

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 focused on changing the lives of young caregivers and families struggling with the daily challenges of living alongside Amyotrophic Lateral Sclerosis (ALS). Since our founding in 2013, we have raised more than \$500,000 to provide compassionate, enduring, and life changing support services to patients, young caregivers, and families living with the challenges of ALS in New England.

The roots of our work can be traced back to November 6th 2009, the day our organization's inspiration and namesake, Susan Ready Matthews, was diagnosed with ALS. Since her passing on April 17th 2011, we have been working tirelessly to build on Susan's legacy of service to ensure patients, young caregivers, and families can access life-enhancing support services and technologies to ensure they are best able to lead rich, meaningful, and productive lives.

Today, we are proud to offer support for families across southern New England access through our Flex Grant Program. The program is available to all residents of New England who have a definitive or probable diagnosis of ALS and have or will incur out of pocket expenses related to their care.

The Flex Grant Program offers financial support through direct reimbursement payments that help to cover costs not typically covered by medical insurance, including medical equipment, healthcare services, home modifications, and much more. A full description of these products and services eligible for reimbursement can be found on Page 4 of this application packet.

Flex Grants are awarded on a rolling basis with applicants being screened and evaluated each month by the Program Committee of our Board of Directors. 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 New England who 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.

Funding Application Submission Process (Pre-Award)

Step 1: Fill out your application by visiting www.bit.ly/tsfflexgrant. 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, neurologist, or social worker/case manager and is available online via the following link: www.bit.ly/susieverify

Step 2: Once your application is received, you will receive a notification by email 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) 217-4884 or Ryan.Matthews@TheSusieFoundation.org

The grant period which you are applying for will be determined by the date your application is fully complete. For first-time applicants, this is the date we receive the Application or Verification of ALS Diagnosis Form, whichever occurs *second*.

Step 3: Now you wait until the end of the month during which you apply. The Program Committee of our Board of Directors convenes monthly to review and select grant recipients. You will be notified of the status of your application during the first week of the month following your application completion date.

Please note: if you do not upload expense receipts with your application, please save any receipts that apply to your funding request. You will need to provide copies of their receipts before we are able to process any possible payment.

Important Dates and Reminders

Deadline for Submission	Approval Notices	Data Range for Expenses	Receipts	Diagnosis Verification
Last day of the month during which you submit a completed application.	Sent via email during the first week of the month succeeding the month during which you apply.	90 days prior and 90 days succeeding your application date.	Due prior to your grant payment	Required for all first-time applicants.



Applicant Selection Process and General Criteria

Grants will be awarded monthly to eligible applicants on an objective and non-discriminatory basis. All eligible applications will be reviewed by The Susie Foundation's Board of Directors Program Committee 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 completes the grant application in its entirety and returns all necessary forms to The Susie Foundation;
- The applicant is in no way directly related to any of the directors of the organization;
- The applicant resides in New England and provides proof of having received a definitive diagnosis of Amyotrophic Lateral Sclerosis (ALS) from their physician, neurologist, or social worker/case manager;
- First-time applicants and those with especially dire and/or debilitating personal, psychological, familial, medical, or financial circumstances are also given priority.

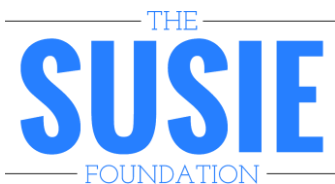
Recipients may apply for and receive grants up to \$1,000 each, but it is up to the applicant to state in their application how much they are applying for and exactly what the assistance will help to cover.

Award Acceptance and Reimbursement Process

Candidates will be notified of their selection via email during the first week of the month succeeding the month during which they apply. If accepted for funding, grant recipients will receive direct reimbursement for expenses. This payment is typically processed via check mailed directly to the applicant, but The Susie Foundation is happy to make accommodations to provide payment to directly to various vendors.

Grantee Eligibility for Future Grant Periods

Any applicant who is selected for funding is eligible to re-apply, limit one application every three months and \$3,000 of total funding per applicant per calendar year.



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 • Expenses related to any residential living programs 	<ul style="list-style-type: none"> • Lawn care and house cleaning services • Caregiving from someone living in the same home
Communication	
<ul style="list-style-type: none"> • Computer, iPad/Tablet. • 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 electric device or 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 • Insurance Co-Pays for Medical Equipment • Utility bills; mortgage/rent payments • Dietary supplements • Medical supplies related to on-going care • Massage therapy • Any type of clothing, groceries, toiletries, shoes, blankets, pillows, and cushions that are directly related to patient care. 	<ul style="list-style-type: none"> • Any over the counter medications with the exception of nutritional supplements. • Health insurance premiums • Non-ALS related doctor or hospital fees (i.e.. vision, dental, etc.) • Exercise equipment • Any type of clothing, groceries, toiletries, home goods, sheets, blankets, pillows, and cushions that are not directly related to patient care.
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 unrelated to patient care (i.e. painting, driveway repair, etc.) • Home security systems

