Adult Congenital Heart Association:
2024 Congressional Advocacy Priorities

About the Adult Congenital Heart Association (ACHA)

The Adult Congenital Heart Association (ACHA) is committed to empowering individuals and families affected by congenital heart disease (CHD) by providing access to resources and specialized care for adult patients with CHD. Founded in 1998, ACHA serves as a vital support network and advocate for the CHD community. ACHA aims to improve the quality of life for those affected by CHD through programs, advocacy, and supporting research.

Congenital Heart Futures Reauthorization Act of 2024

The Congenital Heart Futures Reauthorization Act of 2024 (CHFRA) (H.R. 7189/S. 3757) is a critical piece of legislation to advance CHD research, surveillance, and awareness programs.

Sponsored in the House by Representatives Gus Bilirakis (R-FL-12) and Adam Schiff (D-CA-30), and in the Senate by Senators Dick Durbin (D-IL) and Todd Young (R-IN), this bipartisan legislation will ensure continued authorization for congenital heart disease research and surveillance programs at the Centers for Disease Control and Prevention (CDC) at up to $10 million annually through FY 2029.

Workforce Challenges Impacting ACHD Care

- **There are nearly 2 million adults living with congenital heart disease in the US,** with more adults than children with CHD. The population of ACHD patients is estimated to be growing by 5% annually.
- **Adults with CHD need specialized lifelong care** due to the risk of long-term health problems like developmental delays, difficulty exercising, heart rhythm problems, heart failure, sudden cardiac arrest, stroke, and early cardiovascular death.
- While there are an estimated 3,000 pediatric cardiologists to treat children with CHD, there are just **over 500 ACHD board-certified physicians.**
- **Unfortunately, less than 10%** of ACHD patients receive specialized care.

The Senate version of the legislation includes convening an interagency group of experts on adult CHD (ACHD) patients to identify research gaps and opportunities to address the workforce shortages impacting the ACHD care provider community.

The Adult Congenital Heart Association supports this language being passed into law.

To join as a cosponsor, please reach out to **Chris Jones (Chris.Jones@mail.house.gov)** or **Max Kanner (Max_Kanner@durbin.senate.gov).**

Peer-Reviewed Medical Research Program (PRMRP) Inclusion

The Peer Reviewed Medical Research Program (PRMRP), under the Department of Defense's (DoD) Congressionally Directed Medical Research Program (CDMRP), supports novel approaches to biomedical research in response to the needs of military personnel, their families, and the American public.

Congenital Heart Disease is a current PRMRP topic area for FY24 and was previously included in fiscal years 2014 - 2022. The ACHA urges the Senators to request the inclusion of congenital heart disease as a designated topic under the Peer Reviewed Medical Research Program (PRMRP) at the Department of Defense (DoD) for fiscal year 2025.

National Heart, Lung, and Blood Institute (NHLBI) Funding

As a member of the National Heart, Lung, and Blood Institute (NHLBI) Constituency Group, ACHA supports robust funding for the institute to support research and programs addressing cardiovascular, respiratory, blood, and sleep-related issues.

For fiscal year 2025, ACHA supports a funding level of at least $4.281 billion for NHLBI. This 7.5 percent, or $299 million increase in funding, ensures that our federal research funding keeps pace with recent inflation to ensure continued innovations in health care.

For more information on the Adult Congenital Heart Association or its advocacy priorities, please contact **Janine Guglielmino (jguglielmino@achaheart.org)**, ACHA's Director of Patient Resources & Advocacy.

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