

# CONGENITAL HEART DEFECTS

## Rhode Island Information

### CONGENITAL HEART DEFECTS ARE COMMON

- CHDs are the most common birth defects, occurring in nearly 1 in 100 births.
- ***This means that in Rhode Island, there are on average 108 babies born with a heart defect each year.***

### CONGENITAL HEART DEFECTS ARE CRITICAL

- CHDs are the most common cause of birth defect related infant death.
- ***In Rhode Island, an average of 7 deaths each year are attributed to heart defects.***

### CONGENITAL HEART DEFECTS ARE COSTLY

- Congenital heart defects result in life-long specialized health care utilization.
- In 2009, estimates indicate that hospital costs for stays related to CHD in children were nearly \$1.5 billion. In the same year, with significantly fewer hospital stays, hospital costs for adults treated primarily for CHD were at least \$280 million.
- Compared to the general population, adults with CHD have 3 – 4 times higher rates of Emergency Room visits, hospitalizations, and Intensive Care Unit stays.

**Congenital heart defects (CHDs)** are problems present at birth that affect the structure and function of the heart. They can affect how blood flows through the heart and out to the rest of the body. Common examples include holes in different areas of the heart and narrow or leaky valves.

### YET, WHAT WE KNOW REMAINS LIMITED

- Currently, there is no surveillance information for any age beyond infancy.
- Information collected by each state varies significantly.
- Despite large pools of existing data, the ability to compare data across different sources is limited.
- Cost data remains scarce.

### SCREENING FOR CCHD SAVED MY LIFE

In my first week of life I was an inpatient at three different hospitals, flew in a helicopter and had open heart surgery. My CHD could have been a death sentence...



but thanks to developments in care for children with CHDs I can grow up to be President ...or at least play one on TV. ~Nick Basken

### CONGENITAL HEART DEFECTS SURVEILLANCE IN RHODE ISLAND

Activity	National Best Practice	Rhode Island
<b>Congenital Heart Defect Tracking*</b>		
Infant	✓	✓
Young children	✓	No
Adolescent and Adult	✓	No
<b>Newborn Screening for CCHD</b>		
State Action	✓	No

\*age ranges vary by state as do state specific surveillance practices