

## The ALS Association Wisconsin Chapter Summary Report

### **Information about the Applicant**

The ALS Association Wisconsin Chapter (the Chapter) mission is 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. Our Care Services team offers supportive programs and services, all free of charge, to individuals and families living with ALS throughout the state of Wisconsin, providing support during the challenging time of change and uncertainty. In addition to providing guidance, information and resources, we offer the following programs: monthly support groups for people living with ALS, families and caregivers; communication device program centered on a loan closet of augmentative and alternative communication devices; equipment loan program provides access to durable medical equipment and assistive devices; care service coordinators participate at ALS multidisciplinary clinics; Brian Trinnast Memorial Grant Program provides reimbursement to individuals diagnosed with ALS for approved costs not covered by insurance and to help offset the high out of pocket costs associated with an ALS diagnosis; annual Care & Research Symposium.

### **Statement of Need**

Most people with ALS will have trouble with speech and movement as their illness progresses. Some patients will lose the ability to speak and use their hands, which can be both frustrating and emotionally devastating. A major concern for patients and caregivers is finding a reliable method for the patient to alert the caregiver that help is needed, especially when hand strength is weak and speech hard to understand. We would like to solve this situation by stocking our loan closet with wireless attendant call buttons that are easy to use for the patient and allow the caregiver to move around the home. Another concern for patients is the ability to communicate their needs. Voice banking is a process in which software records your voice and makes a computer version that can help you communicate if you lose your ability to speak. While we have some voice recorders in our loan closet inventory, we have been unable to fulfill all requests which are initiated by speech language pathologists. We would like to solve this situation by increasing the number of voice recorders in our loan closet, allowing all eligible beneficiaries the ability to record their voice so they can communicate their needs to their caregiver or medical providers. Recently, we have learned of the benefits that can be reaped when a patient is given the ability to gain some control of their surroundings using an environmental control unit (ECU). Most people with ALS have impaired mobility, and an ECU can give them independence to operate electronic devices such as computers, lights, and appliances. We can pair an ECU with a communication device, giving this same result to someone who has lost their ability to speak. We do not have any ECUs in our loan closet and adding these will allow us to fill an increasing need in the community we serve.

### **Project Goals and Expected Benefits**

As described above, the wireless attendant call buttons, voice recorders, and ECUs will allow us to fulfill requests for these devices and give patients the ability to “call for assistance,” communicate their needs to caregivers and their medical team and retain some independence in their home.

The expected goals and outcomes of this project are as follows:

1. No wait list for the wireless attendant call buttons, voice recorders and ECUs.
2. Deploy all requested devices within one week of request.
3. Ensure that beneficiaries are trained to use the devices.
4. Beneficiaries are using devices as intended and communication and independence has improved.

### **Project Implementation Plan**

When we receive funding for the devices, we will purchase them from the most competitively priced vendor. Our Care Services Coordinators (CSCs) and Speech Language Pathologists (SLPs), who work in our ALS clinics and outlying communities, will identify that the need exists for the equipment. The equipment will be deployed by the equipment loan coordinator to the patient within one week of the request. As we do today, the distribution of the equipment will be tracked in our patient relationship software. All equipment will be shipped via UPS, where we take advantage of a discounted rate from a local store.

Training and support for the equipment will be completed within 7-10 days of receipt of the equipment. Our CSC, who is a licensed Occupational Therapy Assistant, will provide training for the wireless attendant call buttons. The SLPs will provide training for voice recorders and ECUs. Our CSCs will contact the patient and caregivers every 3-4 months after the equipment is deployed and training is complete, to ensure that the devices are effective and meeting our goals for communication and independence.

When a patient is no longer able to use the equipment, it will be returned to our loan closet so it can be redeployed to another person in need.

### **Evaluation Plan**

1. No wait list for the wireless attendant call buttons, voice recorders and ECUs. All our equipment inventory, requests and fulfillments are tracked in Salesforce. We will use reporting from Salesforce to measure time from request to fulfillment.
2. Deploy all requested devices within one week of request. All our equipment inventory, requests and fulfillments are tracked in Salesforce. We will use reporting from Salesforce to measure time from request to fulfillment.
3. Ensure that beneficiaries are trained to use the devices. We will do qualitative interviews every 3-4 weeks with recipients of the devices to ensure that they are effectively assisting with communication and promoting independence. We will have discussions with the SLPs that oversee the patient's care to further determine success. We will track these interactions in Salesforce so we can capture our results systemically.
4. Beneficiaries are using devices as intended and communication and independence has improved. We will do qualitative interviews every 3-4 weeks with recipients of the devices to ensure that they are effectively assisting with communication and promoting independence. We will have discussions with the SLPs that oversee the patient's care to further determine success. We will track these interactions in Salesforce so we can capture our results systemically.

When a patient can no longer use the equipment, it will be returned to us. At that time, we will survey the family and caregivers with questions about ease of use, effectiveness with communication, and ability to use the equipment to improve independence. These discussions will be tracked in Salesforce so we can capture our results systemically.

### **Budget**

<b>Wireless Call Buttons</b>	<b>\$4,710.00</b>
<b>Voice Recorders</b>	<b>\$2,200.00</b>

<b>Environmental Controls</b>	<b>\$1,450.00</b>
<b>Labor</b>	<b>\$4,260.00</b>
<b>Shipping</b>	<b>\$900.00</b>
<b>Total</b>	<b>\$8,360.00</b>

**Staff Recommendation**

The grant application can be recommended for approval with a slight modification to the budget. We can provide funding to pay for the equipment and shipping; however, we cannot provide funding for the cost of the staff salaries covered under the labor category. We can approve a grant in the amount of \$4100.00