



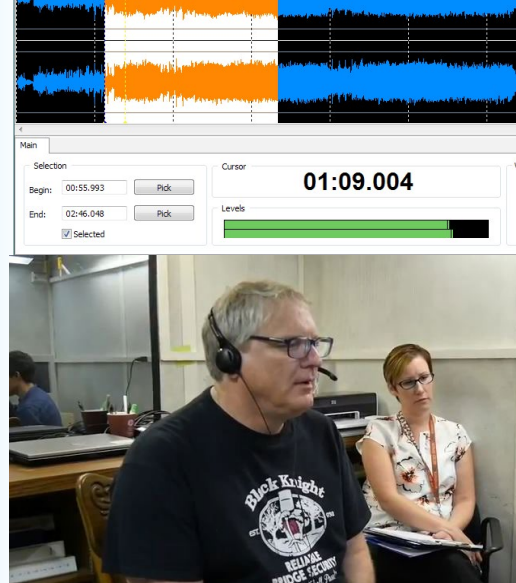
Members of the ALS Community Gather with Representatives from the FDA and Industry to Inform FDA Draft Guidance on ALS

The ALS community recently presented its recommendations to the U.S. Food and Drug Administration (FDA) regarding the Amyotrophic Lateral Sclerosis: Developing Drugs for Treatment Guidance for Industry at a day-long event, called ALS Community Workshop: Therapy Development and Regulatory Pathways, which was held in Washington, D.C., on July 12. Over 90 people attended in person, with many more tuning in online.

[Continue Reading](#)

care corner

Voice Banking is Impacting Lives



Over the past 2 years over 150 people living with ALS, in our service area, have completed voice banking. It is designed to give people who are losing their voice the ability to create a synthesized voice. Voice banking generally takes between 8-10 hours to record the maximum 1600 sentences through a program called Model Talker. The process can be completed from the comfort of your own home or on campus at an affiliated university. Our Chapter has teamed up with speech therapists at 8 universities across Minnesota, North Dakota and South Dakota to assist with the voice banking process. The participating universities include: the University of Minnesota, Twin Cities and Duluth, St. Cloud State, Minnesota State University at Mankato and Moorhead, Minot State University, the University of South Dakota, and the University of North Dakota. Voice banking support services completed on campus will be funded by our Chapter with prior approval. The Gleason Foundation has also generously offered to cover the cost of voice creation through the Model Talker website. If you are interested in voice banking, please contact kristin@alsmn.org.

Flu Season Has Begun

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 2017 through mid-March 2018.
- 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, and 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



Upcoming Care Services Programs

October 9	A Time to Remember - Mankato	October 16	St. Cloud Area Support Group
October 11	Caregiver Support Group - Eagan	October 17	Caregiver Support Group
October 12	Clinics Quarterly Meeting	October 30	Mankato Area Support Group

hey volunteers

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

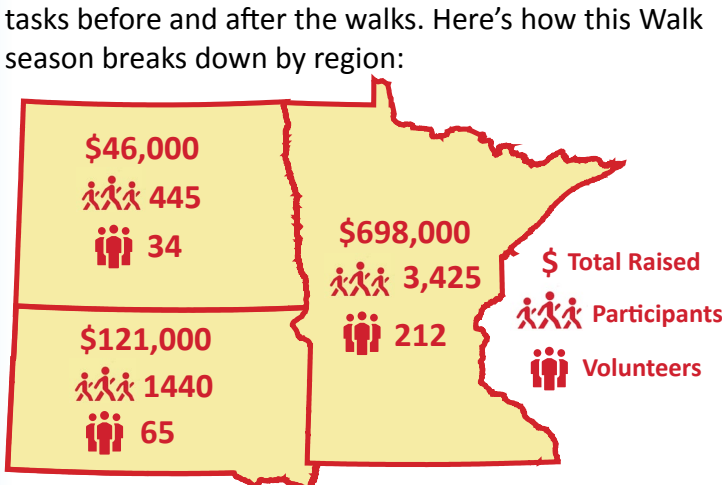
UnitedHealth Group Charity Golf Tournament Surprises with Overwhelming Support

On September 6th, the Chapter was honored to be one of three beneficiaries of the 21st Annual UHG Charity Golf Tournament. This annual event, put on by UnitedHealth Group, engages UHG partners from across the country for a tournament that supports new charities each year. When the Chapter was notified we would be one of the beneficiaries of this year's event, we were told we could expect to receive around \$25,000. In addition, UHG would put together a video highlighting our mission, as well as a direct mail campaign courtesy of their partners. On the night of the event, UHG pulled off a huge surprise by raising an astonishing \$914,000, meaning the Chapter actually received over \$305,000, more than 10 times what we were initially told. This is an incredible gift to the Chapter that adds to the momentum we've been experiencing this year. Special thanks to UHG employee and tournament organizer, Mary Beth Dondelinger, as well as the UHG Charity Golf Tournament Committee, for pulling off the surprise of the year. This incredibly generous gift will go a long way to support our mission.



The 2018 Walk Season Was a Success - Thanks to Your Support!

With our Sioux Falls Walk on September 22, we completed another successful year of Walks. With a Walk season that spans from May to September, we endured chilly mornings, misty afternoons, and even record heat (Twin Cities Walk, anyone?) to drive bold and urgent innovation as we march together toward a treatment and a cure for ALS. Check out some of our favorite memories on our [Flickr page](#)--you might even find a picture of you in the mix! Altogether, we raised an astounding \$865,000 and counting. Volunteers are integral to the success of these walks! Thank you to the volunteers who shared their Saturday morning with us and the 14 volunteers who helped with administrative tasks before and after the walks. Here's how this Walk season breaks down by region:



And don't forget--fundraising in support of the Walk is now easier than ever when you link your Facebook account to your Walk page! Fundraising is open for this year's walks through December 31, 2018. Questions? Please reach out to our [Walk team](#) and we will get you an answer.

And with another successful Walk season over, the Chapter would like to thank our gold and platinum sponsors, without whom we could not have been so successful in our march together toward a treatment and a cure for ALS. Your sponsorship has a direct impact on people living with ALS and their families in the communities we work and live in. We would also like to extend a special thanks to our many returning sponsors--we hope to see you all again next year!

Platinum & Gold:

Avera	Duhamel Broadcasting	Midco	Radio Mankato
C.H. Robinson	In Memory of Bob Nemitz	NewsCenter1	SpartanNash

Thanks C.H. Robinson!

We would like to extend a special thanks this year to the C.H. Robinson team in Sartell for its tremendous support of the St. Cloud Walk to Defeat ALS and the ALS community there. On Walk day, dozens of team members and their families came to Walk to show their support of the colleagues who have been touched by the disease. They even hold events to raise awareness and funds throughout the year to show their support! The team at C.H. Robinson combined with Team Batting for Brent to rally together to show extraordinary support of a former colleague who battled ALS and to support the wider ALS community.

Beyond the Walk to Defeat ALS, C.H. Robinson has been a generous supporter of our Chapter in other ways, including the Kolar Toyota Fishing Tournament and the Light the Journey Gala. It is with the deepest gratitude that we once again say thank you to the entire team at C.H. Robinson.

Thank you for joining the movement!



C.H. ROBINSON

Upcoming Special Events

October 27	Light the Journey Gala	January 30 - February 2, 2019	Black Woods Blizzard Tour
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research updates

MediciNova Announces Positive FDA Feedback to Start Phase III Plan for MN-166 (ibudilast) to Treat ALS

MediciNova, Inc. recently announced that the U.S. Food and Drug Administration (FDA) relayed positive feedback regarding its phase III clinical trial plan to test MN-166 (ibudilast) in a broad population of people with ALS. No safety issues were raised by the FDA and safety will be revisited when results are available in the phase III trial. [Learn more.](#)



2018 Annual Report

The **2018 annual report** is now available. Your support is critical to our mission; inside you will see what your support has allowed us to do between February 1, 2017 and January 31, 2018. Thank you for being a part of the team to create a world without ALS.

