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Dear Friend,

Thank you for ordering a Pedigree Kit to begin tracing your medical history with your family. We hope you will find this tool to be a valuable resource this holiday season as you share this special time with family and friends.

The SADS Foundation encourages families to talk with relatives this holiday season, get their history using the questionnaires in our Pedigree Kit, and help them take the steps necessary to get screened by a heart rhythm specialist for SADS conditions. This will save lives!

Getting your family's health history is as simple as talking about it, writing it down, and then sharing it. If SADS conditions run in your family the Pedigree Kit will be a great source of information, not only for them, but also for their doctors and for researchers who are studying SADS conditions. This kit contains information about family history, risk, and testing, along with all the forms you will need to create a complete family medical history. It is easy to share with your family members around the dinner table.

Once you are finished with the kit, please call the SADS Foundation to share your results and learn how to take the next steps!

Please feel free to contact us if you need more Pedigree Kits or have any questions!

Best regards,

Marcia Baker, M.S. Educ.

Program Director

SADS Foundation

Marcia@SADS.org

Supporting Families. Saving Lives.

4527 South 2300 East #104 • Salt Lake City, UT 84117 • 801-272-3023 • www.StopSADS.org

## Start Today to Protect Your Family!

Thank you for ordering these kits to hand out or mail to your family.

### How to Use the Pedigree Kit

1. First, fill out the **Family Members to Contact** list by entering the names of relatives, living or deceased. Use this list as a guide to help you know who to contact for more information.
2. Next, complete your **Short Questionnaire** and make sure you are informed about SADS conditions. You have to start with yourself first!
3. Then contact other family members by mail, e-mail or phone to get their information (we have included a sample **Family Notification Letter** in your packet) and either mail them or hand them their mini-packets.
4. Make sure this data gets back to the SADS Foundation by calling us at 801-272-3023, faxing the forms to 801-505-0282, or scanning and emailing them to [Marcia@SADS.org](mailto:Marcia@SADS.org).

The number one warning sign of SADS is a family history of unexpected, unexplained sudden death of a young person under the age of 40. Deaths from drowning, single car accidents or even babies who die from SIDS may also be SADS related.

SADS conditions are usually inherited by autosomal dominant transmission- meaning that each child of an affected parent has a 50% chance of inheriting the genetic abnormality. This means about half your family might have the gene that causes a SADS condition. Not everyone who has the same genetic marker will express the same symptoms. **One person can have absolutely no symptoms, but their child with the same gene could have many symptoms.** Often families find that many members are carrying the gene but have no symptoms at all. This is why tracing your family pedigree is crucial to saving lives.

Completing your family health history (or pedigree) can save lives. After a family member is diagnosed with a genetic arrhythmia, it is extremely important that other family members be tested. It is important to know which parent or grandparent has the abnormality since siblings, aunts, uncles, nephews, nieces, and cousins on the affected side are potentially at risk.

Your family pedigree can identify other family members who may be at risk but don't know it. They should be tested with ECGs and genetic testing so that they can get treated to prevent a tragic death.

Telling your family about these disorders can be a challenging experience. Some family member may have strong feelings about hearing this info. Some family members might need more time than others to understand what it all means. Making sure they have access to the correct information is the most important step.

Please remember that the SADS Foundation has an incredible wealth of information on SADS Conditions, Genetic Testing, Insurance Support, Fundraising and Awareness. Please contact us or go to our website for more information. And please be sure to give our info to your family if they have more questions or need support.

*You can download more copies of any of these forms at:  
<http://www.sads.org/living-with-sads/Family-Pedigree/Pedigree-Kit>*

**Remember: Our goal is to help you expand your pedigree so that you can let family members know that they--or their children--need to be tested. This will save lives!**

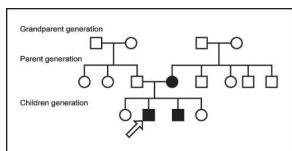
Please contact **Marcia Baker, Program Director**, at [Marcia@SADS.org](mailto:Marcia@SADS.org) or 214.675.5577, or call our office at 801-272-3023 if you need help or have questions.

**Supporting Families. Saving Lives.**

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# Pedigree Project



Paternal aunts & uncles (your father's siblings):

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Maternal aunts & uncles (your mother's siblings):

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Paternal Cousins (Father's Nieces & Nephews):

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Maternal Cousins (Mother's Nieces & Nephews):

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Date: \_\_\_\_\_

Name of Diagnosed Person in your family: \_\_\_\_\_

Your name (or child or family member you are filling this form out for): \_\_\_\_\_

Relationship to diagnosed person: \_\_\_\_\_

Address: \_\_\_\_\_ Phone: \_\_\_\_\_ Email: \_\_\_\_\_

Date of Birth: \_\_\_\_\_ Gender:  M  F



1. Have you been diagnosed with a SADS condition (LQTS, Brugada, CPVT, Short QT) or a related condition (WPW, ARVD)?  No  Yes

If yes, which one?  LQTS  Short QT  CPVT  Brugada,  Timothy's Syndrome  
 WPW  ARVD  Jervell Lange-Nielsen  Other \_\_\_\_\_

2. At what age was a SADS diagnosis made? \_\_\_\_\_ Date of diagnosis: \_\_\_\_\_

3. If you were diagnosed, what, if any treatment applies?

None  Pacemaker  Beta blockers  Mexiletine  Flecainide  
 ICD/Pacer  Sympathectomy  Denervation

4. What, if any, of the following symptoms or family history have you had?

None  Palpitations  Cardiac arrest  Fainting (syncope)  Chest pain  Fatigue  
 Deafness  Near fainting  Shortness of breath  Lightheadedness  Autism  
 Seizures/epilepsy  Webbed toes (or fingers)  Seizure-like movements  Problems with GI (gastrointestinal) system  
 Consistent/unusual chest pain or shortness of breath during exercise  
 A child, parent, or sibling who is diagnosed with SADS  
 An extended family member who is diagnosed with SADS  
 A child, sibling, or parent who had a SADS-related death  
 An extended family member who had a SADS-related death  
 A family member who died in a single car accident, hunting accident, swimming, or hunting alone etc.  
 Anyone in your family who died of heart problems before the age of 40  
 Family history of unexpected, unexplained sudden death in a young person < 40

5. What, if any, of the following screening procedures have you had and which type of doctor conducted the screening?

None  EKG resting  stress test (treadmill)  loop recorder/internal cardiac monitor  
 Holter/event monitor  Genetic testing  Epinephrine study  Procainamide study  
 Catecholamine study  
 Family practice  Pediatrician  Pediatric electrophysiologist  
 Pediatric cardiologist  Internist  Adult cardiologist  Adult electrophysiologist

Who is your doctor? \_\_\_\_\_ City, State \_\_\_\_\_ Facility \_\_\_\_\_

6. What were the results of your screening? (Check all that apply)

A diagnosis was made  The EKG did not conclusively show a SADS condition  
 I have not been screened for SADS  The results were "borderline" or "the high end of normal"  
 The results indicated you did not have a SADS diagnosis  Genetic testing was recommended

7. Please indicate if any family members have experienced any of the following:

fainting (syncope)  SIDS  deafness at birth  palpitations  seizures or a seizure disorder  Sudden death

Who has these symptoms?  children  parents  self  other relative – who? \_\_\_\_\_

8. Have you been genetically tested?  No  Yes If so, did they find your mutation?  No  Yes

What is your mutation? \_\_\_\_\_

**Questions?: Contact Marcia Baker, Program Director, at [Marcia@SADS.org](mailto:Marcia@SADS.org) or 214.675.5577**

**Send this form to: SADS Foundation, 4527 South 2300 East, Suite 104, Salt Lake City, UT 84117**

**Fax to: 801-505-0282; or scan and email to [Marcia@SADS.org](mailto:Marcia@SADS.org).**

Dear \_\_\_\_\_,

I am your relative, \_\_\_\_\_, and I am writing for three reasons:

1. To inform you (or confirm) that some members in our family have been diagnosed with a genetic abnormality of the heart's electrical system that can be life threatening for infants, children, teens, and young adults – but is very treatable with medication;
2. To provide information and resources for screening; and
3. To ask if you will help identify other living relatives who need to be informed and help by sharing if you or any of your family members have:
  - a. any signs or symptoms of this condition;
  - b. had any screening for this condition; and
  - c. been diagnosed. This helps to put together our genetic family tree for this disease and could save the life of a relative!

### About the Disease

These heart rhythm abnormalities are also called Sudden Arrhythmia Death Syndromes (SADS) of which Long QT Syndrome is the most common. There are often no symptoms, but SADS is passed down from parent to child. Each child of a parent with SADS has a 50/50 chance of inheriting this condition. If this condition is diagnosed and treated (often with daily medication) individuals can live a normal life.

When people with SADS experience symptoms, they may include fainting, dizziness, seizures, fatigue, or heart palpitations (when you can feel your heart beating). These symptoms can be worsened by emotions such as fright, anger, startle, and/or exercise. In some unfortunate cases, the heart can “arrest”, or stop beating, which can result in death. A family history of individuals who have any of these symptoms, or who died young (age 40 and below), suddenly or unexpectedly (including SIDS) may also be an indication of a need for screening.

### Screening Resources

**Specialist/Tests:** I am sending you this letter because it is important for you to be screened by an electrophysiologist (a cardiologist who specializes in the electrical system of the heart). The SADS Foundation (801-272-3023) can help you find a knowledgeable doctor, or you can contact the **Pediatric and Congenital Electrophysiology Society** (for children) or the **Heart Rhythm Society** (for adults).

One resting EKG cannot rule out a SADS condition and further tests such as a stress test, Holter event monitor, or epinephrine challenge may be used.

**Genetic Testing:** If the family mutation is known (from another family member's test), genetic testing can help confirm whether you do or do not have SADS. The cost of genetic testing is usually covered by insurance; you will need a doctor to order the test for you. There are many commercial labs; some of the largest are:

- Ambry at [www.ambrygen.com](http://www.ambrygen.com) or call 949-900-5500
- Blueprint at [www.blueprintgenetics.com](http://www.blueprintgenetics.com) or call 650-452-9340
- GeneDX at [www.genedx.com](http://www.genedx.com) or call 301-519-2100
- Invitae at [www.invitae.com](http://www.invitae.com) or call 800-436-3037 – see the free Detect genetic testing program

### Family Genetic Tree

If you are willing to add your family to the family tree, please complete the attached short questionnaire and mail it back to Marcia Baker, SADS Foundation, 4527 South 2300 East, Suite 104, Salt Lake City, UT 84117; or scan and email to [Marcia@SADS.org](mailto:Marcia@SADS.org).

Please call me or email me at \_\_\_\_\_ and let me if you have any questions. You may also contact Marcia Baker, Program Director, at [Marcia@SADS.org](mailto:Marcia@SADS.org) or call the office at 801-272-3023.

Thank you,

\_\_\_\_\_

# My FAMILY HEALTH PORTRAIT

Name: \_\_\_\_\_

Date: \_\_\_\_\_

