

**First local study to unravel sudden deaths in youth**  
**Released by Princess Margaret Hospital and Forensic Pathology Service**  
**About one-third of uncertain causes of death linked to SADS**  
**Half of their first-degree relatives carry SADS genetic variants**  
**SADS HK Foundation's pilot scheme helps family members seek clinical evaluation**

Many sudden deaths in youths or people in their prime occurring every year in Hong Kong are attributed to 'uncertain causes', which preclude follow-up and bring distress to surviving family members. The medical community believes that several such cases are significantly linked to Sudden Arrhythmia Death Syndromes (SADS). SADS is a hereditary disorder that predisposes victims to sudden cardiac death, with no obvious abnormalities detected before its onset, while putting first-degree relatives at high risk for similar disease and death. Early determination of whether the sudden deaths are SADS-related would therefore serve as an important warning to the deceased's relatives and could even save their lives.

Given the complete lack of locally-conducted genetic studies on sudden death victims, SADS HK Foundation has collaborated with Princess Margaret Hospital, the Hospital Authority and Forensic Pathology Service, the Department of Health to launch a research project since 2014, the first of its kind in Hong Kong focused on young sudden cardiac death victims, with a view of uncovering the real causes of their deaths and help surviving family members.

**About one-third of young sudden death victims and more than half of their first-degree relatives carry SADS-related genetic variants    Sudden fainting identified as a common warning sign**

Under the two-year research project, young cardiac death victims with uncertain causes of death or inheritable cardiomyopathy examined at public mortuaries were chosen for molecular autopsies, while their first-degree relatives were referred for clinical assessment and/or genetic screening. Findings revealed that nearly 30% of the 21 sudden cardiac death victims carried SADS-related genetic variants. Approximately a quarter of sudden cardiac cases saw their victims died in sleep and three of them had a family history of sudden deaths. Around 30% of SADS victims experienced fainting for uncertain reasons when alive but failed to seek medical treatment or actively followed up on their conditions. Dr. Mok Ngai-shing, Specialist in Cardiology and Consultant of Princess Margaret Hospital, who oversees this project, said: "A family history of sudden deaths and fainting for uncertain reasons are vital clues to SADS and those with the conditions should seek early medical intervention to avoid missing the golden hour for diagnosis and treatment."

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According to the study, more than 50% of first-degree relatives subjected to genetic screening were found to carry SADS-related genetic variants, requiring follow-up medical care and preventive therapies. Dr. Chloe Mak, Specialist in Chemical Pathology and Consultant of Princess Margaret Hospital, who is responsible for the genetic screening administered in this project, said: “In this study, there are families with a strong family history of two to three sudden death victims with unknown causes. This causes the surviving family members great distress. This study not only partially confirms the causes of death among the sudden death victims but also facilitates their relatives with the dormant SADS disease to receive early preventive treatment based on their conditions, in order to reduce their risk exposure to sudden death.” Next-generation sequencing (NGS) was applied in the investigation into the victims’ causes of death, which yielded important genetic data and valuable experiences for the first time in local SADS research. The study is considered a major leap forward in genetic studies conducted in Hong Kong and also has established the foundation of a feasibility model on incorporating molecular autopsy in forensic investigation, next-generation sequencing analysis in hereditary cardiac disorders, genetic counseling, clinical assessment and referral.

#### **Relatives of deceased SADS victims encouraged to receive medical tests subsidized by pilot scheme**

Besides SADS-related education work, SADS HK Foundation is committed to facilitating early medical examination for patients with the dormant disease to reduce their risk exposure to sudden death. This is why the foundation is presently launching a “SADS Pilot Scheme Subsidizing Relatives for Clinical Consultation” starting from today to December 31, 2018, to subsidize the first-degree relatives of sudden cardiac death victims (age 5 to age below or equal to 40), for first-time cardiac clinical evaluations, with the aim of encouraging them to undergo early medical check-up and curtailing the incidence of SADS-related mortality. For eligibility criteria and other details, please refer to SADS HK Foundation website.

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