Top 10 Take-Home Messages

1. Sudden cardiac death (SCD) is an important public health issue and warrants further study to better quantify its occurrence, its impact on society, and the opportunities for improving outcomes through public education and provision of automated external defibrillators and cardiopulmonary resuscitation (CPR) training.
2. For survivors of sudden cardiac arrest (SCA), victims of sudden unexplained death (SUD), and their relatives, a multidisciplinary team is central to thorough investigation, so as to maximize the opportunity to make a diagnosis. Where there has been an SCD or resuscitated SCA and a genetic cause is suspected, genetic testing and counseling is essential for families, to ensure that risks, benefits, results, and the clinical significance of genetic testing can be discussed.
3. The psychological care of families affected by SUD and survivors of SCA (and their families) should run in parallel with the investigation process. Assessment by professionals trained in psychological care should be offered, as well as grief counseling and peer support, where appropriate.
4. For the investigation of SUD, a detailed personal and family history is essential, with attention to sentinel symptoms during life such as syncope or seizures, witness accounts, premorbid investigations, and inspection of any cardiac rhythm monitoring around the time of death.
5. A comprehensive autopsy is an essential part of the investigation of SUD and should include collection and storage of tissue suitable for genetic analysis. When the autopsy suggests a possible genetic cause, or no cause and the heart is normal, referral to a multidisciplinary team for further investigation is indicated.
6. For victims of SCD or survivors of cardiac arrest where the phenotype is known, genetic testing of the proband focused on likely candidate genes, along with clinical evaluation of family members, aids in identifying family members with, or at risk of developing, the same condition.
7. For victims of SCD or survivors of cardiac arrest where the phenotype is not known, arrhythmia syndrome–focused genetic testing may help arrive at a secure diagnosis, whereas wider testing without careful consideration of the implications of indeterminate results by experienced clinicians may only serve to add uncertainty and lead to misinterpretation of results.
8. For the investigation of SCA survivors, essential inquiry includes detailed personal and family history, witness accounts, physical examination, multiple electrocardiograms (ECGs), and cardiac imaging. Ambulatory monitoring and/or provocative testing (exercise, pharmacological, and invasive electrophysiological) may provide additional useful information. A sample suitable for future DNA testing should be taken early in the patient's course and stored.
9. Genetic investigation of SCA survivors is best undertaken at a center with multidisciplinary care infrastructure and should focus on likely candidate genes known to be causally related to the suspected phenotype. In some cases, genetic evaluation without a suspected phenotype may be undertaken with appropriate genetic counseling, although genetic evaluation of patients with a known nongenetic cause of cardiac arrest is discouraged.
10. The investigation of the families of victims of SUD and survivors of SCA should include clinical and, if known, genetic cascade testing. If the cause of SUD (or rarely, SCA) is unknown, then clinical investigation of first-degree relatives may include physical examination, ECGs, cardiac imaging, ambulatory monitoring, and provocative testing (exercise, pharmacological, and rarely invasive electrophysiological) with multidisciplinary team supervision. Follow-up and periodic re-evaluation are important and are directed by initial findings.