

# PUBLIC HEALTH FRAMEWORK FOR CONGENITAL HEART DEFECTS



**Congenital Heart**  
PUBLIC HEALTH CONSORTIUM

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## CONGENITAL HEART PUBLIC HEALTH CONSORTIUM WEBINAR SERIES

- Public Health Overview of the Congenital Heart Public Health Consortium  
Faculty: Geoffrey Rosenthal, MD, PhD  
February 12, 2014
- Databases for Congenital Heart Defect Public Health Science: Overview and Applications  
Faculty: Tiffany Colarusso, MD, MSE and Kathy Jenkins, MD, MPH  
May 20, 2014
- Lifelong Care for Congenital Heart Defects: The Continuing Journey into and Through Adulthood  
Faculty: Michelle Gurvitz, MD, MS and Susan Fernandes, LPD PA-C  
July 10, 2014
- Public Health Framework for Congenital Heart Defects  
Faculty: Kathy Jenkins, MD, MPH and Margaret Honein, PhD, MPH  
August 12, 2014

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## FACULTY

- **Kathy Jenkins, MD, FAAP, MPH, FACC**  
Senior Vice President, Chief Safety and Quality Officer  
Professor of Pediatrics, Harvard Medical School  
Boston Children's Hospital
- **Margaret Honein, PhD, MPH**  
Chief, Birth Defects Branch  
Division of Birth Defects and Developmental Disabilities  
National Center on Birth Defects and Developmental Disabilities  
Centers for Disease Control and Prevention

The findings and conclusions in this presentation are those of the presenters and do not necessarily represent the official position of the Centers for Disease Control and Prevention

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## LEARNING OBJECTIVES



- By the end of this session, participants will be able to:
  - Identify the core components of the public health approach and how those apply to congenital heart defects
  - Recognize the key components of a public health framework for children and adults living with a congenital heart defect
  - Understand the public health opportunities to reduce the risk and improve long-term outcomes for those with congenital heart defects

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## WHAT IS PUBLIC HEALTH?

"...the science and the art of preventing disease, prolonging life, and promoting physical health and mental health and efficiency through organized community efforts..."

*(Winslow, CEA, Man and Epidemics. Princeton, N.J.: Princeton University Press, 1952.)*

"...the ongoing systematic collection, analysis, interpretation, and dissemination of health data for the purpose of preventing and controlling disease, injury, and other health problems."

*(Thacker, 2000)*

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## PUBLIC HEALTH IN THE UNITED STATES

### What does medicine do?

- Saves lives one at a time



### What does public health do?

- Saves lives millions at a time



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## A PUBLIC HEALTH APPROACH

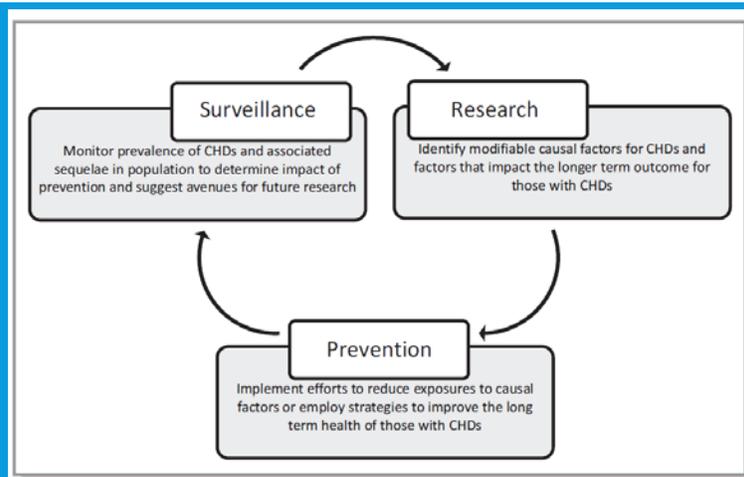
POPULATION-BASED SURVEILLANCE, RESEARCH, AND PREVENTION

- Monitoring/Surveillance
  - Identify magnitude of health problem; track changes; monitor impact of prevention
- Epidemiologic Research
  - Identify modifiable risk factors
- Prevention
  - Develop effective prevention strategies – individual level or community level



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## A PUBLIC HEALTH APPROACH TO CONGENITAL HEART DEFECTS (CHD)



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# PRIORITIZED PUBLIC HEALTH SCIENCE AGENDA FOR CONGENITAL HEART DEFECTS

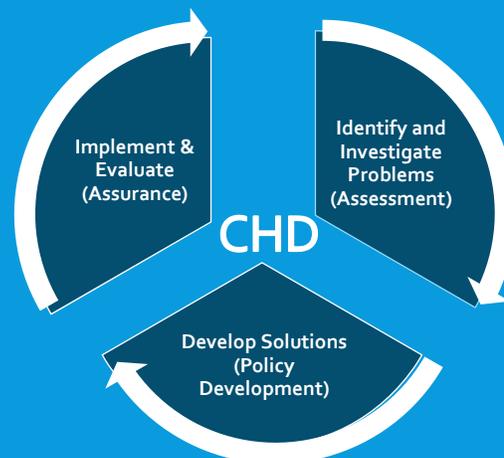


1. Prevalence of congenital heart defects across the lifespan
2. Risk factors for the development of congenital heart defects
3. Long-term outcomes for persons with congenital heart defects
4. Health services delivery for persons with congenital heart defects
5. Public awareness of the burden and impact of congenital heart defects

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## PUBLIC HEALTH FRAMEWORK FOR CHD



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## IDENTIFY AND INVESTIGATE PROBLEMS

ASSESSMENT

### Identify

Public health systems to monitor burden of CHD at all ages in the population

### Investigate

Population-based studies to identify determinants of occurrence of CHD and of adverse outcomes

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## DEVELOP SOLUTIONS

POLICY DEVELOPMENT

### Unite and Align

CHD consortium to inform and educate public policy makers and health professionals

### Reduce Risk

Public health systems and policies to reduce risk of CHD

### Improve Outcomes

Public health systems and policies to improve outcomes in people with CHD

### Equal Access

Public health systems and policies for improved and equitable access to and utilization of care for people with CHD

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## IMPLEMENTATION & EVALUATION

ASSURANCE

### Public Health Programs

Public health programs to reduce risk of CHD

### Public Health Systems

Public health systems link people with CHD to health care and ancillary services

### Healthcare Delivery System

Healthcare delivery system provides high quality care for people with CHD

### Evaluation

Public health data used to monitor and evaluate outcomes, systems and policies for people with CHD

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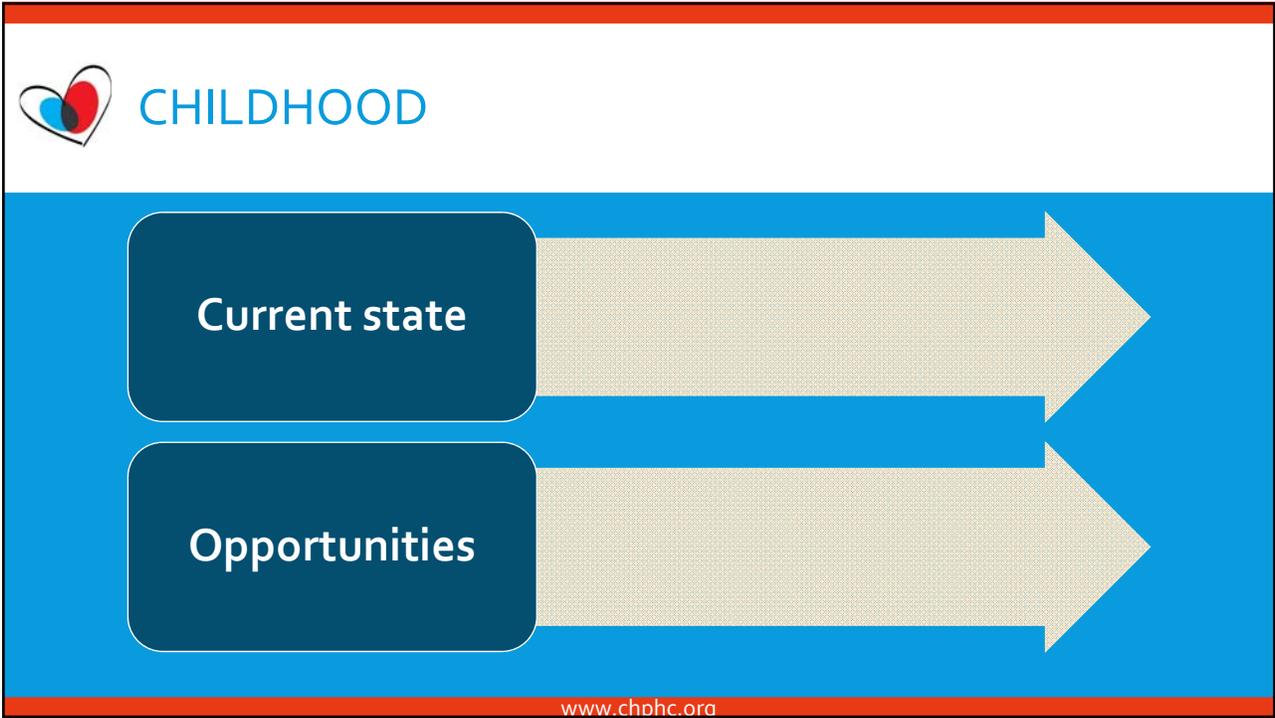


## PRENATAL AND NEWBORN

Current state

Opportunities

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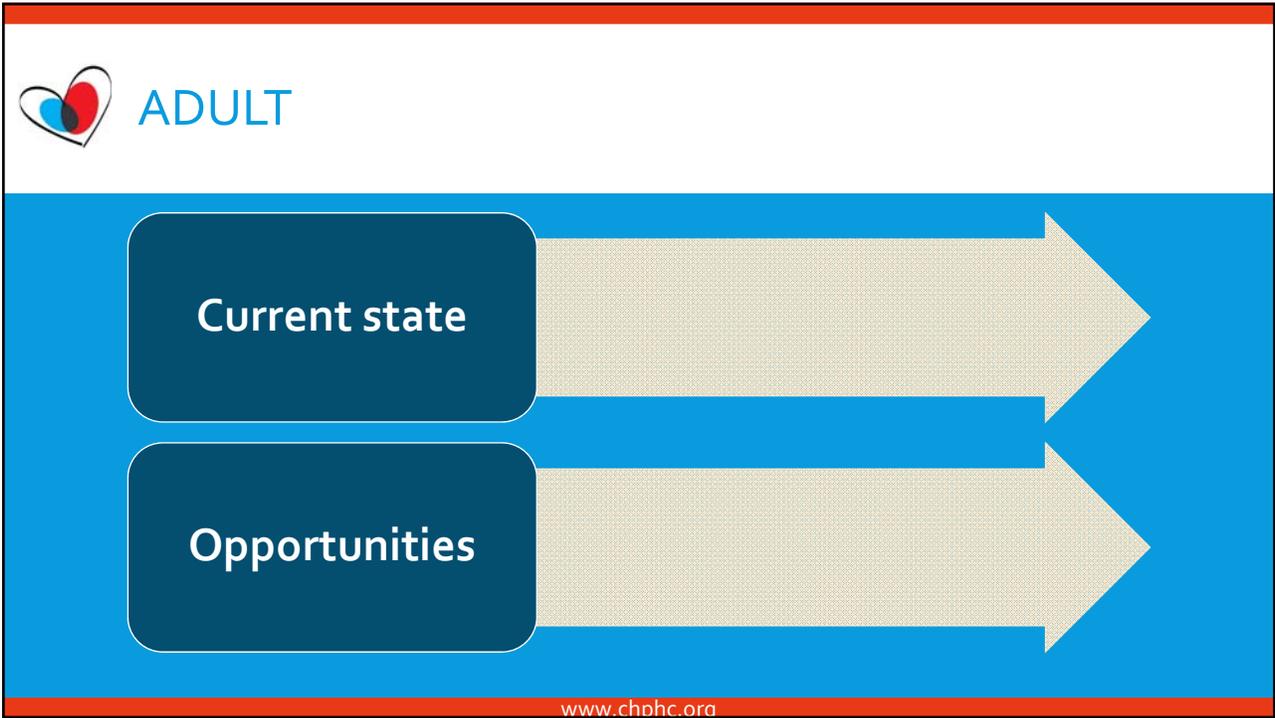
 **CHILDHOOD**

**Current state**

**Opportunities**

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The slide features a white header with a heart icon and the word 'CHILDHOOD'. Below is a blue background with two dark blue rounded rectangles containing the text 'Current state' and 'Opportunities'. Two large, light-colored arrows point to the right from these rectangles. A red footer bar contains the website address.



 **ADULT**

**Current state**

**Opportunities**

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The slide features a white header with a heart icon and the word 'ADULT'. Below is a blue background with two dark blue rounded rectangles containing the text 'Current state' and 'Opportunities'. Two large, light-colored arrows point to the right from these rectangles. A red footer bar contains the website address.



## HOW DOES A PUBLIC HEALTH FRAMEWORK TRANSLATE TO IMPACT?

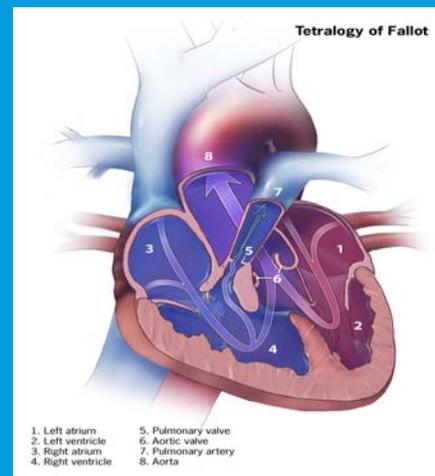
- Public health framework can inform priorities and future directions
- Measureable public health impact includes:
  - Reduced risk
  - Improved detection prenatally and post-natally
  - Improved access to appropriate care
  - Improved health and related outcomes
  - Reduced disparities

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## EXAMPLES: MONITORING CHDS IN THE POPULATION

- What percentage of **tetralogy of Fallot** is identified prenatally, by newborn screening, or after 3 days of life?
- How does the prevalence of severe congenital heart defects among adolescents **vary by region**?
- How many **20-40 year olds** with **hypoplastic left heart** are currently living in the U.S.?

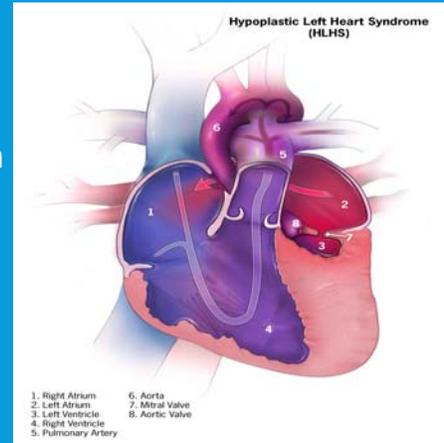


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## EXAMPLES: PUBLIC HEALTH RESEARCH ON CAUSES/RISK FACTORS

- Does exposure to **maternal smoking** in early pregnancy increase the risk of **ventricular septal defects**?
- Can the **increased risk of CHDs** associated with **prepregnancy obesity** be reduced by improving diet quality or increasing physical activity?
- Does exposure to certain **medications** in early pregnancy increase the risk of **hypoplastic left heart syndrome**?



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## EXAMPLES: PUBLIC HEALTH RESEARCH ON IMPROVING OUTCOMES

Does **timing of surgery** impact **cognitive outcome** among children with CHDs?

Is distance to care a **barrier** that affects **outcomes** for adults with CHDs?

How does **pregnancy** impact the health of **women with CHDs**?



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## ADDITIONAL KEY PUBLIC HEALTH ACTIVITIES ON CHDS

- Increasing awareness of the prevalence and severity of CHDs, and their lifelong impact through educational efforts
- Providing technical assistance to states for implementation of newborn screening for critical CHDs to minimize delays in diagnoses that can adversely affect outcome
- Defining and evaluating optimal care for persons with CHDs across the lifespan

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## POTENTIAL USE OF PUBLIC HEALTH FRAMEWORK BY PARTNERS

- Raise awareness of public health significance
- Prioritize activities based on critical knowledge gaps
- Inform stakeholders of key opportunities
- Clearly define the current state and future opportunities by age group

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## QUESTIONS

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## CONGENITAL HEART PUBLIC HEALTH CONSORTIUM

- *The CHPHC was formed in 2009 and represents various organizations across federal, state and local communities who represent the voice of providers, patients, families, clinicians and researchers.*
- **Mission**  
The mission of the CHPHC is to prevent congenital heart defects and improve outcomes for affected children and adults. The Consortium achieves its mission by:
  - Providing leadership and a unified voice for public health priorities
  - Expanding opportunities for surveillance and public health research
  - Informing public policy priorities that benefit public health and affected persons
- **Join Us** [www.chphc.org](http://www.chphc.org)                      **Contact Us** [chphc@aap.org](mailto:chphc@aap.org)

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