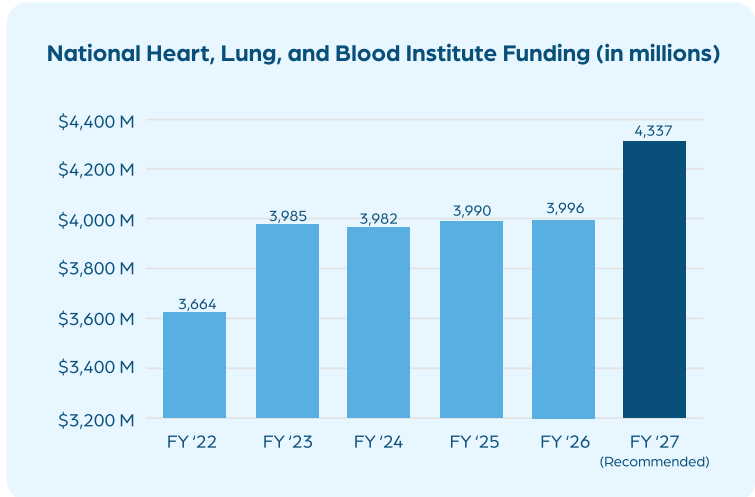


ASK ONE

## Support \$4.3 Billion in Funding for the National Heart, Lung, and Blood Institute (NHLBI)

**Congress should provide at least \$4.337 billion for the National Heart, Lung, and Blood Institute (NHLBI) in the FY 2027 Labor, Health and Human Services, Education, and Related Agencies appropriations bill.**

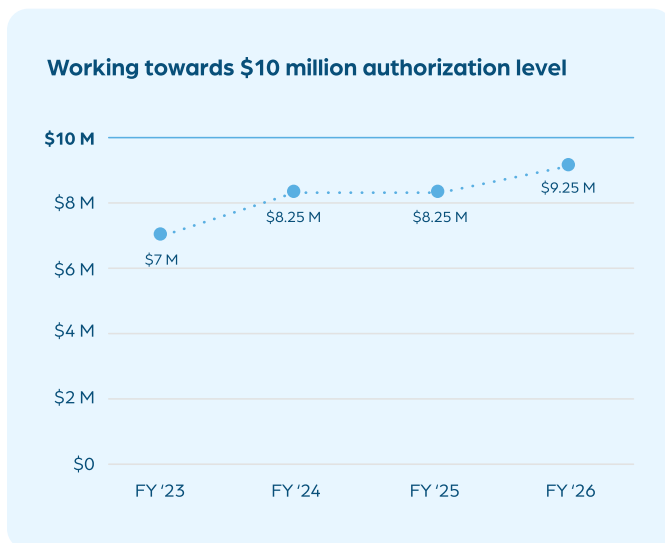
For the congenital heart disease (CHD) community, strong NHLBI funding is critical to advancing research across the lifespan, improving long-term outcomes, addressing gaps in care, and supporting scientific discovery that can improve quality of life for children and adults living with CHD.



\*\*This funding recommendation reflects the projected Biomedical Research and Development Price Index (BRDPI) of 2.7 percent, along with 5 percent real growth

ASK TWO

## Fund the Centers for Disease Control and Prevention’s (CDC) CHD Surveillance Work at \$10 Million



The CDC’s CHD program within the National Center on Birth Defects and Developmental Disabilities supports population-based surveillance to better understand the health and long-term needs of people living with congenital heart disease.

The program was authorized at \$10 million by the Congenital Heart Futures Reauthorization Act of 2024, and in FY 2026 is funded at \$9.25 million. **This funding helps track long-term outcomes for people with CHD by collecting data on survival, comorbidities, and healthcare among children, adolescents, and adults living with CHD.**

## Ensure HHS Delivers the Required CHD Report on ACHD Workforce to Congress

The Congenital Heart Futures Reauthorization Act of 2024, signed into law in November 2024, requires HHS to submit a report to Congress within two years assessing federal CHD awareness efforts, provider education and training, and current adult congenital heart disease (ACHD) workforce capacity. As of May 2026, HHS has not presented this report.

**There are only about 500 adult CHD specialists available to care for a growing population of more than 1.5 million adults living with CHD in the United States.**

The report will help Congress better understand whether the current workforce is prepared to meet the lifelong care needs of the CHD community and identify policy opportunities to expand access to specialized ACHD care. Congress should request an update on the status of this report.

## Include CHD in the Department of Defense's Peer-Reviewed Medical Research Program (Senate Only)

Congress should continue including CHD as an eligible topic area under the Department of Defense's Peer-Reviewed Medical Research Program (PRMRP) under the Congressionally-Directed Medical Research Program (CDMRP).

CHD has been included in the designated topic areas in most years since FY 2014, creating an important pathway for federally supported research into a lifelong condition that affects thousands of military families and TRICARE beneficiaries.

## Join the Congressional Congenital Heart Caucus

Help elevate congenital heart disease as a national policy priority. By joining the bipartisan Congressional Congenital Heart Caucus, members can raise awareness, support federal solutions, and ensure policy reflects the lifelong needs of the CHD community.

### About Every 100th Heart

Congenital heart disease (CHD) affects 1 in 100 babies and 1.5 million adults in the United States. Despite its prevalence and lifelong impact, CHD remains underfunded and underprioritized in federal health policy. Every 100th Heart (EHH) is a national coalition uniting the CHD community to elevate CHD as a federal policy priority.

Founded in 2026 by leading national organizations and with more than 30 coalition members, EHH is working to promote access to coverage and care for CHD patients, drive federal investment in CHD research and innovation, accelerate approval for CHD-specific treatments and devices, and ensure equitable access to heart transplants.

### Our Founding Partners

