

*Sudden Cardiac Death of the Young  
in Michigan:*  
Development and Implementation of  
an Innovative Mortality Review System  
**Michigan Epidemiology Conference**

April 4, 2008

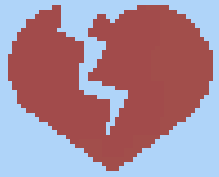
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1) Michigan Department of Community Health

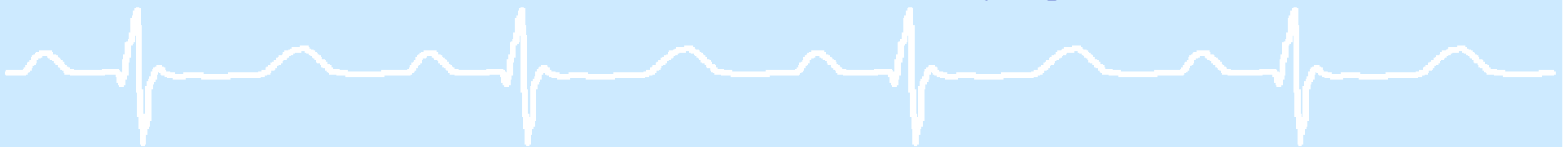
2) Blue Cross/Blue Shield of Michigan 3) Michigan State University

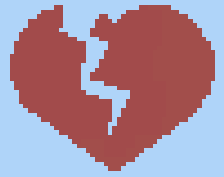


# Sudden Cardiac Death

- An unexpected sudden death due to cardiac cause and occurring out of hospital or in the emergency department\*
- Etiologies vary with age

\* Zheng ZJ, Croft JB, Giles WH, et al. State-Specific Mortality from Sudden Cardiac Death United States, 1999. MMWR Morb Mortal Wkly Rep. 2002;51(06):123-126.

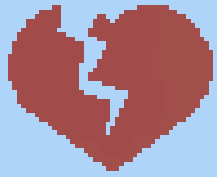




# Sudden Cardiac Death of the Young (SCDY)

- Especially tragic event; often high-profile, associated with young athletes
- Variably defined as < 30, < 35, < 40 years of age
- A potentially preventable condition, due to the heritable nature of certain cardiac disorders
  - More likely to have genetic determinants than similar conditions in older persons
  - Immediate family members of SCDY victims may be at increased risk of sudden death

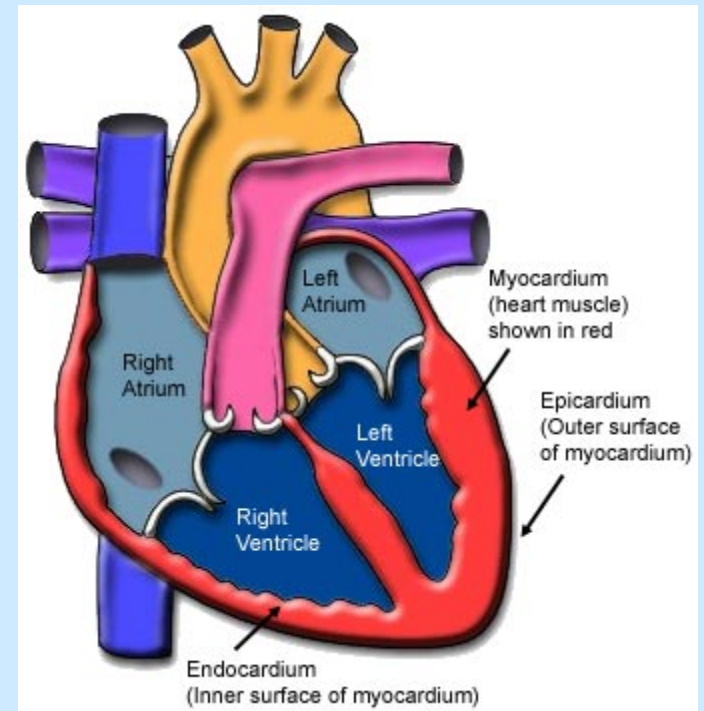




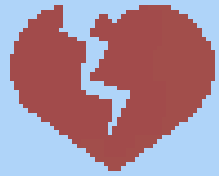
# Genomics & SCDY: Heritable Etiologies

## Congenital Cardiac Malformations

- Coronary artery abnormalities
- Aortic stenosis



[www.texasheartinstitute.org](http://www.texasheartinstitute.org)



# Genomics & SCDY: Heritable Etiologies

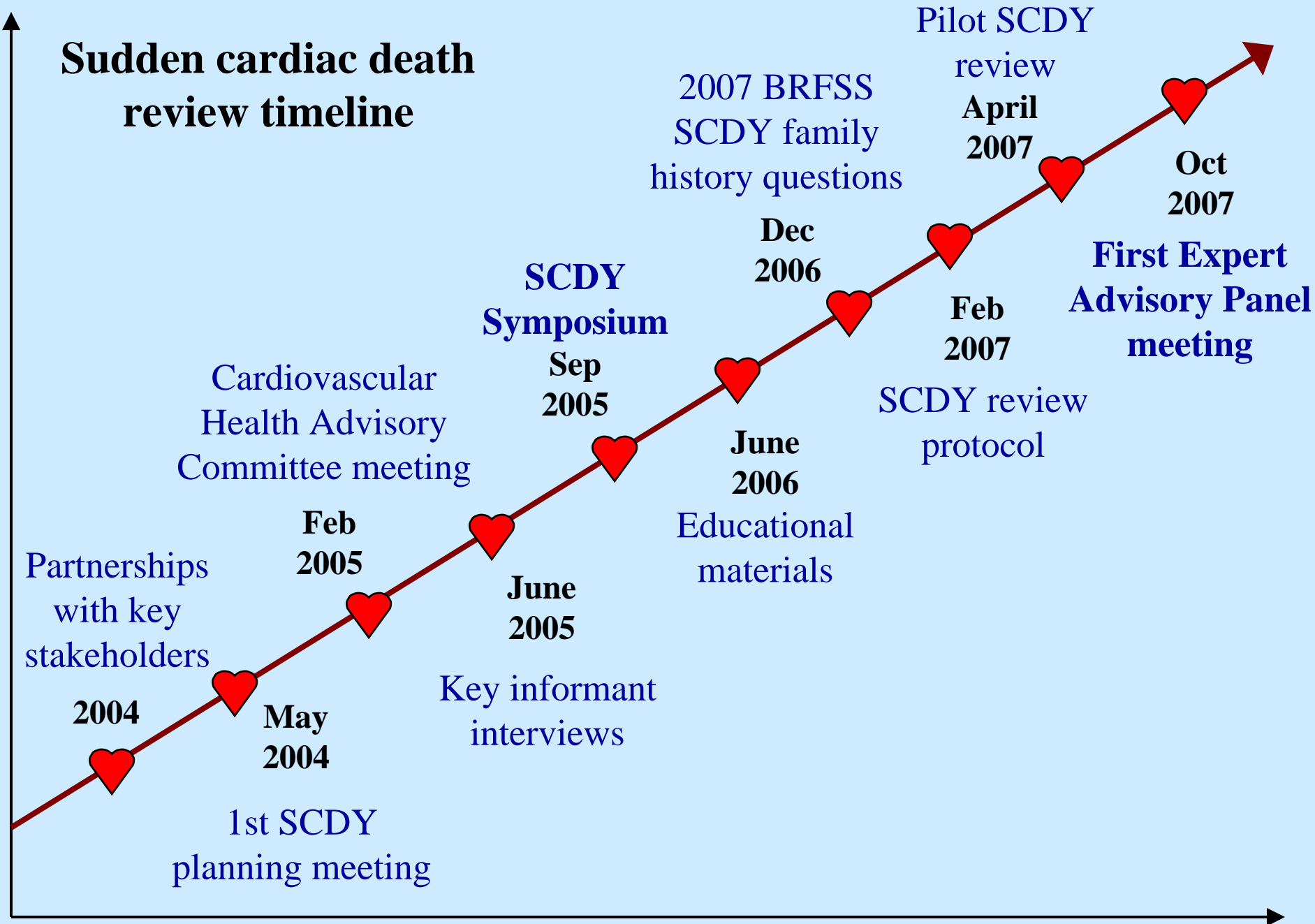
## Cardiac Causes

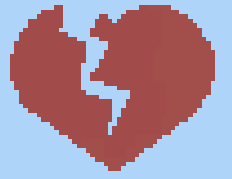
- Hypertrophic cardiomyopathy
- Dilated cardiomyopathy
- Arrhythmogenic right ventricular cardiomyopathy (ARVC)
- Mitral valve prolapse
- Atherosclerosis/ coronary artery disease

## Ill-defined Causes

- Ion channel disorders/ inherited arrhythmias
  - Long QT syndrome
  - Short QT syndrome
  - Brugada syndrome
  - Catecholaminergic polymorphic ventricular tachycardia (CPVT)

# Sudden cardiac death review timeline



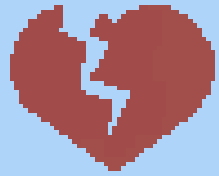


# SCDY Mortality Review System

## Objectives

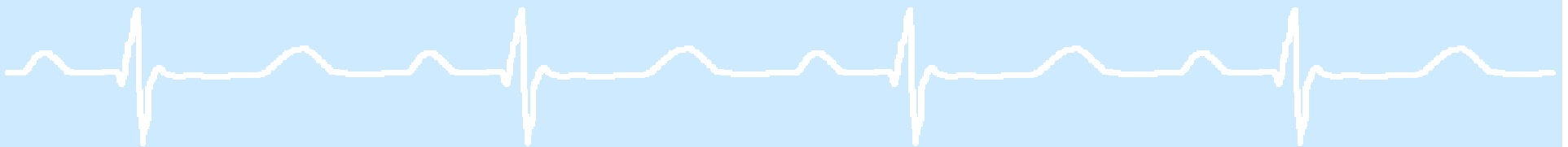
- Conduct an epidemiological assessment of the burden of SC DY in Michigan
- Develop an expert review process to identify public health and medical system changes, and family-based interventions that might lead to prevention opportunities
- Identify unmet needs for education, support, medical/genetic resources and referrals for relatives who may be at increased risk of SCD



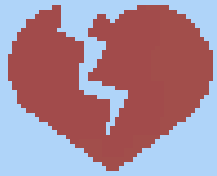


# Tentative SCDY Case Definition

- Michigan resident
- Aged 1-29
- Death occurred out of the hospital or in the emergency room
- Underlying cause of death is cardiac-related (ICD-10 codes: I00-I51), congenital cardiac malformations (Q20-Q24), or ill-defined / unexplained (R96-R99)
  - Causes of death identified on 1999-2006 death certificates from the Michigan Department of Community Health, Division for Vital Records

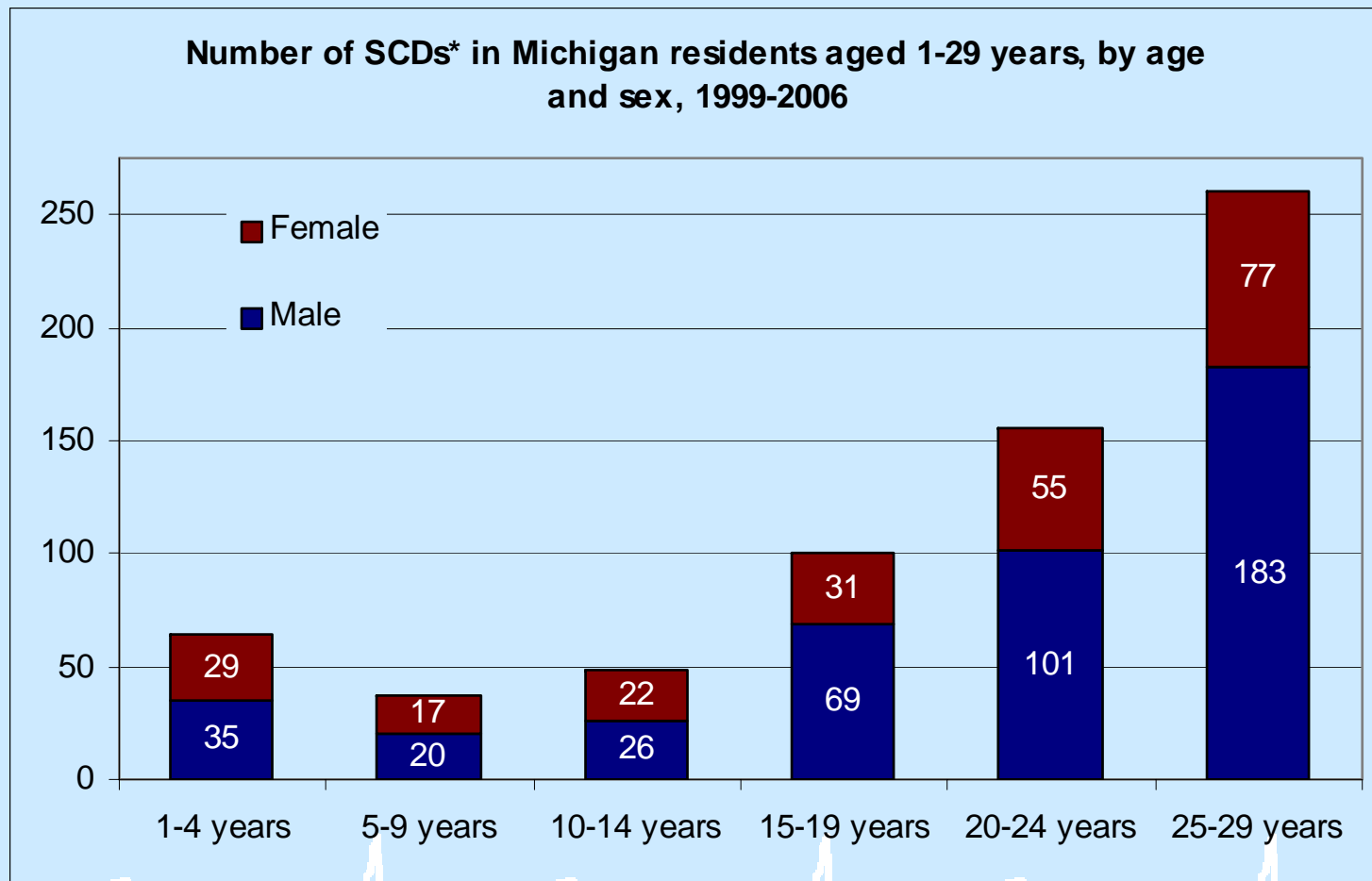


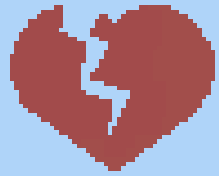




# SCDY by Age and Sex, 1999-2006

n=665

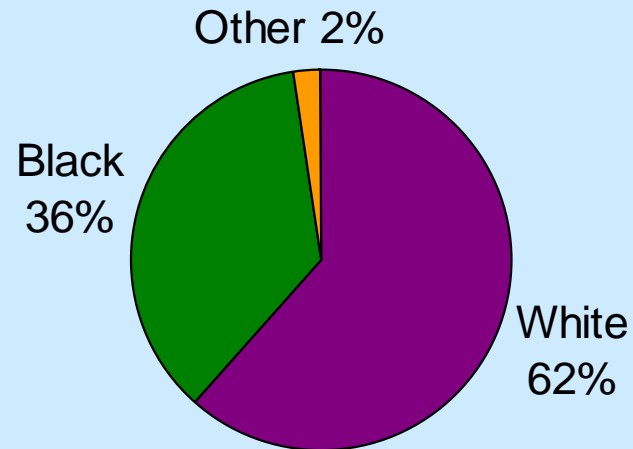


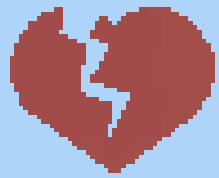


# SCDY by Race, 1999-2006

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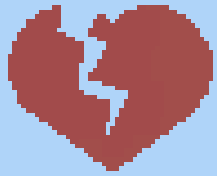
- SCDY appears to affect blacks disproportionately
- 36% of SCDY deaths occurred in blacks, whereas only 18% of the Michigan population aged 1-29 years old is black and 79% is white





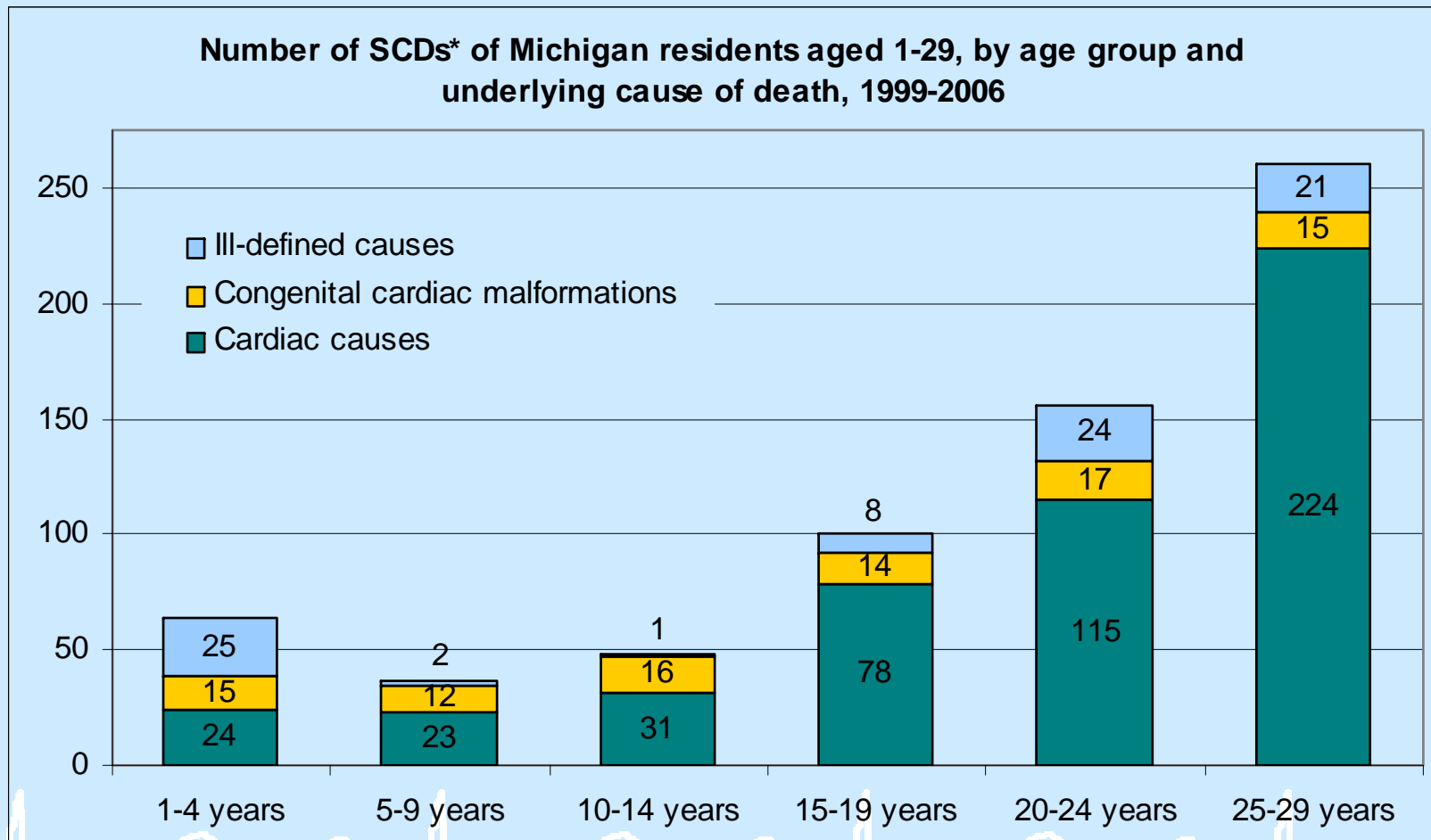
## 10 Most Frequent Underlying Causes of SCDY, 1999-2006

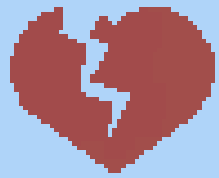
<b>Cause</b>	<b>Number</b>	<b>%</b>
Dilated cardiomyopathy (I42.0)	86	12.93
Other hypertrophic cardiomyopathy (I42.2)	62	9.32
Other ill-defined and unspecified causes (R99)	49	7.37
Cardiac arrhythmia (I49.9)	44	6.62
Congenital malformation of heart (Q24.9)	44	6.62
Cardiomyopathy (I42.9)	35	5.26
Myocarditis (I51.4)	34	5.11
Acute myocardial infarction (I21.9)	30	4.51
Atherosclerotic cardiovascular disease (I25.0)	27	4.06
Instantaneous death (I26.9)	21	3.16



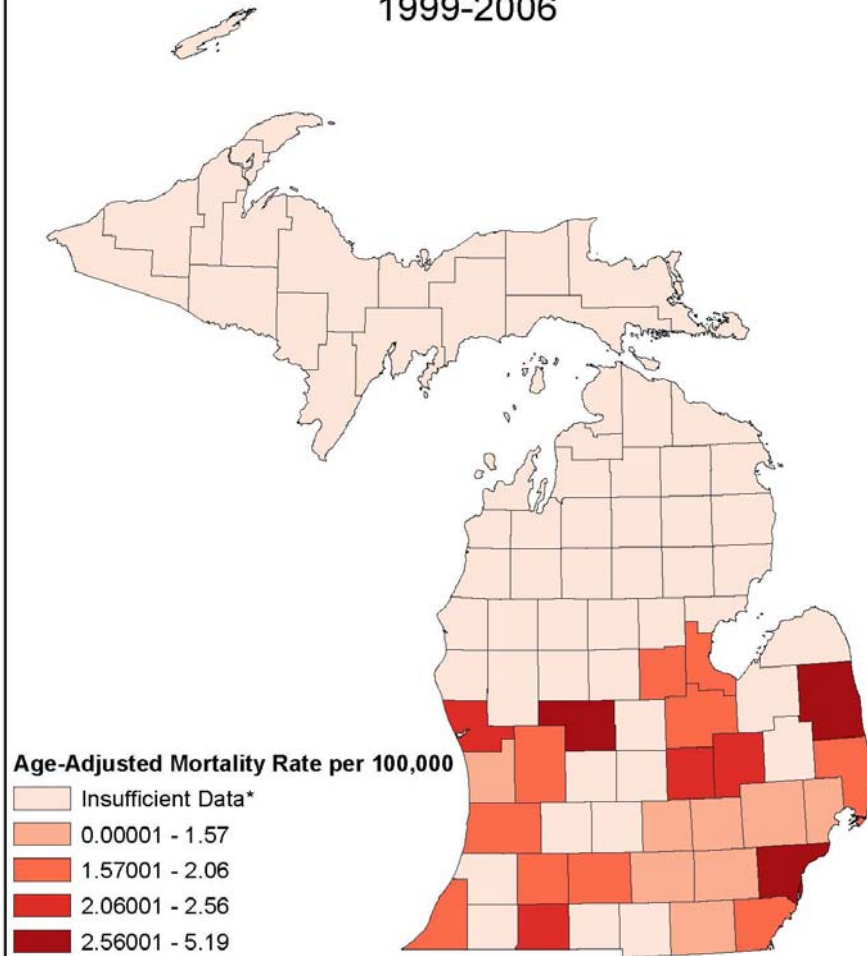
# SCDY by Age and Underlying Cause

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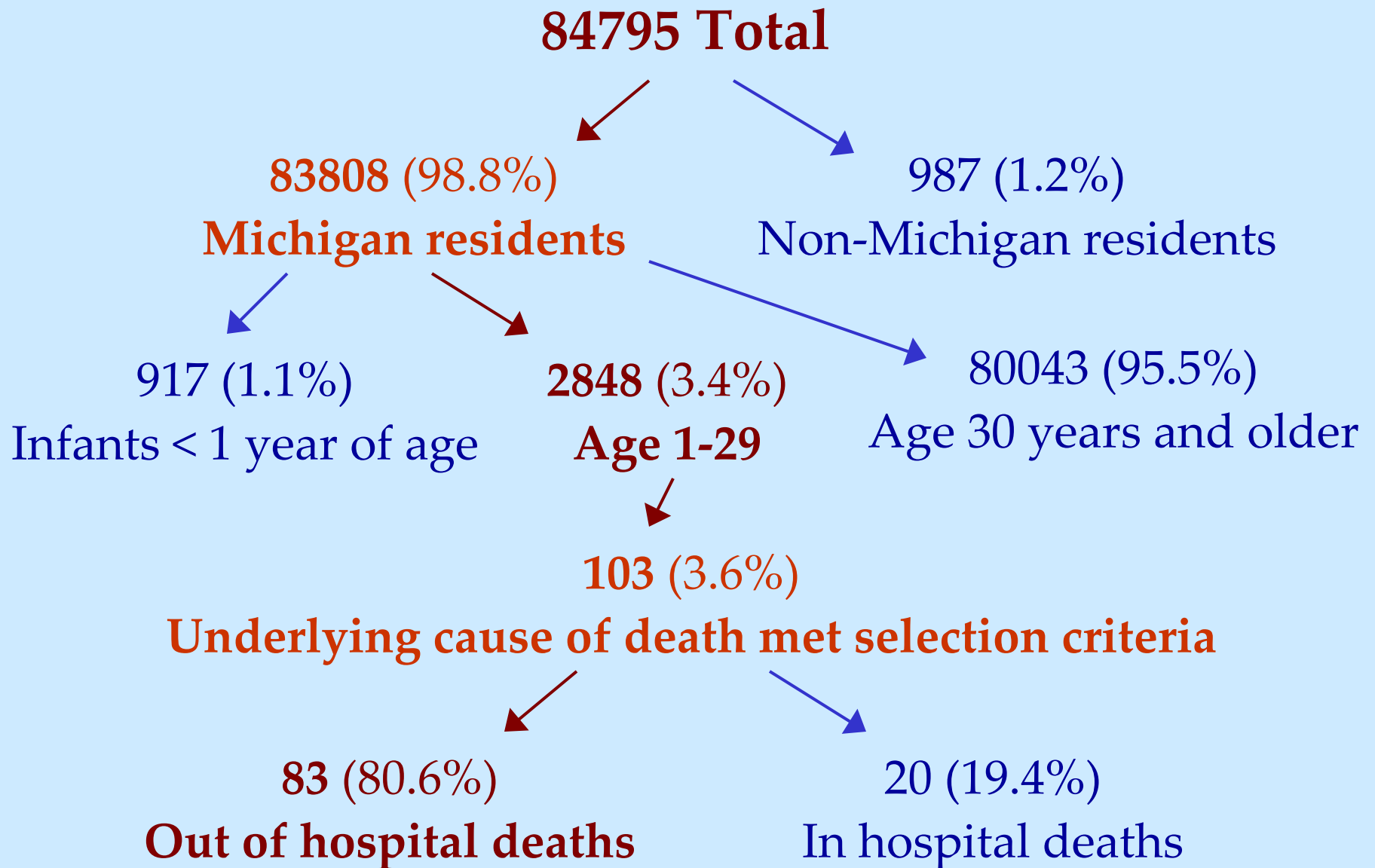


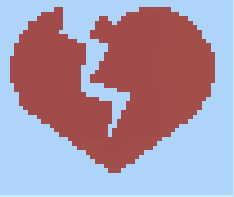
### Age Adjusted Mortality Rate for SCDY, Michigan Residents Age 1-29 by County, 1999-2006



\*Countries with fewer than 5 sudden cardiac deaths from 1999-2006  
Michigan age-adjusted mortality rate is 2.06 per 100,000  
Source: MDCH Vital Statistics  
Age-adjusted to the 2000 U.S. standard population

# SCDY Surveillance: MI Deaths (Jan-Dec 2006)





# SCDY Review Process

Mortality data review

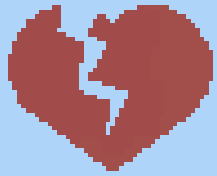
Medical  
records review

Next-of-kin  
interview

De-identified  
case summaries

SCDY Expert Advisory Panel  
meeting

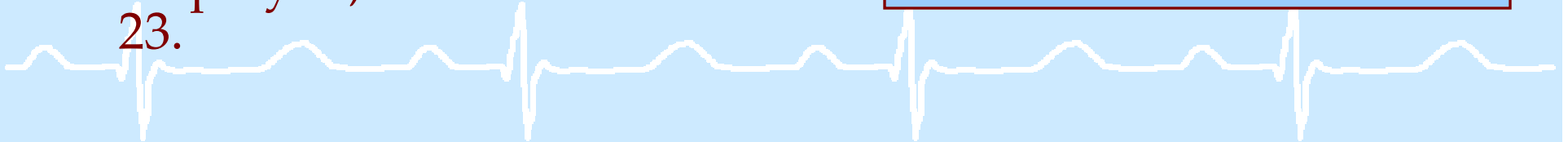




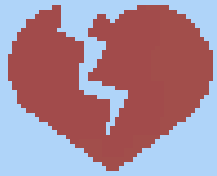
# SCDY Case Study

A black male in his early 20's 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 pulseless. He was pronounced dead on the scene. Cause of death was undetermined by autopsy. He was a non-smoker, steadily employed, and had a BMI of 23.

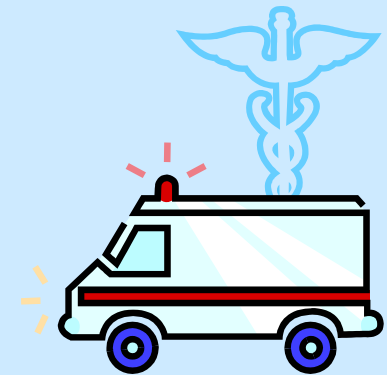
- Previous history of syncope
- Shortness of breath with exertion
- Complained of chest pain and fatigue
- Family history of hypertension
- No health insurance
- Lack of medical care for at least 8 years





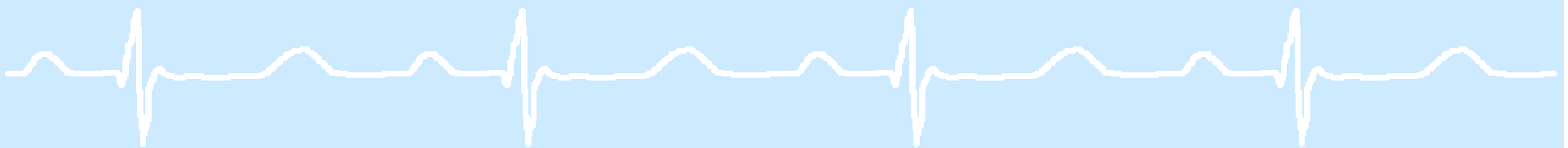


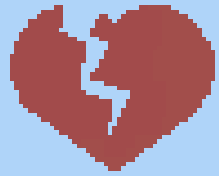
# Initial Findings



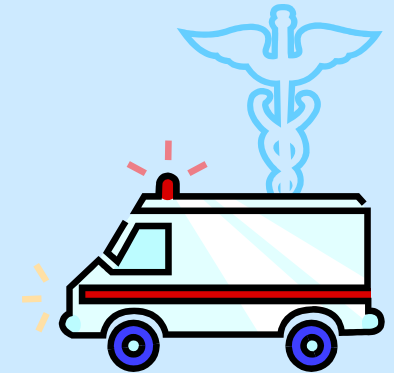
## Patient-related factors

- Education when to seek medical care (chest pain or other symptoms)
- Non-compliance (smoking, meds, MD)
- Family screening / follow-up (children)





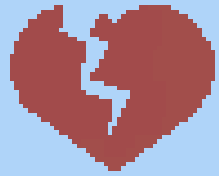
# Initial Findings



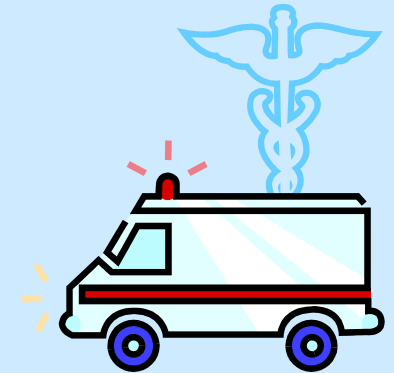
## Physician-related factors

- Need to reinforce standard education messages
- Need to address financial situation of patient
- Awareness of need to screen family members, and when genetics referral indicated
- Education on content of family history screening form





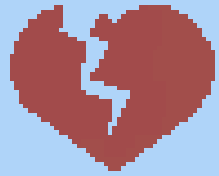
# Initial Findings



## System-related factors

- Lack of health insurance
- Availability of defibrillators for 1<sup>st</sup> responders
- Mechanism to pay for screening of family
- Mechanism for family contact, including assuring autopsy report reaches primary care provider
- Storage of biologic specimen / DNA

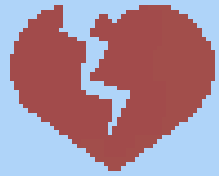




# Limitations

- Source of death information
- Case definition
  - Sensitivity / specificity
- Accuracy / reliability
  - Cause of death (ICD codes)
  - Death certificates
- Novel approach with no defined protocol for state health departments
- Lack of evidence based guidance for population and high risk family screening
- Insufficient funding to review all cases

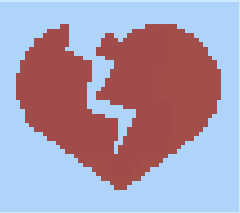




## Next Steps

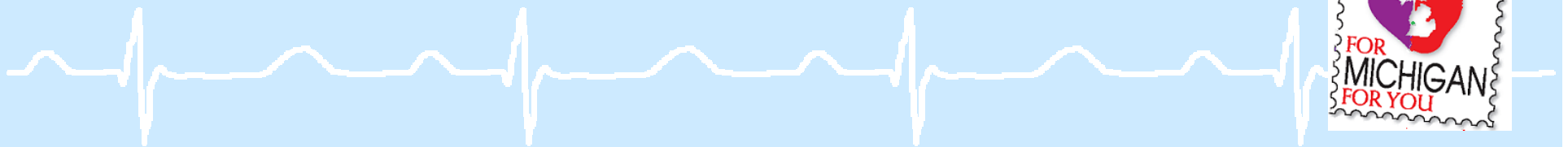
- Refine case definition and protocol
- Consider other sources of death information
- Create a report and disseminate findings at a symposium later this year
- Develop recommendations for interventions that address patient, physician, and system-related factors
- Secure additional funding

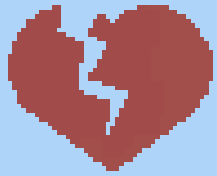




**“I thought we were forgotten....  
I thought no one cared...”**

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





# Acknowledgements

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- Ifeoma Okafor
- Marsha Jacobson
- Michael Beebe

## **SCDY Expert Advisory Panel**

**Mark Caulder & Dr. Michael Lehmann**

