

FOR IMMEDIATE RELEASE

Every 100th Heart Forms to Elevate Congenital Heart Disease on the Federal Policy Agenda

Washington, DC — Feb. 3, 2026 — Today, leaders across the congenital heart disease (CHD) community announced the launch of Every 100th Heart (EHH), a national coalition dedicated to uniting patients, families, clinicians, researchers and advocates to elevate CHD as a federal health policy priority.

Congenital heart disease is the most common birth defect in the United States, affecting nearly one in 100 babies and millions of children and adults nationwide. Yet for far too long, the CHD community has felt it is underrepresented and underfunded in federal policymaking. CHD drives more than \$6 billion in annual hospital costs, and pediatric heart conditions account for an estimated 15 percent of all pediatric hospital charges nationally — despite CHD patients representing just one percent of the population.

Every 100th Heart intends to take its message to policymakers and change that trajectory by advancing a coordinated national policy agenda, raising awareness among policymakers and the public and proposing policy solutions to improve survival, outcomes and quality of life for people living with CHD.

The coalition will focus on four core priorities:

- Ensuring access and coverage so CHD patients can receive the specialized, lifelong care and treatments they need;
- Strengthening federal investment in research and innovation to accelerate breakthroughs in prevention, treatment and cure;
- Expanding access to CHD-specific therapies and devices to improve outcomes across the lifespan; and
- Advancing equity in the heart transplant system to ensure CHD patients have fair access to life-saving transplants.

Every 100th Heart's founding organizations include Additional Ventures, the Adult Congenital Heart Association, the American Heart Association, the Children's Heart Foundation, Conquering CHD, and the Mussallem CHD Alliance. Collectively, these organizations bring decades of experience advancing care, research, and advocacy for the congenital heart disease community, including advocating for the passage of the Congenital Heart Futures Reauthorization Act in 2024. Building on that foundation, Every 100th Heart creates a shared platform for collaboration — one designed to bring more voices into a united strategy. In addition to providing initial funding to support the

coalition's launch and operations, leaders from these organizations will serve on Every 100th Heart's leadership governance, helping guide strategy, policy priorities and clinical engagement for the coalition.

In its first year, Every 100th Heart will focus on expanding to include additional patient and family groups, medical societies and research organizations who can share in the mission of advancing congenital heart disease as a national policy priority. The coalition also plans to launch a CHD Champions Network to equip and empower patients, families, clinicians and other advocates with the tools and training to use their voices effectively to drive practical federal policy change.

“Congenital heart disease affects one in every 100 babies born, yet for families facing CHD — including its most complex forms, such as single ventricle heart disease — the consequences of limited federal investment and fragmented policy are especially clear,” said **Kirstie Keller, Ph.D., CEO, Additional Ventures**. “Making CHD a national priority is essential to accelerating research, advancing innovation and building systems of care that support patients across their entire lives. Every 100th Heart brings the CHD community together around a shared agenda and a unified voice, empowering the collective to drive the sustained commitment and investment needed to transform CHD treatment and care.”

“For nearly two decades, the Adult Congenital Heart Association has been proud to be a leader in advancing critical legislation for federal funding of research for people born with heart defects,” said **Mark Roeder, President and CEO of ACHA**. “Through the Every 100th Heart coalition, we look forward to expanding our advocacy into other policy issues affecting the congenital heart disease community, such as addressing insurance barriers and advancing access to CHD treatments and devices.”

“The launch of Every 100th Heart marks a pivotal step in elevating our efforts to bring national attention to congenital heart disease (CHD),” said **Emily Holubowich, National SVP, Federal Advocacy, American Heart Association**. “For too many families, CHD is a lifelong journey marked by financial uncertainty, gaps in coverage and care and need for additional federal research investment for lifesaving and life-changing discoveries. This coalition unites the CHD community to change that reality. By galvanizing patients, families, clinicians, researchers and advocates, we can champion public policies and progress needed to ensure every person born with CHD has adequate coverage and access to the high-quality care and innovative treatments they need to live longer, healthier lives. The American Heart Association is proud to stand with this dynamic group of organizations to chart a future where CHD is not overlooked, but prioritized in every aspect of federal policymaking.”

“At Conquering CHD, everything we do is rooted in the lives of children and families living with congenital heart disease every day,” affirmed **Sarah Boes, Board Chair of Conquering CHD**. “Through Every 100th Heart, we are working to help drive the medical advancements and national attention needed to change what the future can look like for them.”

“Transforming congenital heart defect care requires a bold commitment to fostering innovation across research, clinical care and policy, and supporting change in our healthcare system is essential to realizing this vision,” said **Orin Herskowitz, President of the Mussallem CHD Alliance**. “We plan to work with the Every 100th Heart coalition to demonstrate that CHD is an actionable area for federal and state policymakers to align incentives and resources, ensuring that congenital heart patients receive the highest quality care and access to the innovative and cost-saving technologies they deserve. We believe the Every 100th Heart coalition will play a pivotal role in bringing together CHD patients and advocates to translate lived experience into action and drive meaningful policy change.”

Every 100th Heart will host an in-person kickoff event on March 28 at the American College of Cardiology’s Annual Conference in New Orleans, Louisiana. The coalition will also convene patients and families, clinicians, policymakers, innovators and researchers for a National CHD Advocacy Summit in Washington, D.C., on May 19-20 for training, networking and policymaker education and engagement.

For more information, visit www.every100thheart.org or follow @Every100thHeart on Instagram and LinkedIn.

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