

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 being a member of the ALS in the Heartland Board of Directors;
- Become an ongoing volunteer (weekly, bi-weekly, monthly, etc.);
- Have crafting and/or scrapbooking skills? Volunteer to help with applicable projects; and/or
- Help sell poinsettias to your friends, family, and coworkers during our upcoming sale.

HOW CAN WE HELP?

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

The agency website is www.alsintheheartland.org.

volunteer board members

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

encircle

A QUARTERLY PUBLICATION OF ALS IN THE HEARTLAND

FALL 2011

touching lives

On October 15, 2011, Slattery Vintage Estates Vineyard and Tasting Room in Nehawka, Nebraska will be the venue for the ALS in the Heartland Wine Bowl. Vineyard owner, Barb Slattery, shares her ALS story:

"Something just wasn't right, our very active Dad just wasn't quite himself. That July day in 1992, when we all noticed a definite change, was the beginning of a nightmare. The shaking of his hand as he tried to help screw the hinge on the box. The noticeable hollow space between thumb and first finger. The weakness and fatigue. Dad just wasn't himself.

Dad was a man of incredible stamina both physically and spiritually. Friends called him 'Big Al', mostly because he had such a big, open heart and presence (and because he had a mean volleyball spike). He earned the respect and admiration of almost everyone he crossed paths with through quiet determination and leading by example. It came as a total surprise when his always happy disposition began to change, and the final diagnosis was finally determined in September. Just 64, newly retired, and planning for possibly the best years of his life with his wife and our mother, Gena, it just didn't seem fair, especially for her.

In 1993 there was no ALS IN THE HEARTLAND. There was little or no help or support. Gena, even more determined than Al, was lost trying to cope with caring for his quickly changing disease.

Al had a Christ-like ability to see the best in people, to listen deeply, and occasionally provide gentle advice. Al was a beacon of faith and hope, and counselor to many—his children, grandchildren, friends, and, as a mortician for John A. Gentlemen Mortuaries, even to grief-stricken families planning funerals. Now, how was he to console himself, and how were we to help? ALS IN THE HEARTLAND, or in hindsight, more involvement with other ALS families, would have certainly been helpful for all of us.

After agonizing over the 'what ifs' and the 'best case scenarios,' Al quietly determined that he was prepared to accept death. Al decided that he would make the most of his remaining time with family and friends; a trip was planned and we began to see him smile again, although through a frail portion of what he used to be. Things progressed quickly and when he was just on the verge of losing both his ability to talk and walk, he passed away. It was May, just eight short months after the diagnosis. Al never made it to a wheelchair, he collapsed after losing his breath and died on May 7, 1993.

Al Heires, a positive influence in the world, loving father, grandfather, husband, brother, mentor, deacon-in-training, runner, tuba, piano, and guitar player, singer, photographer, boy scout leader, helper, teacher, friend, guide, wine-maker, gardener, camper, mechanic, carpenter, mortician, lifelong learner, advisor, and counselor, we carry you in our hearts and we will miss you forever.

The work that ALS IN THE HEARTLAND does is so very valuable and worthwhile. Families can now take advantage of others' experience and get the physical as well as financial and emotional support they need. Please know that your contribution to this great cause will provide invaluable support in a time of great difficulty."



From left to right: Al Heires and his daughter, Barb in 1959, Al Heires.

in this issue

Message from Dan
Touching Lives
Programs & Resources
Nurturing Body, Mind & Spirit
On the Horizon
Events
Did You Know?
Get Involved
Board Members
How Can We Help?

events

October 15, 2011 Wine Bowl – Slattery Vintage Estates Vineyard & Tasting Room, Nehawka
October - November Poinsettia sales
April 15, 2012 Nebraska Community Walk hosted in Omaha, Chalco Hills Recreation Area
June 2012 Bob Hohn Memorial Golf Classic



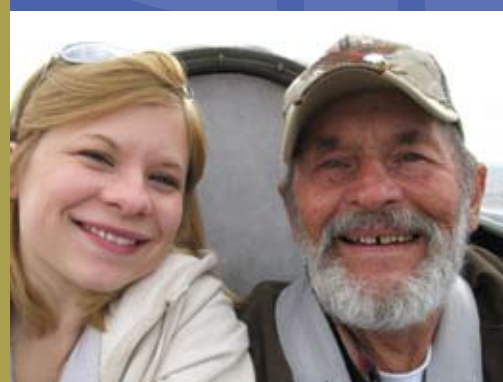
message from Dan

All of us were touched in some way by the events of 9/11. I watched a few documentaries commemorating the anniversary of this horrific event and was struck by one man's story. He was a Muslim and was running away from the collapsing building when he was knocked to the ground. A man of Jewish faith in full traditional attire reached out his hand to help him in the panicked crowd. The Muslim said he never would have imagined this kindness and realized this act of terror brought our nation together as one.

The disease of ALS is similar to this story – it does not discriminate. We at ALS in the Heartland come from a variety of backgrounds. We act as one in this fight against ALS. In the coming months we will send our annual appeal. We need your help as the number of patients and their needs are increasing by staggering numbers. Thank you for your support!

did you know?

- ALS in the Heartland is debuting the new Grief Recovery Program this week.
- In less than five months the dexrampipexole clinical trial was full with 800 ALS patients.
- ALS in the Heartland has a Twitter account – ALSinHeartland.
- Approximately 80% of reported cases of ALS are individuals between the ages of 40 and 70.



Rachel and Jim Kuehn



Joel and Don Hauge

on the horizon

An exciting finding in the ALS research realm has shown it may have the potential to be a breakthrough against the disease. Northwestern University's Feinberg School of Medicine discovered a key protein known as ubiquilin2. When this protein is damaged it is unable to remove or repair damaged proteins in the cell, which can eventually build up to block transmission of normal brain signals. Northwestern states with this discovery researchers could possibly develop a drug to regulate the protein pathways, so there is no build up.

ALS TDI, the world's largest ALS research facility, responded to this article by noting there are two key points to take from the Northwestern results. One, that other research has also identified mutated proteins so it remains to be seen the true effects of ubiquilin2. The second is that it is true that the aggregate proteins in cells do provide a blockage to brain signals. Developing a drug that could dissolve the aggregated proteins provides potential, however it is too soon to say that this would cure ALS.

In summary, the Northwestern study findings have revealed more information about potential physical causes of ALS and the ALS community is anxious for more research to be completed for a more concise answer.

nurturing body, mind + spirit

One can never imagine the moment when they will hear the words that they or someone they love has been diagnosed with ALS. For some it feels like an out-of-body experience; for others it brings the answer to the long-standing question of what is wrong with me; some fall into moments of despair. All of these are normal, understandable responses to hearing this devastating news. So why do we feel so bad if our first response is anger? Why do we hide this reaction from others? Anger is often seen as a negative, pointless reply in any situation, but doesn't learning that ALS has touched your life seem senseless and depressing? Here's some reasons why allowing anger to be a real emotion in this situation can be helpful.

Anger is a strong yet natural reaction to a sudden build up of emotional pressure. It often is teamed with other emotions flowing through your body such as fear, stress, grief, and frustration. However, unlike some of these other emotions, anger leads us to action. And action is a powerful response in any situation.

What actions might be beneficial when hearing the news of an ALS diagnosis? Perhaps anger leads to seeking out a credible and experienced medical team. Maybe you get so angry you call your closest friends and family and assemble a support network for the difficult days ahead in the journey. Possibly anger towards ALS leads you to find the nearest clinical trial and participate hoping to find a way to defeat this disease once and for all. Or maybe this anger allows you to truly feel the weight of this diagnosis and accept the challenges ahead in a way that reflects your inner-most values and perspective on life.

So allow yourself to get angry at this disease. Allow yourself to let others know that ALS makes you so angry you can't even contain it sometimes. Let anger permit you to take action – whether that is for you and your immediate family or for research and legislative efforts that will benefit the families to come. After all, eliminating ALS is the only true way to find complete healing for our community.

Anger is a strong yet natural reaction to a sudden build up of emotional pressure.



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 – view online at www.alsintheheartland.org;
- Group and individual grief sessions provided by a trained Grief Recovery Specialist;
- 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.