



North Carolina Chapter Grant Request for Funds Packet

***PLEASE READ THIS BEFORE COMPLETING YOUR REQUEST ***

→ **TO BE ELIGIBLE FOR THIS GRANT, YOUR PRIMARY RESIDENCE MUST BE IN NORTH CAROLINA AND HAVE A VERIFIED DIAGNOSIS OF ALS**

Important Information

- This is a reimbursement grant program. **Only** items as stated on the ALS Eligible Expenses List (pg. 2), that you have **already paid for during the current period**, may be reimbursed up to the maximum amount of \$750 per period.
- You may submit the Request for Funds form with **copies** of receipts **up to three times ONLY** during the period until the \$750 cap is met. All requests are subject to the availability of funds at the time of submission. Therefore, if partial reimbursement is initially received this does not guarantee you will receive the rest of the \$750 later. Any request submitted over the 3x max will not be reimbursed.
- The sooner in the period you submit your reimbursement, the greater the chance of you being reimbursed, as funds may run out before the end of the period, and you avoid missing the deadline.

PLEASE FOLLOW STEPS BELOW TO BE SURE YOU ARE SUBMITTING REQUEST CORRECTLY

Step 1 - CHECK ALS ELIGIBLE EXPENSES LIST (pg. 2) to make sure receipt(s) you are submitting are ON THE LIST of eligible expenses (if they are not on the list, they are not eligible) AND be sure receipts are between the **acceptable date ranges** for current period (dates below).

Step 2 - Complete Request for Funds form (please complete entire form) (pg. 3),

Answer impact questions, **Read each statement and put a checkmark where it is required** before you **Read** and Sign responsibility statement (pg. 4).

Step 3 - Attach COPIES of Receipt(s) that have already been paid for- You can use Mileage log or Respite Care Provider log if needed as receipts (pg. 5 & 7). **ALL RECEIPTS MUST INCLUDE CLEAR DESCRIPTION AND DATE**

Step 4 - Return by fax or email (must be in the form of a scanned document as an attachment. Please do not send pictures included in the body of email). You can also mail the Request for Funds form with copies of receipts (Info provided on pg 4). **PLEASE DO NOT SEND IN ORIGINAL RECEIPTS – SEND COPIES ONLY and retain a copy of your paperwork.** If you need extra forms, please visit our website at www.alsnc.org, go to Local Care Services, then Chapter Grant where you can download Request for Funds packet or separate forms as needed. You can also request by email or phone from a Care Services staff member.

See dates below. Do not wait until the last minute, if there is an issue with your submission and is received on the in-house date, you will not qualify for reimbursement for that period.

Step 5 - Receive check, which can take **up to 6 weeks**. Checks are void after **90 days** and cannot be re-issued. Please deposit when you receive. If you do not receive check after 6 weeks, please contact Claudia Beirne at claudia@alsnc.org or 919-390-0125.

>>IMPORTANT DATES TO REMEMBER- LATE REQUESTS WILL NOT BE ACCEPTED, **NO EXCEPTIONS** <<

Grant Periods	<u>Request for Funds</u> form along with eligible receipts		Receipts must be <u>dated</u> between
	<u>MUST be postmarked by:</u>	<u>MUST be received In-House by:</u>	
1st (Jan. 21 – July 20)	<u>HARD DEADLINE:</u> July 15	<u>HARD DEADLINE:</u> July 20	Jan. 21 and July 20
2nd (July 21 – Jan. 20)	<u>HARD DEADLINE:</u> Jan. 15	<u>HARD DEADLINE:</u> Jan. 20	July 21 and Jan. 20

ALS Eligible Expenses

- **Please be sure to CHECK THIS LIST BEFORE submitting your Request for Funds form.**
If it is not on this list, it will NOT be eligible for reimbursement.
- **ONLY Accepted: COPIES (NOT ORIGINALS)** of receipts that **CLEARLY SHOW DATE AND DETAIL of item(s)/service(s)** which have already been paid for (**cannot accept quotes or Estimates**).
- **NOT accepted** as Receipts: Copies of checks/cancelled checks, bank statements, credit card statements, insurance explanations of benefits (EOBs) or Medical Portal statements/statement of accounts (must be copy of actual invoice with description of service)
- **Receipts must be within the acceptable date ranges for the current period.**

RESPITE CARE: *the temporary relief for a primary caregiver, enabling them to take a much-needed break from the demands of caregiving (Does NOT include house cleaning, home/lawn maintenance, drivers).*

➤ If care provider is **not** through a professional homecare agency, provider must complete the "Respite Care Provider Log" (included in this packet) which serves as your receipt. Attach to completed "Request for Funds" form (also included) **AND provide a form of ID which includes their address (driver's license/Government issued ID or utility bill)**. Care provider cannot live at the same address as the person living with ALS. (*Request could be subject to non-payment if false information is submitted*)

➤ If care provider **is** through a professional homecare agency, attach a copy of receipt from professional provider to "Request for Funds" form.

COMMUNICATION:

- iPads/tablet/smart phone (limit 1 per person) and communication apps
- speech generating devices (SGDs), voice amplifiers and voice banking
- Electronic writing tablets (example: Boogie Board), communication tablets, Eye Gaze
- virtual assistant/home automation systems, i.e. Alexa, Google Home (limit of 3)
- Personal emergency response system – installation, then monthly fee up to \$75 per month, Home Cam/Doorbell Cam

MEDICAL EXPENSES: (only items listed below)

- Specific prescription copays for **Rilutek/Riluzole, Radicava, Nuedexta, and/or Baclofen (pump) medications ONLY (receipts must include name of medication and date filled)**
- ALS clinic visits co-pays, genetic testing through ALS clinic, Respiratory procedures and respiratory devices, Feeding tube procedure (**receipt must clearly show detail of service**)
- Feeding tube formula, oral nutritional formula (example: Boost/Ensure), liquid thickener
- Durable medical equipment: any type of wheelchair, medical wheelchair cushion, wheelchair repair, wheelchair batteries, wheelchair accessories, lift chair, Hoyer lift & sling/sit to stand lift, shower/bath chair, rollator walker, bedside commode, over the bed table, medical hospital bed ONLY – does not include mattress/sheets or any other adjustable bed or mattresses.
- Adaptive equipment (must be directly related to ALS), incontinence products (does not include catheters)
- Orthotic Devices: AFO braces, hand splints, Figure 8 sling, cervical collar
- Massage therapy provided by a licensed massage therapist (LMBT), must show LMBT number on receipt/invoice
- Counseling (individual and/or family) by a licensed provider

HOME MODIFICATIONS:

- Materials and labor for home accessibility (RECEIPT MUST INCLUDE DESCRIPTION OF HOW IT'S BEEN MADE ACCESSIBLE), grab bars, raised sinks, accessible toilet/seat riser, bidet, shower or bath modification to make it accessible, door widening, expandable door hinges, light switches, doorknobs, Generator (limit 1 per person)
- Portable or permanent ramps, platform lifts, stairlift

TRANSPORATION:

- **Complete a Mileage Log and attach to completed Request for Funds form.** (included in this packet). **Gas receipts are not accepted.**
- Mileage/rental of vehicle or car service **FOR ONLY THE FOLLOWING:** ALS clinic appointments, NC clinical trial appointments (when travel stipend is not provided), feeding tube, Baclofen (pump) and invasive vent procedures, Radicava treatment appointments **Does NOT include mileage for any other medical appointment other than what is listed above**
 - Lodging for clinic appointment ONLY; 1 room for 1 night, limit up to \$140/night, does NOT include meals
 - Automobile accessibility modification (not purchase of automobile/van), wheelchair lifts, ramps, locking wheelchair mechanism, hand controls
 - Driving evaluations



North Carolina Chapter Grant Request for Funds Form

Complete this form every time you request funds

(May submit for funds, along with receipts, 3 times only per period for a maximum amount of \$750)

Person with ALS Information: (Check made out to person with ALS)

Name: _____

***Note: North Carolina physical address must be provided. PO Box only is not accepted.**

Physical Address: _____

City: _____ State: _____ Zip: _____

Mailing Address (if different from physical address): _____

City: _____ State: _____ Zip: _____

Home Phone: _____ Cell Phone: _____

Email address: _____ ALS Clinic Attending: _____

Primary Caregiver Information:

Name: _____ Relationship to person with ALS: _____

If different from above:

Address: _____ City: _____ State: _____ Zip: _____

Home Phone: _____ Cell Phone: _____

Email address: _____

Product/service request for reimbursement: **(Please be sure to check each category on the *ALS Eligible Expenses* list to be sure service/item is listed.** If it is not found on the list, it will not be included in the reimbursement check amount).

PLEASE CHECK ALL THAT APPLY WITH THE AMOUNT REQUESTING:

Respite Care: \$ _____ Communication Devices: \$ _____ Transportation: \$ _____

Home Modifications: \$ _____ Medical Expenses: \$ _____

Total Amount Requesting: \$ _____ (not to exceed \$750)

Answer the following questions: On a scale of 1-5 with 1 being the lowest

1. Having access to this grant will increase my quality of life:
1 - Not at all 2 3 4 5 - Tremendously!
2. Having access to this grant will enable me to adapt to ALS changes:
1 - Not at all 2 3 4 5 - Tremendously!
3. Having access to this grant will offset some of the financial burden of this disease:
1 - Not at all 2 3 4 5 - Tremendously!

FOR ALSA USE ONLY
Amount: _____
Approved By: _____
Date: _____

Something to consider before applying:

In an effort to serve those who are most in need, please consider alternative funding sources such as VA benefits, Medicare, Medicaid, Insurance coverage, Long Term Care insurance, etc. before requesting funds from the NC Chapter. Veterans who are not receiving VA benefits should contact a veteran's service organization (PVA), clinic social worker or a member of the Chapter Care Services Department for guidance.

PLEASE READ AND PUT A CHECK NEXT TO THE FOLLOWING STATEMENTS BEFORE SIGNING:

____ I have checked that the service/item I am submitting is **ON THE ALS ELIGIBLE EXPENSES** list provided (**MUST BE ON LIST TO BE ELIGIBLE FOR REIMBURSEMENT**).

____ The date of my receipt is between the **ACCEPTABLE DATE RANGE** of this period

(1st period = Jan 21 - July 20 2nd period = July 21 - Jan 20)

____ Receipts I am submitting have a **CLEAR DESCRIPTION OF SERVICE AND/OR ITEM PURCHASED** and **INCLUDES DATE OF SERVICE/PURCHASE**.

____ I have included a copy (**NOT ORIGINALS, IF SENDING BY MAIL**) of actual receipt(s). (**NOT** Cancelled Checks, Bank Statements, Credit Card Statements/Receipts, Insurance EOB (Explanation of Benefits), Medical Portal Statements/Account Statements, Quote or Estimate)

By submitting this Chapter *Request for Funds* and signing below, I assume personal responsibility for understanding the North Carolina Chapter Grant Request for Funds process, eligible expenses and hard deadlines. If I include expenses that are not listed on the *ALS Eligible Expenses* list, I understand that **I will not receive reimbursement for these items**. I also understand that **no exceptions** will be made to the grant deadlines and all grants are subject to availability of funds.

Applicant (Print Name)

Signature

Relationship to person with ALS

Date

**Policies and procedures are subject to change without notice.*

Please email (scanned attachment), fax or mail completed Request for Funds form with eligible copies of receipts to the Chapter office at:

**The ALS Association North Carolina Chapter
4 N. Blount Street, Suite 200
Raleigh, NC 27601
Email: claudia@alsnc.org
Fax: 919-755-0910**

If you have any questions, please contact Claudia Beirne at claudia@alsnc.org or 919-390-0125



Respite Care Provider Log (For Non-agency) To be included with Request for Funds form

This is reimbursed to person with ALS

Respite Care is the temporary relief for a primary caregiver, enabling them to take a much-needed break from the demands of caregiving.

***Please Note: Service Provider must attach a copy of ID (license/government issued or a utility bill with the address that must match the address below)**

Non-agency Care Provider Name (Print): _____

Street Address: _____
(cannot live in same residence as person with ALS)

City: _____ State: _____ Zip: _____ County: _____

Phone: _____ Email: _____

Signature of Care Provider: _____

Date (list separately on each line)	Time In:	Time Out:	# of Hours

Total # of Hours _____ x hourly rate \$ _____ = Total Amount Paid for Services: _____

By Signing below, I acknowledge that the above information is true, correct and complete.

Person with ALS Name (Print): _____

Signature: (person with ALS or Caregiver): _____

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Mileage Log

To be included with *Request for Funds* form

- Use *Mileage Log form* for reimbursement (.50 cents/mile) for the following appointments **ONLY** **(Does Not Include mileage for any other Medical Appointment)**
 - Mileage **OR** rental of vehicle/car service to and from ALS clinic appointments (if requesting reimbursement for vehicle/car service, please do not request reimbursement for mileage as this is already included as part of the rental/car service invoice)
 - North Carolina clinical trial appointments (only when travel stipend is not provided)
 - Feeding tube, invasive ventilator and Baclofen pump procedures
 - Radicava infusion

- **Gas receipts are not accepted, please use this form instead.**

Date	Place/Reason for Travel	Miles Traveled	\$ Amount @ .50/mile
			Total:

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Other ALS Financial Resources

1. Ride for Life Grants

- Care for Life Grant:

Individuals with a confirmed medical diagnosis of ALS who do not have healthcare coverage for respite care are eligible for this grant. More info: <https://alsrideforlife.org/programs-assistance/care-for-life-grant-application/>

- Plan for Life Grant:

Provides a **limited number of one-time only legal grants of up to \$1,500 toward the cost of legal services related to ALS.** More info: <https://alsrideforlife.org/programs-assistance/plan-for-life/>

2. Alexa R. Good ALS Foundation

This foundation provides financial assistance and support to SC and NC residents who are stricken with ALS. This assistance may include, but is not limited to, purchase or rental of specialized equipment, sitters and direct assistance to families. **More info:** www.alexargoodals.com Phone: (803)-327-2871

Contact: The ALS Association North Carolina Chapter Care Services representative at your clinic to assist you with this application.

3. HealthWell's ALS Fund

HealthWell provides up to \$15,000 in financial assistance to underinsured individuals living with ALS to help cover the cost of prescription drug copays or health insurance premiums (please note that the ALS Fund does not cover hospital visits or medical devices). To [qualify for a grant](#), applicants must have some form of health insurance (major medical or prescription drug) and an income that is less than [500% of the Federal Poverty Level](#). **More info:** [apply online](#) or by phone by calling (800) 675-8416 and receive instant notification of approval.

4. ALS Guardian Angels

The ALS Guardian Angels grant help families with expenses not covered by Medicare, Medicaid, insurance and other reimbursement programs. Recipients may apply for and receive grants up to \$1,500 each. Grant approval based on need and available funds.

More info: <http://www.alsguardianangels.com/what%20we%20offer.html>
<http://alsguardianangelsdev.com/grantrequest.aspx>

5. A Giving Spirit Foundation Grant

This grant serves mothers with dependent children living in the home who are suffering from a medically diagnosed, physically debilitating disease. Covers the greater Charlotte, NC service area.

More info: <https://www.agivingspiritfoundation.org/need-us>

6. The Association for Frontotemporal Degeneration (AFTD)

AFTD offers three types of grants (Respite, Travel and Quality of Life grants) to people in the FTD community.

More info: <http://www.theaftd.org/> and
<https://www.theaftd.org/living-with-ftd/resources/comstock-grants/>

7. Jim "Catfish" Hunter Foundation

This Foundation offers a grant intended to assist persons living with ALS and/ or caregivers. The grant assists with medical expenses, medical equipment, respite care, travel and/or other needs.

More info: <http://www.catfishfoundation.org/corner/application/>

8. CoopStrong Foundation

The CoopStrong is a non-profit organization formed to honor the memory of Nelson Cooper. CoopStrong seeks to support the fight against ALS by assisting local families living with the disease in the Greenville, NC area and supporting research. **More info:** <https://www.coopstrong.org/>

9. Team Gleason

Team Gleason serves those living with ALS by providing access to innovative technology including getting assistance with an AAC device (Augmentative and Alternative Communication) and **power wheelchair seat elevator, anterior tilt, and/or attendant control.** **More info:** <http://www.teamgleason.org/technologyfaq/>
http://www.teamgleason.org/wp-content/uploads/2018/11/tgif_application.pdf

10. ALS Care Fund (Respite Care Grant)

Patients regularly seen at Carolinas Neuromuscular/ALS-MDA Clinic, Atrium Health, may request a grant application from a clinic staff member. The amount varies according to level of need and available funds, can apply twice a year. **More info:** Shivangee Thorne, LCSW at Shivangee.Thorne@atriumhealth.org or 704-355-0784.

11. ALS Foundation for Life

Assists with the cost of home modifications, medical equipment, therapy services, respite care, transportation and ALS prescriptions based on funding availability and financial need. Tax Returns Required.

More info: <http://www.alsfoundation.org/gethelp> Application: <http://www.alsfoundation.org/pubs/ALS-Grant-Application.pdf>

If you accessed a grant/resource that is not listed on this page, please contact Claudia Beirne at 919-390-0125 or claudia@alsnc.org so that we may add to our list.

Additional Tips

- Have friends or family help you research community resources. Many times friends and family want to help, but do not know how to assist. This gives them a helpful and tangible “to-do”.
- Confirm all your insurance policy benefits – Health, Supplemental, Long Term Care, etc. Explore the possibility that needed equipment, services and supplies may be covered by insurance if you have a doctor’s prescription.
- Consider contacting your local Department of Health and Human Services. Often counties provide services such as respite programs, help in accessing Medicaid CAP services, transportation services, etc.
- Look to your local faith-based and volunteer organizations as well as your local Agency on Aging for support.
- Civic organizations such as the Shriners, Jaycees, Kiwanis, Boy Scouts, etc. may offer help (example, building ramps).
- Access Palliative Care Services (may be covered by insurance) for additional pain and symptom management support.
- Check with your car manufacturer to see if they have funding for installation of adaptive equipment.
- If you attend an ALS Clinic, consult the Clinic Coordinator regarding possible additional resources available.