

Celebrating Care in November

November is National Family Caregivers Month and we use this time to recognize all of the incredible caregivers that support their loved ones living with ALS. Because ALS is progressive, the needs of someone living with the disease will change over time, and thus, so will the responsibilities of the family caregiver. Such a high level of care requires a great deal of time and commitment, so it's important that we celebrate their efforts and offer to help where appropriate.

The ALS Association's **Jack Norton Family Respite Program** provides up to 18 hours of professional in-home care and affords caregivers the opportunity to run errands, visit friends, or simply take a much needed break from their caregiving duties.

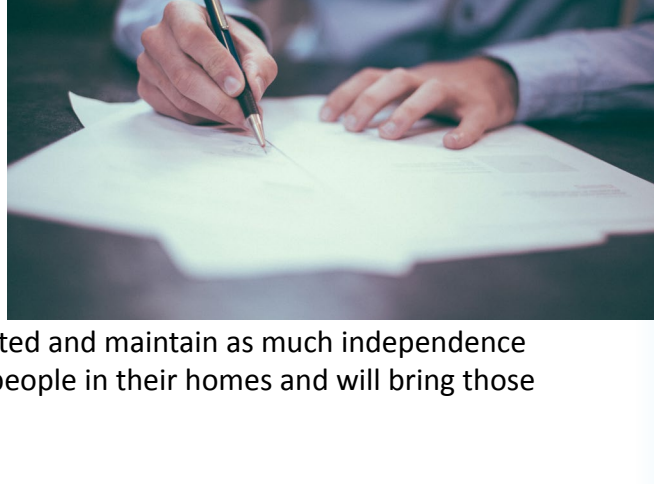
Remember to take a moment during the month of November to acknowledge the friend or family member in your life that takes on a caregiving role. There are more than 44 million Americans caring for a loved one in some capacity and many could use a reminder that they aren't alone on their journey.



care corner

Care Services Survey - Thank You!

Earlier this summer we asked for your feedback on our care services programs. Thank you to everyone who returned our survey. Your feedback and thoughtful responses truly help us make sure that the programs and services we offer are of value to you. We wanted to share some things we will be implementing based on your feedback.



1. Access to smart technologies

Our smart home program continues to expand. Smart home devices can improve access to electronics in the home. Our Chapter took on this pilot in an attempt to stay current with technology and help individuals living with ALS remain connected and maintain as much independence as possible. We continue to test new products that will assist people in their homes and will bring those technologies to those we serve.

2. Learning more about available resources

We continue to revamp our Navigating ALS online tool to help you find resources on transportation, insurance, financial matters, and taxes. Check out pages 33-39 on the **Navigating ALS** tool for more information. We are looking to recruit speakers for our 2019 support groups who can touch on some of these topics for an even more in-depth look at resources that may be helpful to you and your family. For more information on support groups contact Anne or Jennifer at 888-672-0484. We will also be looking to share more educational webinars with people about available resources. Please know you can find a number of videos on our **national ALS website**. These videos range from **Home Safety and Environmental Modification Considerations** to **Traveling Successfully with ALS** along with many other topics.

3. Access to home care

We understand finding caregiving support in your home can be difficult. Remember, our **respite program** is open to full-time family caregivers living with someone with ALS. The Chapter will pay for up to 18 hours of paid home health care. For more information on respite, call one of our care services staff at 888-672-0484 or look **online** for more details. Please know we are also looking at this issue on a national level. We are working with the Centers for Medicare and Medicaid and other associations facing home health staffing shortages, financial challenges, and access issues to see whether policy changes can be made that would make securing home health easier for individuals living with ALS. Although change will not be easy we will be seeking input and working as hard as we can to address these concerns.

We thank everyone who shared their insights in our care services survey and will continue to evaluate our programs to ensure we are providing the best care and support we can to every person impacted by ALS.

Flu Season is Here!

What you should know:

- In Minnesota, North Dakota, and South Dakota, influenza (flu) virus activity begins to increase in October and last year was at peak activity from the beginning of December through mid-March.
- The Centers for Disease Control (CDC) recommends a yearly flu vaccine for everyone 6 months and older, especially those adults (such as with ALS) who are at greater risk of developing influenza-related complications.
- Flu vaccination cannot completely prevent infection but can reduce the severity of flu illnesses and prevent flu-related hospitalization. The flu shot should be given in October, if possible.
- The "other" flu vaccine given by nasal spray is made of live but weakened virus and may cause problems for individuals with ALS. Check with your ALS team before getting this.
- If you are a person with ALS, we strongly encourage you to speak with your physician and/or ALS team about getting an annual flu shot. Family members and caregivers in close contact with a person with ALS should also talk to their physician about getting one too.



And don't forget pneumococcus!

- Pneumococcal pneumonia is a bacterial infection of the lungs. A person with ALS may be at higher risk for developing pneumococcal pneumonia.
- A newer pneumococcal vaccine has been developed mostly for use in children, but is now recommended for some adults, even if they already had the older vaccine.
- Talk with your physician about whether or not you should also receive the pneumococcal vaccine.



Jeff Rubins, MD Pulmonology & Palliative Medicine,
ALS Center of Excellence Hennepin Healthcare

Congratulations

The ALS Association, MN/ND/SD Chapter extends our congratulations to the ALS specialists who were named to the 'Top Doctors' list in the October 2018 issue of *Minnesota Monthly*. Physicians who received this recognition were chosen by 10,000 of their peers from the 11-county metro area. From the ALS Center of Excellence at Hennepin Healthcare, Medical Director Dr. Samuel Maier was listed under the neurology category. Two other team members from this ALS clinic were also listed: Dr. Jeff Rubins under Hospice & Palliative Medicine and Dr. Brionn Tonkin under the Physical Medicine & Rehabilitation heading. Dr. David Walk, the Medical Director at the University of Minnesota M Health ALS Clinic, was also named as one of the top Neurologists. In addition, Dr. Walk serves as one of the medical advisors on the Chapter's Board of Directors. Dr. Deanna Diebold, from the University, was listed in the Pulmonary Category. Congratulations to all five well-deserving physicians.

Midweek Meditation: Caregiving



Join us this November as our guided, 10 minute meditation focuses on caregiving.

Wednesdays at 11:00 AM (CST)
Call: 1-800-768-2983
Access Code: 8464599

Email **Anne** for more info.

Upcoming Care Services Programs

November 8	Caregiver Support Group - Eagan	November 27	Mankato Area Support Group
November 20	St. Cloud Area Support Group	November 28	Caregiver Support Group

Midweek Meditation - Wednesdays at 11:00 AM (CST)

hey volunteers

Clean for a Couple Affected by ALS in Fargo

A 73 year old woman living with ALS and her husband are looking for someone to clean their two bedroom, two bath apartment. The husband loves sweeping and vacuuming so he'll continue to do those and the volunteer will take over the tasks the wife is no longer able to do because of her ALS. This includes dusting and cleaning the bathrooms and kitchen.



They think it will take someone 1-2 hours to clean. While they would love weekly help, they're open to someone volunteering every other week. Any day of the week is fine but because of the husband's work schedule, it will not work for a volunteer to help in the evening; he goes to bed at 6:30 pm.

Want to Connect Directly with Someone? Become a Family Assistance Volunteer



Through the family assistance program, trained volunteers are paired with families affected by ALS to help with everyday tasks. With volunteer assistance, families report decreased stress and increased quality time together.

If you have some time to give and want to establish a relationship with someone with ALS, please consider joining this program. A list of our current requests, including location, frequency, and type of help requested, can be found on the **volunteer page of our website**.

For more information or to express an interest in these opportunities, please contact Laura Winterstein, volunteer engagement manager, at 888-672-0484 or volunteercoordinator@alsmn.org.

event news

Celebrating 25 Years of Service at the Light the Journey Gala



October 27 was a great night for the Chapter as we recognized our 25 years of service at the 2018 Light the Journey Gala. Many tremendous supporters of the Chapter were in attendance at the Radisson Blu Hotel of America to commemorate this accomplishment. Guests enjoyed bidding on unique auction items, socializing, and connecting with others in the ALS community.



This year, we recognized some of the individuals who have been instrumental throughout our history during our Milestone Awards Ceremony through a **feature** about each individual's impact. Attendees were also moved by the **Tofteland family**, whose inspiration and courage as our feature family received a standing ovation from the crowd.

The fundraising result was great, but this event has a unique way of inspiring and motivating some of our biggest supporters throughout the year. We had 390 people in attendance this year, raising just over \$309,000. Of that

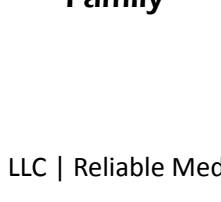
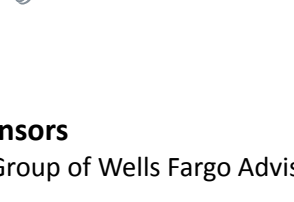
amount, \$125,500 was raised specifically for ALS research, the second highest research total we've had in the Gala's history. Thank you to everyone for contributing to that success!

We would like to extend a special thanks to all of our sponsors for their support of the Light the Journey Gala.

Platinum Sponsors



Gold Sponsors



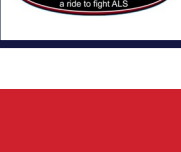
Silver Sponsors

Associated Bank | Lifesprk | Parr McKnight Wealth Management Group of Wells Fargo Advisors, LLC | Reliable Medical Supply

Table Captains

Amy & Ben Brachio | Clay Ahrens | HCMC | HealthPartners Center for ALS | HealthPartners - Dr. Irshad Jafri | The Lufkin Family | Mayo Clinic ALS Team | Midwest Machinery | Minnesota Air | Minnesota Twins | Thomson Reuters | University of Minnesota ALS Program | UPS

Upcoming Special Events



January 30 - February 2, 2019

**Black Woods
Blizzard Tour**



May 11, 2019

**ALS SuperHero
Dash**

City Tins

Looking for a fantastic holiday gift idea? City Tins just launched in the Twin Cities and their reusable tins are filled with coaster gift cards worth \$10 off your tab at 25 local restaurants. It's the perfect way to encourage your friends and family to experience some of the best the Twin Cities food scene has to offer. Better still is the fact that City Tins will donate \$10 of every Twin Cities tin purchased **through this link** to The ALS Association in support of our services; simply chose The ALS Association from the fundraiser dropdown. Sounds like a win-win for your holiday gift giving!



give TO THE MAX

NOV. 15, 2018

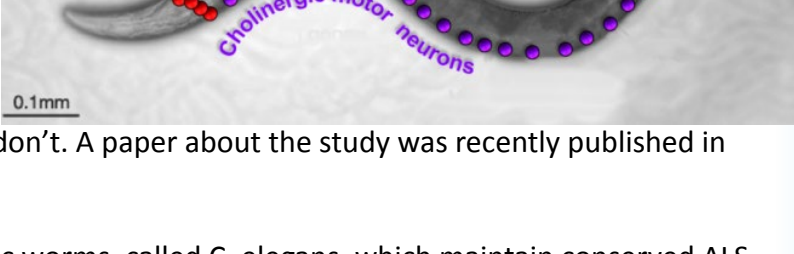
Give to the Max Day 2018 is only one week away! Here at the Chapter, our focus is on empowering people living with ALS and their families by providing them with compassionate care and support, while funding research to discover treatments and a cure for ALS. Show your support and join us for the Great Minnesota Give Together on November 15.

Visit our **page** to learn more or make a donation, and be sure to follow along on social media for the latest Give to the Max Day updates.

research updates

Precise ALS Worm Model Gives Insight into How Motor Neurons Die

Why motor neurons die in ALS largely remains a mystery. In a study funded by The ALS Association, Dr. Anne Hart, professor of neuroscience at the Carney Institute for Brain Science at Brown University, and her colleagues gained insight into why some types of motor neurons die, while other don't. A paper about the study was recently published in PLOS Genetics.



Interestingly, Dr. Hart and her team used first microscopic worms, called C. elegans, which maintain conserved ALS genes seen in humans to create the first precise worm models for SOD1 ALS, the second most common genetic cause of inherited ALS, using gene editing. **Learn more.**



connect with us