



## SADS Conference

Over seventy SADS patient family members met in Salt Lake City, Utah the last weekend in August to talk with experts about everything arrhythmia. Friday afternoon presentations reviewed the workings of the heart and it's electrical system, a discussion of the diagnosis process, and what ECG's can and cannot confirm. The QT interval measurement generated by the ECG equipment must be adjusted by the pulse, called the "corrected QT interval," before it can be considered to support a Long QT diagnosis. Even then, there is an enormous amount of overlap in measurements between QT intervals of patients without LQTS and patients with



*Susan Etheridge, M.D. and Michael Ackerman, M.D. Ph.D.*

Long QT. Drug induced Long QT was covered; current thinking is that genes not yet identified make some people more at risk of a prolonged QT interval while on certain medications.

Treatment options received a lot of attention both days. Beta-blockers are still the drug treatment of choice, but their side effects cannot be discounted. Depression is a not uncommon companion of these drugs, and patients experiencing the blues, trouble sleeping, appetite changes, and/or crying spells should talk with their doctor about changing medications. Other emotional issues surrounding Long QT included recognizing and dealing with the guilt that often accompanies losing a child or sibling, the emotional trauma of multiple ICD firings, and helping family members through the emotional ups

and downs particular to hereditary arrhythmias. Emphasis was put on recognizing that hard times and difficult emotions accompany most families with Long QT—whatever you and your family members are feeling, you are not alone, and on the importance of talking to your doctor about your emotional health as well as heart care.

Jill Hennessy joined us from Genaissance Pharmaceutical, makers of Familion<sup>®</sup>, the new genetic test available to assist with LQTS diagnosis and typing. Unpacking her sample kit, she explained the test process. The processing time for this commercial test



*Kathy Price, conference speaker from Texas  
Katherine Timothy, Utah SADS Board Member*

is approximately six weeks, enormously less than research labs need, and the Familion test is more sophisticated than the one used in many research labs. The test is pricey, although early experience with insurance coverage is promising.

Teens, many of whom were initially reluctant to attend the SADS teen conference, found new friends and learned a good deal too. With no parents allowed, kids had their own chance to talk with our coolest and hippest medical professionals about whatever was on their mind.

## Thanks to Volunteers!

The SADS Foundation conference would not have been the wonderful experience that it was without the dozens of volunteers who helped staff put all the pieces together. Physicians from SADS' board and Primary Children's Medical Center generously donated their time, as did our Teen Track facilitators—Julie and Kellie Kotraba, Matt Purvis, and Greg Astill. Keron Bailey, a two-time conference veteran, drove out from Nebraska to help staff again, this time bringing her sister-in-law Trish Whitaker. Thank you also to Sandra Stayer, here in Salt Lake, who logged many hours both before and during the Conference to make logistics flow smoothly. Conference attendees would have missed a great deal without all of your initiative, good ideas, and precious time.

## In This Issue

- Ryan Bill Update ..... page 2
- Teen Meeting ..... page 3
- Kara Mia ..... page 5
- AED Links ..... page 6



## Carl Joins the Foundation

I started working with the SADS Foundation the week of the annual conference that was held in Salt Lake City. This gave me the opportunity to meet some of you and become familiar with you who are and how important you are to the success of the organization. The conference also gave me a clearer understanding of LQT and the mission of the SADS Foundation.

My background includes experience in public relations, finance and event planning. Having worked with non-profit organizations in the past I am excited about the opportunity of getting to know everyone and helping out where I am needed.



Carl Malaret

## Good-bye Dave!

A big 'thank you' goes to Alice and other SADS staff for the enriching opportunity of working with the foundation and all of you over the last two years. Recently married (perhaps some of you remember Brynja—she was at the conference), we have made our home in Utah but outside of the Salt Lake City area. I leave the foundation, however, with many pleasant memories and experiences. Above all, I'll remember the admiration I feel for all of you. Whether you are grieving a family member lost to LQT, helping a child or sibling live with the effects of SADS, searching for answers surrounding the sudden death of a son, daughter, parent or friend, your courage, strength and tenacity have impressed me beyond words. Please stay in touch with the foundation. Ask for help and give suggestions. Keep up the great work of awakening the world to sudden death syndromes. I wish you all the best.



Brynja and Dave Wind

## Public Access to Published Research

It's time to drop the cost barrier to research developed using taxpayer dollars—given through the National Institutes of Health—and make it available through open access on the National Library of Medicine's PubMed Central database (online). This way SADS—and any of you—can get access to the newest articles reporting research findings without having to pay \$30 or more for each article or having to wait for a year or more until the publication releases the information.

We have been working with the Genetic Alliance and many other groups to encourage Congress and the NIH to make these papers accessible. We need to be able to search for all information in one place and not have to go to many different websites (and pay) to find what we need.

## Teague Ryan Sudden Child Cardiac Arrhythmia Syndromes Screening and Education Act of 2004

Congresswoman Carolyn McCarthy introduced this Bill last May (H.R. 4335), which would provide money for family support and screening. Many of you talked to your Representatives about supporting the Ryan Act and how it affects your family. The bill has since been "on hold" until after the elections. Some minor revisions will be made before re-introducing HR4335 after the first of the year.

We greatly appreciate your continuing participation in this effort. What the Congresswoman needs now are more sponsors for this Act. Current Sponsors are: Rep Israel, Steve [NY], Rep Kildee, Dale E. [MI], Rep King, Peter T. [NY], Rep Owens, Major R. [NY], Rep Rangel, Charles B. [NY], Rep Snyder, Vic [AR], Rep Strickland, Ted [OH].

If your representative is not on this list, please e-mail, call or write to ask him/her to co-sponsor HR 4335. This Bill will help us in our work to prevent sudden cardiac death in the young.

## “Life Chain” of Miracles

About a year after her father’s sudden death, Toni, her brother Jimmy, and I moved to Peachtree City, GA. On the morning of May 19, 1988, I called Toni to get ready for school. I knew she had not been feeling well the past few days. She had complained of a sore throat, and was stressing over her final exams. Toni went into the bathroom and, as she reached for the light, she quietly collapsed to the floor. She was unconscious—her skin an all too familiar color. Her father had passed out several times prior to his death, so when I could not rouse her, I screamed for Jimmy and dialed 911.

I then called our pastor and asked him to start a prayer chain. The fire station was just a few minutes away and Malcolm Cameron, a Peachtree City EMT, was in the shower. As he reached out of the shower for a bar of soap, his pager went off. He put on his clothes and headed to our house. He arrived wet with shampoo still in his hair. He had begun CPR when the ambulance and police arrived. Toni was revived several times with a defibrillator before she arrived at the hospital. Just as they entered the driveway to the hospital, Toni’s heart stopped again. On life support, she was unconscious for the next 17 hours. We did not know what had happened to her, if she would recover, or how long she had been without oxygen.

There is a little chapel at the hospital that I believe has a direct line to heaven. That is where we were when they came to say that Toni was finally awake. After the hospital ran numerous tests all with negative results, Dr. Blincoe, a cardiologist at Piedmont Hospital ordered an echocardiogram. When Toni’s father died of a heart attack, an echogram was done. Both results showed no problems. My husband’s mother had died suddenly in her sleep in 1937 when Toni’s father was only 3 months old. She had never complained of any illnesses. The death certificate stated that the cause of death was acute indigestion. She was in her twenties. With a long fainting history, my husband had agreed to extensive testing, but checked out okay. Then on an afternoon in November of 1986, he died of an apparent heart attack. Doctors ran similar tests on Toni with similar negative results. There were so many unanswered questions over the years.

However, this time there was finally an answer: Elongated Q-T Syndrome, or Long QT. It could be treated. Toni would most likely



Toni Scarbrough

live a healthy life. As we learned more about this strange disease, all the pieces began to fit. On that Sunday morning in May 1988, by the grace of God, my daughter recovered completely. The Lord blessed us with the greatest miracle of all—my daughter’s life. It was the Lord’s timing that caused Malcolm, the EMT, to reach out of the shower the moment the call came in. It has been a “life-chain” of miracles. Toni’s two brothers were tested immediately. While one showed some indication of the Long QT, the other did not. Both were prescribed a beta-blocker, as a precaution.

Robert Campbell, M.D. in Atlanta has tested all six of my grandchildren. Four of them have Long QT. With treatment, they have a better chance to live long and healthy lives. I hope the events since my husband’s death in 1986, and that day in May 1988, when Toni almost lost her life, and all of the events since, have played some small part in the great strides made in diagnosing and treating this mysterious disease. I will be forever grateful for the medical care given to my children and grandchildren. I am forever grateful for the Lord’s blessings in our lives.

- Carol DiGiulio, mother of Toni Scarbrough

### Stories

We love to receive all your stories and are happy to put them online and to publish a story (or more) in each newsletter. But, due to the limited space we have in our newsletter, we can’t always print your complete story. A good length for a printed story is 300–400 words. We will edit your story for you, if you would like, or you can send a shorter version with your main story.

*Please note that the Rachel Tomczek’s complete story, A Life Saved, A Life Given, is online at <http://sads.org/stories/index.htm>. We apologize for the inaccuracies.*

## SADS Networking Program

Have you ever wanted to talk to someone in circumstances similar to your own? Many people benefit from sharing information and insights with other parents who know the pitfalls, frustrations, and anxieties of a life with LQTS. SADS’ Networking Program provides that opportunity for people all over the country—or the world.

We currently have 89 people from 34 states enrolled and six other countries. You are welcome to join (and leave) the group at any time.

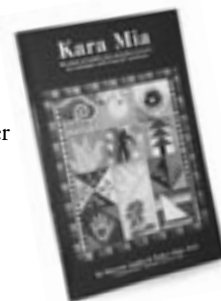
Just go to [www.sads.org/networking.html](http://www.sads.org/networking.html) to join the group. If you aren’t comfortable online, call Carl (1-800-STOP SAD) and he can get the information to you.

## Kara Mia

Many of you have seen or read the book, *Kara Mia* about a young girl’s experience with Long QT Syndrome. This very moving book is co-written by SADS board member, Dr. Walter Allan, and was originally sold through the SADS Foundation and the publisher’s website. It has been out of print for over a year but is now available online in electronic ebook format for free. (A donation to the SADS Foundation is requested.)

“This is a stunning account of a partnership between a family, a physician and their medical/social communities in their journey to unravel a genetic mystery and its impact on them all.” ...Dale Halsey-Lea, R.N., Senior Genetic Counselor, Foundation for Blood Research, Scarborough, Maine.

The ebook can be found at: <http://home.gwi.net/seahorsepress/>. Follow the links on the page to get to the eBook edition of *Kara Mia*.



## Dr. David Jones—Principle

*Kick Off Speech New School Year includes: (for complete transcript go to our website [www.sads.com](http://www.sads.com))*

I spend my day as a middle school principal, guiding the physical, emotional and intellectual development of children between the ages of 10 and 15. Statistics continually show that schools are the safest place a child can be in our nation. Safer than the mall, safer than at home, safer even than asleep.

An average middle school has 900+ students and over 100 adults, all sharing the same roof, oxygen, unique culture. We tend to know the medical issues of our kids and staff well—although always the undiagnosed heart problem is a concern. We also have 50 visitors a day—deliveries, parents and grandparents—picking up children for dentist appointments, families attending a band concert.

A school principal has a basic duty—never violate the trust a parent has placed in you to keep their child safe. It far outweighs the quality of teaching and learning, class size, etc. Lose a child, and there is nothing you can ever do to bring the child back.

Students learning CPR and how to use an AED at school may help save a life. It also does something else for secondary students, which is harder to measure. In a world where decisions are mostly made for them, where it is frequently impossible to feel much power to effect positive change in a big way, it gives each student the skills to save a life. We tell them: “You are trained and trusted. You have value; you can be somebody.”

Last summer Tanner, Scott and Taylor were playing on a rope swing just east of my school. Taylor lost his grip and fell 40 feet—fell on his back—went unconscious. He stopped breathing. Scott called 911 on his cell phone and ran to direct the EMTs to the spot in the forest where Taylor lay, while Tanner bent over his friend and began CPR. Terrified? You bet. Did he do it too fast or too slow? Probably. But, faced with the unconscious body of his friend, Tanner went lip to lip for over 15 minutes. Counting out his chest compressions and keeping oxygen flowing to Taylor’s brain.

Tanner made it real—he used his training to save his friend’s life.

*Our thanks to Kendall Berry for sending this speech by Dr. David Jones for the SADS Foundation to share. We recommend you access full text of this speech and share the need for CPR and AED training with your families and community.*

## Some AED Resources Online

### National Center for Early Defibrillation

<http://www.early-defib.org>

Information and news about AED programs around the country; including how to start an AED program in your community. Also staff consult and will answer questions.

### Project A.D.A.M

<http://www.chw.org/display/PPF/DocID/6050/router.asp>

Project ADAM helps schools start and sustain their own automated external defibrillation (AED) programs. Services include everything schools need to plan, fund and develop their program, including planning templates, access to AED and pediatric health care professionals at Children’s Hospital of Wisconsin.

### Chain of Survival-American Heart Association

<http://www.americanheart.org/presenter.jhtml?identifier=3011804>

### AED Information-American Heart Association

<http://www.americanheart.org/presenter.jhtml?identifier=3011859>

### AED’s Approved by the FDA with links to the company that manufactures them

<http://www.americanheart.org/presenter.jhtml?identifier=3024008>

### State Activities

<http://www.ems-c.org/State/framestate.htm>

### Kids Defib—a registry of AED use in children

<http://www.kidsdefib.com/about.html>

### The National Registry of Sudden Death in Young Athletes

<http://www.suddendeathathletes.org/>

### You Can Make a Difference

Making a difference that would affect many people is something I have thought would be exciting to do. I never dreamed I could make this happen as a 16 year old.

To view the full story, go to [sads.org/stories/index.htm](http://sads.org/stories/index.htm)

- Kellie Kotraba

# Living with Long QT Syndrome

For the child and the whole family, LQTS changes life. We know that LQTS may change your family's life but it needn't become your family's life.

Young children may not understand the changes and restrictions that a LQTS diagnosis brings to their life. Common reactions among children include a feeling they are being punished for disobedience, feelings of shame or guilt and a fear of death.

These reactions may prompt your child to act with hostility toward you, feeling that somehow you have failed him or her. Because children think their parents are all-powerful, your child may believe you can make the LQTS go away.

One of your most important jobs the parent of a child with LQTS is to supervise, encourage and foster the independence your child needs to successfully manage LQTS. Try to avoid being overprotective. Overly protective parents undermine a child's self-esteem.

Self-care is the key to the development of a child's independence and self-esteem. Get your child involved in self-care as soon as he or she is able to master self-management tasks and is emotionally ready.

Adolescence is a tough time for your child—and you. Teens are constantly changing and working toward independence. Understanding and recognizing the limits of your control are key elements in helping your teenager with LQTS work through the challenges of adolescence. Areas of special importance are:

- Understand the Need for Control. Teens want to be masters of their own lives. They want to define their own identities. To accomplish these objectives, they have to keep testing their limits. You can help show how they can use the discipline and control of LQTS to gain strength and mastery in other parts of their lives.
- Recognize the Limits of Your Control. Be realistic. Accept the fact that you can't watch over your teen every minute of the day. You, too, have to learn that it's your child's LQTS, not yours.

You're not alone in your struggle, and there's no reason to feel alone. Get involved in SADS Foundation meetings or another support group and a LQTS organization. Your child will benefit from talking with other young people with LQTS, and you will benefit from sharing information and insights with other parents who know the pitfalls, frustrations, and anxieties of a life with LQTS.

Adapted from information produced by the Juvenile Diabetes Research Foundation International.



*Back left: Matt Purvis, Caroline Haury, Kellie Kotraba, Tiffany Stayer, Greg Astill, Mallory Nault, Julie Kotraba  
Front left: Megan Danna, Kari Kotraba, Jessica Danna, Jaeger Ackerman, Joseph Butcher, Colleen Domdero*



*Julie Kotraba, Kellie Kotraba, Jessica Danna, Tiffany Stayer, Mallory Nault, Eliana London, Joseph Butcher, Matt Purvis, Caroline Haury*

## Teen Session 2004 is a Big Hit

At the 2004 International SADS Conference in Salt Lake City, teens 10 through 18 years old came together from around North America for the first SADS Teen Session. Though apprehensive at first, hearts were joined by the bonds of friendship after just two days of getting to know one another. According to one participant, making these new friends was the best part of the conference.

When asked to give one word to describe her experience, one girl replied, "Fun." The fun started on Friday afternoon with a trip to Kamp Kostopolos. Teens began getting

to know one another as they caught fish and later conquered the low ropes course. Saturday began with games that allowed participants to get further acquainted. CPR/AED Training was next; included in this was hands-on practice with newly acquired skills. After a short break, Dr. Etheridge spoke about how the heart works, and teens enjoyed the opportunity to have their questions answered. Peer to peer discussions, games, and a poster contest kept lunchtime entertaining. After each artist received an award for his or her creative poster design, it was time to sit back and listen to the teen leaders. The leaders,

university students Greg Astill and Matt Purvis, along with high school junior Kellie Kotraba, shared stories of obstacles overcome, strengths gained, and hopes for the future. When Dr. Vincent joined the group, he addressed tough questions teens had written earlier in the day. Dr. Bradley then asked for teens' advice on how to address issues that other adolescent LQT patients face. As the day came to a close, teens exchanged addresses in hopes of keeping in touch. They came as strangers, but they left as friends.

*- Kellie Kotraba*

# SADS Foundation Heroes

## In the past year, gifts have been made honoring....

The Abell Memorial Run  
Evan Balzer  
Mary Frances Balzer  
Eric Balzer  
Thomas J. and Lorraine Barber  
Robin and Steve Berger  
Victoria Brown  
Cyndi Chambers' "Long Run for Long QT"  
W. E. Chambers, Jr. and Family  
T. Jay Christenson  
Kyle Dollman  
Bernadette Driscoll  
Wendy & Matthew Duncan  
Excel Personnel  
Denise Falzon & Family  
Brian Falzon Memorial Road Rally  
Susan Figenshu  
Matthew Gane  
The Gardner Family: Michael, Ryan, Terri, and Wes  
Dr. and Mrs. Robert Gough  
Michelle Haas  
Elizabeth Hermanson  
Chris Hill  
James T. Hoey  
Tania L Hyatt-Evenson  
James and Rachel Irvine  
Trenton Jay Johnson  
Marissa Jones  
Lorraine Linder  
Bobby and Jacqui Lorenz  
The Mann family  
Betty Glenn Marino  
Allison Mishkin  
The Myers family  
The 9/11 Victims  
Kayci Ogden  
Laura O'Hare  
Mr. and Mrs. Eric Pearson and their

daughter  
Edith Plotkowski  
Nathaniel P. Rivard, Jr.  
Fraser Rowell  
Linda Shockley  
James Simpson  
Kyla Smith  
Dick Stafford  
Bob Taylor and Family  
Edward F. Turek  
Dale and Vicky Turner & Pacemaker Motorsports  
Erica Turner  
Emily Voigt  
Emily Warren  
Molly Weingartner  
Kristen Williamson

## And gifts have been made in loving memory of.....

Brian Abell  
Christian B. Acosta  
Chickie Newby Bagosy  
Jordan Alan Baker  
B. Patrick Berg  
Darlene Bloomfield  
Challis Blum  
Caleb Bohman  
Danielle Brender  
Eric Brown  
Kimberlee Butler  
Sarah Callister  
Carson Patrick Coale  
Erik Carlson  
Laura, Elaine & Mary Carpenter  
Jennifer Cassell  
Matthew Chiappetta  
Henry Clark  
John Phillips Conway  
Ed T. Cox  
Albert DeStefano, Jr.  
Chad Eatherly  
Melissa Euken  
Phyllis Anne Hoover Faires  
Brian Falzon  
Nickolas Garner  
Patricia Gill  
Jeanette Gray  
Don Haag  
Ruth Harrison  
Elizabeth Hart  
Donna Holliday  
Beverly Ruth Hoover  
Patrick John Hughes  
Kristin Jacobs  
Carie Jean  
Graeme Jones  
Adam J. Kausak  
Tyler Kelley  
Donna Kelly  
Richard Kessler  
Michael Kilgore  
Heidi Anne Kintana  
Kellie L. Larivee  
Arthur Lawrence, Jr.  
Billy Levy  
Michael David London  
Dr. Hamid Mahmoudzadeh  
Johnny, Kevin and Ginger Mann  
Heidi Marx  
Billy McClellan  
John McKernan  
Kathleen Menger  
Bess Mihalek  
Evelyn Mitchell  
Marie Newman  
Victor A. Nigro  
Elizabeth O'Hara  
Kari O'Rourke  
Betty Osborn  
George Paglia  
Melissa M. Parker

Kara Philbrick  
Wil Pieper  
Marc Pitluck  
Brian Price  
Emilie Puricelli  
Skyler Clark Renke  
Jonathan Respass  
Corrine Prince Rider  
Gerri Ritter  
Nathan Ruud  
Ilana Schaffer  
Frieda Shapira  
Kellie Shockley  
Casey Shockley  
Lindsay Shockley  
Caroline H. Shore  
Joseph Slota  
Stephen A. Smith  
Andrew Stafford  
Wanda Louise Stasnek  
Doug Stepp  
Jeffrey Peter Stiefeld  
Sarah M. Stier  
Craig Allan Stille  
Kenneth W. Storm  
Ashley Sword  
Helen Szostak  
Daniel C. Talomie  
Melissa Sue (Brown) Titas  
Edward VanArsdale  
William Vande Waerdt  
Jacquelyn Christine Waring  
Jennifer Christine Waring  
Mark E. Weiss  
Dr. John A. White  
Brooke Whitworth  
Caleb Wuerzburger

*Gifts made between 7-2003 & 6-2004. Please contact Sarah@sads.org with errors.*

## SADS Joins the New Sudden Cardiac Arrest Alliance

In July, Alice Lara attended the Sudden Cardiac Arrest (SCA) Forum hosted by the NCED and the Congressional Heart and Stroke Caucus in Washington DC. Senator Russ Feingold (D-WI), Representative Lois Capps (D-CA), and Representative Cliff Stearns (R-FL) shared their perspectives about the need to prevent deaths due to SCA. We also heard excellent clinical presentations by Bruce Wilkoff, MD, and Terry Gordon, DO, FACC, and the personal testimonies of Fred Anklam, Paul Neill and Karen and John Acompora. More than 100 people attended the Forum, including members of NCED's SCA Survivor Network, Congressional staff, and representatives of the Food and Drug Administration (FDA), the Centers for Medicare and Medicaid Services (CMS), and many patient associations and professional organizations.

We also participated in a post-forum discussion on the formation of a Sudden Cardiac Arrest Alliance. During the meeting, we agreed to form an alliance of healthcare, public safety and consumer organizations interested in working together to bring greater national attention to the problem of sudden cardiac arrest and survival solutions.

We hope that as the Alliance continues to grow we will be able to create, through collaboration, a collective voice that will bring much greater attention at the national level to the serious public health problem of sudden cardiac arrest.

# SADS in San Francisco

What a super conference—and great contacts SADS made! May 18th we held a family support seminar in San Francisco in conjunction with the Heart Rhythm Society's (HRS) Annual Conference. We had a panel of physicians—both local and from across the country—and a roomful of family members (including some kids). For the first time, we partnered with the Hypertrophic Cardiomyopathy Association (HCMA) to hold this meeting. What a great turnout! We had about 50 people plus the staff of the SADS Foundation, the HCMA & the panel. Questions were asked about both the Long QT Syndrome and Hypertrophic Cardiomyopathy—about diagnosis, treatment, genetic testing, lifestyle changes, etc. A big thanks goes to our volunteer coordinator, Kathy Blum and to our physician panel: Dr. G. Michael Vincent, Dr. Michael Ackerman, Dr. Barry Maron, and Dr. George Van Hare. As a participant said,



“It really does help to hear that other people have the same questions and fears that you do. We all have to learn to make decisions when it comes to what our kids can do. I came away from that night with a

feeling that I need to let go of the fear I have for my son. I don't want to transfer that to him. I want him to live a happy and full life and be able to try new things without worrying about it.”

—Susan Guzzetta, Mom

For the rest of the week, the SADS staff and many local volunteers staffed our booth at the HRS conference. Again, we worked with HCMA and had a fantastic joint booth with over 200 visitors who wanted more information and many more who took our packet (& the HCMA packet) and went online to request information. It was well worth the time and money to educate so many physicians and meet with SADS Advisors and industry representatives!

Much thanks to our booth volunteers: Debbie & Rob Purvis and their son Matthew, Jorge & Kelly Villarreal, Kathryn Blum, R.N.

New things learned at the conference:

- Genetic testing now available from Genaissance
- Wilson Greatbach (makes ICD batteries, etc.) working on a new technology to protect from cell phones; see Medtronic & Guidant links below for ICD precautions:

<http://www.guidant.com/patient/living/>

<http://www.medtronic.com/>

## Notes from the Genetic Alliance Annual Conference in Washington, DC, July 28, 2004

Volunteer advocates, genetics health professionals, pharmaceutical and biotechnology executives and nonprofit managers gathered for three full days to network and learn from each other and the experts. This year featured a number of day-long workshops. One participant articulated a common theme – declaring that she appreciated the “incredible broadening of my experience and knowledge through presentations and discussions with similar organizations and the discovery of new ways to achieve our mission.”

### A Few Outcomes from the Conference:

- Mercy Medical Airlift information for people needing help to get to their physicians appointment or to a conference
- Discussing a joint booth with the Barth Foundation at the health fair at Kennedy Space Center in October
- Getting super information from a staff member of another nonprofit about a fantastic volunteer structure to help SADS utilize volunteers more effectively
- Meeting and discussing issues with directors at the National Institutes of Health, the CDC, the FDA

These meetings included a lively discussion about race in science and society, led by Dr. Harold Freeman, Director of the Center to Reduce Cancer Health Disparities, National Cancer Institute, NIH. Participants also discussed ways to improve access to culturally- and linguistically-appropriate genetics resources and services.

*The Genetic Alliance is an international coalition of over 600 genetic advocacy organizations, academic and industry professionals. Its mission is to increase capacity in genetic advocacy organizations to achieve their missions and to leverage the voices of the millions of individuals and families affected by genetic conditions.*

## Study says Children with ICDs Can Attend Camp with no Problems

Maria Martuscello, RN, BSN and Charles I. Berul, MD from Children's Hospital in Boston conducted a four-year study of children (ages 7-18) with and ICD or a pacemaker who attended their camp. These children (35-45 each year) were allowed to participate in all activities (basketball, swimming, archery, ropes, rock-climbing, etc.) and they had no inappropriate shocks, broken leads, etc. The conclusion is that children with ICDs and pacemakers can attend camp and safely participate in organized activities.—Abstract from the Heart Rhythm 2004 Annual Scientific Sessions.

## Researchers discover another gene causing a severe form of LQT

Calcium channel gene dysfunction causes Timothy syndrome, a multi-system disorder including arrhythmias, syndactyly (webbed fingers &/or toes) and autism.

Collaborative efforts of researchers from Harvard Medical School, University of Utah, University of Pavia in Italy and Boston University School of Medicine identified a calcium channel gene mutation which underlies the cause of the devastating syndactyly associated LQT disorder, Timothy syndrome, named in honor of Katherine Timothy for her distinguished career as a scientist studying the causes of cardiac arrhythmias.

The discovery of this mutation and understanding of its function enhances our understanding of the mechanism of calcium metabolism not only in cardiac cells but also in the fundamental development and physiology of humans.

### Please join us

for a seminar for families impacted by heart rhythm disorders (LQTS, etc.)

The evening of Wednesday, October 27, 2004  
**Omaha, Nebraska**

For more information or to RSVP, contact Gwen Davis  
Phone: 1.800.STOP SAD Email: [gwen@sads.org](mailto:gwen@sads.org)

### Tips for Parents

- Believe what your teenager is telling you
- Be a supportive listener
- Support your teenager in learning how to make their own informed decisions
- Your child will make mistakes. Gently support them in learning from their own mistakes
- Advocate within the school and health care systems or find someone who can
- Document conversations and meetings regarding your child and the requests made for special accommodations within the school and health care systems
- Join groups of other parents for support

