

2021



Congenital Heart Defect
FAMILIES OF TUCSON



ANNUAL COMMUNITY REPORT
PREPARED BY THE BOARD OF DIRECTORS

CHD FAMILIES OF TUCSON

LETTER FROM THE BOARD

Resilience and **Renewal** seem to be the theme that surrounded our organization these past 12 months. We've had to remain flexible, expect change, and when it occurred, adapt. This optimistic approach didn't stem from any particular leader, rather the bonded group of board members that kept a positive tone. We were able to serve our heart families in some extraordinary ways and were fortunate to have some incredible donors to help make that possible. It's truly amazing what a 'community' of people can do when we are called to stand in the place of someone who may be facing their worst fear or embracing one of the biggest battles of their life. This hit home strongly this year as three of our board members spent time inpatient with their heart warriors, who had received open heart surgery and other lifesaving procedures. When you hear that a child needs 'surgery,' a lump in your throat the size of a baseball forms. All of you reading this have a loved one who has been there and felt this. It never gets easier. Yet, that was the reason why we formed CHD Families of Tucson. Each family deserves a tribe of people behind them to rally when the load seems too heavy to carry alone.

We want to extend a special and sincere appreciation for Melissa Nail who helped build this organization from the ground up. She is taking some much-needed time to step back and focus on her family. Her passion and leadership for this organization contributed to the expansion and growth of what it is today. For that, we are forever grateful, and she will always be a part of CHD Families of Tucson.

Given the environment of today, we have proven to have the ability to withstand adversity and bounce back from different life events. We are emerging stronger than ever and look forward to a season of renewal and new growth.

Sincerely,

CHD Families of Tucson Board of Directors

CHD FAMILIES OF TUCSON

WHO WE ARE

For this year's report, we asked each member of the 2021 Board of Directors to share what inspires or motivates her to uplift the heart community through CHD Families of Tucson. Meet our Board and read each member's "My Why" below:



Stacy Lipinczyk

"To build a network of resources and community so that Kinley will always have a support system she can count on."



Caroline Ordoñez

"To connect heart families to the friendships and support I wish I had at the beginning of our CHD journey."



Kim Levin

"To offer support and build a steady community around families like ours during their most challenging times."



Becky Lococo

"To ensure local families affected by a CHD have a community to provide empathy, encouragement, & shared knowledge."



Jessica Graves

"To offer a safe community for our CHD families and children by providing them with resources and support to ensure future successes for our heart warriors."



Sara Peterson

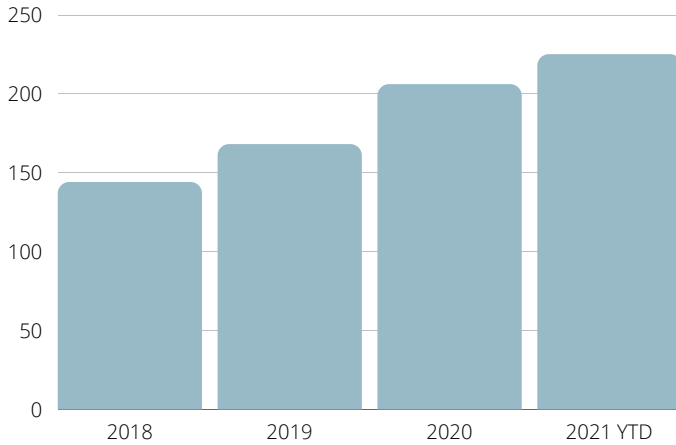
"To partner with and love our heart warriors from hospital to home."



Rachel Simmons

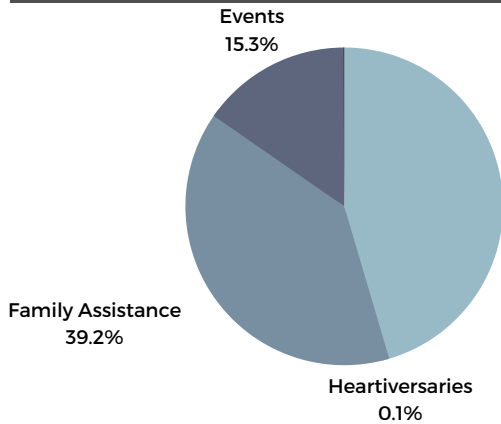
"To welcome families into one big heart family by providing support, friendship, and a place to share both challenges and accomplishments."

GROWTH MEMBERSHIP

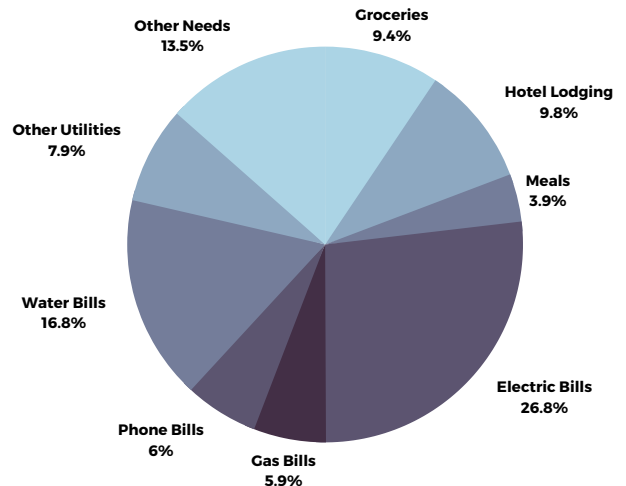


We have seen steady growth within our organization over the past few years. Many of our referrals are internal by word of mouth. One heart family meets another and suggests to join our private Facebook group. We consider these referrals a huge compliment. We take pride knowing that we can be a trusted resource for Southern Arizona Heart Families.

BY THE NUMBERS FINANCIAL SUMMARY



Be Safe Summer Gift Boxes
45.4%



Despite the difficult year faced by our family, friends, and community, CHD Families of Tucson raised \$50,594.33, the most to date in a given year, all because of our extraordinary and generous donors.

CHDFT is proudly run entirely by volunteers, so every single dollar raised goes to benefit our CHD community.

In our 2020-2021 fiscal year, CHDFT was able to spend nearly \$14,000 on families.

CARDIOLOGIST CORNER

DR. BRIAN BLAIR

As a 3rd year medical student, I was on one of my first clinical rotations in the hospital, and I remember my supervising resident warning me of something. He said, “when you put on that white coat, be prepared for patients to ask you about anything and everything.” He said, “they will ask you about their test results, they will ask you when their favorite nurse is working next, and they will ask you what’s on the cafeteria menu that day.” In short, as a doctor, you are everything to your patients. This has never been truer than during the pandemic. I get questions daily about COVID and the vaccine. I am far from an infectious disease specialist, but we’re all doing the best we can for as many people as we can. We’re trying to absorb and digest as much information as we can to keep our kids healthy and safe.

Luckily, it is extremely rare that I see a pediatric patient post-COVID-19 infection with any sort of complication from the virus. Most of the patients come to see me for cardiac clearance for sports. Some come to see me because of symptoms of fatigue or chest discomfort, and I have not yet diagnosed a pediatric patient with post-COVID myocarditis presenting with symptoms like these. Most pediatric patients after a COVID infection report very few symptoms. Mild symptoms consist of fewer than 3 days of fever, body aches, cough, congestion, sore throat. Moderate symptoms include more than 3 days of the same type of symptoms. Severe symptoms would be anyone with significant shortness of breath, pneumonia, an oxygen requirement needing hospitalization or multisystem inflammatory syndrome in children (MIS-C). As far as cardiac clearance goes, anyone with mild symptoms does not need a cardiologist to clear them to go back to sports. They can return to play 14 days after their symptoms have resolved. Anyone with moderate symptoms younger than 12 years old can return to play 14 days after their symptoms have resolved. For kids older than 12 with moderate symptoms in addition to a physical exam with their pediatrician, an EKG is recommended prior to return to play. Anyone with severe symptoms should see a cardiologist prior to resuming sports.

These guidelines should be helpful for the majority of pediatric patients looking to get back to sports after a COVID-19 infection. Extenuating circumstances can come up, of course, necessitating conversations with your doctor. Stay safe, stay healthy, and stay positive!

Brian Blair, MD
Tucson Pediatric Cardiology
Physician Liaison for CHD Families of Tucson



RENEWAL

DONATIONS AND FUNDRAISING EFFORTS

External Giving

- The Levin Family, 2020 & 2021
- Chik-Fil-A Ina & Thornydale, February 2021
- Blue Finch Bakery, February 2021
- All Your Heart Fitness, February 2021
- Quotes for Good - Joel Lipp State Farm Agency, 2021
- SAAHU Golf Tournament, March 2021
- Russ Lyon Sotheby's International Realty, May 2021
- Banner University Medical Center, June 2021

Internal Fundraising

- Logo sweatshirt fundraiser, Fall 2020
- Arizona Gives Day, April 2021
- AZ State Tax Credit, 2021



STEADFAST EVENTS

- Family Connections Dinner - Returning February, 2022!
- Be Safe Summer Gift Boxes
- Community Outreach Committee
 - Holiday Drive In Movie
 - Back to School at Reid Park Zoo
 - Father's Day Axe Throwing

HOLIDAY DRIVE IN MOVIE

Nine months into the pandemic, and nine months without any in-person contact with our Southern Arizona CHD Community, the Board of Directors came together to brainstorm something, anything, that we could safely do as a group. A local outdoor theater company had been successfully hosting drive-in movies that met all state and municipal COVID guidelines and we knew that was our ticket! On December 3, 2020, we partnered with El Toro Flicks, Chik-Fil-A, Popcorn County, and Hot Chocolate Bombs AZ to present a magical holiday showing of *Dr. Seuss' The Grinch*. As cars filed into the Mercado San Augustine Annex, families were greeted by the Chik-Fil-A mascot who delivered chicken sandwiches and Board members who dispersed a bag of fresh-popped popcorn to each vehicle and a specially made hot chocolate bomb for each heart warrior. Though we were socially-distanced within the confines of our vehicles, we were still able to experience an evening filled with holiday cheer.



FATHER'S DAY AXE THROWING

Heart dad's gathered for a night of axe throwing, at St. Hubert's Hatchet House to celebrate Father's Day. These intimate events bring about an enormous amount of connection.



BE SAFE SUMMER GIFT BOXES

Our Be Safe Summer Gift Box Program is arguably our most popular program! Each year we assemble a box of fun basic essentials to send to our heart warriors to stay safe during the hot summer months in Arizona. This year some items included: sunscreen, 'Heart Warrior' yeti water bottle, heart shaped waffle maker & waffle mix, apron, toothbrush & goodies donated by Delta Dental of Arizona, and much more! We partnered with Russ Lyon Sotheby's agents and they helped raise money & distribute the boxes to our families at Reid Park.

STEADFAST

ONGOING PROGRAMS

HEARTIVERSARY CERTIFICATES

Our Heartiversary Certificates recognize the heroism in each CHD child, as we mail them a small gift and a certificate of accomplishment on the anniversary of their first life-saving open heart surgery. This program continues to be volunteer run by our friend and CHD ally: Carly, and her Gramee Paula.



FAMILY ASSISTANCE REQUESTS

The Family Assistance Request program (featured on our website, www.chdtucson.org), allows heart families in our region to submit a request for necessary financial support when the cost of caring for their medically fragile child is overwhelming. We pay utility bills, provide groceries, and cover transportation costs to and from medical appointments. We never give cash gifts, but we do our best to take care of our community by covering needs directly at the source.

ANGEL WARRIOR PROGRAM

Each child that comes into this world with CHD deserves to be recognized. These children fight the toughest battles and have to face so many highs and lows. The ultimate worst is the crippling pain of losing a child. We mourn each loss as a community and it hits hard when one of our own gains their angel wings. We individually stand in the stillness and feel the heartache deeply. This is a gap we can never fulfill, but rather it's an area we can embrace & recognize forever. The Angel Warrior Program will launch in 2022. We engaged heart angel mom, Jennifer Wittman, to lead the program and come up with this creative idea. We will gift a personalized windchime to each family that has lost a warrior. Every time they hear the chime, it will be a soft reminder of that precious angel warrior.

Launching
2022

LOOKING FORWARD...

HEARTS IN HAVANA '22

As we left 2020 and entered 2021, we realized yet again that given the COVID climate it was unlikely that we would be able to safely gather and host our casino night for the second year in a row. Although our disappointment as a board was clear, the safety of our heart warriors, families, and supporters remained our top priority. We found other creative ways to raise funds on a significantly smaller scale, including our first ever sweatshirt sale. Additionally, our community supporters stepped up tremendously to help fill the financial gap left by yet another year without a big fundraiser.

If the last two years have taught us anything, it's that we are resilient and we are hopeful that we will be able to gather on **August 20, 2022** to finally host our Hearts in Havana casino night. Get your outfit picked out now and join us for a night of music, food, dancing, and casino gaming. Please visit our website (www.chdtucson.org) and Facebook page for more information.

Save the date!



SOUTHERN ARIZONA STRONG TAX CREDIT

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!**

**CHDFT DOES NOT PROVIDE TAX ADVICE. PLEASE CONSULT WITH YOUR OWN TAX ADVISOR.

*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.



CHD Families
OF TUCSON

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 at:
www.chdtucson.org/donate/

FROM OUR HEARTS TO YOURS

A Story from the Fouts Family

Ava came into our lives in May of 2011. Like many CHD babies, she was already gathering a lot of medical attention following a 20 week ultrasound that showed she had an interrupted aortic arch.

Amniocentesis showed that she did not have any chromosomal abnormalities, but a surgery would be needed soon after birth to correct the IAA. Unfortunately, ultrasounds in utero were unable to show that a VSD hindered the growth of her pulmonary valve and we were presented with the scary reality that a conduit and valve would be required to connect the output of her Right Ventricle to her Pulmonary Artery. Five days after Ava's birth, Dr. Michael Teodori and his team at The Diamond Children's Center, Tucson UMC, performed a successful surgery to install the RV-PA conduit. Ava spent two weeks recovering in the hospital after surgery.



Although her original conduit was only supposed to last a year, Ava didn't begin showing signs of conduit clouding until she was a very active age four. Under the guidance of her Cardiologist, Dr. Ryan Johnson, Ava's conduit was replaced by Dr. John Nigro at Phoenix Children's Hospital in March of 2015. Her recovery was outstanding, and she was home and active within days. Her conduit is now large enough for an adult, and our hope is that it won't need to be repaired until she is older and the procedure can be accomplished non-invasively through arterial pathways.



Ava has always been active. We define her as having two different modes; sprint or sleep! As parents, we've always encouraged her to climb a little higher, jump a little further, and run a little faster. By the time she was two she had already mastered balance on a bicycle, and she was pedaling without training wheels by age three. It became clear by age five that Ava enjoyed riding her bicycle long distances, and we've encouraged her to enjoy that. She spends hours riding her bicycle on The Loop (Tucson's paved bicycle paths) and on Mt. Lemmon, riding almost to the top of the mountain and circling the entire 60 miles around Tucson. Ava gives encouragement and love to everyone she meets, cheering on other cyclists, runners and walkers. Her outgoing personality and cycling ability garnered the attention of local cyclists and professional racers alike, of whom many have taken her under their wings, accompanying her as she races her bicycle around the area. Her positive spirit shines through her CHD challenges!

CHD Families of Tucson came into our lives a little later than most. In 2018, a board member and fellow cyclist reached out and introduced us to the organization. After experiencing two heart surgeries on "our own," we understood the importance and support that CHD Families of Tucson provides. Ava has enjoyed the wonderful gifts and special dates such as Heartiversary recognition. She has learned through the organization that she is not alone, and that many other children experience the same challenges she has such as Doctor and Hospital visits. This knowledge has helped her feel less like she's fighting this battle by herself and it helped her come out of her shell. As parents, we have used the group Facebook page to offer encouragement and support to families that are helping their children through the stresses that CHD can dish out. The organization is a bright light in what can be a lonely voyage.

**“THE ULTIMATE MEASURE OF A
MAN IS NOT WHERE HE STANDS
IN MOMENTS OF COMFORT AND
CONVENIENCE, BUT WHERE HE
STANDS AT TIMES OF CHALLENGE
AND CONTROVERSY.”**

- MARTIN LUTHER KING JR.

**SUPPORT YOUR LOCAL HEART
COMMUNITY.
GIVE TO CHD FAMILIES OF TUCSON.**

*CHD Families of Tucson is a recognized 501(c)(3) non-profit organization.
Need a tax deduction? Visit our website www.chdtucson.org*



Congenital Heart Defect
FAMILIES OF TUCSON