



Register Now!

7th International SADS Foundation Conference

This year's International Conference is gaining lots of attention and momentum! Folks are already registering for the November 1st-3rd conference in Columbus, Ohio - Don't miss out on your opportunity to attend!

Attention Healthcare Providers: We have added a full day of CME accredited courses for health-care professionals on Friday, November 1st. Topics will include: Overviews on SADS conditions, State of Pre-and Post-Mortem Genetic Testing for Sudden Death Predisposing Heart Diseases, Fetal Channelopathies, Sudden Death in Athletes – Is Prevention Possible, and Screening – Why Isn't It Universal and What Would it Take to Push the Boundary. As always, we will have top notch speakers providing lectures and answering questions, including SADS Board and Scientific Advisors, Michael Ackerman, MD, Susan Etheridge, MD, Robert Campbell, MD and Stuart Berger, MD to name a few. Families are also welcome to attend.

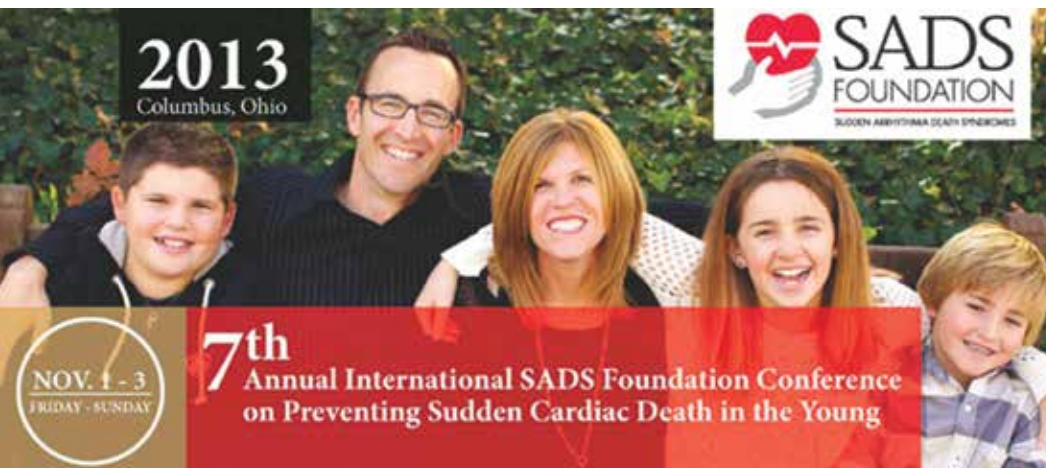
Attention Families: We have a fun-filled, education-packed weekend in store for you! Join us for family activities, beginning with our Ambassador training on Friday, November 1st, DJ dance party on Saturday night, and 1.5 days of access to some of the world's leading experts on SADS conditions. Topics will include: Understanding Your SADS Condition, Latest Treatment Strategies, Screening, Parenting a Child with SADS as They Grow, Athletics, Genetics and the Family, Beta Blockers and Drugs to Avoid, and so much more!

Highlights of the conference are sure to include Dr. Jonathan Kaltman's discussion about screening – learn about why screening is not universal and what it might take to push that boundary. Another "don't miss" will be Dr. Michael Ackerman's lecture entitled, What Explains the Rest of Long QT Syndrome. Have you ever wondered why you can get a negative genetic test result and still have LQTS? Come listen to this informative lecture and learn more!

For agendas, hotel and registration information: www.StopSADS.org.

Become a SADS Ambassador

Interested in becoming a SADS Ambassador? At the 7th International Conference in Columbus, Ohio we will be offering our second round of training. This informative session will cover basic to advanced topics on becoming a SADS expert volunteer. You will learn how to provide family support, run support groups, plan fabulous fundraisers, bring awareness on a large scale to your community, and advocate in the political arena for a safer world for those with SADS conditions. We recommend this training for anyone who wants to be an Ambassador and who can commit a few hours each week to making the world a better place for those with inherited arrhythmias. There will also be new topics covered for already established Ambassadors who are hungry for more information. Please sign up when you register for the conference!



Conference Healing Wall

This year's conference Healing Wall will have a different feeling than years past. Volunteers at Fairfield Medical are creating a garden of quilted flowers for attendees to dedicate to their loved ones. This visual installation will be available for all conference goers as a living and growing art project created together. We will also have the healing wall stories and photos as in years past. If you would like to submit a photo and story for this year's conference Healing Wall and Garden, please contact Anne Maurer at Anne@sads.org.

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.

Board of Trustees

Board President

Michael Ackerman, M.D., Ph.D.
Rochester, MN

Board Vice President

Susan Etheridge, M.D.
Salt Lake City, UT

Board Secretary/Treasurer

Joanna Bewick
Boston, MA
Chris Anderson, M.D.
Spokane, WA
Stuart Berger, M.D.
Milwaukee, WI
Robert Campbell, M.D.
Atlanta, GA
Scott Dailard
Washington, DC
Pete Fischbach, M.D.
Atlanta, GA
Laurie Smith Hooper
Nashville, TN
Anthony Lucatuorto
New York, NY
Martin Tristani-Firouzi, M.D.
Salt Lake City, UT

SADS Founder & Emeritus Trustee

G. Michael Vincent, M.D.
Salt Lake City, UT

International Affiliates

The Canadian SADS Foundation
Pam Husband, Ontario, Canada
Nancy Busse, Alberta, Canada
SADS UK
Anne & John Jolly - Essex, England

Scientific Advisors

Peter J. Schwartz, M.D.
Chairman
Pavia, Italy
Charles Antzelevitch, Ph.D.
Utica, NY
Charles Burel, M.D.
Washington, D.C.
Mitchell Cohen
Phoenix, AZ
Isabelle Denjoy, M.D.
Paris, France
Arthur Garson, Jr., M.D.
Charlottesville, VA
Thomas S. Klitzner, M.D.
Los Angeles, CA
Heather MacLeod, M.S.
Elmhurst, IL
James C. Perry, M.D.
San Diego, CA
Sylvia Priori, M.D.
Pavia, Italy
Dan M. Roden, M.D.
Nashville, TN
Shubhayan Sanatani, M.D.
Vancouver, BC
Phil Saul, MD
Charleston, SC
Katherine Timothy, M.D.
Brigham City, UT
Jeffrey A. Towbin,
Cincinnati, OH
John Friedman, M.D.
Boston, MA
Victoria L. Vetter, M.D.
Philadelphia, PA
Samuel Viskin, M.D.
Tel Aviv, Israel
Arthur Wilde, M.D.
Amsterdam, Netherlands
Frank Zimmerman, M.D.
Oaklawn, IL
Raymond L. Woosley, M.D., Ph.D.
Tucson, AZ

Staff

Alice Lara, President & CEO
Jan Murphy, Director of Development & Marketing
Christine Rice, Medical Education Director
Anne Maurer, Family Support Director
Sarah Marsden, Director of Annual Funds
Amy Dorsey, Office Manager
Brandon Bagley, Bookkeeper
Carol Lai, Awareness Coordinator
Sylvie Batchelor, Awareness Assistant
Rachel Palmquist, Family Support Assistant

Rachel Palmquist

I am very excited to join the SADS Foundation as the Family Support Assistant and look forward to working with the SADS community. I am currently working towards my Masters in Genetic Counseling at the University of Utah and received my Bachelors in Molecular Biology from the University of

Washington. I have a special interest in cardiac genetics and know that there is so much I can learn from working with the SADS community. I am continuously impressed by the strength and resilience of families dealing with inherited disorders and I believe that every individual and family should have access to education and support. I am so happy to join a foundation that is devoted to this



Sylvie Batchelor

Sylvie Batchelor, our Awareness Assistant, is going into her junior year at the University of Utah. She is studying Political Science and International Studies. She has been involved with non-profits since high school and volunteered at the Utah Domestic Violence LinkLine. Sylvie is dedicated to raising awareness for SADS and finding new ways to increase community involvement. The SADS Foundation will truly help meet her goal of making a difference. She is happy to be a part of this team and is ready to start helping in any way she can.



Jan Murphy

I am honored to join the team at the SADS Foundation as the Director of Development and Marketing to further the mission of saving the lives and supporting the families of children and young adults who are genetically predisposed to sudden death due to heart rhythm abnormalities. I come to this position with a Bachelor of Arts in Public Relations from the University of Utah, a Bachelor of Science in Elementary Education from Utah State University, and 17 years of experience in development and leadership in the non-profit community. The loss of young adults or children touches my heart as I have experienced this type of loss personally in my family although from different medical reasons. The opportunity to increase the support of the families dealing with SADS inherited disorders and the physicians who work to treat and cure these disorders as well as the awareness of the public is a challenge I am thrilled to undertake.



Updates Made to QTdrugs List



7/1/2013

Possible risk of torsades de pointes

1. Pasioreotide (Signifor®): a new drug approved for the treatment of Cushing's Disease. The FDA recommends obtaining a baseline ECG before administering the drug.
2. Telavanir (brand name Vibativ®), an intravenous antibiotic
3. Rilpivirine (Brand name Edurant®), also marketed in the combination products Complera® and Eviplera®, as oral antiviral therapy for patients with HIV/AIDS.
4. Vorinostat (Zolinza®) for the treatment of cutaneous Tcell lymphoma

Risk of torsades de pointes

1. Ondansetron (Zofran® and others), a drug for the treatment or prevention of nausea and vomiting
2. Dronedarone (Multaq®), a drug for the treatment of arrhythmias

For patients with congenital long QT syndrome (CLQTS), we recommend that, unless no other option is feasible, drugs on any of the QTdrugs lists should be avoided.

AZCERT.org is now CredibleMeds™

Are You the Parent of a Child who Survived A Sudden Cardiac Arrest in the Past 3 years? If so, we want to hear your story!

You are invited to participate in a research study conducted by Dr. Vicki L. Zeigler, a nurse researcher at Texas Woman's University.

Visit www.StopSADS.org and click on Enrolling Research Studies.

SADS SAFE SCHOOLS Month is approaching!

Attention all families with school age children! Do you have a care plan in place for each of your children in school? Does it need to be updated? The SADS Foundation dedicated the month of September to making sure children with SADS conditions are safe when they go back to school.

The SADS Foundation has developed materials and information to help school personnel educate colleagues as well as recognize warning signs in students. As students spend the majority of their day in the classroom it is essential we ensure it is a safe environment for all.

Here is a checklist for all families to use to make sure their schools are SADS Safe all year.

What the SADS Foundation Recommends:

1. Every child should 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) in schools.
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.

If all these criteria are met, consider encouraging your school to apply for a Heart Safe School accreditation, which will ensure the safety of all the people in your school!

SADS Safe Schools Goal

All Children with a SADS Condition have an updated care plan in place with their school!

Our comprehensive Care Plans and Back-to-School Checklist will ensure that you take all the steps to protecting your child at school. Make sure you complete your care plans as soon as school starts again in the fall.

Order a SADS Safe Schools kit for care plans and awareness materials at [www. StopSADS.org](http://www.StopSADS.org).

HOPE CPR Training

HOPE (Hands On Practical Experience) is a simplified form of CPR using only compressions and no breaths. The HOPE program was created in early 2012 for Medical Center's Community CPR Day. To date, more than 3,500 people have been HOPE trained. The more people trained means odds of having someone near when a person suffers cardiac arrest.

Heart Safe School Accreditation Program

On Friday, April 12th, 2013, Fairfield Medical Center's Snider Community Heart Watch and the SADS Foundation presented West Elementary School Principal Terri Garrett with a plaque for the first Heart Safe Accreditation in the country. Here are some of the criteria West Elementary School met to become a Heart-Safe School:

- Parents and guardians completed a SADS Risk Assessment form.
- All students with a cardiac medical diagnosis have a written care plan available to school staff.
- Medical emergency response drills are conducted on a quarterly basis.
- AEDs are located no further than 90 seconds from anywhere in the building.
- CPR-trained staff to student ratio is one staff member for 50 students.
- All fourth- and fifth-graders received hands-on CPR training.
- SADS Facts About SCA sent home with students for parents and guardians to review.

Learn more about the Heart Safe School Accreditation Program (and see pictures from West Elementary) here: www.StopSADS.org/Heart-Safe-School-Accreditation.



SIRCh goes Live!

Have you been a participant in the SADS Pedigree Project? SADS has updated the Pedigree Project to the SADS International Registry of Channelopathies (SIRCh), and we need you to resubmit your info. Your login will remain the same, but your critical medical information needs to be updated to make this project a success.

This important project will allow researchers all over the world to access the anonymous, de-identified data of families with SADS conditions to use for life-saving research. SADS could not be more proud to contribute to the research community in this way – but we need your help! This safe and secure survey will gather relevant medical information while keeping your identity safe.

Please sign in today to enter your information, or update your profile! The future of medical research depends on you!

Daniel Matthew Mauriello

Daniel Matthew Mauriello, known to the world as Danny, lived a life full of love, laughter, and big adventures. But there was also heartache and pain (although he would never let you know it). He overcame more obstacles than most people do in their entire life. Danny was 6 years old and was the strongest person you could have ever met. He defied many odds against him, cheated death many times; but on the day of his passing, the Lord took him home.

He was a beautiful child of God. On Earth, he was given to Stephen and Lurdes to be his parents, and they loved and raised him with every fiber of their being. They never gave up on him as God never gives up on us. He will be missed enormously by his little brother and best friend, Robby. Many, many people who had the plea-



sure of meeting Danny had the feeling that he was a very special little boy. And he was! His life, even though it was short, will give many other children a chance to live.

Danny taught us all to love fiercely and to laugh and to live like there's no tomorrow.

"PROMISE ME YOU WILL ALWAYS REMEMBER ... YOU ARE BRAVER THAN YOU BELIEVE. AND STRONGER THAN YOU SEEM. AND SMARTER THAN YOU THINK."

-Christopher Robbins

To read more about Danny or to make a donation in his name, visit www.StopSADS.org, Healing Wall.

From Danny's School

Danny was a member of room 16 and the Hillcrest Family. He was my kindergarten student. When my students and the staff at Hillcrest came together to think of how we could cope with the loss of such a joyful child, comfort came to use knowing that we could help more amazing children like Danny. The Hillcrest school donation came from the school staff, teachers, specialists, administrators, and even cafeteria workers donated to help the SADS Foundation. Students in Danny's class have a very special bookshelf filled with their

favorite book to memorialize Danny. Parents of Danny's classmates also donated money.

Raising the money and collecting it along with books for his school memorial came with heartwarming stories even from people who had limited interactions with him. All remember his smile and silly laugh. Donating really gave us in Danny's school community a sense of purpose and hope- that fewer teachers will have to see an empty desk or their students tears for a loss of a child due to SADS.

-Laura Lyons

Ambassadors are on-line!

Our new Ambassadors who were certified at our last training are now listed on our website! Visit www.sads.org/Awareness/SADS-Ambassadors to find an Ambassador in your area and connect with them! If you are interested in becoming an Ambassador yourself, the next training will be offered at our International Conference in November in Columbus, Ohio. Please register today to get a spot in this training program which will prepare you to make a huge difference in your community and you will save lives along with the SADS Foundation.

SADS Heartbeaters:

Devon Parrot and Nicole Bencie

Devon first started playing soccer when he was 3 ½. When he was in kindergarten he began playing baseball and basketball. He was invited to play up a year and was the youngest on his team. Devon also took pride in his speed and agility. He was one of the fastest kids in his grade and two grades above him.



Devon received ICD in June, and his family knows they have a struggle ahead of them. Devon looks forward to still playing sports such as golf, riding bikes, archery. He is looking forward to trying new things.

In December of 2012, Devon was leading the normal life of a 10 year old boy, when he fainted walking from one class to another. He was taken to his pediatrician and then for an EKG, and then for another EKG and an echocardiogram. It was determined that Devon has Long QT type 3.

The Lincoln, Missouri community has been outstanding in supporting Devon and his family. Devon's Beat 5K was a huge success. Only in its first year, it raised over \$7000 for the SADS Foundation and another \$3000 for local events.



Nicole Bencie, age 16, applied for and won a spot in a summer program at Oxford in England.

To read more about Devon and Nicole and see more photos, visit www.StopSADS.org

Bike the Drive

On May 26, longtime SADS volunteer Sharon Lentino, her husband, Jim and her daughter led a dedicated group of people on a 30-mile bike ride on the beautiful Lake Shore Drive during the annual Bike the Drive. This is the first year the SADS Foundation was officially recognized as a Charity Partner in the event, and our first year riders raised over \$1,500!



Keith L. Young Memorial Run

The 5th Annual Keith L. Young 2013 Memorial Walk/Run took place in Green River, WY on June 8th. It was a gorgeous June day and, as usual, the event was a big success – raising \$15,000 this year. Organized by Doreen Young, this race is held every year in memory of Keith Young, who died in 2008 while training for a marathon relay. He loved to run, and this race is a great way to honor this fine man!



Lemonade for SADS

Hi, my name is Makenna Chiaventone and I'm 9 years old. My sister's name is Giana and she is 3 years old.

My mom was getting ready to have a garage sale and I asked her if Giana and I could have a Lemonade stand. My sister Giana has Long QT Syndrome. I told her that money that was made selling Lemonade would be donated to the SADS foundation.

Here is a picture of us selling Lemonade. We were able to make \$40. I hope this helps.

Thanks for all you do to help kids like my sister and others with Long QT.

- Makenna & Giana Chiaventone



from the **TAPROOM** a live interactive webcast event

THE SPRING BENEFIT FOR SADS

5.23 5pm PT / 7pm CT

JEFF BLACK welcomes
GRETCHEN PETERS with BARRY WALSH
and DANNY FLOWERS

SADS FOUNDATION
www.stopSADS.org

CREDIBLEMEDS
powered by AZCERT.ORG

Stop SADS, Live Large Concert in Nashville

The talented Jeff Black, Danny Flowers, and Gretchen Peters with Barry Walsh performed an online live-streaming concert to benefit the SADS Foundation and Credible Meds Thanks to Kissy Black, there was truly beautiful music and a wonderful chance to enjoy a private concert in your own home! Look for more of these concerts to come!



SADS volunteer Shannon Kiss put on another great Annual Celebrate Wayne and Conquer SADS event in Atlanta! She raised over \$7000 in this wonderful event with an auction, great food and people, and live music.

She also had her own Climb to Conquer SADS up Stone Mountain. A group of 25 people walked up the mountain and raised their SADS flags.

Thank you, Shannon!

New Ask the Experts Q&A

With Dr. Prince Kannankeril from Vanderbilt Children's Hospital

"My 3-year-old daughter and husband have CPVT. How effective are the beta blockers they are taking?"

CPVT is a genetic heart rhythm disease which can cause a potentially life-threatening arrhythmia, typically during exercise, stress, or anxiety. Beta-blockers blunt the body's response to catecholamines, so it makes sense that they would be effective in CPVT, and they are recommended universally for anyone with a CPVT diagnosis.

We know that beta-blockers are very effective for many CPVT patients, but about 30% of patients on beta-blockers continue to have serious clinical events (syncope, cardiac arrest, or sudden death). That means the majority (70%) of CPVT patients do well with beta-blockers as their only medicine. Some data suggest, but do not prove, that nadolol is superior to other beta-blockers in CPVT. Most of us who treat CPVT patients use nadolol as our first choice. Nadolol is a good beta-blocker in general, as it can be taken once a day and has very few side effects.

For more information on CPVT and the rest of the article visit www.StopSADS.org. Watch the video on the SADS YouTube Channel.



Student grapples with heart problem, learns to triumph over numerous physical challenges

by Katy Hanna

My little brother saved my life. It sounds overly dramatic to phrase it like that, given that all he did was have a seizure, but he is likely the reason I am still here today. It is a big sister's greatest annoyance.

When my brother had his seizure, our family flew into a panic attempting to figure out why he had had one. Epilepsy was theorized, and he was sent to a neurologist, who referred him to a cardiologist. He was diagnosed with a disease called Long QT Syndrome.

Not many nine-year-olds have a cardiologist and beta blockers, medication that slows the heart and is typically given to older people, but all of a sudden, my little brother did.

Admittedly, I was jealous of the attention he was getting then. To my great disappointment, shortly before my 11th birthday, I was diagnosed, along with my father. For the first three years after I was diagnosed, I was lucky enough not to be a statistic.

Then, I had an event.

To read the rest of Katy's story, visit www.StopSADS.org, stories.

Full Family Care Model – Integration of Pediatric and Adult Care

As you all know, when diagnosing and treating SADS conditions, it's not only about the patient in front of you; rather, it's the entire family who will need quality evaluation and care. SADS is collecting best-practices and new ideas for integrating pediatric and adult care in channelopathies. In some cases the Pediatric EP (seeing the children in the family) and the Adult EP (seeing the parents) meet together to discuss the entire family. Others have a regular multidisciplinary clinic. Still other physicians see the entire family even though they are Pediatric EP physicians.

Do any of these models sound like your practice? How do you best serve the whole family with a SADS condition? Have you partnered with either your adult or pediatric counterpart? If so, we would love to hear about it. Send your information or comments to us at Christine@sads.org.

Our SADS Physician Referral Network includes many Pediatric EP's; however, finding appropriate adult referrals still remains a challenge in some states. If you work closely with an Adult EP in your state and could send us their name and contact information, we would love to reach out to them.

Physician Referral Network is Live!

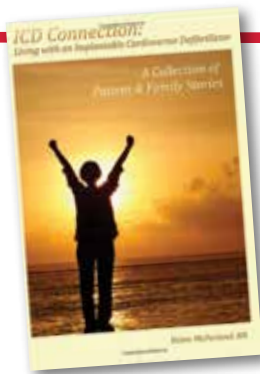
Are you looking for a second opinion or a good electrophysiologist for your family members in another state? The SADS Physician Referral Network is on the web (www.StopSADS.org, Physician Referral) and ready for you to search it! Go on and make sure your favorite EP or Cardiologist is listed. If you cannot find someone in your area, you can always call the SADS Foundation and talk to a real person who can help you find another option for a physician. If you are a physician, or if your physician is not listed, contact Christine Rice, Director of Medical Information.

ICD Connection

A New book available on Amazon

Ten ICD recipients and family members share, in their own words, their unique journey of living with an ICD, cardiac arrhythmia, and for some, sudden cardiac arrest. These personal stories represent a diverse collection of experiences from many perspectives such as age, gender, culture, and diagnoses. These ten authors offer advice, encouragement, and hope to others living with similar experiences.

The book was created and compiled by Helen McFarland, RN, University of Michigan Health System. As a device nurse, McFarland has provided follow-up care for ICD patients for many years.



The SADS Foundation exhibited at the National Association of School Nurses conference on June 27-28 in Orlando, Florida. Over 100 nurses signed the pledge to become SADS Nurse Champions!

Expert Consensus Statement on Diagnosis and Management of Patients With Inherited Primary Arrhythmias Syndromes

Worldwide panel of experts presents the first comprehensive recommendations on patients with inherited arrhythmia at Heart Rhythm 2013.

The Heart Rhythm Society (HRS), the European Heart Rhythm Association (EHRA) and Asia Pacific Heart Rhythm Society (APHRS), released the first comprehensive statement of recommendations on the proper diagnosis and management of patients with inherited primary arrhythmia syndromes.

“The complexity and prevalence of inherited cardiovascular diseases is growing, thereby creating a greater demand for the proper diagnosis and management of patients with these conditions,” said SADS Scientific Advisor Silvia G. Priori, MD, PhD, Fondazione Salvatore Maugeri, Department of Molecular Medicine University of Pavia, Pavia, Italy,

HRS Chairperson. “Clinicians and other healthcare professionals from around the world have come together to address this concern which is top of mind for our field.”

“This document is a great advancement for electrophysiology because it provides one, comprehensive and uniform recommendation on all rare arrhythmia syndromes,” said Arthur A. Wilde, MD, PhD, University of Amsterdam, Amsterdam, Netherlands, EHRA Chairperson and SADS Scientific Advisor.

For more information and to read the full statement, www.StopSADS.org, For Professionals section



SADS Awards Its 6th Annual Courts K. Cleveland, Jr. Young Investigator Awards

We'd like to congratulate this year's winners! In the category of Basic Science, David Auerbach, Ph.D., from the University of Michigan, mentored by Lori Isom, Ph.D., and for Translational/Clinical, Christian van der Werf, MD, Ph.D., from the Academic Medical Center in Amsterdam, mentored by Arthur Wilde, MD, Ph.D.

There were 13 phenomenal submissions and we would like to thank the review committee chaired by Dr. Charlie Berul including, Dr. Michael Ackerman, Dr. Joseph Atallah, Dr. Salim Idriss, Dr. Prince Kannankeril, Dr. Shu Sanatani, Dr. Maully Shah, and Dr. Gregory Webster.

ICD Sports Registry Initial Results

While current consensus statements recommend that individuals with ICDs refrain from sports, the safety of sports for people with ICDs has been unknown. In order to determine the safety of sports for people with ICDs, the ICD Sports Safety Registry identified people with ICDs who were participating in sports and followed them prospectively for up to four years. Initial results were published in the journal *Circulation* recently.

According to the paper, there were no occurrences of death or resuscitated cardiac arrest, or failure of the ICD to terminate an arrhythmia, or arrhythmia- or shock-related injury, during

sports in the study group. These results do not imply that it's safe for every person with an ICD to participate in any sport, but they do suggest that many athletes can participate safely. The decision to return to play after an ICD should be made together between a patient and his or her doctor based on that person's individual situation and current recommendations.

For more information about this paper (including the full manuscript) and the ICD Registry (which is still enrolling) visit www.StopSADS.org, For Professionals section.

CPR training in School

Texas is just one of the growing list of states to require students to take a CPR with AED training course as a requirement for high school graduation. Although there are many states that have introduced bills, currently there are only five states that have been successful in getting this legislation into law. They are Minnesota, Alabama, Iowa, Tennessee and North Carolina.



NSGC and NAME Pass Guidelines for Examining Sudden Death in the Young

The National Society of Genetic Counselors (NSGC) and the National Association of Medical Examiners (NAME) joined Forces and published a milestone position paper for the proper retention of postmortem samples, so that genetic testing may be an option in cases of sudden unexplained death in the young. In this paper, the authors conclude that Medical examiners and coroners not only have the responsibility of determining cause and manner of death, but also function as stewards of public health promotion and monitoring.

We'd like to thank the many genetic counselors involved in these publications and we are thrilled to see them passed and in print—at last!

Thanks Michelle Tipton!

Thank you to Michelle Tipton for speaking at the 2013 Annual UPCRA Spring Conference. Michelle shared her story, “Sudden Cardiac Arrest in the Young - A Personal Story,” about her son Shannon's death from sudden cardiac arrest in 1999. She spoke of her struggle to find out how and why he died—and what she could do to help her younger son, Dustin. After Michelle, Dustin, and Shannon were all diagnosed at the Mayo Clinic with LQTS, and after a series of ICD episodes, Dustin turned his health and his life around. In the Spring of 2011, he ran a full marathon!



Check www.StopSADS.org for the newsletter
to find links to the full articles and other
information from this newsletter.

Climb to Conquer SADS

This year, Dr. Chris Anderson and his stalwart team of mountaineers will be tackling Mt. St. Helens on September 15th. Twelve enthusiastic volunteers have raised \$1,000 each for the SADS Foundation in order to participate in this event. **Here's the challenge to SADS Families everywhere:** participate virtually! Join this extraordinary effort by sponsoring this team. It is easy and fun to raise \$1,000 and have your family's flag carried to the top of Mt. St. Helens. Contact Jan@sads.org for more information about your flag and tips to raise your \$1,000!



What's new on StopSADS.org?

- Ambassadors who were certified at our SADS Conference last year are now listed on our website!
- Physician Referral Network now online. Finding a doctor in your area that is knowledgeable about SADS conditions is now just a click away.
- New "Heart of the Matter" videos every month: experts in SADS conditions answer questions from you.

events

August 13	SADS Safe School campaign begins
September 1	Oktoberfest, Colorado Springs, CO
September 15	SADS Climb to Conquer SADS, Mount St. Helen, WA
September 29	Heartoberfest, Ballston Lake, NY
November 1-3	7th International Conference, Columbus, OH
November 23	Family Seminar, New York, NY

Chance to Win Quilt

Patty Vannoy, an RN at Fairfield Medical Center, donated this beautiful handmade quilt as a donation drawing prize.

Purchase tickets (\$2) at www.StopSADS.org/donate/Quilt-Opportunity-Drawing or at the International Conference.

