

# The Asthma Mortality Review and Sudden Cardiac Death of the Young (SCDY) Mortality Review

## Investigators:



### *Asthma*

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### *Sudden Cardiac Death of the Young (SCDY)*

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# Purpose

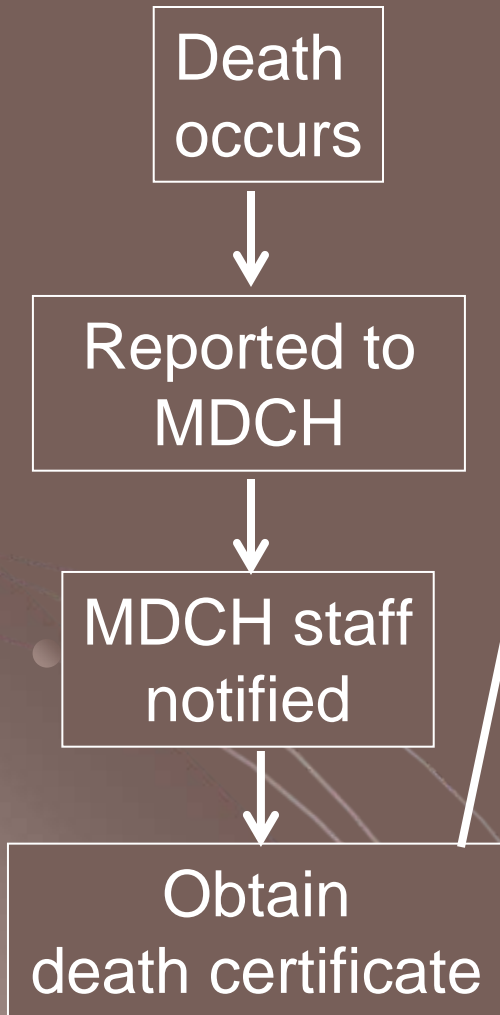
- Implement and refine a process to collect and review medical data
- To identify recommendations as a step toward evidence-based medical system changes and public health prevention efforts that will reduce the occurrence of these deaths
- Identify unmet needs for family-based interventions including education, support, medical/genetic resources

# 2 Death Reviews... A Common Methodology

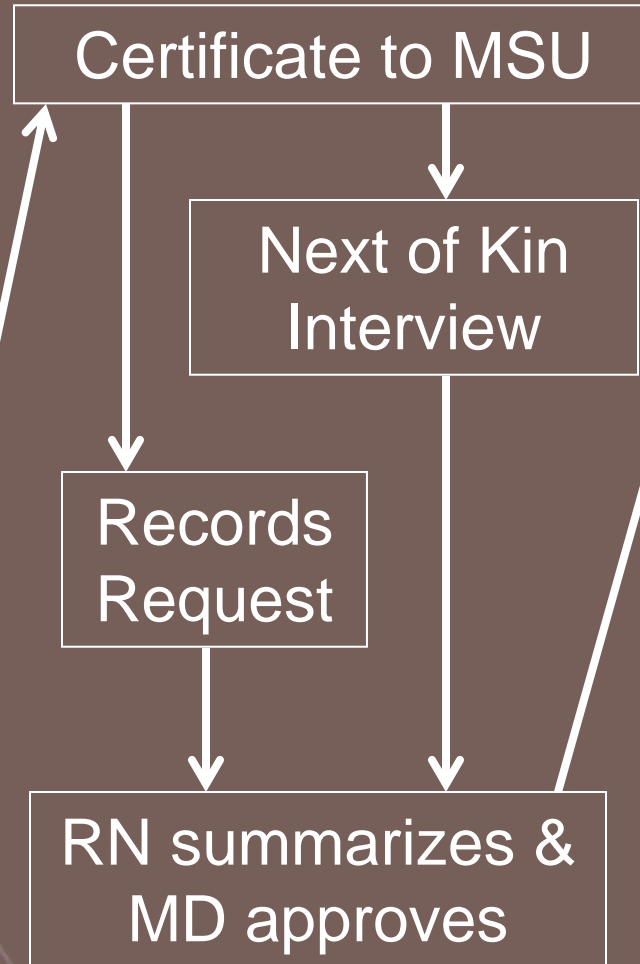


# Asthma Mortality Review Process

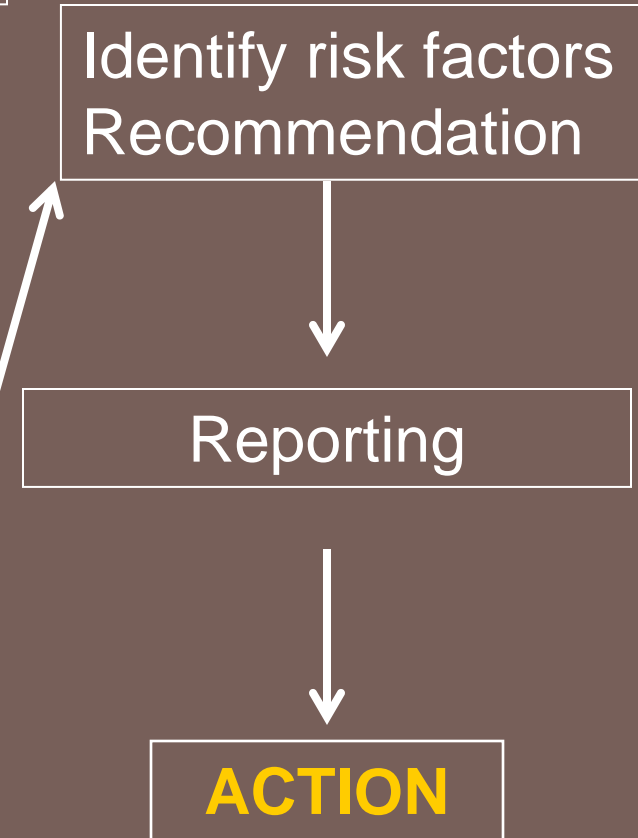
## Notification



## Investigation



## Panel Review



# Data Collection

- Structured interview with next-of-kin
- Records request to Medical Examiner
- Request all records for year prior to death from
  - EMS
  - Hospital
  - Pharmacies
  - Primary and specialty care practices
- Medicaid claims history
- If no interview, difficult to obtain records

# Blinded Case Summaries

- Death Certificate: age, race, sex, month of death
- Interview: SES, psychosocial issues, symptom & management history, information on fatal attack
- Autopsy/toxicology results & day of death reporting
- Pharmacy records: frequency and type of medications filled
- Chart Abstraction: Frequency of visits, medications prescribed, management plan, referrals, available lab and other procedures

# Expert Panel Membership

- Asthma Death:

Specialty, primary care and emergency department doctors, nursing and respiratory staff, social workers

- Sudden Cardiac Death

Cardiac Specialties, primary care and emergency room doctors, nursing, pathologist, geneticist, health plan policy administrator

# Expert Review Panel Responsibilities

- Review and discuss each case
- Develop prioritized list of causal factors
- Develop prioritized list of follow-up activities supported
  - Recommend actions to prevent each case
  - Decide if familial risks exist for surviving family members (SCDY only)
- Review year end summary of recommendations
- Provide guidance on implementation of recommendations



# Asthma Mortality Review Project

## Findings and Activities

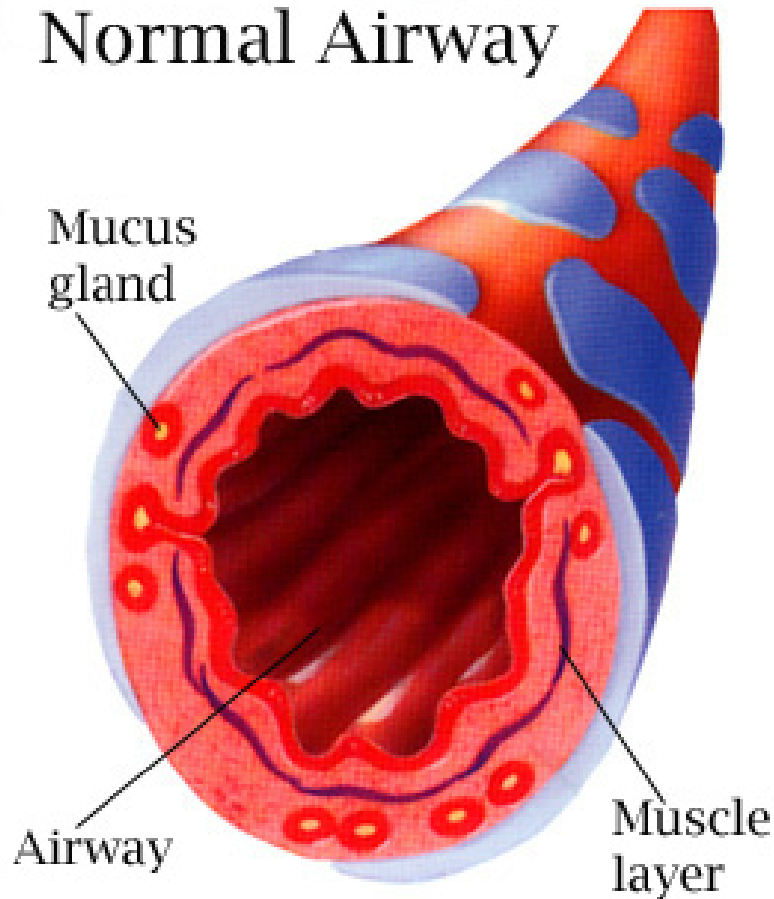


# Asthma Defined

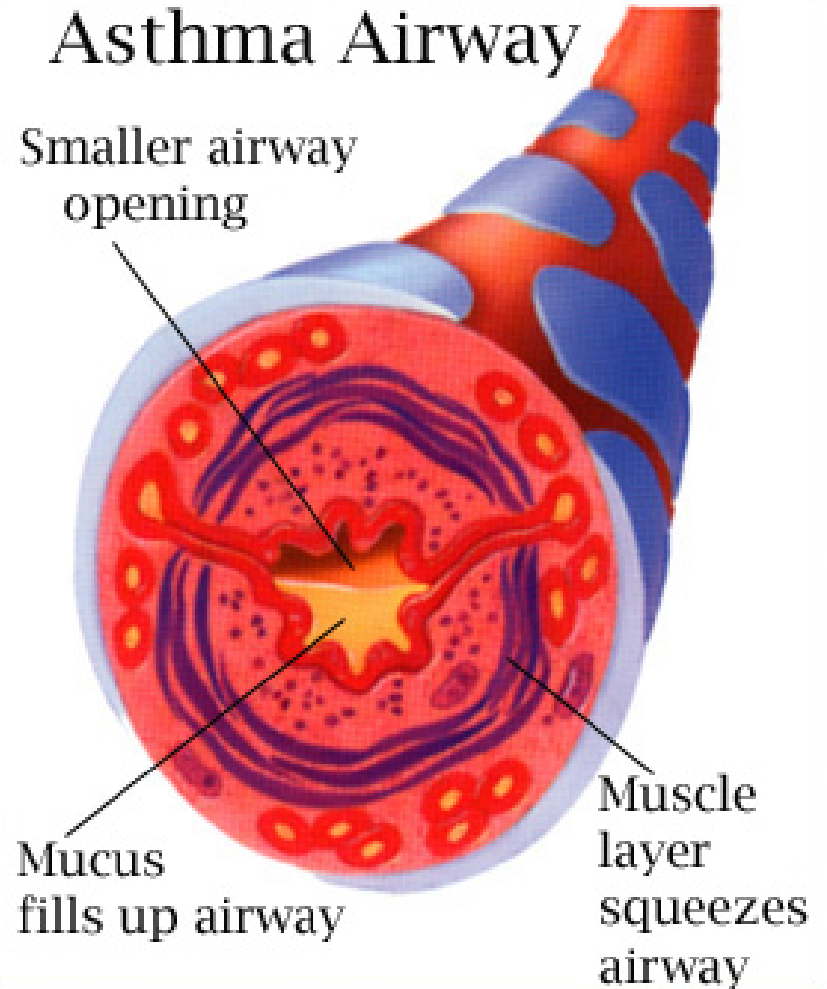
- Chronic inflammatory disease of the airways
- Causes recurrent episodes of
  - Wheezing
  - Breathlessness
  - Chest tightness
  - Coughing
- Episodes are usually associated with airflow obstruction that is often reversible either spontaneously or with treatment

# During an asthma attack...

## Normal Airway

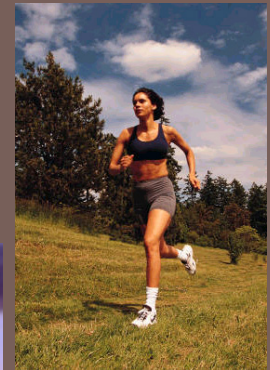


## Asthma Airway



# Triggers of Asthma Attacks

- Narrowing of airways occurs in response to inflammation or hyperresponsiveness to triggers, including:
  - Allergens
  - Infections
  - Diet/Medications
  - Strong Emotions
  - Exercise
  - Cold temperature
  - Exposure to irritants





# How is asthma treated?

## Expert Panel Report 3

### National Asthma Education and Prevention Program National Heart, Lung, and Blood Institute, 2007

#### Key Messages:

- Inhaled corticosteroids are the most effective medication for long term management of persistent asthma
- All patients should receive:
  1. Asthma Action Plan
  2. Initial assessment of asthma severity
  3. Review of the level of asthma control at all follow-up visits
  4. Periodic follow-up visits (every 6 months)
  5. Assessment of exposure/sensitivity to allergens and irritants, recommendations to reduce
  6. Asthma education by qualified health professional
  7. Referral to asthma specialist (when appropriate)
  8. Education re: overuse of rescue medication
  9. Education re: risk factors of asthma death



# Managing Asthma: Asthma Management Goals

- Prevent chronic and troublesome symptoms
- Maintain normal lung function
- Maintain normal activity levels
- Prevent exacerbations
- Minimize ED visits/hospitalizations
- Provide optimal therapy
- Meet patients'/families' expectations of care

# Case Study

## Background

- African-American female pre-teen died from asthma in the fall
- Diagnosis of asthma - infant
- Private health insurance – \$10 co-pay
- Parents said that the emergency department and doctor's office needed to work together.

# Case Study

## Day of Death

- Woke up in the morning and took a couple breathing treatments
- Called the doctor's office, but they were at lunch (11:45 am)
- Said happy birthday to her mother and took another breathing treatment
- Brother told her dad that she couldn't breathe – he drove her to the emergency department
- Lost consciousness on the way to the emergency department
- Died 1:30 pm

## Autopsy

- Both lungs were hyperinflated, exuding mucous
- Mucous plugs in the bronchi and deposition of eosinophils
- No evidence of trauma or injury
- Toxicology was negative for drugs and alcohol



# Case Study

## Medical History

- PCP visits 6 times in year prior to death
- Had not seen a specialist due to some confusion
- ED – 75 times in life, 8 in year prior to death
- Hospitalized – 25 times in life, 4 in year prior to death
- Had been to an asthma clinic 2 weeks prior to death
- Long term control and rescue medicines prescribed
- No smoking, pets, or carpet in her house
- Missed her medications 2-3 times per month
- Had a peak flow meter, occasional use
- Had a written asthma plan and asthma education course
- Had breathing problems almost daily and was awakened at night less than twice per month
- BMI: 95<sup>th</sup> percentile

# Asthma Mortality Review Project\*, 2002-2006

	Children 2-18 yrs 2002-06	Adults 19-34 yrs 2002-05	Adults 45-54 yrs 2006
Medicaid Insurance at Time of Death	71%	41%	50%
Smoker in the Home	46%	57%	64%
Pets in the Home	47%	60%	67%
Asthma Action Plan	33%	9%	0%
Prescribed Inhaled Steroids	40%	35%	39%
Had a Nebulizer	84%	71%	77%
Pulmonary Function Testing Ever	55%	52%	56%
Seen by a Specialist during Lifetime	73%	65%	73%
Previous ED Visit in Year Prior (Avg #)	68% (3.0)	68% (7.3)	73% (3.3)

\*Data presented is based on deaths with available information.

# Misclassification of Asthma Deaths

- 2006 special study of all asthma deaths, age 2 years and older (n=118)
- 68% of all asthma deaths had records consistent with that determination
- Inaccuracies increase with age
  - 100% consistency 2-18 years
  - 23% consistency 85+ years



# Most Frequent Causal Factors of Asthma Death Identified in Mortality Review

- Compliance issues such as elimination of asthma triggers, follow-up with regular medical care.
- Inadequate use of steroids, and overuse of  $\beta$ -agonists.
- Inadequate prescription of steroids by health care providers.
- Need for specialist referral and pulmonary function testing for high-risk patients.
- Lack of regular medical care with primary care providers.

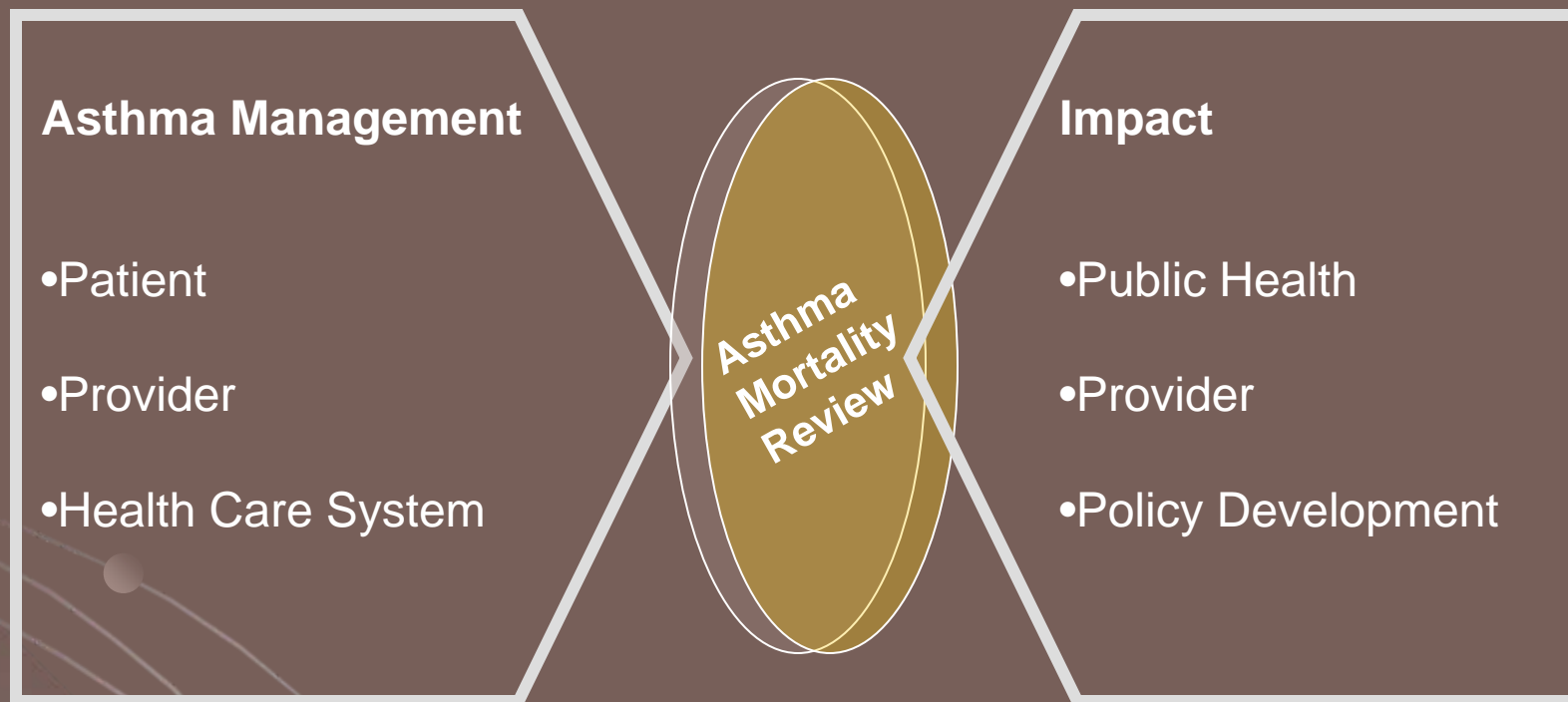


# Asthma Mortality Expert Panel Recommendations

- Case Management
- Timely referral to specialists
- Monitor/Restrict refilling of  $\beta$ -agonists to reduce overuse
- Educate patients and providers (primary and urgent care)
- More comprehensive care in emergency department



# Asthma Mortality Review: A Lens



# Impact

- Shared findings with key stakeholders
- Asthma protocol for MI Child Death Review Program
- Provider education module
- ED discharge instructions project (FLARE)
- Informed the Sudden Cardiac Death Review Project
- Informed the Detroit Asthma Mortality Summit
- Informed the Asthma Case Management Program (MATCH)

# Acknowledgements

- Health Care providers and Medical Examiners
- Family members and friends of deceased
- Asthma Mortality Review Panel Members
- MDCH Division of Health Statistics and Vital Records
- MPHI Child and Adolescent Health staff

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Full report available at:

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



# Sudden Cardiac Death of the Young (SCDY)

Findings and Activities



# Sudden Cardiac Death Defined

- Unexpected sudden death due to a cardiac cause and occurring within one hour of the onset of symptoms in an individual who has been in his/her usual state of health, without any known life-threatening condition  
(Priori et al, 2002)
- An unexpected sudden death due to cardiac cause and occurring out of hospital or in the emergency department  
(Zheng et al, 1999; MMWR, 2002)

# Sudden Cardiac Death of the Young (SCDY) Defined

- 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

# SCDY Risk Factors

- Dependent of the age
- Over age 40 years
  - Atherosclerosis
    - typically complex/multifactorial inheritance
    - rare single gene disorders
- Under age 40
  - Depends on country?
  - Congenital heart defects
    - typically complex/multifactorial
    - single gene disorders, teratogens, chromosome abnormalities
  - Long QT syndrome
    - single gene disorder
    - triggers include exercise, swimming, emotional or physical stress, loud noises
  - Hypertrophic cardiomyopathy
    - single gene disorder
    - trigger includes exercise
  - Myocarditis
    - infectious

# Family History

Family history is the greatest risk factor for SCDY

As many as 40% of victims have been identified as having a heritable disease

## Behavioral Risk Factor Survey (BRFS)

- 2,856 people were asked about SCDY
- 6.3% have a family history of SCDY
- Significantly more blacks (11.2%) than whites (5.4%) reported SCDY

Table 3  
**Family History of Sudden Cardiac Death of the Young<sup>a</sup>**  
*2007 Michigan Behavioral Risk Factor Survey*

	%	95% Confidence Interval
<b>Total</b>	<b>6.3</b>	<b>(5.2 - 7.7)</b>
<b>Age</b>		
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)
<b>Gender</b>		
Male	5.4	(3.9 - 7.4)
Female	7.7	(6.1 - 9.6)
<b>Race/Ethnicity</b>		
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	-- <sup>b</sup>	
<b>Education</b>		
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)
<b>Household Income</b>		
< \$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)

<sup>a</sup> 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.

<sup>b</sup> The denominator in this subgroup is less than 50.

# How are the causes of SCDY treated?

- Dependent on the cause
- Examples:
  - Atherosclerosis (pharmacologic, behavior)
  - Long QT syndrome (pharmacologic, ICD)
  - Hypertrophic cardiomyopathy (pharmacologic, ICD, surgery)
  - Congenital heart defects (surgical)

# Tentative SCDY Case Definition

- Michigan resident
- Aged 1-39
- 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



# ICD Codes (10<sup>th</sup> Revision)

- I00-I09 Rheumatic heart disease
- I11 Hypertensive heart disease -
- I20-I25 Atherosclerotic heart disease - 3
- I26 Pulmonary embolism
- I30-I31 Pericardium disease
- I33 Endocardium disease
- I34-I38 Valve disorders
- I40 Myocarditis -2
- I42 Cardiomyopathy - 7
- I44-I45 Conduction disorders
- I46 Cardiac arrest - 2
- I47-I49 Cardiac dysrhythmias - 6
- I50 Heart failure
- I51 Complications and ill-defined heart disease
- Q20-Q24 Congenital abnormalities of the heart
- R96-R99 Ill-defined causes of death - 3
- Died out of hospital, en route, in emergency room

# Cases Reviewed

- 23 deaths
- 26.1% were females; 56.5% were African Americans
- 39% were students
- 73.9% had a possible heritable cause

# *Michigan Case*

- African American teenage male
- Student, basketball player
- Reported feeling 'skipped beats and fluttering' for 4 months, especially while playing basketball; felt dizzy when rising from chair; felt tired all the time; legs; legs hurt all the time; often asked mom often to place her hand on his chest to feel his 'rapid heart beat'; he thought 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 other specialists

# *Michigan Case Continued*

- Playing basketball, collapsed
- No CPR prior EMS
- Locked AED at site, coach no training on AED
- When EMS arrived, large crowd gathered outside swearing and yelling so police called to allow EMS access
- EMS documented no pulse/not breathing; CPR immediately started
- Pronounced dead in ED
- Autopsy performed: hypertrophic cardiomyopathy listed as cause of death
- Toxicology – negative for alcohol, illicit drugs, positive for caffeine
- No family members tested after the death

# *Sudden Cardiac Death of the Young*

## *Expert Panel: Prevention*

### *Recommendations for this Case*

#### Educate Health Providers

- Quality of pre-participation sports physical

#### Educate Patients

- None

#### System-Level Change

- CPR training for sport coaches
- If AED present on-site, require training and availability
- Improvement of pre-participation sports screening
- Mechanism to notify relative of need for screening

# *Hypertrophic Cardiomyopathy*

- Autosomal dominant
  - 50% risk to first degree relatives
  - All first degree relatives should be screened
- Myocardial hypertrophy (wall thickness greater or equal to 13 mm) in the absence of hemodynamic stress
  - Family history is critical!
  - Decrease in exercise tolerance in young
  - Syncope
  - Abnormal ECG and echo
  - Genetic mutations- 11 common identifies 50-60% of patients (genotype-phenotype correlations known)
  - Treatment dependent on severity (pharmacological, ICD, surgical)

# Limitations

- 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
- Funding!



# A Call to Action

- Advocacy & Support Groups: AHA, SADS, KAYLA, Gillary
- EMS Personnel
- Governor's Council on Physical Fitness
- Medical: cardiology, primary care, genetics, emergency, sports medicine
- Medical examiners
- MI High School Athletic Association
- Professional organizations: MSMS, ACC
- Public health
- Vendors (AED)



## **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

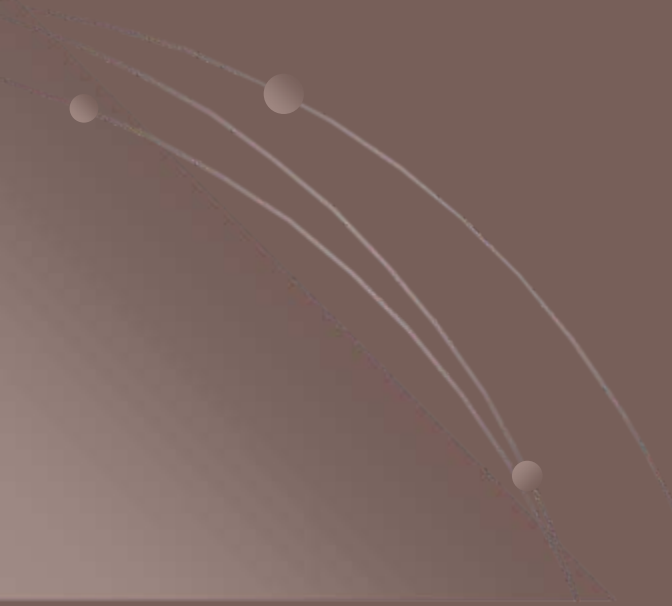
- 1:00 Welcome and Overview of Michigan Sudden Cardiac Death of the Young (SCDY) Surveillance Project  
—Gregory Holzman, MD, MPH  
MDCH Chief Medical Executive
- 1:15 Epidemiology of SCDY in Michigan  
—Beth Anderson, MPH, MDCH Cardiovascular Health Epidemiologist
- 1:35 Findings from the SCDY Mortality 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. Cohe, MD, Spectrum Health
  - Emergency response protocols  
—Robert Swor, 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



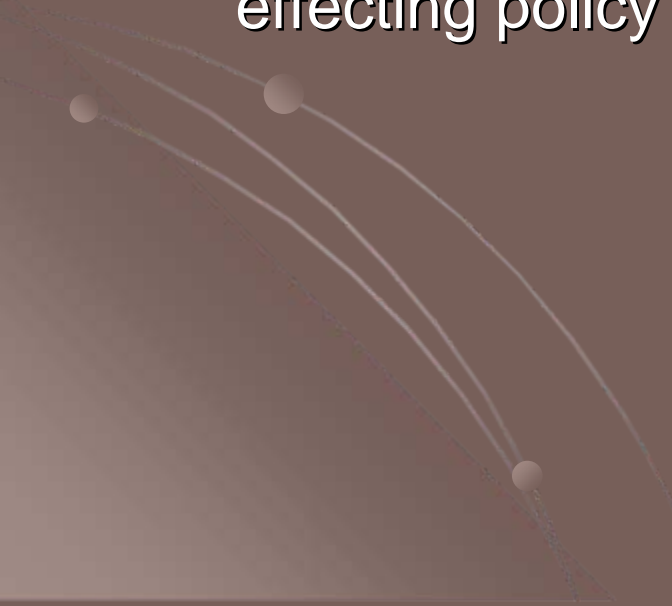
# Action Steps to Address:

- **Pre-participation Sports Screening/Physical and Follow-up**
  - Recommend revisions to MHSAA sports participation form
- **Provider Education and Public Awareness of SCDY Risk Factors**
  - Focus on increasing public awareness through school curricula; create standardized educational presentations for health care provider training
- **Public Awareness of Cardiac Symptoms and CPR/AED Training**
  - Identify gaps in existing CPR/AED training mandates or professional guidelines for specific groups and settings

# Action Steps to Address:

- **Emergency Response Protocols**
    - Explore policies and investigate availability of AEDs for volunteer and other non-EMS responders
  - **Medical Examiner Protocols**
    - Develop protocols to cover DNA banking for SCDY cases; mechanisms for follow-up with families; and standardized coding for negative autopsy findings
- 

# Summary

- Sudden cardiac deaths in young are not common but dramatic
  - Investigations of individual deaths highlight problems that may be overlooked or not evident in compiled statistics
  - Individual case stories are important for effecting policy change
- 

**“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

# *Sudden Cardiac Death of the Young*

## *Expert Review Committee*

### Cardiology Adult

Arthur L. Riba, MD  
Oakwood Hospital and Medical Center

Sharlene Mary Day, MD  
U of Michigan Cardiovascular Center

### Cardiology Pediatric

Arnold L. Fenrich, Jr., MD  
Helen DeVos Children's Hospital

### Emergency Medicine

Robert Swor, DO  
William Beaumont Hospital

### Health Plan

Karen Lewis, MS, MM, CGC\*  
Priority Health

### Primary Care

Henry Barry, MD, MS  
Michigan State University

### Local Public Health

Sugandha Lowhim, MD, MPH  
Ingham County Health Department

### Medical Examiner

Stephen D. Cohle, MD  
Spectrum Health Blodgett Campus

### Medical Genetics

Xia Wang, MD, PhD  
Henry Ford Health System

### Pediatrics

Melissa Hamp, M.D., M.P.H.  
Hurley Medical Center

### Pharmacology

Lynette Moser, PharmD  
Wayne State University

### Sports Medicine

Steven Keteyian, PhD  
Henry Ford Hospital

### Arrhythmia

David J. Bradley, MD  
C. S. Mott Children's Hospital

# SCDY Call to Action Report Available at:

[www.michigan.gov/genomics](http://www.michigan.gov/genomics)



# Discussion Questions

- How might this same process work in your area of expertise? Are there other diseases or risk factors that could use this same approach?
- Who are the audiences that need to hear this information to help move us toward public health action?
- How do we present this information so that it is compelling?