

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,

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