

Health outcomes for people living with congenital heart disease



Congenital Heart
PUBLIC HEALTH CONSORTIUM

Congenital heart disease lasts a lifetime

Congenital heart disease (CHD) is the most common birth defect occurring in nearly 1 in 100 births. As a result of advancements in early treatment, babies are surviving and most children with CHD are expected to reach adulthood. This has resulted in a large and increasing population of children, adolescents and adults living with congenital heart disease.

While survival is likely, this ever-growing population of CHD survivors will likely experience additional issues that arise based on complications of their heart condition or related treatment.

Disabilities are common with CHD survivors

- Developmental disabilities may impact the ability of CHD survivors to succeed in school and ultimately in the workplace.
- Physical disabilities can restrict the ability of CHD survivors to work, play, and exercise to maintain optimal physical health.
- Psychosocial and mental health issues in CHD survivors may result in behaviors that impair social interaction and interpersonal relationships.

Living with a CHD is costly

Lifelong utilization of specialized health care and social services places a burden on both public and private insurance.

- One in three children with CHD is on Medicaid.
- 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.
- Approximately 50% of children and youth drop out of cardiology care and require expensive emergency treatment when preventable healthcare procedures are needed. Trends indicate a reduction in scheduled admissions but an increase in emergency department admissions beginning in adolescence.
- Better understanding of health care utilization trends can be achieved through population-based longitudinal outcomes research.

Brighter futures are possible through research and quality improvements

Defining and evaluating optimal care for persons with CHD across the lifespan and communicating and ensuring patient and family understanding will improve outcomes. Public health policy will support research to better understand important issues such as:

- Impact of timing of treatment on long-term outcomes
- Impact of distance to care as a potential barrier that affects outcomes for children and adults with CHD
- Impact of pregnancy on the health of women with CHD



Sarah was born with only half a heart. She dreams of becoming a dancer one day. However, she is struggling with her school work and keeping up with her friends on the playground. Her challenges won't go away when she's a grown up. Sarah needs more research and improved quality care to be sure her outcomes match her dreams.



Gina was born with a combination of serious heart defects and has undergone several life-saving surgeries. Hiding her defect in her teen years, Gina learned to embrace her differences as an adult through traveling, regular yoga practice and marriage. Fortunately, as a child, she was told that her CHD would require ongoing care from a specialist resulting in quality medical care and the ability to live life to the fullest.