CONGENITAL HEART PUBLIC HEALTH CONSORTIUM

Impact and opportunity of a public health approach to congenital heart defects

WHO WE ARE

In 2009, various organizations across federal, state and local communities came together and agreed that they could positively impact the health of those affected by congenital heart defects (CHDs) by utilizing a public health approach to address many of the issues they face. To this end, organizational members representing the voices of providers, patents, families, clinicians and researchers joined to form the Congenital Heart Public Health Consortium (CHPHC).

Since the inception of the CPHHC, there have been many accomplishments that have advanced our mission and are in alignment with our strategic plan. Several educational and awareness resources have been made available to the public, including the CPHHC web site, CHD fact sheets and educational webinars. In addition, the CPHHC has provided the opportunity for open dialogue between member organizations—improving synergy and unifying public health messaging.

MISSION

The mission of the CPHHC 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

PURPOSE

With 2.4 million people currently living with CHDs in the United States, there is a widespread impact on communities and families. Collectively, CHDs are considered to be the most common type of birth defect, affecting approximately 1 in 110, or 40,000, babies each year, and are a leading cause of birth-defect related deaths worldwide. By working together and leveraging the knowledge and expertise of the many CHD stakeholders, the CPHHC is able to make progress toward improving the lives of these children, adults and families and the communities where they live through the following objectives:

- Raise awareness of CHDs and their comorbidities
- Demonstrate the prevalence of CHDs
- Demonstrate the immediate and lifelong health impacts of CHDs
- Synthesize the public health approach for CHDs
- Appraise the health care access and cost challenges related to CHDs
OUR FOCUS

Since its inception, the CPHHC has identified a set of focus areas to define the scope of efforts for its committees and working groups.

ADDITIONAL INFORMATION ABOUT EACH FOCUS AREA IS AVAILABLE ONLINE AT WWW.CHPHC.ORG

HEALTH SYSTEMS FRAMEWORK FOR CHDs

Babies are born every day with CHDs. For the majority of these infants, outcomes have never been better; however, health outcomes are still uncertain for some complex CHDs. Treatment and care have improved dramatically, leading to better survival and lifelong functionality. Yet people of all ages with CHDs still face many medical, social and personal challenges. The public health systems framework developed by the CPHHC identifies opportunities that can help the population of people in the United States with CHDs live longer, healthier and more productive lives. The framework is anticipated to be a useful tool to align efforts among key stakeholders to effectively address gaps and develop strategies to reduce disease and improve outcomes. The framework includes:

1) Identification and investigation including systems and population-based research
2) Development of interventions and policies, including aligning stakeholders, creating public systems and policies to reduce risk, improving outcomes and ensuring equitable access and utilization care
3) Implementation and evaluation, including education and quality care programs connecting individuals, healthcare and ancillary services and monitoring systems.

DATABASES FOR CHD PUBLIC HEALTH SCIENCE

Public health knowledge gaps about CHDs persist, including the prevalence of CHDs across the lifespan, long-term outcomes and the delivery of health services. There are many databases with CHD data, but they are managed separately by hospitals, specialty organizations, partnerships, and public health and other governmental entities. Researchers may be familiar with some databases but not others. "Databases for Congenital Heart Defect Public Health Studies Across the Lifespan" (JAHA, October 2016) is a review article from the CPHHC that provides an understanding of the complex constellation of databases for anyone planning to study public health knowledge gaps.

The article provides a summary of existing data sources from the following categories: 1) administrative health care databases; 2) birth defects surveillance; 3) clinical CHD databases or registries; 4) surveys; and 5) vital records. The article also includes a discussion about combining databases across categories.
LIFELONG CARE FOR PEOPLE LIVING WITH CHDs

The intent of the CPHC’s focus on lifelong care is to ensure that people living with CHDs maintain continuous congenital cardiology care to enhance their quality of life and overall health and wellness. The following strategies have been implemented to communicate the message that children and adults living with CHDs should receive specialized care throughout their lifetime:

- Dispel the myths that CHDs can be cured, and replace them with an understanding of the need for lifelong congenital cardiology evaluations.
- Mitigate the risk for secondary disabilities that people living with CHDs may face by encouraging patients to stay in care and return to care if they have not seen their cardiologist in a long time.
- Support life planning for women with CHDs and provide education regarding the pregnancy and parenting choices they are faced with.

REDUCING RISK FOR CHDs (PREVENTION)

One focus of the Consortium is prevention of CHDs. Research suggests that there may be certain prevention activities that a mother (and father) can do to help increase the chance of having a baby with a healthy heart.

- Take 400 mcg (0.4) mg or more of folic acid before pregnancy starts.
- Maintain a healthy weight, participate in regular physical activity and follow a healthy diet.
- Talk to their doctor if they have a chronic condition, such as diabetes (may be unrecognized), epilepsy, PKU or high blood pressure, or if they are taking medications.
- Avoid secondhand smoke.
- Stay up to date with immunizations, including rubella.
- Treat high fever early.

NEURODEVELOPMENTAL AND PSYCHOSOCIAL QUALITY OF LIFE

Although once nearly fatal, both survival and life expectancy of individuals with heart defects have significantly increased with early diagnosis, improved surgical interventions and better medical management. This focus area takes a public health approach to addresses the long term outcomes, burden to the individual and his/her family and capacity of the health and human services systems to support survivors is needed to improve quality of life.

- Developmental, physical, psychosocial and mental health disabilities are common with CHD survivors.
- Hospital costs for pediatric patients with CHD exceeded $5.6 billion in 2009, 15.1% of the total costs for all U.S. hospitalizations for children and adolescents aged 0 - 20 years.
- Defining and evaluating optimal care for CHD patients across the lifespan may improve outcomes.
ACCOMPLISHMENTS

Early in its formation, the CPHC developed bylaws, other governance, and committee structures. In 2012, the CPHC developed a strategic plan to be used as a tool to improve the Consortium's focus and direction, to ensure the CPHC’s financial and ideological sustainability, and to demonstrate the CPHC’s relevance and value to member organizations.

Key considerations for the ongoing operations of the Consortium are:

- Programmatic relevance across the lifespan of children, youth and adults with CHDs.
- Opportunities to leverage a collaborative approach and provide a unified voice.
- Collaborative partnerships that strengthen the work of individual member organizations aligned with the CPHC mission.
- Infrastructure to achieve measurable outcomes and impact.

The goals and objectives that make up the biannual operating plan take into consideration realistic expectations of the CPHC as an all-volunteer member organization, as well as staff and volunteer capacity and budget.

BUILD AWARENESS OF THE CPHC AND THE ISSUES RELATED TO ITS MISSION AND FOCUS AREAS

Congressional briefing
CHPHC volunteers participated in the planning and implementation of a congressional briefing held on September 19, 2011. The purpose of the briefing was to increase awareness of CHDs as a public health priority across the lifespan and to highlight the 10th anniversary of the creation of the Centers for Disease Control’s National Center on Birth Defects and Developmental Disabilities (NCBDDD).

Webinar series: Congenital heart advances -- from screens to teens and beyond
This three-part webinar series covered advances in both the science and care management of young patients with a CHD and tackles questions about newborn screening, care transition for older youth and the nuances of neurodevelopmental outcomes. The webinars were held in the fall of 2013. Recorded sessions are available online at www.chphc.org.

Webinar series: Overview and focus areas of the CPHC
This four-part webinar series shared information regarding the Consortium’s direction and the role it plays in public health for people living with a CHD. The series included sessions on each of the focus areas of the CPHC: a database, lifelong care and a public health framework. Webinar recordings are available online at www.chphc.org.

Lifelong care social media campaign
This campaign leverages the online communication outlet Twitter using the hashtag #CHDcare4life. The CPHC launched the campaign on October 20, 2014, with a Twitter chat and continues to reinforce the CPHC’s lifelong care messages through ongoing communications activities.
DEVELOP AND DISSEminate EDUCATIONAL RESOURCES

**CHPHC.org website**
In addition to information about the CPHC, its history and current membership, the CPHC website offers online access to all of the informational resources and handouts listed below as well as a series of video vignettes to address frequently asked questions by parents and caregivers. Informational resources for the public, patients/parents, professionals and public officials available through the website include:

- Primary prevention resources regarding modifiable risk factors, including diabetes, folic acid and smoking (and secondhand smoke).
- Fact sheets with answers to frequently asked questions about CHDs; the most reliable source of facts regarding CHD
- State-by-state surveillance fact sheets.
- Long-term health outcomes for people with heart defects.
- Infographic – a public health framework for CHDs.

**CHPHC organizational overview and presentation**
This summary document and accompanying presentation have been given at more than 18 stakeholder meetings, including the national meetings of the American Academy of Pediatrics, American College of Cardiology, American Heart Association, Mended Little Hearts and the Pediatric Congenital Heart Association.

**Short and long fact sheets**
Fact sheets were developed to address questions related to CHDs, including prevalence, incidence (including birth prevalence), mortality, morbidity (including rates of disability), risk factors, causes, recurrence of risk factors and costs of care. A short-version fact sheet answers five basic frequently asked questions about CHDs in an easy-to-share format. A long- version fact sheet addresses a wider range of frequently asked questions with more detailed information than what is included in the shorter fact sheet, and serves as a source document for sound bites and statistics regarding CHDs.

CONTRIBUTE TO THE LITERATURE BASE THROUGH SYNDICATION OF ARTICLES AND PUBLICATIONS

“Consortium looks to change the lives of CHD patients,” Cardiology, May-June 2012

“Why lifelong care for people living with congenital heart disease is so important,” AAP News, March 2014

“Databases for Congenital Heart Defect Public Health Studies Across the Lifespan (JAHA, October 2016)
OUR MEMBERSHIP

In addition to the multiple direct accomplishments of the CPHC, perhaps the outcome with the most impact is the synergy that continues to occur between the members and member organizations. Partnerships have been established to carry common and consistent messaging to federally elected officials and federal agencies. Further, shared messaging around national health observances such as Birth Defects Prevention Month (January) and CHD Awareness Week (February 7-14) have contributed to the overall impact of the core messages.

STEERING COMMITTEE

- Adult Congenital Heart Association
- Alliance for Adult Research in Congenital Cardiology
- American Academy of Pediatrics
- American College of Cardiology
- American Heart Association
- Children’s Heart Foundation
- Congenital Heart Surgeons’ Society
- Mended Little Hearts
- March of Dimes
- National Birth Defects Prevention Network
- Pediatric Congenital Heart Association
- Society of Thoracic Surgeons
- Federal Advisors
  - Centers for Disease Control and Prevention, National Center on Birth Defects and Developmental Disabilities
  - National Institutes of Health, National Heart Lung and Blood Institute
  - Alliance for Healthcare Research and Quality

MEMBER ORGANIZATIONS

- 335 Heart Foundation
- Adult Congenital Heart Association
- Alliance for Adult Research in Congenital Cardiology
- American Academy of Pediatrics
- American College of Cardiology
- American Heart Association
- Children’s Heart Foundation
- Congenital Heart Surgeons’ Society
- International Clearinghouse for Birth Defects Surveillance and Research
- March of Dimes
- Mended Hearts
- Mended Little Hearts
- National Birth Defects Prevention Network
- Newborn Coalition
- NewSTEPS
- Pediatric Congenital Heart Association
- Pediatric Stroke Network
- Society of Thoracic Surgeons
INDIVIDUAL MEMBERS

The CPHC is comprised of many different clinicians, researchers, professionals and people who are not representatives of any of the member organizations. Their enthusiasm and passion for the mission have been a driving force in the impact and accomplishments of the CPHC.

Individuals who share a passion for our mission are welcome to join us by completing the registration form on the www.CHPHC.org website or by contacting staff via email at chphc@aap.org.

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