



Dear ME/Coroner:

I represent the Sudden Arrhythmia Death Syndromes (SADS) Foundation, a non-profit organization working to save the lives and support the families of children and young adults who are genetically predisposed to sudden death due to heart rhythm abnormalities.

Today I am contacting you in regards to a recent death in our community. From the information provided by several news stories—specifically that the individual was a seemingly healthy young person who passed away suddenly and unexpectedly, it seems that this individual may fit the profile for a cardiac channelopathy disorder. As you know, reasons for many sudden cardiac deaths in the young are not evident during an autopsy. Many cardiac arrhythmia disorders that predispose children and young adults to sudden cardiac death are **genetic**. Thus, the ME plays a vital part in informing families and referring them for testing.

If the autopsy findings are normal or inconclusive, it is very important that families are referred to the SADS Foundation for help with family screening as well as counseling and support. Screening could potentially save the lives of the surviving family members.

If you are unable to do a genetic autopsy, we strongly suggest saving a tissue or blood sample using the following procedures:

1. Blood should be collected in glass or plastic EDTA (purple top) tubes (freeze at -80 degrees C immediately after collection or no more than 5 days after collection). At least two lavender top tubes (EDTA) each containing 5 – 10 ml of whole blood should be collected.
2. Don't treat samples with Formalin
3. If tissue is saved, cardiac tissue is usually preferred. This should also be frozen at -80 degrees C immediately after collection.

For both sources of DNA, standard freezers are OK if -80 degree C freezers are not available.

If you have collected a sample but are unable to store it for further analysis, please contact us.

Finally and most importantly, we ask that you please share our information with this individual's family members. We offer family grief support as well as provide valuable information to families seeking answers after a recent death. I have attached our brochure as well as some other informational sheets for you and the family. If you have any questions about this disease or our foundation, please do not hesitate to contact me.

Thank you again for your time and attention to this information.

Supporting Families. Saving Lives