



Increased Funding Sets into Motion Plans to Speed Development of New Drugs to Treat ALS

A new, groundbreaking effort consists of nearly 100 people from all across the ALS community, including people living with ALS and their family members, more than 10 ALS organizations, leading ALS researchers and clinicians, representatives from the National Institutes of Health and the pharmaceutical and biotech industries. These organizations and individuals will focus on seven specific areas of ALS drug development and provide an ALS community-wide view on topics that include diagnosis, natural history, clinical trials and outcome measures, biomarkers, benefit-risk, frontotemporal dementia, and public policy.

The guidance will serve as a roadmap to help industry navigate the development process and provide the FDA with an ALS community-centered view of how it should approach therapies for ALS. The goals are to make the drug development process, including clinical trials, more efficient, predictable, faster, and effective at assessing drug efficacy. This will speed access, reduce costs, and help ensure resources are most effectively utilized, and incentivize industry to enter the ALS market and develop new treatments for ALS. After the guidance is developed, that material will be available for public comment in the February-March 2016 timeframe before being submitted to the FDA.

The ALS Association established a Patients and Caregivers Advisory Committee to participate in this endeavor, because people with ALS and their family members are central to the success of this project.

“The role of the Patients and Caregivers Advisory Committee is to ensure that the perspective of people living with ALS is incorporated into every element of the guidance,” said Ted Harada, the Committee’s chair and a person living with ALS. “We must be a part of making drug development and clinical trials faster and more effective, and I am strengthened by the many people who have agreed to help drive this initiative forward.”

Click here to learn more about this promising initiative.

event news



Join us at the SuperHero 5K/10K Dash

Calling all SuperHeroes! Dust off your capes and grab your sneakers, The ALS SuperHero 5K/10K Dash is almost here! The Dash takes place on Saturday, October 10, on a certified course at picturesque Lake Phalen Regional Park in St. Paul. Join us as we run or walk in support of all those living with ALS.

A great event for the whole family. In addition to the 5K and 10K options, there’s also a Kids’ Dash with fun prizes for SuperHeroes in training (ages 10 and under). All in attendance are encouraged to dress up as their favorite SuperHero. From Spiderman to SpongeBob who knows who you will see along the route! Let’s work together to Dash out ALS!

Help Light the Journey at our Gala

RESERVE SEATS



Join us to help raise funds to support the programs and services offered to people with ALS and their families and support critical research. The Light the Journey Gala will take place on October 30, 2015 at the Hyatt Regency in Minneapolis. Guests can enjoy a scrumptious dinner, program, exciting live and silent auction, and entertainment. You won’t want to miss this fun evening! **Purchase your tickets** today.



Don’t delay! The Black Woods Blizzard Tour is nearly half full-and more registrations are coming in each day. Secure your spot by **registering online** today! Raise \$1,500 and more (to earn fabulous prizes) to participate.

Hotel, meals and lots of fun are promised. Choose from a full ride (380 miles) or half ride (230 miles) and be a part of the Single Largest Snowmobile Event in the World! Contact **Sandy** for more information or check out **our website**.

Sponsor Highlight



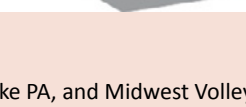
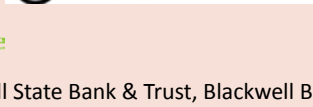
Our Chapter is grateful for the support we have received from Fox Sports North (FSN) over the past six years. FSN’s involvement with the Chapter started with a generous donation of resources and talent to our Black Woods Blizzard Tour. The FSN organization has also been a major supporter of our SuperHero Dash 5K/10K event. They have produced and run TV spots for the event, as well as helped us promote the event via social media. We can always count on FSN for support of our auction fundraising efforts.

For their ongoing support, we are honored to feature them in this month’s sponsor highlight in our Chapter’s newsletter. We appreciate their community partnership and generous support of helping us spread ALS awareness, and generating funds needed for programs and services.

Thank you, Fox Sports North, for making a difference!

Larry Sing Golf Classic

Over 190 golfers joined us in Fargo and Moorhead on Monday, August 24th for our 21st Annual Larry Sing Memorial ALS Golf Classic. Participants took to the course and bid for a cause to raise money for the Hrbek-Sing Communication & Assistive Device Program. The event raised more than \$108,000! Our sincere thanks to all those who participated with us and to those who sponsored the event.

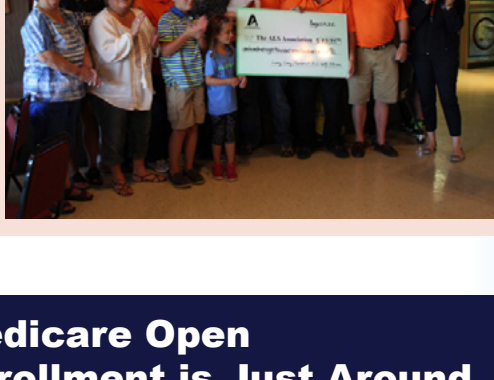


Bayer CropScience

Silver Sponsors: Bell State Bank & Trust, Blackwell Burke PA, and Midwest Volleyball Warehouse.

Hole Sponsors: ADM, Agassiz Seed & Supply, AgroLine, AgXplore, Asgrow/Dekalb, Centrol Inc, CPS, Croplan Genetics, DynaGro, Hefty Seed Company - Lisbon, Maple River Grain & Agronomy, Mosaic, Peterson Farms Seed, Plains Grain & Agronomy, RD Offutt Company, RDO Equipment, Sing/Ahl Families, Syngenta, West Central Ag Services, and WinField Solutions.

Special thank you to the outstanding members of our planning committee: Chair Ray Kotchian (PrairieLand Ag), Anne Nalewaja (BASF), Clyde Kringlen (West Central Ag Services), Coke Smith (West Central Inc.), Joe Narlock (Asgrow/Dekalb), Jordan Sing, and Steve Sing.



care corner

October 15 to December 7 is the time when all Medicare beneficiaries can change their Medicare health plans and prescription drug coverage for the following year to better meet their needs. We highly recommend discussing your health insurance options with an insurance counselor. Insurance counseling is a free service available in each state that provides unbiased information to Medicare enrollees about the plans available in their state.

In order to get the best guidance possible, please consider the answers to the following questions:

- What medications do I currently take/plan to take soon?
- Will my ALS progression over the next year impact my need for:
 - o Durable medical equipment, such as a power wheelchair or hospital bed
 - o A communication device (a machine that helps an individual verbally communicate)
 - o Office visits to an ALS clinic or other physicians

Medicare Open Enrollment is Just Around the Corner!



MN ND SD WI

Click on a state to find an insurance counselor near you

A Day to Remember



An event to honor and remember those who have died of ALS. There will be readings and a time for reflection, sharing stories and candle-lighting.

Monday, October 26, 2015
7:00 – 8:00 pm
Informal reception following

Chapel at Miller Dwan
502 E 2nd St, Duluth MN
(enter parking lot from 2nd St.)

RSVPs are helpful, contact Anne at the Chapter office, 612-672-0484 or anne@alsmn.org

Emergency Preparedness

In the region where we live, we know that inclement weather and the possibility of electricity outages is high. It’s important to be prepared for these types of situations. Individuals with special needs may want to consider the following tips as they plan for possible emergencies. **Click here** for more detailed information about creating an emergency kit and planning for various emergencies.

Tips for People with Mobility Concerns

Tips for People with Communication Concerns

Tips for People with Life-Support Systems



hey volunteers

Musician Needed to Help Celebrate Life in Duluth, MN



Every year we hold Day to Remember events so families and friends can honor their loved ones who have died of ALS.

We are looking for a musician to play quiet and reflective music during our Duluth Day to Remember (Monday, October 26 from 6:30 pm – 8:00 pm in the Miller Dwan Chapel). The musician would choose their own music and we are open to any type of instrument; in the past we have had pianists, guitarists, and harpists play.

Directly Help a Family Affected by ALS

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 any of these opportunities, please contact Laura Winterstein, volunteer coordinator, at 888-672-0484 or volunteercoordinator@alsmn.org.

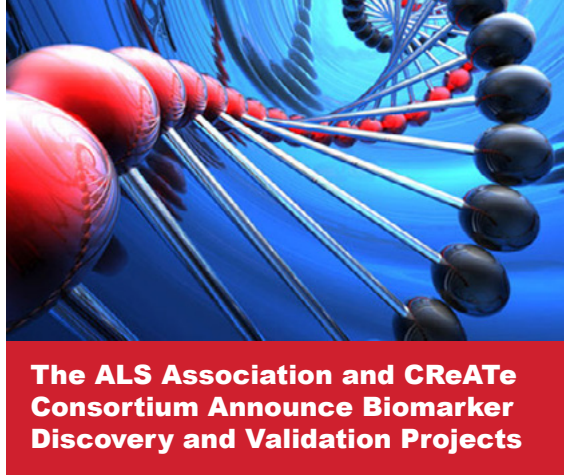
research updates

ALS Association and Target ALS to Expand Tissue Core for ALS Research

The ALS Association is pleased to announce the launch of a new collaborative effort with TARGET ALS to perform whole genome sequencing from people who have died from ALS, to be used for research to better understand the disease and ultimately develop new treatments.

Funding from The ALS Association and the Tow Foundation will be used by The New York Genome Center to determine the entire genetic sequence of people with ALS who have elected to donate their tissues after death to the Target ALS Postmortem Tissue Core.

The Target ALS Postmortem Tissue Core is a unique resource in the field of ALS research, providing high-quality post-mortem tissue for academic and industry researchers throughout the world. The addition of whole genome sequencing to the clinical and pathological data collected on each individual will greatly expand the utility of this resource, providing researchers the ability to explore connections between genes, disease course, and tissue changes.



The ALS Association and CREAtE Consortium Announce Biomarker Discovery and Validation Projects

The ALS Association and the CREAtE Consortium are pleased to announce the selection for funding of two new projects that will advance the discovery and validation of biomarkers relevant to ALS therapy development. **Read More.**

2015 Annual Report

The **2015 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, 2014, and January 31, 2015. Thank you for being a part of the team to create a world without ALS.

A special thanks to Thomson Reuters for their generous support in the design of the 2015 annual report. We are grateful for their continued support and partnership.



Save Money and Support The Cause



Use the DIVI UP mobile app and save money while supporting your favorite organizations. Just download the app, unlock your favorite deals, and start saving.

The DIVI UP app finds deals near you or you can search by cause, business, or deals. It’s simple and easy to save money and do good. Download the app for **iPhone** or **Android** today.



connect with us