

Congenital heart disease (CHD) is the most common birth defect, but it is historically underfunded in the U.S.

Congress can help ensure CHD patients survive and receive the care, research, and innovation they need for life.

What is congenital heart disease?

CHD is a condition caused by structural differences in the heart present at birth. These differences can affect how blood flows through the heart and body. Some are mild and require only monitoring, while others are complex and require surgeries, procedures, medications, and lifelong specialized care. The most complex forms of CHD significantly impact both lifespan and quality of life.

1 in 100
BABIES

are born with CHD, making it the **most common** birth defect.

2.5
MILLION AMERICANS

are currently living with CHD, including **1.5 million adults**.

\$10
BILLION

the annual cost of **CHD-related hospital care** in the U.S.

\$2.2
MILLION

the average **lifetime cost** for patients and families with complex CHD.

What CHD Families Face

Navigating CHD is a lifelong journey of love, resilience, and coordinating complex care. At every step, families demonstrate strength as they advocate for their child, manage chronic care, adapt to ongoing challenges, and continue forward with hope for the future.



MULTIPLE SURGERIES AND PROCEDURES

Patients and families face repeated surgeries, procedures, and hospital stays to manage a complex heart condition.



TRAVEL TO MAJOR MEDICAL CENTERS

Many face frequent, far away travel to receive specialized care at major medical centers.



MISSED WORK AND SCHOOL

Care appointments and hospital stays mean missed work for adults and school for children.



HIGH OUT-OF-POCKET AND CAREGIVING COSTS

The financial burden is significant — medical bills, travel, lodging, meals, and lost income add up over time.



LEARNING, DEVELOPMENT, AND EMOTIONAL HEALTH

Many CHD families navigate developmental delays, school challenges, anxiety, depression, and the emotional toll of lifelong care.



CHALLENGES TRANSITIONING FROM PEDIATRIC TO ADULT CARE

Moving from pediatric to adult care systems can be confusing and emotionally overwhelming.



LIFETIME OF SPECIALIST CARE

Ongoing monitoring and care from a team of specialists is needed for life to stay as healthy as possible.

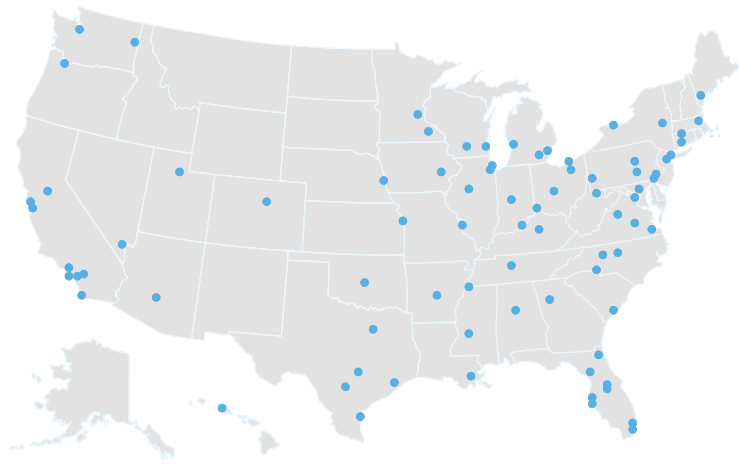


IMPACT LIFESPAN AND QUALITY OF LIFE

The most complex forms of CHD can reduce life expectancy by decades and cause lifelong complications, repeated interventions, and serious comorbidities.

CHD Families Depend on Specialized Centers, Often Far from Home

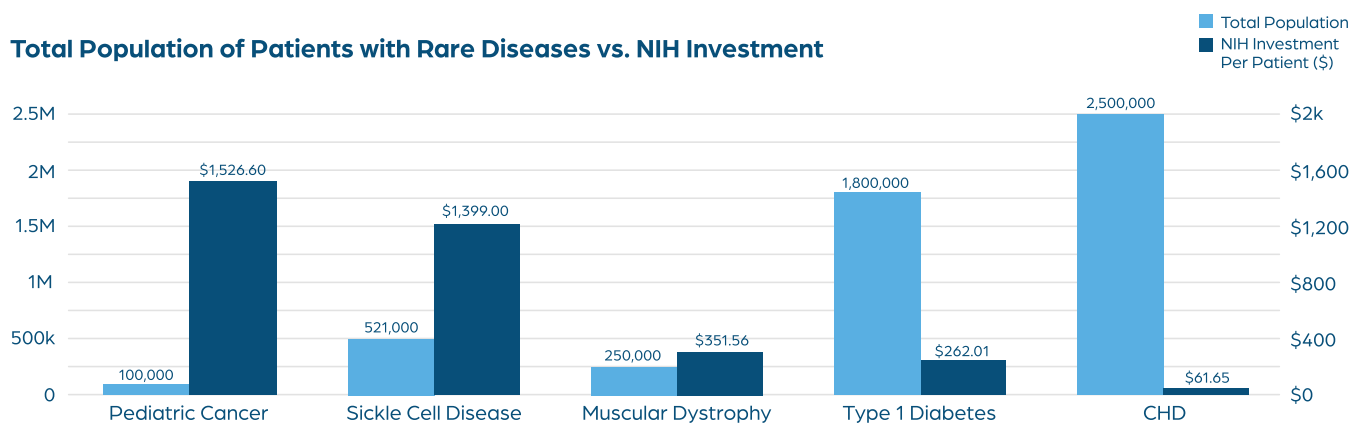
With just over 100 CHD centers nationwide, access to specialized care is uneven. This forces many families to travel long distances for surgeries, specialists, and lifelong follow-up care.



CHD is Common, Lifelong, and Underfunded Compared with Other Conditions

Although CHD is the most common birth defect and requires lifelong and costly care, just 3% of NHLBI's nearly \$4 billion budget supports CHD research.

Total Population of Patients with Rare Diseases vs. NIH Investment



CHD's Biggest Challenges



Chronic underinvestment in research: Despite its lifelong impact, CHD has been persistently underfunded within federal heart research, including at the National Heart, Lung, and Blood Institute (NHLBI).



Access to specialized care: CHD care is highly specialized, and many patients must travel out of state to reach a CHD surgical or specialty center.



Barriers to innovation and reimbursement: Because CHD affects a smaller, more medically diverse population, innovators face challenges in developing new treatments and securing the coverage and reimbursement needed to bring them to patients.



Adult CHD workforce shortage: As more people with CHD live into adulthood, demand for adult congenital heart disease specialists is growing faster than the workforce.