

GET INVOLVED

Are you interested in getting involved but don't know where to start? There's a place for everyone and a way to assist with patient efforts regardless of your circumstances. Here are a few of the many opportunities to choose from:

- Offer to deliver equipment to those in need;
- Tell a friend (or 4) about ALS in the Heartland;
- Volunteer with a patient family in your area;
- Join ALS in the Heartland on Facebook; and/or
- Ask congress to fund research for a cure.

HOW CAN WE HELP?



If you or someone you know is touched by ALS and in need of support or services, please contact Sabrina or Tammy toll free at 866.789.5512 or by email: sabrina@alsintheheartland.org or tammy@alsintheheartland.org.

The agency website is www.alsintheheartland.org.

volunteer board members

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6277 S. 118th Street
Omaha, NE 68137

First Name, Last Name

Address

City, State, Zip

encircle

A QUARTERLY PUBLICATION OF ALS IN THE HEARTLAND

FALL 2010

touching lives

ALS in the Heartland would not be who we are without the incredible patients that allow our agency into their lives and extended families. First and foremost, the agency exists to help those who are battling this devastating disease. Here is the story of one such special woman – Lori McDowell – a patient with ALS and part of the ALS in the Heartland family since November 2008.

"I am a wife, mother, grandmother, daughter, sister, and aunt. I was diagnosed with ALS, Amyotrophic Lateral Sclerosis, commonly known as Lou Gehrig's Disease, 2 years ago this coming November. I am a woman who loves and believes in Christ which is most important. I rely on a hope and courage beyond myself to live through the effects of ALS.

This disease has taken away my abilities to speak anything clearly from what is a simple need to deep desire to speak what is on my heart. I can no longer hold my grandchild, attempt to paint a picture, feed myself, even take care of my own needs or dry my own tears. No longer can I walk, jump, run, even stand on my own. ALS takes your ability to breathe and swallow. I now have a trach for a ventilator at night and a peg tube.

What ALS gives you: revelations of who really loves you and who is a true friend; it has brought people into my life, associated with ALS, who love me—People from all over the world.

Thank you to all who give to ALS in the Heartland. When I had no funds for caregivers, they were the only ones who helped me when no other organization could."

Lori's incredible strength gives hope to those around her. It has been ALS in the Heartland's mission to support families such as Lori's in as many ways as possible. Lori mentions the assistance from the agency for respite services – one of the numerous services offered. This respite voucher program provides financial assistance to ALS patients, their families, and caregivers in need, enabling primary caregivers to get much needed respite while qualified relief provide continual care in the home. Other key services include therapy, support groups, equipment loan and delivery, advocacy, and education. ALS in the Heartland strives to ensure each patient family is encircled with care and support.



Images of Lori enjoying time with some of her family, as well as time with the lilacs during a spring bloom.

events

October 14, 2010 Support Group - 7:00 pm - St. Pius X Parish Center, Omaha

November 11, 2010 Support Group - 7:00 pm - St. Pius X Parish Center, Omaha

December 9, 2010 Holiday Gathering - 6:00 pm - St. Pius X Parish Center, Omaha

April 10, 2011 Nebraska Community Walk hosted in Omaha, Chalco Hills Recreation Area

May 14, 2011 Tuesdays With Morrie Showing - Omaha Community Playhouse

June 10, 2011 Golf Classic - Tiburon Golf Club, Omaha

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message from Dan

Thank you for taking time to enjoy our first newsletter. We plan to distribute newsletters on a quarterly basis. This is our way to connect and keep you better informed.

In the last year, ALS in the Heartland has continued the mission of reaching out to all ALS patients, families, and caregivers in Nebraska and western Iowa. This past quarter alone the agency held many successful community events including two area walks, the Golf Classic, a Summer Wine Festival and a new event, Sizzle Under the Stars. ALS in the Heartland is awed by the amount of support received on so many levels during these events.

In May 2010, ALS in the Heartland was awarded the Compassion Capital Fund grant overseen by the AIM Institute for capacity building. This is VERY exciting for an agency our size and young age to receive a federal grant. From this funding, the agency has launched a media campaign on far reaching Omaha radio stations, established billboards in Omaha and Lincoln, created a new mission statement, long range plan and new color scheme. In short, ALS in the Heartland has a new identity which takes the agency to a new level of service for the ALS community throughout Nebraska and western Iowa.

On behalf of the Board of Directors, agency staff and volunteers, and current patients and families, we thank you for your support.

did you know?

- Approximately 80% of reported cases of ALS are individuals between the ages of 40 and 70.
- In the past 18 months the amount of patients ALS in the Heartland serves has more than doubled.
- 90% of ALS patients pass away within 3-5 years of symptoms.
- ALS in the Heartland's respite voucher program has allowed nearly 60% of patients to complete their journey with this disease while at home.



Left: Don Goaley, and his grandson.



Right: Larry Kuncl, at the 2010 Summer Wine Festival

on the horizon

Several key pieces of news regarding research are important to share. First, ALS in the Heartland is excited to announce that the first phase of the new National ALS Registry is operational and has begun to identify cases of ALS across the country, including those who have lost their lives to the disease. This first phase of the registry has identified thousands of cases through existing national databases for Medicare, Medicaid, and the Department of Veterans Affairs. The next step includes the launch of the on-line web portal, which will enable all people with ALS across the country to self-enroll in the registry later this year. It is the research community's hope that the National ALS Registry will enable many additional discoveries in the diagnosis, treatment, and ultimate cure of ALS.

While the National ALS Registry seeks to identify ALS patients and examine potential commonalities and differences, the ALS research community continues to utilize clinical trials with patients to determine effectiveness of prescriptions or other methods to treat the disease. There are currently seventeen clinical trials occurring nationally and another trial awaiting approval for recruitment of patients. These trials provide invaluable information on the future of halting ALS.

nurturing body, mind + spirit

Each time the seasons change, it is essentially like turning the page to a new chapter. As a beautiful fall is arriving, the weather cools, the days shorten, and holiday celebrations begin. It is also a time where feelings of anxiousness, nervousness, or of being on edge may creep in as children start back to school, pressures increase, and stress from hosting family gatherings feels all encompassing. This season, allow yourself to try some new ways of calming an anxious spirit:

- **Quiet your breathing** - Whenever you are feeling the least bit anxious or nervous try to take notice of any changes in your breathing. Stress can cause hyperventilation (over-breathing). Quiet any rapid paced breaths by replacing them with steady and slow breaths. A daily meditation practice is helpful for maintaining healthy breathing and is also a good preventative measure for repressing anxieties.
- **Give your mind a "time out"** - Any time you are feeling anxious or suffering mentally, it is helpful to temporarily clear your mind of all thoughts that are upsetting you. It is simply not healthy to focus on your problems 24/7. Guided visualizations are excellent mental escapes that can help you to switch your focus away from anything that is troubling you. Picture yourself in a special dream sequence where you can relax and recoup your coping skills. Choose an ocean view, desert oasis, or garden path.
- **Pamper yourself** - Remove yourself from chaos and give yourself some quality alone time. Enjoying a rejuvenating soak is just one of several traditional ways you can pamper yourself. Try taking a solitary walk or ride in the park, settling in the sofa and reading an entertaining novel, or reliving your favorite daydreams in a sunny spot.
- **Lean on Somebody** - Trying to take care of everything can make anyone feel anxious, not to mention exhausted. It can be more of a struggle never asking for a hand than you might have realized. Seek out that soft shoulder to lean on and give yourself a rest.

The staff and volunteers of ALS in the Heartland wish you a wonderful fall season and know we are here to help you nurture yourself at any time.

programs + resources

ALS in the Heartland's position statement is "Support for Today. Hope for the Future." The agency aims to enhance the quality of life of all people affected by ALS, to heighten community awareness of this devastating disease, and to strengthen public and legislative support in the fight against ALS. Specific services provided by ALS in the Heartland include:

- Provision of one-on-one support, education, resources, and counseling provided by a Licensed Clinical Social Worker;
- A respite voucher program which provides financial assistance to employ licensed home-health providers to assist with the ALS patient remaining at home and provide emotional and physical relief to family caregivers;



- Community support groups featuring resources related to ALS and emotional support;
- A large equipment loan pool with delivery provided;
- Connection and assistance for referrals to relevant ALS Medical Clinics;
- Volunteers that can assist families in a variety of ways including companionship, respite, and household errands or chores assistance; and
- Advocacy and research efforts.