



## Seminar Provides Support to Local Families

The SADS Foundation, in conjunction with the University of Nebraska Medical Center, held a Support Group Seminar entitled "Families Impacted by Sudden Arrhythmia Death Syndromes." The event was held at the Medical Center in Omaha, Nebraska on the evening of Wednesday October 27, 2004.

Dr. Michael Vincent from LDS Hospital and the President of the SADS Foundation along with Dr. Christopher C. Erickson and Dr. John D. Kugler who are both with the University of Nebraska Medical Center made up the panel at the seminar. They provided answers to families and cardiac nurses that clarified and explained the challenges of diagnosis, treatment and living with LQT and other cardiac arrhythmias, and stayed until every question was answered.

The event fulfilled its mission of increasing public knowledge of heart rhythm abnormalities. The seminar also answered specific questions families had in order to make informed medical decisions and live with the challenges of these conditions.

The event had a good turnout; 42 people attended the seminar with over 125



handouts being distributed that included the warning signs of LQT. The warning signs of Long QT were also posted at the conference.

We thank the generosity of St. Jude Medical Center, which ensured that there were plenty of refreshments.

Dr. Michael Vincent spent several days at the University of Nebraska Medical Center to speak at a Cardiac Dinner and Grand Rounds following the seminar.

The SADS Foundation will be partnering with various agencies and hospitals throughout the country to provide more family support seminars during 2005 similar to the one held in Nebraska.

### Upcoming SADS Family Support Seminars/Conferences in 2005

Long Island .....	March 14
New Orleans .....	May 3
Philadelphia .....	May 21
Vancouver, Canada .....	June 4
Ottawa, Canada .....	September 24
Chicago (Mini Conference) .....	October 22
Dallas .....	November

For up-to-date info on upcoming seminars, send Carl your e.mail address (carl@sads.org).

### WARNING SIGNS

Your child should be seen by a doctor if she/he has:

- Family history of unexpected, unexplained sudden death in a young person
- Fainting (syncope) or seizure during exercise, excitement or startle
- Consistent or unusual chest pain and/or shortness of breath during exercise

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**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 Board Changes

Susan P. Etheridge, M.D. is an Associate Professor, Department of Pediatrics, University of Utah Division of Pediatric Cardiology and Pediatric Electrophysiology and the Director of the Electrocardiography Laboratory at Primary Children's Medical Center. She is also the Director of the Pediatric Cardiology Fellowship Program. Dr. Etheridge has been a SADS supporter, volunteer and contributor for many years—most recently directing and speaking at our 3rd International SADS Foundation Conference last summer. Dr. Etheridge is a Pediatric Electrophysiologist and an active researcher in

Long QT Syndrome, among other conditions. Dr. Etheridge volunteers every year on a medical mission in a 3rd-World country.



*Susan Etheridge, M.D.*

We welcome Dr. Etheridge and look forward to working with her more closely in the future!

We would also like to thank Dr. Victoria Judd for participating on our Board for the past 2 years. We wish her well in her new endeavors with the Student Health System at the University of Utah.

## Research—Thanks for Your Help

From time to time we publish a call for volunteers to participate in research. By participating in various studies, you and your family have the chance to make a difference for everyone. For instance, we recently reported on a new condition, Timothy's Syndrome, which was discovered when studying some of our families. This has potential implications for LQTS as well as for autism. Here's some follow-up on recent studies advertised in our newsletter:

### Dr. Keating's study (Katherine Timothy)

Katherine had 22 people contact her after reading about the Keating study in our spring newsletter—what a great response! To date, 4 of these families are enrolled in this important study with several more families pending.

### Drug-Induced LQTS study (Dr. Roden)

While it was not nearly as successful as we had hoped, we did receive 6 inquiries as a result of having posted it on your website. However, none of the 6 that contacted us went on to qualify for the study, largely because they actually have congenital LQT (though there was also one case of LQT in a 16 year old and our minimum age is 18).

### Emotional Triggers of Cardiac Arrest study (Dr. Lane)

This study is ongoing. We have had several calls from people who heard about us on the SADS website, but we have been having difficulty finding people who have had a cardiac event within the past three years, are interested in being interviewed about it, and meet other study criteria.

These studies are still recruiting volunteers. "For more information, send Carl your e-mail address (carl@sads.org) or 1-800-STOP SAD.

## Drugs That Prolong the QT Interval and/or Induce Torsades de Pointes

This list is maintained by Raymond L. Woosley, MD, PhD, Director, Center for Education and Research on Therapeutics, University of Arizona; President, The Critical Path Institute (woosleyr@u.arizona.edu).

## Updates to the QT Drug Lists

**These drugs have been removed from the list:**

- Zolmitriptan
- Sumatriptan
- Naratriptan

**These drugs have been added to the list:**

- Roxithromycin
- Gemifloxacin
- Ofloxacin
- Solifenacin
- Citalopram

**A few notes about the Lists:**

Drugs are listed with up to 2 common brand names. There are many more brand names for some of the common drugs, such as pseudoephedrine and erythromycin. It is also important to look at the list of active drugs in medicines that contain a combination of drugs such as Zyrtec-D®, which contains pseudoephedrine. This means that you must look up each ingredient of the drug to see if it is on this list.

*The University of Arizona Center for Education and Research on Therapeutics  
Arizona Health Sciences Center, Tucson, Arizona  
85724-5018*

# Personal Fundraising Pages for SADS Fundraising Volunteers!

## SADS supporters: You can raise more money with less effort!

Running a marathon or participating in a cycling event and want your efforts to benefit the SADS Foundation? Or do you want to celebrate a birthday or anniversary and ask friends to join you in supporting SADS? We've joined with JustGiving.com in an effort to provide SADS volunteers with more easy ways to help us raise funds and share their stories. Thanks to JustGiving's innovative online Personal Fundraising Pages, you can now raise money for the SADS Foundation around just about any event, or with no event at all. Through these pages, SADS is able to combine the passion of supporters like you with the power of the Internet. We invite you to join the online fundraising revolution!

Getting started is easy. It only takes a few minutes to create your Personal Fundraising Page, and you customize the text and the photo on the Page to suit your passions and your purpose. Then, just e-mail the link out to your friends, family, colleagues – anyone you think will help you reach your goal. Personal Fundraising Pages are passionate, powerful, and persuasive, and you will raise more money, with less effort.

## Check out these great Personal Fundraising Page examples:

[www.justgiving.com/pfp/pages/default.asp?id=cgg/13913](http://www.justgiving.com/pfp/pages/default.asp?id=cgg/13913)  
[www.justgiving.com/pfp/pages/default.asp?id=cgg/13782](http://www.justgiving.com/pfp/pages/default.asp?id=cgg/13782)

## Get started:

Go to [www.justgiving.com/sadsfoundation](http://www.justgiving.com/sadsfoundation) and set up your page today!

We believe Just Giving offers volunteers an easy, clear, free, and secure way to share their family's story with friends, co-workers, and family while helping to raise money for the SADS Foundation's programs. Funds raised will help us expand family support services and the community awareness program.

## If you have any questions:

Contact Margaret Berwind-Dart at Justgiving 781-863-6166 or [Margaret@justgiving.com](mailto:Margaret@justgiving.com) or Sarah Marsden at the SADS Foundation 1-800-786-7723 or [sarah@sads.org](mailto:sarah@sads.org)

## Other giving ideas

### Many employers MATCH employee donations.

Please check with your manager or human resources department to see if they will match your gifts to the SADS Foundation. Recent Matching gifts have come from:

Abbott Laboratories	Microsoft
American Express	PG&E
AT&T Wireless	Starbucks
International Business Machines	TAP Pharmaceutical Products
J.P. Morgan Chase	Tenet Healthcare
Merrill Lynch	

### Earn miles while saving lives!

More and more of you have asked us to charge your credit card monthly for a modest gift—and we're quite happy to! Monthly giving allows you to make a generous gift a few dollars at a time, without as much damage to the monthly budget. Sarah Marsden or Carl Malaret in SADS' office (800-786-7723) are able to take your Visa, MasterCard, or American Express information for a monthly gift of \$10 or more.



## Octoberfest!

This past October, 300 of Bill and Sally Layton's closest friends got together in Colorado Springs for the 7th annual Octoberfest to benefit the SADS Foundation. Over the years, this party has grown from a modest barbeque into a serious, multi-grill fundraiser. This year, the organizing team added an auction, which provided Colorado Springs' businesses a way to contribute, and guests more ways to donate to SADS. Thanks to all the Octoberfest volunteers for putting on a great party to save lives from SADS!

## SADS Affiliates

### SADS UK Happenings (<http://www.sadsuk.org/>)

#### Arrhythmia Awareness Campaign, May 2004

This national campaign, organized by SADS UK, STARS, the Cardiomyopathy Association, the British Cardiac Patients Association and Medtronic Ltd, was a huge success—especially for the first year!



#### SADS UK & Oxford Genetics Knowledge Park Conference, June 2004

*Cardiac Arrhythmias, Research and Therapy; A holistic approach*  
A wonderful mix of people—both family members and professionals—made this event informative for everyone.

#### Arrhythmia Alliance Conference, 1st July 2004

Royal College of Physicians—SADS UK was invited by the British government to attend this prestigious event to help develop guidelines for arrhythmias diagnosis.

### SADS Canada Happenings (<http://www.sads.ca/>)

SADS Canada: members are doing major fundraisers (golf tournament, walk) for the first time and very successfully.



Their new newsletter showcases some of the many stories they have to share. Many of these families have also talked to the media and, thus, helped SADS Canada spread awareness.

Approximately 70 people attended the SADS Canada Conference in Toronto in October 2004. They are planning to hold two Family Seminars this year—in Vancouver and Ottawa.

They have also begun piloting a program to work with Public Health Nurses in the schools to increase the awareness of the warning signs.

### SADS Australia Happenings (<http://www.sads.org.au/>)

SADS Australia has been very busy with fundraisers this year—from community benefits to trivia nights to participating in “Shop for a Cause Day.” They now have about 20 support contact people (and families) across Australia and New Zealand.



Recently, they got a portable defibrillator donated to a local school and presented it on January 24th.

QT (Cutie) Kanga is still traveling around the world but will soon be a part of a book of Kanga's adventures. They will also be publishing a website about Kanga shortly, which will include the odd journal entry here and there, a photo album and a ‘postcards from Kanga’ section.

## Mary K. Elizabeth Butt

Oct. 24, 1994-May 3, 2003



My daughter Mary was a happy, healthy 8 - year old. She was in second grade and very involved in school and church. She loved reading and helping her friends and teachers in any way possible. Mary played soccer, baseball, sang in the church choir, and played in the church bell choir. She was a very talented artist. She loved to draw and paint, and went to art camp for the first time the previous summer.

Mary was my oldest child and only daughter. She loved being the oldest and was great at helping her two younger brothers in a variety of ways. She also loved to tease them at times. Mary loved to help me clean the house and do the laundry. Mary was a huge animal lover and adored her cat Tigger, and our family dog Daisy.

On Saturday, May 3, 2003 the life of our family changed forever. Mary was playing in the front yard with her brothers and cousins, when she suddenly collapsed for no reason. A heroic attempt was made to try and resuscitate her and she was life-flighted to Children's Hospital in Columbus, Ohio. The efforts to save her were not successful. Mary died that day, and we had no idea why.



Up to this point Mary was perfectly healthy and had never had any warning signs that anything was wrong. The doctors ruled her cause of death as a cyst on her pineal gland the size of a pea. There were other doctors who did not buy into this cause of death. After six months of meeting with doctors and talking to many friends in the health profession, I was directed that her cause of death could have been heart related. The SADS web site put the final pieces of the puzzle together.

Continued on page 5: *Mary*

Mary: Continued from page 4

Since November of 2003 my father, brother, niece, nephew, and myself have been diagnosed with LQTS. My father, brother and myself all had ICD's implanted and my niece and nephew are currently on beta-blockers. We also discovered during this process that my sister, also named Mary K, died because of LQTS seventeen years earlier.

On the one-year anniversary of my daughter's death we held a walk in her memory. We raised over \$12,000 and used the money to purchase five AED's for the local schools and donated a portion of it to the SADS Foundation to help raise awareness. Although my family has gained life-saving information because of my daughter's death, there isn't a day that goes by that we don't wish that she were still with us. Her winning smile and big brown eyes will forever be etched in our memory. She will live on forever in the hearts of everyone she knew.

## Stories

We love to receive all your stories and are happy to put them online (<http://sads.org/stories/index.htm>) and to publish some of these stories 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.

If you are interested in organizing a

### SADS Foundation Family Support Group

in your area

Please contact Gwen at  
[gwen@sads.org](mailto:gwen@sads.org)

More information/definition can be found on our Website at [www.sads.org/services](http://www.sads.org/services)

## Amanda Swyers

I never questioned why I walked into the gym every morning before the sun rose and left after dark. I wanted to spend all my time training so I could make it to the WNBA because basketball was the one thing I loved. I became so caught up in this goal that tournaments, practices, extra training, and camps became the driving force in my life causing me to give up hobbies that I genuinely enjoyed so that I could fully dedicate myself to basketball. I thought that I was putting my whole heart into it, but ironically it was my heart that forced me to wake up.



It all started at practice one Sunday afternoon in November of 2002 while I was shooting hoops my head started spinning. I sat down on the bench with my mother and told her things were spinning a little. It went away and I didn't think much about it, then it happened again, this time while I was running drills with my basketball team at St. Francis. I couldn't catch my breath; we thought that I was having an asthma attack. My mom took me outside for a walk and got me breathing normal. The next morning playing with my dog I again had the dizzy spell and almost blacked out. The next week my mother forced me to go to the doctor.

My pediatrician, Dr. Arthons, at the UC Medical Center in Auburn was on top of things. After my mom explained what had

happened over the last couple of days and knowing my athletic background she immediately did an EKG. I had no other symptoms and a rather slow heartbeat, which is normal for athletes. She read the EKG and said sorry I'm taking you off all physical activities until I can ship this to the medical center's pediatric cardiologist for a second opinion.

It didn't take long for the cardiologist's office to call and make sure that I was not taking part in any physical activity at all. They needed to run more tests. Dr. Parks at the UC Medical Center gave me the bad news that I had Long QT Syndrome. She immediately started me on beta-blockers. In the meantime she scheduled the surgery for the ICD. It took me three months to get used to the medication. Keeping up seemed like a constant battle with everything while I adjusted to it. With the support and encouragement of teachers and friends I was able to get through this difficult time. It was a feat keeping my grade point average from dropping and keeping my chin up through all the intense stress.

I started taking piano lessons, I took up horseback riding lessons, even tried tap dancing, and anything to fill the empty space that was left with no basketball. Finally, I found joy in volunteering for community service tutoring after school program kids with their homework. By focusing on this group of kids it took my mind off of my losses and made me realize I could survive. They have shown me where my true calling is as a teacher. There is a basketball court right outside the place I tutor and the kids would go shoot around when their homework was done. As time evolved I found myself out there tutoring them in basketball. I am back on the court. Maybe not in the way I thought I would be, but I find coaching just as rewarding as playing.

I would have never discovered my artistic talents; my teaching and coaching talents had this life event not taken place. I won't pretend that I don't wish I were on that court competing, but I have moved on and accepted the fact that my life is going in a different direction any my talents will be used better in a different court, so to speak.

# Genetic Testing for the Congenital Long QT Syndrome

Now that genetic testing for LQTS has matured into a commercially available clinical test rather than a research laboratory-based test, we are receiving lots of questions from family members and physicians—who should be tested? how can I get tested? what does it cost? In May 2004, Genaissance Pharmaceuticals, based in New Haven, CT, introduced the FAMILION™ genetic test to detect cardiac ion channel mutations. Here is some information about getting clinically tested for LQTS that may help answer your questions:

## Who should be tested?

- All patients receiving a clinical diagnosis of LQTS from their physicians and who have not had a genetic test performed previously in a research laboratory.
- Anyone who was tested in a research study and who wants confirmation of his/her research result.
- Family members of a person with mutation-proven LQTS (this is a less expensive, limited test that confirms the presence or absence of specific mutation(s) identified in a relative index case).

If a family member (index case) was tested previously in a research laboratory and now other family members are seeking genetic testing, Genaissance will re-test the initial family member without charge in order to verify/confirm the research finding as long as at least one other family member submits a sample at the same time. This approach constitutes a substantial savings to the family.

## How can I get tested?

Your doctor needs to order this test just like any other medical test. We recommend that you be evaluated by an electrophysiologist or a cardiologist who can then order the FAMILION™ test. If you need a physician, we have a list of physicians around the country.

## What are the steps to get tested?

1. Your doctor will get a packet from Genaissance Pharmaceuticals regarding FAMILION™ ([www.familion.com](http://www.familion.com)). You and your doctor will then go over the materials and fill out the Informed

Consent and the Payment Authorization so that Genaissance can work with your insurance company to determine if your test will be covered. As this is a new test, that may take some time. According to Genaissance, most insurance companies have agreed to pay at least a portion of the cost of the test.

2. Genaissance will let your doctor know when to get your blood sample to send to them.
3. About 6 weeks after beginning the analysis on your sample, your doctor will receive the results from Genaissance.
4. You should then meet with your doctor to discuss these results and get a copy of the Genaissance report. (You should always ask to receive copies of your ECGs, test results, etc.)

## What about other family members and testing?

Your doctor will be able to help you determine if other family members should be tested. In general, if your test is positive, your children, siblings, and parents should be tested, too. This means they will have an ECG and then be tested by Genaissance for your specific mutation. This test is less expensive than the initial test.

Based upon the test results of your close family members, others in your family (grandparents, aunts/uncles, nieces/nephews) may need to get tested, too. You should compile a medical family tree for your extended family in order to make sure that a physician evaluates everyone who might be at risk for LQTS. If you need a form (or instructions) to do this, we can send you a packet ([carl@sads.org](mailto:carl@sads.org) or 1-800-STOP SAD). The Genetic Alliance form ([http://www.geneticalliance.org/ws\\_display.asp?filter=resources\\_family\\_history](http://www.geneticalliance.org/ws_display.asp?filter=resources_family_history)) and the Mayo Clinic form (<http://www.mayoclinic.com/invoke.cfm?objectId=385FC65E-F961-49BA-99B799A3A0DAF885>) are also very useful.

For more information about the FAMILION™ test, call them at 866-326-4546 or look on their website ([www.familion.com](http://www.familion.com)). For all the current information on genetic testing, subscribe to our E.News by sending Carl your e.mail address ([carl@sads.org](mailto:carl@sads.org)).

## Frequently Asked Questions

### Who should be tested?

The FAMILION™ Test is most useful for patients with a strong clinical suspicion of disease or family members of a patient with a defined mutation.

### What specimen is required?

The FAMILION™ Test requires two 10 ml lavender top tubes (EDTA) of whole blood. For children under 5 years of age or under 60 lbs., two 2 ml tubes may be substituted.

### What is the specificity of the test?

It is estimated that the FAMILION™ Test will detect the mutations in 50-75% of the cases of LQTS and 15-20% of the cases of Brugada Syndrome.

### How long will it take to get test results?

Once the analysis begins, test results should be available in approximately 6 weeks. They will be sent directly to the ordering physician.

### Where is the test available?

The FAMILION™ Test is available in all states except California, New Jersey and New York. Genaissance, the company that offers the FAMILION™ Test, is awaiting licensure in these states.

### Will insurance pay for the test?

Genaissance provides a service to help your patient determine if his or her insurance carrier will cover a portion or the entire cost of the test. Genaissance, the company that makes the FAMILION™ Test, will make

## Medic Alert ID Reminder

**If you have a SADS condition, make sure you have a medic alert ID—bracelet, ID tag, or pendant. ([www.sads.org/links](http://www.sads.org/links) for more information)**

every effort to collect payment from insurance companies. It is important to remember that the patient is responsible for the entire cost of the test.

For assistance, call FAMILION™ Customer Service at 1(866) FAMILION or 1 (866) 326-4546 between 9:00 am and 5:00 pm Eastern Standard Time.

# SADS Foundation School Nurses Awareness Campaign

There are approximately 50,000 registered nurses in public school systems across the country caring for more than 52 million students.

School nurses are one of the first lines of defense for our children. They are advocates for student care and counseling for parents as to where to go for help when unexplained syncope or cardiac arrest/sudden death occurs in the schools—but they can only care and counsel if they have been informed. According to SADS boardmember and SCD researcher Katherine Timothy,

*“There is a great need for education of school nurses about LQT and other sudden death disorders, for them to be aware of any possible presenting symptoms, as well as qualified to administer help by way of CPR and/or external defibrillators should an unfortunate event occur. The school nurse is also in the best position to educate all schoolteachers, coaches and administrators as to symptoms, etc.”*

We recognize the important contributions that school nurses make toward the health and well being of our children and youth. School nurses are unsung heroes as they both effectively and efficiently meet the daily and emergency needs of the student populations they serve. May 11, 2005 is National School Nurse Day. We are asking you to target this day to educate and to commend the School Nurses in your community on their years of diligent efforts to keep our children healthy and safe in school.

This past year SADS sent 680 packets to volunteers, who educated school nurses in 15 different states. Volunteers informed nurses about LQT through the materials, speaking engagements and a formal presentation to the Arizona School Nurses Association. With your help we can increase the ability of our school nurses to identify children that need to be diagnosed and save lives.

School nurse packets are available for you to distribute in your community. Please contact Gwen for more information at [gwen@sads.org](mailto:gwen@sads.org).

## Volunteer Media Awareness

As we reflect back on the year we feel an enormous sense of joy and accomplishment to be part of this remarkable foundation. It is a privilege to participate along with you in this open-ended quest toward accomplishing our mission: To save the lives and support the families of children and young adults who are genetically predisposed to sudden death due to heart rhythm abnormalities.

We would like to thank the volunteers whose media efforts include the following: (If you have published an article or been part of a television segment please send the information to us and we will include your efforts on our list.)

### MEDIA COVERAGE

#### Newspaper articles:

##### February

Villarreal Family, San Francisco, CA  
Argus Courier, *The Gift of Life*

##### Kathy Price, Dallas, TX

Dallas Morning News, *Jumping for Joy and for Brian*

##### August

Micoch Family, Salt Lake City, UT  
Salt Lake Tribune, *“In Tune with the Rhythm of Life, SLC conference helps families cope with genetic heart abnormalities”*

##### October

##### Portland, OR

Oregonian, *“Sudden Cardiac Arrest Causes”*

#### Television/Radio News:

##### February

Malloy Sisters, Boston, MA  
The Boson Channel, *Siblings Hope to Beat Genetic Heart Disorder*

##### June

Victoria Brown, Janesville, WI  
WI Television, *Medical Misdiagnoses*

##### November

Everett Family, Wilmington, NC  
WWAY TV3, *Trina's and Tami's Long QT Story, 6:00 & 10:00 news*

##### Wenhold Family, Atlanta, GA

CBS WGCL TV, *Long QT Wenhold Story*

##### December

Wehrbein and Wildhagen Families and Dr. Chris Erickson, Omaha, NE  
The Omaha KETV Channel 7, *Julie's Diary: The Heart of the Family Tree*

If you are interested in sharing your story with the media, A Media Kit detailing how and what to do to contact your local media is available. Please contact [gwen@sads.org](mailto:gwen@sads.org) if you would like more information.

## Calling All Nurses

We need your help to educate your peers in the schools—the school nurse. SADS has developed a presentation and materials for you, an R.N., to deliver to your local school nurses. If you are interested in helping us reach this vital link to our children, please contact Gwen at [gwen@sads.org](mailto:gwen@sads.org).

**With your expertise, we can educate school nurses.**

### Community Information Booths

We want to thank Mary Rogerson, Michelle Steinberg, and, especially, Steve Kugelmann for manning an information booth at the Kennedy Spaceport “Super Safety & Health Day” this past October.

Also, Dick Stafford is a superstar for manning his booth in Arizona during the annual city-wide high school sports physical day.

We would love to support anyone who wants to set up a booth at a local community health fair, medical meeting, etc.

## Insurance Information Available Online

<http://www.healthinsuranceinfo.net/>

The Georgetown University Health Policy Institute has written **Consumer Guides for Getting and Keeping Health Insurance** for every state and the District of Columbia. The Guides summarize your protections in your state. They also publish periodic online newsletters and issue consumer alerts for specific insurance companies.

### **“A Consumer's Guide to Handling Disputes with your Employer or Private Health Plan”**

[www.kff.org/consumerguide](http://www.kff.org/consumerguide)

The Henry J. Kaiser Family Foundation and Consumers Union have developed “**A Consumer's Guide to Handling Disputes with your Employer or Private Health Plan.**” This guide will help you understand the type of coverage you have, what rules apply if you have a dispute with your insurance company, and where to call for more information.

<http://www.insurekidsnow.gov/>

*Insure Kids Now!* is a national campaign to link the nation's 10 million uninsured children—from birth to age 18—to free and low-cost state health insurance. Find your own state's insurance program for children through this Web site or call the toll-free hotline 1-877-KIDS-NOW.

## SADS Youth Connect

### **Ask An Expert**

If you have a question about Long QT Syndrome you can now get an answer from an expert.

Just send us an e.mail ([gwen@sads.org](mailto:gwen@sads.org)) or mail your question to SADS, 508 E. South Temple #20, Salt Lake City, UT 84102—and please include your age.

One of our experts will answer your question and we will publish questions/answers (without names) online.

<http://www.healthcarecoach.com/index/php>

HealthCareCoach.com is packed with facts and do-it-yourself tips on everything from health insurance to patient care - to help you find yourself. Developed by an independent, non-profit group of health law specialists.

### **Updated Site**

Great newly revised LQTS Website at the Mayo Clinic  
<http://www.mayoclinic.com/invoke.cfm?objectid=47C52B5C-DA54-4EF4-864C9B4F3F60A5CB>