Helping families who are living with Congenital Heart Defects

We fight heart disease in children through research, education and advocacy for public health policies. Here are our major approaches to understanding, treating and preventing congenital heart defects.

Fighting heart defects through research
We fund more research on children’s heart diseases than any group except the federal government.

Pediatric researchers study how the heart develops before birth and why congenital heart defects and acquired pediatric diseases occur.

In 2016, we funded 95 new research awards that investigators reported to be broadly related to pediatrics or congenital heart defects (CHD). These awards total more than $13.5 million - part of the $163 million we funded in all aspects of cardiovascular diseases and stroke.

In 2015, we joined with the Children’s Heart Foundation to establish the Congenital Heart Defect Research Award, which has provided $1.87 million in grants since January of 2016.

Together the American Heart Association and The Children’s Heart Foundation will fund up to $22.5 million in congenital heart defect research through the year 2021.

Communicating research results to healthcare professionals
We fund scientific conferences to update understanding of the anatomy, diagnosis and medical/surgical management of congenital heart disease. We publish medical scientific statements on various cardiovascular disease and stroke. The statements are supported by scientific studies published in recognized journals and have a rigorous review and approval process.

Our scientific council called “Cardiovascular Disease in the Young” consists of 1,000 pediatric cardiologists and other pediatric healthcare providers and scientists who are doing research on cardiovascular disease in children.

Through this council, we fund the publication of scientific papers related to CHD Since 2009, 19 statements have been published on pediatric cardiology topics, including traditional risk factors, fetal diagnosis, neurodevelopmental outcomes and diagnostic issues.

At our annual Scientific Sessions, the largest cardiovascular disease scientific meeting in the U.S., many of the lectures and presentations are on the topic of cardiac development and/or CHD.

Providing educational resources and support for families
Visit heart.org/congenitalheartdefects. We have dozens of downloadable tools in English and Spanish to help patients and their families understand and live with CHD, including:

- Web booklets and patient information sheets on CHD in children and adults
- recommendations for preparing teens with CHD for transition to adulthood

Our online Patient Support Network connects people living with CHD with others on a similar journey and offers materials for starting face-to-face community support groups. Visit heart.org/supportnetwork

Working with the congenital heart defect community
Our efforts to support the pediatric heart disease community go beyond just funding research. We interact with the congenital heart community by:

- Providing continuing education and invaluable networking opportunities for pediatric and adult cardiologists at our scientific meetings.
- Publishing pediatric research in our renowned scientific journals.
- Advocating for health reform issues, such as eliminating the “pre-existing condition” limitation on insurability and caps on lifetime medical need.
- Spreading awareness during National Congenital Heart Defects Awareness Week (second week of February) through traditional and social media.
- Collaborating with the Children’s Heart Foundation on a program to support parents of children with congenital heart defects.

Advocating for lifesaving public policies
We work with federal and state policymakers to improve detection, treatment and funding for research on congenital heart defects.

For several years, we have been working to pass state laws requiring a simple, non-invasive screening to help identify newborns at risk for congenital heart defects. Wide use of this “pulse oximetry” test, which measures oxygen levels, would help identify more than 90% of heart defects. In our Midwest Affiliate, we’ve helped pass pulse-ox legislation in 10 of our 11 states.

At the federal level, we’re a member of the Congenital Heart Public Health Consortium, which includes nonprofit organizations, researchers and representatives of federal agencies. We lobbied Congress to establish Specialized Centers of Research in Pediatric Cardiovascular Disease, which resulted in several million dollars being set aside to establish centers. Our Advocacy office also sponsored a summit on “Health Care Issues for Individuals with Congenital Heart Disease.”

In 2014, we worked with the March of Dimes and other public health groups to achieve passage of the Newborn Screening Saves Lives Reauthorization Act, which renews federal initiatives for five years to assist state newborn screening programs, support parent and provider education, and ensure the accuracy and quality of newborn screening tests.

How you can help
Your donation to the American Heart Association’s Legacy of Life Endowment for Congenital Heart Defects Research will help fund research to help healthcare professionals detect, treat and even prevent the congenital heart defects that affect so many precious little lives every year. Any donations will be added to the corpus of the endowment and the income from the endowment only is spent on CHD research.

THE LEGACY OF LIFE ENDOWMENT
provides a perpetual funding source for congenital heart defect research.

For more information on this fund, call 952-278-7905 or email susan.cahoon@heart.org

To donate, please click here to visit our website or make your check or money order payable to the American Heart Association (with Legacy of Life on memo line) and mail to: Legacy of Life Endowment, American Heart Association 208 S. LaSalle St., Suite 1500, Chicago, IL 60604

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