

May is ALS Awareness Month

Make a Difference This May

Awareness is critical to our goal of ending ALS forever. The more people know about ALS, the more they get involved, and the more they support ALS advocacy and research. Through that support, we've made great strides toward finding potential treatments for ALS.

But we need your help to spread the word and keep the momentum going! It's people like you who make everything we do possible.

In this month's edition of the Source, we're featuring a heartfelt editorial from someone living with ALS, and we're excited to announce our largest update to our comprehensive resource guide, **Navigating ALS**. Check it out and let us know if you have any feedback.

Thank you for doing your part during ALS Awareness Month. #ALSaware

care corner

Giving What I Can: Perspective from Someone Living this Reality

My name is Pete Klinkhammer. I (and as a result, my family) was diagnosed with Bulbar onset ALS on June 14, 2013. I had been experiencing symptoms for several months the most noticeable of which was slurred speech and fatigue. Since that time my speech goes from intelligible to unintelligible every day. I had been working as the Associate Director of Services for the Stroke Association of Minnesota and the Minnesota Brain Injury Alliance after having been a county social worker for 23 years.



In a relative instant I went from assuring needs were met, to needing services myself. I was referred by my ALS Clinic to go through a Speech Language Pathology evaluation to learn compensatory strategies and energy conservation. Through that process I was referred to the University of Minnesota's Speech Language Pathology Department and put in touch with extremely caring professionals who held my hand and walked me through the emotional, fatiguing and immensely rewarding process of banking and then digitizing my voice to be used when I lose my ability to verbally communicate.

As I started the process, I invited ALS Association staff to sit in on a couple of my sessions hoping for a relationship between the U of M and The Association could be forged to provide this service to more people living with ALS to have the same opportunity I had. Once I received word that a meeting was set up between the U and The ALS Association I bowed out and let them do what they do best—getting things done for those in need. I share this information to point out that the skills I had used for 30 years in my career had given me the tools to connect resources that just needed a spotlight on them and some encouragement.

As someone living with ALS, what skills do you have? Who do you know? Where have you been that may be of benefit to others who have or will have this disease? When I think of the conversations I had with my children, family and friends, I don't want to anyone else go through that. My responsibility continues to be to my family and to others. ALS hasn't changed who I am. As people living with ALS, our voices and actions are most important in promoting what we need, how we are perceived, and in the care we receive. Without our voices and actions we leave it to others to set agendas.

Knowing that I had a small part in helping The Association provide a new voice banking service is a gift. I will continue to "pay it forward", and I hope that if you are able and inclined, that you do so as well. Contact our kind and compassionate ALS Association Staff to explore what you can do to be of service to others living with this disease as well as their families. They are waiting to hear from you.

hey volunteers

Sioux Falls Musician Wanted Wednesday, May 17

A Time to Remember is an event for families and friends to honor people who have died of ALS. These events feature music, readings, and candle lighting. We are looking for a musician to play quiet, reflective music from 6:30 pm – 8:30 pm. Previous musicians have played piano, guitar, and harp but we are open to many instruments.

If you are a musician and interested in being a part of this moving evening, please contact Anne Supplee, care services coordinator, at anne@alsmn.org or 888-672-0484.



Help at the Rapid City Walk to Defeat ALS on June 24

We are looking for some enthusiastic people to help with our Rapid City Walk to Defeat ALS on Saturday, June 24. By sharing your Saturday morning with us, not only will you receive appreciation and a volunteer t-shirt, you'll also be integral to an event that raises money for ALS research and the programs and equipment we offer free of charge to people affected by ALS. To see the positions available, check out the **Walk to Defeat ALS volunteer interest form**.

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 manager, at 888-672-0484 or volunteercoordinator@alsmn.org.



event news

Black Woods Blizzard Tour Aims High After Million Dollar Milestone

After an amazing and record-breaking year at the 2017 Black Woods Blizzard Tour, we're excited to see what the future holds for this unique event! Registration is now open for 2018 and we're looking for 225 riders to join us as we strive for our \$1.1 million goal. We've asked longtime rider and rockstar fundraiser Jeff Eliason for some pointers on how to successfully host your own fundraiser — something that many participants do throughout the year to support the Black Woods Blizzard Tour. Check out the tips below and be sure to **explore the website** to find out more about this year's ride.

Tips for Hosting Your Own Fundraiser

- Know your audience and when they are available. Keep this in mind when determining location, date, and time.
- When deciding what type of event to host, choose something that you're familiar with and that your friends and extended network will want to be a part of.
- Partner with other events and organizations in the community to host an informational table or booth. These types of venues bring customers to you, then it is just up to you to make them aware and make the sale.
- Always ask for help! Volunteers are key in organizing a successful event and be sure to let them know how much you appreciate their time.



Help Light the Journey at our Gala



The Light the Journey Gala is one of the Chapter's premiere events of the year. This year it will take place at the Radisson Blu Mall of America on October 28, 2017, bringing together more than 500 individuals to honor the ALS community and raise funds in the fight against the disease.

Lifesprk, a proud partner of the Chapter's Jack Norton Respite Care Program, has participated in the Gala each of the last twelve years. Lifesprk has utilized this event to support the clients and families they've served through this program, celebrate the mission of The ALS Association and emphasize their overall commitment to the community.

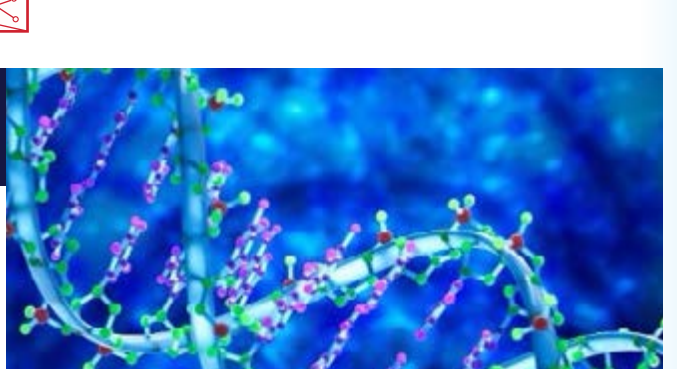
"It's a privilege to support the Light the Journey Gala, an inspirational event that celebrates the progress we are collectively making to build a future without ALS," said Joel Theisen, RN, CEO/Founder of Lifesprk. "We believe that when you let purpose and passion define you, and not your diagnosis — that's living a 'sparked life.' So many living with ALS and their family members need that 'spark' to continue to fight and change the way we live with ALS and we are proud to support those that help them live it."

Learn more about how you can join Lifesprk at the Light the Journey Gala by visiting www.alsmngala.com.

research updates

New C9orf72 Biomarker Shows Promise

Dr. Leonard Petrucelli at Mayo Clinic Jacksonville in Florida and colleagues recently discovered a new ALS biomarker that specifically detects a protein made by the C9orf72 expansion, the most common inherited cause of ALS. Their results are crucial to complement an upcoming clinical trial testing antisense drugs targeting the C9orf72 expansion. **Learn more.**



Misfolded SOD1 is Not a Primary Component of Sporadic ALS

Dr. Sandrine Da Cruz from University of California San Diego (UCSD), along with her colleagues, recently published an important paper that looks into how SOD1 misfolding, the second most common inherited cause of ALS, impacts sporadic ALS (SALS). A huge percentage of ALS cases — approximately 90% are sporadic — meaning we do not know the cause. **Find out more.**