Firefly FUND

Sponsor Packet

Shining a Light on NPC-1

* a **rare disease** commonly known as **Childhood Alzheimer's**

We advocate for better treatments and cures

We support families & patients on their journeys

We collaborate to shine light on rare diseases

FireflyFund.org

Firefly FUND

Save the Date!

FIREFLY DREAMS

A Benefit to Support Rare Disease Research & Education

Thursday, February 19, 2026 at 6:30pm

Brazos Hall
204 E 4th St
Austin, TX 78701

Our Mission

We advocate for better treatments and cures

We support families & patients on their journeys

We collaborate to shine light on rare diseases

Firefly Fund provides crucial support for research and education necessary to accelerate cures for rare genetic diseases that affect children and currently have no cure. Building on our work to advance knowledge and access to therapy for children diagnosed with Niemann-Pick Disease Type C (NPC), we support research to translate these learnings to treatments across other rare and ultra-rare diseases.

The organization is led by rare disease caregivers and patient advocates with lived experience navigating rare disease diagnosis and treatment. Convening coalitions of patient advocacy and industry stakeholders, Firefly Fund is committed to advancing and accelerating access to life-saving and life-changing therapies.

Our Programs

Firefly Fund's core programs provide vital resources and support to patients, families, and clinicians.

Early Diagnosis

Advance efforts to add rare diseases to newborn screening (NBS) lists at state and federal levels. Firefly Fund is dedicated to gathering evidence necessary to add rare diseases to NBS.

In 2017, Firefly Fund launched an initiative to advance newborn screening (NBS) for NPC with a multi-stakeholder working group with the goal of adding the disease to newborn screening lists.

Research

Support translational research and applied science with the goal of accelerating life-changing, life-saving therapies for rare and ultra-rare diseases.

In 2024, Firefly Fund announced a $5 million pledge as the founding sponsor and an initiative to raise funds for the groundbreaking Center for Rare Diseases (CRD) at the University of Texas Dell Medical School.

Access

Provide financial assistance for rare disease patients to alleviate burdensome medical and travel costs related to their diagnosis so they may gain timely, necessary and improved access to care.

Firefly Fund's Rare Disease Navigator Program is a free, confidential support program that helps families navigate their journey to receiving a rare diagnosis and subsequent care.

Learn more about our mission, programs, and ways to get involved **FireflyFund.org**

2026 Gala Donor Tiers

	Number of Guests / Number of Tables	Recognition as "Presenting Sponsor"	VIP Cocktail Service	Logo Recognition on social media	Logo in Program	Verbal Recognition during event	Event Signage
Presenting $25,000	20 / 2	✓	✓	✓	✓	✓	✓
Platinum $10,000	10 / 1		✓	✓	✓	✓	✓
Gold $7,500	10 / 1			✓	✓	✓	✓
Silver $5,000	8 / 1				✓	✓	✓
Bronze $2,500	8 / 1				✓	✓	✓
Table $1,500	6 / 1						✓
Individual $150	1 / –						

Ways to Donate

Online

qr code (or click)

Mail

ANDREWS FIREFLY FUND
P.O. BOX 92616
AUSTIN, TX 78709

send check

Contact

Questions

Suzanna Rosenblatt
(512) 633-0284
suzanna@fireflyfund.org