



Too Young to Die

**Impact of Sudden Cardiac Death
of the Young in Michigan
1999-2008**

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of Community Health



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Impact of Sudden Cardiac Death of the Young in Michigan 1999-2008

Introduction

The Michigan Department of Community Health (MDCH) is pleased to present this report detailing the impact of sudden cardiac death (SCD) in Michigan young people under age 40—an issue of grave public health concern. MDCH has identified sudden cardiac death of the young (SCDY) as a potentially preventable condition in many cases. SCD is especially devastating when it occurs in children or young adults in the prime of life who were previously thought to be in good health. These deaths are a tremendous loss not only for families, but for entire communities, as evidenced by the frequently high profile media attention.

As a result of a new state surveillance project, trends in Michigan SCDY cases are starting to be identified. Analysis of mortality data for the years 1999-2006 reveals as many as 326 out-of-hospital sudden deaths occurring each year to individuals under age 40. The statewide age-adjusted mortality rate was 5.5 per 100,000, but 13 counties had rates higher than the state average. Significant disparities were observed, with more than two-thirds of the deaths occurring in males, and one-third in blacks. Overall, atherosclerotic cardiovascular disease was the most commonly reported underlying cause of death, followed by dilated cardiomyopathy. A telephone survey of 2,856 Michigan adults conducted as part of the Behavioral Risk Factor Surveillance System in 2007 reveals that about 6.3% have a family history of early sudden cardiac death in one or more relatives. Consistent with the disparities observed in SCDY cases, 11.2 % of black non-Hispanic respondents reported a positive family history.

A multi-disciplinary expert panel reviewed recent Michigan cases of SCDY for which detailed medical information had been collected and next-of-kin interviews conducted. Some of the findings from actual Michigan SCDY case reviews are highlighted throughout this document. Although the number of cases is limited, common themes and specific steps related to patient, provider, and public health systems to prevent future deaths are emerging. These action steps relate to pre-participation sports screening, provider education and public awareness of SCDY risk factors, public awareness of cardiac symptoms and training in the use of cardiopulmonary resuscitation (CPR) and automated external defibrillators (AED), emergency response protocols, and medical examiner protocols.

The action steps identified by the expert case review process were presented and discussed by 60 individuals from diverse organizations in September 2008. Participants agreed upon immediate next actions and committed to working to achieve the following outcomes: (1) developing formal recommendations for revisions to the Michigan High School Athletic Association sports participation form; (2) increasing provider awareness of SCDY risk factors, assessment, referral and treatment; and (3) increasing medical examiner awareness of SCDY familial risks and consideration of DNA banking.

The partnership of all concerned individuals and organizations is needed to increase early identification, treatment and intervention—victims of sudden cardiac death are too young to die—and every life lost is one too many.



Chapter 1 **Public Health Impact and Significance**

Reducing early mortality due to heart disease is an important priority for public health. Heart disease is the second leading cause of premature death as measured by years of potential life lost for males and females of most races, except for black males in whom it is the leading cause of early mortality. Overall, heart disease at any age is the leading cause of mortality in Michigan, as reported in the *Healthy Michigan 2010* and *Michigan Department of Community Health (MDCH) Critical Health Indicators Report: 2007* documents.^{1,2}

The estimated number of sudden cardiac deaths of the young (SCDY) occurring in Michigan varies depending on the definition. For this report, SCDY is defined as a cardiac or ill-defined cause of death occurring in the emergency room, en route to the hospital, out of the hospital, or dead on arrival to the emergency room in an individual between 1 and 39 years of age. Using this definition, SCDY is estimated to claim the lives of as many as 326 Michigan children and young adults each year. Of these deaths, approximately 10% are in children and teens under age 20. About 40% occur in individuals between 20 and 35, while nearly half occur between 35 and 39 years of age. Moreover, recent survey data reveal that about 6.3% of all Michigan residents report having at least one biological family member who died suddenly and unexpectedly at a young age.³

Although SCDY is a relatively rare occurrence when compared to SCD in older adults, it has a devastating impact not only on the family but on the larger community as well. When they occur, the tragic nature of these deaths frequently attracts media attention. Questions are often asked, especially--

“Could this death have been prevented?”

Concern about the public health impact of SCDY prompted the MDCH Public Health Genomics Program and the Cardiovascular Health, Nutrition and Physical Activity Section to identify sudden cardiac or unexplained death of the young (under age 40) as a potentially preventable condition. SCDY may have critical implications for the victim's family, especially if the death was related to an inherited condition. Advances in understanding the hereditary causes of SCD have led to the realization that individuals with a family history of SCD have an increased risk of suffering a sudden death themselves.⁴ New findings have emerged about the benefits of identification, treatment and follow-up to reduce the risk of early cardiac death. Some methods for screening and intervention are already known, and other methods are being proposed. While there is still a need to better understand the problem of SCDY in Michigan, there are steps that can be taken now to improve:

- ♥ *DETECTION of individuals at increased risk,*
- ♥ *TREATMENT of those with predisposing conditions, and*
- ♥ *INTERVENTION for victims experiencing sudden cardiac arrest.*

Michigan's SCDY Mortality Review system has identified the following primary and secondary prevention measures:

- ✓ Pre-participation sports screening
- ✓ Provider education and public awareness of SCDY risk factors
- ✓ Public awareness of cardiac symptoms and CPR/AED training
- ✓ Emergency response protocols
- ✓ Medical examiner protocols

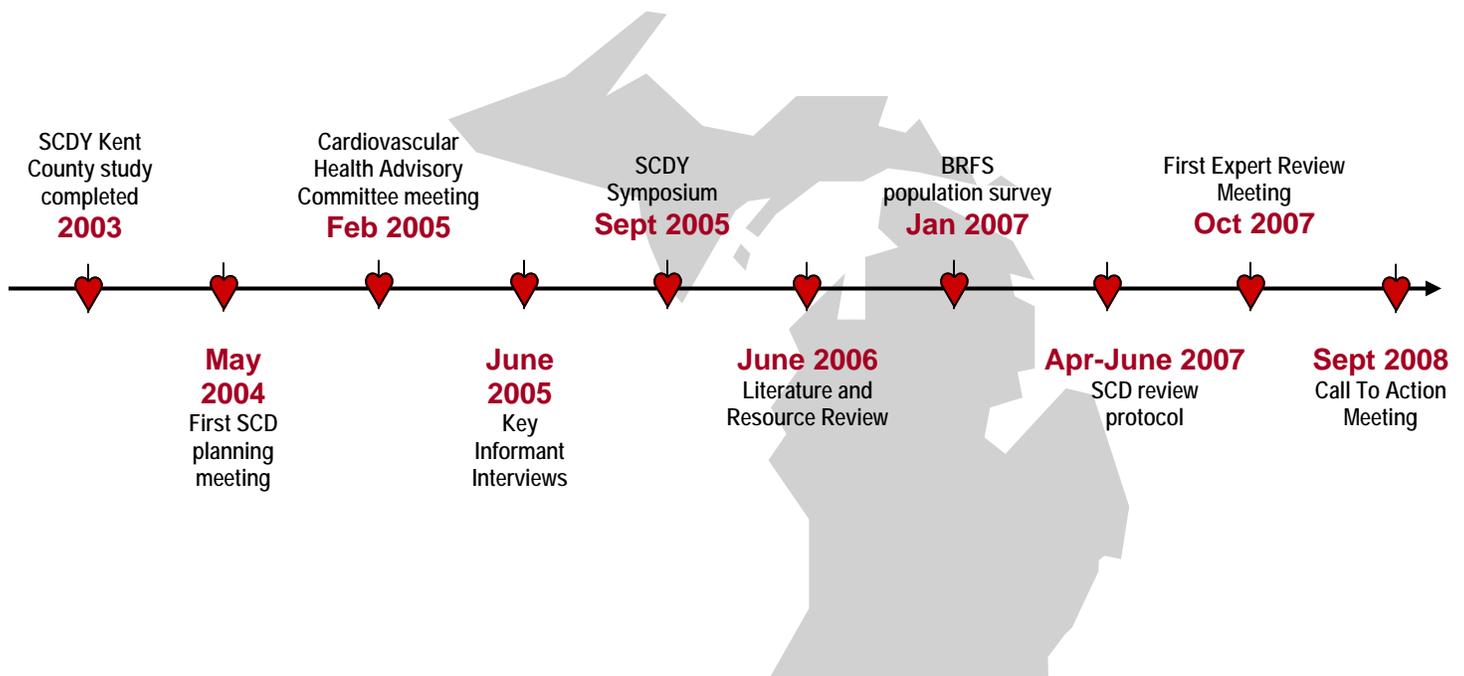
Chapter 2 Epidemiology of SCDY in Michigan

Who is affected by SCDY?
Where do most deaths occur?
Why do they happen?

To begin answering these questions, the MDCH needed to establish a system for monitoring SCDY based on incoming death certificates filed with the State Registrar. Statewide population-based surveillance and epidemiological review of SCDY is a novel endeavor. To our knowledge, no other state public health agency has attempted to systematically assess and address this cause of early mortality. Several events led to the concept of a state-based SCDY surveillance and mortality review project. A study by Dr. Michael Lehman and colleagues first brought attention to the problem of SCDY in Michigan.⁵ The researchers examined records on unexpected deaths to people between 1 and 39 years of age who had received an autopsy in Kent County. The investigators found SCDY occurred mainly in males, 50% of the deaths were due to coronary artery disease, and family history documentation was lacking in medical examiner records.

Beginning in 2004, a series of steps were taken (see timeline below), to identify key stakeholders, examine the need for surveillance, and ultimately establish a mortality review system with the short-term goals of:

- ♥ Developing and refining a process to collect and review demographic and mortality data regarding SCDY in Michigan residents and
- ♥ Conducting epidemiological assessments of the burden of SCDY in Michigan.



Development of SCDY Surveillance in Michigan

Key Steps

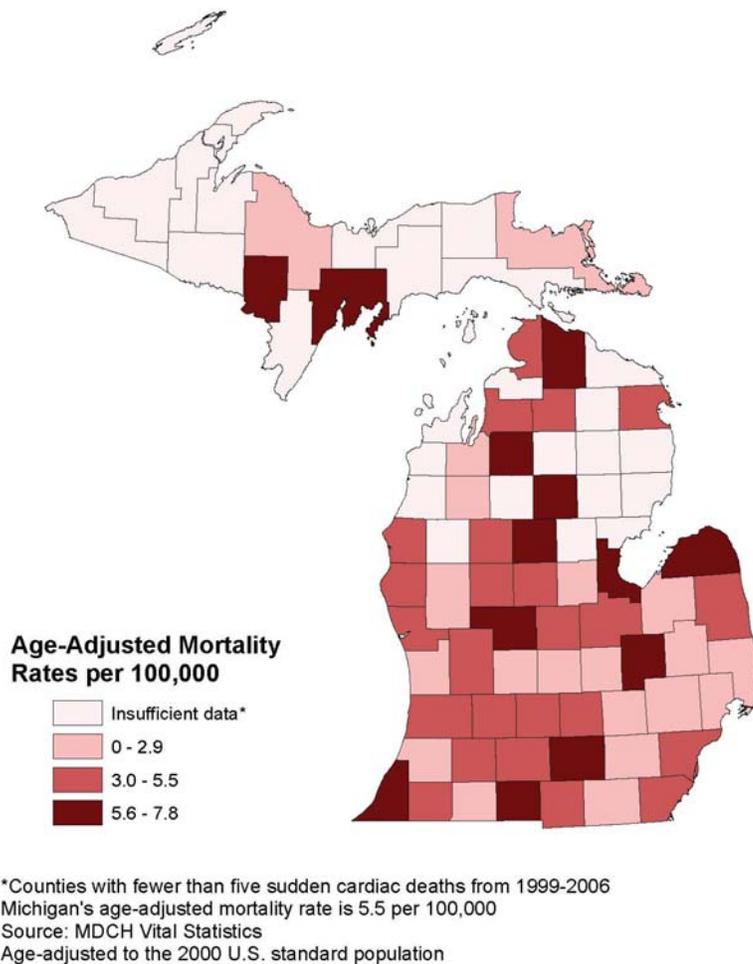
- **Interviews with key medical experts**—provided important information about current practice and procedures following unexpected deaths, revealing considerable variation and lack of consistency in medical examiner post-mortem protocols from county to county.
- **Presentation to the state cardiovascular health advisory committee**—confirmed interest in developing a mortality review system.
- **Symposium on SCDY**—invited national and state experts to review causes of SCDY and set priorities; stakeholders (including family members and advocacy groups) identified the need for a state surveillance system and awareness campaign.
- **Analysis of existing mortality records**—reviewed death certificate data from 1999-2006 retrospectively to estimate burden of SCDY.
- **Population survey**—provided estimates of how many Michigan families are affected by SCDY based on answers to a question on the 2007 Behavioral Risk Factor Survey (a BRFS random-digit-dialed telephone survey) about family history of sudden cardiac death in young relatives.
- **SCDY investigation protocol and data collection instruments**—reviewed by MDCH Institutional Review Board (IRB), and project deemed to be of public health surveillance.
- **MDCH Medical Research Designation**—issued by MDCH Chief Medical Executive as allowed by the Public Health Code to assure that all information collected during the project is kept confidential and used only for public health purposes.
- **Michigan SCDY Expert Review Panel**—met for the first time in October, 2007 to review four SCDY cases. The panel met twice in 2008 to review nineteen SCDY cases.
- **Call to Action Event**—held on September 18, 2008 with 60 participants to discuss and identify key next steps to prevent SCDY in Michigan.

To better understand the burden of sudden death in Michigan young people, mortality data spanning the time period from 1999-2006 were examined for Michigan residents between 1 and 39 years of age whose underlying cause of death was reported on the death certificate using specific codes based on the International Classification of Diseases-Version 10 (ICD-10) system. All inpatient hospital deaths were excluded. During this timeframe, 2,336 deaths were considered to meet Michigan's case definition for sudden cardiac death of the young based on death certificates filed with the State Registrar. Although there appears to be ambiguity regarding some of the codes used to report underlying causes of death, the MDCH Division for Vital Records and Health Statistics classifies all reported deaths to Michigan residents in accord with national coding requirements.

For this time period, the statewide age-adjusted mortality rate for children and young adults ages 1-39 was found to be approximately 5.5 per 100,000 residents. However, there were significant differences between counties, as depicted in Figure 1. Thirteen counties had mortality rates higher than the statewide average, with the rate of SCDY appearing to be highest in Clare (7.8), followed by Kalkaska (7.3) and Genesee (7.0) counties. Wayne county had the largest total number of deaths (838), followed by Oakland (187), Macomb (156), Genesee (127), and Kent (110) counties. The rates for all Michigan counties with more than five reported cases are included in Appendix A.

Age-Adjusted Mortality Rates for SCD, Michigan Residents Age 1-39 by County, 1999-2006

Figure 1



Data were also analyzed by sex, race, place of death, autopsy status, and cause of death (Table 1). The majority of individuals (nearly 48%) died in the hospital emergency room/outpatient setting or were dead on arrival, whereas 42% died at home. An autopsy was performed in more than three-quarters of the cases (78%). The mortality rates varied by sex, race, age, and cause of death.

Significant disparities were observed for sex and race, with more than two-thirds of the deaths occurring in males, and one-third in blacks. Only 17.4% of the Michigan population under age 39 is African-American or black, while 78.6% is white. Therefore, SCDY appears to affect blacks disproportionately.

Overall, the rate for males was 7.6 per 100,000 and for females, 3.4 per 100,000. The rate for blacks (11.9 per 100,000) was significantly higher than the rate for whites (4.6 per 100,000). **The single highest age-adjusted mortality rate was for black males at 15.8 per 100,000** which is nearly two-and-a-half times the rate for white males (6.4 per 100,000). The rate for black females was 8.5 per 100,000, more than **triple** the rate for white females (2.5 per 100,000) [Data not shown].

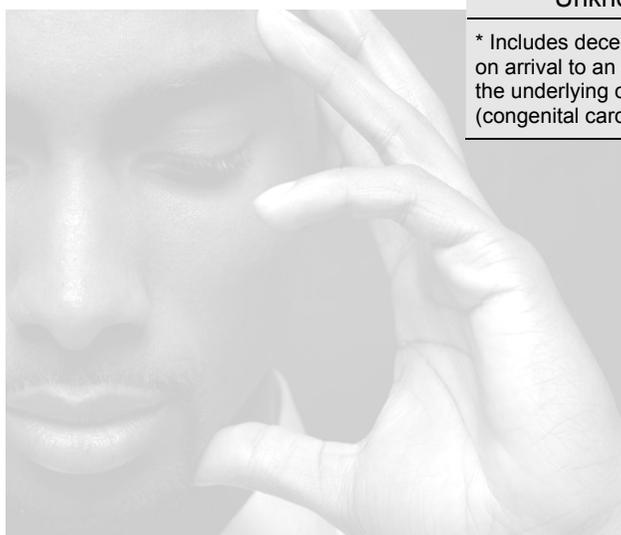
Overall, the number of SCD cases seemed to decrease from ages 5-14 and then exhibited an increasing trend among teens. **The greatest number were reported in adults ages 35-39 years.** The lowest mortality rate was for the 1-9 year old group at 0.5, followed by the 10-19 year old group at 0.9 and the 20-29 year old group at 3.3 per 100,000. There was a dramatic increase between those in their 20s and those in their 30s, with the highest mortality rate for the 30-39 year old age grouping at 13.8 per 100,000.

**Table 1
Sudden cardiac deaths (SCDs)* of Michigan residents
aged 1 - 39 years, 1999 - 2006**

	Number	Percent
Total	2,336	
Sex		
Male	1,615	69.1
Female	721	30.9
Race		
White	1,505	64.4
Black	778	33.3
Other	53	2.3
Age		
1-4 years	64	2.7
5-9 years	37	1.6
10-14 years	48	2.1
15-19 years	100	4.2
20-24 years	156	6.7
25-29 years	260	11.1
30-34	535	22.9
35-39	1,136	48.6
Place of death		
Home	983	42.1
Nursing home, extended care	16	6.8
Hospital: emergency room / outpatient	1,112	47.6
Ambulance	33	1.4
Other / unknown	192	8.2
Autopsy		
Yes	1,832	78.4
No	503	21.5
Unknown	1	0.0

* Includes decedents who died out of the hospital, or in an emergency department, or were dead on arrival to an emergency department, and had one of the following ICD-10 codes reported as the underlying cause of death on the death certificate: I00-I51 (cardiac causes), Q20-Q24 (congenital cardiac malformations), R96-R99 (ill-defined causes).

The significantly increased mortality rate in the 30-39 year old group requires further investigation into possible modifiable risk factors associated with these deaths.



Significant disparities were also observed for age and sex (Figure 2). For all age groups analyzed, males were more commonly affected with SCDY than females. The largest disparity between sexes was observed in the 35-39 year old age group, with males comprising over 70% of cases.

Number of SCDs in Michigan residents aged 1-39 years, by age and sex, 1999-2006

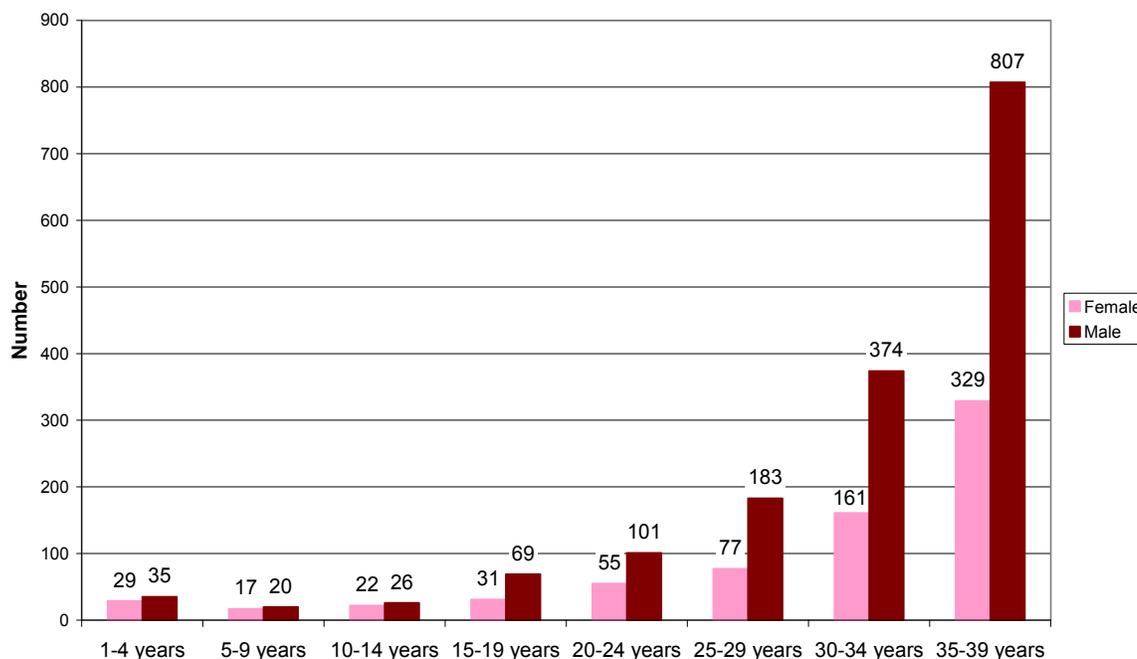


Figure 2

Retrospective Analysis by Specific ICD-10 Codes

For this retrospective review and analysis of Michigan SCDY cases, a methodology was used to examine death certificates similar to that reported by Chugh et al in previously published studies.⁶ Cases were assigned to one of three groups according to eligible codes that included **cardiac** (I00-I51), **congenital cardiac malformation** (Q20-Q24) or **ill-defined** (R96-R99) etiologies. [See Appendix B for definitions of specific causes of SCDY]. Although past studies using death certificate data have been used to generate national estimates, this retrospective method has some limitations with respect to accuracy, and has previously been reported to result in an overestimation of true SCD cases. In addition, analysis of death certificate data alone does not allow investigation of potential modifier effects that might provide additional insight or explanation relative to these causes of death—for instance, the impact of environmental or behavioral factors such as smoking, drug or alcohol use, excessive weight or level of physical activity, etc.

Therefore, further assessments of SCD in the general population using *multiple* sources of case ascertainment (i.e., death certificates, emergency medical response systems, medical examiners, hospitals) would enhance the accuracy of the data presented in this report.

Table 2
Ten most frequent underlying causes of death of Michigan SCD* victims,
1999-2006 (n=2,336)

ICD 10 Code	Cause of death	Number	Percent
I25.0	Atherosclerotic cardiovascular disease	341	14.6
I42.0	Dilated cardiomyopathy	321	13.7
I21.9	Acute myocardial infarction	279	11.9
I25.1	Atherosclerotic heart disease	234	10.0
I42.2	Other hypertrophic cardiomyopathy	146	6.3
I11.9	Hypertensive heart disease without heart failure	127	5.4
R99	Other ill-defined and unspecified causes of mortality	113	4.8
I42.9	Cardiomyopathy	93	4.0
I49.9	Cardiac arrhythmia	88	3.8
I26.9	Instantaneous death	65	2.8

* Includes decedents who died out of the hospital, or in an emergency department, or were dead on arrival to an emergency department, and had one of the following ICD-10 codes reported as the underlying cause of death on the death certificate: I00-I51 (cardiac causes), Q20-Q24 (congenital cardiac malformations), R96-R99 (ill-defined causes).

The overall age-adjusted rate for deaths due to cardiac causes was 4.9 per 100,000, significantly higher than rates for ill-defined causes (0.4) and for congenital cardiac malformations (0.3). The single most frequently reported cause of death was atherosclerotic cardiovascular disease (14.6%), followed by dilated cardiomyopathy (13.7%) and acute myocardial infarction (11.9%), as noted in Table 2.

The relative frequency of different SCDY etiologies varies by sex, race and age. For the top ten causes of death, there were notable differences by race, with blacks disproportionately represented among deaths relating to any cause except acute myocardial infarction and atherosclerotic heart disease. The most commonly reported underlying cause in blacks was dilated cardiomyopathy (n=184) while in whites it was acute myocardial infarction (n=233). The largest discrepancies were for dilated cardiomyopathy and hypertensive heart disease, respectively, where blacks represented about 57% and 54% of all deaths due to those etiologies. (Figure 3)



There were also notable differences between males and females, with males more likely than females to die of any cause except instantaneous death. The greatest difference was in the "other hypertrophic cardiomyopathy" category where females comprised just under 12%, while males represented 88% of all deaths. (Figure 4)

Figure 3

Top ten causes of SCD by race, Michigan residents aged 1-39 years, 1999-2006

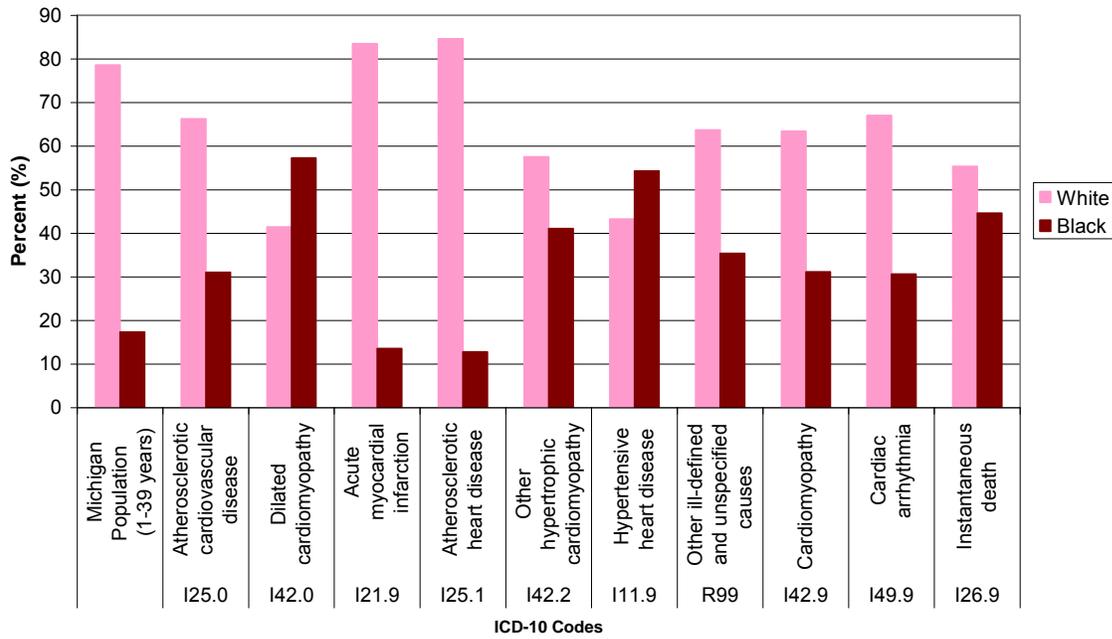
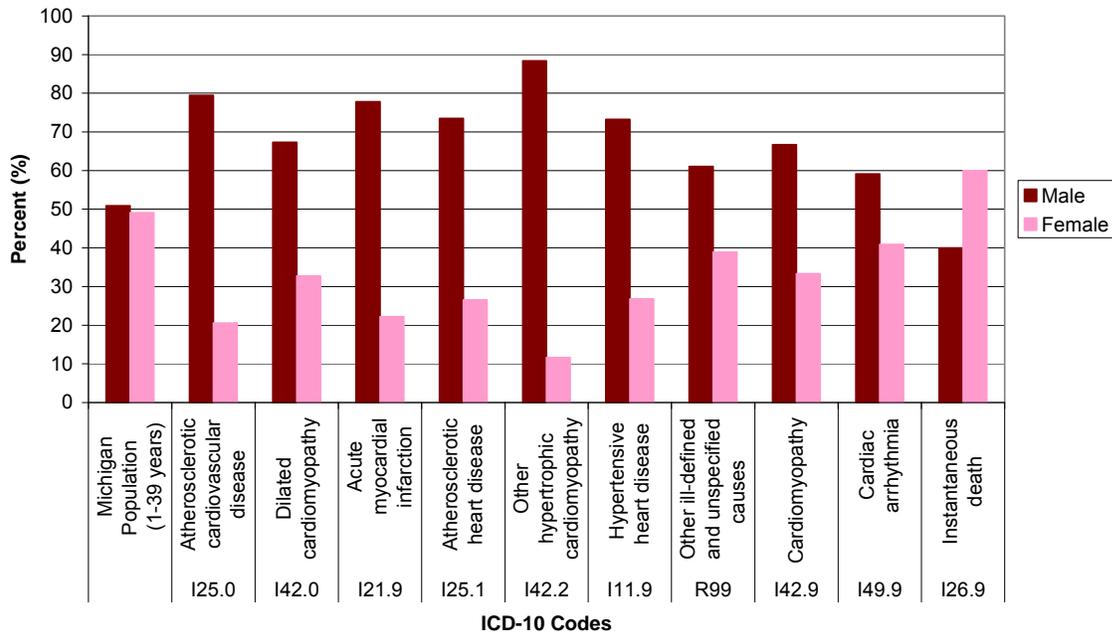


Figure 4

Top ten causes of SCD by sex, Michigan residents aged 1-39 years, 1999-2006



The number of deaths resulting from congenital cardiac malformations remained fairly constant across all age groups with a slight peak (n=26) among 30-34 year olds [Data not shown]. The number of deaths due to ill-defined causes (Figure 5) was highest among 35-39 year olds but extremely low in the 5-14 year age group. Similar to the overall mortality rates for SCDY shown in Figure 2, cardiac causes were more often reported beginning in the mid-teens with the largest number (n=1,077) in the adult 35-39 age group [Data not shown].

Number of SCDs of Michigan residents aged 1-39 by age group and ill-defined causes of death, 1999-2006

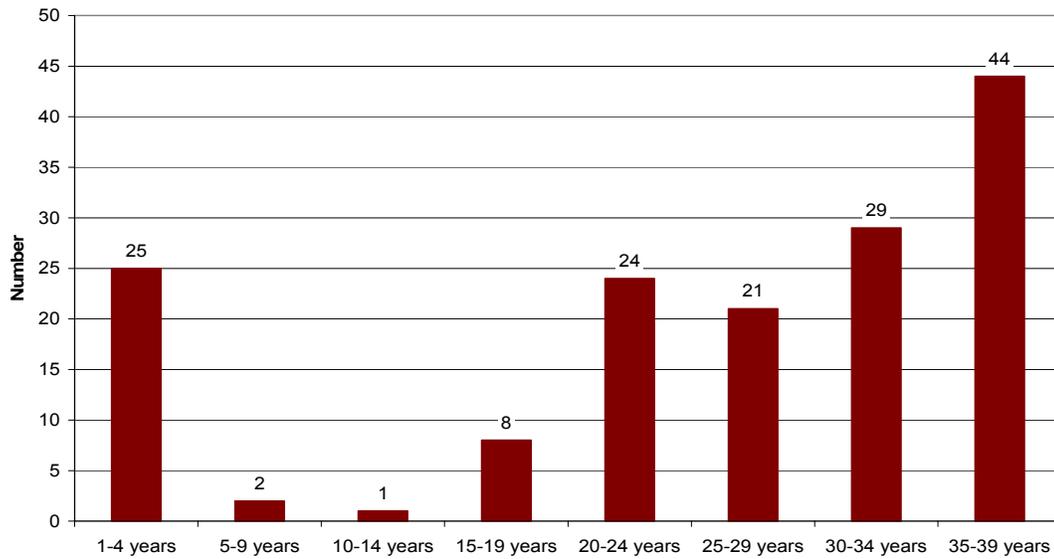


Figure 5

When analyzed by year, there was little fluctuation in the number of SCDY cases due to congenital and ill-defined causes. A slight decrease in cardiac cases was observed in 2004 but the number increased in subsequent years. (Figure 6)

Number of SCDs in Michigan residents aged 1-39 years, by year and underlying cause of death, 1999-2006

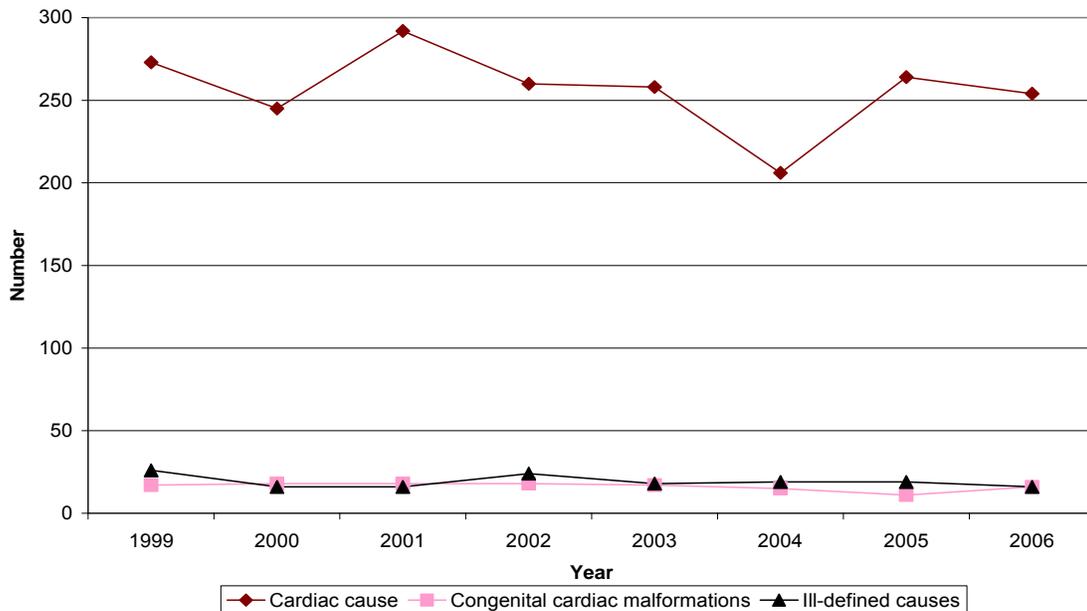


Figure 6



Michigan BRFS and Family History of SCDY

Although age, sex, and race/ethnicity are all risk factors for SCDY, the greatest risk factor for SCDY is family history.⁷ In fact, as much as 40% of families with a victim of SCDY under age 40 have been identified as having a heritable disease. Therefore, collection of family history of SCDY is a vital first step to identify, screen, and manage individuals at greatest risk for SCDY.

Despite increased risks for family members, it appears that family history of SCDY is rarely documented in the clinical setting.⁸ There is a paucity of reports in the medical literature on the psychosocial, emotional or clinical follow-up of family members of SCDY victims. Therefore, in 2007, using the Michigan Behavioral Risk Factor Surveillance System random digit-dialed telephone survey, we asked 2,856 Michigan adults about their family history of SCDY. Overall, the proportion of adults in Michigan with a family history of early sudden cardiac or unexplained death was 6.3% (Table 3).

Table 3
Family History of Sudden Cardiac Death of the Young^a
2007 Michigan Behavioral Risk Factor Survey

	%	95% Confidence Interval
Total	6.3	(5.2 - 7.7)
Age		
18 – 24	3.8	(1.6 - 8.7)
25 – 34	8.6	(4.9 - 14.6)
35 – 44	4.2	(2.4 - 7.1)
45 – 54	7.7	(5.4 - 10.9)
55 – 64	5.9	(4.1 - 8.5)
65 – 74	8.5	(5.4 - 13.3)
75 +	5.4	(3.5 - 8.2)
Gender		
Male	5.4	(3.9 - 7.4)
Female	7.7	(6.1 - 9.6)
Race/Ethnicity		
White non-Hispanic	5.4	(4.3 - 6.8)
Black non-Hispanic	11.2	(7.7 - 16.0)
Other non-Hispanic	9.4	(3.8 - 21.3)
Hispanic	-- ^b	
Education		
Less than high school	10.8	(5.8 - 19.3)
High school graduate	8.8	(6.6 - 11.7)
Some college	4.7	(3.3 - 6.8)
College graduate	4.4	(2.8 - 6.8)
Household Income		
< \$20,000	7.8	(5.1 - 11.7)
\$20,000 - \$34,999	8.4	(5.9 - 11.8)
\$35,000 - \$49,999	8.8	(5.5 - 13.8)
\$50,000 - \$74,999	4.1	(2.1 - 7.9)
\$75,000 +	3.2	(1.9 - 5.2)

^a Among all respondents (n = 2,856), the proportion who reported having at least one biological family member that had a sudden cardiac death, or sudden unexplained death, between the ages of 1 and 39.

Note: Interviewers were instructed not to include spouses of the respondent, infants less than one year of age, as well as drug-related deaths, traumatic deaths (such as car crashes), suicides, homicides, or individuals who had a long illness.

^b The denominator in this subgroup is less than 50.

Consistent with the health disparities found among SCDY victims (Table 1 and Figure 6), there are considerable differences in the proportion of families with a positive SCDY history based on racial/ethnic background (Table 3). Blacks had the highest reported rate of SCDY family history at 11.2%, more than double the rate of 5.4% for white non-Hispanic adults. Adults with a household income of less than \$50,000 also reported family history of SCDY more frequently than those with a household income of \$50,000 or more. Furthermore, adults with a high school degree or less education more often reported a family history of SCDY than those with some college education.

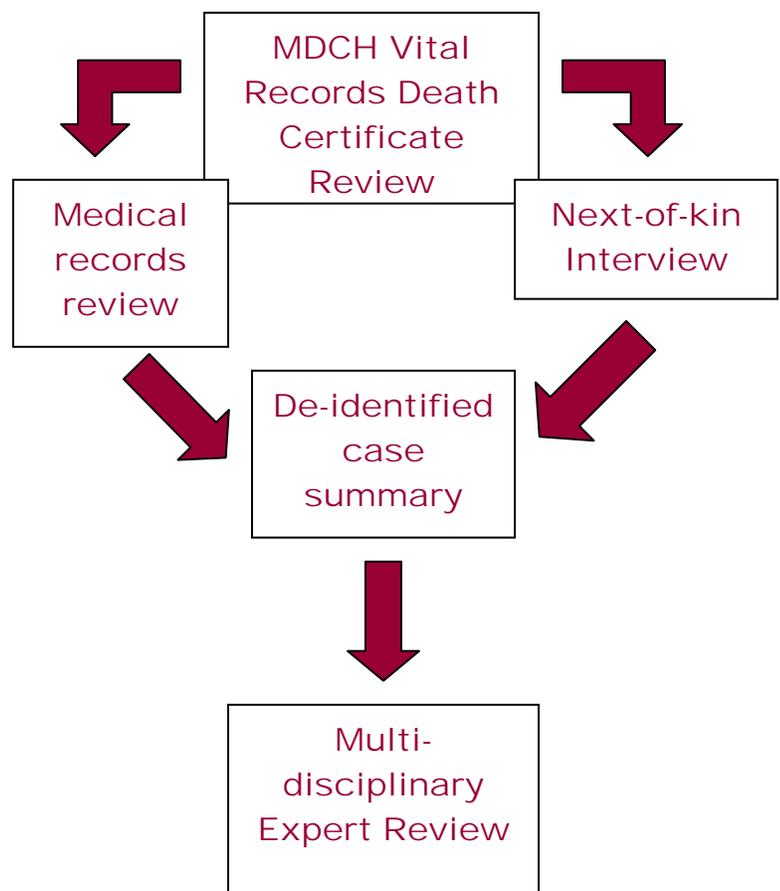
Of adults reporting a family history of SCDY, 26.2% had multiple affected family members, and, about 30% reported a first degree relative (i.e., parent, sibling, child) with SCDY. Individuals with multiple affected family members and/or an affected first degree relative have the greatest risk based on their family history.

Mortality Review

Cases of suspected SCDY were reviewed by a panel of experts representing the disciplines of emergency medicine, pediatric and adult cardiology, medical genetics, cardiac pharmacology, local public health, pathology, primary care, sports medicine, nursing, and a health insurance plan. The goals of the Michigan SCDY mortality review system are to:

- ♥ Implement and refine a process to collect and review medical data and other circumstantial information regarding SCDY in Michigan residents,
- ♥ Use the expert review process to identify recommendations as a first step toward evidence-based medical system changes and public health prevention efforts that will reduce the occurrence of SCD in Michigan, and
- ♥ Identify unmet needs for family-based interventions including education, support, medical/genetic resources and referrals for relatives who may be at increased risk of SCD themselves.

The pilot case review process included collecting information from death certificates, medical facilities, medical examiners, emergency responders, and family members. Cases were selected for in-depth review based on the decedent's age, geographic location, and underlying cause of death as coded on the death certificate and likelihood of a true "sudden death."



MDCH contracted with Michigan State University, Division of Environmental and Occupational Medicine to conduct next-of-kin interviews, collect and review pertinent records, and convene and facilitate the expert mortality review panel.

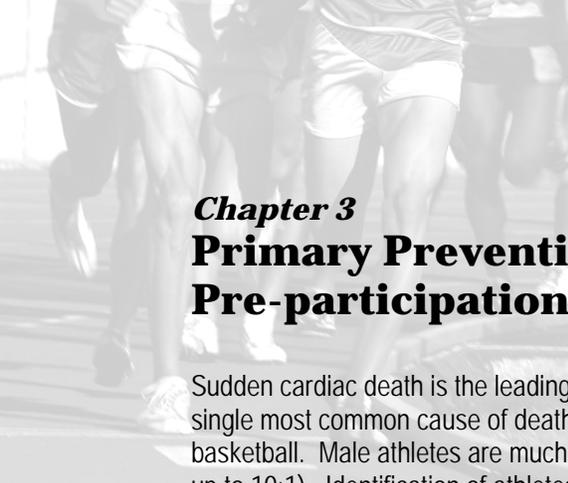
For each case, the panel was asked to:

- ⇒ Confirm the cause of death listed on the death certificate or suggest an alternative diagnosis;
- ⇒ Describe all significant factors that may have contributed to the death, including health system or community issues such as access to an automated external defibrillator (AED) in the location where the death occurred;
- ⇒ Determine the likelihood that additional family members could be at risk and attempt to determine whether appropriate medical interventions for family members were identified or had been recommended; and
- ⇒ Suggest recommendations related to the patient, provider, and system levels that could have prevented the reviewed death or future deaths in the family.

Based on the SCDY cases reviewed to date, the expert panel has identified a need to address certain clinical and systems changes, as presented in the following chapters and summarized in Table 4. The following chapters also highlight actual excerpts from reviewed cases that led to these action steps.

Table 4: Action Steps to Prevent SCDY Identified by the Michigan SCDY Expert Review Panel

<p>Pre-Participation Sports Screening/Physical and Follow-up</p>	<ul style="list-style-type: none"> ⇒ Make formal recommendations to Michigan High School Athletic Association (MHSAA) to revise sports participation form based on mortality case findings and published resources (such as American Heart Association) ⇒ Identify and disseminate clinical guidelines for evaluation and management of students with: <ul style="list-style-type: none"> ▪ Known conditions at risk for SCDY ▪ Possible clinical symptoms of conditions that predispose to SCDY ▪ Significant family history of SCDY ▪ High risk conditions such as obesity or hypertension ⇒ Identify and/or disseminate recommendations to coaches about symptoms and/or conditions that may place athletes at higher risk for SCDY
<p>Provider Education and Public Awareness of SCDY Risk Factors</p>	<ul style="list-style-type: none"> ⇒ Increase public awareness and provider assessment of SCDY risk factors, including family history, through various means including multiple different health system contact points ⇒ Identify and/or recommend clinical screening protocols for those with family history of SCDY or other heart conditions known to predispose individuals to SCD ⇒ Consider developing continuing medical education opportunities regarding SCDY risk factors, assessment, referral and treatment for Michigan health professionals ⇒ Emphasize the need for case management for young adults with chronic disorders (such as diabetes, hypertension, high cholesterol, congenital heart defects, and obesity) ⇒ Identify options for obtaining medications for uninsured and underinsured individuals at risk for SCDY, and disseminate broadly to providers ⇒ Increase awareness and access to appropriate medical and/or genetic services for individuals with a family history of SCDY (i.e., create and disseminate a list of cardiovascular and genetic specialists and clinics to providers, investigate expenses and reimbursement for services including genetic testing)
<p>Public Awareness of Cardiac Symptoms and CPR/AED Training</p>	<ul style="list-style-type: none"> ⇒ Explore existing state mandates or professional recommendations for CPR and AED training (especially for specific groups, such as coaches and police officers, and settings, such as schools and community centers) ⇒ Increase appropriate availability of AEDs and trained users in emergency situations ⇒ Increase public awareness of cardiac symptoms and appropriate actions to follow ⇒ Increase public and community knowledge of CPR
<p>Emergency Response Protocols</p>	<ul style="list-style-type: none"> ⇒ Explore appropriateness of response time and initiation of immediate defibrillation for sudden cardiac arrest cases; provide feedback to EMTs ⇒ Investigate availability of AEDs for all responders ⇒ Make formal clinical recommendations regarding appropriate use of medications in SCDY situations to appropriate EMS organizations
<p>Medical Examiner Protocols</p>	<ul style="list-style-type: none"> ⇒ Suggest consideration of DNA banking for SCDY cases; explore expense and insurance reimbursement options for DNA banking ⇒ Increase awareness of familial risks among medical examiners ⇒ Develop a mechanism to ensure autopsy results and recommended follow-up are conveyed to families and primary providers ⇒ Develop suggested protocols for autopsy of SCDY cases ⇒ For deceased individuals with pacemakers, consider a pilot to independently assess pacemakers' function after SCDY



Chapter 3

Primary Prevention Opportunity: Pre-participation Sports Screening

Sudden cardiac death is the leading cause of death in young athletes.⁹ Hypertrophic cardiomyopathy (HCM) is the single most common cause of death among U.S. athletes, occurring most commonly in those playing football and basketball. Male athletes are much more likely to die suddenly than female athletes (male: female ratio for SCDY is up to 10:1). Identification of athletes at high risk for SCDY is critical in order to prevent adverse events.

An important opportunity for primary prevention is to identify high risk athletes during pre-participation screening. However, guidelines for screening athletes differ widely on an international, national and state basis.^{10,11,12,13,14,15,16} Although some countries routinely incorporate the use of ECGs for early detection of cardiovascular abnormalities in athletes, there has been considerable debate in the United States about the appropriate strategies, effectiveness and logistics of various pre-participation screening methods.^{17,18} It should be noted that *evidence-based* guidelines for pre-participation screening of non-professional athletes currently do not exist, and therefore, in the U.S. there are presently no universally accepted or mandated standards for screening athletes of any age, nor are there approved certification guidelines for the healthcare professionals who perform such examinations.

National research on the best method of conducting pre-participation screening for athletes has led to inconsistent conclusions. For instance, personal and family history, physical examination, and a 12-lead electrocardiogram were used to screen 501 college athletes at the University of Maryland, and no athletes were found to have a cardiovascular disease placing them at risk for SCDY.¹⁹ In contrast, another study of 5,615 high school athletes in Nevada concluded that ECG was more effective than cardiac history and physical exam in detecting serious cardiovascular diseases.²⁰

A 2007 scientific statement published by the American Heart Association (AHA) and endorsed by the American College of Cardiology discusses ethical-medical-legal complexities and provides a thorough overview of the benefits and limitations of cardiovascular screening for competitive athletes, including those playing organized and sanctioned interscholastic sports at the middle- and high school levels, and college (both intercollegiate and club sports) as well as professional sports.²¹ While very little information on cost-effectiveness is available, the authors conclude that the absolute cost of a large scale national screening program with routine ECG testing for 10 million middle and high school athletes would be enormous—in the range of \$2 billion annually. Independent of the cost, there are also concerns about the practicality of implementing widespread mass screening that include logistics, a shortage of qualified physician examiners, and the problem of borderline or false-positive results.

As reported during his pre-participation sports screening, he had been experiencing vague symptoms for the past several months. His heart skipped beats, he was dizzy when getting up from a chair, his legs hurt and he was tired all the time. The teen thought the symptoms meant he was out of shape so he would practice harder. A few days before his death, he told his mother “I’m going to die... my heart’s going to stop.”



The AHA supports pre-participation cardiovascular screening for student-athletes in organized competitive sports as “justifiable, necessary, and compelling on the basis of ethical, legal and medical grounds.” While the AHA Council on Nutrition, Physical Activity and Metabolism did not believe it to be... “prudent or practical to recommend the routine use of tests such as 12-lead ECG or echocardiography in the context of mass, universal screening” it concedes that ... “such a complex initiative would have benefit in terms of detecting greater numbers of athletes with important heart diseases.” The Council also did not ... “arbitrarily oppose volunteer-based athlete screening programs with noninvasive testing performed selectively on a smaller scale in local communities if well designed and prudently implemented.”²²

Despite differing opinions among cardiology experts on the value and feasibility of including additional elements such as routine ECG screening, there is general agreement nationally on the basic elements of cardiovascular screening. The AHA and American College of Sports Medicine recommend that an athlete pre-participation evaluation include detailed family history and physical examination. The recommended 12-point screening protocol for young competitive athletes includes:

The mother voiced concern over the fact that the sports physical form was not seen, filled out, or signed by her. After his death, she found a letter her son had received clearing him to play sports.

- 1) A personal history to assess palpitations, exertional chest pain/discomfort, unexplained syncope/near syncope (fainting), exertional unexplained dyspnea/fatigue, and elevated systemic blood pressure and heart murmur;
- 2) A family history to assess premature death, disability from heart disease in a close relative younger than 50 years old, and known cardiovascular genetic conditions; and
- 3) A physical exam to assess heart murmur, femoral pulses, physical stigmata of Marfan syndrome and brachial artery blood pressure.

If there is a significant finding in the history or physical, a 12-lead ECG, echocardiogram, exercise testing and/or cardiovascular consultation should be considered. Parental verification of any responses provided by a youth is essential for secondary education students.^{23,24}

Several examples of pre-participation athletic screening and physical evaluation forms developed by international and national medical professional organizations or state athletic programs have been identified.^{25,26,27}

Guidelines for athletes with known genetic conditions, such as hypertrophic cardiomyopathy (HCM), and known coronary artery disease have also been published.^{28,29}

There are no federal statutes in the United States that establish the scope of large-scale cardiovascular screening for athletes. Standards for pre-participation screening of high school athletes are often determined by state high school associations, state education departments, local school districts or state legislatures.³⁰ The Michigan High School Athletic Association (MHSAA) provides a medical history form template³¹ for use by schools but has not issued specific guidelines for cardiovascular screening. The Michigan Governor’s Council on Physical Fitness, Health and Sports has issued position statements on prevention of injuries in youth soccer³² and football³³ that recognize the need for cardiovascular screening as a component of the pre-participation physical evaluation.



Chapter 4

Primary Prevention Opportunity: Provider Education and Public Awareness of SCDY Risk Factors

Specific causes of SCD in younger adults and children are more likely to have genetic determinants than similar conditions in older persons. These include inherited arrhythmias, hypertrophic cardiomyopathy, undetected congenital heart defects and early coronary artery disease/atherosclerotic disease. Over the last decade, there has been significant progress in identifying inherited disorders that increase the chance of SCDY.^{34,35}

It is critical for providers and the public to be aware of risk factors for SCDY. Cardiovascular risk assessment should be administered at routine intervals starting in early childhood. There are specific personal and family history questions³⁶ that can indicate a potential risk for SCDY including:

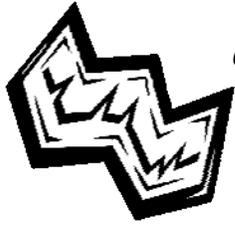
- ⇒ Unexplained syncope/fainting particularly during exercise, emotion or startle
- ⇒ Chest pain or discomfort during exercise
- ⇒ Excessive, unexpected and unexplained shortness of breath or fatigue associated with exercise
- ⇒ Past detection of heart murmur, high cholesterol, myocarditis, or increased systemic blood pressure
- ⇒ Family history of premature death in close relatives younger than 50 years old, including unexplained accidents, drowning, SIDS
- ⇒ Family history of unexplained syncope
- ⇒ Family history of congenital deafness
- ⇒ Family history of individuals with pacemakers or automatic implantable cardioverter-defibrillators (ICDs)
- ⇒ Specific knowledge of the occurrence of certain familial conditions associated with SCDY [see Appendix B]

It was the medical examiner's finding that this teenager died of acute myocardial infarct due to arteriosclerotic disease. He had been diagnosed with high blood pressure a few months before his death. He did not smoke, but was not physically active and his BMI (body mass index) was above the 99th percentile.

After their son died in his 20s, the parents learned that he had been complaining of chest pain and shortness of breath for a couple weeks but did not feel he needed medical attention.

An example of a risk assessment form for use in the clinical setting was published by Campbell and Berger in 2006.³⁷ For those identified with a significant personal or family history of SCD and/or related heart conditions, referral to a cardiologist and/or geneticist who specializes in conditions causing SCD should be considered.





Chapter 5

Secondary Prevention Opportunity: Public Awareness of Cardiac Symptoms and AED/CPR training

Sudden cardiac arrest (SCA) most often results from a sudden, unexpected heart arrhythmia such as ventricular fibrillation during which the heart's electrical impulses become chaotic and ineffective. Blood flow to the brain is lost and death usually follows unless a normal heart rhythm is quickly restored. Defibrillation with a device such as an automated external defibrillator (AED) provides an electrical shock to re-establish the heart's normal rhythm and is the only known treatment for ventricular fibrillation. According to the Sudden Cardiac Arrest Coalition, AEDs can increase the survival rate after SCA by up to 90% if administered within the first few minutes of an arrest.³⁸

An AED was not available during the practice and the boy's coach did not have training on how to use one.

Availability of an AED provides the opportunity for secondary prevention of early deaths. However, symptoms of possible cardiac arrest must first be recognized by bystanders, and an AED must be accessible by trained users with a target goal of three to five minutes from time of collapse to first shock. Currently the chance of surviving SCA is less than five percent. The American Heart Association has identified a "Chain of Survival" that increases the likelihood of survival. The sequence of four steps includes early access (recognizing an emergency exists and calling 911, early CPR, early defibrillation and early advanced care.^{39,40}

The AHA advocates for equipping all EMS first-response vehicles and ambulances with an AED or other defibrillation device. It also supports "Public Access to Defibrillation" (PAD), which means making AEDs available in targeted public and/or private places where large numbers of people gather or where people who are at high risk for cardiac arrest live—venues such as sports arenas, gated communities, office complexes, shopping malls, etc. When AEDs are placed in the community, they need to be part of a defibrillation program

that includes notification of the local EMS office, oversight by a licensed medical authority to ensure quality control, and training in both CPR and use of the defibrillator for persons responsible for using the AED.⁴¹

While the effectiveness of widespread AED availability in the secondary prevention of SCDY is unknown, a number of individuals and families who have survived SCA or lost a loved one to SCDY have started foundations to advocate for placement of AEDs in schools and other public areas.



The deceased's sports team was not affiliated with the school district or the city's recreation program. The coach told the family there was an AED in the building where the deceased had collapsed but it was locked in an office and not available.





Chapter 6

Secondary Prevention Opportunity: Emergency Response Protocols

The MDCH Emergency Medical Services (EMS) and Trauma Systems Section has the legislative authority under the provisions of the Michigan Public Health Code, Part 209 of Public Act 1978 to administer, fund and regulate a statewide prehospital EMS program. This Section is responsible for the licensure of over 700 life support agencies and over 2400 life support vehicles. Every Michigan county or group of counties is required to have a Medical Control Authority which provides pre-hospital emergency care oversight and establishes policies, procedures and protocols within its particular geographic area using state protocol as a minimum level of care required. There are 65 Medical Control Authorities in Michigan. Medical Control Authorities and their policies, procedures and protocols are approved by MDCH if they are different from state protocol.

To our knowledge, there are no uniform policies, procedures or protocols regarding SCDY that exist for the Medical Control Authorities.

According to the American Heart Association (AHA), early CPR and defibrillation within the first three to five minutes after collapse, plus early advanced care can result in greater than 50% long-term survival for witnessed ventricular fibrillation events.⁴²

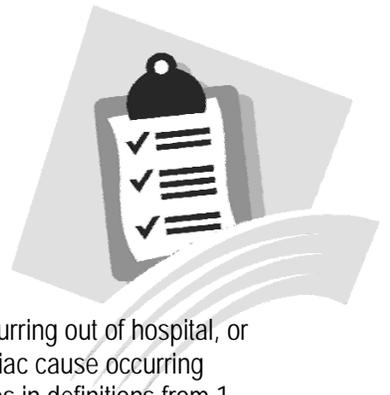
The National Athletic Trainers' Association recently convened a task force to ensure an efficient response to sudden cardiac arrest.^{43,44} The task force states that it is critical for schools to be prepared for cardiac emergencies. They recommend that structured emergency action plans should be developed through discussion with local EMS, school safety officials, first responders and school administrators. The task force further notes that the emergency plan should be practiced annually; the first responders should be trained and certified in CPR and defibrillation; the collapse-to-EMS call time and CPR initiation should be less than one minute; and the access to early defibrillation must have a target time of less than three to five minutes from time of collapse. They also state that sudden cardiac arrest should be suspected for any collapsed and unresponsive athlete. Finally, the task force developed uniform recommendations for management of sudden cardiac arrest in athletes, similar to the "chain of survival" recommendations-early activation of EMS, early CPR, early defibrillation, and rapid transition to advanced cardiac life support.^{45,46} These guidelines are comparable to statements that have been published by AHA taskforces and other organizations on this issue.⁴⁷

A male complained of not feeling well after spending the evening with friends. He drove home, where later a witness saw him begin to shake, then collapse and become unconscious. His mother initiated CPR, and EMS arrived to find him unresponsive and without a pulse. He was pronounced dead at the scene. Cause of death was undetermined by autopsy. He was a non-smoker, steadily employed, and had a BMI of 23. He had a previous history of syncope, shortness of breath, fatigue with exertion, and there was a family history of hypertension.

EMS response time in most communities in the United States has been reported to range from 12-15 minutes.⁴⁸ The time delay is related to many components, including the time to activate EMS by telephone, arrival of EMS at the site, parking of the rescue vehicle, and initiation of first defibrillation shock.

Chapter 7

Prevention Opportunity for Surviving Family Members: Medical Examiner Protocols



Sudden Cardiac Death (SCD) describes an unexpected, non-violent, non-traumatic death occurring out of hospital, or in the emergency room, or being dead on arrival. SCD is usually defined as death from a cardiac cause occurring within one hour from onset of symptoms; however, the time frame for onset of symptoms varies in definitions from 1 to 24 hours.^{49,50} Some definitions further specify whether the death was witnessed or unwitnessed and the amount of time since the victim was last seen without acute symptoms in his/her usual state of health. *Sudden Cardiac Death of the Young* (SCDY) has been variably defined as occurring in people under the age of 30, 35, or 40 years. Most often the term is used for deaths to individuals between the ages of 1 and 39, which is the age range used for identifying cases in Michigan's SCDY surveillance program. SCDY generally occurs in the emergency room or at home with the underlying cause of death reported as cardiac disease (ICD-10 codes: I00-I51). However, the selection of a specific ICD-10 code as the underlying cause of death is often ambiguous; for instance, the rationale for selecting "I26.9 instantaneous death" over the myriad of other available codes for SCDY remains unclear. **One important limitation of the SCDY surveillance project identified by the expert panel is an inconsistency in coding the cause of death (ICD codes) on death certificates. Therefore, there is an urgent need to standardize reporting by medical examiners and others in order to improve data accuracy, completeness and comparability across the state and nationally.**

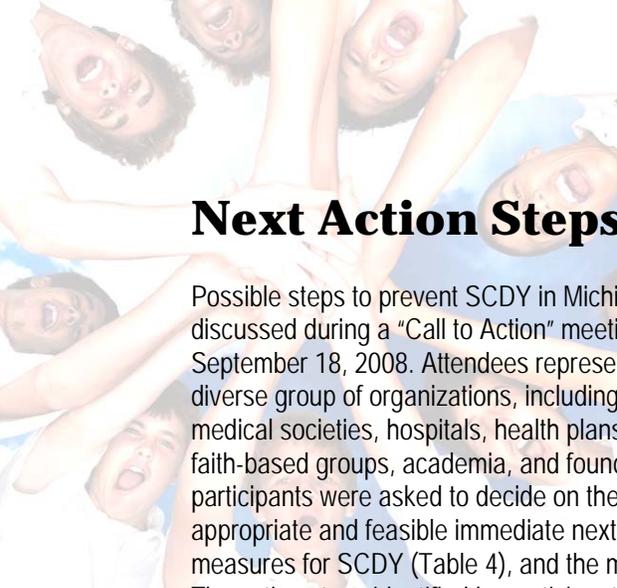
When a young person dies suddenly, it is imperative to investigate the underlying cause in order to identify possible risks for other family members. Routine autopsy can detect many of the structural conditions that predispose to SCDY although to our knowledge, there is no published evidence-based protocol or universal procedure that medical examiners follow when investigating SCDY. **Electrical conditions may not be detected**, and a routine autopsy may conclude that the cause of death was indeterminate. In all cases, it is critical to consider information learned from the autopsy in light of possible genetic implications for surviving family members, and consider DNA testing or banking as part of the post-mortem work-up.

A white female in her 20s was found unresponsive and lying in bed. After a full autopsy, examination of histologic tissue sections and full toxicology, the cause and manner of death were undetermined. There was no documentation that DNA testing or banking was considered.

In the case of familial hypertrophic cardiomyopathy (HCM), a structural cause of SCD often identified on autopsy, there is a one in two chance that first degree relatives (parent, sibling, or child) also inherited the gene for this condition. Clinical recommendations for screening high risk individuals (based on history of an affected family member) include clinical assessment with electrocardiogram (ECG) and echocardiogram at regular intervals starting in childhood. Genetic testing for HCM is also commercially available, and allows for early detection prior to the expression of typical clinical findings.

In contrast to "single gene" disorders such as HCM, the etiology of coronary artery disease is typically more complex, based on both genetic and behavioral/environmental causes (multifactorial). Certain lifestyle choices, such as smoking, high-fat diet, and lack of physical activity, are known risk factors. However, when a young person dies of coronary artery disease, there is likely a strong underlying genetic predisposition. Family members should, therefore, be carefully screened for risk factors related to early coronary artery disease so they can modify other preventable risk factors and monitor for development of coronary artery disease.

Both health care providers and families need to be aware that the presence of SCDY in a biological relative may increase the risk for many other family members due to numerous underlying genetic causes. **It is the potential impact on the entire family that makes a thorough investigation, including autopsy and careful medical consideration of genetic causes, vital in every case of SCDY.**



Next Action Steps

Possible steps to prevent SCDY in Michigan were discussed during a “Call to Action” meeting on September 18, 2008. Attendees represented a diverse group of organizations, including professional medical societies, hospitals, health plans, industry, faith-based groups, academia, and foundations. The participants were asked to decide on the most appropriate and feasible immediate next steps from the list of suggested primary and secondary prevention measures for SCDY (Table 4), and the majority committed to continue working to achieve these system changes. The action steps identified by participants include:

- 1) Coordinating the efforts of multiple organizations to make a formal consensus recommendation to MHSAA to revise the sports pre-participation form;
- 2) Integrating public awareness information about SCDY, family history, and appropriate public emergency responses into Michigan Model for K-12 School Health curricula;
- 3) Creating medical school and residency program curricula on SCDY risk factors, assessment, referral and treatment;
- 4) Increasing DNA banking for SCDY cases; and
- 5) Developing a mechanism to ensure autopsy results and recommended follow-up are conveyed to families and primary providers.

We are grateful for the support from the Centers for Disease Control and Prevention (CDC), National Office of Public Health Genomics that has allowed the Division of Genomics, Perinatal Health and Chronic Disease Epidemiology staff to work with the MDCH Cardiovascular Health, Nutrition and Physical Activity Section, MDCH Division for Vital Records and Health Statistics, and Michigan State University, Division of Occupational and Environmental Medicine in establishing a surveillance system to monitor the occurrence of unexpected deaths. Information from the expert case reviews and surveillance data will be used to determine whether examination of death certificate data is an adequate public health screening tool for identification of young people with sudden cardiac death and appropriateness of the case definition. If so, a more formal protocol will be developed based on the specific ICD-10 codes and other death certificate data fields that are most indicative of a case likely to benefit from further review and in-depth investigation of possible inherited risk factors. As data on larger numbers of cases are compiled, we hope it will lead to development of evidence-based public health recommendations for preventing SCDY.



The Michigan Department of Community Health is committed to the vision that “Michigan will be a safe and healthy state where all people realize their fullest health potential and live enriched and productive lives”. Every life lost to sudden cardiac death of the young distances us from achieving this vision. Together with our partners, MDCH will continue efforts to prevent sudden cardiac death of the young in Michigan.

**“I thought we were forgotten....
I thought no one cared...”**

— Mother of 18 year old victim, upon being asked for a next-of-kin interview

State, National and International Resources for SCDY*

*listed for informational purposes only and does not imply endorsement by MDCH

Michigan Resources*

Beaumont Heart Center
www.beaumonthospitals.com

Children's Hospital of Michigan
www.chmkids.org

CPR Connection of North America
www.cprconnection-na.com

DeVos Children's Hospital
www.devoschildrens.org

Healthy Hope Jiri Fischer Foundation
www.healthyhope.org

Henry Ford Heart and Vascular Institute
www.henryford.com

Kimberly Anne Gillary Foundation
www.kimberlysgift.org/

The KAYLA Foundation
www.kaylasteam.weebly.com

U-M Cardiovascular Center HCM Clinic
www.med.umich.edu/cvc/adult/hcm.htm

U-M Congenital Heart Center
www.med.umich.edu/mott/chc/index.html, click on services

National and International Resources*

American Heart Association
www.americanheart.org

Cardiac Arrhythmias Research and Education (CARE) Foundation
www.longqt.org/

Cardiac Risk in the Young (CRY)
www.c-r-y.org.uk/index.htm

Children's Cardiomyopathy Foundation
www.childrenscardiomyopathy.org

Hypertrophic Cardiomyopathy Association
www.4hcm.org

Heart Rhythm Foundation
www.heartrhythmfoundation.org

Heart Rhythm Society
www.hrsonline.org

Mended Hearts, Inc.
www.mendedhearts.org/

Parent Heart Watch
www.parentheartwatch.org

Project S.A.V.E.
www.choa.org/projectsave

Sudden Arrhythmia Death Syndromes Foundation (SADS)
www.sads.org

Sudden Cardiac Arrest Association
www.suddencardiacarrest.org/

Sudden Cardiac Arrest Coalition
www.stopcardiacarrest.org

Take Heart America: Sudden Cardiac Arrest Survival Initiative
www.takeheartamerica.org/

Sudden Cardiac Death in Athletes: A Clinical Perspective
www.medscape.com/viewprogram/5936



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* denotes formerly at MDCH

Appendix A

Age Adjusted Mortality Rates by County

Eight year age-adjusted mortality rates per 100,000 by county in Michigan, 1999-2006 for sudden cardiac deaths, ages 1-39 years.

County	Rate	95% Confidence Interval	Number of SCDs
Alcona	-	-	-
Alger	-	-	-
Allegan	3.1	(1.5 - 4.7)	14
Alpena	4.7	(0.5 - 8.8)	7
Antrim	5.4	(0.7 - 10.2)	5
Arenac	-	-	-
Baraga	-	-	-
Barry	3.0	(0.8 - 5.2)	7
Bay	6.2	(3.8 - 8.6)	26
Benzie	-	-	-
Berrien	6.6	(4.6 - 8.7)	41
Branch	5.7	(2.3 - 9.0)	11
Calhoun	5.1	(3.2 - 7.0)	28
Cass	3.6	(0.9 - 6.3)	7
Charlevoix	-	-	-
Cheboygan	5.9	(1.2 - 10.6)	6
Chippewa	2.9	(0.4 - 5.4)	5
Clare	7.8	(2.7 - 13.0)	9
Clinton	2.2	(0.4 - 3.9)	6
Crawford	-	-	-
Delta	5.9	(1.8 - 10.1)	8
Dickinson	6.4	(1.3 - 11.6)	6
Eaton	3.6	(1.8 - 5.4)	15
Emmet	5.1	(1.0 - 9.1)	6
Genesee	7.0	(5.8 - 8.3)	127
Gladwin	-	-	-
Gogebic	-	-	-
Grand Traverse	2.9	(1.1 - 4.8)	10
Graiot	4.1	(1.1 - 7.2)	7
Hillsdale	5.5	(2.1 - 8.9)	10
Houghton	-	-	-
Huron	5.7	(1.5 - 10.0)	7
Ingham	4.9	(3.6 - 6.2)	58
Ionia	2.2	(0.4 - 3.9)	6
Iosco	-	-	-
Iron	-	-	-
Isabella	4.3	(1.6 - 7.0)	11
Jackson	5.9	(4.1 - 7.7)	40
Kalamazoo	4.3	(3.0 - 5.6)	43
Kalkaska	7.3	(0.9 - 13.7)	5
Kent	4.2	(3.4 - 5.0)	110
Keweenaw	-	-	-

County	Rate	95% Confidence Interval	Number of SCDs
Lake	-	-	-
Lapeer	1.6	(0.7 - 2.6)	11
Leelanau	-	-	-
Lenawee	1.6	(0.7 - 2.6)	12
Livingston	1.7	(1.0 - 2.4)	22
Luce	-	-	-
Mackinac	-	-	-
Macomb	2.4	(2.0 - 2.8)	156
Manistee	-	-	-
Marquette	1.4	(0.3 - 2.6)	6
Mason	4.3	(1.3 - 7.4)	8
Mecosta	3.4	(1.1 - 4.7)	9
Menominee	-	-	-
Midland	1.8	(0.7 - 2.8)	11
Missaukee	-	-	-
Monroe	3.1	(2.1 - 4.2)	35
Montcalm	5.9	(3.7 - 8.1)	28
Montmorency	-	-	-
Muskegon	4.3	(3.1 - 5.4)	53
Newaygo	2.9	(1.1 - 4.7)	10
Oakland	2.0	(1.7 - 2.3)	187
Oceana	3.2	(0.6 - 5.7)	6
Ogemaw	-	-	-
Ononagon	-	-	-
Osceola	3.3	(0.4 - 6.2)	5
Oscoda	-	-	-
Otsego	5.1	(1.8 - 8.5)	9
Ottawa	1.3	(0.8 - 1.8)	25
Presque Isle	-	-	-
Roscommon	5.8	(1.8 - 9.8)	8
Saginaw	3.2	(2.3 - 4.1)	46
St. Clair	2.3	(1.5 - 3.2)	30
St. Joseph	2.2	(0.8 - 3.6)	10
Sanilac	5.0	(2.5 - 7.6)	15
Schoolcraft	-	-	-
Shiawassee	2.8	(1.4 - 4.2)	15
Tuscola	2.5	(0.9 - 4.1)	10
Van Buren	1.9	(0.7 - 3.0)	10
Washtenaw	1.8	(1.3 - 2.3)	51
Wayne	5.4	(5.0 - 5.7)	838
Wexford	2.3	(0.3 - 4.2)	5

Source: MDCH Vital Statistics
 ICD 10 codes: I00-I51, Q00-Q24 and R96-R99
 -Insufficient data, less than five deaths in the county

Appendix B

Causes of sudden cardiac death	
Single or multiple genes play a role in determining susceptibility to most of these conditions	
Aortic root aneurysm/dissection	Some aortic root aneurysms can be caused by genetic connective tissue diseases that weaken the aortic wall causing aortic aneurysm and subsequent death due to aortic dissection. Examples include Marfan syndrome, familial thoracic aortic aneurysms and dissections, and vascular type Ehlers-Danlos syndrome.
Aortic stenosis	An abnormal narrowing of the aortic valve that impairs blood flow to the arteries and can lead to heart failure, this is three times more common in men than women.
Arrhythmogenic right ventricular cardiomyopathy (ARVC)	The heart muscle becomes thin due to an abnormal amount of fat and scar tissue in its walls. Mainly affects the right side of the heart. Most common cause of SCDY in Italian athletes.
Brugada syndrome	An electrocardiographic pattern of right bundle branch block, ST segment elevation in leads V1 to V3, and sudden death. More common in young males and in Southeast Asians.
Catecholaminergic polymorphic ventricular tachycardia (CPVT)	Arrhythmogenic disorder characterized by exercise, stress- or emotional-induced ventricular tachycardia, syncope or sudden death in the absence of detectable structural heart disease.
Congenital heart block	A condition that impairs the signal from the heart's upper to lower chambers, also called AV Block.
Coronary artery abnormality	A malformation of an artery, present at birth but often undetected.
Coronary artery disease (CAD)/Atherosclerosis	Plaque build-up narrows the coronary arteries and reduces blood flow to the heart muscle. Blood clots are more likely to form, blocking blood flow. Over time, CAD can weaken the heart muscle, leading to heart failure or arrhythmias.
Dilated cardiomyopathy (DCM)	Left ventricular enlargement and systolic dysfunction, which usually results in heart failure with symptoms of congestion and/or reduced cardiac output, arrhythmias, and thromboembolic disease, including stroke. Genetic and acquired (non-genetic/idiopathic) forms exist.
Hypertrophic cardiomyopathy (HCM)	Unexplained left ventricular wall thickening in the presence of a non-dilated left ventricular cavity. HCM can often be genetic. It occurs in 1 in 500 individuals, and is reportedly the most common cause of SCDY in U.S. athletes.
Hypertensive left ventricular hypertrophy	Essential hypertension and enlargement of the left ventricle associated with a risk of sudden death in excess of the risk attributable to hypertension alone.
Long QT syndrome (LQTS)	A disorder of the heart's electrical rhythm leading to an increase in the QT interval that is often asymptomatic. Symptoms may include fainting and an abnormal rate and/or rhythm of the heartbeat (arrhythmia). Deafness is also associated with one type of inherited LQTS.
Mitral valve prolapse	A "floppy" heart valve that can lead to irregular or rapid heartbeats and shortness of breath. Some may be caused by Marfan syndrome or Ehlers-Danlos syndrome.
Myocarditis/endocarditis	An inflammation of the heart muscle, usually caused by viral infection but may occur as a complication of other medical conditions or exposure to drugs.
Short QT syndrome	A disorder of the heart's electrical rhythm leading to a decrease in the QT interval. If untreated, irregular heartbeats can lead to symptoms including dizziness, fainting, cardiac arrest and sudden death.
Wolff-Parkinson-White syndrome (WPW)	A condition that results in an extra conduction pathway for electrical signals within the heart. Symptoms include dizziness, chest palpitations, fainting and rarely cardiac arrest.

Appendix C

Michigan Laws **AED & CPR**

Child Care Centers *are required to:*

- ✓ Have on duty at all times at least one staff person who has been certified in age-appropriate CPR
(Act 217 of 2007)

Emergency Vehicles *shall be equipped with an AED* when dispatched and responding to provide:

- ✓ Medical first response life support
- ✓ Basic Life support
- ✓ Limited advanced life support.
(Act 582 of 2006)

Health Clubs *are required to:*

- ✓ Employ at least one individual who has completed a basic first aid, CPR, and AED course;
- ✓ Have an AED on the premises in an obvious and accessible location;
- ✓ Develop and implement an emergency plan.

The law also protects health club staff, and states they do not have a duty to use the AED. (Act 23 of 2006)

Licensed Athletic Trainers *shall submit proof of CPR training and first aid.* (Act 54 of 2006)

Individuals *who use an AED or provide CPR are protected* from liability in civil action for any damages, except in the case of gross negligence or misconduct. (Act 17 of 1963, amended by Act 173 of 1999)

Teachers *who were recommended for certification after July 1, 2004 must* complete coursework in First Aid and CPR. (Act 451 of 1976, amended by Act 18 of 2003)

School Districts and Intermediate School Districts *shall be provided with:*

- ✓ Information from the Michigan Department of Education on the benefits of AEDs
- ✓ Discounts on AEDs for schools
- ✓ Funds (\$100,000) for high schools and lower-income schools that provide a 50% match
(Acts 332 & 342 of 2006)

Appendix D

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