

Postmortem DNA Banking and Genetic Testing: Information for Families

What is postmortem genetic testing?

A genetic test performed on a DNA sample after someone has died. In appropriate cases, this testing is a tool that may identify the cause of a young, sudden, or unexpected death.

What is DNA banking?

Secure, long-term storage of DNA that can be used for genetic testing. DNA banking preserves the DNA for future testing when postmortem genetic testing does not find a diagnosis or if genetic testing cannot be performed shortly after a death.

How can postmortem genetic testing help?

- **Determine cause of death.** For cases of unexplained sudden death, genetic testing may provide a cause of death up to 40% of the time.¹
- **Protect surviving family members.** If genetic testing identifies the cause of a sudden death, then at-risk family members, like brothers, sisters, parents, and children, can undergo targeted genetic testing to determine whether they inherited the same risk of sudden death and receive medical care to reduce their risk of sudden death.

How is postmortem genetic testing and DNA banking performed?

- Postmortem genetic testing requires DNA, which is usually taken from a blood or tissue sample. How the blood and tissue sample is stored affects the ability to obtain DNA and the quality of DNA.

How do you start the genetic testing and/or DNA banking process?

1. Find the medical examiner name and contact information (address, phone, and fax)

Name: Dr. _____ Phone: _____ Fax: _____

2. Contact the medical examiner. Ask them:

a. Were any samples saved? *yes or no*

b. If yes, what samples are available?

Blood? If yes, 1. What color tube? _____

2. Where is it stored? _____

3. How is it stored? *freezer or refrigerator*

Tissue? If yes, 1. What type of tissue? _____

2. Where is it stored? _____

3. How is it stored? *freezer or refrigerator*

These questions may seem unusual, but the logistics of how the sample was collected and stored are important to determine if and how genetic testing can be done, and if banking is possible.

Who can help you order postmortem genetic testing or DNA banking?

Coordinating genetic testing or DNA banking after a family member has died can be an overwhelming process. Genetic counselors are trained to assist families in this sensitive time with the genetic testing and DNA banking process. Genetic counselors are also experts in compiling and assessing the family history and coordinating referral of family members who may benefit from seeing a cardiologist or other health professional. Both of these activities are also important for families and can provide additional information about risks to family members.

To find genetic counselor near you, visit www.nsgc.org or contact postmortem@nsgc.org.

¹ Tester DJ, Ackerman MJ. The role of molecular autopsy in unexplained sudden cardiac death. *Curr Opin Cardiol* 2006;21:166–172.