

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:

- Attend one or more of the agency's upcoming events;
- Call the office to find out how you can join in ALS advocacy efforts;
- Make an online donation at [www.alsintheheartland.org](http://www.alsintheheartland.org); and/or
- Consider volunteering for a patient family on a consistent basis.

## 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

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# encircle

A QUARTERLY PUBLICATION OF ALS IN THE HEARTLAND

SPRING 2011

## touching lives

ALS in the Heartland celebrates ALS patients, families, and caregivers annually for the ALS in the Heartland Community Walk hosted in Omaha. This year on April 10th hundreds will gather to honor their loved ones. Lori's Legacy is one of the special teams and their team captain – Kristin Corey – shares her story:

*Lori's Legacy: "My mother, Lori Corey, was diagnosed with ALS in December of 2007 and passed away in September of 2009. While going through this awful disease our family was blessed with abundant love and support from family, friends, and the wonderful people involved with ALS in the Heartland. We always knew how much support we had, but it truly became apparent when we participated in our first ALS in the Heartland Community Walk in 2009. For our first walk, we decided to design t-shirts with the slogan "Defeating ALS One Step at a Time;" this was the birth of "Lori's Legacy." We decided to sell the t-shirts as a fund raiser. The t-shirts rose to instant fame and the community's response was overwhelming in their desire to support our family as well as donate to defeating ALS. On the day of the walk, "Lori's Legacy" supporters showed up in force with at least 60 family members and friends present. On that day, my mother was pushed around the lake in a wheel chair by my father until the very last hill where my mother was determined to walk up the last stretch. This showed everyone my mother's unwillingness to give up and let ALS defeat her; she was going to fight until the end. Unfortunately, this was the only walk she participated in as she passed away that September. However, I am so grateful that my mother was able to see just how many people cared for her. In 2010, even though she was not able to be there in body, she was there in spirit, and Lori's Legacy carried on. Our family and friends showed up to the walk sporting "Lori's Legacy" t-shirts that stated "One Step for ALS, Every Step of the Way with Lori." Once again the community rose to the*

*occasion by buying the t-shirts and supporting the fundraiser for the second year in a row. Words cannot express the honor I feel when seeing these t-shirts being worn in the community. Not only has this been a tribute to my mother but it has brought awareness about ALS to the community. It continues to bring me great joy to know that the fundraising efforts have helped make a difference for those who are battling ALS and their loved ones right here in the Heartland. Because ALS in the Heartland has provided me and my family with so much love and assistance during my mom's brave fight with ALS, I want to encourage you to come out to the walk this year to support this noble organization and its efforts to serve those affected by ALS. May Lori's Legacy live on."*



Lori's Legacy Walk teams 2010 (top) and 2009 (bottom), and Lori's family picture from the 2009 walk.

## events

- March 31, 2011** UNL Phi Delta Theta Waffle Bash – 1545 R Street, Lincoln
- 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** Bob Hohn Memorial Golf Classic – Tiburon Golf Club, Omaha
- September 11, 2011** Nebraska Community Walk hosted in Norfolk, Skyview Lake
- October 15, 2011** Wine Event – Slattery Vintage Estates Vineyard & Tasting Room, Nehawka

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## message from Dan

All of us look forward to the Spring and Summer seasons and the opportunity to resume our outdoor activities. At ALS in the Heartland, we begin our event season.

Our first event of the season is our walk on April 10 at Chalco Hills Recreation Area. The walk is our signature event and one where people from all ages will gather and enjoy the day. Many supporters across the nation utilize our First Giving Website to donate online.

May is ALS Awareness month. We are hosting a "friend raiser" on May 14 at the Omaha Community Playhouse. We look forward to spreading the word of ALS through acting.

Our annual ALS in the Heartland Bob Hohn Memorial Golf Classic will finish our spring/summer event season. The date is June 10 at Tiburon Golf Club.

ALS in the Heartland is very proud and excited to announce our 5th Anniversary on June 4. This would not be possible without the many individuals pulling together for our cause.

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

## did you know?

- 5-10% of ALS cases are inherited/familial, while the majority are sporadic.
- May is National ALS Awareness Month.
- More than 80% of every dollar donated to the agency goes directly toward patient services, while the other amount goes toward operating expenses and research and advocacy efforts.
- The agency mission is to provide the highest quality of support and care for ALS patients and their families.



Left: Chip and Lisa Tracey, and Jenn and Dan Goaley enjoying a recent event. Right: Pat Hudek and her grandson, Luke.

## on the horizon

ALS grabbed headlines last fall with the question of "Did Lou Gehrig really have Lou Gehrig's disease?" Although the overwhelming response is that the famous Yankee did indeed have ALS, the debate was renewed regarding if ALS is one disease or a subset of several different ones. As up-to-the-minute discoveries are made about the causes of ALS, this debate continues: is ALS one disease or many different ones with similar manifestations?

The answer to the question is critical as it may shed light on differences between patients in disease prognosis and response to therapy. It may also help shape the conduct of clinical trials. As new genes have been discovered in recent years, the ALS picture has grown more complex suggesting that there may be multiple primary causes of the disease. Experts believe there is much more to come as new genetic tools will allow the discovery of more genes that influence ALS disease risk. Advances continue in ALS research each day providing hope to all.

## nurturing body, mind + spirit

Why is it crucial for ALS in the Heartland to provide "support services" to patients, families, and caregivers? Why is it telling that the agency was founded by individuals and loved ones of ALS patients? Why is it important for the agency to hire a social worker trained as a therapist to provide services to ALS in the Heartland patient families?

Perhaps these answers are because SUPPORT is one of the most beneficial services that can be offered. Support encompasses so very much – it describes the feeling we get when we feel someone's presence and empathy. It can be concrete – a piece of equipment for help with daily living, a place to go to talk with others who are impacted by ALS, financial vouchers for quality respite services. Support can be emotional – someone focuses on us and on our issues. It transcends so much of what we crave during challenging and isolating times.

Here are specific examples of why support is essential and so very needed:

**Emotional connection and support:** Sharing your honest feelings can help you to feel more emotionally connected and less alone, especially if you're feeling isolated from friends and family. A safe and welcoming environment, filled with compassion, reassurance and understanding, has been shown to have positive physical benefits.

**Understanding and shared experiences:** It helps to know you're not alone and to talk to others who have been through similar experiences. Hearing others' stories can be very validating and can help you to see that your reactions, struggles or feelings are not "crazy." Supportive individuals can offer acceptance, and can appreciate you for who you are.

**Exchange of useful information:** Support services can provide and share information about ALS, whether it is community resources, medical information, treatment developments, or related community events.

**Coping skills:** Supportive individuals or groups share ideas for coping. Groups offer the chance to draw on collective experiences. By learning how others have coped with similar problems, and witnessing the coping styles of others, we can improve our own problem-solving abilities.

**Emotional release:** Support offers people the opportunity to appropriately release powerful emotions you may otherwise keep to yourself. It is an opportunity for you to share your feelings, fears, and concerns.

**Emotional and psychological boost:** Support can improve your mood and decrease anxiety and stress. Sharing experiences and making connections can make you feel better about life in general.

**Motivation:** An environment of positive reinforcement, emotional support and hopefulness can encourage you to take good care of yourself. Meeting with understanding individuals on a regular basis can help you to feel motivated to tackle difficult times.

Support is truly one of the most needed ingredients for each of us in our lives. ALS in the Heartland is honored to be a support to all ALS patients, families, and caregivers.



## programs + resources

Support remains the most crucial component of all services offered by ALS in the Heartland. Rather it is during the diagnostic process, during a family's battle with the disease, or in providing an outlet for grief and loss, this agency believes strongly that all should feel supported and comforted.

To accomplish this, the agency strives to offer as many opportunities for support as possible. Seeking one-on-one support? Contact Sabrina Schalley at anytime for a meeting to share thoughts and feelings. Looking for assistance with day to day tasks? ALS in the Heartland has an incredible pool of passionate and caring volunteers. Do you need to talk with others who have walked this journey before or alongside you? Consider coming to one on

the agency's support group meetings. Rather you are new to the ALS experience or have felt its effects for years, the Community Support Groups offer a safe and friendly environment to share and learn. Do you need a piece of equipment to ease your daily tasks? Call us – we have it or will do our best to get it. Do you struggle to let others know about this orphan disease that impacts each of us? ALS in the Heartland is here to help you advocate to legislatures and medical professionals to make the ALS cause known.

ALS in the Heartland was founded and exists to provide support. We are here for you.