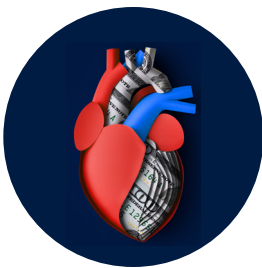


## WHAT IS COMPLEX CONGENITAL HEART DISEASE (CCHD)?

Congenital heart defects (CHD) are problems with the structure or function of the heart that are present at birth. CHDs are the most common birth defect, affecting approximately one in 100 live births, and range greatly in severity and complexity.

Complex congenital heart disease is a set of rare CHDs that affects ~2.5 in 1,000 live births, causes life-threatening complications, and requires lifelong medical care. Survival depends on multiple open-heart surgeries during childhood, long-term hospital stays, life-long therapeutic, physical, and/or mental health treatments, and at times, mechanical support and organ transplants. Approximately a third of people with cCHDs die in childhood.



## What is the economic burden of cCHD?

- The average annual cost of cCHD is nearly \$50K per patient.
- The average lifetime financial burden for cCHD is \$2.1M per patient.
- Within the first five years of life, the average cost is \$650,000 per child, representing nearly one third of total lifetime costs.
- On average, patients lose 31 years of life, which equates to \$4.5M in mortality costs.
- The annual economic burden, including mortality, for all cCHDs in the US is \$74B.

## What is the financial impact on patients and families?

Families pay a great deal of indirect costs (out-of-pocket costs not covered by insurance). Indirect costs include a broad range of expenses, including medical expenses (e.g., copays, uncovered prescriptions, medical equipment) and non-medical expenses (e.g, lost productivity from work and school).

- Of the average annual \$50K per patient cost for cCHD, patients and families pay nearly half (45%) out-of-pocket.
- Within the first 5 years of life, families are responsible for approximately \$190,000 in out-of-pocket costs.
- Approximately 10% of parents change jobs, reduce work hours, or leave the workforce to care for their cCHD child.
- Among those who remain in the workforce, parents of cCHD children miss nearly a full month (19 work days) annually to care for their cCHD child.
- Adult patients also report missing approximately 19 work days per year to attend to their medical care.
- Children aged 6-18 with cCHD miss an average of 20.5 school days per year, which meets the definition of chronic absenteeism, defined as 18 or more missed school days in a year for any reason.

## How does the cost of cCHD compare to other diseases?

On a per patient basis, cCHDs are disproportionately expensive when compared to more common cardiac diseases.

- Annually, the direct and indirect costs of cCHDs are 4X higher than coronary heart disease and 8X higher than congestive heart failure.
- Lifetime costs for cCHD are 44X more expensive than congestive heart failure, with direct costs 32X higher and indirect costs 74X higher.

### Source:

Pickles, D. M. & Keller, K. (2025). The economic burden of complex CHD in the United States. *Cardiology in the Young*, 35(9), 1751–1758. doi:10.1017/S1047951125109256

