

When a Child Dies Suddenly

The tragic loss of a child is devastating and leaves the family shocked and overwhelmed. Families who experience the sudden, unexplained death of a child often are left with questions about their other children. "Are they at risk? Should I get them tested? For what and how should I do that?" While many conditions that can cause the sudden, unexplained death of a child are inherited.

You should make a very careful and detailed family medical history that would include details of anyone who has died before the age of 40. Any drownings or car accidents (especially if the person is alone) should be suspected for a cardiac condition. The Risk Assessment Form and/or the Family Pedigree materials are useful tools if you don't have access to a Genetic Counselor to help you do this.

How Do I Find Out Why My Child Died?

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If the autopsy findings are normal or not conclusive: i.e., a "mild myocarditis" or a "slight cardiomyopathy", ask the coroner to test for long QT syndrome, CPVT, or Brugada Syndrome. This testing is available from PGxHealth (<http://www.pgxhealth.com/genetictests/familion/>) OR GeneDx (http://www.genedx.com/site/cardiology_genetic_testing_services)

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If the coroner or medical examiner can't test for these SADS conditions, ask for blood and/or tissue to be saved using the following procedures:

- Blood should be collected in plastic EDTA (purple top) tubes and frozen at -80 degrees C immediately after collection (or no more than 5 days after collection). At least two 9 ml lavender top tubes (EDTA) of whole blood should be collected.

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If tissue is saved, cardiac tissue is usually preferred. This should also be frozen at -80 immediately after collection.

If the family history suggests a cardiac cause of the death, parents and siblings of the decedent should be screened with an electrocardiogram (ECG) and echocardiogram (ECHO)

for long QT syndrome(or other channelopathy) or a cardiomyopathy.

Cardiac disorders (such as the Long QT Syndrome) should be suspected when:

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- 1. The sudden death occurs in a young, seemingly healthy individual and no physical cause can be found for the death.
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- The individual seemed essentially healthy in life and the autopsy findings are normal or not conclusive: i.e., a mild myocarditis or a slight cardiomyopathy.
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- 3. The events surrounding the sudden death are unusual–for example, the drowning of an experienced swimmer, or a one-person car accident in the middle of the day.
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- 4. The individual had a history of syncope or seizure-like activity. (Please note, however, that approximately 30% of those who suffer a fatal cardiac arrest from LQTS had never experienced such symptoms and their absence does not rule out LQTS.)

For more information, please contact Adrienne or 1-800 STOP SAD.