Placing Children at the Heart of Research

2020 Year-End Update

www.ChildrensHeartFoundation.org
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Our mission is to advance the diagnosis, treatment, and prevention of congenital heart defects by funding the most promising research.
A Message From Our President & CEO and Board Chair

What a year it has been. Without question, 2020 has surprised and stretched us in ways we could have never imagined. This year challenged us to be more creative and to be more aware, but also invited our heart families to share hearts that hope with the rest of the world during uncertain times. And even though we were physically distanced and cancelled in-person events, we grew closer to our supporters in many ways.

Connecting with Heart Families

Through these unusual times, the health and safety of our heart families has been our top priority. Committed to providing timely and critical information to our heart families, The Children’s Heart Foundation hosted five Facebook Live conversations exploring topics related to COVID-19 and congenital heart defects (CHDs). Led by our Medical Advisory Council (MAC) chair, Dr. John Costello, and past chair, Dr. Jennifer Romano, these sessions were viewed over 38,000 times and served as a resource for heart families and our supporters nationwide.

In the spring, we engaged with homebound heart families by creating Art for Hearts activities and contests on social media to provide entertainment. Window art, multi-dimensional masterpieces, and outdoor creations were part of these competitions that culminated with a virtual talent show, attracting entries from across the country. Our board members and staff enjoyed it so much, they even donated contest prizes to prolong the fun.

Connecting with Supporters & Volunteers

One of the biggest ways we stayed close to our supporters and heart families was through our Congenital Heart Walks, which were hosted virtually nationwide in 2020. One-day walk events transitioned to several days of virtual “walk week” activities that included arts and crafts projects, research updates, a Disney sing-along, and a huge favorite – Bingo with Barb! These virtual walk festivities allowed participants to interact with one another and create human ties when so many families were feeling isolated. And with the help of our volunteers, walkers, donors, and sponsors, our 2020 Congenital Heart Walk series raised over $1.1 million! Check out this video for a recap of our 2020 virtual walks!

We also stayed connected to our supporters with the help of our regions and dedicated region leaders. And because events were virtual, volunteers from various regions were able to work together in new ways. For non-walk events like the Red Tie Ball: Untied, COVID-19 created challenges, but our resilient volunteers worked tirelessly to support our mission.
Connecting to Researchers & the Medical Community

To keep the CHD community connected amidst the pandemic, The Children’s Heart Foundation hosted twelve Virtual Research Receptions in June and an additional six in the fall. Our supporters learned from the nation’s CHD experts in intimate, small-group settings as doctors spoke about their research and how their work could impact the ways in which CHDs are treated. As these talented experts shared their passion for CHD research, they also invited attendees to ask questions and engage in authentic conversations.

Our speakers (including some living with CHDs of their own) covered a diverse range of CHDs and research topics, while sharing a commitment to the mission of The Children’s Heart Foundation. Many spoke personally about how the funding they received from The Children’s Heart Foundation was critical to the success of their research.

Connecting with Hearts that Hope

Since we recognize how heart families are the true champions of hope, we launched a multifaceted Hearts that Hope campaign. Heart families know the importance of taking one day at a time through constant uncertainty. They never give up, and neither does The Children’s Heart Foundation. Our campaign has shared this message with the world and was brought to life by a new song written for The Children’s Heart Foundation. Listen to it here!

On behalf of The Children’s Heart Foundation, thank you for your support. We are driven to advance the diagnosis, treatment, and prevention of congenital heart defects – or CHDs – by funding the most promising research. Our dedication to that mission is stronger than ever and we’re proud to have funded nearly $14 million of CHD research and scientific collaborations to date. We look forward to taking on a new year as we celebrate the 25th anniversary of The Children’s Heart Foundation and continue Placing Children at the Heart of Research.

With hearts that hope,

Barbara Newhouse, President & CEO

Martha Hauber, Board Chair
Placing Children at the Heart of Research

The Children’s Heart Foundation’s mission is to advance the diagnosis, treatment, and prevention of congenital heart defects by funding the most promising research. Why? Because for more than two million Americans living with CHDs, research is their best chance at longer and better lives. Research is their greatest hope.

Although it has been an unprecedented year, the need for CHD research funding from private sources like The Children’s Heart Foundation is more critical than ever before. With a clear commitment to this cause, we funded more than $735,000 in CHD research and scientific collaborations in 2020.

As in years past, our research portfolio spanned four key initiatives:

1. Independent research funding
2. Collaborative research with the American Heart Association through joint Congenital Heart Defect Research Awards
3. Funding the American Academy of Pediatrics’ Pediatric Cardiology Research Fellowship Award
4. Funding of Cardiac Networks United research initiatives.

With Heartfelt Thanks

The Children’s Heart Foundation extends heartfelt thanks to Martha Hauber, our outgoing board chair, for her many years of dedication and expertise. For more than 15 years, Martha has held various roles within the organization at both the regional and national level, and has served as board chair since January 2019. Martha’s passion for our mission stems from her personal experience with the impact of CHD research, and she remains more passionate about this mission than ever. Thank you, Martha, for all you have done and continue to do for The Children’s Heart Foundation!
Since 1996, The Children's Heart Foundation has now funded nearly $14 million of CHD research and scientific collaborations. In many cases, we’ve provided start-up funding for research that’s gone on to earn support from larger entities such as the National Institutes of Health or the U.S. Department of Defense, along with pharmaceutical and/or medical device industries. The research we fund is truly moving the needle.

**Independent Research: Investing “Seed Money” in Pivotal Projects**

Each year we extend an annual call for research proposals and receive applications from investigators around the world. Independent research projects are annually scored by our Medical Advisory Council based on scientific integrity, investigator credibility, and mission alignment.

In addition to funding new research, we provided second-year funding to three important projects in 2020. Despite delays caused by COVID-19 and circumstances in the world, 2019’s funded investigators made significant progress.

- **Kristopher B. Deatrick, MD** [University of Maryland], is continuing to work on Stem Cell Therapy for Post-Cardiopulmonary Bypass Low Cardiac Output Syndrome. In the second year, research will focus on stem cell science and stem cell products used for the main interventional part of the experiments.

- **Youngjae Chun, PhD** [University of Pittsburgh], continues his efforts on A Self-Growing Percutaneous Heart Valve Frame to Treat Congenital Heart Disease. He has fabricated the first growing heart valve frame prototype! Preliminary results from the in vitro dynamic test have been conducted; degradation tests using another metal are underway. Second-year research will involve a biodegradation study with vascular cell growth under the radial force exertion, which will be conducted after setup is done. The second aim is the design and fabrication of a hybrid valve frame, and an initial computational modeling for one of the major parts of the device is nearly complete.

- **Allen Everett, MD** [Johns Hopkins University], will continue studying the Role of Cyclohexanone Toxicity in Mediating Congenital Cardiac Surgical Outcomes. Dr. Everett has identified significant independent associations between cyclohexanone levels and important perioperative and neurodevelopmental outcomes. He has also screened 240+ metabolites that may reflect altered metabolism and vascular injury after pediatric cardiac surgery, and he found that changes in certain metabolite levels improve the performance of conventional cardiac surgery risk models. Now he will strive to determine if cyclohexanone concentrations are related to altered metabolite levels, which may help identify causal pathways, and examine whether associations identified between cyclohexanone levels and perioperative morbidity and mortality are age dependent.
In 2017 The Children’s Heart Foundation funded Dr. Mark Rodefeld from Indiana University and his research to create a Fontan Blood Pump that simulates a heart pump and could reduce the need for heart transplants! In March of this year, Dr. Rodefeld was awarded a $5+ million grant from the National Institutes of Health to continue his research on this revolutionary device. “The Children’s Heart Foundation funded this work substantially on two separate grants and got this over the finish line for me to get the NIH grant – the gold standard funding for biomedical research,” Dr. Rodefeld explains. “You can’t get NIH funding without showing convincing evidence … and the only way you can do that is with funds – like those I received from The Children’s Heart Foundation – to help you get that initial evidence.”

American Heart Association: Working Together to Fight CHDs

Collaborative funding with American Heart Association supports the Congenital Heart Defect Research Awards, which selects investigators who are advancing the prevention, diagnosis, and treatment of CHDs.

In February of 2020, The Children’s Heart Foundation and American Heart Association announced a joint commitment of $1.3 million to fund the following research:

- **Colleen Witzenburg, PhD, MS** [University of Wisconsin-Madison], for work in predicting long-term heart and pulmonary artery growth in congenital heart disease.

- **Jason Boehme, MD, BS** [University of California-San Francisco], for work in metabolic reprogramming in pulmonary vascular disease.

- **Parth Mukund Patel, MD, BS, BA** [Massachusetts General Hospital], for work on achieving tolerance in NHP heart transplant recipients with donor exosomes.

- **Audrey Dionne, MD** [Boston Children’s Hospital], for work predicting arrhythmogenic risk in post-operative congenital heart disease patients.

- **Margaret Rose Ferrari, BS, MS** [University of Colorado-Denver], for work with tissue engineered contractile Fontan circuit for single ventricle patients.

- **Devin Marisa Parker, MS** [Dartmouth College], for work on healthcare utilization and quantifying the burden of care as it relates to the first U.S. population-based estimates of CHDs.

- **Hee Cheol Cho, PhD** [Emory University/Georgia Institute of Technology], for work on hardware-free cardiac pacing for congenital heart block patients.

- **David Kalfa, MD, PhD** [Columbia University], for work on in-vitro and in-vivo mechanical stability and growth of a bio-hybrid heart valve.
In October, the American Academy of Pediatrics (AAP) selected David Staudt, MD, PhD, to receive its 2020 Pediatric Cardiology Research Fellowship Award – an award made possible by an educational grant from The Children's Heart Foundation.

We are proud to fund the AAP's Pediatric Cardiology Research Fellowship Award yearly to ensure that future researchers are encouraged to enter into pediatric cardiology research.

Staudt is a pediatric cardiology fellow at Stanford University. His research – Unraveling Molecular Modifiers of Hypertrophic and Restrictive Cardiomyopathy – will study characteristics that can help identify genetic susceptibility that causes hypertrophic (thickening of heart muscles forcing the heart to work harder) and restrictive (heart chambers becoming stiff over time) cardiomyopathies. This research is important because it begins to identify genetic mutations and the underlying causes of both cardiomyopathies – and this could lead to therapies that could counteract or prevent.
Heart disease in children can be caused by genetic mutations, but having a mutation does not guarantee that a patient develops a particular disease," Dr. Staudt explains. "Through this fellowship funded by The Children’s Heart Foundation, I aim to investigate the molecular and genetic mechanisms of congenital heart disease and pediatric heart failure, with the hope of eventually developing new therapies to help heart function in these diseases.”

**Cardiac Networks United: Looking at Data to Make a Difference**

Last year The Children’s Heart Foundation began supporting Cardiac Networks United (CNU), a pediatric and congenital cardiovascular research network that encompasses two-thirds of all congenital heart centers in the U.S., or about 85 institutions. Through 2023, we will provide a total of $1.5 million to CNU. Our funding facilitates the sharing, integration, and management of research data. As a result, we also foster collaborative learning and quality improvement activities across the networks. This year, CNU also fostered new collaborations with the Fontan Outcomes Network, Adult Cardiac Critical Care Consortium, and Pediatric Heart Transplant Society.

Now with eleven active research projects, CNU seeks to improve outcomes for children and families impacted by congenital heart disease in a timely manner. One of its current efforts – the PAC3 Chest Tube Project – earned an outstanding research award from the American Heart Association and is being implemented at nearly 20 hospitals in America right now, as researchers look at the optimal time for chest tube removal in our youngest heart warriors!

“We are just scratching the surface of CNU’s possibilities and will pursue many more innovative and impactful research projects that improve the lives of heart families fighting CHDs,” shares Michael Gaies, MD, MPH, MSc, CNU co-director from the University of Michigan. “These research initiatives would not be possible without support from The Children’s Heart Foundation.”
Other Ways We’re Making an Impact

Advocacy Efforts
This year The Children’s Heart Foundation proudly partnered with Mended Little Hearts and the Adult Congenital Heart Association to host our first collaborative telemedicine webinar. We also worked together on a virtual advocacy outreach campaign. Spanning Sept. 28 to Oct. 9, the effort reached state and local legislators nationwide to raise awareness about congenital heart defects and the critical need for increased research funding.

Young Adult Board
In 2020, we welcomed ten incredible volunteers to our newly formed Young Adult Board: Cortney Barnett and Colby Groom (co-chairs), Faith Brackett, Jane Lee, Billy Lyman, Stephanie Scaglione, Doug Sexton, Adam Thomas, Cameron Vicknair, and Caitlin Winschel. Along with serving as a voice for children and adults with CHDs, our Young Adult Board members help The Children’s Heart Foundation better understand the challenges of living with CHDs and share valuable perspectives on critical research needs.

Diversity & Inclusion
Congenital heart defects do not discriminate. They impact families of every race, ethnicity, and socioeconomic sector. CHD research must reflect the inclusion of all populations. This year, we have begun exploring research to benefit populations who have been traditionally underserved. On a broader scale, our Diversity & Inclusion Task Force is leading the charge to identify racial disparities, address the needs of those who are marginalized, and spark change.

Looking Ahead with Hearts that Hope to Fulfill our Mission
While we were limited by the uncertainty of 2020, we have certainly surpassed those limits. This report highlights some of the many ways we have developed creative solutions, connected with people in new ways, and realized much success.

As we mark our 25th anniversary in 2021, we will build on the best parts of this year. Working together, we’ll fulfill our mission to advance the diagnosis, treatment, and prevention of CHDs by funding the most promising research. We will place continued emphasis on connecting heart families with funded researchers, debutting new and exciting projects to create further visibility (and dollars for research!) for our cause, and always sharing hearts that hope.