



ALSNWWI Support Group

**A Gathering of Individuals Touched by ALS
Share Joy, Sorrow, Laughter, Tears, and Hope.**

Receiving a diagnosis of ALS is challenging and can be very overwhelming. The ALS support group provides a safe place where patients, families, & friends Gather to share information, support, and resources with others who understand.

*Questions, concerns, or input please contact:
Julie Chamberlain, LPN, 715.271.7257 or alsnwwi@gmail.com*

*Our Next Meeting will not be until THURSDAY, 07/09/15.
The Healing Place will be our special guest in July.
(Second Thursday of each month, 1:00pm – 3:00pm at Chippewa Valley Bible Church,
531 E. South Ave. Chippewa Falls, WI 54729)*

Please Join Us Sunday, June 14th for the ALS Walk & Wheel-A-Thon.

***ALS Annual Walk & Wheel-A-Thon
June 14, 2015 at Chippewa Falls Fair Grounds:
10:30am Online registration begins
11:30am Free picnic & T-shirts
12:00 – 12:45pm Team photos
1:00pm Walk begins (1-3 miles)!***
Website: www.alsnwwi.org

Donations can be sent directly to: Community Foundation of Chippewa County, ALS Support Group of NW WI endowment fund PO Box 153 Chippewa Falls, WI 54729

A big THANK YOU to Sue, Michele, & Jen for being the face and voice in representing the upcoming walk interviews on TV13 & TV18. So well done and so very appreciated!!!

~ May 2015 ~

13 people were present. John Jaeckel joined the group to share the exciting news of the Birkebeiner's partnership with ALS to raise funds and awareness for this challenging disease! Thank you to John & Deanna for your hard work and determination!!

The American Birkebeiner Ski Foundation (ABSF) has announced their new, three-year "Skiers for Cures" partnership with the ALS Association–Wisconsin Chapter.

Amyotrophic Lateral Sclerosis (ALS) is a motor neuron disease, first identified in 1869 by French neurologist Jean-Martin Charcot. Although the cause of ALS is not completely understood, recent years have brought a wealth of new scientific understanding about the physiology of this disease, also known as Lou Gehrig's disease. Lou Gehrig first brought attention to the disease back in 1939 when he retired from baseball after being diagnosed with ALS.

"We are very excited to join the fight against ALS through our 'Skiers for Cures' program," said Ben Popp, executive director of the American Birkebeiner Ski Foundation. "I hope our partnership will bring resources and visibility to their ongoing efforts to support those with ALS and find a cure for this terrible disease."

"Skiers for Cures" is a charitable partnership that works to raise awareness and funding, to help find a cure for health issues affecting many in the skiing community. In the case of ALS, over 400 Wisconsin patients are battling the disease. With a new diagnosis made every 90 minutes, that is more than 5,600 individuals every year afflicted by this terminal disease.

"While we've achieved a much greater understanding of the disease, the sad reality is that the cure still remains elusive," said Melanie Roach-Bekos, executive director of ALS Association-Wisconsin Chapter. "But every day and every research dollar raised brings us a step closer to unlocking a cure. We're still working on unlocking the ALS mystery. It's heartening to know that more significant advances have been made in the past decade, especially with the ALS Ice Bucket Challenge, than the nearly century and a half since Charcot identified the disease. This gives us hope and encourages us to step up our efforts to find a cure. The time is now."

Hayward resident John Jaeckel said he is "stoked" about the Birkie adding ALSA of WI as their new charitable partner. The 17-time Birkie skier was diagnosed with ALS in 2009. "I know too well the weight of being diagnosed with a disease that is untreatable and incurable. I believe that ALS is not incurable but just underfunded. This new partnership will help fund research that will discover new treatments and eventually a cure!"

John and his wife, Deanna, worked tirelessly with Popp to bring ALS to the forefront of the Skiers for Cures partnerships. "It makes me very proud to have been part of this process." Jaeckel said.

For more information about the ALS Association-Wisconsin Chapter, visit www.alsawi.org.

http://www.apg-wi.com/upnorth/health_source/news_and_events/birkie-announces-new-charitable-partnership-with-als-association/article_e5291700-e9eb-11e4-9615-b7ffaeeef7e8.html

Caring for our Caregivers

**Sans Souci Massage
927 Loring St. Suite 4
Altoona, WI 54720**

**Has generously offered a massage a month to our caregivers.
All appointments are made through the Julie at the ALS
Support Group Office 715.271.7257. If you are interested in
this wonderful treat or you know of someone, please call.
Thank you Sans Souci for this generous gift!**

We welcome you and your families to celebrate birthdays and special happenings in your life at group. Please feel free to bring photos/treats, etc... to share as you desire. We also want to support challenging days and other events that may require extra care so please feel free to reach out to us so we may rally together through additional emails, visits, etc! We are on this journey together!

Take good care of each-other!

*Deb Erickson, LPN
ALS Outreach Assistant
www.alsnwwi.org*

ALSNWWI Support Group is a non-profit organization that has been operating in the Chippewa Valley since 1992, serving over 9 counties. Services include: Monthly support group meetings; Outreach support service for home visits; Local resources & referrals, Educational materials; Financial assistance for items not covered under Medicare or private insurance; Community advocacy. **Annual Walk & Wheel-A-Thon is held the second Sunday in June at the Northern Wisconsin State Fairgrounds in Chippewa Falls - Save the Date!**

Caregiver Stress

Provided by Today's Caregiver Newsletter

Caregiver Newsletter, May 21, 2015 • Issue #814 by Michael Plontz

Home Healthcare: An Attractive Alternative

The majority of caregivers would like to keep their loved ones as close to them as possible. It's a way to gain better control over their care and studies show that loved ones often fair better in familiar surroundings. However, giving care in the home can be a little overwhelming while trying to keep up with life's other responsibilities. Home healthcare may be the answer.

Home healthcare can provide the whole gamut from healthcare to social services to patients in familiar, comfortable surroundings—namely the patient's home or the home of their caregiver. Not only is care given by a professional, but the family is educated on a variety of subjects in order to better equip them to care for their loved one. It helps give the loved one a greater sense of independence while keeping the family together. These services are available for all health problems, all ages, and for as long as an hour or around the clock.

Home healthcare is not limited to nursing care and physical therapy, but may include homemaking services such as food shopping and preparation, doing laundry, and housekeeping. Social services include helping families cope with the unique set of problems associated with caring for an elderly or sick person. Other services may include hospice or respite care. hospice services deal with the social, emotional and physical care of terminally ill patients and their families. Respite care may include equipment service, home-delivered meals, and transportation and escort programs.

Home healthcare is usually a team effort. Licensed practical nurses, home health aides and registered nurses are the part of the team that travels to and from the residence to provide healthcare. Specialists like dieticians, physical therapists or speech therapists may be needed also. A physician may be involved to outline specific care needs. Homemakers, chore workers, and volunteers may be employed to deal with the non-medical care of the loved one and their residence.

As with all endeavors, knowledge is the most powerful tool with which to be equipped. There has been some controversy lately concerning criminals who are licensed home health aides and those working as aides who are not even licensed. The following questions should be helpful in making a home health care decision.

These questions should at least get you started on your quest to find the best and most affordable home healthcare available. Remember, home healthcare does not mean that you can't handle it anymore. It does mean that you recognize your limitations and you

need help. Home healthcare lets loved ones maintain some independence while allowing you to have help maintaining your loved one.

Home HealthCare Checklist

- Is there a free evaluation visit?
- Is this agency certified?
- Is it accredited?
- What is the agency's philosophy?
- What is the agency's reputation in the community?
- What type of personnel are available?
- How are the employees screened?
- If you don't like an employee, can you request a different one?
- Are the employees insured?
- What is done if an employee cancels?
- Does the agency provide any specialty services?
- Can you drive me to an appointment if necessary?
- Does the nurse have a written plan of care and does he or she do follow-up visits?
- Will my insurance pay for this?
- Will my insurance pay for private duty or long-term nursing?
- What is the cost the cost per hour?
- If I have no resources, can you refer me to an agency that can assist me?

Making Occupational Therapy a Vital Component of Your ALS Care Plan

Robin Samuel, OTR/L, MSCS is an occupational therapist affiliated with the [University of Minnesota Certified Treatment Center of Excellence](#), an ALS multidisciplinary clinic. She specializes in working with patients impacted with neuromuscular and neurological disease and estimates that she spends a quarter of her time seeing people with ALS.

Occupational Therapy: Myths and Misperceptions

“One of the biggest misconceptions surrounding occupational therapy or OT is that it has something to do with one's job,” said Samuel. “It's really about helping people find practical solutions to maintaining independent function in their daily activities.”

When someone with ALS steps into Samuel's clinic for the first time, she conducts a thorough assessment of daily living abilities that affect quality of life. Samuel is interested in understanding the challenges someone with ALS may encounter when performing their daily activities whether that may be brushing their teeth, cooking, using the computer, or being able to take a shower.

Because people with ALS may also experience some cognitive and/or behavioral changes that can manifest in the form of impaired critical thinking skills or loss of judgment, Samuel and her colleagues screen for changes that could impact safety or the person's ability to make important decisions about their ongoing care.

Enhancing Quality of Life

“Our primary goal is to help each person we see maintain their best quality of life,” explained Samuel. “As there is no common measuring stick to base our care plan, we strive to address each person's individual needs, values and safety concerns.”

For example, Samuel says that some people value spending time on their computer and need assistance to stay connected to the digital world due to decreased dexterity or arm weakness. Others may want to find solutions to continue participating in meaningful social activities or hobbies. Depending upon each person's unique physical challenges and personal priorities, Samuel and her colleagues develop a plan of action. This may include recommending adaptations to the home environment, identifying mobility equipment needs and providing assistive technology education.

Getting Started

Samuel acknowledges that some people may live a great distance from an ALS Clinic with a multidisciplinary team, but emphasizes that the drive to see an occupational therapist and other team members is worth it. Even for those newly diagnosed, there are so many adaptations that can be customized to address immediate and future challenges including fatigue, limb weakness, and mobility problems that interfere with completing daily tasks that make prioritizing an appointment a vital component of an effective ALS care plan.

New and Innovative Technologies

Samuel notes that new technologies are being developed all the time. A [Bestic Feeder](#), for example, is a robotic device that allows someone with limited hand and arm function to feed themselves with the touch of a switch. Some [local chapter offices of The ALS Association](#) may have this device or other types of adaptive devices available in their equipment loan programs.

Other exciting advances include environmental control devices such as [WeMo by Belkin](#), which allow multiple electronic devices in the home to be controlled by a few taps on a smartphone or tablet.

Occupational Therapists like Samuel have the expertise to help people connect with technology specialists who can stretch the ability of everyday technologies to meet the needs of those with ALS. For example, a joystick-operated power wheelchair can also be programmed to control a computer mouse. An eye gaze computer system can also be set up to help a person communicate with their family and friends with just the movement of their eyes to select computer screen content.

Low Tech, High Benefits

As new technology innovations are constantly on the horizon, the possibilities for people with ALS are endless. It's important to always ask your occupational therapist, "What's new?" in addition to making your wants, wishes and priorities clear to ensure you're paired with the right adaptive equipment and technologies.

That said, sometimes the most useful tools may already be at your fingertips. Samuel says, "Needle nose pliers can be useful when fine motor control begins to wane."

Other adaptations for daily living could be as small as purchasing and using a wheeled shower commode chair that slides over a tub edge, adding a bidet to the bathroom toilet to help with hygiene or wearing a thumb brace to help improve ability to pick things up.

Samuel notes that she often learns from her patients and that working together creatively is often the best prescription. She recalls having a patient in her clinic with weakened hands that attached zip tie loops to his shoes to make getting them on easier.

<http://www.alsa.org/als-care/resources/als-insight/articles/may2015-making-occupational-therapy-a.html> provided by ALS Insight

Research Updates provided by ALS Connections

Progress in Drug Development Reviewed at The ALS Association Drug Company Working Group Meeting

May 5, 2015

News about a new drug, a new delivery method, a new trial, and a new approach to working with the Food and Drug Administration (FDA) were the highlights of The ALS Association's annual Drug Company Working Group meeting, held in April in Washington, D.C., in conjunction with the American Academy of Neurology (AAN) Meeting.

"This meeting is an important opportunity for those working in ALS drug development, and those who are interested in getting into the field, to learn about progress and share new approaches," said Lucie Bruijn, Ph.D., M.B.A., Chief Scientist for The ALS Association.

iPS Cells Uncover Potential Benefit of Epilepsy Drug

Kevin Eggan, Ph.D., of Harvard University, explained how induced pluripotent stem cells (iPS cells) have been used as a drug discovery tool, leading to an [upcoming clinical trial](#) that will test a drug shown to be effective in cells derived from people with ALS. The drug, called Retigabine, is an FDA-approved treatment for epilepsy. It reduces neuronal firing, “quieting” nerve cells to prevent them from harmful over-excitation.

Recent work has begun to focus on the potential importance of over-excitability of motor neurons in ALS, especially “upper” motor neurons, which run from the brain to the spinal cord. Dr. Eggan developed iPS cell lines from people with ALS to explore this phenomenon. In this technique, skin cells are chemically transformed into stem cells, which are then further treated to make them become motor neurons. In this way, they can be studied in the lab in large numbers.

Dr. Eggan’s study of over-excitability of ALS cells showed that Retigabine helped normalize the excessive firing of neurons in cell culture, and that this treatment improved the survival of these cells. The original experiment was done in cells from people with mutations in the SOD1 gene. “So we asked, ‘Is this also relevant to other types of ALS? This is where the value of iPS cell lines comes in,’” Dr. Eggan said, since the same testing protocol can be easily tried in each of the cell lines from different genetic form of the disease. Indeed, cells from each line displayed over-excitation, and Retigabine was beneficial in them all.

This has led to the development of a clinical trial that will soon commence at 12 study centers that are part of the Northeast ALS Consortium (NEALS) clinical trial network funded by The ALS Association. People with ALS will be enrolled to undergo a non-invasive procedure called transcranial electromagnetic stimulation, which induces a brief excitation of neurons in the brain. Subjects will receive either placebo or Retigabine, and the effect of treatment on excitation will be determined. If the drug helps reduce excitation in subjects in the trial, it may be considered for a longer-term trial, to determine if it can slow the disease.

Novel Drug Delivery System May Overcome Blood-brain Barrier

Susan Rosenbaum, J.D., Founder and CEO of Lauren Sciences, described her company’s development of a novel drug delivery system. Many potentially beneficial drugs, including protein-based growth factors or DNA-based antisense molecules, cannot cross the blood-brain barrier. This means that they must be delivered directly to the central nervous system to have an effect. Such delivery is possible but is more invasive and risky than taking a drug either orally or intravenously. Dr. Rosenbaum’s company has developed a biologically based system that encapsulates such drugs and shuttles them across the blood-brain barrier, allowing peripheral administration for a drug that acts in the brain.

In technical terms, the system is a lipid-based spherical vesicle that encloses the drug within it. The lipids of the vesicle can be modified with a variety of “head groups,” or

outer portions, which can be customized for different cell targets, such as motor neurons. “The vesicles cross the blood-brain barrier without disrupting it,” Dr. Rosenbaum noted.

The company is developing the system to deliver glial-derived neurotrophic factor (GDNF) in ALS, based on experiments showing that GDNF can promote survival of motor neurons. They have developed the necessary head groups for motor neuron targeting and selective release, she said, and are now working on encapsulating the GDNF in the vesicle. After that, they will look at efficacy of treatment in a mouse model. “Ultimately we hope to translate these into clinical studies,” Dr. Rosenbaum said.

Update on Upcoming Tirasemtiv Trial

Andrew Wolff, M.D., Chief Medical Officer for Cytokinetics, gave the group an update on clinical trials of tirasemtiv. This drug increases muscle output at mid-levels of exertion, temporarily restoring some lost strength for everyday activities such as picking up an object. Results from early trials were promising, but the recently completed BENEFIT trial did not meet its major objective of showing a change in the ALS Functional Rating Scale score at the end of treatment. But there were improvements on a respiratory measure called slow vital capacity (SVC), which was encouraging. “We believe this is a clinically meaningful effect that warrants further study,” he said. With that in mind, a larger, Phase 3 trial is planned.

Dr. Wolff noted that several lessons from the BENEFIT trial are being used to shape the new trial, including better compensating for early dizziness—a common side effect—and a slower increase in dose, to increase tolerability. The double-blind trial will be 48 weeks in length and is projected to start in the second quarter of 2015. No enrollment information is available at this time, but The ALS Association will disseminate news about the trial as it emerges.

Developing an ALS-specific Guidance Document to Speed Clinical Trials

The evening’s final presentation featured discussion about The Association’s initiative to develop an ALS-specific “guidance document” that would be submitted to the FDA. This initiative intends to bring together patients, caregivers, ALS advocacy groups, academics, and industry. It will be a consensus-based work product that incorporates stakeholder views in areas such as clinical trial design, biomarkers, surrogate endpoints, patient-reported outcomes, benefit-risk, natural history, diagnosis, public policy and others. The guidance will provide an ALS community-centered view of how the FDA should approach therapies for ALS with the aim of accelerating clinical trials, providing more clarity to industry, and ultimately delivering effective treatments to patients in a more timely fashion. The Association also will further engage both the FDA and NIH as part of this initiative such that the guidance initiative can have an impact on ALS drug development even before a final work product is submitted to the FDA. The project is the first ever patient focused guidance initiative for ALS drug development and is modeled after a similar effort recently conducted for Duchenne Muscular Dystrophy.

Working with the Muscular Dystrophy Association (MDA), The ALS Association in 2012 requested the FDA convene an ALS-specific hearing. The FDA did so, leading to a

2013 request from The ALS Association and MDA for development of a guidance document. However, the agency does not have the resources to develop such a guidance for every disease. Therefore, The ALS Association is utilizing resources made possible by last summer's Ice Bucket Challenge to launch this critical initiative and bring together all stakeholders within the ALS community to move it forward. . The Association has set an ambitious timetable for a project of this magnitude and plans to submit a final work product to the FDA during the first quarter of 2016. During that time, the ALS community will have multiple opportunities to provide input and inform the development of the guidance.

“This groundbreaking effort should lead to faster trials, accelerate drug development and bring new treatments from the lab to patients as soon as possible” said Dr. Bruijn. “We are working with the entire ALS community, including other ALS organizations, industry, academia, government, and most importantly patients and caregivers. We are confident this effort will make a significant difference in the fight to find a treatment for ALS.”

End.