

First Name, Last Name  
Address  
City, State, Zip

## 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:

- Consider volunteering on an ongoing basis;
- Contact the office to learn more about registering for and creating your online community walk team fundraising page;
- Inquire with your place of work about gift matching or similar nonprofit support programs; and/or
- Attend a support group.

## 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](mailto:sabrina@alsintheheartland.org) or [tammy@alsintheheartland.org](mailto:tammy@alsintheheartland.org).

The agency website is [www.alsintheheartland.org](http://www.alsintheheartland.org).

### volunteer board members

Melissa Brewer  
Brian Dervin, *Treasurer*  
Dan Goaley, *President*  
Shirlee Goaley, *Secretary*  
Kurt Grote, *Vice President*  
Sharon Kuncel  
Denis McCarville  
Jeanette Obal  
John Patterson  
Kathy Pecha  
Dolores Poulin  
Jacquie Stewart  
Mark Tooher  
Chip Tracey  
Dave Trebold  
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# encircle

A QUARTERLY PUBLICATION OF ALS IN THE HEARTLAND

WINTER 2011

## touching lives

ALS in the Heartland is honored to have worked with over 75 patients in 2010. Ann Hanson is one of these patients. Her husband, Howard, shares their journey with ALS:

*"Ann Hanson was diagnosed with ALS on October 31, 2008. Prior to that date, she had numerous trips for MRI's, CAT Scans, muscle biopsy, spinal tap and several blood tests. Ann first noticed early in 2007 that she started dropping items and her legs would give out without notice. In February 2008, she collapsed in a school parking lot. Her husband, Howard, loaded her up and took her to Kearney to have her situation diagnosed. She was referred to a spinal surgeon, who performed surgery on some herniated discs. The physician thought that would help her walk normal again. Unfortunately, she fell again in May 2008 and it was decided to do a scope of her knee in June to determine any weakness in the knee joint. No problems were found, but 10 days later she developed blood clots in both legs. This eliminated any chances for additional back surgery. Everything went downhill from that time. She went through numerous tests to eliminate several diseases as ALS is hard to diagnose. After Ann's ALS diagnosis, she met with an attorney and put her "papers" in order in regard to Power of Attorney, Medical Directive and Will. On January 30, 2009, Ann became unresponsive and Howard rushed her to Good Samaritan Hospital in Kearney and she was in intensive care for 10 days. It was in her directive to have a trach and feeding tube inserted shortly after being admitted. She was then transferred to Madonna Rehabilitation Hospital in Lincoln. Ann was dismissed 41 days later to return to her home at Johnson Lake, Nebraska after Howard received training on taking care of Ann at home. With the aid of a PMS valve, she was able to speak for some time. She is dependent upon the use of a DynaVox, speech support from UNK staff, and a white marker board to communicate.*

*Ann has caregivers on a 24/7 schedule and she has unfortunately spent different times in intensive care unit for pneumonia. Ann has participated in two ALS awareness walks. She continues to be an inspiration to her family, caregivers, friends and medical community. Her attitude is "live each day as a gift, because tomorrow is not promised." She looks forward to different holidays, seeing her three children, and Ann adores her eight grandchildren. Ann and Howard celebrated their 47th wedding anniversary in 2010. Ann has received excellent support from ALS in the Heartland, her Church, family, friends, community and medical personnel. She continues to be an inspiration to everyone who knows her. She is living testimony that you can have ALS and still be part of a family."*



Images of Ann Hanson enjoying time with some of her family.

## events

- 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
- October 15, 2011** Wine Event - Slattery Vintage Estates Vineyard & Tasting Room, Nehawka

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## message from Dan

As 2010 has come to a close, we should reflect on our achievements and take this time to spend with our family and friends. At ALS in the Heartland, 2010 was a year of success by changing the lives of many! I am proud to announce the support of Sandy Hohn and the Bob Hohn ALS Foundation named after her late husband, Bob.

ALS in the Heartland is making a difference in communities throughout Nebraska and western Iowa. We continue, almost on a daily basis, to receive praise and thanks for the services we provide. ALS in the Heartland prides itself with our one on one support and case specific services. Over the past 4 1/2 years, we realize that each and every patient is unique. ALS in the Heartland can be flexible and satisfy the needs of EVERY patient and their families.

Recently, ALS in the Heartland hosted holiday gatherings in Columbus and Omaha. It was easy to share stories with everyone at the events. As I listened to others speak of their loved ones, I was also able to reminisce about my father. Although the journey for each of those inflicted is individual, there are similarities that were shared that help us be our own family of sorts. Words will never describe the emotions on the faces of current patients and families of past patients. The gatherings are just one way we can reach out and spread comfort to the ones we serve and to show that ALS in the Heartland is here for everyone. What was amazing to me was hearing them tell me that they are here for ALS in the Heartland.

On behalf of the Board of Directors, agency staff and volunteers, current patients and families, we appreciate your continued support. Thank you and have a joyous and safe 2011!

## did you know?

- The causes of ALS are not completely understood and the diagnosis of ALS is difficult.
- ALS in the Heartland is on Facebook.
- As many as 30,000 Americans live with ALS.
- ALS in the Heartland's equipment loan program includes more than 200 items.



Left: Michelle Zadina, and her mother, Sandra Howard.  
Right: Dolores and Roger Poulin.



## on the horizon

In a wonderful advancement for ALS research, on October 19, 2010 every person living with ALS in the United States may self-enroll in the National ALS Registry. For the first time since ALS was discovered in 1869, the National ALS Registry will identify cases of ALS from throughout the United States and collect vital information leading to the cause, treatment and cure of the fatal neurodegenerative disease that took the life of baseball legend Lou Gehrig and which now bears his name. The National ALS Registry may be the single largest ALS research project ever created. Hundreds of patients have already added their information to this site. Please call ALS in the Heartland with any questions about this imperative tool.

In research news, Neuralstem, Inc. updated the progress of its ongoing Phase I human clinical trial of the company's spinal cord stem cells in the treatment of ALS at Emory University in Atlanta, Georgia. The company announced in October that, after reviewing the safety data from the first six non-ambulatory patients, the trial's Safety Monitoring Board has unanimously approved moving to the next group of ALS patients, all of whom will be ambulatory. Additional stem cell research continues in San Francisco, Israel, and San Diego. All of these studies will provide information on the impact of stem cell injections in ALS patients.

## nurturing body, mind + spirit

The holiday season creates joy and stress, comfort and anxiety. And, a new year brings with it hope and opportunity, but also pressure and demands. All of these things are especially true for those of us dealing with challenges such as grief and loss. Finding a way to enjoy time away from the demands of work, disease, family, and other stressors is essential. One special way to do so is to engage in your creative side.

Nurturing one's individual creativity has many benefits for each of us. Here are a few examples:

- Increased self expression;
- Increased self esteem and emotional well-being;
- Improved activities of daily living;
- Create balance and order;
- Give a sense of control over external stressors;
- Make something positive out of a loss, bad experience, or depression; and
- Maintain an individual's integrity.

Some might shy away from trying something new or spending time doing something that might seem silly or uncomfortable at first, but there are many ways to express creativity. Consider which of these might be something you would like to try or to take up again:

- Dance;
- Music;
- Poetry;
- Theater;
- Painting and drawing;
- Photography;
- Scrapbooking; and
- Writing.

Each of these allows for various styles and time commitments. It does not matter if you are a novice or an expert – just attempting a few moments of creativity daily will create affirmative and helpful emotions and attitude.

## programs + resources

ALS in the Heartland was founded nearly five years ago by families directly impacted by the devastating disease of ALS. It has always been the agency's mission to provide support directly to patients in Nebraska and western Iowa through needed services such as equipment, counseling, support groups, and the respite voucher program. To date, over 125 patients have received these essential programs.

Another incredible resource for ALS patients has joined forces with ALS in the Heartland. The Bob Hohn ALS Foundation has made the decision to partner with this agency to continue to provide the necessary supports needed for patients in our local communities. The support of a group such as the Bob Hohn ALS Foundation will only strengthen the services offered by ALS in the

Ann Hanson, the patient featured on the cover of this newsletter, has continued to write poetry as a creative outlet throughout her illness with ALS. She shared one of her poems in hopes to inspire others:

### THE MANY FACES OF THE LAKE

*The sun dancing across the water makes  
bright shiny lights everywhere,*

*I feel warm and happy inside.*

*The dark windy storm clouds make the water  
look green and angry,*

*I feel frightened inside.*

*The water is smooth and quiet and everything  
reflects in it like a mirror,*

*I feel peaceful inside.*

*The wind makes big waves with white, foamy tops,  
I feel tired and forlorn inside.*

*The water becomes a painting of beautiful colors  
as the sun sets,*

*I feel the presence of GOD.*

by, Ann Hanson



Heartland. We are honored to continue Bob's charge of ensuring ALS families possess crucial services and equipment while living with this disease.

ALS in the Heartland offers services such as:

- Provision of support, education, resources, and counseling;
- A respite voucher program which provides financial assistance to employ licensed home-health providers;
- Community support groups;
- A large equipment loan pool;
- Connection to relevant ALS Medical Clinics;
- Volunteers that can assist families in a variety of ways; and
- Advocacy and research efforts.