



Congenital Heart Defect
FAMILIES OF TUCSON

2022

CHD FAMILIES OF TUCSON

LETTER FROM THE BOARD

Navigating through the pandemic and finding our new cadence actually came with ease as our board defined the path forward in 2022. Our main priority has always been to keep our families safe and limit exposure to germs as much as possible. This meant that this year, our typical programs and fundraising events had to be planned and then re-planned. We wanted to make sure that the population in which we serve, immunocompromised children, were staying safe. Nevertheless, when plans changed, we adapted right along with them.

With consistent change comes opportunities for growth, and we dove right in to take advantage of it! We have successfully grown the internal membership in our group, launched a new program recognizing our angel warriors, hosted a very profitable and interactive fundraiser featuring dueling pianos, and brought our community together to hear from the local cardiologists and surgeons on the cardiac landscape in Southern Arizona.

Put a group of powerful, open-minded women together facing tough situations, and you can consider us the Champions of Change. Together we will continue to grow, make an impact, and overcome any adversity to serve our Southern Arizona Heart Community.

Sincerely,
CHD Families of Tucson Board of Directors



CHD FAMILIES OF TUCSON

THE BOARD



Rachel Simmons

Sara Peterson

Kim Levin

Stacy Lipinczyk

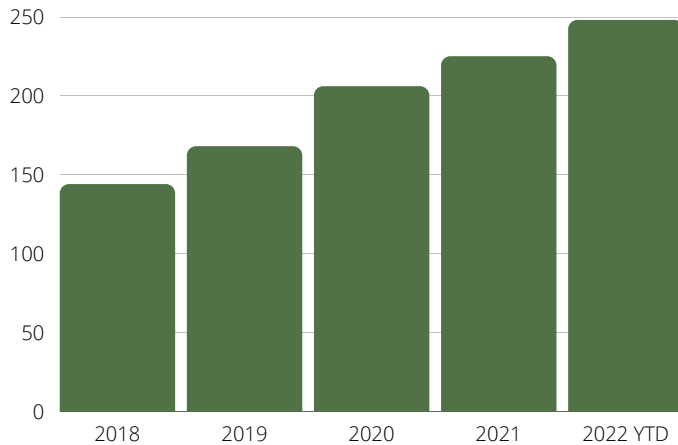
Caroline Ordoñez

Becky Lococo

Jessica Graves

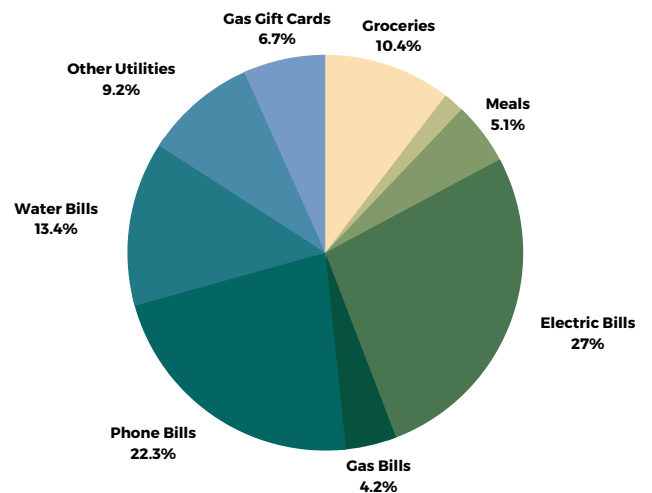
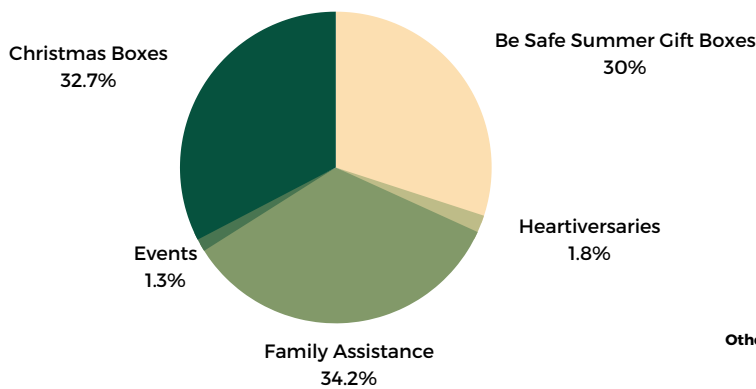
WE ARE ABLE TO CONTINUE TO FULFILL OUR MISSION AND SERVE SOUTHERN ARIZONA HEART FAMILIES BECAUSE OF THIS HARDWORKING, 100% VOLUNTEER LED, BOARD OF WOMEN. WE ARE A UNIQUE ORGANIZATION IN THAT WE DO NOT HAVE LARGE OVERHEAD TO COVER OR SALARIES TO BE PAID. OUR PROFITS DIRECTLY BENEFIT OUR HEART FAMILIES. WE NEVER TAKE FOR GRANTED ALL THE TIME AND EFFORT THESE WOMEN PUT INTO OUR NON-PROFIT, AND WE THANK THEM FROM THE BOTTOM OF OUR HEARTS.

GROWTH MEMBERSHIP



We have seen steady growth within our organization over the last 5 years with a majority of our referrals being made internally and by word of mouth. Our families are eager to share our information and resources when they meet other parents of heart warriors. We consider these referrals a huge compliment and we take great pride in knowing that we are a trusted resource for Southern Arizona Heart Families.

BY THE NUMBERS FINANCIAL SUMMARY



CHD Families of Tucson was able to nearly double the amount spent on families in our 2021-2022 fiscal year. Through our programs like Family Assistance, Be Safe Summer Gift Boxes, and our Christmas giving, CHDFT provided just under \$24,000 to Southern Arizona heart families. Our volunteer-led Board of Directors could not be prouder of the efforts taken this year to ensure our heart families were less impacted by the financial hardships that come with having a heart child in care. CHDFT is thankful to have the generous support of our extraordinary donors who allow CHDFT to operate and provide this financial and emotional support to our Southern Arizona heart families and community.

CARDIOLOGIST CORNER

DR. RYAN JOHNSON

Your kids are Amazing!

As I reflect on 2022, the words that come immediately to mind are amazement and inspiration. I am amazed at the resiliency of children and adults with congenital heart disease and inspired by what they can achieve. For a child or parent of a child with complex congenital heart disease, it is often difficult to think about life beyond the next follow up or echocardiogram but with outcomes of today's surgeries, survival into adulthood is expected. As the number of adults living with congenital heart disease has now well exceeded the number of children with CHD, we have the opportunity to watch our patients and children shape their own lives and impact on our communities. Navigating the ups and downs of life with congenital heart disease, we often tend to focus on what they can't do. While there are sometimes physical limitations and clinically necessary restrictions, we should try at every opportunity to encourage our kids to focus on what they can do. "Through adversity comes triumph" embodies the journey of many patients and families with CHD. I believe sharing some of their triumphs will help the next generation of CHD kids strive to be their best.

We all know the national heart heroes such as Shaun White who was born with Tetralogy of Fallot and went on to become the most decorated Olympic snowboarder of all time, or Arnold Schwarzenegger who was born with aortic valve stenosis requiring multiple valve replacements en route to having a hugely successful body building and acting career and later became the Governor of California. On a personal level, I have been inspired by a former patient that struggled for several years after heart surgery, in and out of the hospital and is now graduating from nursing school and will be working in the CVICU at a major children's hospital. I received her graduation announcement and she talked about how her journey influenced her choice to become a pediatric nurse to help and hopefully inspire others along the way. I am amazed by a former patient who despite complex CHD developed a love of cycling and often rides up Mount Lemmon highway "dropping" many adults along the way. She had the courage to compete in a crit race this year and took first place inspiring us all to shoot for the stars. I have found inspiration on a professional level this year having had the pleasure of meeting Taylor Houlihan who has tricuspid atresia with a Fontan and is in her 4th year of medical school planning to go into pediatrics. She is an amazing voice for CHD and energizes others to live their best life through her social media platform "Fontan with a future". Finally, it was amazing to meet Dr. Thomas Glenn who has HLHS with a Fontan, graduated from the University of Arizona and is now a 3rd year pediatric cardiology fellow at Rady Children's Hospital. Thomas talks passionately about his journey and provides incredible insight to transitional care. He encourages providers and parents to talk with CHD kids early and often about their hopes and dreams and motivate them to not just survive but to thrive despite their chronic illness.

The CHD community is amazingly diverse and full of individual stories of triumph and heartbreak. Through heartbreak often comes advocacy and through triumph comes inspiration. I hope that these stories provide inspiration and an example of the incredible things people can achieve despite having CHD. Please tell your kids to follow their dreams because they are all amazing!

Ryan Johnson, MD
Phoenix Children's Specialty Care - Tucson
Physician Liaison for CHD Families of Tucson



CONNECTING COMMUNITIES

FAMILY CONNECTIONS EVENT 2022

Arguably one of our most popular events amongst our heart families is our Family Connect Dinner. After months of COVID postponements, we were finally able to gather as a single heart community at the Children's Museum of Tucson and invite physicians from our local cardiology and cardiac surgical groups to share their insights on the current landscape of cardiac care in Southern Arizona.

The panel discussions, with questions submitted directly from our members, helped foster the relationships between our CHD community and our care providers, outside of the sterile hospital and clinic environments.

Families also had an opportunity to hear from providers that they may not normally see, but who are working equally as hard to advance the field and deliver the best care possible for every child born with congenital heart defects in Arizona.

After the panel discussions concluded for the evening, parents, heart warriors, and physicians alike had an opportunity to further connect with one another while they explored the exciting exhibits in the museum.

This year's panel included providers from Banner University Medical Center, Phoenix Children's Hospital, as well as Tucson Pediatric Cardiology.



COMMUNITY OUTREACH EVENTS

- Be Safe Summer Gift Boxes
- Community Outreach Committee
 - Mother's Day Brunch
 - Father's Day Top Golf Event
 - Back to School Pool Party



MOTHER'S DAY BRUNCH

We treated many of our wonderful heart moms to a delicious brunch at Locale to celebrate Mother's Day. Great conversations were had, stories were told, and most importantly, personal connections were made amongst our wonderful moms.



FATHER'S DAY TOP GOLF

Heart dads gave it their best shot at Top Golf for a little Father's Day celebration. Developing these bonds and support systems amongst one another is essential when raising a child with complex medical conditions.



BACK TO SCHOOL POOL PARTY

We cannonballed into the start of the school year with our first-ever CHD Pool Party! While our families splashed in the cool water, we were able to distribute resources for school supplies as well as fuel cards to help make sure the school year got off to a great start!



BE SAFE SUMMER GIFT BOXES

Now considered to be a bona fide tradition, our Be Safe Summer Gift Box Program was once again a huge hit this year! We strive to help keep our heart kiddos safe and healthy each summer in the Arizona heat by providing items in our annually-curated box. This year, we included sunscreen, an umbrella, a mini refrigerator to keep medicines and waters cold during road trips or long days of doctors appointments, chapstick, toothbrush and toothpaste, as well as goodies donated by Delta Dental of Arizona, and much more!

CONTINUITY

ONGOING PROGRAMS

HEARTIVERSARY CERTIFICATES

Our Heartiversary Certificates recognize the heroism in each CHD child. Each year, on the anniversary of their first life-saving open heart surgery, we mail them a small gift and a certificate of accomplishment. 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

Every child who comes into this world with a CHD deserves recognition. These children fight the toughest battles and 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 launched in 2022 and we have sent out 2 windchimes to families whose angel warriors have gained their wings. Jennifer Wittman, a heart angel mom herself, continues to lead the program. Our hope is that every time they hear the chime, it will be a soft reminder of their precious angel warrior.



REMINISCING

ROCK YOUR HEART OUT 2022 FUNDRAISER

This year brought the return of our in-person fundraising event! We decided to shake things up by inviting Fun Pianos! Dueling Piano show to perform at our **Rock Your Heart Out** fundraiser at Skyline Country Club.

Guests enjoyed a signature cocktail and appetizers on arrival, took photos in our photo booth, and then enjoyed a delicious dinner and Heart Family story. The grand finale to the evening was a wonderfully interactive dueling piano experience consisting of music, a lot of laughter, singing into spoons, dancing, and a re-enactment of Top Gun's "You've Lost that Lovin' Feelin'."

Thank you to those who joined us! We hope you had as much fun as we did raising money for our Southern Arizona Heart Warriors.



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 as well as 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 CANNOT AND DOES NOT PROVIDE ANY 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 at:
www.chdtucson.org/donate/

FROM OUR HEARTS TO YOURS

A Story About BaBari

In September of 2020, my 9 year old daughter was diagnosed with Pulmonary Hypertension. We traveled back and forth to Phoenix Children's Hospital for care and she was started on several medications, but every time we would go back home, she would not feel well again and we would end up back at Phoenix Children's Hospital. After a CT scan of her lungs in May of 2021 revealed what looked like PVOD (Pulmonary Veno-Occlusive Disease), the doctors immediately had us flown to Texas Children's Hospital. Tests revealed that BaBari had a very rare autoimmune disease called Overlap Syndrome and this included Systemic Scleroderma and Juvenile Dermatomyositis. Little did we know this would be the beginning of a very long journey for us. We were admitted to Texas Children's Hospital ICU in May of 2021 and finally discharged over 1 year later in August of 2022. There were many times that the doctors had lost all hope and tried to prepare us for the worst. BaBari coded 2 times and nearly died. This has been the hardest trial that I as a mother have ever had to endure. Before BaBari became sick, I had my own business and also worked full time for Banner Hospital as an RN. I never needed to ask anyone for financial assistance. Thankfully due to Covid, there was relief for our mortgage or I am sure we would have lost our home. We still had all of our utilities that had to be paid, and that is where CHD Families of Tucson helped us so much. I cannot even begin to say how thankful I am for their support. They paid our utilities for many months, I don't know of any organization that would do that. It was thousands of dollars that they covered for us while I sat by my daughter's bedside. I want to thank everyone in the community who supports this organization. It is the greatest gift that can be given. I cannot imagine having to leave my daughter's side at the hospital to have to go to work. The support of CHD Families of Tucson made it possible for me to stay by her side and give her the support she needed.

Sincerely,
Anna Ganago & Family



THE REASON OUR **COMMUNITY** IS
SUCCESSFUL IS BECAUSE IT
BRINGS TRUE VALUE TO MEMBERS.

THE **COMMUNITY** STARTED
ORGANICALLY FROM USERS. THEN
WE SAW WE COULD NUTURE IT TO
REALLY MAKE IT GROW.

- **VERED RAVIV SCHWARTZ**

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*



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