



# The Benefits of Supporting ALS Programs in South Carolina

## Overview

At any given time, approximately 900 South Carolina residents<sup>1</sup> are living with Amyotrophic Lateral Sclerosis (ALS), sometimes referred to as “Lou Gehrig’s Disease.” ALS is a fatal, progressive, neurodegenerative disease with no known cure or effective treatment options.

In South Carolina, The ALS Association provides assistance to people living with ALS and their families. With cases of ALS projected to **increase by 69 percent** over the next 25 years<sup>2</sup> and anticipated advancements in diagnostics and treatments, turning a fatal disease into a chronic one, more patient families than ever before are looking for these free and vital services.

## Addressing ALS in South Carolina

With an understanding of the critical medical needs faced by families struggling with ALS daily, and the many budget constraints, The ALS Association is looking to obtain a reoccurring line-item funding for ALS Care Services of \$500,000 in the FY24 budget. The South Carolina Department of Health and Human Services (SCDHHS) would provide the oversight of these funds and work in coordination with The ALS Association on the care services provided.

Securing funding for people with ALS in South Carolina is not only critical to their well-being, but it is also a cost-effective measure that would save the state significant funds on an annual basis. These care service programs may include Durable Medical Equipment (DME) loan programs, multidisciplinary ALS clinics, assistive technology programming, transportation stipends, and grants for respite care amongst other priorities.

## Financial Impact of ALS

Because each family is different, financial situations vary. However, with no cure or effective treatment options, the out-of-pocket cost of care for a person living with ALS can **exceed \$250,000 per year**, which often leads to the depletion of retirement or medical bankruptcy. Additionally, the person living with ALS, and usually their spouse, may have to leave their jobs and sacrifice their salary and employer sponsored health insurance.

## Supporting Veterans

While the cause of ALS is still unknown, studies prove that military veterans are nearly twice as likely to develop and die from ALS than members of the public<sup>3</sup>. Thanks to the advocacy efforts of The ALS Association, the Veteran’s Administration (VA) has classified ALS as a service-related disease and has extended important benefits to active-duty personnel and veterans diagnosed with ALS.

This is a critical issue for South Carolina, and over 400,000 military personnel and veterans live in the state<sup>4</sup>. The ALS Association provides care coordination and support to meet all immediate needs of veterans in South Carolina while they wait for VA benefits. This ensures that those who have fought for us can access critical services and support as they face their biggest battle: ALS.

**Contact** Lindsay Gill, Managing Director, Advocacy, [Lindsay.Gill@als.org](mailto:Lindsay.Gill@als.org), 210-860-7407

<sup>1</sup> <https://www.iqvia.com/locations/united-states/blogs/2022/07/disparities-in-medicare-access-for-people-under-65-living-with-als>

<sup>2</sup> Traynor, Chio, Geiger, Price, Calvo, Arthur “Projected increase in amyotrophic lateral sclerosis from 2015 to 2040.” Nature Communications, Volume 7, id. 12408 (2016)

<sup>3</sup> [https://www.als.org/sites/default/files/2020-04/navigating-als\\_military-veterans\\_als-in-military-white-paper\\_0.pdf](https://www.als.org/sites/default/files/2020-04/navigating-als_military-veterans_als-in-military-white-paper_0.pdf)

<sup>4</sup> <https://scdhec.gov/sites/default/files/Library/CR-012238.pdf>



OUR VISION: Create a world without ALS.

OUR MISSION: To discover treatments and a cure for ALS, and to serve, advocate for, and empower people affected by ALS to live their lives to the fullest.

NATIONAL OFFICE • 1300 Wilson Boulevard, Suite 600, Arlington, VA 22209 • PHONE 202.407.8580 FAX 202.464.8869 • [als.org](http://als.org)



## Case for Support for Care Services Funding in South Carolina

The ALS Association currently serves 236 families in South Carolina and is looking to obtain a reoccurring line-item funding for ALS Care Services of \$500,000 in the FY24 budget to provide priority care services program support for people living with ALS in the state.

### **\$50,000 to support Quality-of-Life Grants for individuals living with ALS in SC**

One of the most pressing needs of the ALS community in South Carolina is assistance with the extreme financial burden of living with ALS. The annual healthcare cost for a person living with ALS can be as high as \$250,000 or more per year and varies depending on the stage of the disease.

We currently offer Quality-of-Life grants of \$600 per family per year, and our current annual budget is \$5,000, which means that we can only provide about 8 grants per year. Obviously, the needs are much greater than what we're currently able to provide. Financial support of 100,000 would allow us to increase the grant amount we are able to provide to \$1,500 per family per year and support more families in a more impactful way.

The program helps pay for a variety of critical supports and services, with the goal of helping people to live independently for as long as possible and improve their safety, well-being, and overall quality of life. This Quality-of-Life grant program is particularly critical to people living with ALS in the more rural and economically challenged areas.

Recognizing the different types of challenges encountered in the progression of ALS, the program helps people with ALS, and their caregivers, to obtain the following types of services:

- Home care (including respite care for caregivers)
- Minor home modifications
- Durable medical equipment not obtainable through our loan closet program
- Prescription medication costs not covered by insurance/medical expense copays
- Transportation services

### **\$245,000 to establish a Loan Closet with Assistive Technology (AT) and more Durable Medical Equipment and improved service delivery and reduce costs of care**

Recognizing a severe need for additional assistive technology and medical equipment for our ALS families across South Carolina, we began work in June to assess the growing needs in the area and develop a plan to build assistive technology support and enhance our loan closet offerings in South Carolina. Financial support in the amount of 245,000 for this purpose would have a major, lasting impact on ALS families, helping to bridge existing service barriers in SC.

Barriers currently include the high cost of this equipment, which is often only partially covered by an individual's insurance, as well as the difficulty of many families to access this type of equipment either through us or our partners at the two South Carolina ALS Clinics in Charleston and Greenville. Individuals living in remote areas of the state, not close to either of these clinics, often are asked to make special

trips to the clinic for AT evaluations, and they simply do not make a second or third trip to get the evaluation and ultimately the equipment.

With this financial support, we will be able to provide better and more assistive technology and durable medical equipment to our ALS families in SC and assist our ALS clinic partners by providing equipment that they can use to educate and train both patients and clinic staff on the features and advantages of assistive technology and durable medical equipment. Access to this type of equipment through our Loan Closet can be truly life changing—helping patients, caregivers, and healthcare providers communicate longer and with more ease.

### ASSISTIVE TECHNOLOGY

Assistive technology for people living with ALS includes a variety of tools and devices that improve quality of life allowing people with ALS to communicate, access their computer/tablet/phone and environment despite their limitations caused by ALS. Our assistive technology program provides equipment at no charge, and the equipment can be used as long as it is needed. In most cases, each piece of equipment typically gets used by more than one person in its lifetime due to the nature of the disease. Examples of equipment and items for AT:

High Technology Equipment: Devices that are more complex, typically computer based.

- Speech generating devices (SGD's): electronic devices that synthesize speech.
- Eye gaze control systems: devices that use eye movement to select letters and words on a computer to synthesize speech.

Lite Technology Equipment: Devices that are usually digital and may require a battery or power source.

- Text to speech computer software programs: programs that consist of an on-screen keyboard and mouse that allows use without needing a person's hands.
- Text to speech apps: apps for use on smart phones or tablets that convert text to speech.

Low Technology Equipment: Devices that are readily available, do not require much training and typically do not require batteries or electricity.

- Communication boards: boards that can be carried to aid communication by pointing on to images, words, pictures, drawings, or letters
- Writing tablets: devices used to communicate when people still have the ability to write.

Voice Preservation (\$5,000 for 25 voices): Voice banking is a process that allows an individual to record a set list of phrases and sentences with their own voice while they are still able. The recordings are then used to create a personal synthesized voice for future use with a speech-generating device. Capturing the essence of their voice before they could lose it, is a crucial step in preserving their identity. This program provides one on one training and support to patients to complete their recordings.



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- Voice banking systems: devices that allow people with ALS to store the sound of their voice and recorded words and phrases before they lose their ability to speak.
- Message banking: creating a pool of pre-recorded messages/stories/sounds using a person's natural speech while it is still intelligible.

### Adaptive Equipment:

- The Obi feeding robot (\$8,200): An adaptive eating device for individuals with upper extremity strength and mobility limitations. This device allows its users to be in control of what they eat and when. This can increase independence, social interaction, and meal enjoyment.

Assistive technology is a means to help improve the lives of people with ALS. Communication devices allow people with ALS to communicate more effectively when they can no longer communicate on their own. This helps people become more independent, communicate medical decisions, and overall become a more active participant in their family and community. In addition, access to the Internet through email and chat rooms provides a medium to communicate with other individuals and caregivers for support and information resources.

### DURABLE MEDICAL EQUIPMENT

Access to Durable Medical Equipment (DME) is a huge need for people living with ALS. This type of equipment, while often covered by insurance, is expensive and can break, requiring months to obtain, be fixed, or replaced. Our Loan Closet can fill this gap and allows continuity of care that people living with ALS desperately need. DME includes a range of mobility devices that can help a person living with ALS move safely, conserve energy, and remain more independent. Walking aids like a cane, four-wheel rollator walker, or ankle foot brace (AFO) can help with balance and stability. Manual and transport wheelchairs can help with rest while moving about a person's home and community. And power mobility devices can provide freedom of movement even if one has limited physical mobility.

### SHIPPING & DELIVERY/PICK-UP COSTS, WAREHOUSE & GOCODES QR INVENTORY SYSTEM

We would like to use a portion of the loan closet funding if granted to help pay for additional storage, and delivery and pick-up of loan closet equipment. We recognize that this is a large ask but currently, South Carolina families are having to wait an average of 2-3 weeks for a piece of much needed equipment from our loan closet. This can seem like an eternity for a person living with ALS and their caregiver trying to navigate such a debilitating, progressive disease. This financial support would allow us to eliminate current wait times and access barriers South Carolina families are experiencing by affording us the opportunity to partner with a service provider, Bungii, that would work in partnership with our loan closet storage locations to support them in delivery and pick-ups of loan closet equipment.

Below are average costs from another ALS Association service area that uses state support to utilize Bungii in partnership with their loan closets, which has helped them close similar care gaps and would especially allow us to get loan equipment out to our more remote South Carolina families in a timely



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manner. The average cost for Bungii deliveries and pick-ups within 40 miles or less is \$95-\$105. Those over 40 miles account for most requests and run \$131 on average.

<b>ALS Association YTD 2022</b>	
Average Cost of Delivery	\$131
Average Distance	41 miles
Total Deliveries	163
<b>Service Level Analysis</b>	
Non-Contact	36
Power Wheelchair	42
Room of Choice	74
Round Trip	11

Our goal is for our loan closet partners to have the support as needed through a Bungii delivery and pick-up service network in Greenville, Charleston and Columbia, enabling delivery to anywhere in SC (since all cities in SC are within 150 miles of Greenville, Columbia, and Charleston they fall within their coverage area).

### **\$2,000 GoCodes QR Inventory System for improved loan closet inventory management and service delivery**

GoCodes is an inventory management system that allows assistive technology and durable medical equipment to be QR coded and tracked more easily through a database system. This system allows for real time inventory updates so that our care services and loan closet partners can more easily identify where needed equipment is located and improve service times for those we serve.

### **\$3,000 SUPPORT GROUP TECHNOLOGY**

ALS can be a very isolating disease, and many find attending our support groups very helpful to their mental health and overall well-being. As ALS progresses, it can be very difficult to travel and engage in activities therefore, we'd like to offer a hybrid option as South Carolina families have a strong desire to come together both in-person and virtually and there is technology available to create inclusive, hybrid support group meetings called Owl Labs. \$3,000 in support would allow this possibility.

### **\$165,000 TO START A NEW SC RAMP REUTILIZATION LOAN PROGRAM**

Funding support would allow us to be able to start a much-needed Ramp Reutilization Loan Program in SC. This program would provide individuals with ALS safe entry and exit from their home by providing them with an ADA compliant reusable steel ramp. Our identified ramp partner would provide SC families with a free, onsite assessment of their ramping needs and pending approval by ALS Association SC, would install ramp and then uninstall when no longer needed without structurally affecting their home. The uninstalled ramp materials would then be returned to our loan pool and utilized for future families needing a ramp free of charge improving safety and quality of life.

### **\$35,000 ALS MULTIDISCIPLINARY CLINIC FUNDING**



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The ALS Association supports a network of multidisciplinary ALS health centers across the US including two in South Carolina at Medical University of South Carolina and Greenville Health System. These two centers meet the highest clinical care and treatment standards and afford people living with ALS and their families in SC much needed access to specially trained ALS experts that can address many of their needs in a single visit reducing costs of care, patient, and caregiver burden, and improving quality of life. ALS Clinics also allow opportunities to learn about and participate in clinical trials research as well as meet their ALS Association Care Services Coordination team that work alongside ALS clinic team and provides ongoing family support creating a bridge between their home and healthcare system.