WHO WE ARE

Our Vision
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.

WHAT IS A COMMUNITY FUNDRAISER

A community fundraiser is any event that is not sponsored by The ALS Association that raises funds and awareness for our Chapter’s mission, programs and services. Examples of community fundraisers include:

- Ice Bucket Challenges
- Bake Sales
- Golf Tournaments
- Poker Runs
- Races, Walks & Fun Runs
- Sporting Events
- Dinners
- Much more!

WHAT YOU ARE SUPPORTING

Durable Medical Equipment Loan Pool
The Loan Pool provides durable medical equipment to persons with ALS to help them maintain their independence and physical safety. The loan pool includes equipment donated by individuals and their families, and is housed in multiple locations throughout our service area. Examples of equipment loaned include: wheelchairs, hospital beds, tub slide shower chairs, and ramps.

Hrbek-Sing Communication and Assistive Device Program
The Hrbek-Sing Communication and Assistive Device Program allows individuals who have lost their ability to communicate due to ALS to borrow augmentative communication devices that are not covered by medical insurance. The program also provides electronic aids to daily living and computer access so that people with ALS can maintain independence as their disease progresses.

Jack Norton Family Respite Program
The Jack Norton Family Respite Program provides much-needed respite to full-time family caregivers. Skilled homecare personnel come into the home to care for the person with ALS, allowing the family caregiver to relax, keep appointments, or visit with friends. Families are eligible for up to 18 hours of respite care per month.

Home Safety Program
The Chapter will pay for OT/PT home visits that are not covered by insurance. The OT/PT visits focus on home modifications/safety evaluations, recommendations for durable medical equipment, range of motion and stretching exercise instruction, transfer training, and activities of daily living.

Family Assistance Program
The Family Assistance Program is designed to lighten the burden of ALS by offering trained volunteers to help a person with ALS and his/her family with daily tasks (e.g., meal preparation, house cleaning, yard work).
**WHAT IS ALS?**

*Amyotrophic lateral sclerosis*

ALS is a progressive neurodegenerative disease that affects nerve cells in the brain and spinal cord.

ALS usually strikes people between the ages of 40 and 70, but it can strike anyone at any time. There are more than 16,500 Americans living with ALS.

Although there is not yet a cure or treatment that halts ALS, scientists we fund through our global research program have made significant progress in understanding what causes ALS. But their work is not done. Together, we work toward a cure.

**FACTS ABOUT ALS**

- **5,000+** people are diagnosed per year
- **10%** of cases are inherited through a mutated gene
- **2-5 years** is the average life expectancy
- **Every 90 minutes** someone is diagnosed and someone passes away
- **$250,000** is the estimated out-of-pocket cost for caring for a person with ALS
- **$2 billion** is the estimated cost to develop a drug to slow or stop the progression of ALS
- **90%** of cases occur without family history

**SYMPTOMS**

*Progressive loss of muscle control*

- ALS gradually prohibits the ability to:
  - Speak
  - Grasp objects
  - Swallow
  - Move
  - Walk
  - Breathe

**DIAGNOSIS**

*Difficult to diagnose*

- ALS is often diagnosed by ruling out other diseases, which may take months or years

**MILITARY**

*Veterans are more likely to get ALS*

- ALS affects veterans who served in peacetime and war
- ALS impacts veterans, regardless of the branch of service or the war they served in

There is **NO CURE** for ALS.
MESSAGE TO COMMUNITY FUNDRAISER ORGANIZERS

The ALS Association, MN/ND/SD Chapter is grateful for your fundraising event that benefits our organization. These events contribute to our overall fundraising efforts and assist in heightening awareness about ALS.

The information in this guide outlines the responsibilities and expectations for a community fundraiser organizer. It is intended to help you understand the role our organization plays in the execution of these events: for example, the extent to which we can assist you in your event planning and day-of activities. We appreciate you partnering with us to help people with ALS live fuller lives by providing them with compassionate care and support while contributing to the fight to treat and cure ALS.

THE ROLE OF THE ALS ASSOCIATION, MN/ND/SD CHAPTER IN COMMUNITY FUNDRAISERS

Throughout the process of planning your event, our Chapter can assist you in the following ways:

• Online fundraising platform to promote event and fundraise
• Providing suggestions and guidance by way of email or phone
• Providing Chapter-developed materials - graphic design assistance may be available, please inquire
• Sending donor acknowledgments to donors who make a contribution to the Chapter – only if the donor’s check is made payable to: The ALS Association, MN/ND/SD Chapter
• Use of the Chapter logo – only after prior Chapter review and approval
• Providing a silent auction item, if applicable and available
• Use of Chapter letterhead for your event
• Use of the Chapter’s Federal Tax ID number to waive any sales tax
• Printing materials for your event
• Providing T-shirts or other promotional items for event participants
• Providing raffle licenses or assisting community fundraisers with raffle license permits
• Coordinating volunteers for your event
• Providing event organizers with external website setup
• Assisting event organizers with fees associated with the event
• Using the Chapter’s information to ask for cash and in-kind donations for the event
• Supporting events for which the proceeds are donated to an individual or family directly
• Soliciting sponsors for your fundraising event and/or provide any donor, volunteer, or celebrity information, mailing lists, and/or press contacts

Our Chapter will not be able to assist in the following areas:

• Use of Chapter letterhead for your event
• Use of the Chapter’s Federal Tax ID number to waive any sales tax
• Printing materials for your event
• Providing T-shirts or other promotional items for event participants
• Providing raffle licenses or assisting community fundraisers with raffle license permits
• Coordinating volunteers for your event
• Providing event organizers with external website setup
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CONSIDERATIONS WHEN PLANNING YOUR EVENT

The ALS Association reserves the right to decline endorsement of an event if other nonprofit organizations are beneficiaries and/or are involved in the event without mutual compliance.

All community fundraisers should be accessible to people with disabilities. The event should take place at a location that meets ADA regulations. Community fundraisers should promote and make arrangements for any special accommodation needs with participants, volunteers and staff. If the activity is being conducted as a tribute to someone, event organizers must seek the individual’s approval in advance.

Promotion

The event will be promoted and conducted in a manner to avoid statement or appearance of The ALS Association endorsing any product, firm, organization, individual or service. The event must be appropriate in nature and reflect positively on The ALS Association. The Chapter reserves the right to decline any connection to the event if we believe it may negatively reflect upon The ALS Association.

- All promotional materials must clearly state the percentage of proceeds and/or the portion of the price that will benefit The ALS Association.
- The ALS Association and the Chapter logos must be used appropriately in conjunction with such an activity and requires pre-approval.
- The logos may not be altered in typeface, color, configuration and/or position.
- Any use of the logos must adhere to established graphic standards. If, in the sole opinion of the Chapter it is not used appropriately, we may unilaterally withdraw permission to use the logo.

Community fundraiser organizers must be correct and consistent when using the name of our organization in text, whether it appears in a letter, brochure, newsletter, etc. In text, the first reference must always be “The ALS Association.” Note the capitalization of the letter “t” in “The.” When referring to ALS as Lou Gehrig’s Disease, note that the “D” is always capitalized.

Due to copyright law, Lou Gehrig’s image may not be used on any fundraising material where you are asking for money. You may not list the name Lou Gehrig in the title of your activity or event without permission from the Curtis Management Group (CMG), the operators of the Lou Gehrig estate. (IE: The Lou Gehrig Classic sponsored by Acme Markets). Note that if the name or likeness of Lou Gehrig is approved, a fee is usually involved. The ALS Association staff person with whom you are working can give you further guidance if/when this request is appropriate.

All promotional material, including advertising, brochures, flyers, letters and press releases are a reflection of The ALS Association and this Chapter and must meet our standards. Therefore, all collateral distributed in mass must be pre-approved by a Chapter representative.
Financial
The ALS Association, MN/ND/SD Chapter has no fiduciary responsibility for your event and assumes no liability for its planning or execution, including promotion, setup, staffing (including volunteers), or the collection and management of funds/donations. Only net proceeds from the event should be received from the event organizer – gross event revenue and expenses will not go through the Chapter.
If payments are made to the event organizer, and the event organizer is not an IRS qualified organization, the payments will not be eligible for deduction for income tax purposes.

Liability
Your event needs to comply with all federal, state, and local laws with proper licensing, including fundraising rules and regulations. You will need to obtain all permits and/or licenses necessary for fundraising in the city in which the event is being held, which includes the hosting of raffles and/or other games of chance.
If alcohol service is approved by The ALS Association, the restaurant or facility only should serve attendees and/or participants and must have the proper license. Proof of age will be required and signs posted to that effect. Alternative means of transportation must be available to attendees or participants.
You will be responsible for determining the extent of and obtaining liability insurance for the event – sufficient to cover any claim that may arise from the event.

Sponsorship
When securing sponsors for your event, the Chapter requests that you contact us prior to reaching out to an existing Chapter event sponsor. Current sponsors can be found on our website.

Thank you for your willingness to support our organization. Your creativity and generosity make it possible for us to serve individuals and families living with ALS in our region. Contact a chapter representative at (888) 672-0484 or email info@alsmn.org with questions.