

# ALS

**Volume III Issue 1**

“  
It’s  
important  
we continue  
our fight  
”

## Man’s family, friends join to help find cure for disease

By Diane Gasper-O’Brien

Excerpts from an article that appeared in October 10, 2001 *Hays Daily News* prior to the Walk to D’Feet ALS event in Hays, Kansas.

Jean Haley says that ALS is not a disease of one person but rather one of an entire family, friends and neighbors.

That’s why family and others close to Doug Kirkman are banding together to try to help find a cure for the fatal disease. “Dough’s Dirty Dozen” will be a group of 12 teams that will be walking in memory of Kirkman at Saturday’s “Walk to D’Feet ALS” at Fort Hays State University’s Lewis Field Stadium.

One of those participating Saturday will be Haley, a patient service coordinator for the Keith Worthington Chapter of the ALS Association. Haley’s area covers central and western Kansas and Northern Oklahoma.

It’s important that we continue our fight against this disease,” Haley said. “Out of my 60 patients in my area, there are no two people who are really progressing the exact same way.”



Proceeds from the walk, the first of its kind in Hays, will go to the Chapter. Kirkman’s widow, Mari, also is determined to help increase awareness about the neuromuscular degenerative disease. Mari Kirkman is adamant about her mission. Just two weeks ago, she lost her 59-year-old husband to amyotrophic lateral sclerosis, commonly know as Lou Gehrig’s disease. “I hope in my lifetime, if there isn’t a cure, that they can at least find a treatment that can increase life expectancy,” Mari Kirkman said.

She stresses that ALS can strike anyone. Only 5 percent of those who contract the disease have inherited it. The other 95 percent are stricken randomly. “It’s a very non-discriminatory disease,” she said. Gehrig, a New York Yankee, died in 1939 after contracting the disease. Doug Kirkman was stricken with ALS in 1999, and died two years later.

*Continued on page 2*

**VA Finds Gulf Vets Have Higher Rate of ALS**  
see page 2

**WICHITA/HUTCHINSON  
SUPPORT GROUP NEWS**

Our ALS Christmas Support Group and Recognition Dinner was quite a success last Thursday, December 6th at the MacNamara Banquet Room of St. Joseph Hospital. We had a combined group of the Hutchinson and Wichita Support Groups, families and volunteer supporters, numbering 110 persons coming as far away as Oklahoma City.

Everyone dined on a sumptuous feast of traditional Turkey, Dressing, Green Beans, Mashed Potatoes and Gravy or Honey-Smoked Ham and all the trappings. The evening featured the talents of the KWCH-TV news-anchor Kim Setty who not only interjected bits of humor into the Awards Ceremony but, also told a heart-wrenching story of her Mother-In-Law's battle with ALS, which eventually took her life.

The January Support Group - Wichita will remain at its normally scheduled time of 7 PM on the 1st Thursday of the month January 3rd with each participant encouraged to bring a Thought of Hope. Something personal and important in their lives to be shared with the group, as we focus on the Hopefulness of the New Year. We will end with a contribution by Melba Madden, at her request.

The January Support Group - Hutchinson will also remain as originally scheduled at 2 PM on the 1st Wednesday of the month January 9th. Each participant will also be asked to bring along a Thought of Hope, as we decide which direction our group will follow in the New Year.

**TOPEKA  
SUPPORT GROUP NEWS**

The Topeka ALS support group met on November 26, 2001 at the VA in Topeka with 18 in attendance at the meeting. The guest speaker was Laura Herbelin, EMG Technician and Assistant to Dr. Richard Barohn in the research program. Laura presented the different research being conducted in this area and the various ramifications of the studies. She responded to questions about other research and drug studies. Nancy Lindquist, Patient Service Coordinator, distributed literature about other research and discussed several of the Keith Worthington Chapter programs. Refreshments were provided by members of the group to celebrate a number of birthdays in November.

**OMAHA  
SUPPORT GROUP NEWS**

The Omaha support group had not met at print time.

*Continued from page 1*

"It's scary to think that in 60 years, the life expectancy hasn't changed," Mari Kirkman said. "There has been some improvement, but not enough. So my main goal is to increase awareness so we can try to raise more funds for research. Research is what it's all about."

Doug Kirkman was a long-time local dentist, practicing in Hays since the 1970s. He enjoyed hunting and fishing and had no thoughts of retirement when he first started noticing symptoms in 1999. Once her husband was diagnosed with ALS, Mari Kirkman said they had two goals - live as normal as possible and begin the fight to raise awareness and help with research.

Doug Kirkman first was affected in the lower half of his body, and the disease gradually affected motor movement over his entire body. Earlier this year it became too difficult for Kirkman to swallow, and he had a feeding tube surgically placed in May. Unlike some with ALS, Kirkman was able to speak up to the end. Kirkman died the morning of September 26 at his home.

"He wanted to stay at home, and although he was homebound since Christmas, we had a wonderful group of friends who would stop by, stay with him while I went grocery shopping, attended church, or ran errands," Mari Kirkman said. "We decided we would not let (ALS) control us."

Kirkman said she also received a lot of support from the Keith Worthington Chapter; especially Haley. "She really helped

me to understand the disease and what was being done in research," Kirkman said. "She helped me to become more educated about it." Now she has vowed to continue the fight.

"We were really hoping Doug would still be here for the walk," Mari Kirkman said. "But he'll be with us in spirit. And he would have been really pleased to see this many people already signed up to walk." In addition to the 12 Kirkman teams, there will be at least 10 more teams and several other individuals walking. More than 300 walkers are expected to participate.

Some of those will be representing Alvin Werth, a retired farmer and musician from Hays who died at age 69 in July after a four year battle with ALS. "Our family has received so much support from the Keith Worthington Chapter," said Millie Bickle, Werth's daughter, "and we wanted to help the chapter continue its important work in supporting families living with ALS and funding ALS research."

Werth's widow Jan, agreed. "I don't know what I would have done without all their help," Jan Werth said, also naming the Muscular Dystrophy Association, Professional Home Health of Hays and the Herndon Speech-Language-Hearing Clinic at FHSU as organizations that helped during her husband's illness. "If I wouldn't have had all the help from them, I wouldn't have been able to have kept him at home," Jan Werth added. "And he wanted to stay at home. With their help, we were able to keep him at home."

**News from ALSA**

The following information is from a news release sent out by the Department of Veterans Affairs on December 10, 2001. The ALS Association is passing this news on to you for informational purposes only. Department of Veterans Affairs Finds Desert Shield, Desert Storm Vets Have Higher Rate of ALS According to a news release on December 10, 2001 from the Department of Veterans Affairs, researchers conducting a large epidemiological study supported by both the Department of Veterans Affairs and the Department of Defense have found preliminary evidence that veterans who served in Desert Shield-Desert Storm are nearly twice as likely as their non-deployed counterparts to develop amyotrophic lateral sclerosis. This study, begun in March 2000, involved nearly 700,000 service members deployed to Southwest Asia, and 1.8 million who were not deployed to the Gulf during the period August 2, 1990 to July 31, 1991. The study found 40 cases of ALS among deployed veterans. Although the researchers found the risk of ALS to be twice as high for deployed veterans, it is a rare disease and the number of affected individuals is small. Scientists would expect to find 33 cases in a similar-sized population over the same time period. "These findings are of great concern and warrant further study," said Secretary of Veterans Affairs Anthony J. Principi. "I intend to make certain that VA's medical resources and research capabilities are fully focused on this issue." For more information about this study, please visit [www.alsa.org](http://www.alsa.org).

## What Hospice Is: Not a Place, But a Philosophy of Care

The term "hospice"—from the same linguistic root as "hospitality"—traces back to medieval times, when it referred to a resting place for weary or ill travelers. The word's modern usage was coined in 1967 by Dame Cicely Saunders, a British physician and nun, who founded the first modern hospice, St. Christopher's, in a London suburb.

Saunders introduced the idea of specialized holistic hospice care for dying people to the United States at a 1963 Yale University lecture to medical students, nurses, social workers, and chaplains. She showed pictures of terminally ill cancer patients, illustrating dramatic differences before and after patients received symptom control and social and spiritual support. Such interdisciplinary care is the hallmark of hospice care. There are now 3,139 U.S. hospices. Three-fourths are nonprofit, but for-profit hospices are entering the industry faster than new nonprofits.

The Medicare Hospice Benefit (MHB) pays for 75 percent of hospice care, with private insurance covering 12 percent, and Medicaid and donations each covering about 7 percent, so public funds pay for most hospice care. Yet most beneficiaries still aren't aware of the benefit. "Hospice is a no-cost item to an elderly patient and their family," says Jon Keyserling, Vice President of Public Policy for the National Hospice and Palliative Care Organization (NHPCO). "It's paid-up health insurance."

While the hospice philosophy remains consistent across the country, hospices may vary markedly, especially in the types of treatments patients can receive. Palliative treatments can be expensive. Smaller hospices with spartan community support are less likely to risk financial viability on patients who choose costly treatments or whose prognosis is lengthy enough to risk Medicare reimbursement denial. "Good hospices are accountable to HCFA's criteria for terminality but are not driven by them," says Jane Schafer, MA, Suncoast's admissions director. "They are willing to stick their necks out for patients who might not meet all the medical criteria, but who meet other hospice criteria. If you live in that tension, you create open access. If you live in the black and white, your access is diminished." [from *State Initiatives in End-of-Life Care*, Issue 11, August 2001]

### SPRINGFIELD SUPPORT GROUP NEWS

On Tuesday, November 27<sup>th</sup>, a holiday open house was held in place of the regular support group meeting. This was an opportunity to introduce everyone to the new Springfield office and wish them happy holidays at the same time.

From 5 to 8pm approximately 30 ALS patients, families and friends joined the Springfield staff (Kim, Betty & Sue) for food, fellowship and a little Christmas spirit. The office was dressed in garland and lights, a beautiful tree and holiday music. Several patients traveled over an hour to attend this special event, some visiting for the very first time.

### KANSAS CITY SUPPORT GROUP NEWS

The Kansas City Night Support Group met on Sunday, December 2 at the St. Joseph Hospital Community Center for the annual ALS Holiday Party. This year, combined with the annual Volunteer Appreciation, there were over 150 people in attendance including patients, caregivers, families, volunteers, Board members and staff. Everyone enjoyed delicious food, holiday music, a volunteer slide show and Santa Claus.

The topic for the January 6th meeting will be "Home Remodeling and Access" presented by Rosalyn McHenry.

### LINCOLN SUPPORT GROUP NEWS

There was no meeting in November or December. The January meeting will be on Wednesday January 30 at 7:00 at the Madonna Rehab Hospital, 5401 S St. Rm Sheridan C.



At the Wichita holiday party the Phi Delta Theta's of WSU presented the Chapter with a check for \$17,500 -- Money raised at the 2001 Dullea Classic.



The First Annual Don Rand Team Roping Benefit for the ALS Association was held on Saturday, December 1, at Lea's Indoor Arena in Rogersville, Missouri. Proceeds from the event honoring ALS patient, Don Rand, go to research and development to help find a cure for ALS.

Spectators, including ALS patients, families and friends watched approximately 200 ropers in various events while enjoying homemade chili, burgers, hot dogs, polish sausage, an assortment of baked goods, (all made by volunteers), and a variety of hot and cold beverages.

Donna Driskell and Molly Hayden (event coordinators) conducted a live auction. The event raised \$2,900 for the ALS Association.

## 2002 JANUARY How are Social Security and SSI Benefits Taxed?

We are often asked whether **Social Security and SSI benefits** are taxable. The answer depends upon a number of factors that vary:

**SSI benefits are simply not taxable.** SSI is an entitlement or welfare program. The minimum benefits paid to a claimant are tax-free. Remember that a claimant must have assets under \$2000 to be eligible for SSI in the first place.

**Social Security (SSDI) benefits**, paid based on someone's work record, **may be taxable.** If the **only income** for a claimant and spouse is SSDI, **the benefits will not be taxable** and there is probably no necessity of filing a tax return. If there is any **other income**, then a portion of the SSDI benefits may be **subject to tax liability.**

As a **general rule of thumb**, if you add half of your Social Security benefit amount for the year to your adjusted gross income, and the total is over \$25,000 (\$32,000 for a couple), then up to 85% of the SSDI benefit may be taxable. As with all questions of taxation, many variables apply, and the **advice of a qualified tax advisor is recommended.**

The retroactive lump sum benefit checks are another source of confusion. If the **back benefit covers a number of years of disability, how is it counted for tax purposes?** If the money is for prior tax years, is it taxable this year? There is a **method of counting half of the back benefit amount as if it had been paid in earlier years**, which in many cases will eliminate tax liability for the current year.

Again, consult a qualified tax advisor or ask the IRS for publication number 915 for more detailed information. This information is also available online at [www.irs.gov](http://www.irs.gov), and then look for **IRS Publication 915.** [from Burnett & McArdle's *Social Security Newsletter*, March, 2001]

## Text to Speech Software Now Available!

"ReadPlease 2002" is a free utility for converting text to speech. When installed on a PC with a sound card & speakers, it can speak with good clarity any text that is typed or loaded into the program's windows. There are 4 selectable built-in "voices" -- 2 female and 2 male. The installation file can be downloaded directly from the creator's Web site, <http://www.readplease.com> However, the file is large enough that users with telephone dial-up Internet connection may find it takes too long to download. The program's creator has kindly consented to our duplicating the installation file on CD-ROM to make it more readily available in the future to ALS patients.

*Rob McCormack, at MoneyTree Software, is the creator of ReadPlease. The following is the story, in his own words, behind the creation of the ReadPlease program:*

*"You were right about motivation for writing ReadPlease. Here is my story."*

*"I really wrote ReadPlease to learn about Text-to-Speech technology for my father. My brother and I are making a reading machine for my 82 year old father (computer, joystick, scanner, no mouse, no monitor, no keyboard). It is amazing what we can do now-a-days. He has macular degeneration and misses reading a great deal. We can place Time Magazine on the scanner (7 stories on one page, in 3 column format, with pictures)— and the computer reads it to him almost without a single error. It all fits in a portable – water tight sports-case. We will call it "Gamut Reader" since his initials are GAM."*

### Memorials

Ron Hess  
Mearl Owens  
Jay Wooten

## University of Wisconsin-Madison ALS Trial of Breast Cancer Drug, Tamoxifen

ALS researchers at the University of Wisconsin-Madison announced the start of a new clinical drug trial of Tamoxifen for ALS patients. The one-year study will enroll 100 patients and will measure muscle strength as an end point measure of the drug's effectiveness. This is not a placebo-controlled clinical trial, but a dose-ranging study in which each ALS patient will be randomized to some dose of Tamoxifen. All doses range from below cancer chemotherapeutic doses through such dose levels. On completion of the one-year trial, all patients will have an opportunity to receive the drug on an "open label" program at the most effective dose. Patients should not take Tamoxifen outside of this trial until its safety and potential efficacy are defined and confirmed by clinical trials similar to that underway at the University of Wisconsin-Madison. Patients must be able to travel to the study site at Madison Wisconsin every three months throughout the one-year study with a total of five to six study visits. Adverse effects of Tamoxifen seen in some breast cancer patients with long term high doses of the drug include increased incidence of uterine cancer, stroke and venous thrombosis (blood clots). Tamoxifen is a pill taken by mouth. The dosage in this clinical trial is taken once or twice a day.

"Patients receiving Tamoxifen in this study may not see any immediate effect," cautioned Benjamin Brooks, M.D. who is the principal investigator of the clinical trial. "We hope to be able to measure muscle strength improvement or maintenance over the course of the one year study period," Brooks stressed.

Interest in Tamoxifen began when clinicians at the University of Wisconsin-Madison

noted that an ALS patient receiving Tamoxifen for breast cancer had an unusually mild form of ALS. Other ALS clinicians have recently informed Dr. Brooks that they may have seen similar rare occurrences. This clinical observation led to laboratory work using a mouse model of motor neuron degeneration. Mice infected with a virus show initial signs of motor neuron degeneration at 28 days post infection. Disease progresses to a moribund condition at 36 days. Treatment of the mice with Tamoxifen delayed onset of symptoms until 36 days, and mice became moribund at 48 days post viral infection.

A possible disease mechanism being investigated in this clinical trial is that Tamoxifen is a protein kinase C inhibitor that could produce an anti-glutamate effect. An excess of glutamate is believed to play a role in ALS due to its toxic effect on motor neurons. Rilutek has been demonstrated to have a similar effect on glutamate as is theorized for Tamoxifen.

For more information on this clinical drug trial and enrollment criteria contact: Kathryn Roelke, RN, or Jennifer Parnell, BA  
Phone: (608) 262-7175, (608) 263-9057, (608) 265-2451  
Fax: (608) 263-0412  
Email: [ALSCRC@neurology.wisc.edu](mailto:ALSCRC@neurology.wisc.edu) Web site: [www.NEUROLOGY.WISC.EDU](http://www.NEUROLOGY.WISC.EDU) Click on "Clinical Trials"

# Holiday Cheer!

**In December the Chapter was filled with holiday cheer as friends and families joined together for an open house, holiday parties and volunteer recognition.**



SPRINGFIELD



WICHITA



KANSAS CITY



## NORTHEAST ALS CONSORTIUM CLINICAL TRIAL OF CELEBREX IN PEOPLE WITH AMYOTROPHIC LATERAL SCLEROSIS

The Northeast ALS consortium is conducting a multicenter (25 sites) study of Celebrex in patients with ALS. Enrollment begins December 2001.

### BACKGROUND

Celebrex is a cyclooxygenase-2 (COX-2) inhibitor that is FDA approved for the treatment of arthritis. Pre-clinical studies support the hypothesis that drugs that inhibit COX2 activity may be neuroprotective in subjects with ALS. Glutamate-mediated excitotoxicity and oxidative toxicity are possible factors in the pathogenesis of ALS. Cyclooxygenase-2 may play a key role in these processes by producing prostaglandins, that trigger astrocytic glutamate release and by inducing free radical formation. COX-2 inhibition in an organotypic spinal cord culture model of ALS provided significant protection against loss of spinal motor neurons.<sup>1</sup> Preliminary data suggests that COX-2 inhibition prolongs survival in the G93A mutant superoxide dismutase transgenic mouse model of ALS (Rothstein et al, unpublished data). Laboratory findings from the work of Drachman and Rothstein led to this clinical trial of Celebrex.

### STUDY DESIGNS

The study is a double-blind placebo controlled study of Celebrex. Enrolled subjects will receive either Celebrex or placebo over a 12 month period. Twice as many people will receive Celebrex than will receive the placebo in this trial. In addition, Celebrex will be provided to enrolled subjects regardless of group assignment at the end of the 12 month study period for up to one year. The total number of subjects to be enrolled is 300 (approximately 12 patients per study site.) Enrollment is expected to take six to twelve months across all 25 participating sites. Celebrex is a capsule taken by mouth. In general, Celebrex is well-tolerated. Possible side effects include gastrointestinal disturbances, kidney problems and allergic reactions. People with known allergic sensitivity to sulfa antibiotics should not take Celebrex. It is hoped that Celebrex will slow the rate of progression of ALS. At this time it is not known if the study medication will provide any benefit. The knowledge gained from this study may be of future benefit to ALS subjects.

Over the course of the 12-month research period, muscle strength, breathing strength, and activities of daily living function will be measured along with estimated counts of functioning motor nerves.

### CAUTION

Celebrex is an investigational drug for ALS. Unexpected adverse effects can occur. If you are not enrolled in the Celebrex clinical drug trial, do not take Celebrex without consulting with your physician or other health care provider.

### FUNDING

The study is funded by Pharmacia and the Muscular Dystrophy Association.

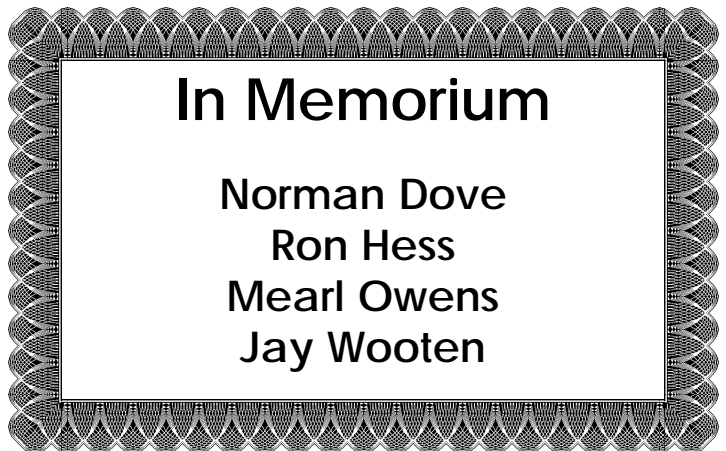
### INFORMATION AND ENROLLMENT INQUIRY

The coordinating center for the Celebrex trial is Massachusetts General Hospital. For more information about the study please call Fran Murphy, Massachusetts General Hospital, Neurology Clinical Trials Unit @ (617) 726-9122 ([www.alsconsortium.org](http://www.alsconsortium.org)). For the names of the study site

locations, or to inquire about enrolling in this clinical drug trial at a specific site, refer to the site contact listing found at <http://als.org/research/drugdev24.cfm>

### NORTHEAST ALS CONSORTIUM (NEALS)

Established in 1995, the NEALS Consortium is a collaboration of clinical and basic scientists focused on rapidly and safely translating basic science discoveries into therapeutic trials in ALS. The Consortium co-chairs are Merit Cudkovicz, MD, MSc and Jeremy Shefner, MD. Consortium scientific advisors are Robert Brown, MD, Phil D, Robert Friedlander, MD and Jeffrey Rothstein, MD, PhD. In less than one year, the NEALS Consortium took the basic science laboratory results from Drachman and Rothstein to the human clinical drug trial. Other ALS "Study Groups" are conducting drug trials and symptom management clinical research. These "Study Groups" are generally organized geographically and include the Western ALS Study Group (WALS), the Great Lakes ALS Study Group and the Mid-Atlantic ALS Study Group.



## BENEFITS

"The National Council on the Aging (NCOA) and America Online Inc. have launched a new online service that identifies all federal and state assistance programs available to older Americans.

The program - called Benefits-Check-Up - is a free public service that will help individuals quickly and easily determine what benefits they qualify for and how to get them.

More than 5 million older Americans are currently missing out on benefits programs that can provide help with health care, transportation, income support, legal services, housing and energy assistance, meals and other important services, says NCOA President James Firman. NCOA is a nonprofit advocacy group for older Americans based in Washington.

Individuals can access the new service through the following Web address: [www.benefitscheckup.org](http://www.benefitscheckup.org)"

# JANUARY BIRTHDAYS

|                  |            |                  |            |
|------------------|------------|------------------|------------|
| Gary Mastellar   | January 1  | Leroy Deines     | January 20 |
| Charles Driscoll | January 2  | Gerald Manford   | January 23 |
| Victor Weber     | January 2  | Michael Morris   | January 24 |
| Phyllis Henness  | January 2  | Donaldeen Carl   | January 24 |
| Goldie Thurnau   | January 5  | Robert Grilz     | January 24 |
| Cathy Davis      | January 6  | Bessie Crafton   | January 25 |
| Don Post         | January 9  | Eddie Forbes     | January 27 |
| William Haines   | January 9  | Edward Hollander | January 28 |
| Doretha Jordan   | January 14 | Doyle Black      | January 29 |
| Ivan Brame       | January 19 | Marlene Chappell | January 30 |
| Melvin Hammke    | January 20 |                  |            |

## FOR SALE

QUICKIE II, adult, lightweight (27 lbs) titanium wheelchair in good condition with padded, swing-away arm rests, 8" pneumatic casters for easy ride on rough surfaces, 24" rear wheels with wheel locks and aluminum hand rims; 17" frame width, medium backrest with 8 degree bend and rear anti-tip tubes. The Jay seat, lumbar support and foot pedals easily disassemble for easy transport. Only used 10 months. Purchase price was \$1,784 (reduced from \$2,095). Sale price is negotiable. Call (573)445-2451 (Columbia MO area).

1998 GENERAL MOTORS MOBILITY CONVERSION VAN (loaded); 5,000 miles. Includes Jazz Electric Wheelchair. Please call for more details: (913) 557-9212 or email [emurrow@hotmail.com](mailto:emurrow@hotmail.com)

JAZZY POWER CHAIR, Model 1120, upgraded no-flat tires and joystick control. Used only 6 months. Retail is approx. \$5200. Priced at \$2000. Contact Britt at (913)681-6356 (H) or 913-341-4200 (W).

HANDICAPPED EQUIPPED 79 CHEVROLET VAN, 34,000 original miles, Ricon rear lift, \$2000. Please call for more details. (913) 789-8451 or email [maryc@kcnet.com](mailto:maryc@kcnet.com)

NEW ELECTRIC WHEELCHAIR, Model 9000 Action Power, complete with two batteries and charger. Includes Owner's Operation and Maintenance Manual. Call: 816-246-7761 or 816-564-4841.

1995 CHEVY CONVERSION VAN ½ ton, 37,000 miles, excellent condition. Asking 15,000. Call (785)-841-6937 (Lawrence, KS area) after 4:00 pm or e-mail [jehime78780@aol.com](mailto:jehime78780@aol.com) for more information.

HOSPITAL BED, SERENITY HOME CARE BED BY MEDLINE. 2 years old. Used only one year. Semi-electric. Paid \$1800, asking \$500. Call Wendy at 913-371-2238.

1998 FORD ECONOLINE 150 custom van with raised roof and side entry wheelchair lift (\$5000). 25,000 miles. Loaded, new tires, TV, and 4 wheelchair lockdown units. Like new condition, engine well maintained. See to appreciate. \$22,000. Call 816-822-8274.

1998 ELEC. WHEELCHAIR INVACARE ACTION RANGER II STORM SERIES, Loaded with Jell seat, Remote Programmer, Joystick/Switches/Indicator, Anti-Tippers, adjustable High Back/Headrest Recliner, standard and deluxe foot/leg rests, mirrors and other add-ons. Excellent Condition. Also 2 Battery Chargers, 1 used 24 volt, Action-Model18350 Invacare and one new/unused 24 volt dual mode automatic, Lester Electrical, Model-18350. Manuals included. Best Offer. Call: 785-272-3349 (Topeka area)

1997 POWER WHEELCHAIR, EVEREST & JENNINGS, Joystick control, new seat, clean and in great working condition. Small & compact to go through most doorways as well as tight spots in bathrooms, etc., yet large enough to handle most people. Includes batteries & charger. Arm rests can pivot or remove for transfers, swing out foot rests. \$1900.00 new. Asking \$500.00. Includes books & operating instructions. Call 816-373-2215.

1998 POWER WHEELCHAIR, EVEREST & JENNINGS, Joystick control, like new condition. \$2,500 new. Asking \$900.00. Used approximately 6 months. Small & compact. Needs batteries. Includes charger. Arm rests pivot or remove and foot rests swing out. Call 816-257-0641.



## EMAIL ADDRESSES TO BETTER SERVE YOU:

**Beckie Cooper**  
Executive Director  
[bcooper@alsa-midwest.org](mailto:bcooper@alsa-midwest.org)

**Sally Dwyer**  
Program Director  
[sdwyer@alsa-midwest.org](mailto:sdwyer@alsa-midwest.org)

**Dawn Oliver**  
Development  
[doliver@alsa-midwest.org](mailto:doliver@alsa-midwest.org)

**Terry Betzelberger**  
President  
[info@alsa-midwest.org](mailto:info@alsa-midwest.org)

**Meeting Reservations**  
[msloan@alsa-midwest.org](mailto:msloan@alsa-midwest.org)

### Patient Services

#### Kansas City-

**Sarah Tucker**  
[stucker@alsa-midwest.org](mailto:stucker@alsa-midwest.org)  
**Nancy Lindquist**  
[nlindquist@alsa-midwest.org](mailto:nlindquist@alsa-midwest.org)  
**Linnea Brandt**  
[lbrandt@alsa-midwest.org](mailto:lbrandt@alsa-midwest.org)  
**Patty Hill**  
[phill@alsa-midwest.org](mailto:phill@alsa-midwest.org)

#### Springfield

**Betty Bruce**  
[bbruce@alsa-midwest.org](mailto:bbruce@alsa-midwest.org)

#### Wichita-

**Jean Haley**  
[jhaley@alsa-midwest.org](mailto:jhaley@alsa-midwest.org)

### Fundraising

#### Kansas City-

**Tonja Britt**  
[tbritt@alsa-midwest.org](mailto:tbritt@alsa-midwest.org)  
**Keri Morrison**  
[kmorrison@alsa-midwest.org](mailto:kmorrison@alsa-midwest.org)  
**Merritt McShane**  
[msloan@alsa-midwest.org](mailto:msloan@alsa-midwest.org)  
**Kristine Tarwater**  
[ktarwater@alsa-midwest.org](mailto:ktarwater@alsa-midwest.org)

#### Springfield

**Kim Goble**  
[kgoble@alsa-midwest.org](mailto:kgoble@alsa-midwest.org)

#### Wichita-

**Kathleen Wille**  
[kwille@alsa-midwest.org](mailto:kwille@alsa-midwest.org)

**Chapter Website**  
[www.alsa-midwest.org](http://www.alsa-midwest.org)  
**National Website**  
[www.alsa.org](http://www.alsa.org)

**THE DIALOG**

Keith Worthington Chapter  
8340 Mission Rd. Suite B-4  
Prairie Village, KS 66206

Non Profit Org.  
U.S. Postage  
**PAID**  
Shawnee Mission, KS  
Permit No. 1249

Address Service Requested

8 • **The Dialog**

J  
A  
N  
U  
A  
R  
Y  
2  
0  
0  
2

- |    |      |  |    |      |  |
|----|------|--|----|------|--|
| 2  | Wed  | <b>Hutchinson Support Group</b> 2 pm<br>Grace Episcopal Church, 20th & Main  | 16 | Wed  | <b>KC Day Support Group</b> 2 - 3:30 pm<br>Village Presbyterian Church<br>6641 Mission Rd. Prairie Village, Kansas         |
| 3  | Thu  | <b>Wichita Support Group</b> 7 pm<br>Grace Presbyterian Church<br>5002 E Douglas   | 22 | Tues | <b>Springfield Support Group</b> 7pm<br>Springfield ALS Office<br>1447 F South Enterprise                                  |
| 8  | Tues | <b>Kansas City Support Group</b> 7 - 8:30 pm<br>Second Presbyterian Church, 55th & Oak<br>Rosalyn McHenry will speak on "Home<br>Remodeling and Access | 30 | Wed  | <b>Lincoln Support Group</b> 7 - 8:00 pm<br>Madonna Rehab Hospital<br>5401 South St, Rm Sheridan C<br>Will meet bi-monthly |
| 10 | Thu  | <b>Omaha Support Group</b> 7pm<br>St. Pius X Parish Center<br>6905 Blondo Street, Omaha  |    |      | <b>Topeka Support Group</b><br>Next Meeting TBA  |
| 11 | Fri  | <b>KC Caregiver Support Group</b> 12:30 - 1:30 pm<br>ALS Office<br>8340 Mission Rd. B4, Prairie Village, Kansas<br>Please RSVP (913) 648-2062          |    |      | <b>Jefferson City Support Group</b><br>Next Meeting TBA  |

**"What is ALS"** Orientation Series  
By appointment. Please call (913) 648-2062

THE CHAPTER SERVES KANSAS, NEBRASKA, AND WESTERN/CENTRAL MISSOURI

With Offices in the Following Cities, Contact the Office Nearest You!

**Kansas City/Nebraska**  
Linnea Brandt & Nancy Lindquist  
**(800) 878-2062**

**Wichita**  
Jean Haley  
**(800) 553-9056**

**Springfield**  
Betty Bruce  
**(888) 386-1200**