



North Carolina Chapter Grant Request for Funds Packet

All requests are subject to availability of funds

ELIGIBILITY REQUIREMENTS

- Primary residence is in **North Carolina**
- One time completion of ALS Verification Form, signed by an ALS clinic neurologist. Chapter will keep form on file. If you attend an ALS clinic, The ALS Association Care Services staff member will assist in getting this form completed.

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 are not required to hold and submit receipts for the entire amount of \$750 at one time (although you can request the total amount). You may submit the Request for Funds form with **copies** of different receipts up to **three times** 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 automatically guarantee you will receive the rest of the \$750 later. WHY? This allows us to track budgeted grant funds more precisely which gets more funds to those who need it in a timely manner.

PLEASE FOLLOW THESE STEPS TO REQUEST FUNDS

Step 1 - Check ALS Eligible Expenses list (pg. 2) to make sure receipt(s) you are submitting are on the list of eligible expenses **and** be sure receipts are between the acceptable date ranges for current period.

*If you are unsure, please contact Claudia at claudia@alsnc.org or 919-390-0125 before submitting.

Step 2 - Complete Request for Funds form (pg. 3), **Answer** impact questions and **Read** and **Sign** responsibility statement (pg. 4).

Step 3 - Attach Copies of Receipt(s), you can use Mileage log or Respite Care Provider log if needed as receipts (pg. 5 & 7). Please do not send original receipts.

Step 4 - Return by mail, email (scan-no pictures) or fax (info provided on pg. 4), the **completed** Request for Funds form with **copies** of receipt(s). Please retain a copy of your paperwork and original receipts. You will only be notified if funds are not available. You can find the Request for Funds Packet and forms:

- 1 Online at www.alsnc.org, go to Local Care Services, then Chapter Grant, here you can download Request for Funds packet or separate forms as needed
- 2 From a Care Services staff member at clinic or request by email or phone

Step 5 - Receive check which can take up to 6 weeks. Checks are processed and mailed approximately the 20th of each month. Checks are void after 90 days and cannot be re-issued. Please deposit when you receive.

- **Late requests will not be accepted, no exceptions.** See dates below. Do not wait until the last minute.
- **TIP:** Add reminders to your calendar or smart phone so you get your paperwork in on time!

IMPORTANT DATES TO REMEMBER

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

ALS Eligible Expenses

- Please be sure to check this list before submitting your Request for Funds form.
- **Accepted:** Copies of invoices and/or receipts that clearly show detail of item(s)/services listed below
- **Not accepted:** phone pictures of receipts, copies of checks/cancelled checks, bank statements, credit card statements, insurance explanations of benefits (EOBs) or medical provider (portal) statements
- **IMPORTANT DATES TO REMEMBER**

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Respite Care:

➤ If care provider is *not* through a professional homecare agency, provider must complete the Respite Care Provider Log. This serves as your receipt. Attach to completed Request for Funds form. (Both forms are included in this packet and can also be downloaded online at www.alsnc.org go to Local Care Services, then Chapter Grant and download).

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

- Short-term, personal care of person with ALS, to relieve the primary caregiver. (Does NOT include specific house cleaning or home/ lawn maintenance services). Respite care provider cannot live at the same address as the person living with ALS. Further care provider information may be requested for reimbursement.

Communication:

- iPads/tablet (limit 1 per person) and communication apps
- virtual assistant/ home automation systems, i.e. Alexa, Google Home
- Copays for speech generating devices (SGDs)
- Electronic writing tablets (example: Boogie Board)

Medical Expenses:

- Specific prescription copays for **Rilutek/Riluzole, Radicava, Nuedexta, and/or Baclofen (pump)** medications ONLY
- ALS clinic visits, genetic testing through ALS clinic
- Respiratory procedures and respiratory devices
- Feeding tube procedure, tube feeding formula, oral nutritional formula (example: Boost/Ensure), liquid thickener
- Durable medical equipment: any type wheelchair, medical wheelchair cushion, wheelchair repair, wheelchair batteries, wheelchair accessories, lift chair, hoist lift & sling, shower/bath chair, rollator walker, bedside commode, copay for medical hospital bed (does not include specialized mattresses or beds)
- Orthotic Devices: AFO braces, hand splints, Figure 8 sling, cervical collar
- Massage therapy provided by a licensed massage therapist (LMBT)
- Counseling (individual and/or family) by a licensed provider
- Personal emergency response system – installation, then monthly fee up to \$75/mo.

Home Modifications:

- Materials and labor for home accessibility, grab bars, raised sinks, accessible toilet/seater, bidet, shower or bath modification, door widening, expandable door hinges, light switches, door knobs, virtual assistant/ home automation systems (i.e. Alexa, Google Home)
- Generator (limit 1 per person)
- Portable or permanent ramps, platform lifts

Transportation:

➤ Complete a Mileage Log and attach to completed Request for Funds form. (Both forms are included in this packet and can be downloaded online at www.alsnc.org go to Local Care Services, then Chapter Grant and download). Gas receipts are not accepted.

- Mileage/rental of vehicle or car service to and from ALS clinic appointments, NC clinical trial appointments (when travel stipend not provided), feeding tube, Baclofen (pump) and invasive vent procedures, Radicava treatment appointments ONLY
- Lodging for clinic appointment ONLY; 1 room for 1 night, limit up to \$140/night, does NOT include meals
- Automobile accessibility modification: 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 up to 3 times for a maximum amount of \$750/period along with different receipts

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: _____

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 item(s) are listed. If item 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: \$ _____

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 when you can 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 the following before signing:

I have read the *Request for Funds Packet* and agree to abide by all requirements as noted.

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 (1st period: July 20 and 2nd period: January 20). 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.

Please mail, email (scan-no phone pictures) or fax completed forms and/or 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**



Mileage Log
To be included with *Request for Funds* form

- Use *Mileage Log form* for reimbursement (.50 cents/mile) for the following:
 - Mileage OR rental of vehicle/car service to and from ALS clinic appointments
 - North Carolina clinical trial appointments (when travel stipend not provided)
 - Feeding tube, invasive ventilator and Baclofen pump procedures
 - Radicava infusion appointment

➤ 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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Respite Care Provider Log (non-agency) To be included with *Request for Funds* form

To receive reimbursement, please answer the following questions:

Overall, how helpful will the respite care grant be in providing care for the person with ALS?

Significant

Considerable

Moderate

Minor

None

Overall, will the respite care grant make a positive difference in your life?

Yes

Somewhat

No

Overall, will the respite care grant help lower your stress level?

Yes

Somewhat

No

Non-agency Provider Name (Print): _____

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

Phone: _____ Email: _____

Signature of Care Provider: _____

Date	Time In:	Time Out:	# of Hours	Type of Care Provided (personal care only)

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: _____ Date: _____

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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 faith-based organizations in your community for support. Most of the time membership is not required.
- 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.