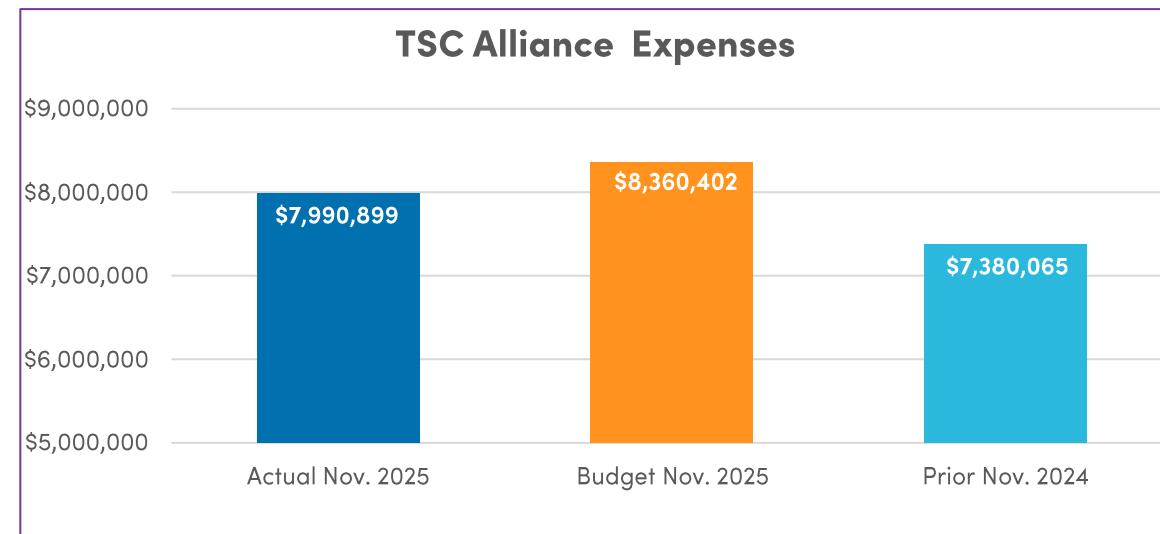
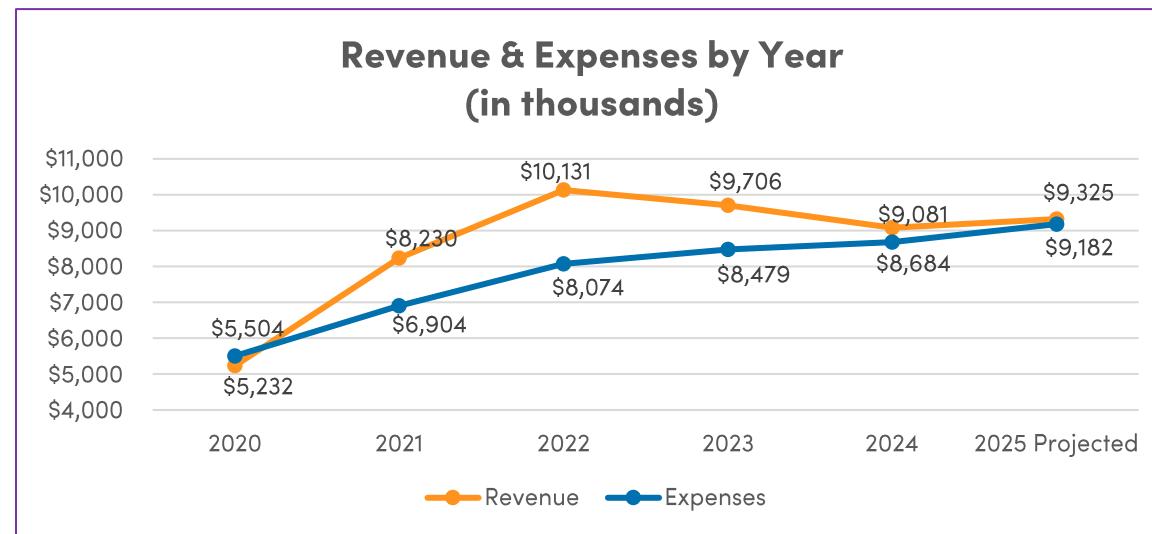
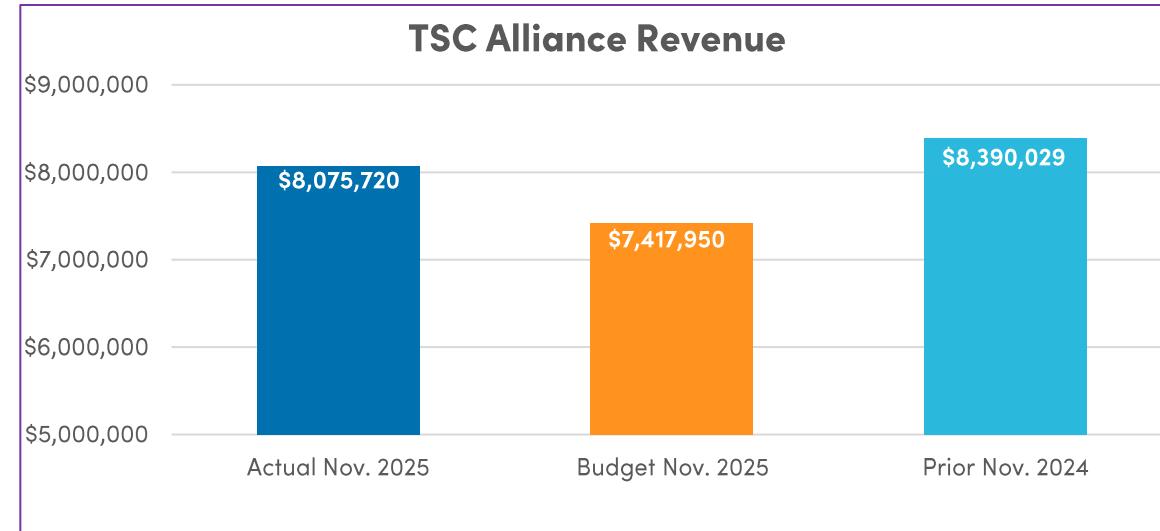
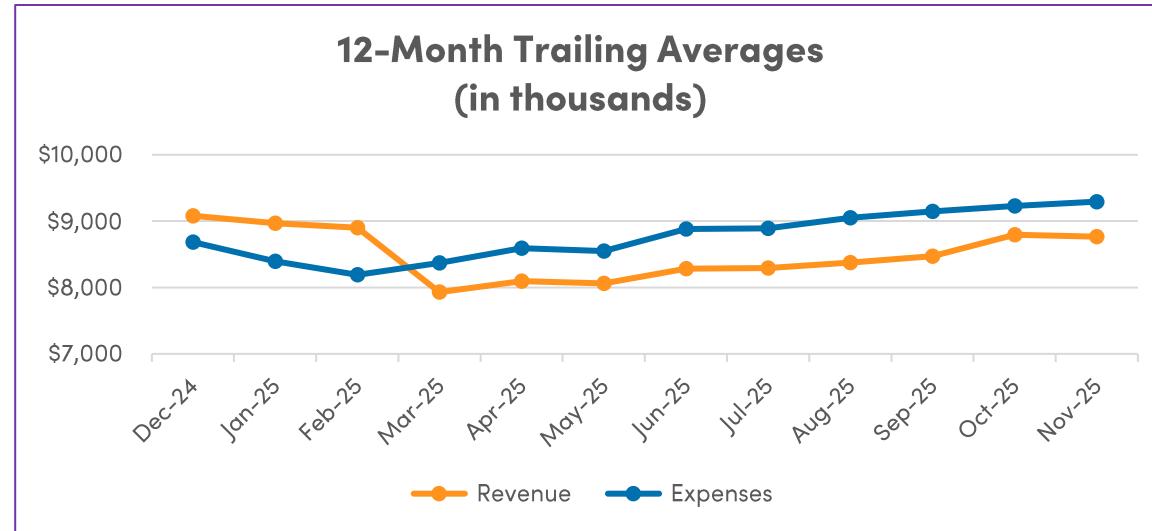


CEO Report

November 2025



Financials



Programmatic Ratios (as of 11/30/25)

79.9%

Programmatic
Expenses

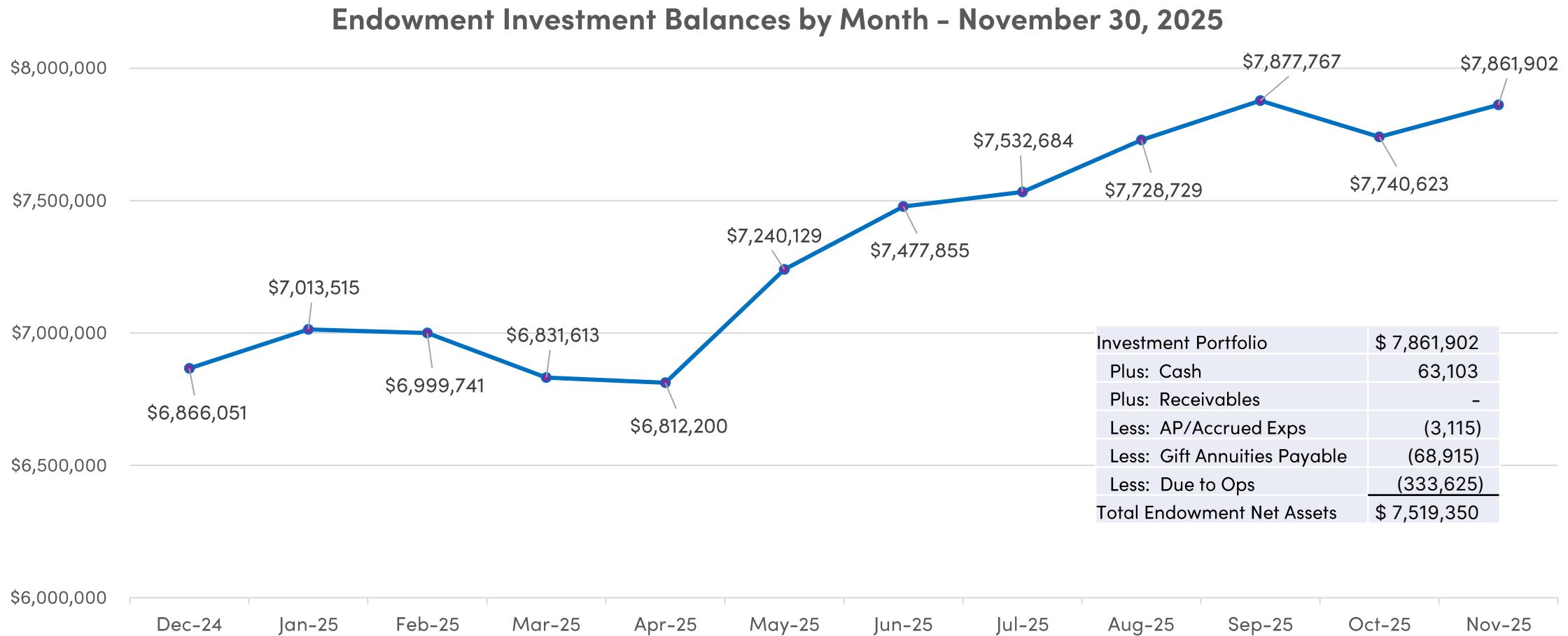
20.1%

Fundraising &
Admin Expenses

13.2%

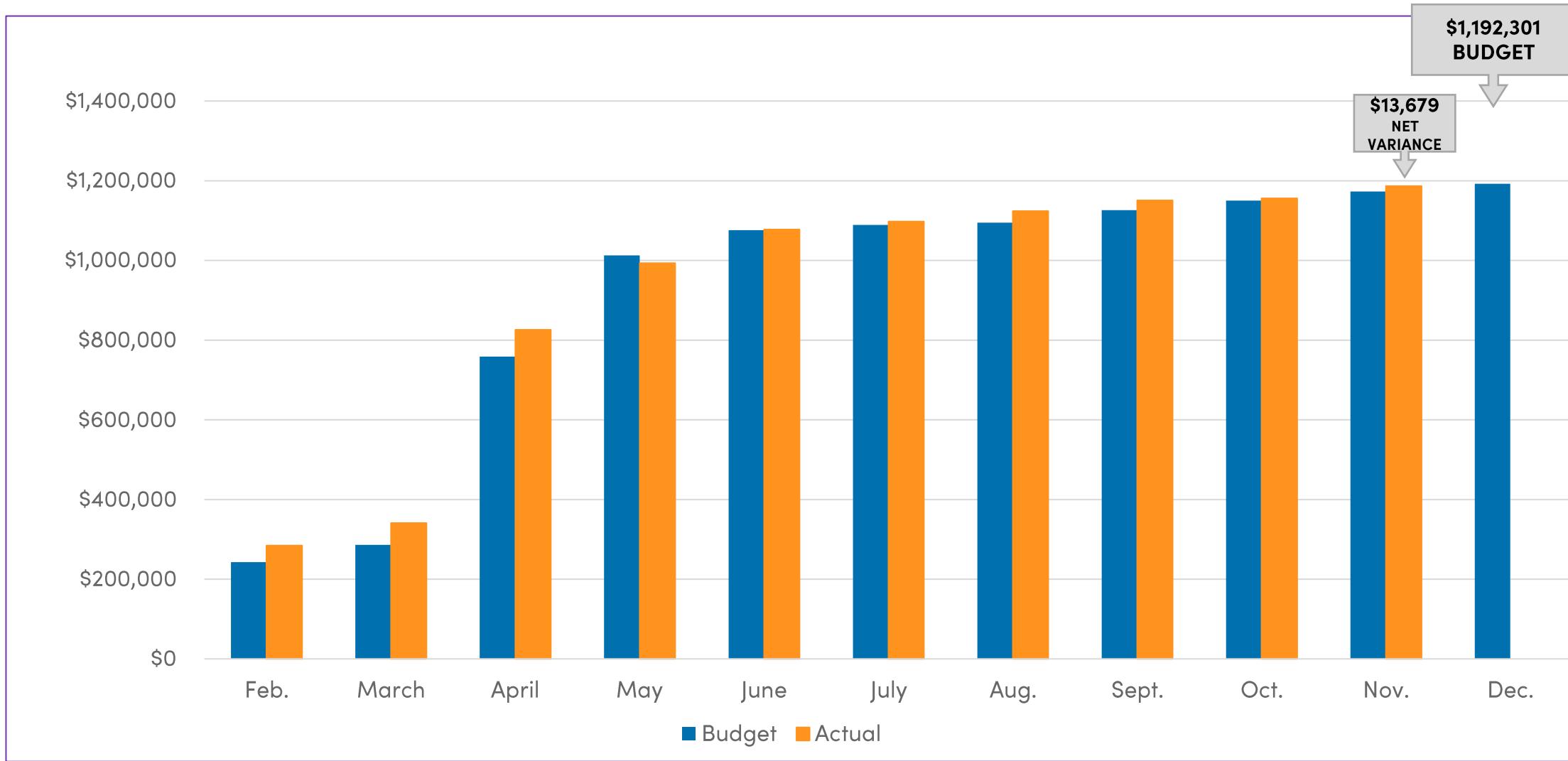
Fundraising Costs
as a % of Revenue
Raised

Endowment Fund Investment Balance – over past 12 months

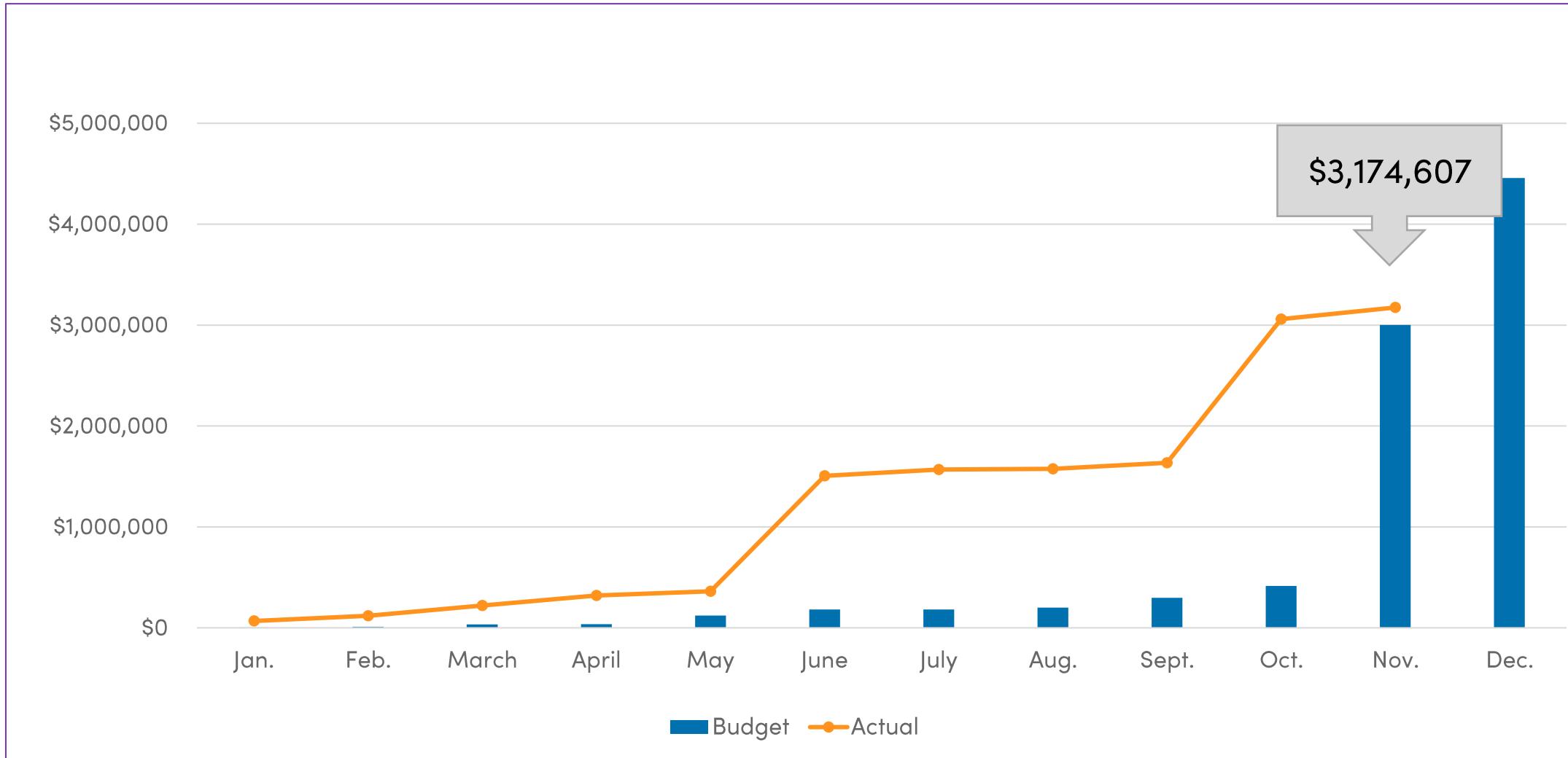


2025 NET special events

15% Organizational
revenue coming from special
events (goal: 15%)



2025 Research Campaign fundraising goal \$4,458,600



Research Campaign progress

**56% of
Goal**

\$22,521,507 of
\$40 million raised

**1,834
Donors**

46% Major Individual Gifts
38% Foundations
9% Events
3% Corporations
3% Sponsorships
1% Appeals and NIH

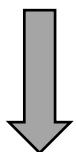
78.4%

Donors giving their
most significant gift to
date (among donors
giving \$10,000+)

2,000

Donors in the database
upon which the campaign
goal was based

- 35 pledges
- 131 in active cultivation



Current: \$3,174,607 (71%)

2025 Goal:
\$4,458,600

2025 initiatives:

Launch of TSC Research Matters Newsletters, June Electronic Research
Appeal, October Printed Research Appeal

Translational Research – Highlights Advancing Compounds to Clinical Trials

Translational Research

- **Clinical advances:**
 - Cassava Sciences and Aeovian Pharmaceuticals continue to engage with the Clinical Research Network, both companies have agreed to present their technologies at the annual Clinic Directors & Staff Meeting at American Epilepsy Society.
 - Dean Aguiar, PhD; Vice President, Translational Research presented at the LA Regional Conference and during the November Adult Topic Call to continue to raise awareness of the translational research program and upcoming opportunities for the TSC community.
- **Preclinical Consortium:**
 - Zoë Fuchs, Senior Manager, Translational Research presented a poster with mTOR inhibitor dose-response data (Tsc1GFAP model) at the annual Society for Neuroscience meeting (San Diego, CA). There were many non-TSC neuroscientists who visited the poster from both academia and industry.
- **Translational research revenue, expenses, and overhead:**
 - We continue to exceed the budgeted revenue goal for 2025 and are in a strong position heading into year-end!

Preclinical Consortium Activity

Compounds Tested
Since 2016

108

Experiments
Since 2016

313

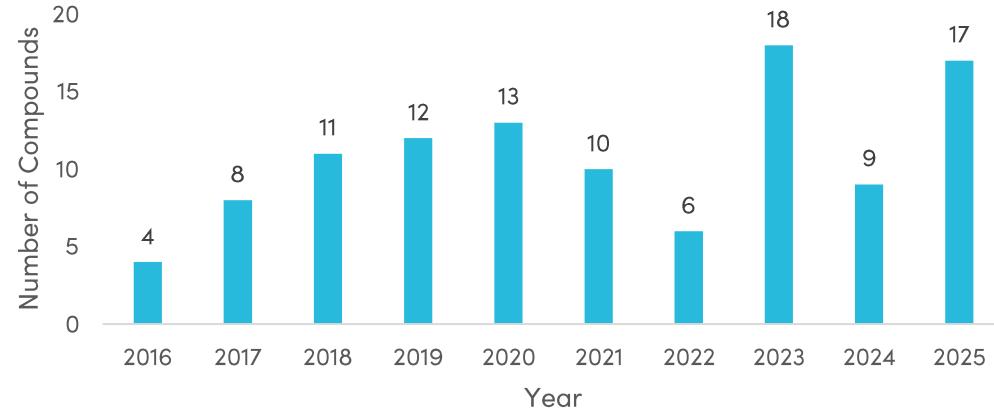
Active Industry
Partners

12

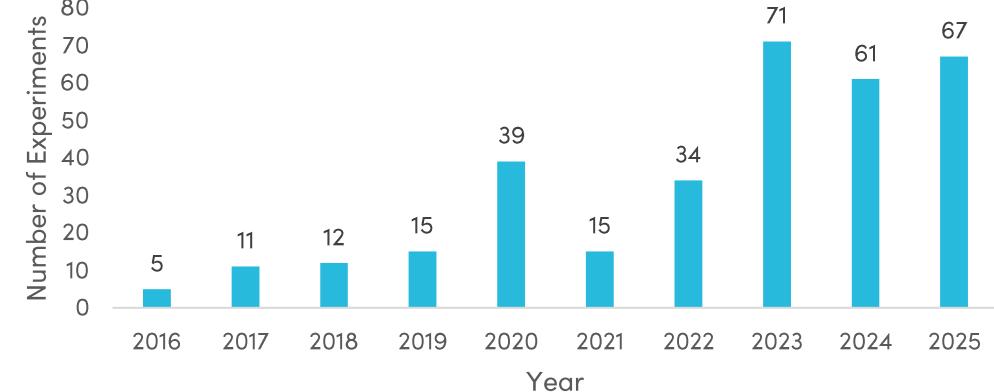
Industry Partners
Since 2016

31

Compounds per Year
Year to Date



Experiments per Year
Year to Date



Translational Research Revenue

Category	Amount (\$)
2025 Budgeted Contract Revenue (Industry funded studies + membership fees)	1,702,083
Industry Contract Revenue (YTD)	2,164,882
Currently Under Contract to be Earned	(148,203)
Projected Excess over Revenue Goal	611,002
Industry Contract Expenses (Study costs)	1,683,263
Overhead from Industry Studies = Unrestricted Funds (Industry Contract Revenue – Contract Expenses)	481,619
TSC Alliance Expenses (Bucket A studies, Van Andel Institute animal colonies)	525,850
Net Overhead = Unrestricted Revenue (Overhead from Industry Contract Revenue less TSC Alliance Expenses)	(44,230)

Biosample Repository

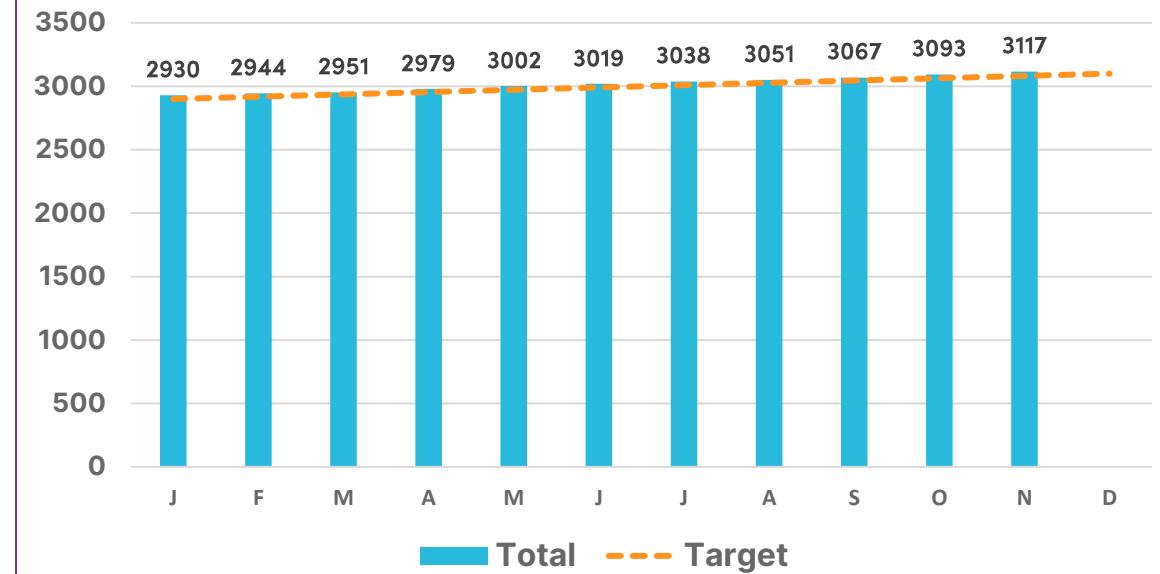
2025 Running Totals

- Total Biosamples: **3,117 (+19)**
- **8** from mobile phlebotomy
- Total NHD Participants: **2,932 (+17)**

Distributions

- Total since inception: **4,036**
- To **57** distinct researchers for **63** distinct projects

Biosample Collection vs. Goal 2025



Community outreach through November

6,386

Peer-to-peer
support
interactions

102

School meetings

1443

Volunteer
training hours
provided

10

New volunteers

13

TSC Support Navigator
Meetings

Digital stats through November

81,886

Social media engagements through October

650+

Social media interactions in November

Eleventh Annual Infantile Spasms Awareness Week Scheduled for December 1-7

NEWS PROVIDED BY
TSC Alliance →
Nov 25, 2025, 08:00 ET



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SILVER SPRING, Md., Nov. 25, 2025 /PRNewswire/ -- From December 1 to 7, 2025, a coalition of organizations will mark the Eleventh Annual [Infantile Spasms Awareness Week](#) (ISAW). The goal of ISAW is to increase awareness and understanding of infantile spasms by offering educational materials to providers, caregivers, and the public; announcing new and useful research and support initiatives; and informing patients and caregivers help is available. The campaign is supported by the [Infantile Spasms Awareness Network](#) (ISAN), a coalition of 42 international organizations that have come together to inform families, healthcare providers and caregivers about the signs of infantile spasms.

107 Million

Potential Audience from 261 pickups of Infantile Spasms Awareness Week press release

