

THE  
**SUSIE**  
FOUNDATION

# Annual Report

2025



[TheSusieFoundation.org](https://TheSusieFoundation.org)





# Our Impact

We provided 109 Flex Grant Awards to offset the financial burdens faced by families living with ALS throughout New England.





# Our Impact

These Flex Grants totaled  
\$67,000.45 of support  
provided directly to ALS  
families in-need throughout  
New England.





# Who These Grants Have Helped

- **62.1 years old** was the average age of our grant recipients this year. Our youngest recipient was 26 years old and our oldest recipient had just celebrated her 88th birthday.
- **4.7 years** is the length of time that our average grant recipient has been living with ALS. We granted funds to those newly diagnosed, as well as those living with ALS for more than 24 years.
- **20.8% of Flex Grant recipients** either had dependent children at home or were relying on their child/children as their primary source of home caregiving support.





# Why These Grants Are Needed

- **\$150,000 - \$200,000** is the estimated annual cost of on-going care for an individual living with ALS (Obermann, M., & Lyon, M., 2014).
- **98.4% of Flex Grant recipients** require physical assistance from caregivers in order to complete at least one activity of daily living.
- **62.1% of families that received Flex Grant funding** earned less than 200% of the federal poverty level for their county.

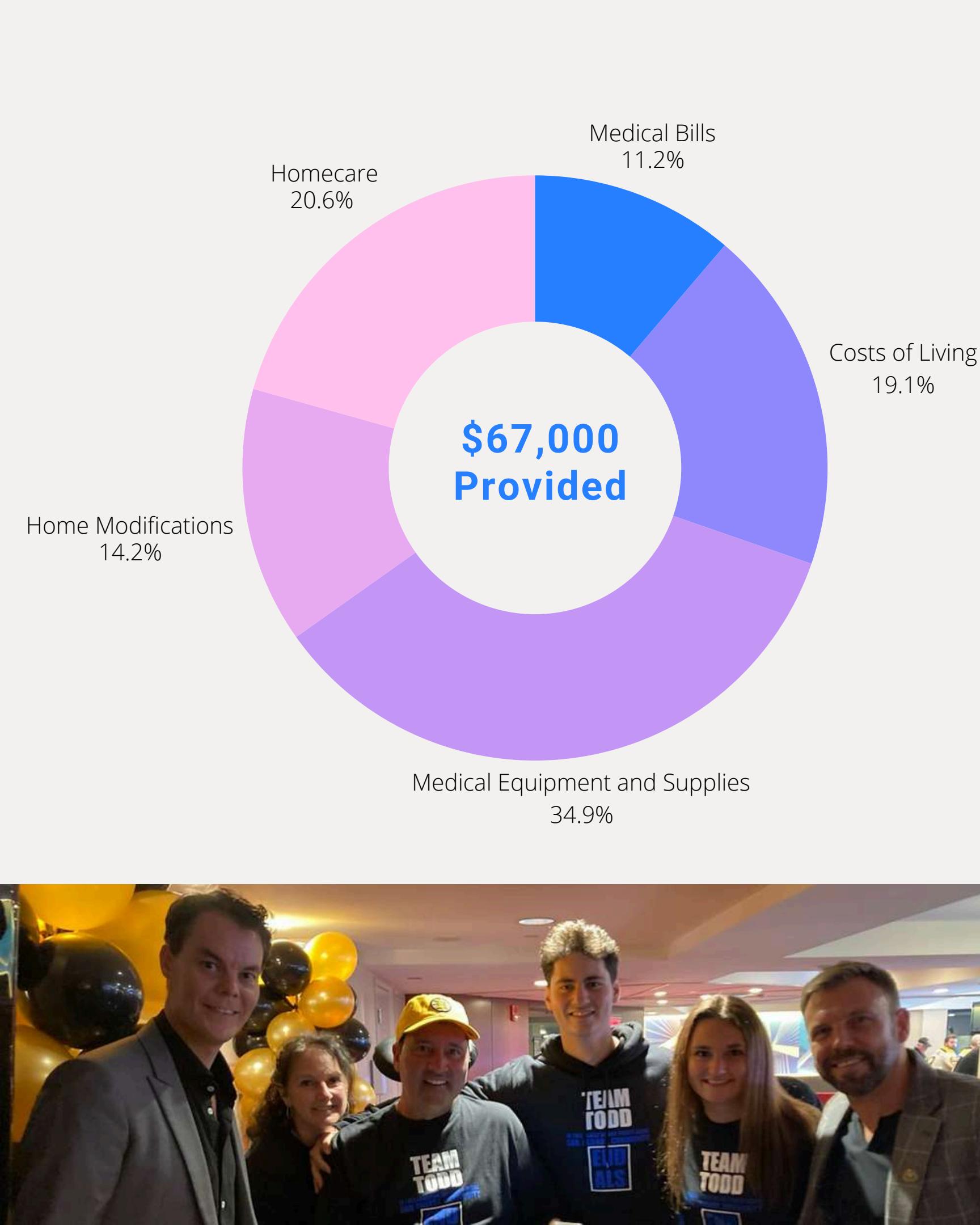




# What These Grants Have Purchased

- **\$23,375.20 (34.9%)** helped families afford durable medical equipment (e.g., wheelchairs, assistive technology, stair lift, adjustable bedding) and supplies.
- **\$13,832.40 (20.6%)** helped families afford in-home healthcare services that support the activities of daily living (e.g., showering, meals physical therapy)
- **\$12,776.10 (19.1%)** helped families afford the costs of living (e.g., rent, mortgage, utility bills) that help them remain living safely in their homes.





# What These Grants Have Purchased

The Flex Grant Program continues to serve as a cornerstone of The Susie Foundation's mission, delivering critical, direct support to families facing the daily realities of ALS. By reducing the financial burden of care, we help families prioritize what matters most: time together, safety, and dignity at home.

In 2024, the Flex Grant Program disbursed \$23,375.20 (34.9% of total grant expenses) toward durable medical equipment—enhancing mobility, independence, and quality of life. Another \$13,832.40 (20.6%) supported vital in-home healthcare services, ensuring families had the daily support they need. An additional \$12,776.10 (19.1%) helped cover essential living expenses, such as rent and utilities, allowing families to remain in safe, accessible environments.



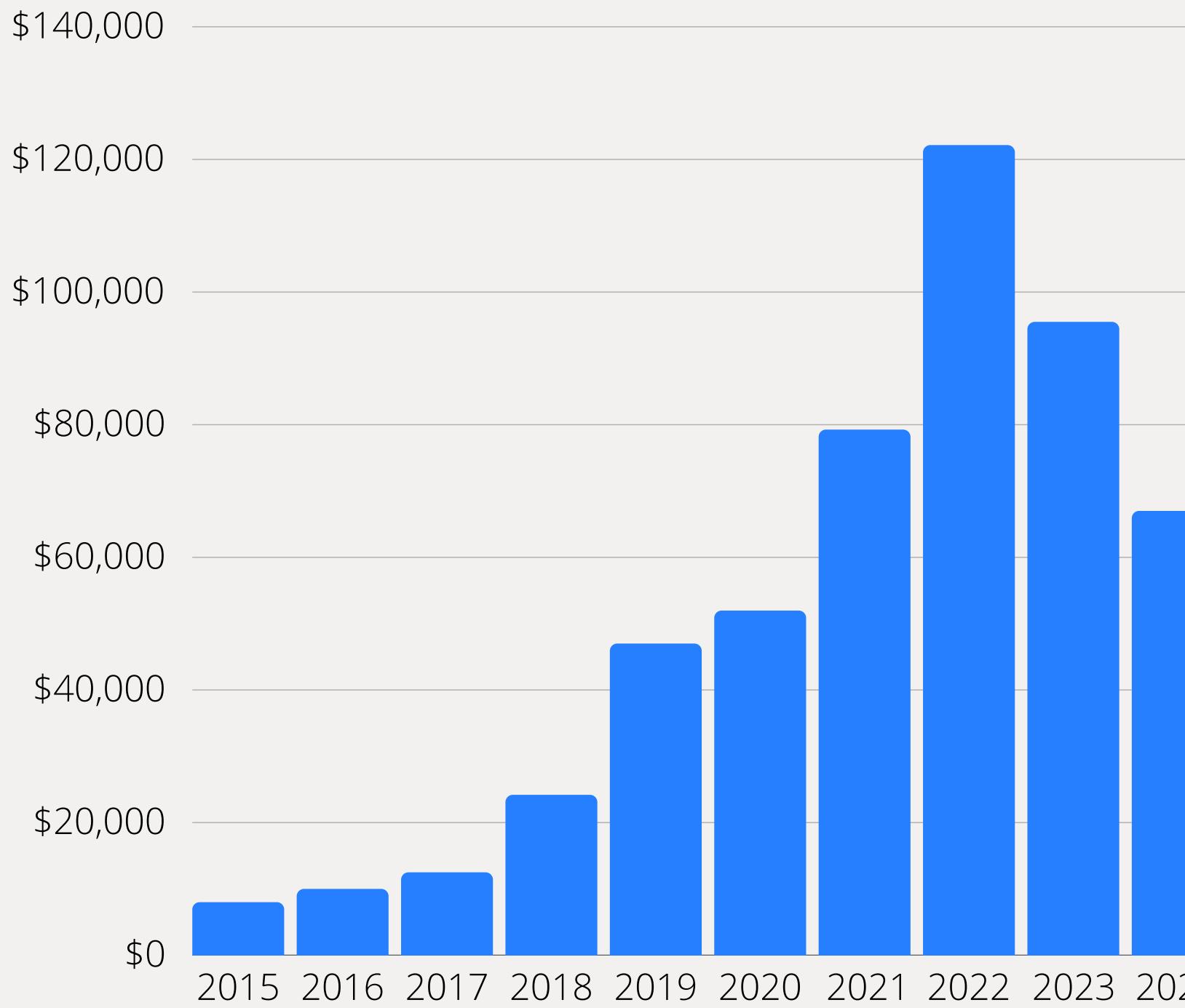


# The Impact These Grants Have Made



- **97% of Flex Grant recipients** reported that the funding they received help to improve their overall quality of life.
- **66% of Flex Grant recipients** reported that the funding they received help to improve their overall independence.
- **63% of Flex Grant recipients** reported that the funding they received help to improve their overall independence.

● Annual Support Provided to Families



# Our History of Impact

Launched with a vision to provide tangible, direct support to those grappling with the financial strains of living with ALS, our Flex Grant Program has become a beacon of hope and support for many. **To date, we have disbursed \$524,224 directly to 605 families throughout New England.**

The Flex Grant Program's impact extends far beyond financial assistance; it embodies the spirit of community and shared humanity that stands at the core of our mission. By providing crucial support for expenses not covered by insurance or other aid programs, the Flex Grant Program has enabled families to navigate the challenges of ALS with greater ease and less financial strain.

The true impact of this support is best captured in the words of the families we serve. Their stories illustrate the power of your generosity — and the lasting difference it makes each day.





# Feedback from Families

We know that a little support can make an extraordinary difference. Through the Flex Grant Program, we help families living with ALS reclaim comfort, dignity, and precious time together. In their own words, our recipients share how your generosity has brought hope and strength to their journeys.



## **Michaela Shoemaker, Jamestown, Rhode Island**

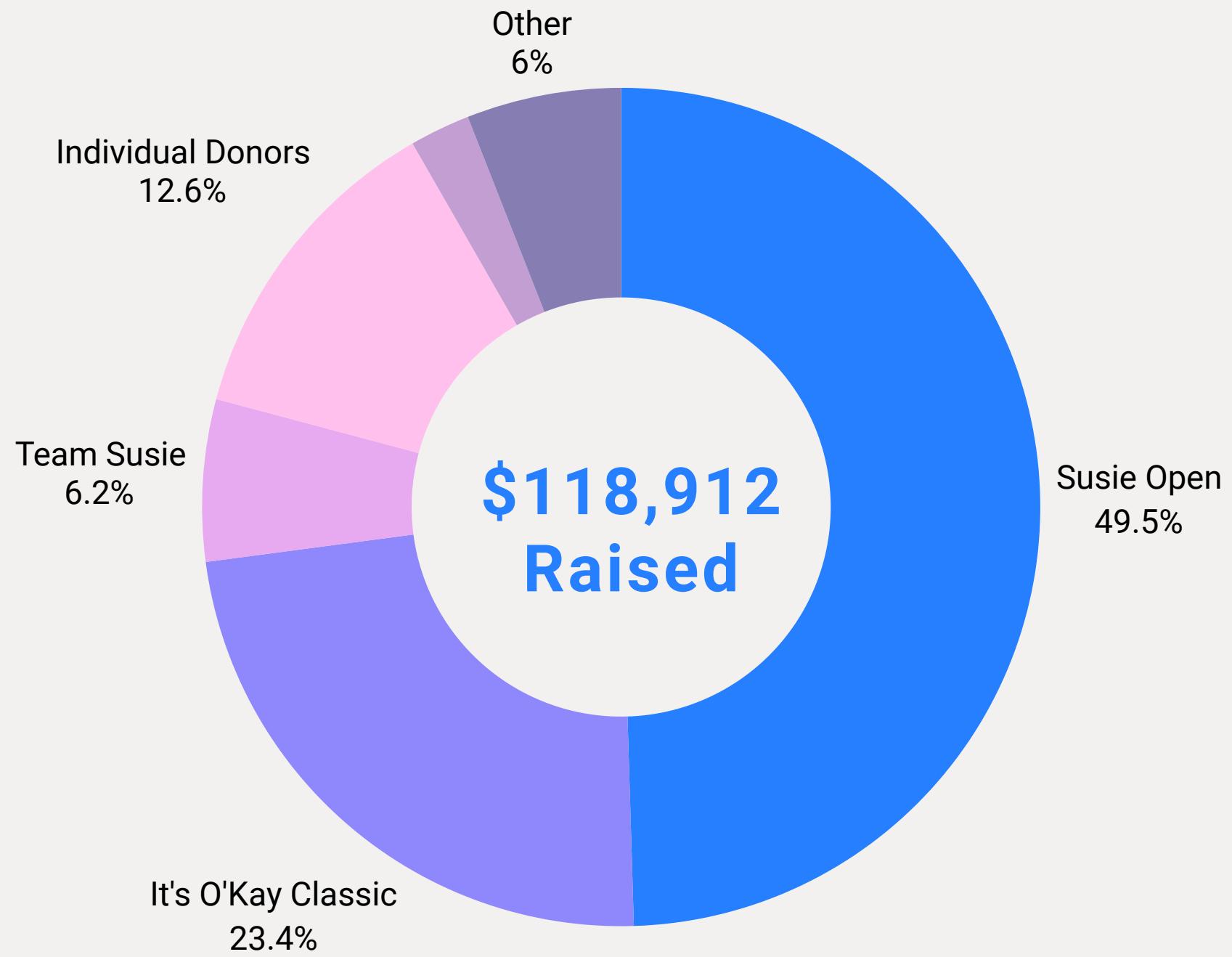
"While she is still able, the ability to independently get outside and experience fresh air and nature with family means everything. This grant has helped fund a wheelchair-accessible ramp, providing dignity, mobility, and joy."

## **Lauren Silva, Littleton, Massachusetts**

"Over the last couple of months my legs have gotten weaker, and the need for better assistive equipment has become urgent. These funds will help provide a lift chair that not only allows me to stand safely but preserves a small piece of my independence."

## **Sofia Hyatt, Amesbury, Massachusetts**

"Requesting funds to help cover the cost of caregiver support during critical overnight hours. Having a caregiver means I can sleep safely, breathe easier, and my family can focus on spending meaningful time together rather than being overwhelmed by around-the-clock medical needs."



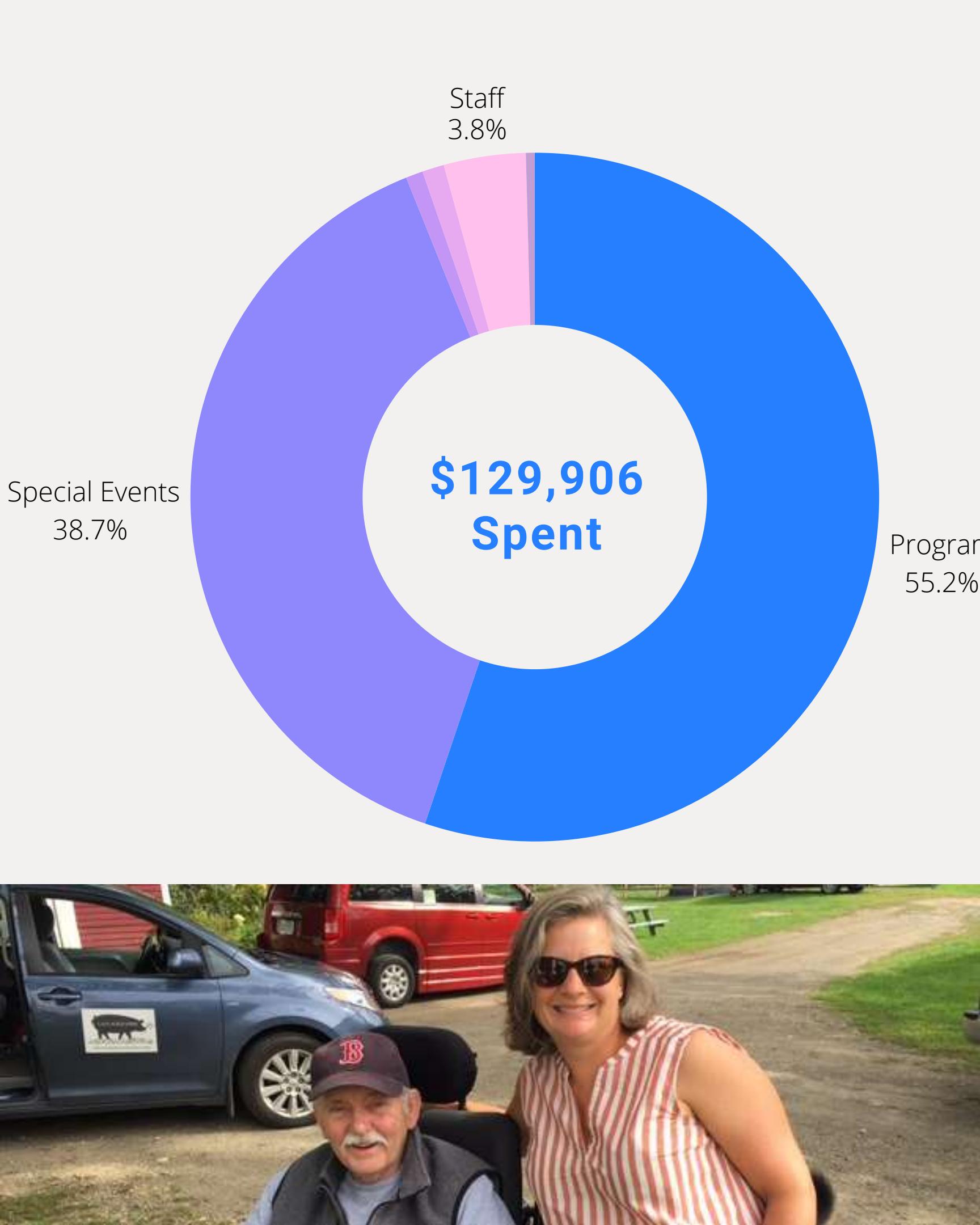
## A Closer Look at Our Revenue

This past year, The Susie Foundation experienced an extraordinary outpouring of generosity, leading to one of our strongest fundraising years to date. We are proud to report that our annual revenues were significantly strengthened by the success of our special event initiatives.

From our inspiring golf tournaments to the always unforgettable Susie Fest, these events not only brought our community together in celebration, but also fueled our mission in meaningful ways. Collectively, special events generated \$96,405—accounting for 81% of our total revenue for the year.

Thanks to the dedication of our supporters, volunteers, and sponsors, these efforts continue to drive tangible impact for families living with ALS across New England.





# A Closer Look at Our Expenses

We are proud to share a transparent overview of The Susie Foundation's financial health, underscoring our commitment to fiscal responsibility and the thoughtful, impactful use of every dollar entrusted to us.

At the heart of our financial strategy is a clear priority: maximizing support for families living with ALS. **In 2024, program expenses totaled \$71,606 – accounting for 55.2% of our overall spending.** This significant investment reflects our unwavering dedication to direct services, including the Flex Grant Program, individualized support services, and critical assistance initiatives that help families navigate the complex challenges of ALS with greater strength and security.

# Meet Our Team



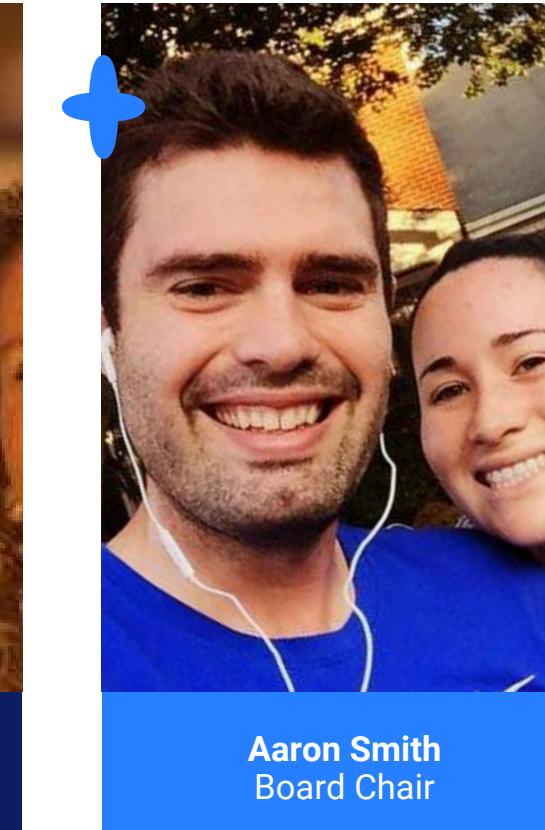
**Shea, Ryan,  
and Liz**



**Ben Roberts**  
Board Member



**Sam Grenus**  
Board Member



**Aaron Smith**  
Board Chair



**Ben Kozera**  
Board Member



**Dr. Andrew Shannon**  
Board Member



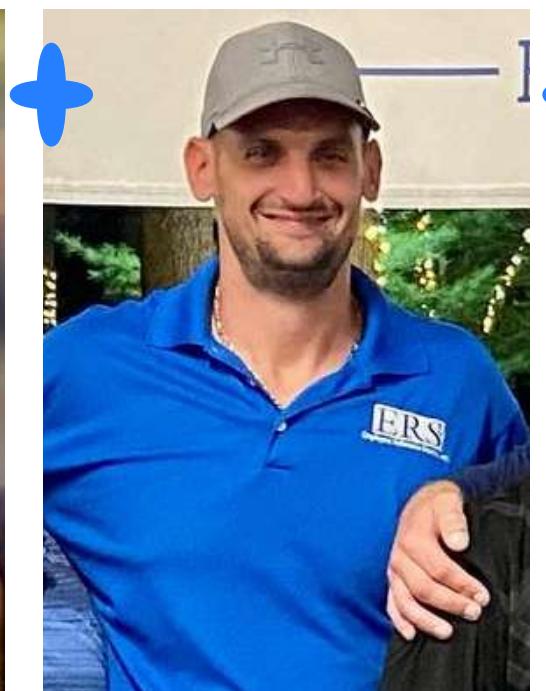
**Mike Stankus**  
Board Member



**Lisanne O'Reilly**  
Board Member



**Chris Hershey**  
Board Treasurer



**Eric Turmel**  
Board Member

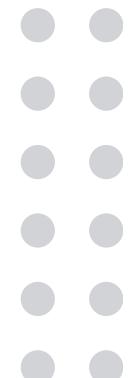


**Neil Mathews**  
Board Secretary



# Thank You

**Here's to achieving even more together in 2025.**



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