

***Public Health
Perspective on
Eliminating Health
Disparities in Genomics***

Conference to
Eliminate Health Disparities in
Genomic Medicine

May 30, 2013

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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

Key Funding Events in MDCH Genomics Timeline

*Funding cannot be used for research, clinical services or lobbying

* LSSN Formed by MDCH Genomics with CDC end of FY11 funds

MDCH Begins Planning for Universal FH Screening 2013

*MDCH Genomics receives a 5-year CDC cooperative agreement to incorporate genomics into chronic disease

*MDCH Genomics receives 3-year CDC cooperative agreements to enhance previous work in breast cancer genomics

*MDCH receives 2-year HRSA infrastructure grant to conduct statewide genetic needs assessment

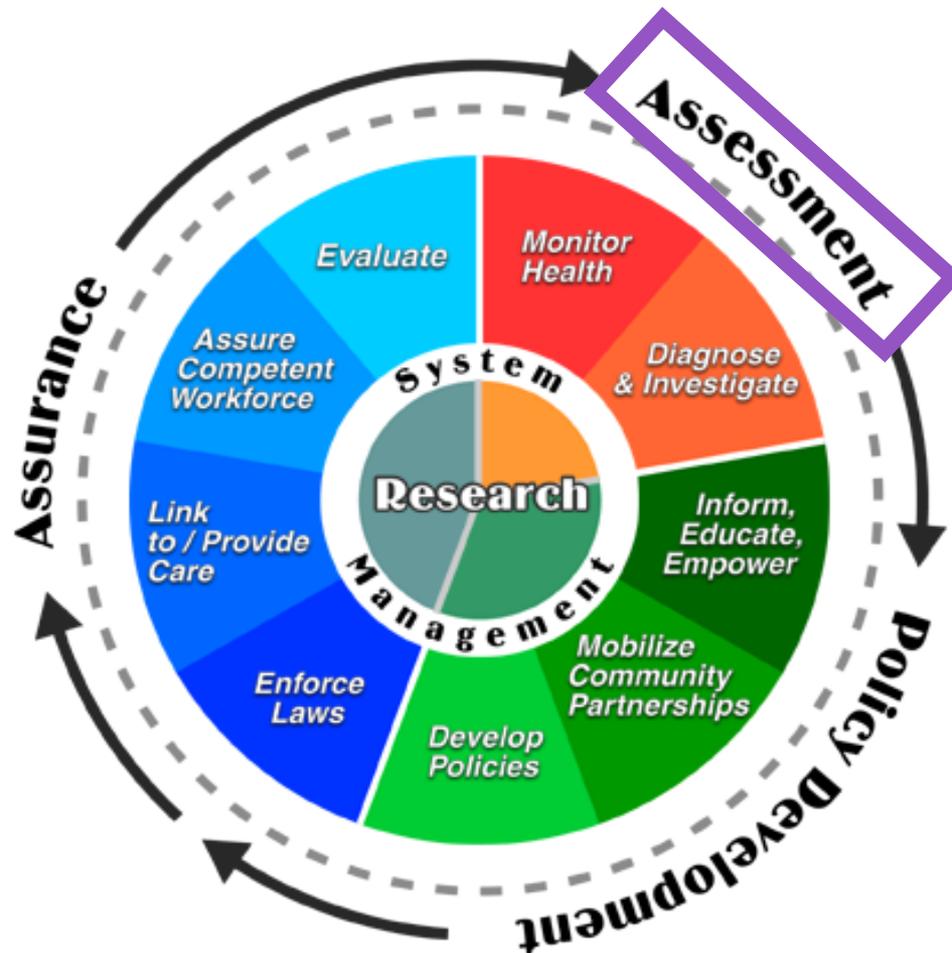
*MDCH Genomics receives 3-year CDC cooperative agreement to promote cancer genomics best practices

Prevention Research Center of Michigan with UM School of Nursing and MDCH Genomics receives 3-year CDC Special Interest Project focusing on young breast cancer survivors and relatives

Genetics Through the Life Cycle: Improving Health and Preventing Disease State Plan, 2003-2008

2000
2001
2002
2003
2004
2005
2006
2007
2008
2009
2010
2011
2012
2013

Three Core Public Health Functions and Ten Essential Services



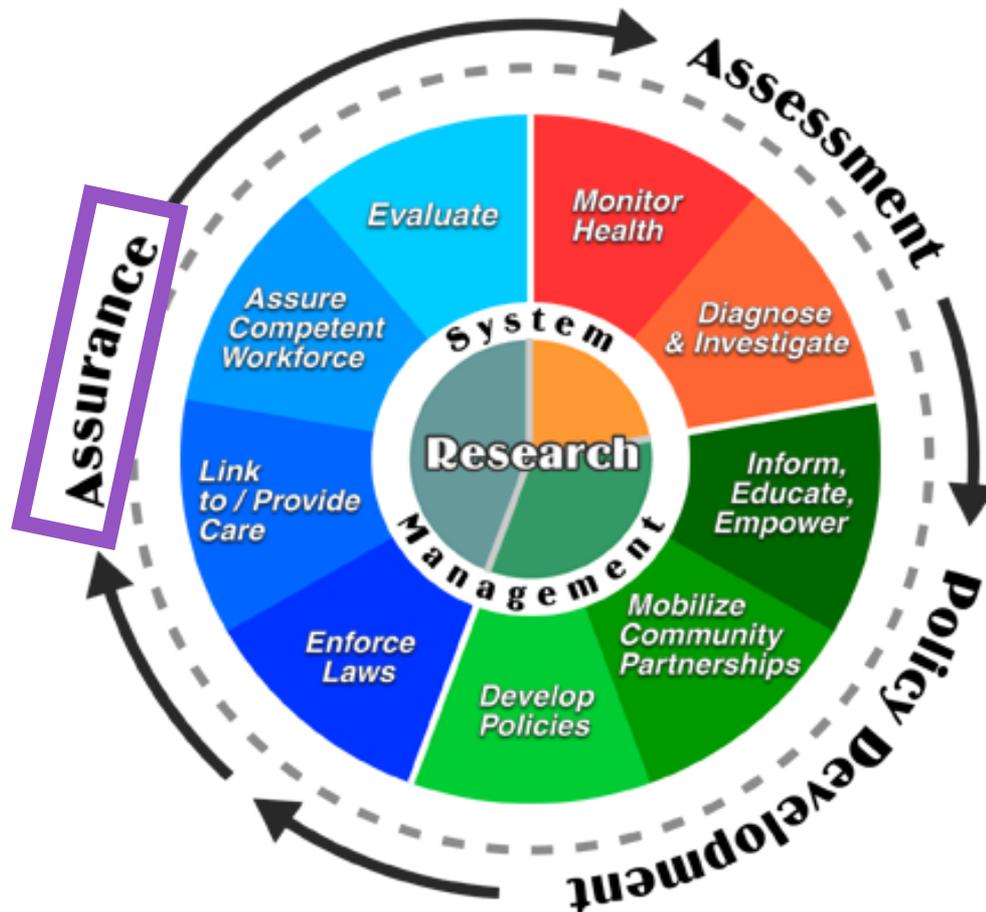
- **Assessment:** The regular systematic collection, assembly, analysis, and dissemination of information, including genetic epidemiologic information, on the health of the community

Three Core Public Health Functions and Ten Essential Services



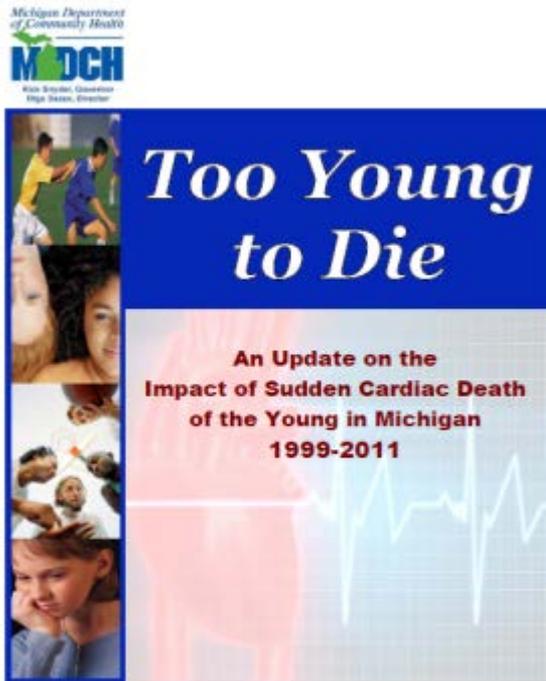
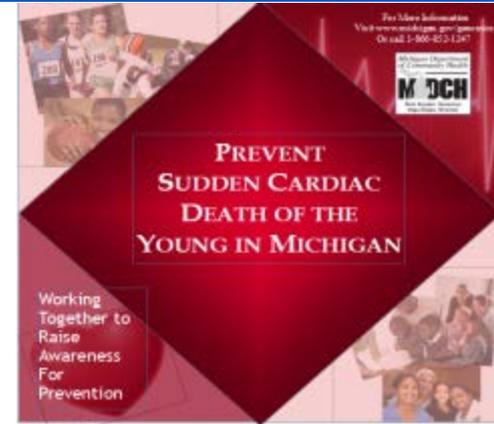
- **Policy Development:** The formulation of standards and guidelines, in collaboration with stakeholders, which promote the appropriate use of genomic information and the effectiveness, accessibility, and quality of genetic tests and services

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



Future work

Epidemiological study of impact

Michigan Alliance for Prevention of SCDY (MAP-SCDY)

MI-SCDY Surveillance and Prevention Project

High school pre-participation sports screening

Expert panel review of deaths



Review of Michigan Death Certificates Demonstrate Significant Health Disparities

Table 1
Sudden cardiac deaths (SCDs)* of Michigan residents
aged 1 - 39 years, 1999 - 2009

	Number	Percent
Total	3,134	
Sex		
Male	2,179	69.5
Female	955	30.5
Race		
White	1,961	62.6
Black	1,089	34.7
Other	84	2.7
Age		
1-4 years	91	2.9
5-9 years	45	1.4
10-14 years	64	2.0
15-19 years	137	4.4
20-24 years	213	6.8
25-29 years	380	12.1
30-34 years	716	22.8
35-39 years	1,488	47.5
Place of death		
Home	1,339	42.7
Nursing home, extended care	28	0.9
Hospital: emergency room / outpatient	1,462	46.6
Ambulance	34	1.1
Other / unknown	271	8.6
Autopsy		
Yes	2,474	78.9
No	658	21.0
Unknown	2	0.1

* 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

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

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 2
Ten most frequent underlying causes of death of Michigan SCD* victims, 1-39 years, 1999-2009 (n=3,134)

ICD 10 Code	Cause of death	Number	Percent
I25.0	Atherosclerotic cardiovascular disease	464	14.8
I42.0	Dilated cardiomyopathy	444	14.2
I21.9	Acute myocardial infarction	331	10.6
I25.1	Atherosclerotic heart disease	303	9.7
I11.9	Hypertensive heart disease without heart failure	221	7.1
I42.2	Other hypertrophic cardiomyopathy	180	5.7
R99	Other ill-defined and unspecified causes of mortality	124	4.0
I42.9	Cardiomyopathy	121	3.9
I49.9	Cardiac arrhythmia	109	3.5
I26.9	Instantaneous death	86	2.7

* 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

MDCH Genomics Greatest Health Disparities: Family History of SCDY

Michigan 2007 Behavioral Risk Factor Survey (MiBRFS)

- 2,856 Michigan adults were asked about SCDY
- 6.3% have a family history of SCDY
 - 26.2% with multiple relatives
 - 35.5% with first degree relative
- Significantly more blacks (11.2%) than whites (5.4%) reported SCDY

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.

BRFS SCDY Family History Data

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

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

*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.

[†]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.

[‡]p < .05.



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



Journal of Community Health. April 27, 2010.

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

Sudden Cardiac Death of the Young in Michigan: A Call to Action

Thursday, September 18, 2008
Michigan Department of Community Health (MDCH)
Capitol View Conference Center
1:00 p.m.—5:00 p.m.

AGENDA

- 
- 1:00 Welcome and Overview of Michigan Sudden Cardiac Death of the Young (SCDY) Surveillance Project
—Gregory Holzman, MD, MPH
MDCH Chief Medical Executive
- 1:15 Epidemiology of SCDY in Michigan
—Beth Anderson, MPH, MDCH Cardiovascular Health Epidemiologist
- 1:35 Findings from the SCDY Mortality Review
—Kenneth Rosenman, MD
Chief, Division of Occupational and Environmental Medicine,
Michigan State University
- 2:05 Introduction to Action Team breakout groups
—Rochelle Hurst, BSN, MA
Acting Director, MDCH Division of Chronic Disease and Injury Control
- 2:15 Networking Break with display tables/move to breakouts
- 2:45 Action Team breakout groups with brief reports on current status/initiatives
- Pre-participation sports physicals and screenings
—Gregory Holzman, MD, MPH, MDCH
 - Medical examiner protocols
—Stephen D. Coble, MD, Spectrum Health
 - Emergency response protocols
—Robert Swior, DO, Beaumont Hospital
 - Provider education and public awareness of SCDY risk factors
—Sharlene Mary Day, MD, University of Michigan
 - Public awareness of cardiac symptoms and CPR/AED training
—John Shupra, Life EMS Ambulance
- 4:20 Break/reconvene to large group
- 4:30 Team presentations and review of action agenda
—Gregory Holzman, MDCH Chief Medical Executive
—Jean Chabut, MDCH Deputy Director of Public Health Administration
- 5:00 Adjourn

- 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

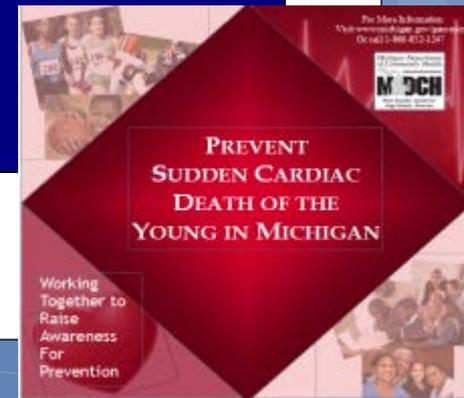
MDCH Genomics Working with Multiple Sectors to Prevent SCDY in Michigan

- **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**
 - Michigan State Medical Society, American College of Cardiology- Michigan Chapter, American Academy of Pediatrics-Michigan Chapter, William Beaumont Hospital, Detroit Medical Center, Spectrum Health, Henry Ford Hospital, Michigan Osteopathic Association, Michigan Association of Physician Assistants, Michigan Association of Certified Nurse Practitioners, Society of Adolescent Medicine- Michigan Chapter, Michigan Association of Family Practice, Michigan College of Emergency Physicians, Michigan Association of Medical Examiners, Michigan Athletic Trainers Association, local EMS
- **Media**
 - Local television news
 - Detroit Free Press
- **Communities**
 - American Heart Association, Michigan Association of Health, Physical Education, Recreation and Dance, Michigan Fitness Foundation, Michigan High School Athletic Association, Hypertrophic Cardiomyopathy Association, Sudden Arrhythmia Death Syndromes Foundation, Sudden Cardiac Arrest Association, faith-based groups, Kayla Foundation, Gillary Foundation, Wes Leonard Foundation, families
- **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

Partners, Partners, Partners...!

“...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”





Future work

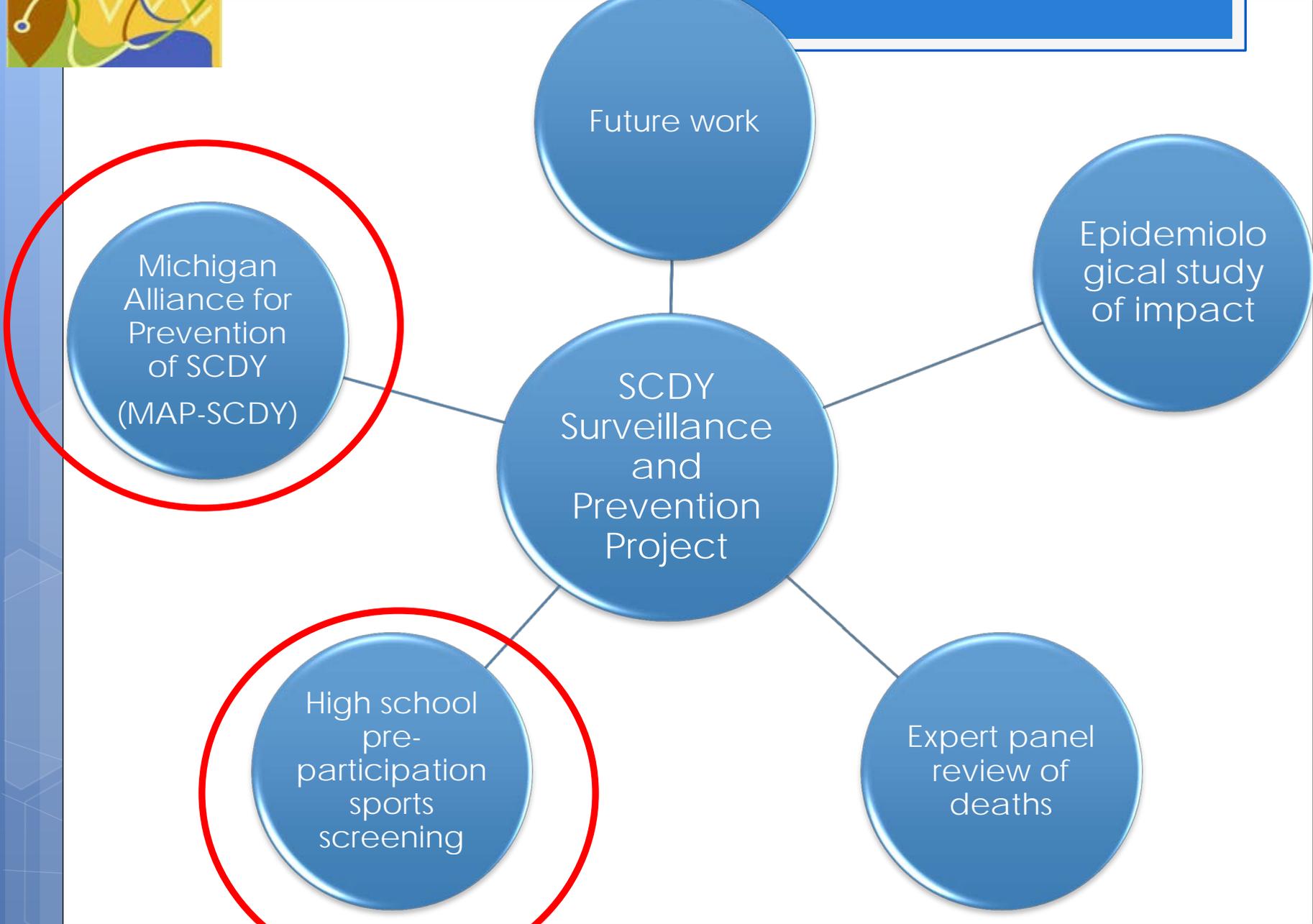
Epidemiological study of impact

SCDY Surveillance and Prevention Project

Michigan Alliance for Prevention of SCDY (MAP-SCDY)

High school pre-participation sports screening

Expert panel review of deaths



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 in 2011/2012
 - 500,000 forms distributed per year

Heart Health

Family History

PREPARTICIPATION PHYSICAL EVALUATION HISTORY FORM

(Note: This form is to be filled out by the patient and parent prior to seeing the physician. The physician should keep this form in the chart.)

Date of Exam _____ Name _____ Date of birth _____
 Sex _____ Age _____ Grade _____ School _____ Sports _____

Medicines and Allergies: Please list all of the prescription and over-the-counter medicines and supplements (herbal and nutritional) that you are currently taking

Do you have any allergies? Yes No If yes, please identify specific allergy below.
 Medicines Pollens Food Stinging insects

Explain "Yes" answers below. Circle questions you don't know the answers to.

GENERAL QUESTIONS	Yes	No	MEDICAL QUESTIONS	Yes	No
1. Has a doctor ever denied or restricted your participation in sports for any reason?			26. Do you cough, wheeze, or have difficulty breathing during or after exercise?		
2. Do you have any ongoing medical conditions? If so, please identify below: <input type="checkbox"/> Asthma <input type="checkbox"/> Anemia <input type="checkbox"/> Diabetes <input type="checkbox"/> Infections			27. Have you ever used an inhaler or taken asthma medicine?		
3. Have you ever spent the night in the hospital?			28. Is there anyone in your family who has asthma?		
4. Have you ever had surgery?			29. Were you born without or are you missing a kidney, an eye, a testicle (testis), your spleen, or any other organ?		
HEART HEALTH QUESTIONS ABOUT YOU	Yes	No	30. Do you have groin pain or a painful bulge or hernia in the groin area?		
5. Have you ever passed out or nearly passed out DURING or AFTER exercise?			31. Have you had infectious mononucleosis (mono) within the last 6 months?		
6. Have you ever had discomfort, pain, lightheadness, or pressure in your chest during exercise?			32. Do you have any rashes, pressure sores, or other skin problems?		
7. Does your heart ever race or skip beats (irregular beats) during exercise?			33. Have you had a herpes or MHA skin infection?		
8. Has a doctor ever told you that you have any heart problem? If so, check all that apply: <input type="checkbox"/> High blood pressure <input type="checkbox"/> A heart murmur <input type="checkbox"/> High cholesterol <input type="checkbox"/> A heart infection <input type="checkbox"/> Kawasaki disease Other: _____			34. Have you ever had a head injury or concussion?		
9. Has a doctor ever ordered a test for your heart? (For example, ECG/ECG, echocardiogram)			35. Have you ever had a hit or blow to the head that caused confusion, prolonged headache, or memory problems?		
10. Do you get lightheaded or feel more short of breath than expected during exercise?			36. Do you have a history of seizure disorder?		
11. Have you ever had an unexplained seizure?			37. Do you have headaches with exercise?		
12. Do you get more tired or short of breath more quickly than your friends during exercise?			38. Have you ever had numbness, tingling, or weakness in your arms or legs after being hit or falling?		
HEART HEALTH QUESTIONS ABOUT YOUR FAMILY	Yes	No	39. Have you ever been unable to move your arms or legs after being hit or falling?		
13. Has any family member or relative died of heart problems or had an unexpected or unexplained sudden death (age 50) including drowning, unexplained car accident, or sudden infant death syndrome?			40. Have you ever become ill while exercising in the heat?		
14. Does anyone in your family have hypertrophic cardiomyopathy, Marfan syndrome, arrhythmogenic right ventricular cardiomyopathy, long QT syndrome, aortic CT syndrome, Brugada syndrome, or catecholaminergic polymorphic ventricular tachycardia?			41. Do you get frequent muscle cramps when exercising?		
15. Does anyone in your family have a heart problem, pacemaker, or implanted defibrillator?			42. Do you or someone in your family have sickle cell trait or disease?		
16. Has anyone in your family had unexplained fainting, unexplained faintness, or near drowning?			43. Have you had any problems with your eyes or vision?		
BONE AND JOINT QUESTIONS	Yes	No	44. Have you had any eye injuries?		
17. Have you ever had an injury to a bone, muscle, ligament, or tendon that caused you to miss a practice or a game?			45. Do you wear glasses or contact lenses?		
18. Have you ever had any broken or fractured bones or dislocated joints?			46. Do you wear protective eyewear, such as goggles or a face shield?		
19. Have you ever had an injury that required X-rays, MRI, CT scan, injections, therapy, a brace, a cast, or crutches?			47. Do you worry about your weight?		
20. Have you ever had a stress fracture?			48. Are you trying to or has anyone recommended that you gain or lose weight?		
21. Have you ever been told that you have or have you had an x-ray for neck instability or atlantoaxial instability? (Down syndrome or dwarfism)			49. Are you on a special diet or do you avoid certain types of foods?		
22. Do you regularly use a brace, orthotic, or other assistive device?			50. Have you ever had an eating disorder?		
23. Do you have a bone, muscle, or joint injury that bothers you?			51. Do you have any concerns that you would like to discuss with a doctor?		
24. Do any of your joints become painful, swollen, hot, warm, or look red?			FEMALES ONLY		
25. Do you have any history of juvenile arthritis or connective tissue disease?			52. Have you ever had a menstrual period?		
			53. How old were you when you had your first menstrual period?		
			54. How many periods have you had in the last 12 months?		

Explain "yes" answers here

I hereby state that, to the best of my knowledge, my answers to the above questions are complete and correct.

Signature of athlete _____ Signature of parent/guardian _____ Date _____

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

Data to Action

After reviewing de-identified case summaries, the expert panel recommended patient-, provider-, and system-level changes to prevent future deaths. MDCH staff continues to work with multiple partners including academia, health care delivery systems, industry, communities, and families to accomplish these changes. More than 25 action steps have been identified and grouped into five areas: pre-participation sports screening, provider education and public awareness, public awareness of cardiac symptoms and CPR/AED training, emergency response protocols, and medical examiner protocols.

Provider Education and Public Awareness of SCDY Risk Factors	
<p>Sudden Cardiac Death of the Young video (Part 1) (Part 2) Craig Tucker, MD, MD, Family Physician and Chief Medical Executive, Michigan Department of Community Health provides an overview featuring two family stories.</p> <p>Hypertrophic Cardiomyopathy Barbara Day, MD, Director, Hypertrophic Cardiomyopathy Clinic, Assistant Professor of Cardiovascular Medicine, University of Michigan</p> <p>Identification and Treatment of Sudden Death Conditions in Young Patients David Bricker, MD, Director, Pediatric Heart Rhythm Service, CHS and Children's Hospital, Associate Professor, Department of Pediatrics and Communicable Diseases, University of Michigan</p>	<p>Identifying Genetic Risk in Surviving Family Members Angela Tziperman, MD, CDC Director, Genetic Counseling Program and Asst. Professor, Clinical Center for Molecular Genetics and Genomics, Wayne State University</p> <p>SCDY: Recognition, Screening and Evaluation Richard Humes, MD, Director, Division of Cardiology, Children's Hospital of Michigan, Professor of Pediatrics, Wayne State University</p>
Public Awareness of Cardiac Symptoms and CPR/AED Training	
<p>April 2010 Michigan Student Athlete Cardiac Awareness Month</p>	
Medical Examiner Protocols	
<p>SCDY: The Forensic Pathologists Perspective Rebecca Corbett, MD, Forensic Pathologist and Chief Medical Examiner, Kent County, MI</p>	

www.michigan.gov/scdy



Genomics and Health Impact Blog

A blog devoted to discussing best practices and questions about the role of genomics in disease prevention, health promotion and healthcare.

[Public Health Genomics](#) > [Genomics and Health Impact Blog](#)

Can Sudden Cardiac Death of the Young be Prevented?

Categories: [genomics](#), [heart disease](#)

March 1st, 2012 3:06 pm ET - Guest Blogger

Debra Duquette, MS, CGC, Genomics Coordinator & Beth Anderson, MPH, Michigan, Genomics Epidemiologist, Michigan Department of Community Health

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 their 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 charged 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. ¹ Each year in Michigan alone, approximately 300 people aged 1-39 years die suddenly of a cardiac cause. ² Importantly, SCDY is known to have a strong hereditary component in many cases.



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February 20, 2012

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The Legacy Of Wes Leonard

You may have heard about the Michigan high schooler 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

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After the autopsy, when the doctor found white blossoms of scar tissue on Wes Leonard's heart, he guessed they had been secretly 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 21½ 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

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



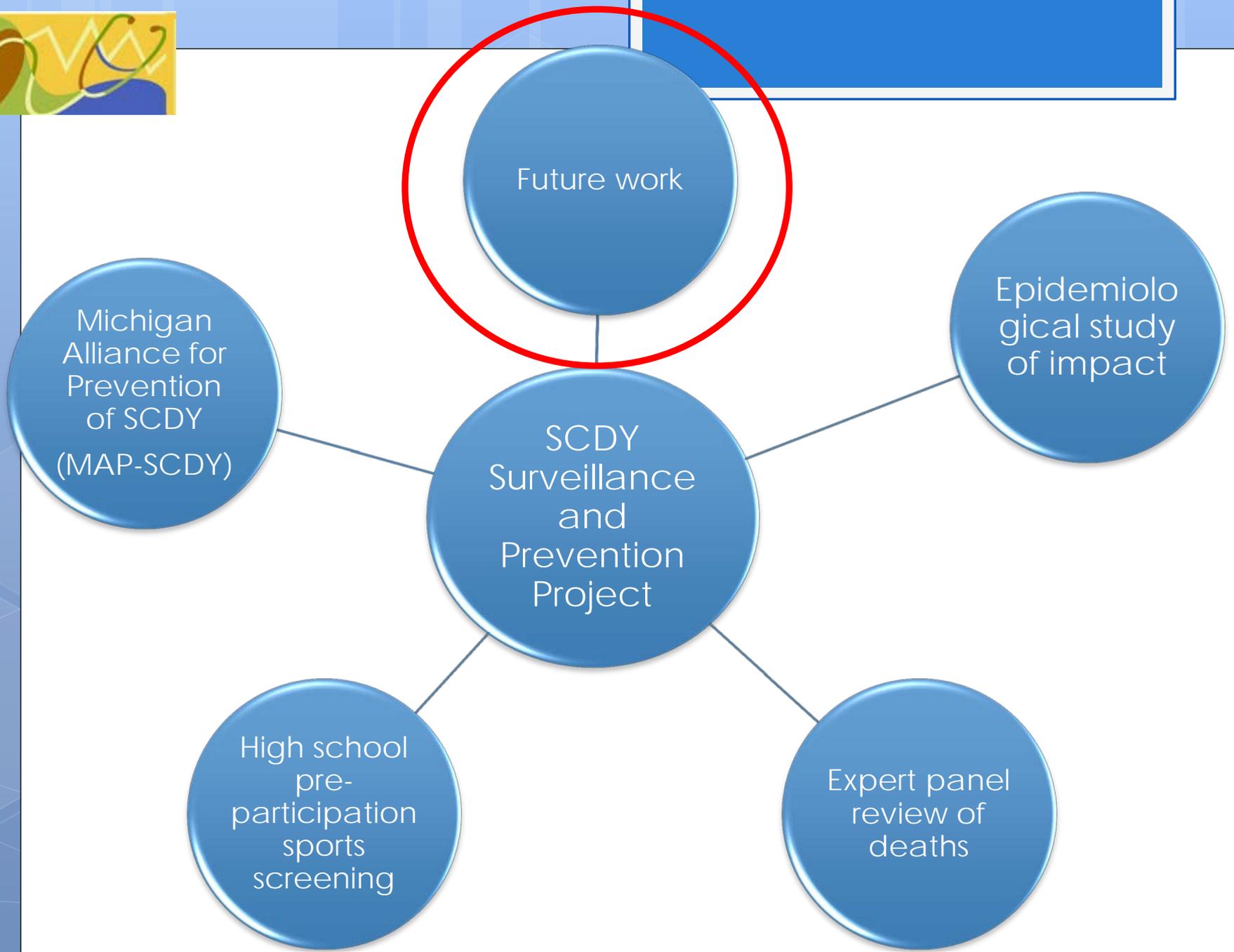
How to become a MI HEARTSafe School

Basic Criteria:

- A **cardiac emergency response plan** with designated responders who are CPR/AED certified.
- 10-24% of staff are **CPR certified**, trained to use the AED, and available to respond to an emergency.
- A sufficient number of accessible and properly maintained **AEDs** with fully charged batteries, ready to use, on-site with proper signage.
- The performance of at least one **cardiac emergency response drill** per year including both students and staff.
- All athletic pre-participation screening completed with **revised MSHAA form** (updated in 2010).

**“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



Future work

Epidemiological study of impact

SCDY Surveillance and Prevention Project

Expert panel review of deaths

High school pre-participation sports screening

Michigan Alliance for Prevention of SCDY (MAP-SCDY)

In Development: Expand SCDY Mortality Review

- NHLBI Report on Screening for SCDY (Kaltman et al. *Circulation*. 2011; 123:1911-1918)
 - 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

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Screening for Sudden Cardiac Death in the Young: Report From a National Heart, Lung, and Blood Institute Working Group
Jonathan R. Kaltman, Paul D. Thompson, John Lantos, Charles I. Berlin, Jeffrey Berlin, Joshua T. Cohen, Nancy R. Cook, Donatello Corrado, Jonathan Drener, Kevin D. Frick, Stuart Goldman, Mark Hlatky, Prince J. Kannankeril, Laurel Leslie, Silvia Prieto, J. Philip Saul, Carrie K. Shapiro-Mendoza, David Siscovick, Victoria L. Vetter, Robyn Bonneau, Kristin M. Burns and Richard A. Friedman
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Key Points from Public Health Perspective to Eliminate Health Disparities

- Investigate existing national, state and local public health data for health disparities related to genomics
- Integrate genomics into existing public health programs and infrastructure whenever possible
- Engage multiple sectors (including industry, foundations, non-profits, government, clinicians, media) to eliminate health disparities related to genomics
- Create or enforce policies to ensure benefits of genomic medicine is accessible to all individuals especially vulnerable and under-served population ; and, create or enforce policies to protect especially vulnerable populations from any potential harm from genomics

Examples of Utilizing State BRFSS Data to Assess National Public Health Genomics Issues

- 2009 State BRFSS in Connecticut, Michigan, Oregon, and Utah compared to 2008 national HealthStyles survey to measure awareness and use of DTC personal genomic tests
- Awareness ranged from 15.8% in Michigan to 29.1% in Oregon
 - For all four states and nationally, greater awareness significantly associated with higher education, incomes of \$75,000 or higher, & ages 50-74
 - Greatest awareness in respondents with \$75,000 or higher household incomes in Oregon (41.2%)
 - Least awareness in respondents with less than \$25,000 or lower household incomes in Michigan (9%)
- Four states and national survey found less than 1% of population reporting using DTC personal genomic test

Examples of Utilizing State BRFSS Data to Assess National Public Health Genomics Issues

- 2010 State BRFSS in Michigan, Connecticut, Ohio and Oregon included questions to measure:
 - Public awareness of GINA
 - Public attitudes on necessity of laws to prevent life insurance genetic discrimination
- Michigan BRFSS found 13.3% of adults aware of GINA
 - More aware of GINA if black (17.0%), college graduate (17.1%), or if had collected own family history (18.9%)
- 84.8% of Michigan adults thought very or somewhat important to have laws that prevent genetic test results from being used to determine life insurance coverage and costs
 - More likely to support if younger and female



Thank you!

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