



2021  
Annual  
Report

*The Board of Visitors*   
**ryan house**  
open doors, open hearts



With our **world-class care** and programs, we embrace **all children** and their families as they navigate **life-limiting** or end-of-life **journeys** through:

- ♥ Palliative and respite care that addresses the emotional, spiritual, and social needs of the family
- ♥ Continuity of care from diagnosis to end-of-life
- ♥ Expert care provided by our prestigious care partners and highly-trained staff
- ♥ A loving community that offers ongoing support and compassion

# Thank you for keeping our doors open with your hearts!



## Greetings friends of Ryan House—

I'm Bob Serr, Ryan House Board Chair and grandparent to my adorable 11-year-old granddaughter, Paisley Mae, who has a rare genetic condition that requires 24/7 care from my wife, Pam and me.

We are one of the many

Ryan House families that receive mission-critical care each year. We personally understand the stress and pressure a family goes through caring for a medically fragile child, and the amazing respite and relief that a family experiences knowing that their special kiddo will be well taken care of during a stay. Our Miss Paisley has a ton of fun and is superbly and kindly treated for all her medical needs by care team, while also enjoying all the wonderful activities and volunteers at Ryan House. Knowing Paisley is so well cared for during her visits gives us immense peace of mind so that we can fully enjoy our time away and reenergize.

During the 2020-2021 fiscal year, Ryan House provided 24,816 hours of respite care and supported 135 families through life-limiting or end-of-life journeys. It is your generous support that allows us to provide these critical services free of charge to all Ryan House families.

Ryan House has an amazing partnership with Hospice of the Valley, a compassionate and loving care team, a committed group of volunteers, a professional and engaged leadership team, and a unique and wonderfully diverse and dedicated Board of Directors and Committee Members. They all work diligently to ensure that the support each of you provides is stewarded well to uplift and encourage each of our Ryan House families. Your continued support is so critical and so very appreciated!

*With gratitude,*

**Bob Serr**  
2021-2022 Board Chair



## Hello and welcome to our annual report!

In the past year, Ryan House has been busy welcoming more kids back for respite, including new families coming for their first stay, and more volunteers who graciously give their time to do everything

from playing with the kids to baking in the kitchen.

Ryan House would not be what it is today if it weren't for the support we receive from you, our community. It's because of you that we are able to continue to provide critical care to the children and families we serve as they navigate life limiting or end-of-life journeys. We are deeply grateful!

I am equally grateful to share that while the past few years have been especially hard for so many, Ryan House remains strong and true to its mission. We continue to be the only organization providing this care in Arizona and only one of three in the country.

As you look inside this year's annual report, you'll find feature stories from longtime Ryan House supporter, Mercy Care, a local not-for-profit Medicaid health plan, that has been supporting Ryan House since 2011, as well as a glimpse into the Draper Family's journey which showcases how Ryan House helps to bring even more love and joy to each of them.

You'll also see the impact your support has made this past year as we welcomed and supported hundreds of children and family members into the house while continuing to navigate some of the most challenging times. Thank you for your continued support.

*From our hearts to yours,*

**Tracy Leonard-Warner,**  
MHI, MT-BC  
Executive Director



## 2021 Board of Directors

### Executive Committee

**Kathy Hanley**, Chair  
**Bob Serr**, Vice Chair  
**Rob Maver**, Treasurer  
**Alan Meda**, Secretary  
**Rob Guthrie**, Member at Large  
**Ashley Crowell**, Member at Large

### Members

**Max Bartolomea**  
**Oliver Fultz**  
**Lynn Hoffman**  
**Tom Jarvis**  
**Marc Lerner**  
**Paula Lovesy**  
**Rita Meiser**  
**Michelle Ronan**  
**Shannon Schroeder**  
**Laura Westfall**

### Ex-Officio Members

**Rachel Behrendt**  
DNP, RN, NEA-BC  
Senior Vice President,  
Operations,  
Hospice of the Valley  
**Tracy Leonard-Warner**  
MHI, MT-BC

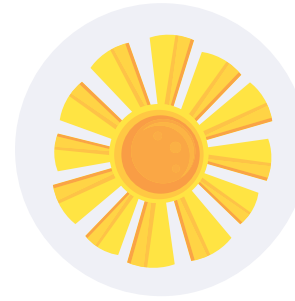


**We are transforming the quality of life for Arizona's most medically complex children.**



### **Respite Care**

Respite care is a gift of time; short-term overnight stays that help a family take breaks from the stress of 24/7 home care.



### **Palliative Care**

Palliative care aims to holistically identify and alleviate the physical, psychosocial, spiritual, and emotional pain for both the child and the family, enhance quality of life and minimize suffering.



### **Pediatric End-of-Life Care**

Families with a child facing end-of-life receive supportive planning and compassionate care consistent with clinical, cultural, and ethical standards.



### **Grief and Bereavement Support**

Along with our partners, we offer Sibling Bridges of Support and Hope, family counseling through various programs, a memorial wall, an annual community event to honor children who have died, and Treasured Memories boxes to families that are filled with special keepsakes.



### **Life-Enhancing Therapeutic Activities**

Certified child life specialist, certified music therapist and trained volunteers provide activities that address the isolation, pain, and fear children and siblings face with diagnosis and improve quality of life.

# Mercy Care & Ryan House

What does a nonprofit offering integrated health care plans to underserved populations have in common with Ryan House? As it turns out - a lot.

Mercy Care, a local not-for-profit Medicaid health plan, has been supporting Ryan House since 2011. Their support has evolved into a programmatic partnership between the two that aligns heart, compassion, and humanity.

Mercy Care's goal is to reinvest in Arizona by supporting organizations that are supporting the community in a significant way. This helps Mercy Care deepen its impact. So, when the opportunity came along to contribute funds specifically for respite care in 2021, through Ryan House's Support-a-Stay program, Mercy Care jumped at the chance to help children and families when they're at their most vulnerable. The result ... a donation which funded respite stays for one child for an entire year totaling \$28,200.

"Ryan House provides such a unique, invaluable service to the community," said Trisha Stuart, director of community relations for Mercy Care. "We wanted to help fill a gap and provide families with the respite they so deeply deserve. We want to help Ryan House give parents peace of mind, and the ability to regroup and refresh."

"If we can give kids and families relief and make them more comfortable, that's one of the best investments we can make in the community," she said.

For more than 35 years, Mercy Care has been diligently working to support community causes, initiatives, and organizations. Its broad network of providers offer physical and behavioral health care services and supports for Medicaid-eligible families, children, including those in foster care, seniors, and individuals with serious mental illness and developmental/cognitive disabilities. Mercy Care also provides access to care for those in their service area who are eligible for Medicaid and Medicare.

Supporting Ryan House in a significant way also aligns with Mercy Care's values, including the need to advance health equity.

"Mercy Care is a health plan with a heart," said Stuart. "Advancing health equity is important to us, especially when we're caring for special populations."

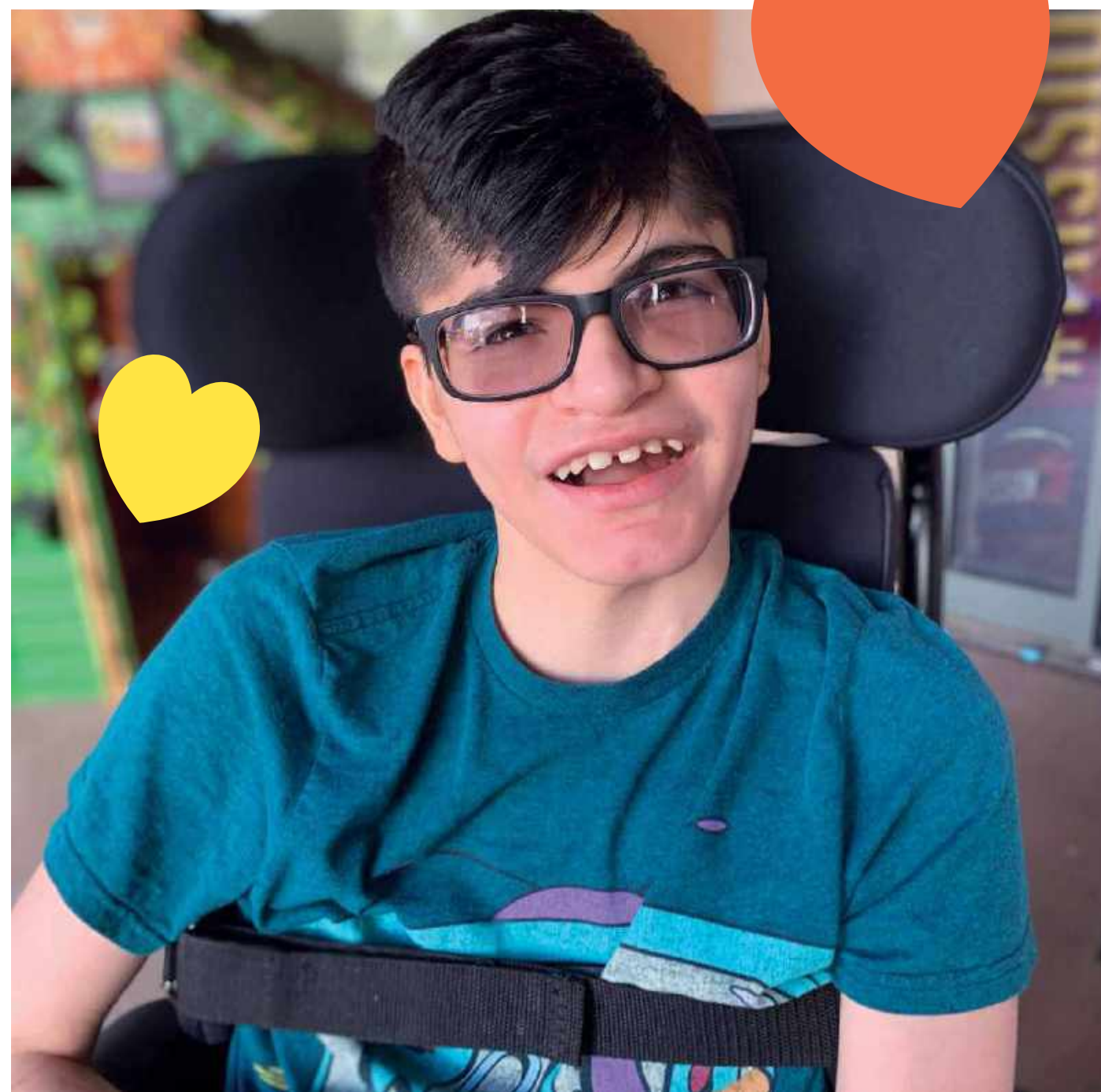
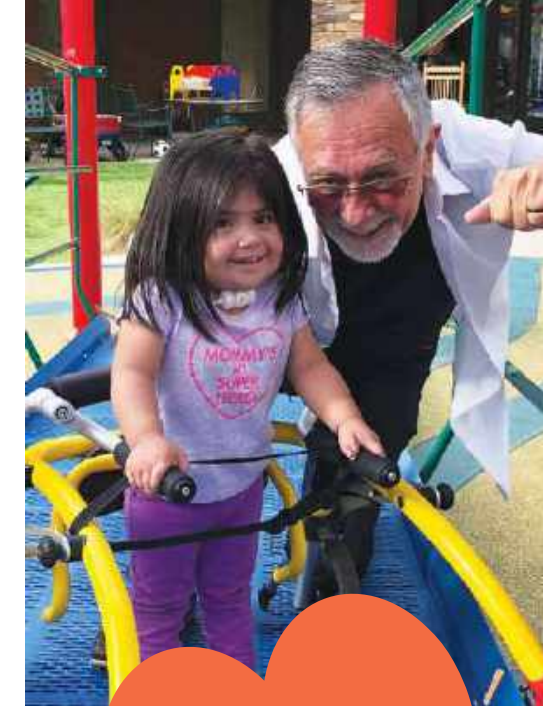
Mercy Care has also supported Ryan House by filling a seat on its Board of Directors. First in 2018 with Marc Lerner, a hearing attorney for Mercy Care. And, when his term ended in 2021, Mercy Care recommended Keeley Dean to fill his spot.

As the Director of Medical Management and Operations at Mercy Care, Dean has a unique skill set and perspective she brings to the Ryan House Board of Directors. In addition, as a long-time supporter of Ryan House, she also has a personal reason for her many contributions over the years. Members of her family, who live out of state, have health conditions that would make Ryan House a perfect place for respite - if only they lived in Arizona. Supporting Ryan House is Dean's way of supporting her family. As the newest Ryan House board member, she looks forward to bringing her expertise, collaboration, and compassion to her role.

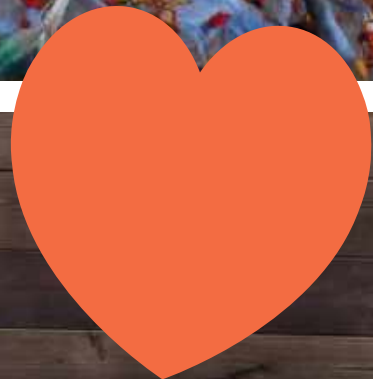
Dean sees how deeply Mercy Care has invested in the community through Ryan House, which is another example of her organization living out its values to the fullest. For Dean, Mercy Care's continued commitment to Ryan House is heartwarming and is a wonderful example of two organizations that care deeply about the people in our community working together.

"We want to help our communities live healthier lives and achieve their full potential," said Dean. "Mercy Care is such a strong supporter of the community, and this is just a perfect match."

"Mercy Care is a health plan with a heart," said Stuart.



Aligning Heart, Compassion, & Humanity



## Five Children Means More Love and Joy for Parents Nicole and Michael Draper

For many, having a big family can be overwhelming. But for Nicole Draper – who has 10 younger siblings – having five children has brought her nothing but more love and joy.

It came as a welcome surprise when she and her husband, Michael, already the parents of a 5-year-old and 4-year-old twins, found out they were expecting their second set of twins, two identical boys.

Their joy turned to concern when Nick and Nate were both diagnosed with dilated cardiomyopathy in utero; they were born in 2005 with this rare, severe heart condition. At the time, no doctors in Arizona were performing infant heart transplants, so the family temporarily relocated to Los Angeles. But how would they ever decide which child would receive a new heart first?

Thankfully, they didn't have to make that impossible decision. On the way to L.A., Nate developed hemorrhaging in his brain, so he was not eligible to receive a heart immediately. Nick stayed in the hospital, finally receiving his long-awaited heart after seven agonizing months, then remained hospitalized for additional treatment. Nate was discharged for a short time but got sicker and had to return to the hospital; as time passed, he made enough progress to no longer need a transplant! After almost a full year, both boys were cleared to go home.

As the boys got older, it became clear they were delayed in their development. At three years old, Nick had multiple seizures, and upon further testing, doctors discovered the boys had nuclear mitochondrial disease, a genetic condition that affects how the body produces energy at a cellular level.

This didn't stop the Drapers from ensuring that their two youngest boys lived their fullest and happiest lives possible. In addition, their adoring siblings Caitlin, and twins Brendan and Emma, were learning empathy, hard work and independence because of having two brothers with medically complex conditions.

Nick – who always had the more severe complications – met with a palliative care team as he was getting a tracheostomy. "Do you know about Ryan House?" they asked. Nicole didn't and was stunned to learn about

an amazing resource like Ryan House that offered overnight respite care for up to seven nights at a time. "Why didn't anyone tell me?" she wondered, thinking it sounded too good to be true.

When they first visited Ryan House with Nick and Nate in 2014, she and her husband looked around in wonder. The outdoor playground, music room, kind nurses and volunteers, and constant activity stood out as distinct first impressions. During stays at Ryan House, the boys also enjoyed the big shady porch, swimming in the pool, music therapy, and walks.

"I always felt like they were having a staycation at Ryan House," Nicole recalled. Many of the facility's features, like the giant bathtub, were more accessible to maneuver than what they had at home.

More recently, Nick's energy levels began to dip. He was sleeping more, experiencing breathing and GI issues, and was in and out of the hospital often. Sadly, Nick passed away in August 2021 at 16.

"Nick was tired, and we expected it at some point, but were not really ready for his passing," she said. "We deeply miss his cute smile and fun personality, but he is no longer suffering or stuck in limbo and that is a huge blessing."

The entire family takes comfort in knowing that Nick is no longer in pain. Each of the siblings has been inspired by their brothers in various ways and has found ways to keep Nick in their hearts. His sisters, Caitlin, and Emma are pursuing careers in healthcare, and Caitlin is a regular Ryan House volunteer. Caitlin, Emma, and Brendan love their brothers so much and now devote all their attention to Nate. Nate continues to have respite stays at Ryan House and enjoys his time there immensely.

"Through the years, Ryan House has given us the opportunity to have meaningful, typical family time and escapes that we wouldn't have been able to experience without that kind of help," she said. "The staff have always given me peace of mind knowing that the boys are well taken care of and doing activities they love, which has really helped me to not feel bad or guilty about leaving them there for a much-needed respite."

# Who We Serve



In FY 21, **298** children and families were enrolled in our respite program. Ryan House provided **24,816** hours of respite care to **90** children with life-limiting conditions and supported **45** children and their families at end-of-life.

Approximately **91%** of the children qualifying for services at Ryan House reside in Maricopa County.

**100% of families** would recommend Ryan House to their family and friends

**100% of families** are able to participate in activities that are meaningful to them

**100% of caregivers** experience less stress and anxiety

**100% of families** feel connected to a community of support

# FY21 Financial Snapshot

## Assets

	2021	2020
Current Assets	\$ 5,835,887	\$ 4,663,351
Long Term Assets	\$ 219,561	\$ 198,729
<b>Total Assets</b>	<b>\$ 6,055,448</b>	<b>\$ 4,862,080</b>

## Liabilities

Current Liabilities	\$ 352,027	\$ 352,882
<b>Total Liabilities</b>	<b>\$ 352,027</b>	<b>\$ 646,653*</b>

## Net Assets

Without Donor Restrictions	\$ 4,784,027	\$ 3,999,374
With Donor Restrictions	\$ 919,394	\$ 216,053
<b>Total Net Assets</b>	<b>\$ 5,703,421</b>	<b>\$ 4,215,427</b>

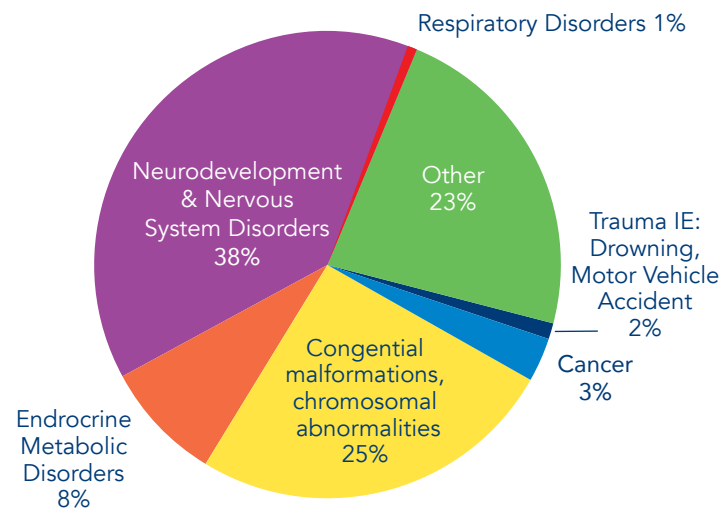
**Total Liabilities and Net Assets** \$ 6,055,448 \$ 4,862,080

\*Includes Paycheck Protection Program Loan

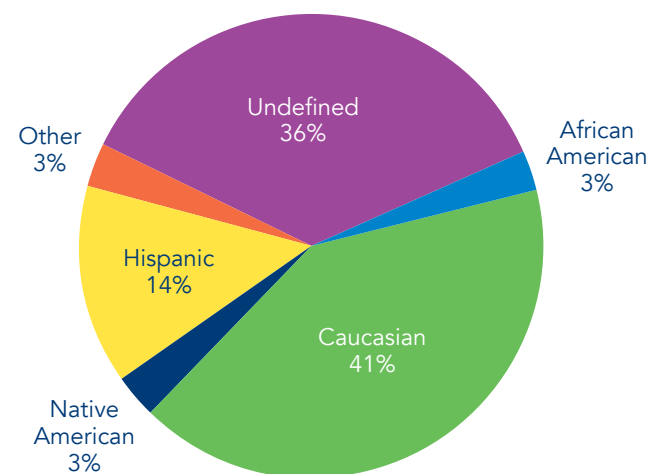
Statement of Activities for the Year Ended September 30, 2021

<b>Total Support and Revenue</b>	<b>\$ 4,376,667</b>	<b>\$ 2,729,770</b>
<b>Total Expenses</b>	<b>\$ 2,888,673</b>	<b>\$ 2,852,097</b>
<b>Change in Net Assets</b>	<b>\$ 1,487,994</b>	<b>\$ (122,327)</b>

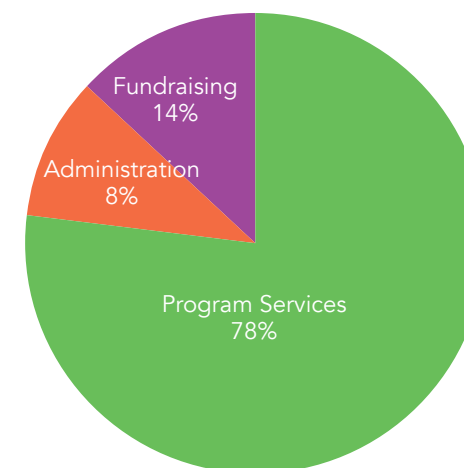
FY 21 Diagnoses



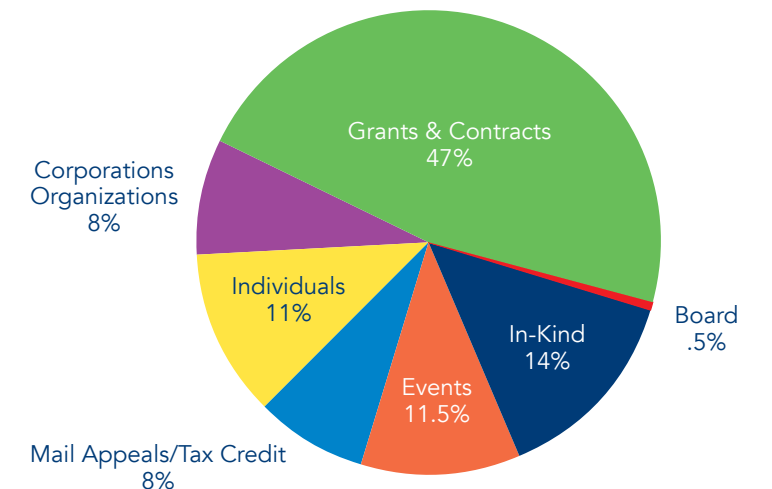
Race



Expense Allocations



Sources of Operating Support & Revenue



We are honored to recognize our most generous donors since our founding in **2004**. This group has supported the children and families of Ryan House with cumulative gifts or pledges or qualifying planned gifts of **\$25,000** or more through September 30, 2021.



## Lifetime Giving Honor Roll



### Over \$1,000,000

Arizona Department of Health Services  
The Board of Visitors  
Hospice of the Valley  
Virginia G. Piper Charitable Trust

### \$500,000 - \$999,999

Gila River Indian Community  
The Kemper & Ethel Marley Foundation  
Three Desert Winds Foundation  
Thunderbirds Charities

### \$100,000 - \$499,999

Arizona Biz Bash Inc  
Arizona Central Credit Union  
Arizona Diamondbacks  
Arizona Elks Major Projects  
Bank of America  
BHHS Legacy Foundation  
Blue Cross Blue Shield of AZ  
Paul Chait Memorial Golf Tournament  
Community Health Charities

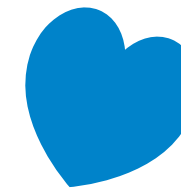
The DeMatteis Family Foundation  
Entercom  
Executive Council Charities & The SAY Campaign  
Fiesta Bowl  
Karen & Robert C. Hobbs, Sr.  
Lynn Hoffman  
The Humana Foundation  
Junior League of Phoenix  
Kitchell Corporation  
LaneTerralver  
Media That Deelivers  
Phoenix Suns Charities  
Bob Powers  
John and Alice Powers Foundation  
Nina Mason Pulliam Charitable Trust  
The Estate of F Theodore & Diane E Reid  
Judy & Bill Schubert  
The Steele Foundation  
True Story Films  
ViaSun  
Joy Wili/Pam & Bob Serr/Paisley Mae Foundation

### \$50,000 - \$99,999

Arizona Coyotes Foundation  
Arizona Eastern Star Foundation  
Arizona Public Service  
Cristina & Trevor Chait  
The Charro Foundation  
Jessica Jennifer Cohen Foundation II  
David & Ruth S Coleman Foundation  
Sharon & Robert Cottor, M.D.  
DC Ranch Community Foundation - Heartstrings  
Dutch Bros. Coffee West Valley  
Diane & John Eckstein, M.D.  
Edra Drake  
Fort McDowell Yavapai Nation  
Gases and Welding Distributors Association  
Jacque Weiss & Richard Glazer, D.M.D.  
Kathleen & Michael Hanley  
IFDA  
JPMorgan Chase Bank, N.A.  
Mercy Care  
Love Abounds Foundation  
Doris Lumsden Foundation  
McDonough Corporation  
The Moreno Family Foundation  
Jill & Gene Nagel  
National Bank of Arizona  
Otto & Edna Neely Foundation  
Karrie & James F. Pierson, III  
John Propstra  
Leslie Propstra  
Joan C. Ray Charitable Foundation  
The David E Reese Family Foundation  
The Estate of Rocco Emma  
Shutterfly  
Kristin & Drew Stanton  
Faye & Tom Tait  
Thompson/McCarthy Coffee Co.  
United States Tennis Association, Inc.  
Western Alliance Bank of Arizona  
West Valley Lutheran Thrift Shop  
Alan D. & Wendy R. Wilson Foundation  
Marylou & Carlos J. Zilveti

### \$25,000 - \$49,999

Patricia & Patrick Althoff  
Arciterra  
Arizona Commercial Real Estate Women  
The Arizona Republic  
Azadi  
Bashas'  
Nancy & George Bogle  
Judith & Budd Busche  
Cardinals Charities  
Shirley C. Caris Family Foundation  
Susie & Wally Chester  
Clean Machine Car Wash LLC  
CopperPoint Mutual Insurance Company  
Holly & Jonathan Cottor



Cox Charities  
Davidson Family Foundation  
Davignon Charitable Fund  
Dignity Health  
DC Ranch Community Council  
Karen & David Divine  
Jacquie & Bennett Dorrance  
Colleen & Jim Edwards  
Elks National Foundation  
Excellence in Giving  
The Alberta B. Farrington Foundation  
Ira Gaines & Cheryl Hintzen Gaines  
Goodwill of Central & Northern Arizona  
Christine & Robert Guthrie  
The Bruce T. Halle Family Foundation  
Nancy & Lee\* Hanley  
Susan & Richard Hare Family Foundation  
Patrick Harlan  
Nicole & Michael Hazen  
Jeanne & Gary\* Herberger  
Jane & Mario Iacobelli  
Kappa Kappa Gamma – Epsilon Delta  
The Keller Foundation  
Randy & Earl G. Kendrick, Jr.  
J.W. Kieckhefer Foundation  
Liam's Room  
Louis Legacy Foundation  
Major League Conditioning  
Ina & Murray Manaster  
Larry H. Miller Charities  
MM Brand Agency, LLC  
Connie Moore  
Michelle & Marc Morris  
The Pakis Family Foundation  
The Bob and Renee Parsons Foundation  
William L. & Ruth T. Pendleton Memorial Fund  
City of Phoenix  
PGA Tour, Inc.  
The Power Open, Inc  
Ryan Companies  
SRP  
Southwest Gas Corporation  
Werner Schumacher  
Suzanne Sikora  
Liz & Christopher Sokolowski  
Anne & James W. Spellman  
Sundt Construction  
TriWest Healthcare Alliance  
Lynn & Chip Tolleson  
US Airways  
Valley Anesthesiology Foundation  
Vitalyst  
The Walmart Foundation  
Cindy & Michael Watts  
The Wayne Foundation  
Cindy & Paul Weiser  
Wentworth Property Company  
Diane Willian  
Willmeng Construction



\*In Memoriam





**ryanhouse.org**

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We are 100% funded by donations. As a registered 501(c)(3) and Arizona qualifying charitable organization, any donation made, including your Arizona charitable tax credit, is tax deductible. Allocating your donation to Ryan House serves as a lifeline to our families.

As a 501(c)(3), Ryan House is eligible to receive stocks, bequests and legacy gifts.  
Please call (602) 200-0767 for more information.