

RAISING PUBLIC AWARENESS ABOUT SUDDEN DEATH in the YOUNG

Unlike many other disorders, SADS conditions can be stopped by simple education. Educating the public about SADS is one of the primary goals of the SADS Foundation because making the public aware of the symptoms *saves lives*.

The SADS Foundation strongly encourages each volunteer to embark upon a public awareness campaign in his/her community. Even if you use no organized media, by informing and educating people who work with children and young people (coaches, teachers, recreation centers, church youth leaders, etc.) and parents of the symptoms of the LQTS, children can be protected. **Saturate your community with information about SADS.** Anyone who comes into contact with young people should know how to recognize symptoms.

Remember, in all your presentations, to make these points:

- Children and young adults who die from SADS usually appear healthy
- Warning Signs: family history of unexpected, unexplained sudden death; fainting or seizure during exercise, excitement or startle; consistent or unusual chest &/or shortness of breath during exercise
- These conditions absolutely treatable and treatment saves lives
- Mention the SADS Foundation contact information. Hotline 800 STOP SAD

I. CENTERS/CLUBS & COMMUNITY GROUPS FOR CHILDREN AND YOUNG ADULTS

The following organizations and locations are likely places for a young person to experience recognizable symptoms. Remember, you want to reach the adults who are organizing and supervising the activities as well as the parents/grandparents. There are certainly some places that are specific to your community and will not be listed here. Brainstorm to come up with all of the possibilities.

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| A. Boys and Girls Club | H. Little League, Soccer groups, football, etc. |
| B. Y.M.C.A. | I. Amusement/Water Parks |
| C. Y.W.C.A. | J. Local Churches and Minority Groups |
| D. Jewish Community Centers | K. The Military |
| E. Governmentally Run Recreation Centers | L. Community Health Clinics |
| F. Boy Scouts | M. Community Social Centers |
| G. Girl Scouts | N. Community Health Fairs |

II. SCHOOLS

Every state and its school districts have different methods of communication. Try the following departments and also ask people involved in your local education system if there are other avenues in place to effectively disseminate information.

- DEPARTMENT OF HEALTH**
Most states have an individual within the Department of Health over School Health Programs. Contact this person to get out information to school nurses and counselors via newsletters and/or meetings and seminars.
- STATEWIDE EDUCATION ASSOCIATIONS (TEACHERS UNION)**
Most states have annual conventions sponsored by such groups. Nearly every teacher and counselor and some parents attend these sessions. Ask if you can either sponsor a session on LQTS or Sudden Cardiac Death, or get included in another program. They may also have booths, so check into renting a booth space; perhaps team up with another local organization like the AHA to defray costs.
- EDUCATION STATE OFFICE**
Call the Education State Office and ask if they have a program devoted to the health of its students. If they don't, ask if they have any system (which you may use) to get information out to all the school districts in the state.
- P.T.A.'S/HOME & SCHOOL CLUBS**

Call the state office and push for newsletter inclusion and meeting and seminar mentions. Local PTA's usually publish their own newsletter and meet monthly in each school. Ask if you can attend the meeting and take a few minutes to talk about Long QT and follow up with a newsletter article.

E. PRIVATE SCHOOLS

F. DAY CARE CENTERS/PRE-SCHOOLS

III. OTHER ORGANIZATIONS/GROUPS

A. OTHER SUPPORT GROUPS

There are usually all kinds of support groups in a given community. Local children's hospitals may well have them formed for parents who have lost children. Compassionate Friends is a national organization with support groups across the country for parents who have lost children. Contact the local leaders of such groups and ask if our information can be incorporated into their Leader's Manual. Thus, if the leader is aware of Long QT and an individual enters the group with an unexplained death, the leader can suggest Long QT to the new member.

B. YOUR COMPANY/OFFICE

Company Newsletters often spotlight an employee and when they ask YOU to be in the newsletter, include your LQTS story and the SADS Hotline.

C. YOUR OWN FAMILY

Make your extended family aware of the diagnosis of LQTS in their family and encourage them to go in for stress tests. More than any other group, immediate *and extended* family members of an LQTS individual must be made aware of the genetic implications of the diagnosis and the risks involved if they are not tested for the disorder.

D. COMMUNITY GROUPS (ESPECIALLY IF YOU ARE A MEMBER)

Many community groups, such as the Junior League, Lion's Club, Kiwanis, special interest groups/clubs (book clubs, motorcycle clubs, etc.) will allow you to speak or distribute literature to their members.

METHODS TO REACH THE PUBLIC

A. NEWSLETTERS, E.NEWSLETTERS, WEBSITES

Always ask if an organization has a newsletter and if they will include an article about LQTS and the SADS Foundation. People usually read newsletters from organizations with which they are involved very carefully, thus it is an ideal way to reach people. If space is limited, ask for even a few lines to list the symptoms and the SADS Hotline (800 STOP SAD). Always stress the urgency of your message and that lives can be saved if these symptoms are recognized.

B. PUBLIC SPEAKING/PROGRAMS

Some of these organizations have evening programs for parents or other active individuals and they are often looking for a fresh idea. Suggest the topic "Sudden Cardiac Death in the Young". You, or someone else from the group, can speak about their own experiences and come armed with literature and brochures from the SADS Foundation. You can also use our videotape as part of your presentation.

C. INFORMATION

Give them a handful of our brochures and ask if they can be visible and readily available at the office and the recreation centers. Also give them a physician's packet to keep in a reference file.

D. STAFF MEETINGS

Some organizations may be small enough that an announcement can be made at a staff meeting and brochures handed out to all of the counselors and supervisors.

E. PARENT MEETINGS/ORIENTATIONS

Ask them if you can talk about Long QT during a portion of the meeting and offer copies of our brochure.

F. FUND RAISING EVENTS

If asked, many community groups and organizations will hold a special event and donate the proceeds to the SADS Foundation. If not, they may be willing to participate in an event which you organize (e.g. Jump-a-Thons, Fun Runs). *See fund raising ideas handout.*

NOTE: Please ask these organizations to publish the SADS Foundation Hotline (800 STOP SAD) number rather than your number for those people who want more information. That way we can enter interested people in our database, make certain they get our newsletter, and the caller can be guaranteed a toll-free call.

III. PHYSICIANS/MEDICAL PERSONNEL

A. CARDIOLOGISTS

Send a letter, with our brochures included, to all of the cardiologists in your area (look in the Yellow Pages)

and ask them if they have patients with Long QT Syndrome. If so, ask them if they would like to receive additional materials to give to their patients. Also, ask them to contact us if they would like to be on the Physician Referral List. Please note on the letter that people can receive our newsletter and additional materials even if they don't want to be actively involved with the SADS Foundation.

B. CORONERS / MEDICAL EXAMINERS

Coroners usually work closely with family members after the loss of a child. If nothing can be found on an autopsy, the coroner is responsible for informing the family of other possibilities for the cause of death.

Coroners are the primary source of information for a family that has lost a child without a reason and they must know to suggest the Long QT Syndrome to these families. All county coroners should be highly versed about the Long QT Syndrome and have pamphlets to give to a family in the event that he/she cannot find a cause of death from an autopsy. You can send a letter, as above, to all coroners in your area.

C. PEDIATRICIANS / GENERAL PRACTITIONERS / NEUROLOGISTS

Most often, when a child experiences syncope or seizures, he/she will go to his/her pediatrician who will usually refer the child to a neurologist. Pediatricians and general practitioners need to be aware of LQTS and to realize that it is not really rare. Thus, they would consider a cardiac cause when a child has unexplained fainting and seizures. The neurologist should refer neurologically normal children who are experiencing syncope and seizures to a cardiologists for further testing.

D. EMS SYSTEM (EMTs, Paramedics)

The first people on the scene when someone experiences cardiac arrest or syncope are the community Emergency Services. Contact the state EMS certification board and ask that information on the Long QT Syndrome be included in the certification training. EMT's should realize that fainting (syncope) in a child could be the symptom of a serious condition. Also see if SADS information could be included in staff meetings and newsletters.

E. SCHOOL NURSES/ EMERGENCY ROOM NURSES

Every state (and many local areas) has a school nurse association. These associations have regular meetings for training, etc. This is a great venue for a presentation/training or to have a booth with materials, etc. Just handing out materials to all attendees is a good way to raise awareness among school nurses. You can also write an article for newsletters.

F. HOSPITALS/CLINICS

Deliver physician packets to Hospitals or Cardiology Groups to have as reference and LQTS brochures, Agency brochures to hand out to newly diagnosed patients.

EDUCATING MEDICAL PERSONNEL

In addition to all the above methods for raising public awareness and educating specific groups, the SADS Foundation wants to provide medical personnel with extra educational opportunities.

A. MEDICAL MEETINGS/SEMINARS PRESENTATIONS

Presentations can be made at these meetings that would be tailored to the specific group (e.g. pediatricians, emergency room nurses, paramedics, electrophysiologists). To ensure the medical accuracy of the material, you should contact the SADS Foundation for help with the speaker, material, etc.

B. INFORMATION BOOTHS AT MEDICAL MEETINGS/SEMINARS

You (& other volunteers in your area) can staff a booth at a medical meeting. We have materials for display (along with signs, display boards, etc.) and brochures and handouts for attendees. Your role would be to organize the booth, answer any questions (if able to) and get contact information from those interested.

**Contact SADS if you have any questions or need any materials. Good Luck!
And thank you for all that you are doing to support families and save lives!**