



# Hypertrophic Cardiomyopathy Association

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March 7, 2013

New Jersey Senate  
Assembly Health, Human Services and Senior Citizens Committee

RE: S-1911 A-3042 "Children's Sudden Cardiac Events Reporting Act"

Dear Committee:

The Hypertrophic Cardiomyopathy Association, HCMA, is a 501 c 3 organization representing those with the genetic heart condition which represents the leading cause of sudden cardiac arrest, SCA in those under the age of 40, including young athletic people.

The Hypertrophic Cardiomyopathy Association fully supports the Children's Sudden Cardiac Events Reporting Act S 1911 A-3047.

Hypertrophic Cardiomyopathy (HCM) is the leading cause of sudden cardiac arrest in the young and it is important to gather additional data on those lost by HCM and other causes. Better identification of those who die or nearly die in this manner will enable us to invoke programs and change that will identify those at risk in advance. The creation of this registry would enable the scientific community an opportunity to review each case and identify actionable risk factors and create programs that would reach others at risk. It would also help to enhance the ability of medical examiners to properly identify cause of death, communicate and guide families to appropriate care and services.

Senate Bill S1911 – Assembly bill A 3047 the "Children's Sudden Cardiac Event Reporting Act" is an important step to better understanding and combating sudden cardiac arrest in our youth. At this time there is very little data in an organized fashion on the frequency and causes of sudden death – or aborted sudden death in this population. The closest thing to organized data we truly have is the Center for Disease Control's Wonder Database which is several years old by the time the data is available and provides only a review of death certificate data. Based on this dataset we know that an estimated 140 people between 1 and 24 years of age die each year in the USA with hypertrophic cardiomyopathy. HCM, on their death certificate. We also know that each year a total of 1600 people die with HCM on their death certificate, and 54% are under the age of 54 years, thus this is a problem of the young, otherwise healthy population. However, researchers have a difficult time with this dataset as it is not always clear if the death certificate data is accurate as it is not assessable for review.

The HCMA has compiled a report on "Sudden Cardiac Arrest Risk in the Young" which explains the problem in depth, which we encourage you to read. We see a challenge with this bill that we hope the Commissioner of Health and Senior Service will address and that is the method of reporting "near deaths", as there are many potential health care professionals that may be involved in the care of the patient and we are concerned that it may fall through the cracks. We would also hope that the Commissioner seek for the medical examiners to retain suitable blood samples be retained for potential genetic testing post mortem. The collection of data of the number of deaths, the manner of death and basic family history will enable us to improve identification of those at risk and response systems in the event of SCA.

The HCMA looks forward to working with board established in this Act to ensure that national experts in HCM have an opportunity to provide critical input and assessment of the data compiled in this registry.

Thank you for the opportunity to provide this testimony and serve on this board.

Sincerely,

Lisa Salberg  
CEO and Founder

HCMA