

Dear \_\_\_\_\_

I want to let you know about some important health information I recently learned that may also affect you as one of my relatives.

I've been diagnosed with a heart condition called Long QT Syndrome (LQTS). This puts me at an increased risk of developing a dangerous heart rhythm that could lead to sudden death if left untreated. Fortunately, LQTS is treatable.

LQTS is genetic and runs in families. This means that all my first-degree relatives (parents, siblings, children) have a 50% chance of also having LQTS. Other family members (aunts, uncles, nieces, nephews, cousins, grandchildren, etc.) may also have inherited this genetic condition. This means there's a chance that you're also affected.

Symptoms of LQTS include sudden fainting or seizure during exercise, excitement or startle, or sudden cardiac arrest.

My doctor has recommended that you be screened by a SADS expert doctor, called an electrophysiologist. This will probably include having an EKG, stress test, and genetic testing. If you need help finding a heart rhythm specialist, please go to <https://sads.org/what-now/find-a-doctor/>.

**Even if you have never had a symptom, you can still have LQTS and still need to be screened.**

The good news is that LQTS is totally treatable--usually with daily medicines. If this condition is diagnosed and treated, individuals can live a normal life.

Genetic Testing: Genetic testing should be done as part of the screening for LQTS. The cost of genetic testing is usually minimal now, or even free in some cases. Insurance providers generally cover most of the cost.

I am writing because I care about you and I want everyone in our family to know if they have LQTS or not, and, if they do, to get the best treatment available.

The SADS Foundation is a patient advocacy and research organization. I have found the website very helpful and the community I have met through SADS to be very supportive. **Please call the SADS Support line at 801.948.0654 or email Genevie, SADS Family Support Director, at [Genevie@SADS.org](mailto:Genevie@SADS.org)** with any questions or to learn more about Long QT Syndrome, genetic testing, or screening.

I hope this information has helped, and please feel free to contact SADS with any questions.