

Surveillance for Sudden Cardiac Death (SCD) of the Young in Michigan

Program Overview

A. Background

Tragic at any age, unexpected sudden death is especially devastating when it occurs in children, youth, or young adults in the prime of life who were previously thought to have been in good health. Often associated with young athletes, such unexpected deaths tend to result in high profile media coverage. Thus, there has been considerable interest in this problem nationally, and the American Heart Association has recently issued a scientific statement reviewing recommendations and considerations related to pre-participation screening for competitive athletes.¹ The Michigan Department of Community Health (MDCH), Division of Genomics, Perinatal Health and Chronic Disease Epidemiology (GPHCD) has identified sudden unexpected death of the young (under age 40) as a potentially preventable condition, due to the heritable nature of certain cardiac disorders. Specific causes of sudden cardiac death (SCD) in young people are more likely to have genetic determinants than similar conditions in older persons. These include etiologies such as inherited arrhythmias, hypertrophic cardiomyopathy, undetected congenital heart defects, and early atherosclerotic disease. As much as 40% of families with a young SCD victim have been identified as having heritable disease.² Individuals with a family history of SCD may also be at increased risk of sudden cardiac arrest or death.

The GPHCD/Genomics Unit has begun a public health surveillance program to review unexpected deaths occurring in young people, with an initial focus on a few counties in Michigan. The purpose is to obtain information on the factors involved in these deaths and thus determine if there are ways to prevent future deaths. A tentative case definition, protocol for SCD investigation and data collection instruments were developed in collaboration with Michigan State University. Additionally, existing SCD resources have been compiled and educational materials for public as well as professional audiences are being developed. To complement these efforts and obtain further information on the number of Michigan families affected by SCD in a young relative, two questions regarding family history of SCD have also been placed on the 2007 Michigan Behavioral Risk Factor Survey, with results expected in 2008.

B. Program Objectives

Overall, the factors that contribute to SCD of the young are not well known or understood. Accurate review and interpretation of the events surrounding these SCDs in Michigan can assist in developing useful SCD prevention recommendations for families, the general public, health care systems, and providers. The ultimate goal of this program is to reduce the burden of SCD of the young in Michigan by identifying public health and medical system changes as well as family-based interventions that might be undertaken to increase awareness of opportunities for prevention, as well as appropriate screening and treatment for relatives potentially at risk.

The specific objectives of the program are to:

- 1) Implement and refine a process to collect and review demographic and medical data, as well as other information regarding the circumstances of SCDs in Michigan residents aged 1-39 years

¹ Maron BJ, Thompson PD, Ackerman MJ et al. Recommendations and Considerations Related to Preparticipation Screening for Cardiovascular Abnormalities in Competitive Athletes: 2007 Update. A Scientific Statement from the American Heart Association Council on Nutrition, Physical Activity, and Metabolism. Endorsed by the American College of Cardiology Foundation. *Circulation*. Published online March 12, 2007.

² Tan HL, Hofman N et al. Sudden unexplained death: heritability and diagnostic yield of cardiological and genetic examination in surviving relatives. *Circulation*. 2005; 112:207-213

- 2) Inform families, when indicated, of potential risk factors related to heritable causes of SCD; and identify unmet needs for education, support, medical/genetic resources and/or referrals for relatives who may be at increased risk of SCD
- 3) Develop consensus-based recommendations, as a first step toward evidence-based recommendations, to guide public health prevention efforts for reducing the occurrence of SCD in Michigan

C. Methods

The Genomics Unit is responsible for implementing this program in collaboration with MDCH Division of Vital Records and the Cardiovascular Health, Nutrition and Physical Activity Section. This project is funded in part by a CDC Cooperative Agreement for the integration of genomics in chronic disease prevention programs. SCD case information will be collected from death certificates, medical facilities, medical examiners, and emergency responders. The Genomics Unit has also contracted with Michigan State University (MSU) Division of Environmental and Occupational Medicine to conduct next-of-kin interviews, case reviews and convene an expert mortality review panel. Information obtained from the interviews and medical records will be compiled in blinded case summaries, and presented for review to a diverse panel of experts. The panel will be asked to:

- Confirm cause of death on death certificate or suggest alternative diagnoses
- Describe all significant factors that may have contributed to the death, including health system or community issues such as access to automated external defibrillator (AED) in the location where death occurred
- Determine the likelihood and number of additional family members who might be at risk for sudden cardiac arrest or death; and attempt to determine whether appropriate medical interventions for family members were identified or recommended in relation to the index case
- Determine whether examination of death certificate data is an adequate public health screening tool for identification of young people with sudden cardiac death, and if so, recommend which specific ICD-10 codes and other death certificate data fields are most indicative of a case likely to benefit from further review and in-depth investigation of possible inherited risk factors

Using information and recommendations gathered during the initial phases of the program, the Genomics Unit plans to prepare a final protocol for ongoing statewide public health review of SCDs occurring in young people. Based on recommendations received from the expert review panel, the protocol will include screening parameters and a final case definition for use in ascertaining cases needing further public health investigation. As aggregate data on larger numbers of cases are compiled, the Genomics Unit aims to develop evidence-based public health recommendations for preventing SCD of the young, in collaboration with MDCH cardiovascular staff and the Cardiovascular Health Advisory Committee. The recommendations might address identified needs for systems changes such as accessibility to AEDs; consistency in county medical examiner work-ups; greater attention to family history of sudden death, fainting or other risk factors; screening tools and methods used in well-child and sports physical examinations; or a widespread public awareness campaign.

For more information on sudden cardiac death of the young, please contact the Public Health Genomics office at genetics@michigan.gov