



2022 Fiscal Year

Annual Report

January - December 2022



Our Year In Review



INITIATED SUPPORT FOR CAMP HLC NEW ENGLAND

Provided support for young ALS caregivers to attend camp.

We partnered with Hope Loves Company to provide no-cost access for young people to attend Camp HLC New England, a therapeutic retreat exclusively for young people impacted by ALS.

HOSTED TWO SUCCESSFUL GOLF TOURNAMENTS

The Susie Open and It's O'Kay Classic combined to raise \$109k

Our annual golf tournaments - The Susie Open and It's O'Kay Classic - continued their impressive traditions by attracting more than 300 attendees and raising more than \$109,000.

TEAM SUSIE CONTINUED SUCCESSFUL LEGACY

Participants across New England raised more than \$12k

Team Susie was featured at both the Falmouth Road Race and the Hartford Marathon, while our runners raised more than \$12,000 to support families with ALS throughout New England.

SUSIE FEST REMAINED AN ANNUAL HIGHLIGHT

Our stellar Young Professionals Committee raised more than \$14k

Susie Fest offered one of the most memorable nights of the year by attracting more than 120 attendees to Bad Sons Brewing Company in Derby and raising more than \$14,000.

MOST FLEX GRANT FUNDING IN HISTORY

The program provided more than \$114k directly to families with ALS

We surpassed our goal of providing at least \$100k directly to families living with ALS throughout New England - the most in any single year since our agency's founding.

A Closer Look at Our Success

764 Donors

Generously contributed to our mission in a multitude of different ways, while helping us raise a total of \$258,205 to support families with ALS.



439 Attendees

Joined us for The Susie Open, The It's O'Kay Classic, and Susie Fest, while helping to raise a total of \$123,462 at these special events.



21 Fundraisers

Joined Team Susie and raised a grand total of \$12,367 by running, walking, and jogging at race events throughout New England.





Our Impact: Flex Grants

We provided 118 Flex Grant Awards to offset the financial burdens faced by families living with ALS throughout New England.

The Susie Foundation | 2022 Annual Report



The Card Family | Clinton, CT



Our Impact: Flex Grants

These Flex Grant Awards totaled
\$114,824.97 of support provided
directly to ALS families in-need.

The Susie Foundation | 2022 Annual Report



The Paulsen Family | Belmont, MA

Who Our Flex Grants Helped



59.4 YEARS OLD

Our Flex Grant Awards supported individuals living with ALS who were, on average, 59.4 years old. Our youngest recipient was 31 years old, our oldest was 82 years old.



4.2 YEARS LIVING WITH ALS

Our Flex Grant Awards supported individuals who had been living with ALS for an average of 4.2 years. 46.7% of these Flex Grant recipients were first-time applicants.



28% CARING FOR KIDS

33 of 118 Flex Grants Awards were provided to families caring for school-age children. These families averaged 2.1 children per household who were 14.1 years old on average.

Why Our Flex Grants Are Needed



UP TO \$200,000 PER YEAR

Studies have estimated that an ALS diagnosis can cost families as much as \$200,000 in annual out-of-pocket expenses to provide ongoing care for a loved one.*



96.6% OF RECIPIENTS

96.6% of our Flex Grant recipients require physical assistance in order to complete at least one activity of daily living (e.g., bathing, eating, toileting, medications)



60.2% OF RECIPIENTS

60.2% of the families supported by our Flex Grant Awards earned less than 200% of the federal poverty level as determined by the Department of Health and Human Services.**

*Obermann, M., & Lyon, M. (2014). Financial cost of amyotrophic lateral sclerosis: A case study. *Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration*, 16(1-2), 54-57.

**Poverty guidelines. ASPE. (n.d.). Retrieved February 19, 2023, from <https://aspe.hhs.gov/topics/poverty-economic-mobility/poverty-guidelines>

What Our Flex Grants Helped to Purchase



DURABLE MEDICAL EQUIP.

\$29,479.12 (25.7%) of Flex Grant funding helped families better afford durable medical equipment that ranged from motorized wheelchairs and in-home patient lifts, to handicap-accessible vehicles and shower chairs.



HOMECARE SERVICES

\$22,812.00 (19.9%) of Flex Grant funding helped families better afford homecare services that helped families access in-home medical and non-medical support services to ease the burden of daily life with ALS.



COSTS OF DAILY LIVING

\$22,743.00 (19.8%) of Flex Grant funding helped families better afford the costs of living that ranged from rent payments and nutritional supplements to medical supplies and home generators.

The Impact Our Flex Grants Had



IMPROVED QUALITY OF LIFE

100% of Flex Grant recipients reported improvements to their overall quality of life upon receiving financial support for expenses ranging from homecare to medical copays.



IMPROVED INDEPENDENCE

45% of Flex Grant recipients reported improved independence upon receiving financial support for expenses ranging from essential home renovations to adaptive technologies.

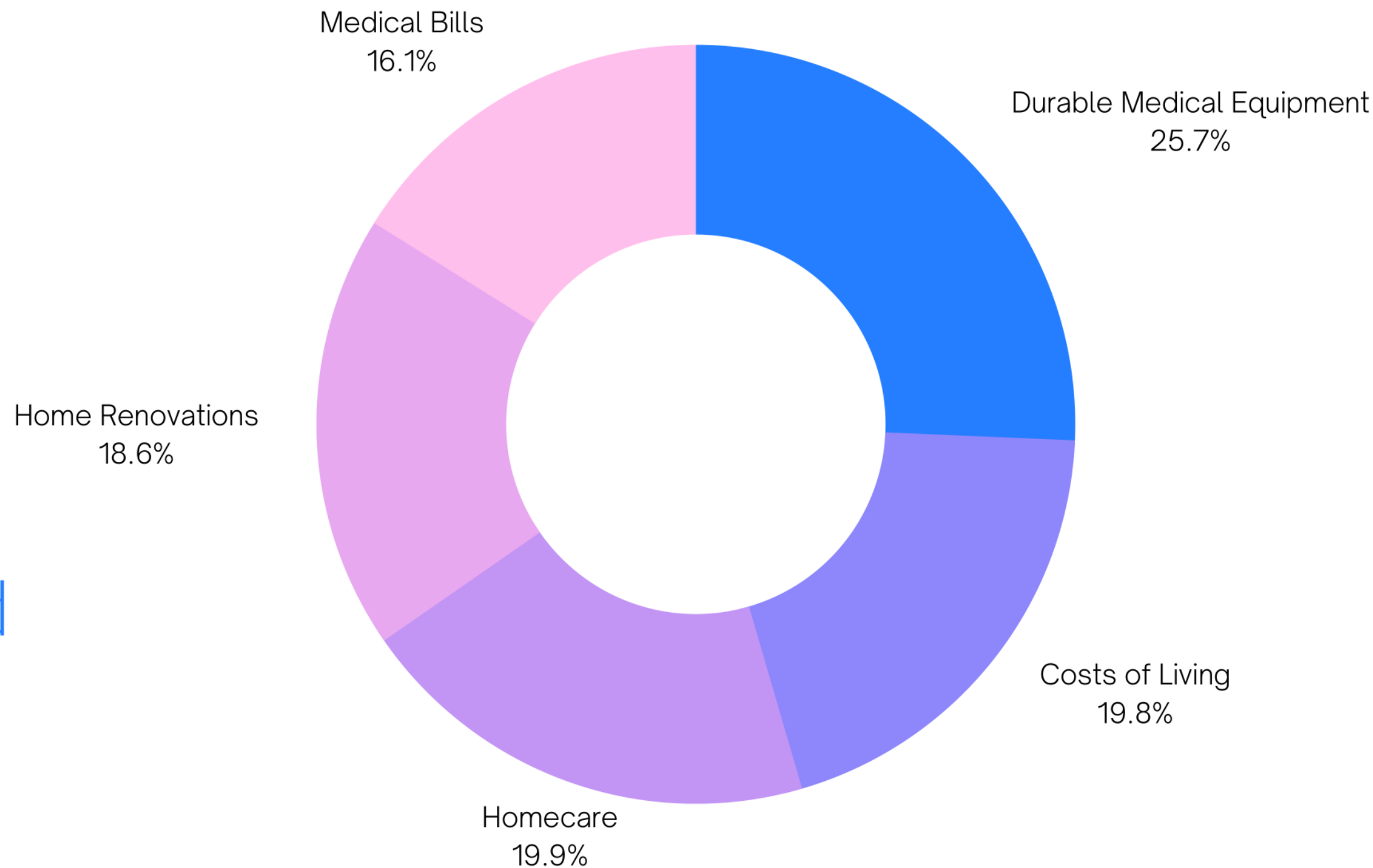


IMPROVED MOBILITY

27% of Flex Grant recipients reported improved mobility upon receiving financial support for expenses ranging from handicap-accessible van repairs to the installation of wheelchair ramps.

Flex Grant Overview

These Flex Grants totaled
\$114,824.97 of support provided
to families throughout 2022.



Feedback From Our Families

The Susie Foundation
2022 Annual Report



Impact of Our Flex Grant Program

"ALS is a cruel disease. Each day brings a new set of challenges, none of which are something we want. When we find something good, we treasure it. Our new handicap-accessible bathroom was something 'good' for us. The Susie grant was another beautiful gift. Thank you!"

Family in Bow, NH

Feedback From Our Families



Impact of Our Flex Grant Program

"Thank you so much for your generous Flex Grant towards our wheelchair van. It is heartwarming to know that there are such wonderful, caring people who are committed to making the lives of ALS patients better. Susie must have been a remarkable woman to have inspired all of you to work so hard at raising funds and reaching out to impacted families."

Family in Otisfield, ME

Feedback From Our Families

Sustainable Development
Goals



Impact of Our Flex Grant Program

"I would like to express my appreciation for the recent Flex Grant to help improve my bathroom and make it safer for me. I am grateful to The Susie Foundation for letting me stay at home safely! Thank you for all you and Susie does for people with ALS."

Family in Meriden, CT



Our Impact: Camp HLC

We sponsored Camp HLC New England to provide young ALS caregivers access to emotional, educational, and therapeutic support services.



The Impact of Camp HLC New England



NO-COST ACCESS

Our partnership with Hope Loves Company provided no-cost access for young people to attend Camp HLC New England, a three-day, overnight retreat that is provided exclusively to children and young adults who have or have had a loved one battling ALS.



FUNDED AN ENTIRE CABIN

Funding provided to Camp HLC New England allowed eight local young people to gain access to a wide variety of emotional, educational, and therapeutic support services, as well as enriching activities, provided by Hope Loves Company.



THREE-DAY EXPERIENCE

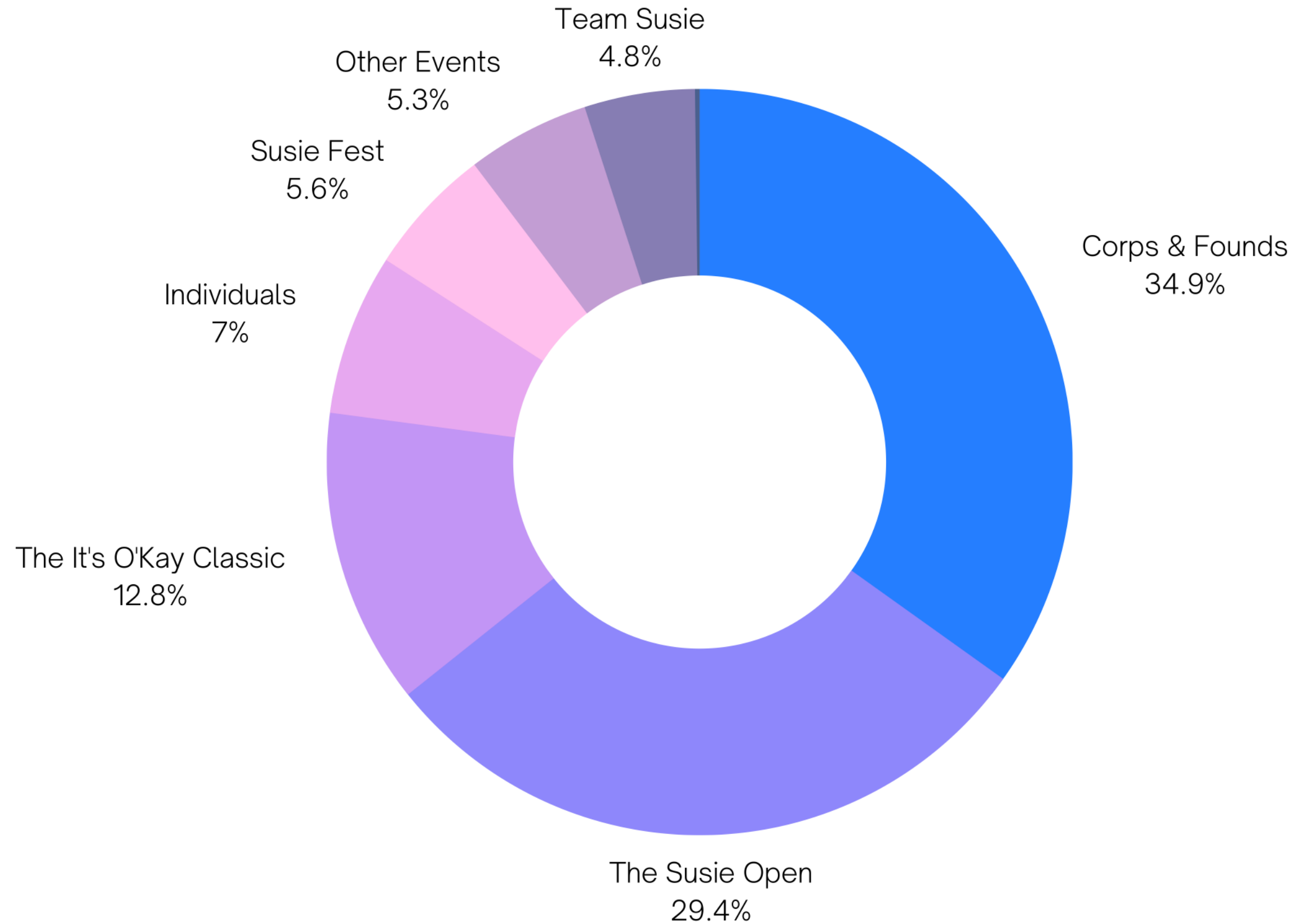
Each camper had access to a suite of activities and support services that featured hikes, games, zip lines, rock climbing, boating, fishing, a ropes course, archery, yoga, arts and crafts, group therapy sessions, music, and much more.



Financial Recap

We totaled \$258,205 in revenues in FY22

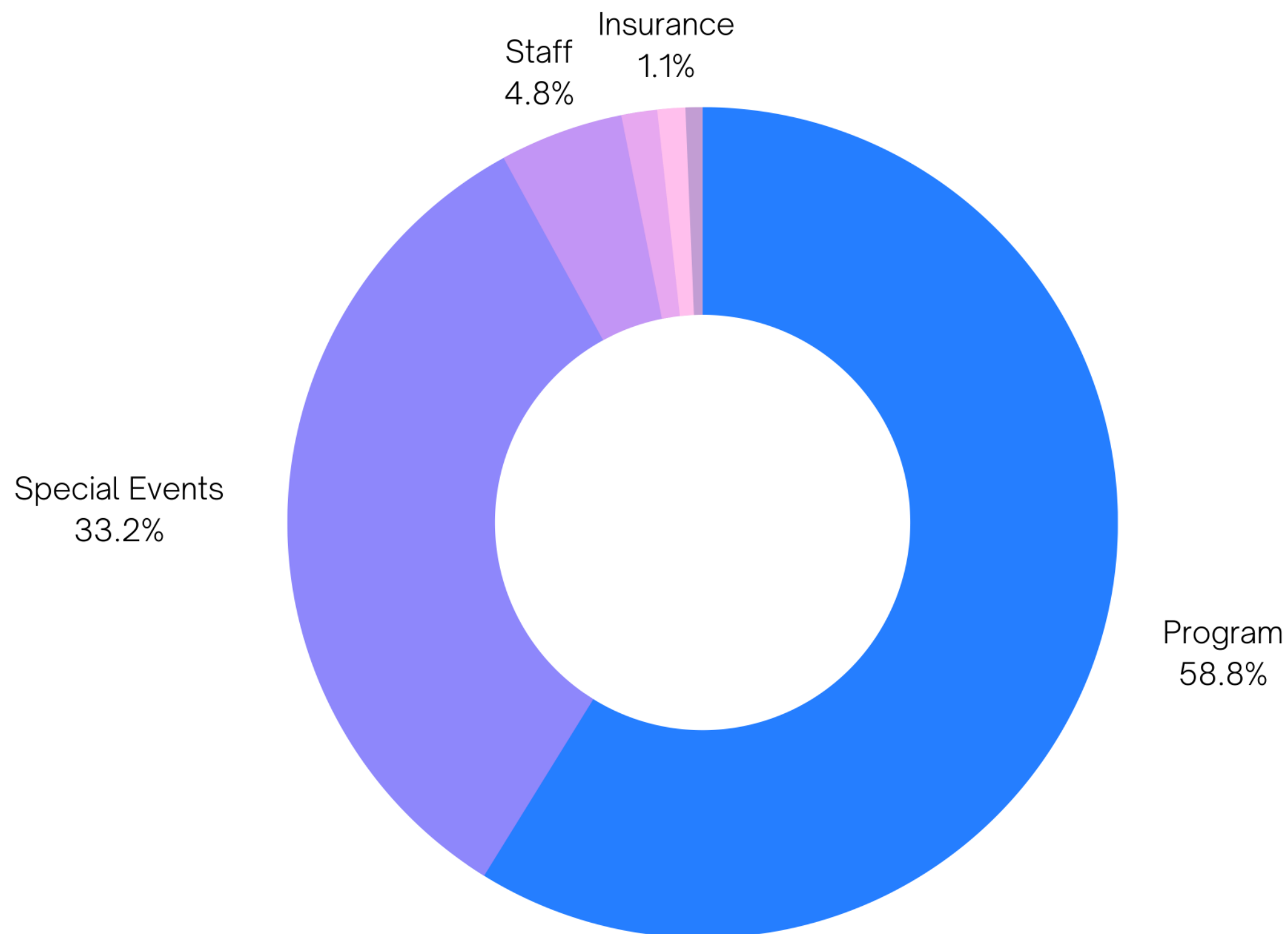
The Susie Foundation | 2022 Annual Report



Did you know? Since their inception five years ago, our golf tournaments have raised \$414,717 to support our mission.

Financial Recap

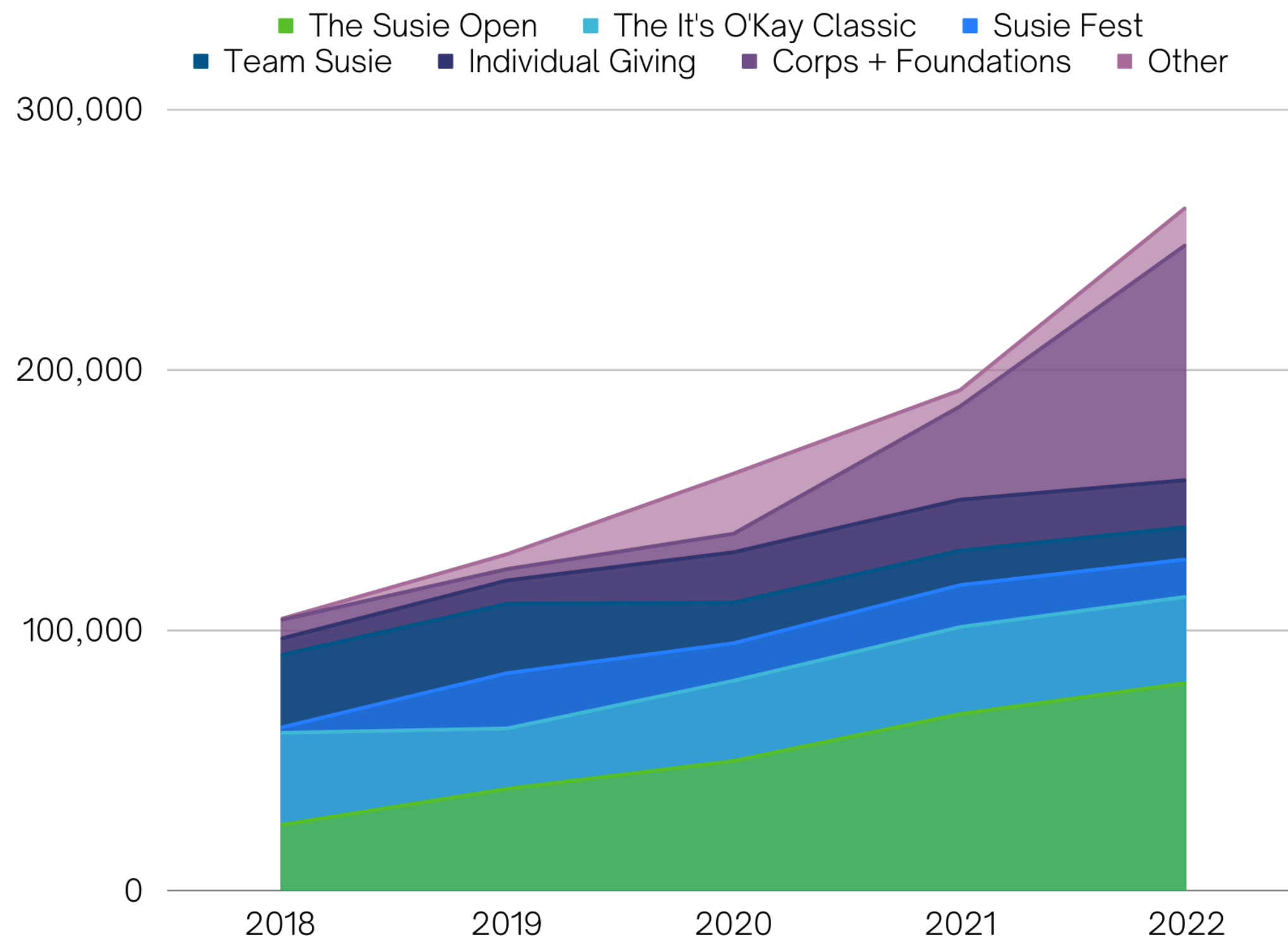
We totaled \$207,705 in expenses in FY22



Did you know? Since our founding, we have provided \$370,420 directly to families living with ALS.

Financial Recap

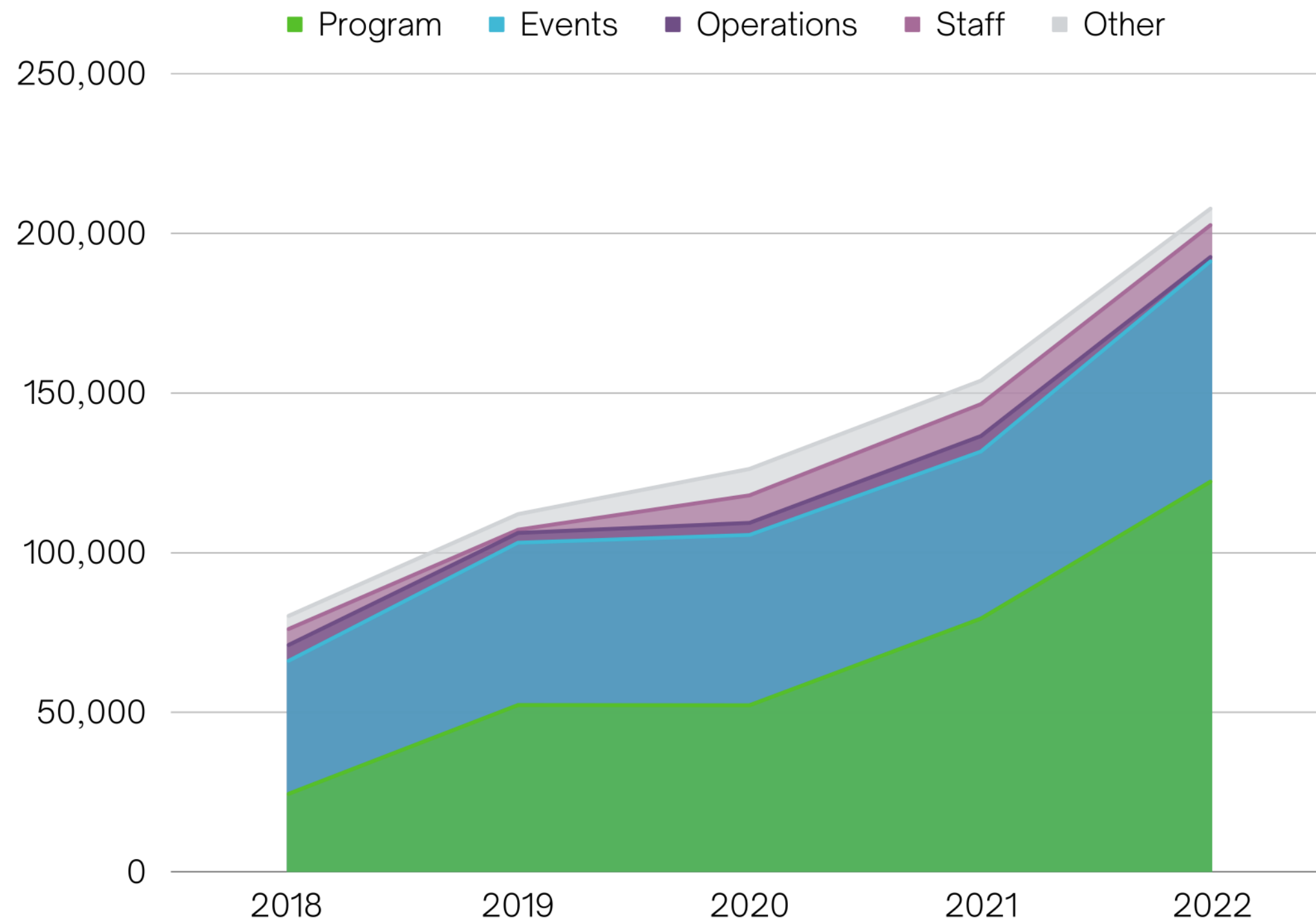
Annual revenue trends
since 2018



Did you know? Since our founding, we have raised a grand total of \$1,014,256 to support families living with ALS.

Financial Recap

Annual expense trends
since 2018



Did you know? Since our founding, only 8.6% of our proceeds have been spent on operating expenses.

Our Aspirations in 2023

Continue Support for Families

We are committed to providing \$85,000 in total Flex Grant Awards to ALS families across New England.



Increase Support for Camp HLC

We are committed to providing \$10,000 in funding to ensure youth access to Camp HLC New England.



Build Our Fundraising Portfolio

We are focused on continuing to build our successful fundraising portfolio and celebrating our first decade of operation.



Our Team

Agency Leadership



**RYAN
MATTHEWS**

Founder / Executive Director



**LIZ & SHEA
MATTHEWS**

Directors of Morale

Board of Directors



**AARON
SMITH**



**NEIL
MATTHEWS**



**CHRIS
HERSHEY**



**DR. ANDREW
SHANNON**



**ERIC
TURMEL**



**LISANNE
O'REILLY**



**MICHAEL
STANKUS**



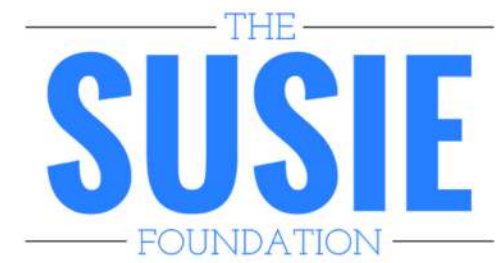
**SAM
GRENUS**



**BENJAMIN
KOZERA**



**BEN
ROBERTS**





Contact Us

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to get involved today.

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