

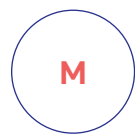
Small Steps



# Big Impact

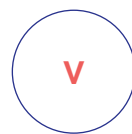
Fred's Footsteps





- Our MISSION -

Fred's Footsteps provides a bridge of financial support for working families in the greater Philadelphia region who find themselves in crisis due to the costs associated with caring for a seriously ill, injured, or disabled child.



- Our VISION -

So a child's care can be a parent's only worry.

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The Team



## Dear Fred's Footsteps Community,

2022 was a year of growth for Fred's Footsteps. In addition to our team growing, our committees and board set their sights on the future. But most notable is how our program grew to accommodate **40% more families.**

### STAFF

This year, we added a full-time Operations and Systems Coordinator to the Fred's Footsteps staff, Kate Slider. In addition, we've shored up resources in event planning and execution, and social media to ensure the team at Fred's is poised to serve the growing demand of families in need.

### BOARD

We laid the groundwork for a more diverse and inclusive Board of Directors – with the expectation of beginning to reach these goals in the next fiscal year. In addition, we updated board governance policies and agreed to undertake a new strategic plan in 2023 to ensure our executive leadership team is in the best position to support the growth of Fred's Footsteps through our upcoming 20th anniversary and beyond.

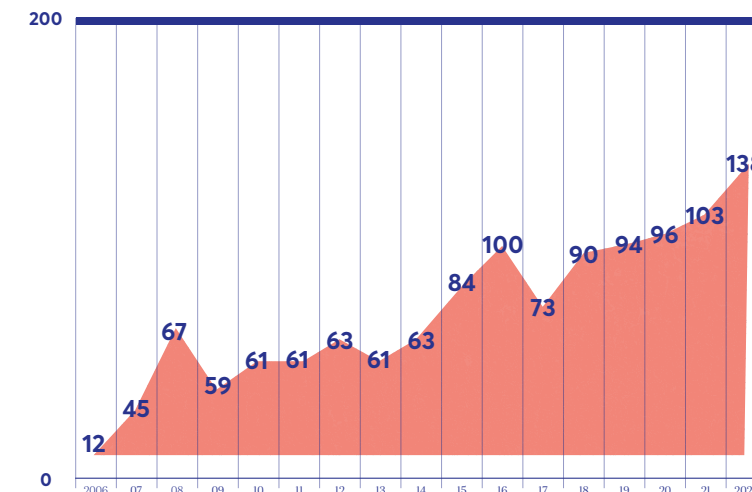
### FAMILIES

In 2022, we served 138 families. That's a nearly 40% increase from 2021's record of 103 families. This service equates to over \$800,000 in household bills, rent, and mortgages, home modifications, accessible transportation, and other non-medical bills: an organizational record.

#### How were we able to meet this influx in family need?

With the additional staff resources who worked tirelessly with each family to tailor our financial support to their most pressing needs. In addition, our new, streamlined application process implemented in 2021 more efficiently guides social

Families Accepted by Year



workers representing our families through our process, and allows for greater access to our program. Also, our dedicated Grant Advisory Committee worked overtime to read and vet the additional applications each month.

**Most importantly, this was made possible through the generosity of corporate and community partners, donors, and supporters.** Supporting additional families means raising additional funds, and this community has shown up for us – and our families – like never before.

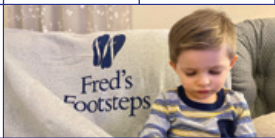
We thank you all,

*Sylvia & Christine*

Sylvia DiBona & Christine DiBona Lobley



# The financial impact of caring for a medically-complex child



Over 50% of in-home nursing shifts for medically-complex children are unable to be covered due to the nursing shortage<sup>1</sup>

Families with medically-complex children spend, on average, 5X the amount on health care expenses compared to more typical families<sup>2</sup>

<sup>1</sup> Burling, S. "The pandemic has created a 'crisis' in home care, keeping some kids from leaving the hospital: 'It's like these babies are in jail.'" *The Philadelphia Inquirer*. May 23, 2021.

<sup>2</sup> Sidra, M., Sebastiani, M., et. al. Reported costs of children with medical complexity—A systematic review. *Journal of Child Health Care*. June 2022.

Only 13% of Americans have access to paid family leave<sup>3</sup>

According to a study by *The Journal of Pediatrics*, more than 54% of families with a medically-complex child reported that a family member stopped working as a result of their child's health<sup>4</sup>

<sup>3</sup> Mehta, D. "How to Ask for Maternity or Paternity Leave When Your Company Has No Policy." *The New York Times*. April 2020.

<sup>4</sup> Thomas, J., Shah, S.S., & Simmons, J. Financial and Social Hardships in Families of Children with Medical Complexity. *The Journal of Pediatrics*. May 2016.

Parents of children with special healthcare needs miss double the workdays per year than parents without a special needs child<sup>5</sup>

Half of U.S. adults don't have the cash to cover an unexpected \$500 health care bill, according to a nationwide poll conducted by the Kaiser Family Foundation<sup>6</sup>

<sup>5</sup> Liptak, et al. Impact of Caring for Children with Special Health Care Needs on the Workforce: Implications for Out-of-Pocket Costs and Work Supports. *National Survey of Children with Special Health Care Needs (NS-CSHCN)*. 2008.

<sup>6</sup> Lopez, L., Kearny, A., Montero, A., et al. Health Care Debt In The U.S.: The Broad Consequences Of Medical And Dental Bills. *Kaiser Family Foundation*. June 2022.

Medical debt is now the most common form of debt on consumer credit records<sup>6</sup>

Families with a child who is ventilator dependent saw an average monthly increase of \$437 in their utility bills<sup>7</sup>

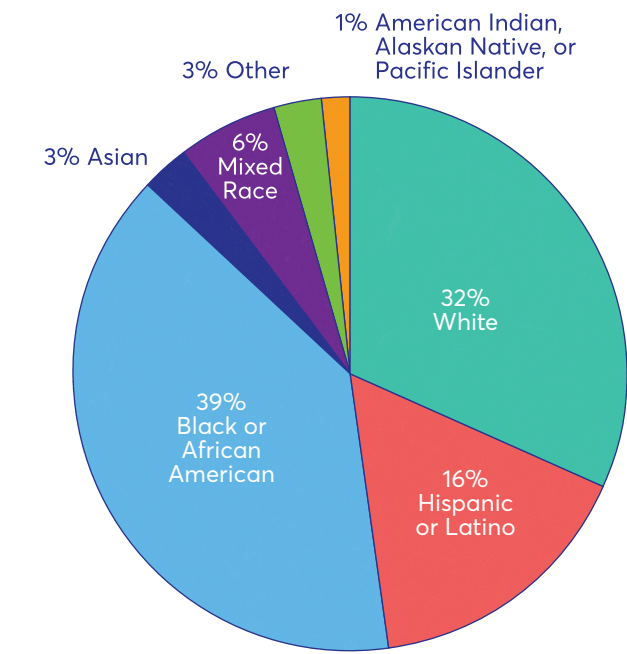
<sup>7</sup> Carroll, C., Seid, M., Adams, W., & Freytag, R. Electricity Costs Associated with Home Mechanical Ventilation. *Journal of Pediatrics*. 2005.



# Who are Fred's Footsteps families?

In 2022, we served 138 families. That's a nearly 40% increase from 2021's record of 103 families.

## Race

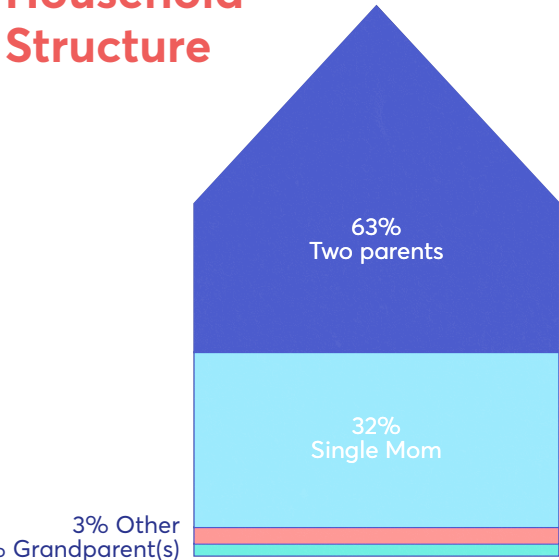


## Diagnosis

Prematurity	20%
Neurology	13%
Trauma (Gunshot, car accident, etc.)	12%
Congenital	10%
Cancer	10%
Pulmonology	8%
Cardiac	7%
Renal/Kidney	6%
Cerebral Palsy	4%
Hematology	4%
Orthopedic	2%
Gastroenterology	2%
Other	2%

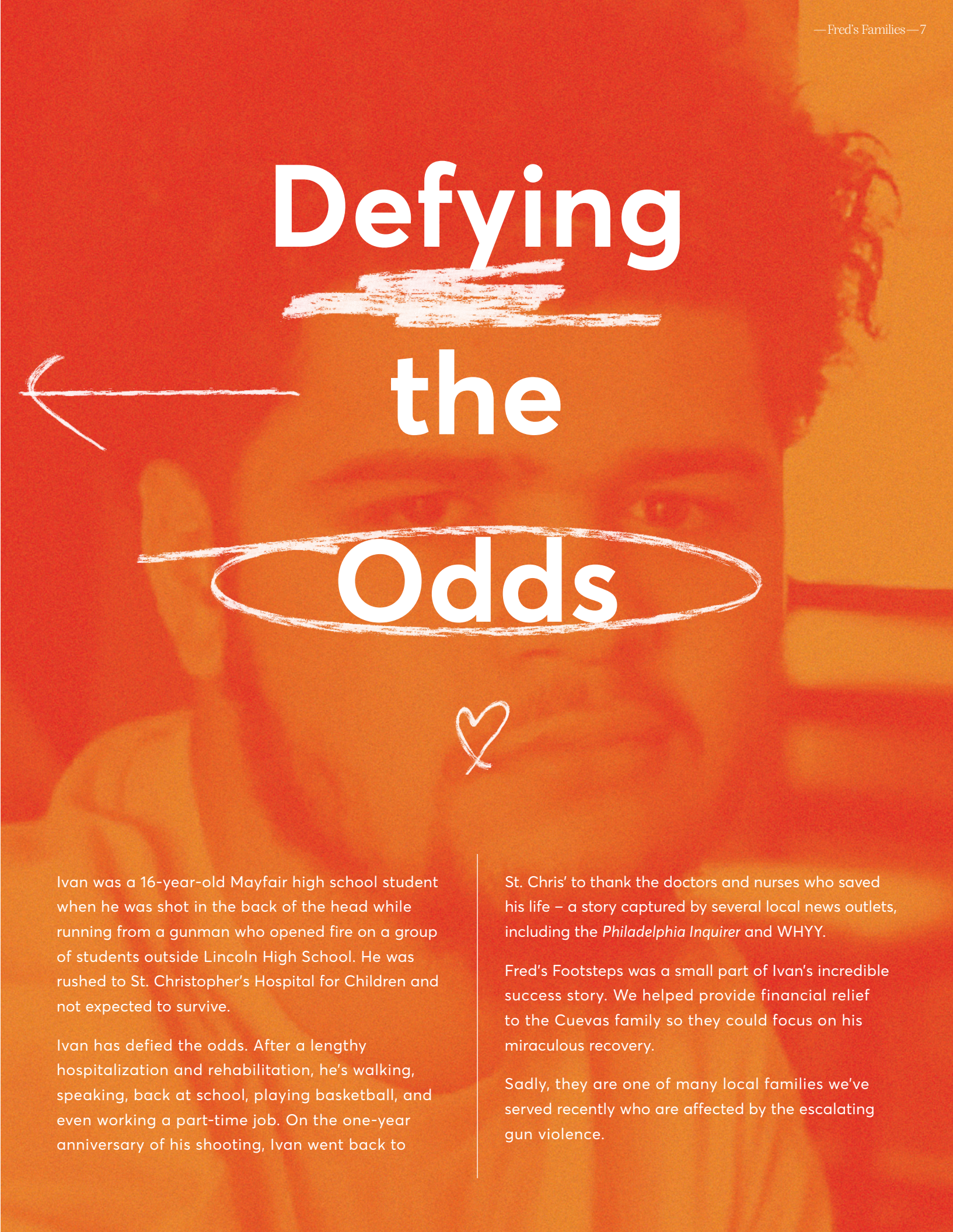
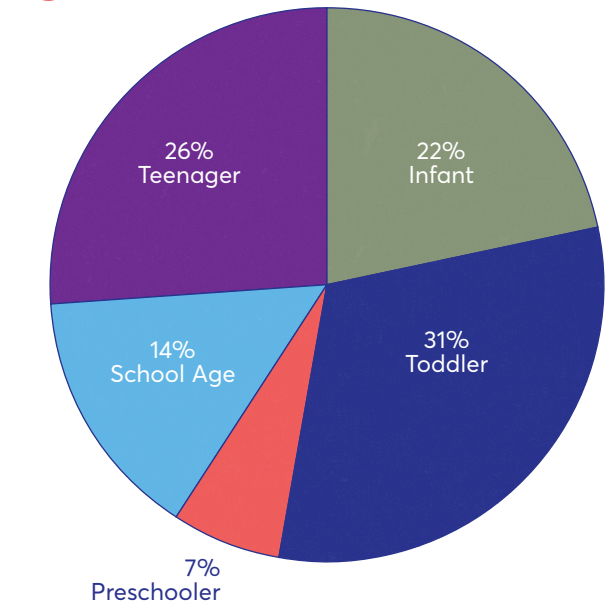
Since 2020, Fred's Footsteps has seen a 142% increase in trauma applications.

## Household Structure



Over 35% of the children in our program are cared for by a single mom, grandparent, or other caregiver.

## Age



# Defying the Odds

Ivan was a 16-year-old Mayfair high school student when he was shot in the back of the head while running from a gunman who opened fire on a group of students outside Lincoln High School. He was rushed to St. Christopher's Hospital for Children and not expected to survive.

Ivan has defied the odds. After a lengthy hospitalization and rehabilitation, he's walking, speaking, back at school, playing basketball, and even working a part-time job. On the one-year anniversary of his shooting, Ivan went back to

St. Chris' to thank the doctors and nurses who saved his life – a story captured by several local news outlets, including the *Philadelphia Inquirer* and WHYY.

Fred's Footsteps was a small part of Ivan's incredible success story. We helped provide financial relief to the Cuevas family so they could focus on his miraculous recovery.

Sadly, they are one of many local families we've served recently who are affected by the escalating gun violence.

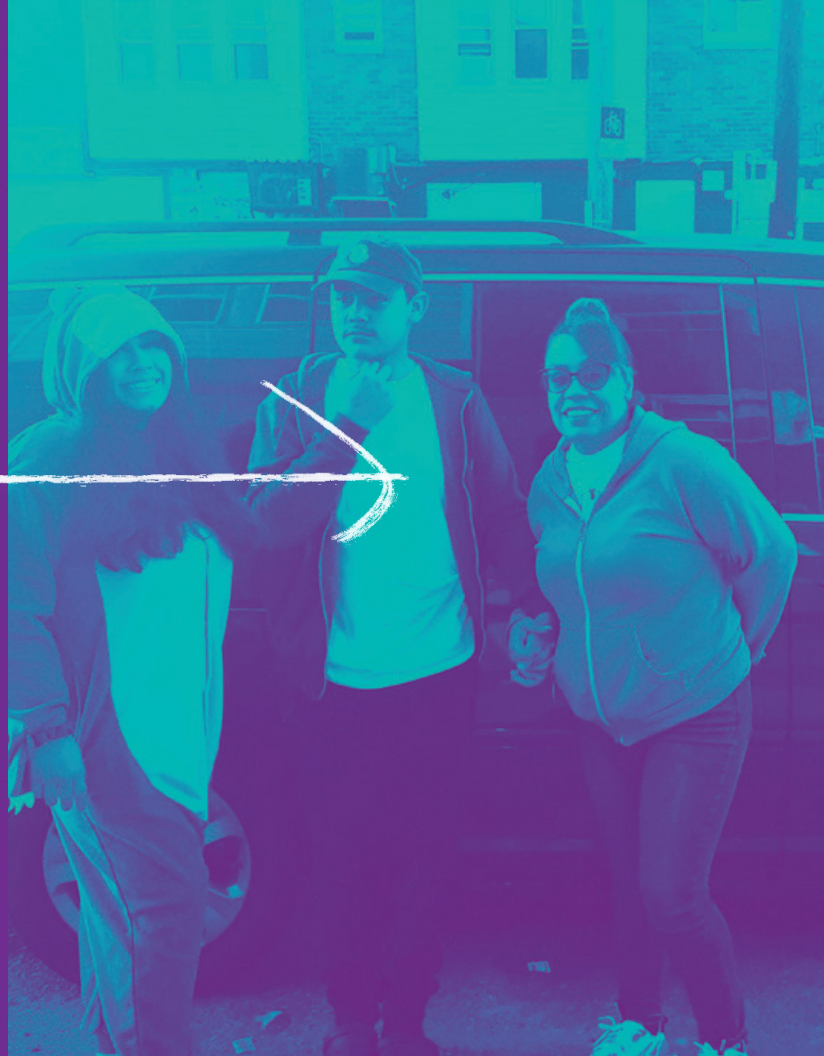




"I really do not know what we would have done without your organization. Being able to be at the hospital, and not have to worry about how I'm going to keep food on the table and a roof over our heads with your mortgage assistance was such a relief and much appreciated. I had to take a leave of absence from work to be at Cecelia's side. Without Fred's Footsteps, I would not have been able to be with my daughter. I am forever grateful for you."

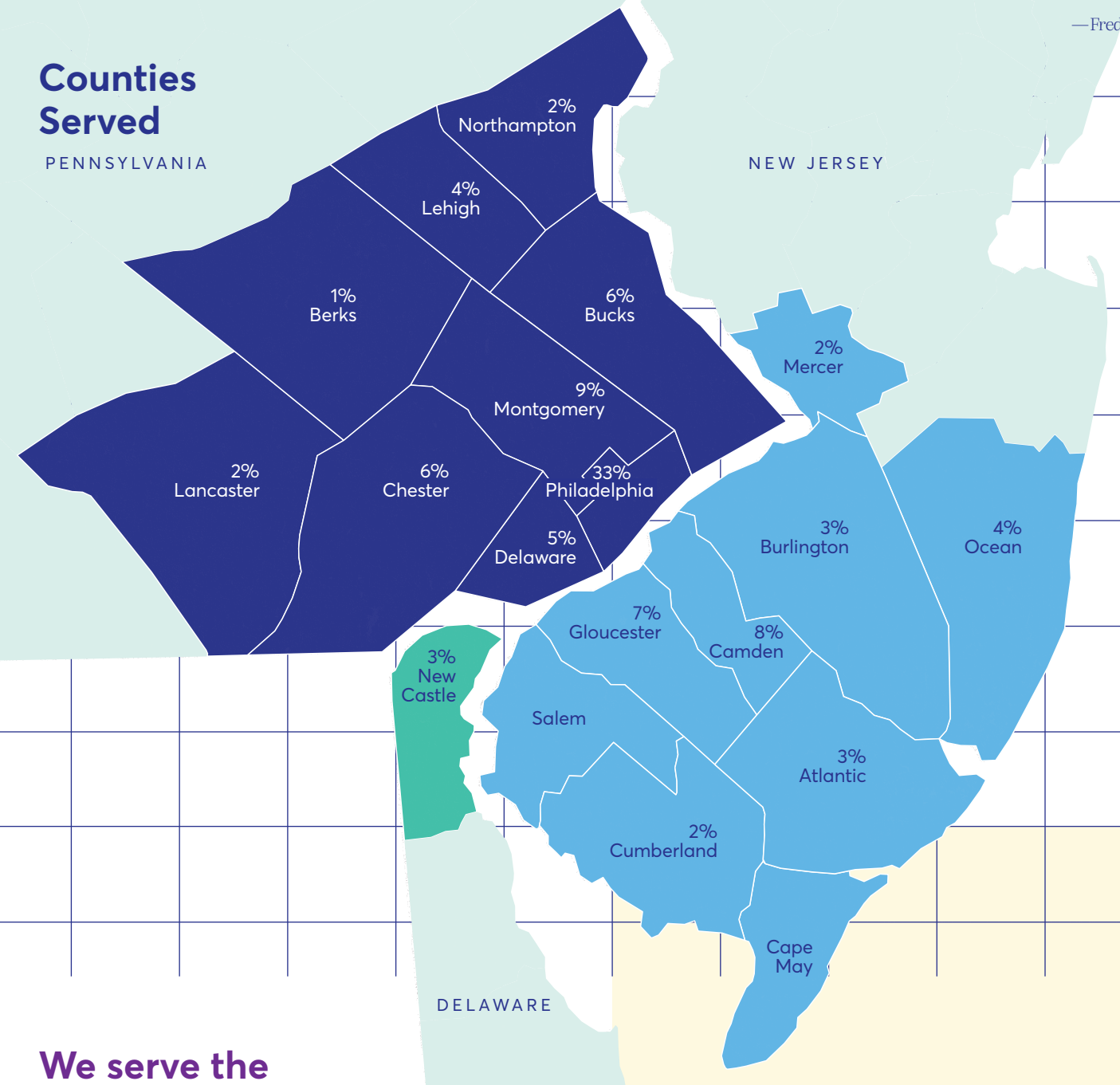


"Your organization has not only truly changed my son Gilbert's life, but our family's as well. We were able to purchase a van with your support, and we also received a gift card to help with his school supplies. We no longer have to worry about getting reliable transportation to and from school or his appointments. He can experience the outside world and know he too is a part of it! Please know that what you all do is change lives and make such an impact in people's hearts."



## Counties Served

PENNSYLVANIA



## We serve the ALICE community

### Asset Limited, Income Constrained, and Employed

These are people working hard to make ends meet. They often earn too much money to qualify for government assistance, yet barely enough to provide even basic necessities for their families. Add a seriously ill, injured, or disabled child to this delicate balancing act, and a financial crisis is inevitable – making our work in this community so imperative.

Over 75% of our families in 2022 fell below the "ALICE" line, meaning they are one emergency away from a financial crisis.

*Alice in Focus: Children. United Way of Pennsylvania. April 2022.*

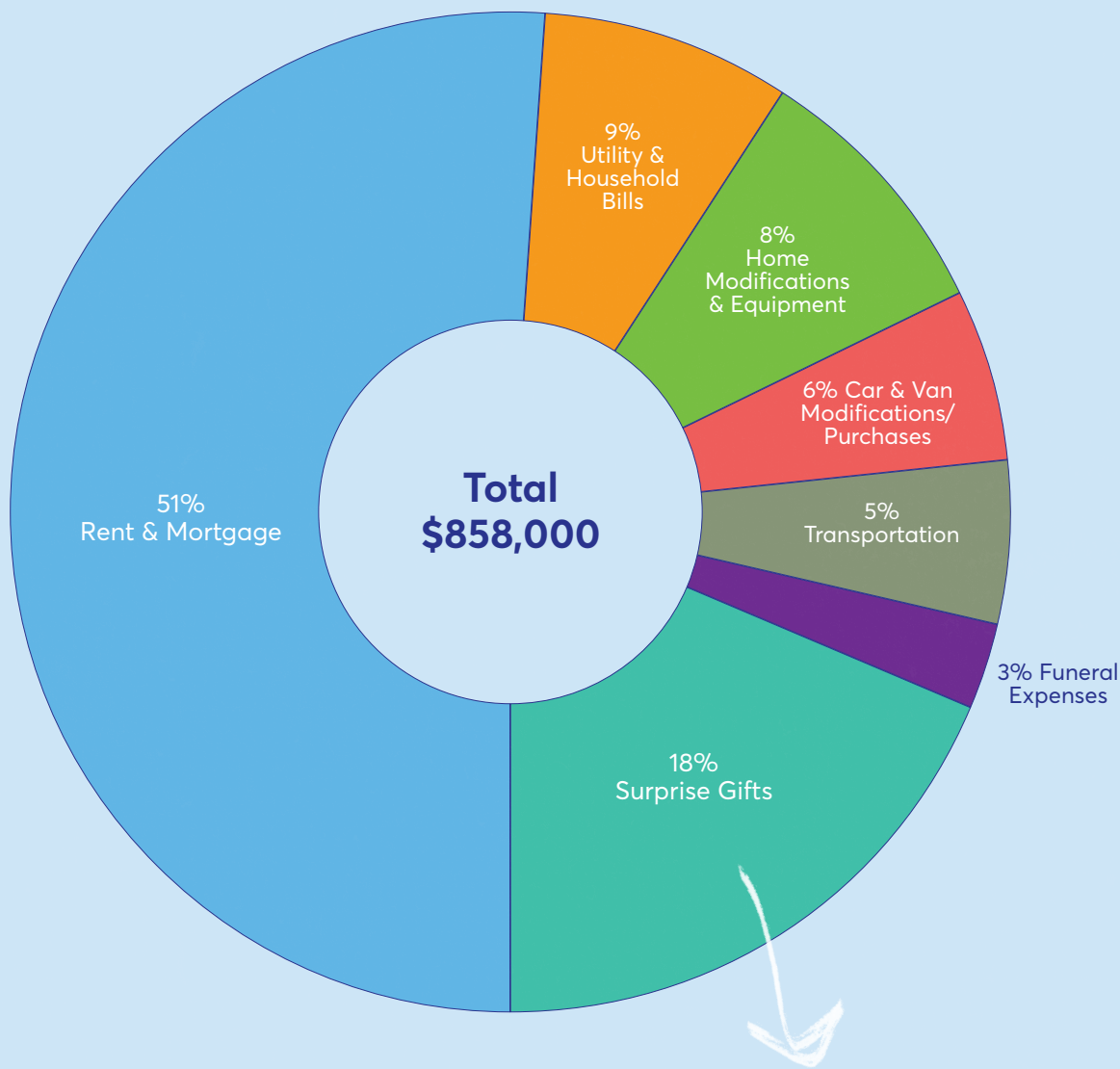
Statistics are helpful to paint a picture, but the reality is each percentage point you see represents **a family**—one whose life has been upended by their child's illness. Each has their own story of love, worry, grit, and resilience, and each family has turned to us for help.

**Because of you**, we are part of their story of hope.



# What did your generosity fund?

In 2022, our support to local families totaled \$858,000, an organizational record!



Four times over the course of the year, families receive a **surprise gift** from Fred’s Footsteps: Spring, back-to-school, Thanksgiving, and winter holidays.

Each of these represents a difficult time of year for families struggling to make ends meet due to the financial strain of their child’s medical needs. Fred’s Footsteps is able to alleviate some of the pressures

each season brings so our families can catch their breath. In addition to a branded gift, the package always includes a generous gift card to top retailers or grocery chains to allow the families the dignity to shop for themselves.

This represents a significant portion of our budget, and has an equally meaningful impact on our families.

# Giving the gift of time

Gavin was born with chronic kidney disease and lived with it his entire life. But in fall of 2022, the time came that a transplant was needed. Fortunately, his mom, JoAnn, was a match and able to donate. However, as a single parent, this necessitated a leave from work, creating a financial hardship for the family. Fred’s Footsteps assisted with rent and car payments to help them over this bump.

“With the help of Fred’s Footsteps, I was able to concentrate on both Gavin’s and my own recovery from transplant without worry of how I would pay my rent, or if I would lose my car. We are forever grateful for the generosity, kindness, and hope that Fred’s Footsteps shared with us.”

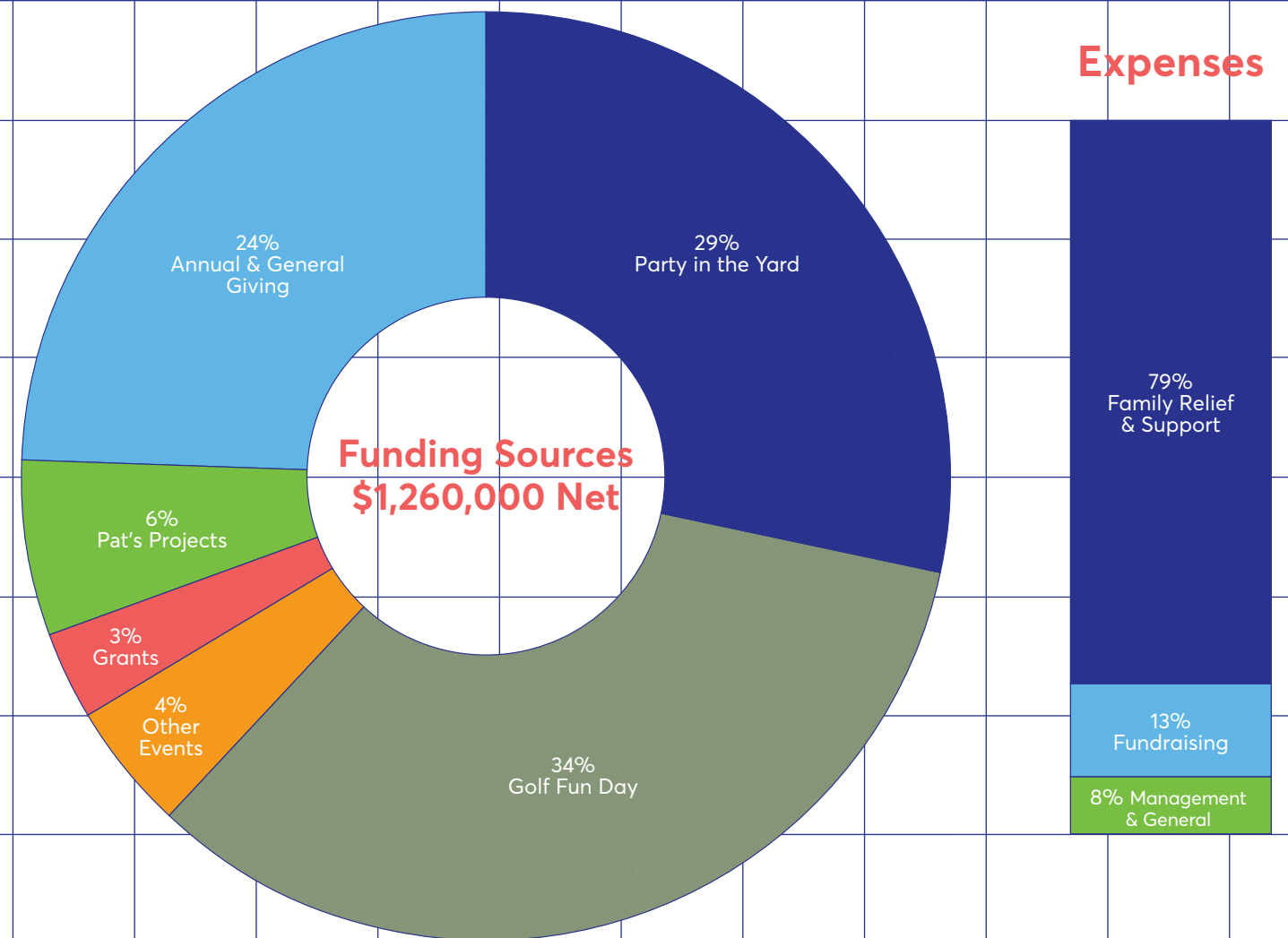


“Thank you for the incredibly generous gifts for Christmas. It really made a huge difference in what I could do for my kids. Things have been really tight. I know I was not alone in worrying about how we were going to make it happen this year. I was able to do the ‘Mommy’ thing and the ‘Santa’ thing and not stress about it. Your gift made a world of difference.”

“Our new home took some of Wilfredo’s independence away due to [cerebral palsy and] safety issues in the bathroom, but Fred’s Footsteps gave it back by allowing Wilfredo to get the bathroom remodeled to meet his safety needs. We are so very thankful to Fred’s Footsteps for helping Wilfredo resume the task of using the bathroom, still with assistance, but with some independence because it is now wider and safer.”

## Financials

Fred’s Footsteps is deeply committed to financial accountability and transparency. We recognize the trust our donors put into us with each and every donation.





# Fierce, brave, and bold

Leonardo Flores Mendiola was born on July 17, 2022 to loving and adoring parents, Ricardo and Mariela. At first he seemed to be a healthy, bouncing, baby boy, but as complications arose in his first hours of life, he was quickly moved to the NICU, then transferred to CHOP for more specialized care. The family remained at the CHOP NICU while Leo's care team worked to determine a cause of his distress.

Finally, genetic testing came back. At three weeks of age, Leo's diagnosis hit the family hard; it was a rare genetic condition called mitochondrial DNA depletion syndrome associated with DGUOK gene. They were told their baby boy would have only one year to live. The family was devastated receiving this terminal diagnosis.

Nevertheless, seven weeks after his birth, Ricardo and Mariela had a moment of joy when the family was able to bring him home for the first time. While they were excited, it was also intensely overwhelming. As the family shared, there was a lot of learning, arranging, medications, and complex care – including feedings every 3 hours

around the clock. Then there was the marathon of doctors' appointments and emergency hospital visits as Leo's health began to decline.

Ricardo and Mariela were Leo's champions throughout it all. They went to the ends of the earth searching for a treatment path for their son. They left no stone unturned. Ricardo was in discussion with gene therapy researchers in England, along with a team in Australia, Spain, and Washington state trying to find potential alternative avenues of care. They even brought Leo to Pittsburgh for a second opinion. The opinion was the same as the first; Leo was not a candidate for a liver transplant. There was nothing more they could do to save his life.

As Ricardo explains, they were determined to do something. But sometimes doing nothing is a course of action. "Sometimes doing something is doing nothing." But, Ricardo shares, "It was hard to let go."

Sadly, at the end of 2022, Leo's condition worsened and he was admitted back to the hospital. Leo passed away on January 2, 2023 at 5 months old.

"Your support bought us more time with our son. If it were not for Fred's Footsteps, we would not have been able to be with him as much time as we were, and that would have been something we could never have gotten back. You helped us out tremendously. We had so much going on, but you allowed us to focus on our son. Our minds were focused on him, spending time with him, and getting his needs met. We didn't have to worry about our financials or having a place to live. We have so much gratitude, from the bottom of our hearts."

"Leo's was a bright light that shined in the hearts of all who knew him. He had a smile that could soften any heart and fill it with joy. His personality was true to his name – fierce, brave, and bold. He fought many battles and came out victorious. His will never wavered in the face of adversity. Leo will be remembered for the love that he inspired in people's hearts and for his loving smile. His passing has touched many hearts and has taught us to be fierce, brave and bold in our everyday lives."

*In loving memory of*  
**Leonardo Flores Mendiola**  
July 17, 2022–January 2, 2023

No family story from 2022 better represents our mission, vision, and heart like Leo's. This family's story embodies advocacy, resourcefulness, resilience, tenacity, and love. The Fred's Footsteps team thanks the Flores Mendiolas for sharing Leo's life and story so graciously with our community.

Ricardo overheard another family discussing Fred's Footsteps in the hospital waiting room, became curious, and looked us up. He thought it was worth a chance and asked Leo's social worker to apply for support.

Fred's Footsteps initially funded 3 months of rent while Leo was in the NICU, and a few more once he was moved to palliative care. And when the time came, we helped with the funeral expenses.

Ricardo and Mariela share their story to raise awareness of Leo's rare condition, destigmatize the grieving process, and help other families going through medical crises.





## Fred's Supporters

Our heartfelt thanks to our donors who consistently show up for our families

## \$50,000 AND UP

Sylvia DiBona & Family  
Exelon  
Independence Blue Cross

**\$25,000 – \$49,999**

## Accenture

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Every effort has been made to ensure an accurate and up-to-date recognition list of our donors. Please contact our Development team to report any errors or omissions. Thank you!



# Introducing Pat's Projects

Supporting home-accessibility projects



**Pat's Projects** is a dedicated fund for home modifications within the Fred's Footsteps organization. It honors the legacy of our founding Board of Directors member and cherished friend of Fred's, **Patrick B. Gillespie, Sr.** Pat's Projects supports home renovation and accessibility projects that provide safety and independence for children in our program.

Patrick B. Gillespie, Sr. was a founding member of the Fred's Footsteps Board of Directors, serving for over 17 years until his death on August 29, 2022. He was Fred DiBona's dearest and most cherished friend who, together with his wife, Arlene, and their children, became one of our organization's most dedicated supporters.

Pat was a longtime business manager for the Philadelphia Building and Construction Trades Council, former Pennsylvania state representative, and Army Vet. He forever changed the physical and economic landscape of the Philadelphia region.

## PAT'S PROJECTS INCLUDE:

**Bathroom renovations** to improve accessibility with adaptations such as larger space and doorways, roll-in shower, grab bars, lowered sink, and other needs, all helping a child or young person receive the dignity of care in a safe and private environment, as well as improve the caregivers' ability to help care for them.

**Wheelchair ramps, lifts, and stair/chair glides** to allow a child to safely enter and exit their home, securely move from upstairs to downstairs, and be more engaged in their living space and the outside world.

**In-home equipment** such as Hoyer lifts, ceiling track systems, and specialized beds for a child to be moved, and sleep safely in their home, and to assist their caregivers with these needs.

# Board of Directors

Board as of May 2023, \*Fellows Board Seat

- Sylvia DiBona**  
Board Chair, Fred's Footsteps
- Christine DiBona Lobley**  
Executive Director, Fred's Footsteps
- Michael A. Bova**  
Managing Director, Accenture
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Principal, DiBona Associates, LLC
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- Patrick Gillespie, Jr.**  
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CEO, tango
- Juan Lopez, CPA**  
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- William Sautter**  
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- Molly Watson**  
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# Fred's Footsteps Staff

- Christine DiBona Lobley**  
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Director of Strategy and Marketing
- Kate Slider**  
Operations and Systems Coordinator
- Diane Smith-Hoban, MSW**  
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- Marie Vacca**  
Director of Development
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