



Dear Prospective Flex Grant Applicant:

We thank you for your interest in The Susie Foundation's Flex Grant Program. The program seeks to aid families impacted by ALS by providing financial assistance to those families with expenses that are not traditionally covered by private insurance, Medicare, Medicaid, and other assistance programs.

The Susie Foundation is a 501(c)(3) non-profit organization built and run by a completely volunteer staff and board of directors. The organization is committed to securing a future free from ALS by working tirelessly to compassionately support the self-identified needs of patients, families, and caregivers in their pursuit of fuller, richer, and more meaningful lives.

The Susie Foundation is pleased to be able to offer help to those patients and families in need of assistance. The program is available to all residents of Connecticut, Massachusetts, and Rhode Island who have a definitive or probable diagnosis of ALS and are homebound – meaning that they cannot leave home without a considerable and taxing effort.

The Flex Grant Program offers financial support through reimbursements to help cover the costs of respite care, adaptive devices not covered by medical insurance, certain medical expenses and equipment, as well as home modifications. A full description of these products and services eligible for reimbursement can be found on Page 4 of this application packet. Grants are awarded biannually through a selection process administered by our Board of Directors and based, in part, on the availability of funds. First time applicants, as well as those exhibiting dire and/or debilitating personal, psychological, familial, medical, or financial circumstances may be given priority.

For more information about this program, please review the policies and procedures on the following pages.

If you have any questions regarding the application, please contact Ryan Matthews, Executive Director of The Susie Foundation:

Tel: (203) 490-6694

Email: Ryan.Matthews@TheSusieFoundation.org

If you would like to apply, please visit our website and online application for more info:

Website: TheSusieFoundation.org/flex-grant

Online Application: bit.ly/tsfflexgrant



Policies and Procedures of the Flex Grant Program

Eligibility Requirements

Eligible applicants include all residents of Connecticut, Rhode Island, and Massachusetts who are homebound and have a definitive diagnosis of Amyotrophic Lateral Sclerosis (ALS). Applicants must fill out the entire grant application and return it to The Susie Foundation by the application deadlines outlined below in order to be considered. First-time applicants must complete the Verification of ALS Diagnosis form, which includes Physician's signature.

To note, the program only reimburses applicants for specific expenses. Please consult the list of eligible and ineligible expenses found on Page 4 of this packet before submitting your application. Also, please be aware the program requires applicants to submit receipts and/or proofs of payment before furnishing final payment to the applicant.

The program prohibits applicants who are in any way directly related to the directors of the organization.

Proposal Submission Process (Pre-Award)

Step 1: Fill out the application form. Make sure you complete each question and sign the application packet on the last page. If this is your first time completing an application make sure a Verification of ALS Diagnosis form is completed by your Physician or Neurologist.

Step 2: Once your application is received, you will receive a notification either by email or mail (if there is no email address on file) stating that we have received your application. If you do not hear from us within two weeks, please contact Ryan Matthews either by phone or email at: (203) 490-6694 or Ryan.Matthews@TheSusieFoundation.org

The grant period which you are applying for will be determined by the date you send in your application.

Step 3: Now you wait until the deadline for that grant period. Please save any receipts that apply to your grant application and fall within the acceptable date ranges as listed in the table below. Please do not mail in any receipts until after you receive your approval letter.

Important Dates

Grant Period	Application Deadline	Approval Letters Sent Out	Acceptable Data Range or Expenses	Receipts Due By
Spring	April 30th	First week of May	October 31th-April 30th	July 20th
Fall	October 30th	First week of November	May 1st-October 30th	January 20th



Applicant Selection Process and General Criteria

Grants will be awarded bi-annually to eligible applicants on an objective and non-discriminatory basis. All eligible applications will be reviewed by The Susie Foundation's Board of Directors and award recipients will be chosen through majority vote. This vote will be based upon a number of specific selection criteria, as well as overall fund availability.

The Susie Foundation's Flex Grant selection criteria are as follows:

- The applicant's completes the grant application in its entirety and returns all necessary forms and paperwork to The Susie Foundation by the application deadline stated above;
- The applicant is in no way directly related to any of the directors of the organization;
- The applicant resides in Connecticut, Massachusetts, or Rhode Island, provides indisputable proof of having received a definitive diagnosis of Amyotrophic Lateral Sclerosis (ALS) from their physician or neurologist;
- The applicant effectively demonstrates through their application that they are homebound and that they cannot leave home without considerable and taxing effort;
- First-time applicants and those with especially dire and/or debilitating personal, psychological, familial, medical, or financial circumstances are also given priority.

Recipients may apply for and receive grants up to \$1,000 each, but it is up to the applicant to explicitly state in their application how much they are applying for and exactly what the assistance will help to cover.

Award Acceptance Process

Candidates will be notified of their selection via a notification letter during the first week of the first month following the application deadline. This letter will be sent by email or, if that method of delivery is unavailable, through standard mail. Applicants must accept or decline this award within fifteen (15) business days.

Award Reimbursement Procedure (Post-Award)

After acceptance, grant recipients will receive direct reimbursement for expenses only after submitting receipts and/or proof of payment with the signed Billing Statement for Reimbursement form, along with any receipts related to the product, modification, or service.

Grantee Eligibility for Future Grant Periods

Following the submission of an awardee's Billing Statement for Reimbursement, as well as any and all receipts associated with that form, any applicant who is selected for an award is immediately eligible to re-apply for the next grant period. To note, applicants must re-apply before being considering for subsequent grants.



Products and Services Eligible for Reimbursement

Eligible Reimbursements	Ineligible Reimbursements
Respite Care	
<ul style="list-style-type: none"> • Professional Home Care • Patient sitting services by anyone NOT living in the home 	<ul style="list-style-type: none"> • Expenses related to any residential living programs • Lawn care and house cleaning services • Caregiving from someone living in the same home
Communication	
<ul style="list-style-type: none"> • Computer, iPad/Tablet. Limit 1 device per year • Computer software/apps for communication • Augmentative Communication Device (e.g. Dynavox, Eye Gaze, Tobii, Surface, etc.) 	<ul style="list-style-type: none"> • Computer repairs and/or virus protection • Internet fees or phone bills • Televisions or television-related devices (i.e. AppleTV, Chromecast, etc.) • Computer tables/desks, printers/scanners • Any type of computer and/or tablet accessory not directly related to communication.
Medical Expenses	
<ul style="list-style-type: none"> • Prescription costs related to FDA approved Rilutek, Radicava, Nuedextra – includes generic forms • Durable Medical Equipment including, but not limited to, lift chairs, Hoyer Lifts, commodes, wheelchairs, prescribed wheelchair cushions (ex. ROHO), etc. • ALS clinic fees and co-pays • PEG Tubes procedure copays, feeding formula, and replacement supplies • Respiratory support devices and supplies • Diaphragm pacer copays • AFO Braces and Splints • Insurance Co-Pays for Medical Equipment • Utility bills; mortgage/rent payments • Vitamins, supplements, 	<ul style="list-style-type: none"> • Any over the counter medications. • Any over the counter medical supplies • Health insurance premiums • Home security systems • Non-ALS related doctor or hospital fees (i.e.. vision, dental, etc.) • Any type of massage therapy, including acupuncture. • Exercise equipment, including pool fees. • Any type of clothing, groceries, toiletries, shoes, incontinence supplies, sheets, blankets, pillows, and cushions.
Home Modification	
<ul style="list-style-type: none"> • Material and labor for improving overall home accessibility including wheelchair ramps, door widening, stair lifts, bathroom and bedroom modification, grab bars, hand rails, etc. • Home generators • Hospital beds 	<ul style="list-style-type: none"> • Home maintenance and repairs (i.e. painting, driveway repair, etc.)