

Placing Children at the Heart of Research

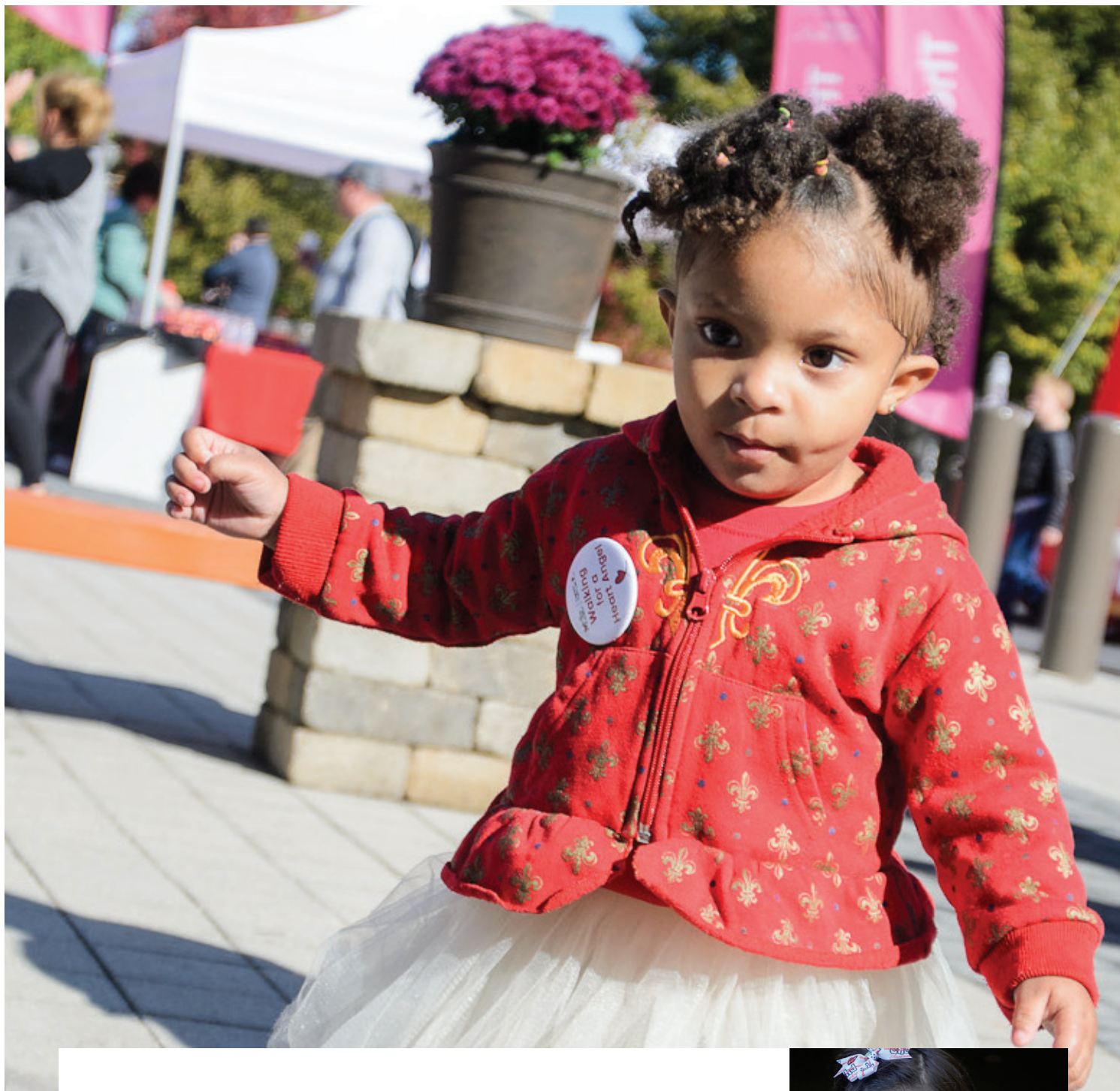


2019 Year-End Update

www.ChildrensHeartFoundation.org

847-634-6474





“ Our mission is to fund the most promising research to advance the diagnosis, treatment, and prevention of congenital heart defects – America’s most common birth defect.



Creating Positive Change

As 2019 began, The Children's Heart Foundation welcomed Barbara Newhouse as its new Chief Executive Officer. Our new CEO has had an impressive career that spans nearly 40 years and encompasses various leadership roles at some of the most recognizable not-for-profit organizations in the country, including ALS, the Arthritis Foundation, the Autism Society, American Cancer Society, and the Alzheimer's Association. The Children's Heart Foundation's new leader has sparked positive change as she leads a team driven by a single mission.



Understanding and Treating Congenital Heart Defects

The Children's Heart Foundation exists for one reason: to fund the most promising research to advance the diagnosis, treatment, and prevention of congenital heart defects — or CHDs.

For 23 years we have been the nation's leading organization solely dedicated to funding CHD research. Our vision? A world in which everyone born with a congenital heart defect can live a long, healthy life.

Research funded by The Children's Heart Foundation is saving lives and has already improved survival rates, longevity, and quality of life for CHD patients in dramatic and life-changing ways. In the past two decades, death rates from congenital heart defects have dropped by 37.5 percent. As a result, the Foundation is now supporting research on the developmental, transitional, and long-term care needs affecting the millions of Americans with CHDs who are living longer lives than ever before.



119

Research
Projects Funded

\$13M

Funded Research &
Scientific Collaborations

23

Years of Funding

Funding CHD Research and Scientific Collaborations

Thanks to our generous supporters, The Children's Heart Foundation has funded more than **\$13 million** of CHD research and scientific collaborations to date, and over **\$1.4 million** this year alone.

The Children's Heart Foundation funded eleven new research endeavors in 2019 through our independent funding process and collaboratively with the American Heart Association through the Congenital Heart Defect Research Awards.

Newly funded research projects will explore several areas, including:

- Converting an open surgical approach to a minimally invasive procedure by exploring a novel tool and technique to place pacemakers and implantable defibrillators in infants and children who are too small to have leads placed in their veins.
- Examining how important brain networks are altered in adults with CHD to figure out better methods to improve long-term outcomes for current CHD patients and future survivors.
- Creating a heart valve that grows with a child, eliminating the need for multiple heart surgeries.
- Improving congenital cardiac surgical outcomes by reducing patient exposure to potentially harmful medical plastics within hospital settings.

These research efforts will help experts learn even more about the long-term care needs of individuals living with CHDs, as well as how to continue to improve their overall quality of life.

Partnering to Promote Improvements in Congenital Heart Care

In August, The Children's Heart Foundation and Cardiac Networks United announced a new partnership that will advance the diagnosis, treatment, and prevention of congenital heart defects through data collection initiatives. This year alone we have invested \$300,000 in this collaboration, which will merge data, expertise, and resources from several congenital heart networks — including nearly two-thirds of U.S. congenital heart programs, or about 85 hospitals, nationwide.

“ The Children's Heart Foundation has led the way in funding research that enables patients with congenital heart disease to live longer, healthier lives, and we couldn't think of a better partner in this exciting work.

– Sara Pasquali, M.D., *C.S. Mott Children's Hospital*



Over the next five years, The Children's Heart Foundation will give \$1.5 million to support large-scale research and quality improvement initiatives led by Cardiac Networks United, through the University of Michigan Congenital Heart Center at C.S. Mott Children's Hospital and Cincinnati Children's Hospital, along with their collaborating networks: Pediatric Cardiac Critical Care Consortium (PC⁴), Pediatric Acute Care Cardiology Collaborative (PAC³), Cardiac Neurodevelopmental Outcome Collaborative (CNOC), Advanced Cardiac Therapies Improving Outcomes Network (ACTION), and the National Pediatric Cardiology Quality Improvement Collaborative (NPC-QIC).

Research initiatives through this collaboration have already shown promising results, including hospitals reducing postoperative deaths by 24 percent and improving care for children with critical heart conditions, and exploring ways to remove chest tubes earlier in babies and children who are recovering from heart procedures. This is not only exciting for the researchers and practitioners, but also directly affects individuals living with CHDs and their families.

Working together, The Children's Heart Foundation and Cardiac Networks United strive to make a lasting impact on the lives of patients and families impacted by CHDs.

Pushing for Increased Federal Funding of CHD Research

One in every 110 babies is born with a congenital heart defect, and there are more than 2.5 million children, teens, and adults living with CHDs. In fact, congenital heart defects are America's most common and deadly birth defect, yet government-funded CHD research is grossly underfunded.

To advance the treatment and care of CHD patients across their lifespans, increased federal government funding is imperative. The Children's Heart Foundation will be establishing an Advocacy Forum in Washington, D.C., to be a voice for those living with CHDs today and tomorrow.

Without additional support from the federal government and private foundations like The Children's Heart Foundation, research remains unfunded and hope for CHD patients fades.

Moving Forward to Fulfill Our Mission

This year-end update highlights only a small portion of what The Children's Heart Foundation has accomplished in 2019 with your support. **And yet our work is far from over!** As we continue to fund the most promising CHD research, we rely on the generosity of supporters who share our passion for saving and improving the lives of children born with congenital heart defects.

Thanks to research funded by The Children's Heart Foundation, CHD patients are living longer and fuller lives than ever before, but we dream of the day when CHDs are eliminated entirely. Working together, we will fulfill our critical mission and continue *Placing Children at the Heart of Research*. **Can we count on your help?**