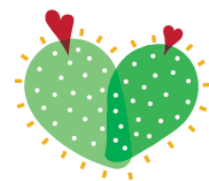




COMMUNITY REPORT

2019 // PREPARED BY THE BOARD OF
DIRECTORS



CHD Families
OF TUCSON

LETTER FROM THE DIRECTORS

To date, 2019 has been our most expansive year yet. CHD Families of Tucson continues to be 100% volunteer-led, but the roles being filled by our four board members in 2018 required nearly full-time attention. We decided that at this pace, the model of working full-time on a volunteer project was not sustainable, so we added three new board members in 2019 to help manage our growing needs. Our new leaders have been instrumental at the helm of our community projects, from Family Assistance to Outreach, and we all have been finding more balance and joy in our efforts as a result.

Speaking of efforts, in 2019 our group membership increased by 27%. As we transitioned from a small organization to a non-profit servicing hundreds of people, we had to find a way to connect families and provide emotional support with a new approach. Our Community Outreach Committee organized quarterly gatherings for families, and we are so impressed with their results. Last year, we were proud of the fact that we had given away nearly \$4,500 through our family assistance program. This year, we are humbled to say that we've given well over \$10,000 through our application process.

Because our giving has increased so much, and our administration costs are still low, we were able to apply for the Arizona State Tax Credit this year, and we were approved on January 1st. We look at this credit as not only a source of revenue, but also a title of credibility given to us by the State after they looked at our operations and financial statements. We are happy to provide you, our donors and supporters, with another layer of accountability as you trust us to care for the pediatric cardiac community. Thank you for continuing to believe in our organization.

Stacy Lipinczyk
Director of Operations

Melissa Nail
Creative Director

Where we are
TODAY

THE 2019 BOARD OF DIRECTORS



Back row (from left): Melissa Nail, Caroline Ordoñez, Jessica Graves, Stacy Lipinczyk

Front row (from left): Becky Lococo, Rachel Simmons, Kimberlee Levin

Photo credit: Jaime Lynn Wendt Photography



Hard at work during the annual strategic planning conference. Helmed by Stacy Lipinczyk, the conference marks the beginning of our fiscal year and sets in motion the programs and budget for the entire year.

The 2019 Chairs of the Community Outreach Committee, Caroline Ordoñez (left) and Rachel Simmons (right)



Our 2019 Fundraising and Events Chair, Sara Peterson, PT, DPT

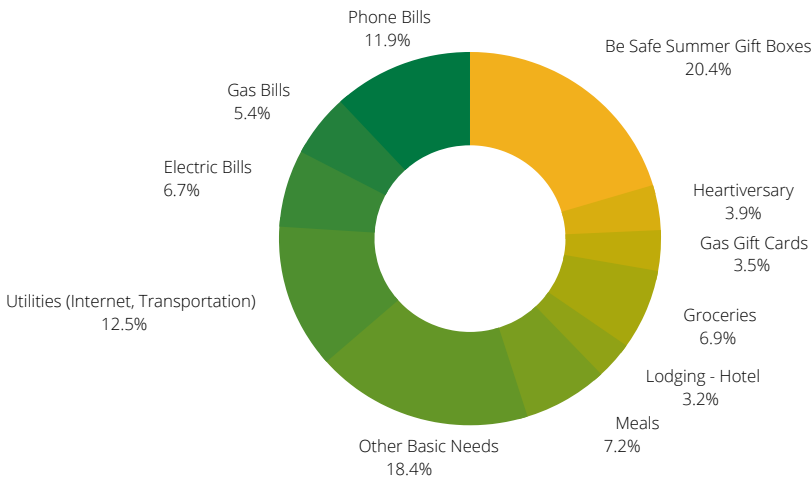
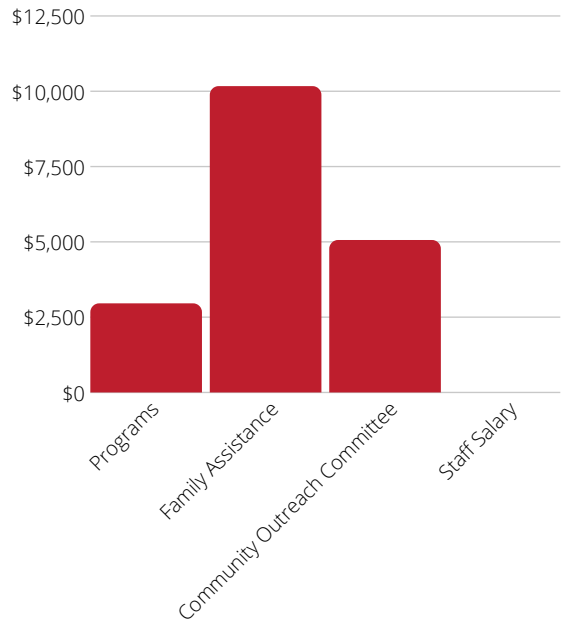


focus on
COMMUNITY



As the theme continues, our operating budget grew tremendously in 2019, all in a positive manner. To help manage our ever growing and more complex financials, we brought on board, Aimee Roberts, a certified public accountant, to assist us. Aimee generates our monthly P & L, inputs all our expenses, provides monthly reports for our board meetings, and manages the overall budget. She humbly volunteers her time to our organization, and we are forever grateful.

We remain a 100% volunteer led board of directors, and we are still proud to say that monies donated go to directly benefit our heart families! As you can see by the graph & pie chart, our family assistance program is the main focus of our dollars spent on a monthly basis. Being granted the status of an Arizona Tax Credit Eligible Organization, allows our donors to give with confidence. As we constantly gain new membership, that need for financial assistance continues to grow.



WHAT KIND OF SUPPORT IS NEEDED?

Overwhelmingly, families ask for help with utility bills. As a board, we review the request and determine if it meets our requirements for tax credit eligibility. The chart to the left breaks down our giving by percentage in order to show our donors and friends how the needs of struggling families are being met.

Our Finance

OVERVIEW



programs

EDUCATION

Advocacy begins with education. Families make better choices for their CHD children when they understand the diagnosis, the risks, and the options on the table.

2019 FAMILY CONNECT



In an effort to make Family Connect as accessible as possible, CHDFT provides a meal and childcare, at no cost, to our CHD families.

2019 CONSULTING PHYSICIAN: DR. BRIAN BLAIR

Throughout the year, we are often asked questions that require educated input. In 2019 we partnered with Dr. Blair to answer some basic questions on pediatric cardiology. His guest blogs (available on our website) answer questions about physical activity and other FAQs.



Many thanks to our 2019 panelists. Back row, clockwise from left: Dr. Blair, Dr. Macias, Dr. Fox, Dr. Seckeler, and Dr. Colombo, shown with members of the Board.

Family Connect is a project we are especially proud of, as it highlights a strength that is specific to Tucson. Once a year, we bring physicians, care team members, and other specialists to highlight their programs and present a picture of the latest and greatest in cardiac care. We congratulate the teams from Banner UMC Cardiology and Phoenix Childrens Hospital for their transparency and their willingness to present directly to parents.



Dr. Blair and his wife, Laura Belleau Esq.

programs

FAMILY ASSISTANCE

Family Assistance is the flagship program of CHDFT. Medical research shows that among families of children with special healthcare needs, parents of children with CHD report a higher prevalence of financial burden than those without. Interestingly, the statistic holds even among families with higher education and a higher reported income. The fact remains, congenital heart defects are costly, and families are fighting with everything they have. At CHDFT, we work to alleviate the burden by providing assistance for basic needs. While parents sit next to hospital beds losing their ability to generate income, we keep lights on, tables filled, gas in the tank, and so on. Having been there ourselves, we understand that removing these stressors is a vital part of the healing process.

Family Assistance Chair, Kim Levin



programs EMOTIONAL SUPPORT

COMMUNITY OUTREACH COMMITTEE

Our Community Outreach Committee brings heart families together on a regular basis. We believe its important for our children to grow up feeling that there are other warriors "just like them" in our area.



The Community Outreach Committee at the "Hero Day" Air Show hosted by Davis Monthan AFB

HEARTIVERSARY CERTIFICATES

Heartiversary Certificates are meant to celebrate the strength and warrior spirit resting in our smallest, toughest fighters. Spearheaded by a teen survivor, this program encourages peer-to-peer interaction.



Teen CHD survivor Haley Hinkle with her parents Courtney and Phillip.

SOCIAL MEDIA

Social Media is one of the first places a newly diagnosed parent will seek out. Our online presence directs families to supportive, accurate, calmly presented information.

"Welcome to the tribe. You are surrounded by survivors, givers and a place to call home. Please let us know if you need anything at all...."
FACEBOOK GROUP MEMBER

LOCAL PRESENCE

Maintaining a **local presence** helps remind other parents and diagnosed children that support is just around the corner. The Board of CHDFT works hard to stay visible and bring attention to the most common birth defect in children.



Directors Stacy Lipinczyk and Melissa Nail on the set of The Morning Blend (KGUN 9)

funding efforts CROONERS & COCKTAILS



Special thanks to our Event Coordinator Sara Peterson (shown with Heart Dad Justin Nail)

Our annual fundraising event was an ode to Rat Pack Era Las Vegas. Guests played casino games, danced, and enjoyed signature cocktails on the deck at Skyline Country Club. Overall, \$30,000 was raised to benefit children born with heart defects.

We could not have had this level of success without our presenting sponsors, Alex and Kimberlee Levin. Thank you for investing in Tucson's heart community!



Event Sponsors Kim and John Levin, with Melissa Nail, Dr. Erica Heitmann, and Presenting Sponsor Alex Levin



We are so grateful for our event photographer Dominic Ortega and his wife, Myriam



Congenital Heart Defect
FAMILIES OF TUCSON

THE CROONERS & COCKTAILS
COMMITTEE WOULD LIKE TO THANK
THE FOLLOWING SPONSORS

Presenting Sponsor

**THE LEVIN FAMILY
FOUNDATION**

Event Sponsors

**LEVIN FUNDING GROUP
PORT OF TUCSON
MRS. MARGARET CONNELLY
SYNCARDIA SYSTEMS
M3 ENGINEERING AND DESIGN**

Table Sponsors

**BOB & SHELLI LIPINCZYK
JOE & TAMI NIETUPSKI
SOUTHERN ARIZONA NETWORK FOR DOWN
SYNDROME (SANDS)
ROB & CINDY BAKER
BOBBY & STACY LIPINCZYK
GADARIAN & CACY PLLC
WILLIAMS AND ASSOCIATES
DR. BRIAN BLAIR
TMC HEALTHCARE
KINNEY JOHNSON**



funding efforts

CHARITY GOLF TOURNAMENT

This year, we were selected as the beneficiary for the Annual Canyon's Crown Charity Golf Tournament. It was a treat to spend time with our favorite CHD golfers and help spread awareness about congenital heart defects to a new crowd. We are so grateful to Erin Stockellburg and the owners of Canyon's Crown. Thank you from the bottom of our hearts for your incredible support!



CANYON'S CROWN
RESTAURANT & PUB



When your tournament falls on the same day as the Kentucky Derby, a golf visor can double as a derby hat.

(Tournament Organizer Erin Stockellburg with Event Speaker Melissa Nail)



Team Dominic from CHD Families of Tucson won the tournament. Talk about playing with heart!

from our hearts to yours FAMILY LETTER



This is what intubation, monitoring, and IV support looks like while a heart baby waits for serious surgical intervention.

August was born October 15, 2018, a seemingly healthy baby boy.

He got sick here and there but recovered quickly. When he was five months old he got sick and it seemed like instead of getting better he got worse. I took him in and out of urgent cares and hospitals and they said he just had a cold. On February 28th I took him to his pediatrician and while they were checking his oxygen level using pulse oximetry the nurse ran out. I got scared. The doctor came in the room and immediately requested an oxygen tank while dialing 911. The next thing you know we are in the ambulance with the sirens on. Doctors at the hospital worked to clear his lungs but he wasn't improving. Nothing worked. Finally they determined that he was going into respiratory failure, and needed to be intubated. I cried as they moved him to the PICU. As the machines worked his lungs, we prayed over him with a priest and discussed options with social workers. I couldn't stop crying. I stood over baby August, watching, when his machine started to beep. His heart had completely stopped. A nurse jumped on him and started CPR and I fell on my knees begging Jesus, "please don't take my baby, please!"

August was diagnosed with an inoperable mass in his heart that was contributing to the failure of his lungs. He required a heart transplant to survive. While he waited for his new heart, he was on a life support system called Extracorporeal Membrane Oxygenation, or ECMO. ECMO is a treatment that uses a pump to circulate blood through an artificial lung back into the bloodstream of a very ill baby. This system provides heart-lung bypass support outside of the baby's body.

My son's diagnosis changed my life forever. A representative from CHD Families of Tucson came over one day while August was on ECMO with a big basket of items that we needed and some groceries. It was such a big surprise it was a great feeling that someone cared. As he recovered, we enrolled in the Family Assistance Program to cover basic needs like transportation, grocery delivery, and utility services. It was actually very simple applying for assistance, it a great foundation and I'm glad to be a part of it. When you've never had a sick child before the adjustment process can make you feel lost and overwhelmed with stress and sadness. It helps to have a foundation by your side that is well known by the care teams at Phoenix Children's Hospital. CHDFT, Thank you for all your kind staff and all your hard work that you do for families that are in need. Thank you for keeping my lights on for my children, Thank you for keeping me from getting my car repossessed. No words can express how thankful for you guys. I know that my son has a long wait but we know that we have help.

from the board SPECIAL THANKS

Our homegrown organization would not be where it is today without the support of a handful of people who mean the world to us. Special thanks go out to:

Steve & Betty Peterson • Joe & Tami Nietupski • Bob & Shelli Lipinczyk • Rick & Paula Sims • The Employees at UPS • Jeanne Scott • The Allreds • The Knox Family • Phoenix Childrens Cardiology • Banner Pediatric Cardiology • Brandy & Brandicus Coleman • Heather Hansen Photography • Jaime Lynn Wendt Photography

We dedicate 2019 to our families. The missed dinners, hectic schedules, and calls are only possible with the help of our supportive husbands and children. We do this for families just like ours. These are the faces that keep our hearts beating.





Congenital Heart Defect

FAMILIES OF TUCSON

MAKE A DIFFERENCE AND HELP CHILDREN BORN WITH A CONGENITAL HEART DEFECT

CHOOSE WHERE YOUR TAX DOLLARS ARE SPENT IN ARIZONA

ASK YOUR TAX PROFESSIONAL ABOUT THE

ARIZONA STATE TAX CREDIT



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