

SADS NEWS

FOUNDATION
Supporting families. Saving lives.



London Hosts First Int'l SADS Conference



Situated in the heart of London at Regents Park, The Royal College of Physicians was a wonderful setting for the Conference. The Royal College of Physicians is the oldest and most prestigious English medical foundation, incorporated by Royal Charter of King Henry VIII in 1518.

We had over 150 family members and 40 physicians for our 1st International SADS Conference in London, England.

The two days were filled with learning, supporting and making new friends.

Ann and John Jolly worked for over a year to produce this wonderful event and we all benefitted from their

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FAR LEFT: Dr. Vincent, Andrea Jones (Canada) and participants discuss the issues.

LEFT: Katherine Timothy and Dr. Andrew Grace (UK) stop to chat in the main auditorium after a presentation to the whole group.

BELOW: Alice Lara talking with Anne (holding Kanga from Australia) and John Jolley, the driving force for our first International Conference.



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Supporting families. Saving lives.

Mission: To save the lives of children and young adults who are genetically predisposed or otherwise susceptible to sudden death due to cardiac arrhythmias and to provide education and support to families and the medical community who are dealing with these disorders.

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Dave Wind, Program Coordinator

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New Board Members

DR. MICHAEL J. ACKERMAN, M.D., PH.D. is an Assistant Professor of Medicine, Pediatrics, and Molecular Pharmacology at Mayo Medical School and is a pediatric cardiologist and director of the Long QT Syndrome Clinic at Mayo Clinic in Rochester, MN. Dr. Ackerman has been a SADS supporter and contributor for many years. Dr. Ackerman's Sudden Death Genomics Laboratory focuses on genomics, mutational analysis, and novel gene discovery related to diseases causing sudden death in infants, children, adolescents, and young adults. The primary diseases investigated include long QT syndrome, sudden infant death syndrome, and hypertrophic cardiomyopathy.



Dr. Michael Ackerman



Dr. Peter Schwartz

The Long QT Syndrome Clinic directed by Dr. Ackerman provides comprehensive state-of-the-art evaluation, treatment, and management for the whole patient including genetic testing and two active NIH-funded clinical research studies devoted to better understand long QT syndrome in patients and to hopefully assist in the identification of individuals at greatest risk for sudden death.

We welcome Dr. Ackerman and look forward to working with him in the future.

PROF. PETER J. SCHWARTZ is one of the pioneers in the research of long QT syndrome. Dr. Schwartz has been the Chair of our Scientific Advisory Committee for many years. He currently is Professor and Chairman of Cardiology at the University of Pavia and Policlinico S. Matteo IRCCS, Pavia, Italy.

Prof. Schwartz is actively involved in post myocardial infarction clinical trials and has authored more than 900 publications in the area of cardiology. His major fields of interest are the relationship between the autonomic nervous system and life-threatening arrhythmias, the long QT syndrome, identification of patients at risk of sudden death, and the prevention of arrhythmic mortality.

We appreciate the expertise of Dr. Schwartz and are glad that he will be working with us on the policy-making Board.

OUR FUNDERS NEED TO KNOW

If any of you are distributing SADS' information, talking to other families (family support), attending health fairs or other community events with SADS' materials, Dave would love to hear about it! The foundations that fund SADS want to know the numbers of people we touch and the impact we have across the country. Please e-mail Dave (dave@sads.org) or send your statistics to him.

Good Luck Rachel

"It's been a wonderful year at the SADS Foundation and I have enjoyed getting to know many of you. We've had a number of milestone successes and I wish I could be here to see the growth we anticipate over the next few years. I will miss everyone who is a part of this important work," says former development director, Rachel Day.



Rachel is moving on to bigger and better things in Boston. She will be getting married this spring and we know will also have a super career path in that large city. We will miss her and want to thank her for all her hard work for SADS.

Welcome to SADS Sarah Marsden DEVELOPMENT DIRECTOR

"Having done fund raising for a number of human services nonprofits, I'm excited to contribute my efforts to the SADS Foundation team! Still learning my way around the office, I have not yet had the opportunity to meet or talk with many of you. Nonetheless, it's easy to appreciate the profound commitment the SADS Foundation members make to its life-saving programs.



"I look forward to becoming better acquainted with you, and continuing SADS legacy of leadership in reducing death and sorrow caused by sudden arrhythmias."

Volunteer. Picnic



This year's annual Volunteer Picnic was a great success as volunteers celebrated a year of alert schoolchildren and medical personnel to the dangers of SADS.



Canadian SADS Update

The Canadian SADS Foundation is happy to report that Pam Husband has been persuaded to stay on for another term as their Executive Director.

A very industrious group of individuals in the province of Alberta, under the diligent leadership of Nancy Busse, has been successful at raising significant funds through Bingo activity. These fund-raising endeavours will provide a steady stream of funding in order for our organization to carry on with its major mission of promoting education and awareness throughout Canada. Information packages will continue to be distributed at no charge to anyone

requesting information.

During this past year The Canadian SADS Foundation has focused on promoting awareness to a wide variety of medical groups. Members are extremely grateful to the coroners and medical examiners across Canada who have demonstrated their support of the organization by distributing a pamphlet and by referring families to SADS when an otherwise healthy young person has died suddenly with an apparent sudden cardiac death event.

Paramedics also play an integral role. During the performance of their duties, paramedics often have an opportunity to recognize symptoms in the individ-

ual they are treating and alert the emergency room personnel and the family. Canadian SADS is very proud to have been invited to provide a speaker at the Ontario Paramedics Association Conference on September 27, 2002.

Nancy Busse and Pam Husband were thrilled to have the opportunity to represent The Canadian SADS Foundation at the International Conference in London in October. "We enjoyed meeting new friends and sharing ideas for increasing international education and awareness about sudden cardiac death in the young," they said.

— NANCY BUUSE, ALBERTA

SADS!
The Canadian SADS Foundation

OUR HEROES: Stories of Survival

Matthew Jones

At 12 years old, my son Matthew was an avid basketball player and few things were as important in life as playing ball. Like many of his peers, Matthew diligently attended every practice with energy and excitement and sometimes left feeling a little tired. It was during one practice that Matthew not only felt tired but he also felt a little strange — a feeling that would change our lives forever.

Written by Deanna Jones

Contributed by
Jennifer Harrison
Media Relations Coordinator
Children's Healthcare of Atlanta

After running sprints, Matthew suddenly fell to the floor. He was tired, weak and short of breath. Matthew was rushed to the hospital where doctors conducted multiple tests but found nothing wrong. After he was released, I refused to take him home. I had already lost

After his diagnosis, Matthew had to stop playing basketball but he didn't let that slow him down.

one child to "unknown natural causes" and was not going to lose another.

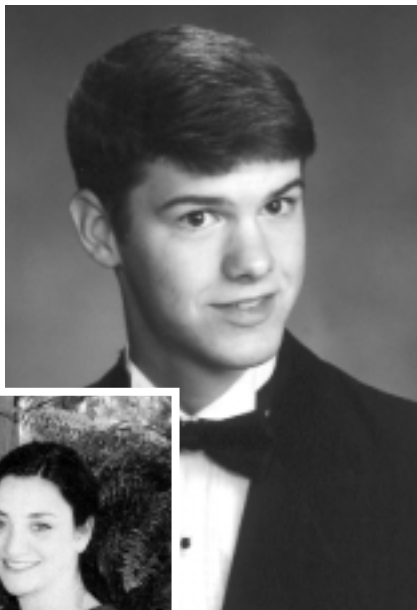
Matthew was transferred to Children's Healthcare of Atlanta where, after much

research and testing, he was diagnosed with Long QT Syndrome. The diagnosis offered answers about the earlier death of my youngest son and was a life-changing discovery for Matthew and the rest of our family.

After his diagnosis, Matthew had to stop playing basketball but he didn't let that slow him down for long. He decided to

focus his attention on other things, such as school-work and helping children. In 1999, Matthew graduated salutatorian of his class and began his freshman year at

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Jane O'Brien and Katie Weaver

Our names are Jane O'Brien and Katie Weaver and we have a heart condition called Long QT Syndrome. We were acquaintances in high school until each experienced sudden deaths of loved ones. Jane's mother passed away at the end of our senior year, just before our prom 2001. Katie lost her older sister, Kelly, less than six months later. Neither one of the deaths were easily explained until the family members were given EKGs and diagnosed with Long QT Syndrome.

Written by Jane and Katie

We happened to be working together at the same store when we started talking and found out we both had the same heart condition. We quickly bonded and knew right away that there was a distinctive purpose for us. Ever since then our mission has been to spread Long QT Syndrome (LQTS) awareness.

LQTS is a silent and often undiagnosed killer. LQTS is usually inherited, though it can be caused by some medications. Symptoms can include: rapid heart beat, dizzy spells, unexplained fainting, and in Kelly's case seizure-like activity misdiagnosed as common seizures. Many times LQTS symptoms occur in children through young adults, although commonly over looked. Often times the first symptom is sudden death of a young person. LQTS can be easily diagnosed with a quick,

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Matching Campaign

This fall we were presented with a wonderful opportunity. Two of the parents we work with, Mark and Allison Finkelstein, helped initiate a year-end appeal, and offered to match whatever donations came in. Matching campaigns like this provide a great way for small foundations like ours to grow.

Allison and Mark lost their son, David, when he was just two years old. They, like so many of you, were determined to prevent other children from dying needlessly. They wrote a beautiful letter about their experience with Long QT Syndrome, and how the death of their son inspired them to try to help other families and patients

Thanks to all of you, we received \$19,000 towards this matching gift.



The Graeme Jones Memorial Golf Tournament

On October 22, 2000 Graeme Jones lost his life to Long QT Syndrome. In order to honor Graeme, his father, Blair, hosted the Graeme Jones Memorial Golf Tournament on September 28th at the Reserve Vineyards & Golf Club in Hillsboro, Oregon. A full field of golfers, a great course, wonderful greens and plenty of sun made the perfect day to educate and create

awareness to Long QT, Sudden Cardiac Arrest and AEDs. A very special "Thank You" to the directors, speaker Richard Lazar, MC Michael Turner, 14-year-old Nick Dugas and the members of Our Redeemer Lutheran Church. Without the support from all of you, this event would not have been the success that it was! We also thank AED INSTRUCTOR FOUNDATION for their gift of the Zoll AED.

Brian Abell Memorial Run

Over 200 people ran (or walked) in the fifth annual Brian Abell Memorial Run in Pennsylvania last October. Every year, Dick and Maryellen Abell organize and obtain underwriting for this event. The SADS Foundation received over \$6,000 from the 2002 event. One participant gave a presentation about how, as a result of the materials she received last year, her teenage daughter was evaluated and diagnosed with a heart condition. "It was very heartwarming to hear that a potentially fatal event has been avoided and to see the woman with her healthy daughter," said the Abells. We all thank the Abells for their hard work and dedication!

No Ball 2002

This was our best year yet! Just when we think things can't get better, your generosity reminds us that they can. We are so grateful to many of you who made this year's event such a success.

We owe special thanks to the committee members who worked especially hard. They courageously shared their stories with their friends and families, which not only helped bring in funds, but also spread awareness about Long QT Syndrome and the work of our foundation. We appreciate their commitment and example.

Paul and Nikki Bryant
Rita and Roger Euken
Caroline Figenshu
Larry and Rona Greenstein
Dorothy and James Renner

Marryann Anglim
Carley Tsaglos
Denise Falzon
Dale and Victoria Turner
James Haughey



Racing for Long QT

Pacemaker Motorsports has just completed its third season racing in the Southern New England Pro Four Modified division. Their 28-foot trailer is a moving billboard for SADS and the Long QT Syndrome.

Dale and Vicky Turner travel throughout New England, sharing the news of Long QT and racing their car.

Each year they donate their winnings to the SADS Foundation.

What a great way to make people aware of this treatable medical condition!

Thanks to Vicky and Dale

for all your hard work and generosity on behalf of the SADS Foundation.



Erica Peery (daughter of car owner Dale Turner) in front of the racing van with Brandon (age 10), Austin (age 6), and Jesse (age 2).

Stories of Survival

Matthew Jones

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Shorter College in Rome, Georgia. Now 21-years old and still following his dreams, he is hoping to graduate with a degree in microbiology and some day to work for the Centers for Disease Control.

Matthew is the best thing I ever did in this world. He still has the same integrity, determination and fun-loving personality he had as that 12-year-old basketball player. We are so proud of him!

Jane and Katie

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painless and simple EKG. LQTS is not curable but very treatable.

Both of us have had defibrillator/pacemakers implanted and are doing very well.

Our goal is to reach out to men, women, and children about prevention of drug-induced Long QT Syndrome and inherited Long QT Syndrome. We feel September is the best time to spread the knowledge because it is Long QT awareness month.

International Conference

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hard work and skill! In addition to setting the agenda, contacting the speakers, booking the venue, and fund raising (we received a grant from the PPP Foundation for \$20,000) they did an absolutely fantastic job in promoting the conference—and also spreading awareness.

Anne and John appeared (or arranged for a volunteer to appear) on multiple television and radio programs, including the BBC, “London Tonight” and Meridian TV News.

We have already begun the planning for our 2nd International SADS Conference October 25, 2003 in Atlanta, Georgia (see back page of the newsletter). Don't miss it!

SADS could not accomplish this critical work without you, our dedicated volunteers. You are the “frontline force”—raising awareness in your local community, supporting others dealing with their child's diagnosis, and raising money to help us save the lives of countless children.

HELP SADS

National Contact Volunteers receive phone calls and emails from people inquiring about LQT syndrome and other heart arrhythmias. They also refer people to physicians, or other appropriate organizations for genetic testing, educational literature, etc.

Awareness Volunteers help to increase the level of knowledge about LQT syndrome by providing literature to local organizations i.e. schools, hospitals, clinics, community centers, youth groups, etc. They may staff ‘information’ booths at appropriate events or raise awareness through public speaking and media coverage.

Education Volunteers are well-qualified to educate the medical community by presenting information at conferences and other meetings to nurses, physicians, medical students, coroners, EMTs, etc.

Fund-raising Volunteers hold special events and donate the proceeds to the SADS Foundation or other appropriate organizations — helping further the work to decrease the suffering caused by LQT syndrome, etc. Examples include a fun run, jump-a-thon, or simply asking friends and family for donations.

Support Facilitation Volunteers facilitate face-to-face support group meetings. They have experience and expertise in this area. They work closely with the SADS Foundation in providing network referrals to interested families.

Advocacy Volunteers work with legislators, government representatives, unions, and school boards, etc. to pass legislation or implement policies requiring EKG testing and the availability AEDs in schools, etc.

Special Event Committee Volunteers provide assistance to the SADS Foundation in organizing and orchestrating specific events throughout the year. One example is the SADS Foundation International Conference.

SADS Office Volunteers perform a variety of functions dependent upon the needs of the SADS Foundation office. In addition to clerical work and help with bulk mailings, some volunteers may assist with the website, etc.

> To volunteer, talk to Dave at 800/786-7723 or dave@sads.org



Tax Tips for Volunteers

When you volunteer for SADS (or any other non-profit organization) you can deduct your expenses on your income taxes. You can't deduct the cost of your time but you can deduct any out-of-pocket expenses, car expenses, special uniform expenses, etc.

The IRS says that you can deduct the cost of gas and oil that are directly related to giving the service. You can't deduct general repair and

maintenance. Or, you can use the standard mileage rate.

Keep track of any miles you spend as a volunteer for SADS (taking brochures to schools, staffing a booth at a health fair, etc.) and add it up at the end of the year. I find it easiest to keep track on my day-planner, listing the miles traveled, the activity and the organization. You should also keep receipts for any materials you purchase for your volunteer work—listing the activity and the organization.

If you want more information about this, we have added a link to the IRS documents on our website (www.sads.org) or you can get Publication #526 from the IRS.

School Nurses Of Arizona Meet SADS

Over 125 nurses from throughout Arizona attended the Annual Conference of School Nurses of Arizona held at the Prescott Resort on July 26, 2002. Organized by Dick Stafford, a SADS National Contact Volunteer, our booth was a great success.

Chris Percelli and Kathy Gannon helped Dick prepare packets which included a poster, school nurse sheet, school health sheet, Long QT Brochure, SADS Brochure, and a business card. As the afternoon session ended they were flooded with nurses.

As Dick reported: "We had a very brief time to either introduce ourselves and LQT or to answer individual questions. Having Chris and Kathy there was a necessity. One person could not have handled it by him/herself. Because Chris and Kathy are both nurses, I felt much better handing technical questions to them. Each is gifted and passionate about wanting to help. We were challenged to have enough time with each person to say—in 60 seconds or less—what we wanted."

Dick greeted visitors to the booth with this introduction: "We are here representing the SADS Foundation which does education and research regarding the Long QT Syndrome. Are you familiar with Long QT?"

Dick would then turn to the illustration in the brochure

"Are you familiar with Long QT?" he would ask. Well, these nurses certainly are now, thanks to these volunteers.



From left: SADS volunteers Kathy Gannon, Chris Percelli, and Dick Stafford, and NASN Vice President Shirley Rodriguez.

and refresh their memory.

"We want to provide this packet of information to you," he continued, "and ask you to do a couple of things that could make a life and death difference for one of your students. Would you read these brochures so that you will have the latest info on LQT? Would you please display this poster in your office or other appropriate place to remind you and others about LQT? Would you also 'keep your antennas up' for children who faint or have seizure-like episodes whether they occur at school or elsewhere? Those parents should have their children checked by their physician."

The volunteers also tried to connect everyone with the SADS website at www.sads.org.

"This event was a great success for SADS—not only because of the people our volunteers met at the conference, but also because of the knowledge they gained about communicating with school personnel. I know that this will be a great help to us in further developing our school materials and a manual for all our volunteers," said Alice Lara, SADS Executive Director.

Long QT Awareness Week 2002

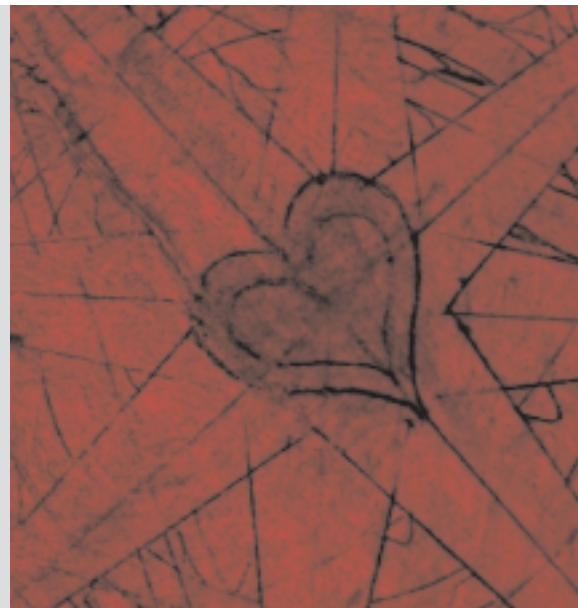
Long QT Awareness Week reached thousands this year because of you—the many devoted SADS volunteers. We had over 40 volunteers from 24 different states across the nation working on a variety of projects during September, 2002.

Approximately 4,200 brochures were distributed to family members, medical clinics, schools, community centers, coroners, physicians, nurses, EMTs, coaches, etc. Some of you were able to work with the media as well. Many of you were instrumental in the

placement of life-saving automatic defibrillation devices (AEDs) in schools and other critical locations.

We are excited for the coming year as we have decided to modify LQT Awareness Week to become LQT Awareness Month — an even greater opportunity to spread the word about cardiac arrhythmias which could lead to sudden death in the young.

We placed many materials and 'how-to' documents online this year which we hope you will continue to use as needed.





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2ND INTERNATIONAL SADS CONFERENCE

Preventing Unexpected Sudden Cardiac Death in the Young



October 25, 2003

Buckhead Sheraton Hotel

Atlanta, Georgia

*Co-sponsored by
Children's Hospitals of Atlanta*

We have begun planning a wonderful conference for physicians, families and community members. Proposed topics include: Long QT Syndrome, Cardiomyopathies, ARVD diagnosis, treatment & questions; Genetic Testing; Building a Family Pedigree; AED's; The Importance of Awareness; Living with a Chronic Disease; ICD/Pacemaker Issues.

Watch for more information on our website (www.sads.org) and in the mail. If you are interested in helping us with the conference, please e-mail us at sads@sads.org or phone 800-STOP-SAD.

www.sads.org

Volunteer page: Materials for distribution and "how-to-do-it" resources for our volunteers. You can also sign up online to volunteer with SADS.

SADS International Conference: Learn more details, volunteer for, or register for the conference in Atlanta.

Links page: Expanded and more informative listing of useful resources.

National Contacts: If you need to talk with someone in your state, look here.

Drugs to Avoid: Updated for all drugs.

Interesting Links:

<http://www.csun.edu/~hfmth006/chaser/> CHASER specializes in children born with congenital heart defects (CHD).

<http://www.dna.com/diseaseHome/diseaseHome.jsp?site=dna&link=LongQTSyndrome.htm> This section will give you a wealth of information about Long QT Syndrome.

<http://www.irs.gov/formspubs/page/0,,id=11928,00.html> Information about charitable contributions—including volunteer contributions.

If you don't have access to the Web, we will mail or fax you any materials.