

ANNUAL REPORT 2020



Congenital Heart Defect
FAMILIES OF TUCSON

PREPARED BY THE CHDFT BOARD
OF DIRECTORS



**DISTANT,
NOT
DIVIDED**

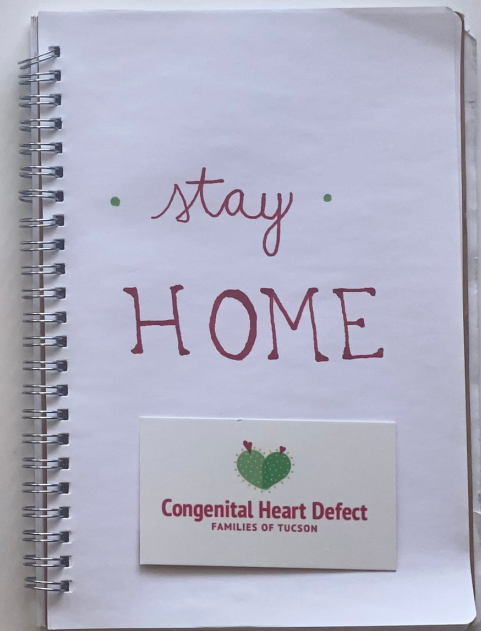
"The simple element that makes it all function is connection through shared experience."

LETTER FROM THE DIRECTORS

The mantra that's displayed prominently in our private parent support group is simple: our most valuable resource is our network of parents who have been where you are. At the core of each of our three branches of support is a simple concept: this group is about parents helping parents. The simple element that makes it all function is connection through shared experience. The year 2020 brought a whole host of issues to non-profit organizations across the globe. Donations dried up. Nearly 75% of organizations polled by Charity Navigator and Reuters reported that their main fundraising events were cancelled, and CHD Families of Tucson was no exception. Our primary focus, alleviating immediate need in order to help parents find and support each other, became an elusive goal. How were we to bring people together in this unprecedented era of extreme isolation?

Interestingly, it's our homegrown, family-style leadership that has been our greatest strength in the midst of the Covid-19 outbreak. Quarterly get-togethers turned into weekly online check-ins. "Live at Five" was born, and Director Stacy Lipinczyk's weekly livestream brought families together to laugh, joke and vent, but also to express concern and take the pulse of the group.

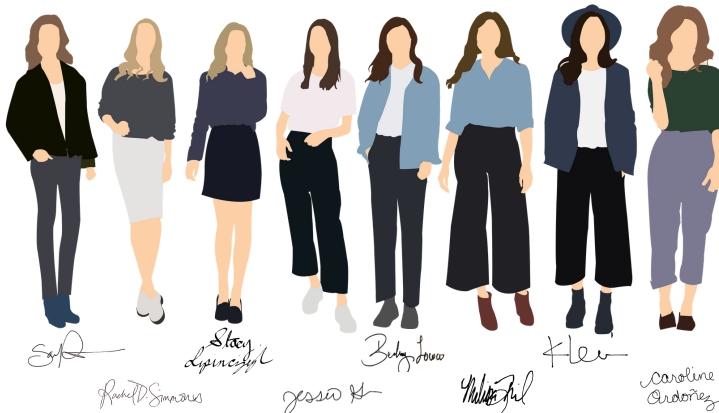
Live at Five began to feature health and education options in the form of online yoga classes, group therapy, and Q&A sessions led by our local cardiologists. With the production of what we were offering pared down, the nature of the group shifted. What Stacy and these medical/health professionals were offering was not just services, but solidarity. Families responded in kind. As Ronald McDonald houses across the country closed doors, we had Tucson heart families offering airline points to put traveling inpatient families up in hotels. An initiative to provide a meal for every family in our group led to an outpouring of support for local restaurants. Parents were dipping into hoarded medical supplies to share what they had in the face of shortages. We lived our lives separately but together. We celebrated, grieved, shared, and prospered as a community bound by struggle but committed to hope. We can do this together; we know that now more than ever. It's been an honor to facilitate this growth in 2020, and we look forward to carrying this organization into the coming year.



2020

VISION

Leadership in a global pandemic takes ingenuity, creative thinking, grit, and commitment.



**THE CHDFT
BOARD OF
DIRECTORS**

In addition to the effects of the Novel Coronavirus, 2020 prompted most Americans to think about issues of race, gender, and inclusiveness in ways we never had before. According to a study done by Battalia Winston, only 42% of non-profits are led by women. 87% of all Executive Directors in non-profits are White, with only "minimal representation of African-American, Asian, and Hispanic individuals."

At CHDFT, we consider our female leadership to be an asset, and believe that the multicultural families represented on our Board paint an accurate picture of the families of Congenital Heart Defects. During our Annual Board Retreat (held on Zoom), our board identified five barriers to hosting equitable events for our families. Those barriers are:

- Cost
- Transportation
- Childcare
- ADA Accessibility
- Communication

As a Board, we have pledged to abstain from hosting events without addressing at least three of these barriers. We remain committed to that promise.



**CHD Families
OF TUCSON**

MEMBERSHIP IN 2020

As we grow, the importance of tracking our demographics also increases. Keeping an eye on our numbers helps us better serve the members we have, and helps us identify areas in which we need to develop.

17%

Membership increase in 2020. Despite a loss of face-to-face contact, the support base continues to grow.

33%

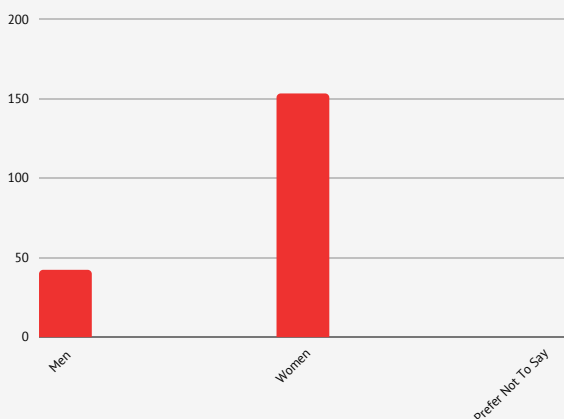
Rise in male membership throughout 2020.

REACHING OUT IN 2020

A look at our membership showed us that we were not reaching men in the same way we were reaching women. Due to efforts made in 2020, we have increased our male membership by 33%.

MEMBER DEMOGRAPHICS

With the permission and participation of our members, we remain committed to improving our system and continuing to provide support that is equitable, accessible, and welcoming to all families impacted by Congenital Heart Defects.



In July of 2020, CHDFT welcomed a new "Heart Dad" and our 200th member. We celebrated by wishing his family well and sending them a gift card to a Locally Owned Tucson restaurant for some tasty takeout.

FINANCIALS FOR 2020

In this Fiscal Year, our Board of Directors raised **\$45,881.65** to cover our costs of operations.

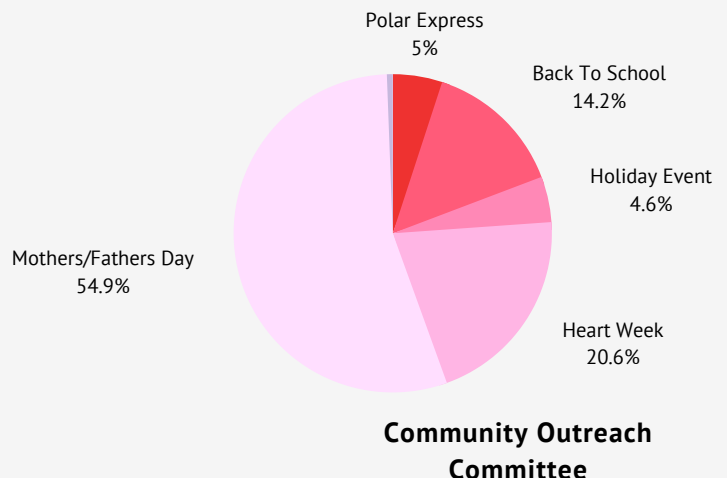
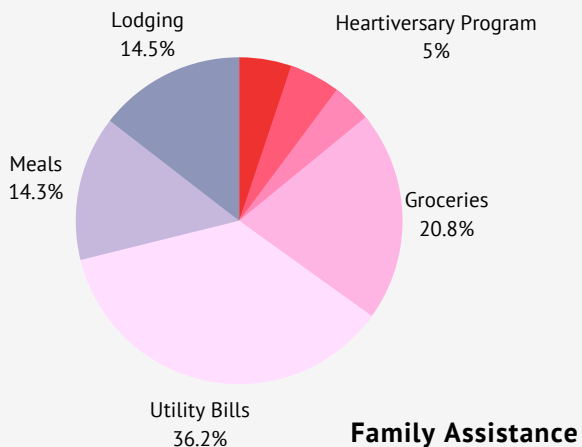


GIVING MORE

Because our budget expanded in our previous fiscal year, our 2020 spending had to increase as well in order for us to remain AZ Tax Credit Eligible. We are pleased to report that we fulfilled our commitment and increased spending on basic needs for heart families by 102%.

PROGRAM BREAKDOWNS

In 2020, CHDFT spent a total of \$35,489.93 on Tax Credit Eligible Programs & Services, which was 63.57 % of all accumulated expenses. Below are percentage breakdowns for our two most expensive programs, Family Assistance (Financial Support) and the Community Outreach Committee (Emotional Support).



A WHOLE NEW WORLD FUNDRAISING



In 2020, we had hoped to stamp the passports of our friends and supporters as we welcomed them to the streets of Havana. Instead, we had to put a different stamp on the whole event. We grieved.

As we look at our demographics and our financial report, we see that while our membership is steadily growing, and their need for assistance is increasing, our funding is down. This is to be expected; times are tough for everyone. To help supplement our Family Assistance Program, we are planning to lean heavily on tax credit-based donations. If you owe taxes to the State of Arizona, and you would like to see a dollar-for-dollar credited to you, we ask that you please keep us in mind!

*see you
next year!*



STAY TUNED...

Want to be the patron saint of bringing a tired inpatient parent a cup of coffee? The superhero who provides a tank of gas to a family in need of a cardiac clinic visit? Stay tuned and prepare yourself for our Winter Giving Campaign!

Keep reading for more
information on the
Arizona State Tax Credit

Programs

ONLINE

EDUCATION

How can we make online education engaging?

This was the question that really made our heads spin when the reality of our situation settled in. Where we normally host Family Connect, bring consulting cardiologists to events, and have several opportunities each year to set up information booths available to the public, we now had to re-format everything. We opted for online classes and Q&A sessions with an unplugged feel.

"Get up and play" connect events turned into free online yoga classes for parents and children. Our annual cardiology panel became informal Facebook Live events with a comfortable, intimate feel. Wellness-themed gatherings morphed into a plan to have licensed trauma therapists present curriculum on accepting the usefulness of all emotions.

Overall, CHDFT has hosted four educational events since we moved to a distanced format. We remain active as we guide our families in new ways to strengthen the mind and body for a heart-healthy lifestyle.



Director Stacy Lipinczyk is a Patient Family Representative involved with the Congenital Hearts of Arizona: Barriers/Gaps in Care Committee. In her role, she works with community organizers and esteemed cardiologists to identify gaps in care on a local level. She brings this hands-on experience to the CHDFT support group as she models and teaches patient advocacy.



Programs

ONLINE

FAMILY ASSISTANCE



safety for every chd child.

At the onset of the Covid-19 pandemic, CHDFT did their part to keep heart kids safe by providing cool air humidifiers made with a UV light feature to kill bacteria. Studies show that viruses spread faster in environments with low relative humidity, while an environment with 40-60% RH slows viral spread. 62 Honeywell humidifiers were mailed to local families with at-risk children.

01

be safe summer project.

As pediatric heart patients moved to distance learning and stayed home, CHDFT worked to create excellent Summer Kits. Items in these kits promoted hydration, provided sun protection, and encouraged children to exercise in fun and healthy ways, all free of charge for heart families who apply.

02

family assistance applications.

While an economic slump tightened belts across the country, CHDFT's Family Assistance (FA) program became all the more crucial. FA covers basic needs for diagnosed heart families, including food, transportation, shelter during hospital stays, and most importantly, utility bill coverage for families in need.

03

quarantine meal initiative.

Every member in our support group was given the opportunity to apply for this initiative in which CHDFT mailed out gift cards to grocers or restaurants on a strictly local level. It was a rare opportunity to both put food on the table and give back to the business owners in our own backyards.

ONLINE

EMOTIONAL SUPPORT



Our Heartiversary Program is designed to recognize the warrior spirit in each individual Open Heart Surgery Survivor. Applicants receive a certificate and a small token of admiration from our support group. In 2020, this volunteer role was passed from Haleigh, a teen CHD Survivor, to our friend and ally, Miss Carly and her Gramee Paula. We are very thankful for both Haleigh's work and for this dynamic duo!



"Live at Five," our virtual happy hour, is hosted every week by our fearless leader Stacy Lipinczyk. We enjoy this laid-back time to socialize with anyone in the support group who wants to participate.

In a typical year, hospitalized new members can request a visit from a member of the Board of Directors. During this visit, we will gift them with a "survival basket" and information about our available resources. This year, we are counting on our partnerships with local pediatric centers to spread the word. Their essential team members have gone above and beyond to refer us, and being

entrusted with their confidence has been a true honor.



To help inpatient families feel like we're still with them, we partnered with the Southern Arizona Association of Health Underwriters (SAAHU) to equip the Pediatric Intensive Care Unit at Diamond Children's Medical Center with a "Dream Racer." This piece of equipment is designed to promote recovery by encouraging children to move their bodies after surgery.

Apart, but together: the Dream Racer

family

LETTER

Written by Cait Wanasek

"**The** 20-Week Anatomy Ultrasound is an exciting time! Typically, this is when you get to find out the gender of your baby and see all the different bones and ligaments they are growing. Our case was a bit different. First of all, we were having TWINS! We had already found out at the 16-week ultrasound that we were blessed with a boy and a girl! It was at this appointment however, that we found out our little boy had a heart defect. Having no prior knowledge of anything related to cardiac issues... this was devastating to us. That being said, we were urged to join the CHD Families of Tucson support group.

To be honest, I was hesitant at first. I was overwhelmed in general and not sure what to expect. But after being referred again to the group, I decided that this thing was bigger than my feelings of being overwhelmed and scared.

"Being able to connect with other families who also have children living with CHD has been the biggest support system to lean on."

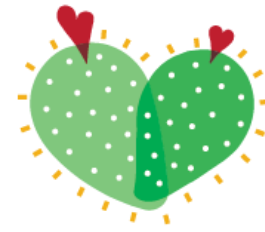
Cait (pictured) is a Wisconsin native, establishing roots for herself here in the Sonoran Desert. She's a proud wife and mother, with a passion for learning about the world we live in through travel and hands-on experiences.

So, I joined the group. I can honestly say it's the best decision that I made at that time. Being able to connect with other families who also have children living with CHD has been the biggest support system to lean on. From being able to post questions on the group's Facebook page to other parents regarding upcoming procedures and what to expect, to participating in fundraisers and in person events that are hosted to get everyone to connect and show support for the journey that we are all on...is truly amazing.

I want to thank the members of CHD Families of Tucson for supporting each other not just the parents of heart warriors, but our heart warriors themselves. These kiddos will always have an incredible support system as they continue to fight. Thank you."



ARIZONA TAX CREDIT



CHD Families
OF TUCSON

CHD Families of Tucson is a qualifying Charitable Organization (QCO CODE 22013). If you donate to CHDFT, your donation is a dollar-for-dollar tax credit, so the donation will come right off of your Arizona state taxes! Any Arizona taxpayer can donate to CHDFT and take advantage of this tax credit. Your gift will help keep the lights on, water running, air conditioning going, provide groceries, and more, for Southern Arizona children with congenital heart defects and their families going through difficult times due to their CHDs. To claim this credit, use Form 321.*

*Best of all? You can donate to a qualifying charitable organization, like CHDFT, in addition to donating to a qualifying foster care organization, or any public school!***

*The maximum qualifying charitable organization credit allowed is \$800 for married filing joint filers and \$400 for single, heads of household, and married filing separate filers.

**CHDFT does not provide tax advice. Please consult with your own tax advisor.

Your AZ Tax Credit eligible donation can be mailed to:

CHD Families of Tucson
PO Box 91324
Tucson, AZ 85752



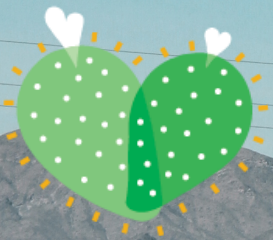
Want to donate right now? Use your smartphone or mobile device to scan this code. You will be directed straight to our secure online donation page.

You can also visit us any time at www.chdtucson.org/donate/

Together, Apart.

When we come together as a group to benefit one another, we can beat anything.

A special message from



CHD Families
OF TUCSON

