



Dear SADS Media Volunteer,

We want to thank you for your support of the SADS Foundation. As you know, conditions like Long QT Syndrome are treatable and children can live happy, productive lives if they are diagnosed and treated.

Please include the following points when talking to the media:

1. Children and young people who die from these conditions usually appear healthy, vital and normal.
2. 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
3. LQTS and other conditions are absolutely treatable and treatment saves lives!
4. For more information, please visit [www.stopSADS.org](http://www.stopSADS.org)

**SADS Foundation's 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.

Public awareness is the number one priority for the SADS Foundation this year. When you tell your story to the media (radio, magazine, TV, newspaper, community newsletter), you are not only letting parents know the warning signs that may protect their children, but also physicians, nurses, and teachers who see and treat children every day. Media has a very broad reach and can affect change in many groups.

We are asking you to contact the media in your community and tell your story. This is a great chance to raise awareness of SADS conditions in your community. When national media have stories about a subject, local media like to follow up with local stories.

If you need help working with media please refer to the attached materials or contact Jan Schiller at [jan@sads.org](mailto:jan@sads.org) or 801-272-3023.

**Working together, we will save lives!**

Supporting Families. Saving Lives.

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## **Working with the Media**

### ***Using the media is a very effective way to spread awareness about SADS***

#### **Before any kind of mass media campaign is initiated, please keep the following in mind:**

- ◇ The media loves to cover local community events and activities. Each year we encourage volunteers to take advantage of that fact. The media can be a tremendous ally. Please utilize them by sharing your story, and any events you plan, to spread awareness in your area about the Long QT syndrome.
- ◇ Always call the SADS Foundation before contacting the media on your own. That way, we can send them a media packet, set up an interview with a physician, and review the article for accuracy prior to its publication.
- ◇ The best results are achieved when more than one technique is used and when several techniques support each other. For example, a speaker at a special event should be publicized through news releases and photographs as well as promoted in advance through posters, flyers, and articles in newsletters. Overall, the most successful strategy is to identify the public to be reached and to choose one or more appropriate and effective techniques for getting your message across to them.

#### **Remember to always 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 and/or shortness of breath during exercise.
- ◇ These conditions are absolutely treatable and treatment saves lives.
- ◇ Mention the SADS Foundation contact information: 801-272-3023 and [www.StopSADS.org](http://www.StopSADS.org).



## Steps to Contact the Press

### ❖ **Identify who would like to hear your story**

- ◆ Perhaps a reporter who is interested in children and health issues is a good choice.
- ◆ Research the publication/station before you contact them. Have background knowledge of what reporters cover and the style of the publication.
- ◆ Contact everyone you think might be interested. Contact local and national newspapers, magazines, online publications, network and cable television, radio. No publication is too large or too small.

### ❖ **Send a media kit and/or a press release**

- ◆ The SADS Foundation is happy to provide media kits and general pre-written press releases for you.
- ◆ Get a media kit to the reporter before you talk with them. Media kits provide background information and resource materials that provide history, accomplishments, statistics, events, recent news releases, contact information, and other answers to frequently asked questions. We are happy to provide brochures and other materials for this kit.

### ❖ **Tell them your story.**

- ◆ You can write, call, email, or fax reporters to tell them how SADS has affected you.
- ◆ Talk to the editor/reporter about how your personal story would make an impact on your local community. Suggest different points of interest for different story angles.

***Use the SADS Foundation's three warning signs in every story!***

- ◆ Give them the SADS Foundation number 801-272-3023 and website address [www.StopSADS.org](http://www.StopSADS.org), so that we can respond to any questions and send out applicable information.
- ◆ Be honest and prepared. Have accurate facts and as much information as possible. Refer the reporter to the SADS Foundation if you are unsure of anything.
- ◆ Look for a variety of sources with whom to share your story. Don't give up. You may even meet with a reporter for lunch to tell him or her your story and explain about the SADS Foundation.
- ◆ Reporters are usually under deadlines and need information quickly. Be available and ready if they contact you, as they do not have time to wait for you to return their messages.

### ❖ **Follow-up with a call** to the reporter within 3 - 5 days.

- ◆ Keep reporters informed of events and story ideas on an ongoing basis (support group get-togethers, youth activities, fund raising events, conferences, meeting, speakers, etc.).
- ◆ Send a thank you letter to the reporter.
- ◆ Share your story with the SADS Foundation, noting the date, source and media contact, and photos if at all possible.



### **Helpful Ideas - Print Media**

#### ◆ **Feature Articles**

- ◆ Feature articles spotlight an individual or family with SADS. Share your story and facts about SADS with the media.

#### ◆ **Sports-Oriented Articles**

- ◆ If your story involves death or fainting during athletics, share your story with a sports beat reporter.

#### ◆ **Letters to the Editor**

- ◆ Write a letter responding to a previously published story that interested you and mention the SADS Foundation.
- ◆ Write a letter of thanks about a recent article and reiterate some of the major points.
- ◆ Express thanks to the general public for supporting a fundraising event or campaign or some other SADS Foundation sponsored activity.

### **Helpful Ideas - Television and Radio**

- ◆ Contact the stations you watch and also stations that are interested in health stories.
- ◆ Post Awareness Month events on website calendars and call the station with information. Contact them before planned events and invite them to attend. Make SADS families and doctors available to be interviewed at the event. We can help you with spokespeople for the media—please contact us!
- ◆ Call the medical reporter and see if he or she would like to do a story on SADS conditions and share your story.

### **Other Ideas**

- ◆ Local television stations often have “Community News” segments. This is a great time and place to announce your events and activities for SADS Awareness Month.
- ◆ Television and newspaper medical reporters cover stories about individuals and families with health conditions the effects on the family such as a big change in lifestyle or an untimely death. Contact and share your story with them, offering information about SADS. Be sure they list the SADS Foundation’s phone number 801-272-3023 and website [www.StopSADS.org](http://www.StopSADS.org)!
- ◆ University newspapers also will highlight community events.
- ◆ Papers at your workplace or your child’s school also would be a great place for an article.

**Remember to tell the SADS Foundation how it went. Let us know if the media are telling your story and send us a copy of any story or picture.**

The staff at the SADS Foundation is available to you as a resource. If you need materials or information, please contact the SADS Foundation at 801-272-3023 or via e-mail at [sads@sads.org](mailto:sads@sads.org). You may also visit the SADS Foundation at [www.StopSADS.org](http://www.StopSADS.org).

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**SADS**  
**FOUNDATION**  
SUDDEN ARRHYTHMIA DEATH SYNDROMES

Contact: First and Last Names  
Title:  
Office:  
Cell:  
E-mail:

***Month Date, Year***

**Heading**

**Message**

Place the most critical information at the beginning. If it is about an event, place the date and place first.

**End with the following at the bottom of the page or on a separate page:**

Listed below is information about the SADS Foundation. We can be reached 801-272-3023 or [sads@sads.org](mailto:sads@sads.org) for further information.

SADS Conditions:

**Sudden Arrhythmia Death Syndromes (SADS) are genetic heart conditions that can cause sudden death in young, apparently healthy people. These conditions can be treated and deaths can be prevented.**

Warning Signs:

**Family history of unexpected, unexplained sudden death under age 40; fainting or seizure during exercise, excitement or startle; consistent or unusual chest pain &/or shortness of breath during exercise.**

Our Home Page:

**[www.StopSADS.org](http://www.StopSADS.org)**

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## Sample Article

### ***Contact the SADS Foundation for help writing your own article***

#### **Could Your Child be at Risk for Sudden Cardiac Death?**

Your child (or a young person you know) may be at risk for sudden cardiac death due to an inherited heart condition (a SADS condition). Many people who suffer from SADS feel healthy and have absolutely no idea that something might be wrong until it's too late. However, a few warning signs and symptoms may cause you to think twice...

#### **Your child should see a doctor if he or she has any of the following:**

- ◆ A family history of unexplained, sudden death in a young person (under age 50) —including drowning suddenly or one-car accidents.
- ◆ Fainting (syncope) or seizure during exercise, excitement, or following a startle.
- ◆ Consistent or unusual chest pain and/or shortness of breath during exercise.
- ◆ Signs of a serious heart condition that must be immediately addressed by a physician.

Each year in the United States, approximately 4,000 children and young adults die suddenly and unexpectedly due to cardiac arrhythmias. These conditions include Long QT Syndrome, Short QT Syndrome, Catecholaminergic Polymorphic Ventricular Tachycardia (CPVT), Brugada Syndrome, Wolff-Parkinson-White (WPW) Syndrome, and others. These conditions are hereditary, and therefore, more than one family member will be at risk. It is critical that all family members be tested if any family member is diagnosed with a SADS condition.

#### **What the SADS Foundation Recommends**

- ◆ Every child should have a risk assessment completed at regular intervals: preschool, before and during middle school, before and during high school, and before participation in organized sports.
- ◆ The Sudden Arrhythmia Death Syndrome (SADS) Foundation offers a simple, comprehensive risk assessment form “Pediatric Sudden Cardiac Death Risk Assessment Form” that you can download from our web site ([www.stopSADS.org](http://www.stopSADS.org)).
- ◆ Every school should have an emergency plan in place that includes a plan for cardiopulmonary resuscitation (CPR) as well as an automated external defibrillator (AED) within close proximity. Getting to a person within 3 to 5 minutes is vital.
- ◆ All high school students should be trained in CPR and AED as a requirement for graduation.
- ◆ Everyone should be aware of the warning signs that may indicate someone is at risk for a sudden cardiac arrest.

The SADS Foundation wants to make sure that each child grows up happy and healthy! Please fill out the risk assessment form for your child (available on our website at [www.stopSADS.org](http://www.stopSADS.org) or at 801-272-3023). If he or she answers “yes” to any of the questions, please have your physician check your child’s heart. Please contact the SADS Foundation for further information.

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