Sudden Cardiac Death of the Young Surveillance and Prevention Program: Michigan’s Experience

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Michigan Department of Community Health (MDCH)

Mission:

MDCH will **protect, preserve, and promote** the health and safety of the people of Michigan with particular attention to providing for the needs of **vulnerable and under-served populations**

Vision:

Improving the experience of care, improving the health of populations, and reducing per capita costs of health care
Three Core Public Health Functions and Ten Essential Services

- **Assessment**: The regular systematic collection, assembly, analysis, and dissemination of information, including genetic epidemiologic information, on the health of the community.
Policy Development: The formulation of standards and guidelines, in collaboration with stakeholders, which promote the appropriate use of genomic information and the effectiveness, accessibility, and quality of genetic tests and services.
Three Core Public Health Functions and Ten Essential Services

- **Assurance**: That genomic information is used appropriately and that genetic tests and services meet agreed upon goals for effectiveness, accessibility, and quality.
Example of Using Core Public Health Functions: Michigan Sudden Cardiac Death of the Young (SCDY) Surveillance and Prevention, 2003-2013

**Aim:** Prevention of SCDY (1-39 years of age) in Michigan through early detection of individuals at risk, treatment of those with predisposing conditions, & intervention for victims experiencing sudden cardiac arrest

[www.michigan.gov/scdy](http://www.michigan.gov/scdy)
MI-SCDY Surveillance and Prevention Project

Future work

Epidemiological study of impact

Michigan Alliance for Prevention of SCDY (MAP-SCDY)

High school pre-participation sports screening

Expert panel review of deaths
Age-Adjusted Mortality Rates:

Statewide: 5.5 per 100,000

White Males: 6.1 per 100,000

Black Males: 16.5 per 100,000

White Females: 2.4 per 100,000

Black Females: 8.3 per 100,000

1-9 years: 1.0 per 100,000

10-19 years: 1.2 per 100,000

20-29 years: 4.1 per 100,000

30-39 years: 14.5 per 100,000

Review of Michigan Death Certificates Demonstrate Significant Health Disparities
Top Ten Causes of SCDY in Michigan

- Blacks most common cause was dilated cardiomyopathy (n=255)
  - More than half of dilated cardiomyopathy and hypertensive heart disease deaths were in blacks
  - Blacks disproportionately represented among top 10 causes of deaths (except acute myocardial infarction)
- Males also represented more than 60% for the top 10 causes of death (except instantaneous death)
  - 86% of ‘other hypertrophic cardiomyopathy’ in males

<table>
<thead>
<tr>
<th>ICD 10 Code</th>
<th>Cause of death</th>
<th>Number</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>I25.0</td>
<td>Atherosclerotic cardiovascular disease</td>
<td>464</td>
<td>14.8</td>
</tr>
<tr>
<td>I42.0</td>
<td>Dilated cardiomyopathy</td>
<td>444</td>
<td>14.2</td>
</tr>
<tr>
<td>I21.9</td>
<td>Acute myocardial infarction</td>
<td>331</td>
<td>10.6</td>
</tr>
<tr>
<td>I25.1</td>
<td>Atherosclerotic heart disease</td>
<td>303</td>
<td>9.7</td>
</tr>
<tr>
<td>I11.9</td>
<td>Hypertensive heart disease with the heart failure</td>
<td>221</td>
<td>7.1</td>
</tr>
<tr>
<td>I42.2</td>
<td>Other hypertrophic cardiomyopathy</td>
<td>180</td>
<td>5.7</td>
</tr>
<tr>
<td>R99</td>
<td>Other ill-defined and unspecified causes of mortality</td>
<td>124</td>
<td>4.0</td>
</tr>
<tr>
<td>I42.9</td>
<td>Cardiomyopathy</td>
<td>121</td>
<td>3.9</td>
</tr>
<tr>
<td>I49.9</td>
<td>Cardiac arrhythmia</td>
<td>109</td>
<td>3.5</td>
</tr>
<tr>
<td>I26.9</td>
<td>Instantaneous death</td>
<td>86</td>
<td>2.7</td>
</tr>
</tbody>
</table>

*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 identified ICD-10 codes reported as the underlying cause of death on the death certificate.
Behavioral Risk Factor Survey (BRFS) Overview

- Annual telephone survey
- Adults ages 18 years and older
- Self-reported behaviors
- State-specific, population-based prevalence estimates
**Table 3**

**Family History of Sudden Cardiac Death of the Young**

2007 Michigan Behavioral Risk Factor Survey

<table>
<thead>
<tr>
<th>%</th>
<th>95% Confidence Interval</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Total</strong></td>
<td>6.3</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
</tr>
<tr>
<td>18 – 24</td>
<td>3.8</td>
</tr>
<tr>
<td>25 – 34</td>
<td>8.6</td>
</tr>
<tr>
<td>35 – 44</td>
<td>4.2</td>
</tr>
<tr>
<td>45 – 54</td>
<td>7.7</td>
</tr>
<tr>
<td>55 – 64</td>
<td>5.9</td>
</tr>
<tr>
<td>65 – 74</td>
<td>8.5</td>
</tr>
<tr>
<td>75 +</td>
<td>5.4</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>5.4</td>
</tr>
<tr>
<td>Female</td>
<td>7.7</td>
</tr>
<tr>
<td><strong>Race/Ethnicity</strong></td>
<td></td>
</tr>
<tr>
<td>White non-Hispanic</td>
<td>5.4</td>
</tr>
<tr>
<td>Black non-Hispanic</td>
<td>11.2</td>
</tr>
<tr>
<td>Other non-Hispanic</td>
<td>9.4</td>
</tr>
<tr>
<td>Hispanic</td>
<td></td>
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<tr>
<td>_b</td>
<td></td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
</tr>
<tr>
<td>Less than high school</td>
<td>10.8</td>
</tr>
<tr>
<td>High school graduate</td>
<td>8.8</td>
</tr>
<tr>
<td>Some college</td>
<td>4.7</td>
</tr>
<tr>
<td>College graduate</td>
<td>4.4</td>
</tr>
<tr>
<td><strong>Household Income</strong></td>
<td></td>
</tr>
<tr>
<td>&lt; $20,000</td>
<td>7.8</td>
</tr>
<tr>
<td>$20,000 - $34,999</td>
<td>8.4</td>
</tr>
<tr>
<td>$35,000 - $49,999</td>
<td>8.8</td>
</tr>
<tr>
<td>$50,000 - $74,999</td>
<td>4.1</td>
</tr>
<tr>
<td>$75,000 +</td>
<td>3.2</td>
</tr>
</tbody>
</table>

* 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.
Table 3. Prevalence of health-related characteristics among Michigan adults by family history of sudden cardiac death of the young (SCDY)

<table>
<thead>
<tr>
<th>Health-Related Characteristic</th>
<th>Has Family History of SCDY&lt;sup&gt;†&lt;/sup&gt;</th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes % (95% CI)</td>
<td>No % (95% CI)</td>
<td>(\chi^2) P-Value</td>
<td>Wald-F P-Value&lt;sup&gt;‡&lt;/sup&gt;</td>
<td></td>
</tr>
<tr>
<td><strong>Health Care</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No health insurance</td>
<td>17.8 (11.0-27.5)</td>
<td>10.6 (9.0-12.5)</td>
<td>0.1048</td>
<td>0.5798</td>
<td></td>
</tr>
<tr>
<td>On Medicaid insurance</td>
<td>23.1 (15.4-33.1)</td>
<td>10.6 (9.0-12.4)</td>
<td>0.0034&lt;sup&gt;‡&lt;/sup&gt;</td>
<td>0.1971</td>
<td></td>
</tr>
<tr>
<td>No personal doctor</td>
<td>13.0 (7.9-20.5)</td>
<td>15.0 (12.9-17.4)</td>
<td>0.5396</td>
<td>0.5940</td>
<td></td>
</tr>
<tr>
<td>No routine checkup in past year</td>
<td>29.3 (20.1-40.5)</td>
<td>31.3 (28.7-34.0)</td>
<td>0.7059</td>
<td>0.9948</td>
<td></td>
</tr>
<tr>
<td>No blood cholesterol test in past 5 years</td>
<td>27.4 (17.9-39.6)</td>
<td>20.1 (17.6-23.0)</td>
<td>0.2286</td>
<td>0.3939</td>
<td></td>
</tr>
<tr>
<td><strong>Health Status</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fair to poor general health</td>
<td>16.1 (11.1-22.7)</td>
<td>14.3 (12.6-16.2)</td>
<td>0.5613</td>
<td>0.8687</td>
<td></td>
</tr>
<tr>
<td>Rarely-never receive needed emotional support</td>
<td>12.3 (7.1-20.4)</td>
<td>6.2 (5.1-7.6)</td>
<td>0.0773</td>
<td>0.0619</td>
<td></td>
</tr>
<tr>
<td>Has a disability</td>
<td>26.4 (19.6-34.6)</td>
<td>21.8 (19.8-23.9)</td>
<td>0.2296</td>
<td>0.1432</td>
<td></td>
</tr>
<tr>
<td>Obese (BMI ≥ 30)</td>
<td>34.0 (25.0-44.4)</td>
<td>27.6 (25.2-30.2)</td>
<td>0.2203</td>
<td>0.3252</td>
<td></td>
</tr>
<tr>
<td><strong>Chronic Conditions</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ever diagnosed with high blood pressure</td>
<td>39.5 (30.8-49.1)</td>
<td>27.9 (25.8-30.2)</td>
<td>0.0131&lt;sup&gt;‡&lt;/sup&gt;</td>
<td>0.0019&lt;sup&gt;‡&lt;/sup&gt;</td>
<td></td>
</tr>
<tr>
<td>Ever diagnosed with high cholesterol (among tested)</td>
<td>42.4 (33.0-52.4)</td>
<td>40.8 (38.1-43.5)</td>
<td>0.7492</td>
<td>0.7620</td>
<td></td>
</tr>
<tr>
<td>Ever diagnosed with diabetes</td>
<td>13.1 (8.9-19.1)</td>
<td>8.6 (7.5-9.9)</td>
<td>0.0801</td>
<td>0.0684</td>
<td></td>
</tr>
<tr>
<td>Ever diagnosed with cardiovascular disease</td>
<td>10.0 (6.2-15.8)</td>
<td>9.5 (8.3-10.9)</td>
<td>0.8345</td>
<td>0.9661</td>
<td></td>
</tr>
<tr>
<td><strong>Behaviors</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Current smoking</td>
<td>32.2 (23.3-42.6)</td>
<td>20.1 (17.9-22.6)</td>
<td>0.0243&lt;sup&gt;‡&lt;/sup&gt;</td>
<td>0.2078</td>
<td></td>
</tr>
<tr>
<td>No leisure-time physical activity</td>
<td>20.2 (13.3-29.5)</td>
<td>19.3 (17.2-21.5)</td>
<td>0.8199</td>
<td>0.8181</td>
<td></td>
</tr>
<tr>
<td>Inadequate physical activity</td>
<td>48.3 (38.2-58.5)</td>
<td>47.3 (44.5-50.0)</td>
<td>0.8542</td>
<td>0.8022</td>
<td></td>
</tr>
<tr>
<td>Inadequate fruit and vegetable consumption</td>
<td>82.4 (75.6-87.6)</td>
<td>78.1 (75.7-80.2)</td>
<td>0.1973</td>
<td>0.2502</td>
<td></td>
</tr>
</tbody>
</table>

<sup>†</sup>Reported having at least one biological family member who had a sudden cardiac death, or sudden unexplained death, between the ages of 1 and 39.

<sup>‡</sup>Generated from multivariable logistic regressions with each health-related characteristic as the dependent variable, family history of SCDY as the independent variable, and age group, sex, race, education, and household income as possible confounding variables.

<sup>‡</sup>p < .05.
SCDY Surveillance and Prevention Project

- Future work
- Epidemiological study of impact
- Michigan Alliance for Prevention of SCDY (MAP-SCDY)
- High school pre-participation sports screening
- Expert panel review of deaths
Michigan SCDY Expert Mortality Review Panel

- Confirm the cause of death or suggest an alternative cause
- Describe the factors that may have contributed to the death
- Identify possible risk to family members
- Suggest recommendations for prevention of future deaths

Michigan Case Study

Clinical and Family History
- African American teenage male
- Student, basketball player
- Symptoms 4 months – “skipped beats and fluttering” especially while playing basketball; dizzy when rising from chair; tired all the time; legs hurt all the time; he thought these symptoms meant he was out of shape so he would practice harder
- Private health insurance coverage
- Family History - mother had “stroke“ as teen; maternal uncle had heart attack at 40 years old
- Sports physical 4.5 months prior
- Never referred to cardiologist or specialist
- Weight 82nd percentile

Day of Death
- Playing basketball, collapsed
- No CPR prior to EMS, police were needed to allow EMS access
- Locked AED at site, coach had no training on AED
- No pulse/not breathing

Autopsy
- Hypertrophic cardiomyopathy
- Toxicology – negative for alcohol, illicit drugs
- Family members not made aware of genetic implications
Expert Panel Findings

**Patient-related factors**
- Education when to seek medical care
- Family history and screening

**Physician-related factors**
- Quality of pre-participation sports physical
- Awareness of need to screen family members, and when genetics or cardiology referral indicated
- Education on content of family history screening form

**System-related factors**
- CPR training for coaches, or CPR training for community and schools
- If AED present on-site, require training and availability
- Update Michigan High School Athletic Association pre-participation sports screening template to include 2007 AHA 12 point screen and 2004/2010 national consensus recommendations
- Mechanism for family contact, including assuring autopsy report reaches primary care provider
- Storage of biologic specimen / DNA
Data to Action, 2008-2013

Based on SCDY expert mortality review, 21 action steps identified to prevent SCDY

Grouped into 5 major themes:
- Pre-participation sports physicals and screenings
- Provider education and public awareness of SCDY risk factors
- Emergency response protocols
- Public awareness of cardiac symptoms and CPR/AED training
- Medical examiner protocols
MDCH Genomics Working with Multiple Sectors to Prevent SCDY in Michigan

- **Academia**
  - Wayne State University, Michigan State University, University of Michigan, Oakland University, Ferris State University

- **Employers/industry**
  - AED distributors, Health plans

- **Health care delivery system**

- **Media**
  - Local television news' Detroit Free Press; other local newspapers

- **Communities**

- **Government**
  - Michigan Department of Community Health (Cardiovascular Section; Vital Records; Genomics; EMS), Michigan Department of Education; Centers for Disease Control and Prevention, state legislatures, local health departments, NHLBI
“…no important health problem will be solved by clinical care alone, or research alone, or by public health alone- But rather by all public and private sectors working together”

JS Marks. Managed Care 2005;14:p11
Supplement on “The Future of Public Health”
SCDY Surveillance and Prevention Project

- Future work
- Epidemiological study of impact
- High school pre-participation sports screening
- Expert panel review of deaths
- Michigan Alliance for Prevention of SCDY (MAP-SCDY)
Example of SCDY Policy Development Accomplishment: MHSAA Pre-participation Screening and Physical Form

- **Pre-participation Sports Screening:**
  - Work group with 50-55 members, including Michigan High School Athletic Association (MHSAA)
  - Reviewed published literature on evidence-based and/or consensus recommendations for pre-participation sports screening and forms from 50 states
  - Recommended revised form (based on national consensus form) to MHSAA; adopted by MHSAA Board of Directors, December 2010
  - Required to be used since 2011/2012
  - 500,000 forms distributed per year
Example of SCDY Assurance Accomplishment: Creation of MDCH SCDY Website

- Posted by MDCH in August 2010
- Features educational video with MDCH Chief Medical Executive and 2 families
- MDCH SCDY data
- 6 Expert Presentations
- February 2013 Governor’s Proclamation
- Links to national and state resources

www.michigan.gov/scdy
Can Sudden Cardiac Death of the Young be Prevented?

A Michigan Story on Lessons Learned and Action Steps to Take

The winter months have arrived and with them comes a certain madness, specifically March Madness. On March 12, 2012 the NCAA men's college basketball tournament will commence. Most of the focus will be on cheering for the teams we picked to win our brackets; however, as Michigan learned last year, this isn't the only thing we need to focus on.

On March 3, 2011, with less than 30 seconds left in overtime in Fennville High School's final regular season men's basketball game, a winning layup was scored that brought Fennville's team an undefeated record. With district playoffs in Fennville's future, the gymnasium was full of celebration. Within moments, the crowd went silent as the star player collapsed to the ground. Wes Leonard, the player who had scored the winning basket moments before was now unconscious. Over 2,000 fans stood stunned, waiting for paramedics to arrive. Although an AED was present at the school, it was not trained and CPR was not performed because people did not think that cardiac arrest could be at fault in someone so young. Wes was later declared dead at a local hospital and the autopsy showed that he died of cardiac arrest due to an enlarged heart.

Sudden deaths of young athletes bring attention to an important public health problem known as sudden cardiac death of the young (SCDy), which occurs in non-athletes, too. On average, an estimated 66 athletes die suddenly of cardiac cause each year in the United States. Each year in Michigan alone, approximately 300 people aged 1-39 years die suddenly of a cardiac cause. Importantly, SCDy is known to have a strong hereditary component in many cases.

A Legacy of West Leonard

You may have heard about the Michigan high school student who made a game-winning basket and then died. Here's the rest of the story: a violent car crash, a bone-shaking tackle, a near-perfect season, a reluctant substitute and a search for the will to carry on.

THOMAS LAKE

After the autopsy, when the doctor found white blossoms of scar tissue on Wes Leonard's heart, he guessed they had been secreted building there for several months. That would mean Wes's heart was slowly breaking throughout the Fennville Blackhawks' 2010-11 regular season, when he led them in scoring and the team won 20 games without a loss.

It would mean his heart was already moving toward electrical meltdown in December, when he scored 26 on Decatur with that big left shoulder clearing a path to the hoop. It would mean his heart swelled and weakened all through January (25 against Hopkins, 33 against Martin) even as it pumped enough blood to fill at least 10 swimming pools.

This heart pounded two million times in February, probably more, heaving under its own weight, propelling Wes's 6'2", 230-pound frame along the glimmering hardwood with such precision and force that finally a kid from Hartford gave up on the rules and tackled him in the lane. By March 3, the night of Wes's last and most glorious game, his heart weighed 211 ounces, double the weight of a normal heart, and it gave him all he needed from the opening tip to the final buzzer. Then the wiring failed, the current going as jagged as a thunderbolt, and Wes fell to the floor with his big heart quivering.

If all this seems implausible—that Wes could play so well for so long with such faulty equipment—consider a scientific phenomenon called functional reserve. The human heart has a reservoir of unused ability, like a powerful batter who is never thrown out at bat. The batter can hit a home run even after he has been hit by a pitch. That's the way the human heart works, too. Wes had the resilience of an unknown batter, a baseball player without a name on his uniform, waiting for the right turn to come. And when the right turn came, when the right bat came, Wes hit a home run.
Michigan Alliance for Prevention of Sudden Cardiac Death of the Young (MAP-SCDY)

- **Vision**: The MAP-SCDY strives to prevent sudden cardiac death of the young.

- **Mission**: The MAP-SCDY is a statewide collaborative network that provides leadership, education, and resources to help communities prevent sudden cardiac death of the young.

- Created in 2012 by MDCH Genomics

- Over 50+ members representing multiple sectors

- **Current goals:**
  - Increase public awareness
  - Award MI HEARTSafe School Award Program from MDCH and Michigan Department of Education Directors
  - Keep apprised of current legislation efforts

[www.mgrc.org/miheartsafe](http://www.mgrc.org/miheartsafe)
“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
SCDY Surveillance and Prevention Project

Future work

Michigan Alliance for Prevention of SCDY (MAP-SCDY)

Epidemiological study of impact

High school pre-participation sports screening

Expert panel review of deaths
In Development: Expand SCDY Mortality Review

  - NHLBI working group unanimously supports development of a research agenda that would determine the best approach to reduce SCDY
  - NHLBI and CDC announce plans for SCDY registry in 2013
    - To include surveillance system, registry and DNA samples to support research
  - Partner with National and State Child Death Review teams
  - MDCH Genomics developed SCDY factsheet for CDR reviews in 2012
    - can be accessed at www.michigan.gov/scdy
Another State Example: New Jersey Legislation

- Senator Fred Madden established ‘New Jersey Student Athlete Cardiac Screening Task Force’ in 2009
  - Developed 9 recommendations to enhance screening and identify ways to prevent SCDY in student athletes between 12-19 years of age
  - Released in April 2012
    http://www.njleg.state.nj.us/OPI/Reports_to_the_Legislature/student_athlete_cardiac_screening_task_force_06152011.pdf
Another State Example: New Jersey Legislation

- Task Force recommendations led to package of bills in 2013
  - S1910
    - Requires certain insurers to cover cost of annual PPE for student athletes
  - S1911/A-3047- ‘Children’s Sudden Cardiac Events Reporting Act’
    - Requires health professional to report sudden cardiac events under 19 years of age to Dept of Health and Senior Services
    - Establishes Children’s Sudden Cardiac Event Registry
    - Establishes 11-member Children’s Sudden Cardiac Events Review Board
    - Law Passed in August 2013
Another State Example: New Jersey Legislation

- **S1912- ‘Scholastic Student Athlete Safety Act’**
  - Requires student athletes in grades 6-12 to be screened using AAP/AAPF PPE form
  - Informational SCA pamphlet for student athletes and parents to be distributed as part of PPE
  - Requires health professionals to complete training program for performing PPE as condition of licensure renewal
  - Law Passed in June 2013

- **S2461**
  - Expand medical exams for all children to include cardiovascular disease risk assessment
  - Passed Senate
Thank you!

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