



SADS Awareness MONTH Get Involved!

September is SADS Awareness Month! We work to increase the public's awareness of conditions that can cause sudden cardiac death in young people. With the help of our volunteers we have made great progress making the school community in our country—and especially school nurses—aware of 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—and expand our influence to include community and recreation centers, local Boys and Girls Clubs, and any after-school activities your child may be involved in.

SADS Awareness Month provides an invaluable opportunity to get the word out, promote awareness nationwide and help save lives. With your help, we can create SADS Safe Schools in every state and make our communities safer for those with SADS conditions.

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What can parents and volunteers do to help?

Create SADS Safe Schools

- Utilizing the New SADS School Check List, make sure your school is informed and has implemented a care plan or 504 plan for your child
- Advocate for the risk assessment questions to be added to student physical screening forms.
- Assure that your school is ready with a medical emergency plan, including AEDs, should your child need it?
- Put SADS posters in all schools—in hallways, teachers' lounges, gyms, etc.
- Publish an article in your school(s) newspaper or distribute (mail) a hand out to parents (SADS has samples)
- Organize a SADS presentation for school personnel, parents, PTA, state (or district) School Nurses' Association, local sports leagues and others—we will help!

Create SADS Safe communities!

- Distribute SADS materials (packets and posters) in your community's schools, recreation centers, Boys and Girls Clubs, your local Y.M.C.A and Y.W.C.A's, and/or to any after-school activity in which your child is involved.
- Visit the Emergency Rooms in your area and make sure they understand and are prepared to care for your child's condition
- Alert the media! If your family has LQT (or another SADS condition) tell your story to the media
- Give a personal gift to help cover the costs of materials and

Visit www.StopSADS.org or call 1-800-STOP SAD to volunteer or for more information.

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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SADS Welcomes New Board Members and Scientific Advisors

Board members:

We are very pleased to announce the selection of two new Board members: **Sylvia G. Priori, MD, PhD**, associate professor of Cardiology, University of Pavia (Italy) and soon to be the director of a program at New York University and **Stuart Berger, MD**, Professor of Pediatrics at the Medical College of Wisconsin, Medical Director of the Herma Heart Center at Children's Hospital of Wisconsin and medical director of Project A.D.A.M., an initiative aimed school AED programs. "Dr. Priori's stellar basic and clinical research and Dr. Berger's clinical experience and dedication to sudden cardiac arrest in the young as the founder of Project A.D.A.M. make them ideal candidates to share their expertise and vision to help move the SADS Foundation forward," said Michael Ackerman, MD, PhD, SADS Foundation Board Chair and associate professor of medicine, pediatrics and molecular pharmacology, Mayo Clinic College of Medicine.

New Scientific Advisors

The SADS Foundation is honored to announce the addition of the following six distinguished medical experts to the Foundation's Scientific Advisory Council:

Heather MacLeod, MS, Children's Healthcare of Atlanta, Sibley Heart Center, Atlanta, Georgia

James C. Perry, MD, Children's Heart Clinic, Midwest Adult Congenital Cardiac Center, Minneapolis, MN

Shubhayan Santani, MD, FRCPC, Dept. of Pediatrics, University of British Columbia, Vancouver, BC

J. Philip Saul, MD, Medical University of South Carolina, Children's Heart Center of South Carolina, Charleston, SC

John Treidman, MD, Dept. of Cardiology, Children's Hospital of Boston, Boston, MA

Frank Zimmerman, MD, the Heart Institute for Children, Hope Children's Hospital, Oak Lawn, IL

"We welcome our colleagues to the SADS Foundation and appreciate their expertise and experiences that will strengthen the Foundation's ability to provide up-to-date research, medical information and resources to the thousands of children and parents needing to understand more about cardiac arrhythmias and how to live and thrive with these conditions," stated Dr. Michael Ackerman, SADS Foundation Board Chair.

The 17-member Scientific Advisory Council provides guidance to the Foundation on matters relating to medical research, genetic conditions, prevention, protection and treatment developments, and pediatric and adult patient care issues.

Joanne Robinson, M.S.

Director of Family Support & Volunteer Development



I graduated from Brigham Young University with both a Bachelors, and Masters of Science, in Community Health. I have spent 9 years working to improve infant and children's health in the non-profit and the public sector. Now, I am very excited to focus on programs that will stop sudden cardiac deaths!

I have two wonderful sons, a great husband, and two Jack Russell Terriers! Our family often finds ourselves outside playing soccer, or walking in rivers or streams, with our dogs.

Aliah Hall

Aliah was our summer intern this year and helped us out tremendously with the Climb to Conquer SADS. Aliah is a student at the University of Utah, studying for a master's degree in Social Work. We're glad that she was able to join us up at Mt. Rainier this year and her help was invaluable in putting our event together. Thank you Aliah and good luck to you!



Olivia, our new Awareness Month Intern, is thrilled to be with SADS and to be serving the families and helping us "spread the word."



Sarah Jo, our new Office Assistant, has been busy working on the database, researching a new phone system and finding free office furniture.

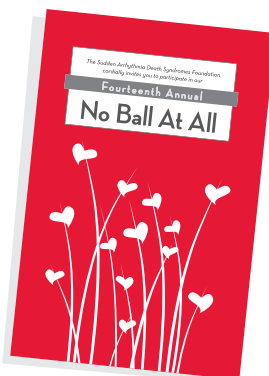
The greatest party that we never throw!

No Ball At All is going great so far this year. No Ball At All is our yearly fundraising non-event where, instead of dressing up and stepping out, you get a chance to support SADS from the comfort of your own home. This year's donations have been steadily streaming in since the first mailing went out in April. And we couldn't be happier about it.

Remember, it's never too late to donate! You can donate online via our new, safe and secure website at www.StopSADS.org

Thanks to the No Ball At All 2008 Committee

We would like to thank our diligent Dinner Committee for this year's No Ball At All Event. The Dinner Committee is a group of volunteers who go the extra mile for this non-event by sending No Ball invitations and personal letters to their friends, family, and colleagues. They help tremendously to support the No Ball fundraising effort, and simultaneously raise awareness in their own communities.



- Cindy Baker
- Deborah and Terry Meissner
- Chris and Denise Falzon
- Lene and Jim Righeimer
- Lori and Brian White
- Marsha and Steve Peterson
- Alex and Molly deGroh
- Pam Osterhout-Batten
- Shauna and Rowdy Hatch
- Shelly Wright
- Tracy Curtis
- Connie and Darrell Ogden
- Alice Smith
- Colleen Kausak
- Vicki and Terry O'Neill
- Vanessa Leone
- Scott and Kathi Blum
- Carla Haglund
- Christina Satterfield
- Denise Larivee
- Mrs. Linda Smith Grisham, Mrs. Sally Hook, the Hooper Family, the Smith Family and the Rice Family

Thanks guys! You're the best! If you'd like help out on next year's Dinner Committee, email Michelle at michelle@sads.org or call our toll free number at 1-800-STOP-SAD.

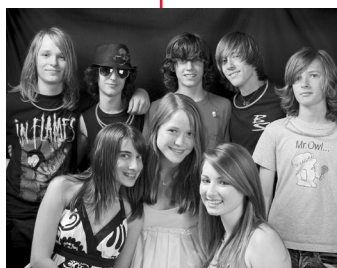
SADS Participates in Federal Giving Campaign

The SADS Foundation is pleased to announce that it has been accepted to participate in the Combined Federal Campaign (CFC) program, the largest annual workplace charity program. The mission of the CFC Campaign is to promote and support philanthropy among all federal employees, including civilian, postal and military workers around the world. As an eligible CFC charity, federal employees will be able to designate donations to SADS.

The 2008 CFC Campaign will kick off in September with the theme – **"Hope Wanted: A little changes a lot."** Federal employee contributions to SADS will provide hope to a family living with a child with Long QT or other cardiac arrhythmia; help increase awareness of the risk of sudden cardiac death; and, ultimately save more young lives.

Alice Lara, SADS president/CEO will be participating in the CFC Campaign kick-off events in Ogden and Salt Lake City and will have an opportunity to speak about the work of the SADS Foundation to federal worker attendees.

Please encourage all federal employees to donate to the SADS Foundation using our CFC code – 56112.



SADS Families' Birthday Party Donations

Our SADS families always come up with new and creative ways to help out the organization by hosting fundraisers. One way to support SADS, and to have a great time doing it, is to ask for birthday donations like these people...

Violette Levy

In June, Sharon Cramer of Sarasota, FL and her 16-year-old daughter, Violette Levy, had a sweet 16 birthday party fundraiser for SADS. Violette asked that, in lieu of gifts, her guests give donations to SADS in memory of her little brother Billy. Violette's party was a tremendous success. She raised over \$1,000 to benefit SADS families and we couldn't be prouder of Violette and the work she's done for our organization. Thank you Violette!

James Curtis

James asked his family and friends to donate to SADS instead of presents for his birthday this past February. James's sister, Kelly Chamberlain, died from previously undetected Long QT Syndrome in July of 2006 and he wanted this to be in her memory. We're grateful to James and his loved ones who gave to us in her memory.



The Lucatuorto Family

In April of this year Anthony Lucatuorto celebrated his 40th birthday and asked his friends and family to give donations to SADS in honor of his daughter Annie, who was diagnosed with Long QT syndrome about 2 years ago. We received over \$2,000 in donations thanks to Anthony and his family. Thank you to the Lucatuortos!

Second Annual Climb to Conquer SADS

Presented by PGx Health

For our second annual Climb to Conquer SADS we returned to Alta Crystal Resort, a beautiful mountain refuge just an hour and half outside Seattle. The event was a wonderful success with families coming from all over the country to participate in the seminars and festivities. Yes, we had seminars and festivities.

Drs. Ackerman and Ethridge returned to give seminars and were joined by Dr. Chris Anderson, Dr. Terrence Chun and RN, Kathy Conlin.

In the end we had a successful conference, two triumphant summits and, so far, have raised over \$115,000 for our cause. What a success, Thank you all.

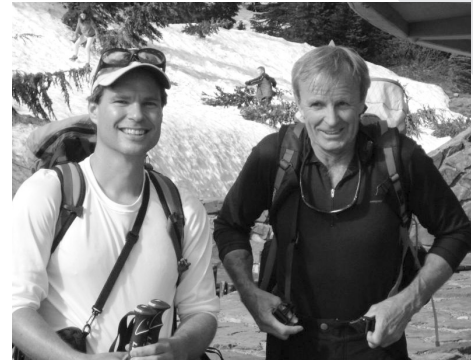
Thanks to our Summit Sponsors:

**Boston Scientific and
St. Jude Medical!**

For a listing of our other sponsors visit
www.StopSADS.org

Climb 08 Says THANKS!

With the great success of Climb to Conquer SADS 08, we'd like to send a special thanks to all of you who made this event possible. We give a special thanks to the steering committee, which has worked year around to raise funds and plan this event. With a heart felt thanks to Nancy Adams and her sister, Patty Nolan for again providing all the delicious food for staff, volunteers and families. For media coverage and sponsorship we thank Sacred Heart Medical Center (Thanks for everything, Danita) and Dr. Chris Anderson for being the face and drive behind Climb. We thank the climbers for Climbing, along with REI and Maxim for supplying ropes and other provisions. Lastly but certainly not least we thank the families who came out to support and participate in this wonderful event. We thank everyone for their kindness, their help, support and enthusiasm. We hope to see you all again next year. And to all of you who could not make it this year we invite you to join in the fun and learning next year. Thank you all.



Chris Anderson & John Roskelley

Climbers

Rich Bennett, 2nd year	Kathy Grabel, 1st year
Sara Schmelzer, 1st year	Erich Hofeld, 1st year
Jason Baker, 2nd year	Bryson Williams, 1st year
Brian Hoots, 2nd year	Roland Lamarche, 2nd year
Heather Schauvin, 1st year	John Roskelley, 1st year
Gerick Simonson, 1st year	Chris Anderson, 2nd year



Lene and Rebecca Righeimer

Lene's journey began on December 27, 2003. Her family, consisting of herself, her husband Jim, and their daughters Rebecca (4) and Morgan (2) had been celebrating Christmas with their extended family members. The little girls were very excited! After coming home from the party, Lene bathed the girls in the bathtub and tried to clothe them and brush their hair as they continued to play with each other. The next thing she knew, Lene turned around to find her daughter Rebecca on the floor making little growling sounds with her eyes half open.

After a moment, Lene realized there was something seriously wrong with Rebecca. Lene ran to Jim with Rebecca in her arms. Handing their daughter over to Jim, Lene called 911. After 50 minutes of resuscitative procedures, Rebecca's heart was shocked back into rhythm—but her brain had been without oxygen for too long. There was no explanation for Rebecca's condition.



It was shortly thereafter that the Righeimers had their first encounter with a cardiologist who mentioned the term "Long QT", but failed to explain the condition further. Lene left the meeting thinking that her child had died of a heart attack. After that, Lene and Jim made the painful decision to take Rebecca off life support. "Such a healthy little girl could not have died of a heart attack," Lene recalls, so she decided to investigate "Long QT" online. Lene found the SADS website and contacted Dr. Vincent, who urged her to have Rebecca's blood screened (this had to be done via birth blood screening card because Rebecca's body had already been embalmed). The blood tested positive for Long QT. After years of research and waiting, the Righeimers finally got answers. Lene's whole family was tested and found that Lene and her next child, Eleanor, were also positive for LQTS. They now take beta-blockers and are doing well.

Being proactive about SADS education has led Lene to find meaning in the sorrow. "If I can let other people know about Long QT," Lene says, "then Rebecca will not have died in vain."

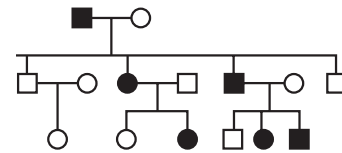
Family Pedigree Project Update

Do you know if your SADS condition comes from your mother or father's side of the family? Have all your 1st degree relatives (parents, children, full siblings) been screened for your SADS diagnosis? Do you know who of your other relatives (grandparents, uncles, aunts, nieces, nephews, grandchildren, half siblings) are at risk for SADS?

The number one risk factor in sudden cardiac arrest is a family history. With this project, we will help you find out about your family history, find family members who don't know they should be checked (and their children) and maybe even find family members you didn't even know.

Through the Family Pedigree Project, SADS can help you map out your family history (pedigree) to identify family members who are at risk. As part of the project, materials will be provided to assist you when you contacting these other family members about their possible risk and need for screening. We will also have lots of online resources to help you research your distant family if you wish to expand your pedigree.

Starting in September, SADS interns and/or staff will be contacting you by telephone to offer individual assistance. Help us save lives by educating families "degree" by "degree!"



Here is what you can do now:

- Contact Joanne@sads.org or 1-800-STOP SAD if you would like to be among the first to participate.
- Participate in the SADS Discussion Board at www.sads.org/index.php/Discussion-Board/ for the latest updates on this project and to share & get help in protecting your family and extended family

With SADS Family Pedigree Project, we WILL save lives!

SADS Heart Beaters

The Lustig Story

On the night of January 29, 2006 Selena Lustig was at a sleepover at her neighbors. Her parents, Adrian and Larry, woke to their neighbor telling them that Selena had a seizure and wasn't breathing. The mother of Selena's friend administered CPR for 6 minutes while waiting for emergency services to take over. Two attempts to defibrillate her heart were unsuccessful and she hadn't been able to breath on her own for 10 minutes. A Lieutenant told the Lustigs they may want to speak to a chaplain. But fortunately, with a breathing tube and epinephrine, they were able to get a heartbeat and make the drive to Seattle. In Seattle, Selena was treated by a Pediatric Electrophysiologist.

The EKG in the hospital indicated Selena had a long QT wave. After the diagnosis, everyone in the family had EKG's and Larry, Daniel (22) and Selena (15) were all diagnosed with LQTS. Through genetic testing they learned their family has LQT type 2.

Selena and her parents made the decision to get an ICD implanted. Before Selena's event, she had been playing basketball. The women's basketball coach at the University of Washington caught wind of Selena's story and came to visit with a player from the team. The player, who also had an ICD, came to show Selena that she could live with it.

Selena's recovery was remarkable! According to Adrian, "so many good things lined up in order for her to survive". Larry says that, through the experience of almost losing her, Selena made her family unit tighter, too. "It was terrible, but also an unbelievable learning and growing experience," he says.



New Volunteer Program Coming in January 2009!

New Volunteer Program Coming in January 2009!

SADS has always had wonderful volunteers! Volunteers are the backbone of this foundation and have contributed so much to help save lives and support families living with SADS conditions!

With the addition of our new Family Support and Volunteer Development Director, Joanne Robinson, we can now organize and train our volunteers in a more formal way to enhance the existing family support services.

By first conducting a needs assessment to determine what type of local and national services and support would be most helpful to families, we can develop the volunteer structure—and training—to best meet those needs. (see enclosed survey).

There are many different types of SADS volunteers now—including people who organize a fundraising event, SADS Awareness Month volunteers, people who provide direct support to new families on the phone or online, etc. Some of the new volunteer positions include:

Local Network Coordinator to help local families meet each other and provide an educational forum and informal support (often through recreational activities.)

Telephone Support Volunteer is a person who agrees to be contacted, by telephone or e-mail, by people in their area.

Support Group Leader to organize a group to increase knowledge about SADS conditions, and provide more formal support for individuals and family members affected by SADS conditions.

PLEASE fill out the enclosed Survey (or access it on www.StopSADS.org) so that we can serve you better! Thanks for all your help!

ADHD and Arrhythmias: What SADS Recommends

Recently, the American Heart Association released a new recommendation stating that “children diagnosed with ADHD should have a thorough heart work-up, including an electrocardiogram, before taking stimulants such as Ritalin to treat the condition.”

Regardless of this new AHA recommendation, families with a SADS condition (especially long QT syndrome) know that most of the medications used to treat children with ADHD can be found on the list of Drugs To Avoid (www.qt drugs.org). However, the evidence justifying their listing has largely been “guilt by association rather than true evidence” asserts Dr.

Ackerman. That is, since many long QT syndrome triggering events are related to exertion, excitement, adrenalin, therefore adrenalin-like agents (i.e. ADHD stimulants) may be potentially dangerous.

SADS has always recommended that stimulant therapy may be reasonable for some individuals with both long QT syndrome and ADHD. It is all about risks and benefits. In these settings, it is critical that the family, their heart rhythm or long QT specialist, and their ADHD specialist work closely together to determine what is in the best interest for that child/family.

For all children, SADS continues to recommend a thorough history and physical (see our Risk Assessment Form) by the child’s doctor every few years at these times: preschool, before/during middle school, before/during high school and before participating in organized sports. If this assessment reveals a possible risk, then an ECG should be performed, carefully interpreted, and if necessary, a proper referral to a pediatric heart rhythm specialist should be made.

SADS is a leader in education, research and advocacy for families at risk of arrhythmias that can cause sudden death in young people.

SADS Invites Physicians to Participate in Awareness Month

The SADS Foundation invites medical professionals to make SADS Awareness Month the springboard for saving more young lives.

September is SADS Awareness Month – a time for reaching out to schools, community groups and the local media to increase the general public’s knowledge of the warning signs that may identify the child or adult at risk for sudden cardiac death.

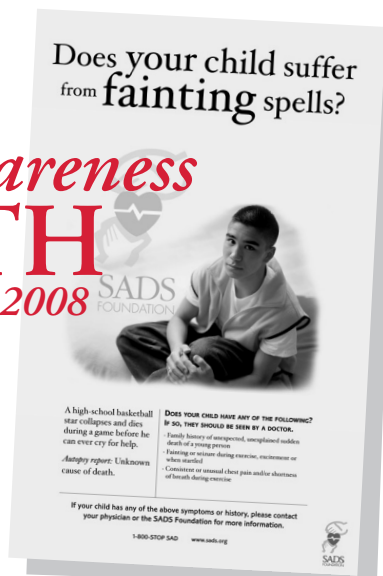
We are asking you, as a physician expert, to initiate a SADS Awareness Month campaign in your local community. Working with your nurse, office manager and/or patient(s), the Foundation can provide the materials and expertise you need to successfully increase awareness in your local community.

Here’s how you can help increase awareness and understanding of these potentially deadly cardiac arrhythmias:

- Involve your patients in a SADS Awareness/Fundraising Campaign (we can provide the organization, support and materials to help).

- Display SADS material in prominent places in your offices and local hospitals
- Encourage patients to utilize the SADS Family Pedigree Kit to identify other at-risk individuals in their family who need to be evaluated by you or another expert.
- Give a presentation to the state (or district) School Nurses’ Association, Pediatric Association, the parents or PTA in local schools and advocate for adding the SADS Risk Assessment questions to physical screening forms for young people.
- Write an article about SADS conditions for your local newspaper &/or give an interview on local radio/TV.
- Together the healthcare community and the SADS Foundation can save lives! Contact us for more information and materials olivia@sads.org or 1-800-STOP SAD (786-7723).

**SADS Awareness
MONTH**
September 2008



Submit Your Stories, and Photos

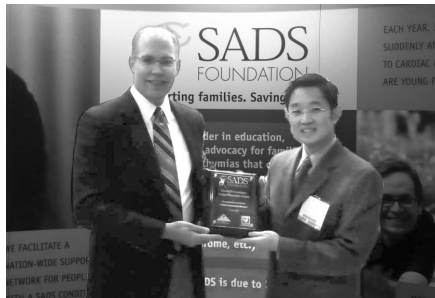
You can now submit your own stories—with pictures—of your family, your children, yourself. Telling your story helps others and promotes awareness at www.sads.org.

Get Connected! SADS Discussion Board:

Participate in SADS Discussion Board with topics on genetic testing, insurance, medical questions, parent to parent, etc. A great way to “meet” other SADS families and also get your questions answered by an expert. www.StopSADS.org

1st Annual SADS Foundation Young Investigator Award in Cardiac Channelopathies

Dr. Jeffrey J. Kim, Assistant Professor of Pediatrics, Baylor College of Medicine was the recipient of the **1st Annual SADS Foundation Young Investigator Award in Cardiac Channelopathies** which was presented at the annual Pediatric and Congenital EP Society (PACES) evening meeting in May. His award-winning manuscript describes the identification of a new long QT syndrome susceptibility gene that encodes syntrophin alpha and provides further electrophysiological characterization of its associated phenotype. More importantly, this discovery stretches the current paradigm of primary channelopathies and lends credence to the novel concept that defects of non-ion channel proteins can indeed affect ion channel gating kinetics and cause secondary channel dysfunction leading to LQTS. Proof-of-concept studies such as this may cause us to shift our focus to new classes of proteins and candidate genes, helping us to explain the residual 20-25% of LQTS patients who currently remain genotype negative.



“This inaugural award is very important to the SADS Foundation as we are striving to encourage research into the cardiac channelopathies and recognize the next generation of outstanding investiga-

tors like Dr. Kim as they pursue questions that ultimately will benefit the families that we support”, said Dr. Michael Ackerman, SADS Foundation Board Chair and director of Mayo Clinic's Windland Smith Rice Sudden Death Genomics Laboratory and Long QT Syndrome Clinic.

The award committee received numerous submissions and we would like to thank them for their service: J. Philip Saul, MD, Medical University of South Carolina—chair; Michael Ackerman, MD, PhD, Mayo Clinic; Robert Hamilton, MD, University of Toronto.

Dr. Kim began his research career at Columbia University College of Physicians and Surgeons, then attended the University of Illinois College of Medicine and finally came to the Baylor College of Medicine and Texas Children's Hospital for a fellowship in Pediatric Cardiology. In the midst of his clinical training, Dr. Kim also continued his pursuit of molecular research, where he worked on the identification of novel genes implicated in both Long QT Syndrome and Dilated Cardiomyopathy. Currently, Dr. Kim remains clinically active on both the heart failure and electrophysiology services. His research interests include arrhythmias in heart failure as well as the molecular and genetic basis of arrhythmias and sudden death.

Information about our first Young Investigator Award recipient, Dr. Kim, and the unique research that was done can be obtained from the SADS Foundation's new website, www.StopSADS.org, a comprehensive health information center.

Research Highlights

Excerpts from the SADS Quarterly Literature Review

Researchers believe a fever can trigger life-threatening changes in patients with long QT syndrome (LQT-2).

Researchers from the Netherlands and the University of Wisconsin in Madison measured the electrical activity in the heart over time of two LQT-2 patients. Both had the same HERG mutation. The scientists found fever was associated with prolonged QT intervals in these individuals.

Arthur Wilde and Craig January, the team leaders, injected the mutation into a cultured human cell line. It had the same effect as in the patients, including altered electrical currents across cell membranes at high temperatures caused by fever. They concluded similar changes in heart cells at the high temperatures associated with fever could trigger the potentially lethal electrical activity.

Journal of Clinical Investigation, June 2008

New Treatment for Some People with CPVT

If you (or your patient) have CPVT and have received multiple shocks from your ICD, surgical left cardiac sympathetic denervation may be useful to prevent shocks.

Left cardiac sympathetic denervation for catecholaminergic polymorphic ventricular tachycardia.

Wilde AA, Bhuiyan ZA, Crotti L, Facchini M, De Ferrari GM, Paul T, Ferrandi C, Koolbergen DR, Otero A, Schwartz PJ.

N Engl J Med. 2008 May 8;358(19):2024-9. PMID: 18463378 [PubMed - indexed for MEDLINE]

LQTS and Risk

This paper discusses the known risks of children with various types of LQTS and the risk of adults over age 40.

Congenital long-QT syndromes: Who's at risk for sudden cardiac death? Circulation. 2008 Apr 29;117(17):2178-80.

No abstract available. PMID: 18443247 [PubMed - indexed for MEDLINE]

Brugada Syndrome and Risk

Brugada syndrome (BrS) is an inherited disorder that predisposes some people to sudden cardiac death (SCD). It is not well established which BrS patients are at risk of severe arrhythmias. This study looks at whether standard 12-lead electrocardiogram (ECG) would give useful information for this purpose.

Risk assessment in Brugada-syndrome: the way back to the surface ECG. Paul M, Schulze-Bahr E.

J Cardiovasc Electrophysiol. 2008 Apr;19(4):384-5. Epub 2008 Feb 12. No abstract available. PMID: 18284490 [PubMed - indexed for MEDLINE]

Passing GINA into Law:

What This Means for You

On May 21, 2008 President George W. Bush signed into law the first civil rights legislation of the new millennium - the Genetic Information Nondiscrimination Act (GINA)! GINA provides protections against genetic discrimination in both the health insurance and employment settings.

The Genetic Information Nondiscrimination Act protects all Americans by:

Prohibiting insurers in both the group and individual health insurance market from using genetic information to determine eligibility or establish premiums. Prohibiting employers, including employment agencies and labor organizations, from using genetic information to make hiring or promotional decisions, or when determining eligibility for training programs.

Jacob, a boy who carries a gene for a disorder called Long QT Syndrome (LQTS), was denied coverage under his father's health insurance policy because of his "pre-existing condition." Jacob's father wanted Jacob to be insured, but even after their state enacted a law prohibiting genetic discrimination, Jacob's insurance company still refused to cover him. After fighting the insurance company for a year and a half, Jacob's family finally won and got Jacob the health insurance he needed.

As we continue to help people whose insurance company won't pay for genetic testing, we also want to hear from people who can't get (or can't afford the high rates of) health insurance due to their SADS diagnosis. If you have a story to tell or need some help, post on our SADS Discussion Board at www.StopSADS.org or contact us at 1-800-STOP SAD.

Camps for SADS Kids

We love our SADS kids and hope they had the best summer ever! And summertime for lots of SADS families means attending camps for kids with heart conditions. For many of our kids, it's their favorite part of summer. Did your child attend a camp this year or are they planning to attend one? Which camp did they go to? Did they like the food? Was their underwear run up the flagpole? Email Michelle (michelle@sads.org), or jump on the discussion board on our website and let us know about your kid's experience with camp this summer.

SADS Needs Your Email Address

We are trying to save money (and trees) by mailing less and emailing more. So, if you don't want to miss out, sign up for our ENewsletter today! Visit www.StopSADS.org or just give us your email address: <mailto:sads@sads.org>.