will continue to consult with SADS and will be an Emeritus member of the SADS Foundation Board of Directors. We will greatly miss his guidance, his good advice and his caring personality. He has been a mentor to many of us and an example to all of us.

We wish you well, Dr. Vincent, in your new life!

If you want to send a personal message to Dr. Vincent and/or to share your thanks and your story of him with us, please visit our website at [www.sads.org](http://www.sads.org).

## Dr. Vincent's Message

Good friends, this Holiday season, which is full of love, charity and kindness, is a wonderful time of year for the SADS Foundation and for all persons who strive to be of help, support and assistance to their fellow beings.

For me, it has a special meaning in that, as of the end of this year, I am moving to another stage of my life, of continued service but in a somewhat different sphere. I am leaving full-time practice and employment in Medicine and will devote my time to volunteer medical missionary and other service to my Church, and spend more time with my family and hobbies. I will continue to speak at selected meetings and conferences and to publish results from my 33-year database and experience of Long QT syndrome patient care and research.



As part of this transition I have resigned my position as President of the SADS Foundation, and have turned these responsibilities over to highly qualified and wonderful individuals who will carry on my goals that led to start-

ing SADS—that of service to all who are concerned about genetically mediated arrhythmias and their consequences. I thank all those with whom I have had the privilege to work in this great activity. I certainly hope to have communication and contact with at least some of you in the future.

Best wishes to all for a joyful holiday season and a happy and productive new year.

*G. Michael Vincent, MD*

## SADS Awareness Month and School Nurse Project

This year Awareness Month was better than ever! Our goal of proclamations in every state declaring SADS Awareness Month got off to a great start. We had volunteers in the states of California, Georgia, Louisiana, New Hampshire, New York, Pennsylvania, Texas, Utah, West Virginia, and Washington.

As part of the 2006 SADS Awareness month, 383 people distributed SADS information to schools—261 were School Nurses, and the balance were family members, school board representatives, nurses and others. Material was sent to 41 different states, and to Ontario, Canada.

We greatly exceeded our original goal of reaching 150 school nurses in 35 states. And, the numbers above represent only a portion of the people reached as many of the participants report sharing information with other school nurses, teachers, coaches, etc. We have also made several presentations to school nurses and have quite a few scheduled for early this year.

To learn about what some school nurses have done in their area this year, visit [www.sads.org/School/index.htm](http://www.sads.org/School/index.htm)



## SADS Awareness Month Proclamation

*Dr. Vincent and SADS volunteers attend the signing of a proclamation declaring September as SADS Awareness Month in Utah.*

## School Nurse Presentations

Bonnie Gane, R.N. & Bernadette Driscoll, R.N. piloted our new presentation to a group of school nurses in New Jersey this fall. "The presentation went very well", said Bonnie, "and the fact that Bernadette and I both had personal stories to tell made it that much better." We will be continuing and expanding this program in 2007. If you would like to participate or to get more information visit [www.sads.org/School/index.htm](http://www.sads.org/School/index.htm).



## Volunteers Raise \$29,000 for SADS!

We had several successful fundraisers organized by volunteers! Together they have raised approximately \$29,000 for SADS!

We cannot thank them enough. If you are interested in hosting a fundraiser for SADS, please contact Alicia at [gates@sads.org](mailto:gates@sads.org).

Colorado Springs, Colorado. This was the most successful event yet, raising \$5,320!



Congratulations to our wonderful volunteers!

### **The Ryan Weidler Memorial Golf Invitational**

This event was held in July in Pennsylvania. They raised \$13,255! Please see page 6 for more details on the event and Ryan Weidler.

### **Octoberfest**

Bill and Sally Layton held their 9th Annual Octoberfest on September 30th in

### **The First Annual Hike For Your Heart**

The Widmann Family held this event in September in California to honor Kealey and Allie Widmann who have been living with Long QT for four years now. They raised \$1,090!

### **Christie's Heart-oberfest**

The first Annual Christie's Heart-oberfest was held on October 14, 2006 in New York by Craig and Barbara Tolosky. The event was held in memory of Christie Tolosky who passed away from Long QT in June of 2005. They raised over \$9,250 for SADS! Please visit their website at <http://www.christiesheartoberfest.com/401.html> for more information.

## Medtronic Foundation Makes Donation on Behalf of Global Heroes

The Medtronic Foundation recently donated \$1,000 to the Sudden Arrhythmia Death Syndrome Association on behalf of Medtronic Global Hero Amy Lake. Amy is an avid runner with Ventricular Tachycardia, and she is living a full and active life with the help of Medtronic's Gem III defibrillator. She was chosen by Medtronic to be part of its inaugural class of 14 Global Heroes after a worldwide search for runners whose lives have been improved with the help of medical device technology.

"Medtronic has a long and proud tradition of helping people with chronic health conditions to live full and active lives," said Dr. Steve Oesterle, Medtronic senior vice president of medicine and technology and veteran of 12 marathons. "Whether it's just one

mile, 10 miles or 26 miles, we hope these Global Heroes inspire others to follow in their footsteps."

Amy was able to successfully complete the rigorous Medtronic TC 10 Mile race. She completed the course in 1:25:00. "The race day went great," Amy said. "I hope my participation sends the message that you don't have to let a medical condition limit you from being active. I believe that being chosen as a Global Hero sends this message!"

For more information about Amy, the race and next year's race, visit [www.sads.org](http://www.sads.org).

### Our Apologies

In the annual report we incorrectly printed the proceeds from the Brian Falzon Memorial Road Rally and the Layton's Octoberfest. The Brian Falzon Memorial Road Rally actually raised \$9,415 for SADS and the Layton's Octoberfest raised \$7,000. We would like to apologize for the mistake and again express our deep appreciation for all the hard work put into these events.

### Thank you to Bernadette Driscoll and Shirley Gaster!

A big thank you to Bernadette Driscoll and Shirley Gaster for their thoughtfulness. For Bernadette's birthday they requested that guests give donations to SADS in lieu of gifts. They raised over \$500! If you are interested in a similar event, please contact Alicia at [gates@sads.org](mailto:gates@sads.org). We can create special donation slips for your occasion!

## She had an “I Love You” From Me for Each Day of Her Life

By Joan Lamar-Moss, a birth mother and an adoptive mom.

On July 14, 1984, I gave birth to a beautiful baby girl. She looked just like a miniature version of her birth dad with her auburn hair and blue eyes. I gave her the birth name “Sarah Elizabeth.” I knew she probably would not have this name long, but it was a name I always said I would give my first-born daughter.

While in the hospital after the delivery, for three days I held Sarah as much as I could. I was relieved that Sarah was healthy, happy for her soon to be family, and hopeful for her future and for mine. I also felt true love for my baby. On our last day together, I held Sarah for as long as I could. I remember thinking I would probably never be able to say the words “I love you” to her again, so I repeated those words to her for the final two hours as I held her in my arms. I thought that way she had an “I love you” from me for each day of her life.

Ron and I signed the relinquishment papers on July 23, 1984. I remember feeling numb. I also remember thinking “This is best for my baby. I can heal later.” Back then, I was not offered a lot of post placement counseling. I “grieved” on my own.

In July of 1995, about one week after Sarah’s 11th birthday, I received the most horrible news from my answering machine. It was the adoption agency that had placed Sarah. The caller identified herself as a social worker and proceeded to say, “There is a major medical emergency involving your birth daughter.” I called immediately, and found out that she was in a coma in a hospital. My birth daughter had suffered a cardiac arrest while swimming at



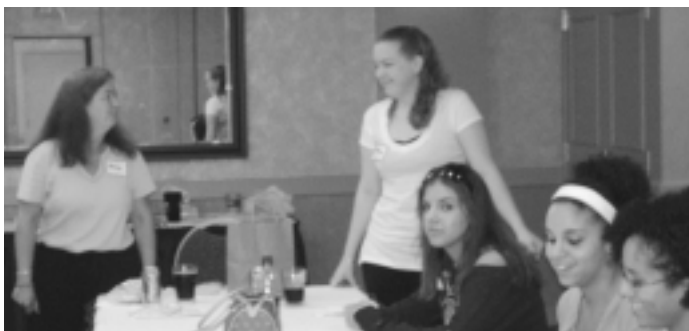
Left to Right: Faith (5 years), Ginte (21 years), Grace (9 years)

a summer camp. The social worker could not tell me anything other than that. I was frantic. This time was more difficult for me than having to place Sarah for adoption. The social worker said that my birth daughter’s family wished to contact me. Of course I agreed to this. That same day, the family called to let me know that she was hanging on and showing bits of improvement. Although, “Sarah” was not out of danger yet, I was told that I should be tested for a genetic heart condition since I had the same symptoms as my birth daughter. I was also told the name they gave her was Gintare (Ginte was her nickname). It turned out we both have a heart condition called Prolonged QT Syndrome. It causes ventricular arrhythmias and can be fatal if not treated appropriately. Both my birth daughter and I had been misdiagnosed with epilepsy.

Soon after finding out that I had this disorder, which is passed through a dominant gene, my husband, Steve and I decided to adopt our family from China. We adopted Grace Chen Ping on August 4, 1996 and Faith Lin Xiu Tao on January 14, 2001.

Placing Sarah (Ginte) for adoption was probably the most difficult decision I will ever have to make. It was also the best decision I ever made. I am so blessed to be able to know her. I know she is safe and loved in the world. My heart is at peace with my past. Now, I have been blessed with the opportunity to raise Grace and Faith. I have made a spiritual promise to their birth mothers that their daughters will grow up knowing they did the best they could for their girls considering their circumstances in life at the time. I also understand that because of having Prolonged QT syndrome I have Ginte, Grace and Faith in my life.

### SADS Seminar in Boston a Success!



Michaella Gagne, (seated 3rd from left) who is Miss Massachusetts, spent some time with the Long Qteens who were organized by Claire and Jessica Doyle.

### Barbara Butcher Arrhythmia Teen Bowling

#### Plano Super Bowl, Plano, TX

Sometimes it helps to meet people your own age who face the same challenges that you do. Jeff and Barbara Butcher hosted a family bowling day in Plano, Texas. Heart to Heart of Dallas Children’s Medical Center sponsored this first get-together for teens with an implanted cardio defibrillator (ICD) or an arrhythmia diagnosis such as Long QT Syndrome, ARVD, Brugada, etc.

Two hours of bowling, shoes, and snacks were provided to those teens, ages 12 to 18, participating. Parents were welcomed to stay and visit with each other or to get a lane of their own and roll a few balls.

This is the first event of what they hope to be many more!

## For Ryan and for Others

By Carol Weidler, Ryan's mom

No event, successful or not, can begin to lessen the loss we feel each day since Ryan died, but it can help us pay tribute to his life and to produce something valuable for others in the world.

This thought was the motivation behind the First Annual Ryan Weidler Memorial Golf Invitational that our family organized in May of 2006. Through the generous financial and emotional support of businesses, groups, and private individuals, and the tenacious efforts of family and friends, we were able to generate a profit of over twelve thousand dollars that has since been donated to the SADS Foundation. Ryan himself would have enjoyed this tournament for several reasons.

In the all-too-short twenty-six years of Ryan's life, he developed an impressive work ethic and consequently achieved much recognition. He was a gifted athlete, playing football, basketball, and baseball throughout high school. He excelled most in basketball, which he continued on the varsity level during his four years at Dickinson College. He was a disciplined player and a selfless team member. But his favorite social sport was, in fact, golf, which he played regularly with family. His

summer job of caddying gave him an appreciation for the game and enhanced his skills. Thus, he would have loved the tournament: an opportunity to challenge himself competitively, but also a time to laugh and have fun.

Further, Ryan would have loved the opportunity to share time with friends and, particularly, family. It was Ryan's grandfather who first introduced him to golf as an adolescent, and that was only one of the many special traditions that shaped Ryan's life. He was devoted to his family as he was to his fiancée whom he had planned to marry six months after his untimely death, and he regularly and thoroughly enjoyed time spent with those he loved.

Finally, Ryan's habit of self-sacrifice would have been exercised had he been present for this tournament. (Indeed, his sister and cousins fondly nick-named him "Marty" for his acts of selflessness or "martyrdom"!) Ryan felt a personal obligation to "give back", and he would have loved the thought of helping others through donating his personal time and talent. Even



though he was, at the time of his death, still a young man climbing the business ladder, he realized the importance of contributing to causes greater than himself, and he practiced this belief.

On February 26th, 2005, suddenly and without any warning Ryan died in his sleep. He had been a healthy and happy young man on the threshold of an exciting and rewarding life. Without any concrete clues to explain his death, doctors surmised that an undiagnosed, unsuspected heart arrhythmia was most likely the culprit. No family history linked him to this condition; no signs of the condition have since appeared in family testing.

Every day we, his family, miss Ryan. Though our faith is strong, we mourn the lost opportunity for Ryan to experience all that is good in this life. In spite of his physical absence, he remains a part of all that we are and all that we do. We are hopeful that the money raised from the Ryan Weidler Golf Invitational will strengthen the efforts towards SADS research so that the instances of tragedy, like that of Ryan's death, may one day be permanently eliminated.

## New on [www.sads.org](http://www.sads.org)

### Events and Photos:

<http://sads.org/Development/main.html>

### New SADS merchandise:

We have new merchandise on our website and we also have others selling things & donating the proceeds to us – especially a great new t-shirt! See page 8 for more. <http://sads.org/merchandise/friends.html>

### New articles:

*When a Child Dies Suddenly—What a Family Should Know:* includes information about how to find out what happened and when to test other family members. <http://www.sads.org/Materials/Child%20dies1.html>

**Implantable cardioverter-defibrillators (ICDs) in the Young** – some materials to help you find the information you need when deciding on an ICD. <http://www.sads.org/ICD/ICDindex.htm>



**Exercise and LQTS** – The Bethesda Conference Recommendations (also a link to the full text of the 36th Bethesda Conference – which contains sections on screening, use of AEDs, and other cardiac conditions like Brugada syndrome, CPVT, HCM, etc) <http://www.sads.org/Materials/Exercise/LQTS.htm>

### New Links:

**Project A.D.A.M.** – AEDs in schools project with lots of useful information for your school. <http://www.chw.org/display/PPF/DocID/26050/router.asp>

**Project S.A.V.E.** – (Sudden Cardiac Death: Awareness, Vision for Prevention and Education) is a consultation program provided by Children's Healthcare of Atlanta, for schools in Georgia. <http://www.choa.org/default.aspx?id=2871>

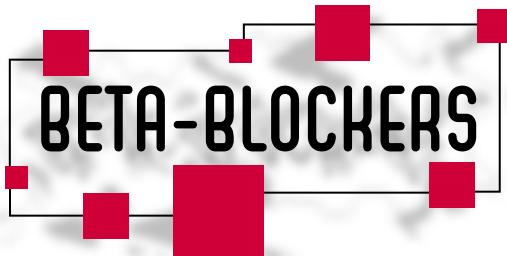
**Sudden Cardiac Arrest Association** – to keep you informed about Sudden Cardiac Arrest, its prevention and treatment. <http://www.suddencardiacarrest.org/default.asp>

**The Partnership for Prescription Assistance** – help for people who can't afford their prescription medications. <https://www.pparx.org/Intro.php>

# Use of beta-blockers in Long Qt Syndrome

Based on 33 years of seeing LQTS patients every week in my clinic and on current evidence I know that beta-blockers are very good therapy for LQT1 and LQT2 patients to prevent sudden death and cardiac arrest. They must be taken every day in order to receive this high degree of protection.

There has not been a formal comparison of the efficacy and side effect profiles of the various beta-blockers. However, the most commonly used medications by many experts are nadolol (Corgard)



and long-acting propranolol (Inderal). Both of these need be used only once per day. They are best given each morning so the highest blood levels and effects will be present during the daytime when patients are most active and subject to stress and anxiety. Side effects (fatigue being the common one) can be diminished by starting with a low dose and gradually increasing over weeks to a few months to the desired level. The exercise test is helpful in more specifically determining when a suitable beta-blocker effect has been reached.

We have seen, over the last 10 years, a marked increase in the use of the implantable defibrillator (ICD). This is a great and potentially life-saving device, but needs to be used wisely and appropriately.

Please review the indications, and risks versus benefits, of the various treatments with an experienced cardiologist who is knowledgeable about these issues whenever considering treatment strategies for yourself or a family member. The great thing about medicine is that we constantly learn, adjust, and improve health care as best practice information becomes available.

*G. Michael Vincent, MD*

References concerning the treatment comments are available on our website at [www.sads.org/](http://www.sads.org/)

## Genetic Testing— What’s Your Experience?

Now that the genetic test for LQTS has been available for a few years we are seeing it used more and more to help in the diagnosis and treatment process. We also know that people have had difficulties when they ask their insurance to pay for this test—both with the amount the insurance agrees to pay and, sometimes, by the denial of payment.

We need information about your experiences in order to help with this problem. If you have been genetically tested by Familion, please take a minute to tell us your story [sads@sads.org](mailto:sads@sads.org) or you can call us at 1-800-786-7723.

## Insurance and Long QT Syndrome

Have you had problems getting affordable health insurance with your LQTS diagnosis? What about insurance for your children? As most of you know, SADS has been working for several years to pass a federal law to prevent genetic discrimination in insurance and employment. It has almost—but not quite—passed for the last two years.

Meanwhile, we know many of you have had problems—or concerns—with health insurance. We want to document this problem so that we can use it to pass

this legislation and to work with insurance companies to increase coverage of such things as genetic testing.

We will be e.mailing a short survey in January to get feedback from all of you on these issues. Please sign up for e.mails from SADS ([www.sads.org](http://www.sads.org)) or let us know if you have had problems and don't use e.mail so that we can document your story. With everyone's input, our case will be much stronger and we can make things happen!



What about insurance  
for your children?

# SADS Keepsake Necklace

## Just in Time for Valentine's Day

This necklace is a beautiful Swarovski crystal heart in red, blue, pink or diamond color and will be a treasure for years to come. This is a lovely gift to give to friends and family members while also helping to raise needed funds for the SADS Foundation.

The necklaces come in 3 lengths: 16", 18" & 20" with the crystal heart pendant in medium and large sizes (\$21 for the smaller heart and \$25 for the larger heart plus \$1 for shipping/handling).

Support SADS and give a gift to someone you love! You can purchase your necklaces at [www.sads.org](http://www.sads.org).



## T-Shirt for SADS

Kathleen Smith, co-president of TrackCouture, has a special shirt designed in her sister's honor. Wendy died in 2005 of LQT. Purchase the shirt for \$29.99 at <http://www.trackcouture.com/charity.aspx>.



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