

Dear Prospective Flex Grant Applicant,

We understand that an ALS diagnosis brings profound challenges—emotionally, physically, and financially. At The Susie Foundation, we believe that no family should face this journey alone. That’s why we created the **Flex Grant Program**: to provide direct financial assistance for the essential but uncovered costs that come with ALS care.

Since our founding in 2013, we have raised more than \$1.3M to support ALS families across New England. Our mission is deeply personal—**inspired by Susan Ready Matthews**, who was diagnosed with ALS in 2009. Since Susan’s passing in 2011, we have been committed to ensuring that **patients, young caregivers, and families** can access the resources they need to live with dignity, comfort, and support.

How the Flex Grant Program Can Help

The **Flex Grant Program** provides **direct reimbursement payments** to ALS families for out-of-pocket expenses that are not typically covered by private insurance, Medicare, or Medicaid. These funds help alleviate the financial burden of ALS, ensuring families can focus on what truly matters—**caring for their loved ones**. Eligible expenses include, but are not limited to:

- **Medical Equipment** (e.g., power wheelchairs, communication devices)
- **Home Modifications** (e.g., wheelchair ramps, stair lifts, accessible bathrooms)
- **Healthcare Services** (e.g., home health aides, skilled nursing, respite care, clinic copays)
- **Basics Needs & Other Essential Costs** (e.g., home heating, rent payments, nutritional supplementation)

Who Can Apply?

The **Flex Grant Program** is available to **residents of New England** who have a **definitive ALS diagnosis** and have incurred or will incur out-of-pocket expenses related to their care.

Grants are awarded during quarterly cycles, with applications due by January 1st, April 1st, July 1st, and October 1st. First-time applicants, as well as those facing urgent medical, financial, or caregiving hardships, may be given priority.

How to Apply

If you are interested in applying, please visit our website:

Website: TheSusieFoundation.org/flex-grant | Online Application: bit.ly/tsfflexgrant

For any questions or assistance with your application, please reach out to:

Ryan Matthews, Executive Director | Email: Ryan.Matthews@TheSusieFoundation.org | Phone: (203) 490-6694

At **The Susie Foundation**, we are here to lighten the load, ease the burden, and stand beside you every step of the way. If you or a loved one could benefit from financial support, we encourage you to apply.


You are not alone. We are here for you.

- *The Susie Foundation Team*

 @thesusiefoundation

 ryan.matthews@thesusiefoundation.org

 thesusiefoundation.org

 203-490-6694

POLICIES AND PROCEDURES OF THE FLEX GRANT PROGRAM

Eligibility Requirements

The Flex Grant Program is available to all residents of New England who have a definitive diagnosis of Amyotrophic Lateral Sclerosis (ALS). To be considered for funding, applicants must complete and submit the full grant application by the outlined deadlines.

First-time applicants must also complete the Verification of ALS Diagnosis Form, which requires a signature from a physician, neurologist, or social worker/case manager.

This program provides reimbursement for specific expenses only. Before applying, please review the list of eligible and ineligible expenses found at the end of this packet.

Additionally, all applicants must submit receipts or proof of payment before funds can be disbursed. Individuals directly related to the organization's directors are not eligible to apply.

Funding Application Submission Process (Pre-Award)

Step 1: Complete Your Application

- Visit www.bit.ly/tsfflexgrant to fill out and submit your application.
- Ensure all questions are fully answered and that you sign the last page of the application packet.
- First-time applicants: Your application will not be considered complete until we receive your Verification of ALS Diagnosis Form, which can be accessed online at www.bit.ly/susieverify.

Step 2: Application Confirmation

- Once we receive your application, you will receive an email confirmation.
- If you do not hear from us within two weeks, please contact:
- Ryan Matthews, Executive Director
 - Email: Ryan.Matthews@TheSusieFoundation.org
 - Phone: (203) 490-6694

Step 3: Application Review & Selection

- Grant periods are determined by the date your application is fully complete.
- For first-time applicants, this means the date we receive both your Application and Verification of ALS Diagnosis Form (whichever occurs second).
- The Program Committee of our Board of Directors meets at the end of each month to review and select grant recipients.
- You will receive notification of your application status during the first week of the following month.

Important Application Notes

- If you do not upload expense receipts with your application, please keep copies of all relevant receipts.
- Receipts must be submitted before any approved funding can be processed.
- For questions or additional information, please don't hesitate to reach out. We are here to help.

Important Dates and Reminders

Grant Cycle	Deadline for Submission	Approval Notices	Data Range for Expenses	Receipts	Diagnosis Verification
Winter	January 1st	Sent via email on or before Jan 20	6 months prior to submission deadline	Due prior to your grant payment	Required for all first-time applicants.
Spring	April 1st	Sent via email on or before April 20	6 months prior to submission deadline	Due prior to your grant payment	Required for all first-time applicants.
Summer	June 1st	Sent via email on or before Jun 20	6 months prior to submission deadline	Due prior to your grant payment	Required for all first-time applicants.
Fall	October 1st	Sent via email on or before October 20	6 months prior to submission deadline	Due prior to your grant payment	Required for all first-time applicants.

Applicant Selection Process and General Criteria

The Flex Grant Program provides direct financial assistance to ALS families based on a fair, transparent, and non-discriminatory selection process. Grants are awarded twice per year, with all eligible applications reviewed by The Susie Foundation's Board of Directors Program Committee.

Grant recipients are selected by a majority vote, based on a combination of specific eligibility criteria and available funding.

Flex Grant Selection Criteria

To be considered for funding, applicants must meet the following criteria:

- The applicant completes the grant application in full and submits all required forms.
- The applicant is not directly related to any of the organization's directors.
- The applicant resides in New England and provides proof of a definitive ALS diagnosis from a physician, neurologist, or social worker/case manager.
- First-time applicants and those facing urgent medical, financial, or caregiving hardships may be given priority.

Applicants may request up to \$2,000 per grant cycle, but must specify in their application the amount requested and how the funds will be used.

Award Acceptance and Reimbursement Process

- Applicants will be notified via email during the first week of the month following their application.
- If awarded funding, grant recipients will receive direct reimbursement for approved expenses.
- Payments are typically issued via check mailed to the applicant, but The Susie Foundation can arrange direct payments to vendors upon request.

Grantee Eligibility for Future Grant Periods

Approved applicants are eligible to reapply each cycle, with a maximum total funding cap of \$4,000 per calendar year per applicant.

Products and Services Eligible for Reimbursement

Eligible Reimbursements	Ineligible Reimbursements
Respite Care	
<ul style="list-style-type: none"> • Professional in-home care services • Patient sitting services by anyone NOT living in the home • Short-term respite stays in a licensed facility • Long-term residential living programs 	<ul style="list-style-type: none"> • Lawn care and house cleaning services • Caregiving from someone living in the same home
Communication & Assistive Technology	
<ul style="list-style-type: none"> • Computers, iPads, or tablets specifically for ALS communication. • Speech-generating devices (Eye Gaze, Tobii, Dynavox, Surface) • Communication software and apps • Adaptive keyboards, switches, and mounts 	<ul style="list-style-type: none"> • Computer repairs and/or virus protection • Internet fees or monthly phone service bills • Televisions or television-related devices (i.e. AppleTV, Hulu, Netflix etc.) • Computer desks, printers, or general office equipment
Medical Expenses & Equipment	
<ul style="list-style-type: none"> • FDA-approved ALS-related prescription medications (Rilutek, Radicava, Nuedexta, and generic equivalents) • Durable Medical Equipment (power wheelchairs, lift chairs, Hoyer lifts, commodes, ventilators, hospital beds, prescribed wheelchair cushions) • Respiratory support devices and accessories 	<ul style="list-style-type: none"> • Over-the-counter medications (except physician-prescribed nutritional supplements) • Health insurance premiums • Non-ALS related medical expenses (dental, vision, hearing) • Alternative therapies (massage, acupuncture)

<ul style="list-style-type: none"> • ALS clinic co-pays and fees • PEG tubes, feeding formula, and necessary supplies • Diaphragm pacers and related medical devices 	<ul style="list-style-type: none"> • General fitness or exercise equipment • Cosmetic or elective medical procedures
Home Modification & Accessibility	
<ul style="list-style-type: none"> • Wheelchair ramps, stair lifts, door widening, accessible bathroom and bedroom modifications • Grab bars, handrails, and lift systems • Electrical modifications necessary for medical equipment use • Backup power generators for ALS medical needs 	<ul style="list-style-type: none"> • General home repairs unrelated to accessibility (painting, driveway repairs) • Home security systems or alarm installations
Personal & Daily Living Support	
<ul style="list-style-type: none"> • Adaptive clothing and specialized bedding for ALS care • Medical-grade cushions, positioning devices, and pressure relief mattresses • Disposable medical supplies (gloves, incontinence supplies, suction catheters) 	<ul style="list-style-type: none"> • Standard clothing, shoes, and general household goods • Non-medical pillows, blankets, and linens • General toiletries and beauty products
Other Essential Support Services	
<ul style="list-style-type: none"> • Home accessibility evaluations by a licensed professional • Transportation assistance for ALS medical appointments • Hospital beds 	<ul style="list-style-type: none"> • General home organization or cleaning services • Routine transportation (personal car payments, gas, or vehicle insurance)