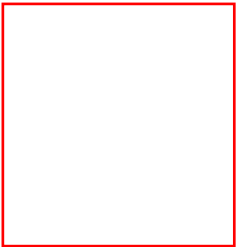


# ALS

MARCH 2008

Volume X

Issue 2



**The Keith Worthington Chapter Walk to Defeat ALS™ web sites for this year are now officially up and running! Go to [www.alsa-midwest.org](http://www.alsa-midwest.org) and click the Walk logo button.**



## Fans Choose Brett for 1970's Statue Giveaway

Voting underway at [oroyals.com](http://oroyals.com) on which 2000's Royal will be honored



The ALS Association Keith Worthington Chapter is proud to announce that our Honorary Spokesperson, George Brett will be honored with a commemorative statue giveaway to fans at an Omaha Royals game next season. Brett was chosen by fans in an online poll at [www.oroyals.com](http://www.oroyals.com) over the past month as the Omaha player from the 1970's for that honor. He beat out former Omaha players Frank White, Willie Wilson and Dan Quisenberry and former O-Royals manager Jack McKeon.

Brett was inducted into the Baseball Hall of Fame in 1999. At the conclusion of his 21-year career in 1993, he was the only player in Major League history to amass more than 3,000 hits, 300 home runs, 600 doubles, 100 triples and 200 stolen bases. Brett was the first player to win batting titles in three decades (1976, 1980, 1990) and was the A.L. MVP in 1980, when he batted .390. He joins Mike Sweeney and David Cone as former Omaha players to be featured in the promotional series.

People may now vote online for the commemorative statue of an Omaha player or manager from the current decade to be given away at an Omaha Royals game in 2008, as the Royals celebrate their 40th season in Omaha.

## Leaving a Legacy

As the need to provide services to those with ALS grows, it is important to ensure that the important programs of The ALS Association Keith Worthington Chapter will continue to be available to those that need them. Bequests and other planned gifts are important ways that individuals can help make sure that no one faces this disease alone.

Bequests are gifts made through a will and allow you to leave money or property to the Chapter without affecting your family's current financial security.

### Types of Bequests

You can structure a will bequest to The ALS Association Keith Worthington Chapter in a variety of ways:

**Specific Bequest:** With a specific bequest, you designate who is to receive a certain dollar amount or designated property. Bequests can be cash, securities, real estate or other personal property. This type of bequest should be used when you have very precise wishes about the disposition of funds or items.

**Percentage Bequest:** Percentage bequests are an excellent way to ensure that all the people and organizations you care about are remembered in your will without trying to forecast what your specific assets will be worth at the time of your passing. This type of bequest will often direct the executor or administrator of your will to liquidate (sell) all your assets and then give a designated percentage of those proceeds to your beneficiaries. The percentage method ensures that each beneficiary will receive the proportionate share that you wish them to have, regardless of fluctuations in the value of your assets. For example, if you wish to leave your estate equally to your three children and the Keith Worthington Chapter, you would designate that each would receive 25% of your estate.

**Residual Bequests:** You may designate who is to receive whatever remains in your estate after your other beneficiaries have received their bequests.

**Contingent Bequests:** By making a contingent bequest, you stipulate who will receive a portion of your estate if one or more of your named beneficiaries passes away before you or declines their gift.

It should be noted that these same types of gifts can also be made through your revocable (living) trust.

If you have not already done so, please consider including a gift to The ALS Association Keith Worthington Chapter in your estate plans. If you have included the Chapter in your estate planning, we would appreciate you notifying us so we can extend an invitation to join our Lou Gehrig Legacy Society and recognize your generosity. Please call our office at 913-648-2062 and we will be happy to send you information about becoming a member of the Society.

# ALS Research

The following research information is from The ALS Association web site - [www.alsa.org](http://www.alsa.org).

## Disease Process of ALS

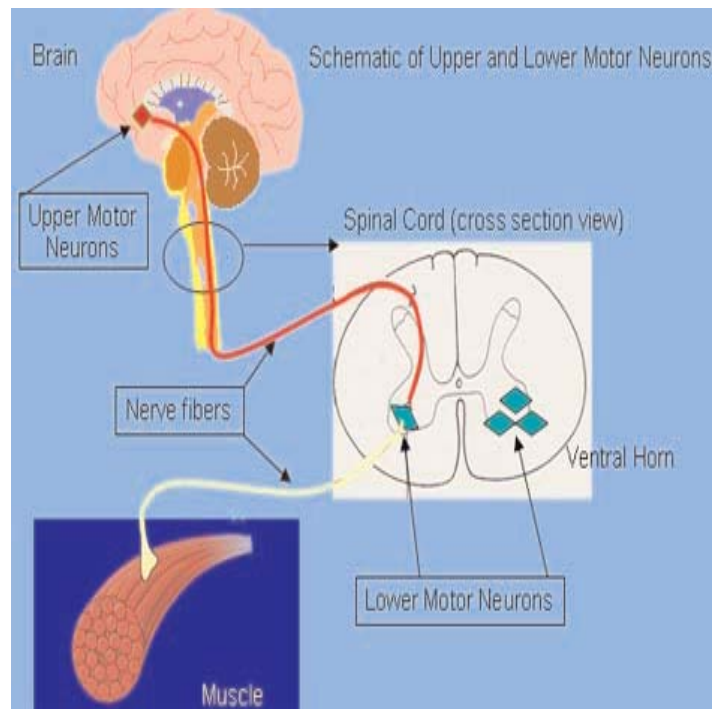
### Overview Summary

Amyotrophic lateral sclerosis (ALS) kills motor neurons, the large cells of the spinal cord that send nerve fibers out to control the muscles. Also, motor neurons in the part of the brain governing voluntary movements are destroyed in ALS. These so called upper motor neurons send nerve fibers down from the brain to control the lower motor neurons in the spinal cord. Clinicians are also finding that certain cognitive portions of the brain may be affected in ALS as well.

### Why are Motor Neurons Affected in ALS?

No one knows why the motor neurons are dying in the disease. But researchers have many ideas that lend to speculation. And speculation leads to design of experiments that will find out more about the disease, with funding by The ALS Association (ALSA). Motor neurons must support and supply an incredibly long fiber extended out to make connections. Even though the main part of a motor neuron is of typical size for a cell, its long fiber, called an axon, must travel up to a meter as part of the nerve tracts reaching down to the lower spinal cord, or from the cord out to the fingertips and toes.

Due to the extraordinary metabolic demands of their job, the motor neurons may be particularly vulnerable to any biochemical insult. Motor neurons may be uniquely at the mercy of anything that impedes production of cellular fuel, or impacts cellular supply lines that distribute crucial components to and from the far flung endings of these impressive cells.



### Aspects of Motor Neurons Suspect in ALS

Studies of the proteins within the nerve fibers called axons that keep them supported and supplied have highlighted their role in maintaining the motor neurons.

Prolonged excitation is toxic to nerve cells. Neurobiologists recognize that the nerve cell messenger, glutamate can cause harm when its messages are overwhelming. Abundant evidence points to glutamate as a destructive factor in ALS.

There are increasing clues that inflammation contributes to the death of motor neurons in ALS. Evidence suggests that the resident immune cells of the nervous system, the microglia cells, are activated by the disease process of ALS, provoking too much inflammation .

Mitochondria are the power plants of all animal cells, and must be especially busy in motor neurons. Indeed, changes in these cell organelles are evident before one can find a physical change such as hind limb weakness in mice that mimic ALS.

Programmed cell death is a series of events where a cell essentially shuts itself down. The stepwise self destruction called apoptosis is an orderly way to remove cells that are damaged beyond repair. In ALS, interrupting apoptosis might prove a way to intervene in the destructive process of the disease.

Mutations can produce an improperly folded protein that disrupts cellular functions. Some inherited forms of ALS are caused by mutations in the protein SOD1.

### Crucial Clue to ALS: Mutations in Copper-Zinc Superoxide Dismutase

In 1993 a large collaborative group demonstrated that in some inherited cases of ALS a genetic change alters an abundant enzyme within cells called copper-zinc superoxide dismutase 1 (CuZnSOD1, now usually called SOD1). This enzyme serves to keep cells safe from metabolic waste that can damage if not rendered harmless. A mistake in the genetic code, that is, a mutation, places the wrong amino acid in the sequence for SOD1.

Mice that scientists engineered to express the mutant gene for SOD1 are among the laboratory models for research into the causes and avenues towards treatment of ALS.

The fact that these mice recapitulate so many features of ALS gives hope that all cases of ALS can be addressed by the common features that come to light through study of the SOD1 mutation. ALSA funded researchers at the same time are searching relentlessly for other genetic and environmental factors that might explain the disease and lead clinicians to better therapy.



**Keith Worthington Chapter**

**1978 30<sup>th</sup> Anniversary 2008**

**30 Years - 30 Stories - 30 Reasons to Hope!**  
*Through the eyes of a few, many are inspired.*

**Keith Worthington Chapter, 1978-2008**

**Call for Stories**

Please send us your story!

In recognition of the 30th anniversary of the Keith Worthington Chapter, we'd like to recognize and promote 30 of your personal stories to help spread the word about ALS and raise awareness of the important programs and services this chapter offers. While we know 30 stories will only represent a fraction of the stories of people living with ALS in Kansas, Nebraska and Western/Central Missouri, we know that by highlighting 30 stories from 30 very different people, we'll be able to bring new attention to ALS in this, our 30th year. The final stories will be posted on our web site and featured in promotional and press materials throughout 2008, and you may be asked to participate in media interviews in your area. If you'd like your story to be considered, please send us the following information by the end of February.

- Name
- Age
- Date of diagnosis
- Hobbies
- A little about your family (spouse, kids, grandkids...)
- Answer the following question in 100 words or less: How has ALS affected your life?

For more information, call Sally Dwyer at 913-648-2062.



**ANNOUNCING -**

**The ALS Association's 2008  
 National ALS Advocacy Day and Public Policy Conference**

Sunday, May 11 - Tuesday, May 13  
 Renaissance Washington, DC Hotel  
 999 9th Street, NW  
 Washington DC 20001

For additional information, please call the Capital Office of The ALS Association toll-free at 1-877-444-ALSA, or visit The ALS Association Web site at [www.alsa.org/policy](http://www.alsa.org/policy)

**YOUR HELP IS NEEDED!**

It's time for The Keith Worthington Chapter to begin scheduling visits to the district offices of Kansas, Nebraska and Missouri Senators and Representatives

If you are interested in becoming an ALS advocate, please contact Sally Dwyer, Program Director, 913.648.2062 or email [sdwyer@alsa-midwest.org](mailto:sdwyer@alsa-midwest.org)

**The ALS Association  
 Keith Worthington Chapter**



## Call for email addresses!

When the Keith Worthington Chapter started in 1978, information to patients/families/friends was given through visits, mail and phone. TODAY, with the advancements of technology, information can often be disseminated through email - quickly and easily.

To do this, we need YOUR email addresses!

Please send an email to Laura at [lball@alsa-midwest.org](mailto:lball@alsa-midwest.org) with your name, home address and email address.

*Email addresses will remain the sole property of the Keith Worthington Chapter.*

## Upcoming 2008 Events - Mark Your Calendars

### Somewhere Over the Rainbow

Night of Hope 2008

May 3, 2008 at the Overland Park Sheraton

Table for 10 \$1000/ Ticket for 1 \$100



Don't miss out on an evening of delicious food, entertainment and touching inspiration. Join us in recognizing those who make our work possible and to hear from our keynote speaker, Noah ben Shea, poet laureate for The ALS Association.

Reserve your table or seat today. Sponsorship opportunities are also available. For more information, contact Laura at 913-648-2062.

Casino Night, Springfield - April 4, 2008

Night of Hope, KC - May 3, 2008

Light of Hope- May 15, 2008 Omaha  
May 15, 2008 Wichita

Joe McGuff ALS Golf Classic, KC - May 19, 2008

Kerry Gray ALS Pro/Am, Wichita - June 22/23, 2008

Flint Oak, Wichita - Fall 2008

Walk to Defeat ALS™ - Walks held in August, September and October throughout the service area.

## 3rd Annual ALS Vegas Vacation Casino Night & Auction



Friday, April 4, 2008 7 p.m. to Midnight

Oasis Inn & Convention Center, Springfield, MO

\$50 per person in advance, \$60 at the door and \$500 for a table of 8

The fun begins at 7:00 pm with an open buffet, music and entertainment, and a chance to mingle. An opening ceremony to introduce local people with ALS, corporate sponsors, and the Chapter's mission will be followed by an evening of great gaming and an exciting silent auction. The end of the evening will bring even more excitement with a live auction and a drawing for raffle prizes-including a trip to Las Vegas! For more information or to volunteer, please contact Mindy Wallace, at 888-386-1200 or [mwallace@alsa-midwest.org](mailto:mwallace@alsa-midwest.org).

### Joe McGuff ALS Golf Classic

May 19th, 2008

Nicklaus Golf Club at LionsGate

Celebrities: George Brett and Tom Watson

For information, contact Kristin at 913-648-2062.

### Kerry Gray ALS Pro-Am

June 22/23, 2008

Wichita Country Club

For information, contact Colleen at 913-648-2062



## ALS Genetic and Environmental Risk Study

Researchers at Massachusetts General Hospital are continuing to seek individuals for participation in an ALS Gene Study conducted by Dr. Robert H. Brown Jr. The purpose of this research study is to identify genes and environmental factors that may cause or increase the risk of developing amyotrophic lateral sclerosis (ALS). This study includes individuals with ALS, possibly some family members, and unaffected, unrelated controls. Participation requires a one-time blood sample, completion of questionnaires about environmental and family history, and permission to review medical records pertaining to the onset and progression of the disease for those with the disease. All costs are covered and travel to Boston is not necessary. Arrangements can be made to have participants' blood drawn locally.

Eligibility: Any person who is diagnosed with ALS and possibly some family members. We are also recruiting unrelated, unaffected individuals as population controls, such as spouses and friends.

We would love the opportunity to work with you. Please contact us at:

Nicole Couture or Diane McKenna-Yasek  
Massachusetts General Hospital  
Cecil B. Day Laboratory  
114 Sixteenth Street, Rm 3125  
Charlestown, MA 02129

Tel: 617-726-5750

Fax: 617-726-8543

Email: [ncouture@partners.org](mailto:ncouture@partners.org)

Email: [dmckennayasek@partners.org](mailto:dmckennayasek@partners.org)

MARCH 2008



Is your company looking for a way to shine in the community? Look no further – Walk to Defeat ALS™ offers opportunities to become a corporate sponsor and/or form a corporate team. Improve teamwork, increase employee morale and help out a wonderful cause! For more information or to find a walk in your community, please contact:

Kansas City

Kristin Spence

(913) 648-2062

[kspence@alsa-midwest.org](mailto:kspence@alsa-midwest.org)

Nebraska

Sherrie Hanneman

(402) 991-8788

[shanneman@alsa-midwest.org](mailto:shanneman@alsa-midwest.org)

Central/Southwest Missouri

Mindy Wallace

(417) 886-5003

[mwallace@alsa-midwest.org](mailto:mwallace@alsa-midwest.org)

Wichita

Colleen Wachter

(913) 648-2062

[cwachter@alsa-midwest.org](mailto:cwachter@alsa-midwest.org)

### Programs & Services Update

(from the January 2008 report)

	In January 2008	Fiscal Year End
New patients	12	133
Number of patients who have died	3	105
Consultations made by Service Coordinators	569	5,320
Number of clinics held	3	42
Patients attending clinic	24	324
Number of support group meetings	13	168
Patients attending support group meetings	17	327
Total number attending support group meetings	89	1,881
People attending speaking presentations	72	3,096
Number of equipment items on loan	455	n/a

#### In Memoriam

We send our sympathy and support to the families and friends of those who have recently died after battling ALS.

John Camper  
Willard Landrum  
Gary Martindale  
Doris Carlson  
Steve Travers

#### Memorials

Thank you to the families of the following for designating our Chapter for donations:

John Camper  
Gary Martindale  
Doris Carlson

## EQUIPMENT EXCHANGE

## ITEMS FOR SALE

## VANS

**1999 Ford Econoline Conversion Van.** Has lift and many extras. 86,000 miles. \$9,500. Call Bruce at 402-291-1697.

**1998 Ford Windstar.** 52,000 mi. New carpet. \$20,000. Call Daphne at 417-844-4814.

**1992 Chevrolet G20 Van.** Has Braun lift. 90,000+ miles. \$4000. Call Sherrie at 816-884-3071.

**2003 Dodge Grand Caravan,** Rampvan. Perfect condition, 98,000 miles, new tires, new rear shocks, serviced Feb 06, asking \$26,000. Call 888-386-1200 or e-mail djmathis1@alltel.net for details.

**1995 Ford Econoline 150 full-size van.** Leather interior, Braun lift, 113,000 miles. Call Pam Garcia 402-345-0879 or 402-917-6478 (cell).

**'98 Dodge Grand Caravan.** 72K, Lowered floor with ramp and tie downs. New brakes and tires. Clean and excellent condition. \$14,500.00. Call Rosie Anderson, 913.205.2848

**1991 Chevy conversion Van.** Handicap accessible. Ricon platform lift. Excellent condition. \$6000. Call Joann Rand at 417-753-3282.

## WHEELCHAIRS

**ALL POWER Permobil wheelchair.** Slightly used (approximately 6 months). Some surface scratches, otherwise in perfect shape. Asking \$2,500. 816-377-4351.

**Permobil C300 Wheelchair.** 6 mos. old. \$7,000. Call Daphne at 417-844-4814.

**InvaCare Chairman Power Wheelchair.** Incl. ventilator tray, head controls. Like new, used only 5 times. \$6,299 or best offer. Call Fernando 816-213-0607.

**M91 Power Wheelchair.** Flat Free tires. EX controller, Swingaway foot rest, 22 ML gel batteries. Purchased 2004 for \$6,450. Asking \$2,500. Call Eileen Otto at 913-888-9998.

**InvaCare Storm Series TDX4 Power Wheelchair.** Storm Series TDX4 incl Formula Invisible Super Low Tilt, tilt/recline/elevate, Formula PTO Plus & joystick controller. 2 yrs old. Pickup or delivery available in Springfield/ Joplin. List price \$10,305; asking \$6,200. Call Francine 636.530.6001.

**Quantam 600 series power chair.** Reclines to lay down with legs up. Call Pam Garcia 402-345-0879 or 402-917-6478 (cell).

**Reclining Quickie Wheelchair** with headrest, elevating leg rests, removable arm rests, gel cushioned seat. Contact Angela at (620)763-2621 or angela@ckt.net.

**Hoveround power chair w/battery pack and charger.** Excellent condition. \$1550. Call Melvin 913-498-3129.

**Wheelchair,** sized for a woman. Excellent condition. \$125. Call Melvin 913-498-3129.

**Like new Merit Red Power Wheel Chair** with large rear wheels. Model #2005. Asking price \$23,000.00. Used only a few times. Call: Mrs. J. J. Wyatt 316/207-8186 or Pamela Rayer 316/721-0939.

**Wheelchair,** Permobil C300. Reclines, Joystick. \$6500. Call Linda at 816-238-3991

**Jassypower chair model #1122.** Highback remote plus controller. \$1000. 816-588-7118 or 816-588-3500.

## PLATFORM LIFTS

**Access Industries Indoor/Outdoor Vertical Platform Lift,** Model PLS 96. Used little 750 lbs. capacity. \$5,500 - . Call (314) 374-4480.

## MISCELLANEOUS

**STAIR GLIDE** and seat for 7 steps. Straight access. Can be mounted to steps or wall. Call 913-712-8657 or 952-457-1520. Will donate.

**E-Z STAND,** 5000 series. Brand new - valued at \$5000. Asking \$1,500. Call Michelle 402-994-2204.

**DYNAVOX Series 4.** Less than 1 year old. Stand included. Asking \$2,200. Call Daphne at 41-44-414.

**SCOOTER,** Pride Shuttle Mobility Scooter, variable speed control; 2 batteries, 110v built-in charger; baskets. Good condition. \$550.00 Call Sharon (417) 276-3363.

**SCOOTER LIFT.** Bruno electric swing arm scooter lift. \$550.00 (Installation not incl.) Call Sharon (417) 276-3363.

**CHAIR GLIDE,** Summit Stairway, installed Nov. 2006. Straight stairway. Incl. all paperwork and instructions. New \$2926, asking \$1900. Please call Chelly 913-661-0374.

**LIFT CHAIR,** beige power recliner, excellent condition. \$550. Call Melvin at 913-498-3129.

**DYNAVOX** with carrying case. Like new - purchased in 2005. \$6,000 or best offer. Please call Audra Youman 308-632-8984.

**SCOOTER CHAIR.** Never used. Pd \$6,000, asking \$3,500. Call Darlene 402-352-2083.

**LIFT SYSTEM** Sure-Hands Patient Lift System w/ 3-room access. \$7000 or reasonable offer. Contact Marilyn Gray (316) 831-0123.

**WHEELCHAIR TUB BASE.** 30x60 Barrier Free. Only used twice. Cost \$515, asking \$200. Please call George 816-461-0980.

**SHOWER CHAIR PVC.** Call Pam Garcia 402-345-0879 or 402-917-6478 (cell).

## SEVERAL ITEMS AVAILABLE:

- Sure Hands lift system, \$6,000
  - Deluxe Wheelchair - \$12,000
  - Portable commode chairs, walkers, plastic ankle supports, size large
- Call Margie Lafevers 870-424-6325.

Inclusion in Dialog is not an endorsement of these products.

**If your item has been sold,  
or if you would like to place an ad,  
please contact Laura at 913-648-2062, or  
lball@alsa-midwest.org.**

## CONTACT INFORMATION

## Directors

*Kansas City* (913) 648-2062

**Beckie Cooper, Ext. 210**

**Executive Director**

bcooper@alsa-midwest.org

**Sally Dwyer, Ext. 212**

**Program Director**

sdwyer@alsa-midwest.org

**Eileen Brown, Ext. 209**

**Development Director**

ebrown@alsa-midwest.org

**Pete Story**

**President**

info@alsa-midwest.org

## Patient Services

*Kansas City* (800) 878-2062

**Linnea Brandt, Ext. 206**

lbrandt@alsa-midwest.org

**Nancy Lindquist, Ext. 204**

nindquist@alsa-midwest.org

**Sarah Tucker, Ext. 202**

stucker@alsa-midwest.org

*Nebraska* (402) 991-8788

**Shannon Todd**

stodd@alsa-midwest.org

*Springfield* (888) 386-1200

**Debra Harlan**

dharlan@alsa-midwest.org

*Wichita* (800) 553-9056

**Jean Haley**

jhaley@alsa-midwest.org

## Fundraising

*Kansas City* (913) 648-2062

**Colleen Wachter, Ext. 221**

cvwachter@alsa-midwest.org

**Kristin Spence, Ext. 211**

kspence@alsa-midwest.org

*Nebraska* (402) 991-8788

**Sherrie Hanneman**

shanneman@alsa-midwest.org

*Springfield* (417) 886-5003

**Mindy Wallace**

mwallace@alsa-midwest.org

*Wichita* (316) 612-0188

**Colleen Wachter**

cvwachter@alsa-midwest.org

**Jo Harris**

jharris@alsa-midwest.org

**Chapter Website**

[www.alsa-midwest.org](http://www.alsa-midwest.org)

**Walk Website**

<http://walkkwc.alsa.org>

**National Website**

[www.alsa.org](http://www.alsa.org)

# THE DIALOG

Keith Worthington Chapter  
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Mission, KS 66202

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## 8 • THE DIALOG

### March Support Group Dates

*Phone RSVP's are requested if marked with \*  
Toll-free phone numbers are listed below.*

MARCH 2008

4	*Kansas City Evening <i>(Bill Kock, Silver Cross, Lift Equipment)</i>	7:00 p.m.
5	Jefferson City	1:30 p.m.
5	Hutchinson	2:00 p.m.
6	Wichita	7:00 p.m.
11	*Omaha <i>(please note new location)</i>	6:30 p.m.
11	*Springfield <i>(please note new location)</i>	6:30 p.m.
14	*Kansas City Caregivers	12:30 p.m.
19	*Kansas City Day (yoga)	1:30 p.m.
15	Wichita Caregivers	11:00 a.m.
20	Salina	7:00 p.m.
24	Topeka	3:30 p.m.
25	Nebraska Phone Group	7:00 p.m.
27	*Carl Junction	11:00 a.m.

### Support Group Locations

<b>Hutchinson, KS</b> Grace Episcopal Church 20th & Main	<b>KC Caregivers/Survivors</b> ALSA Bldg - 2nd Floor Mtg Rm <b>Please RSVP</b>	<b>Richmond, MO</b> Call Lea 816-776-6007
<b>Salina, KS</b> Church of the Cross Methodist Corner of W. Claflin & Rush St.	<b>KC Day (YOGA)</b> ALSA Bldg - 2nd Floor Mtg Rm	<b>Jefferson City, MO</b> Southridge Baptist Church 1815 Vieth Drive
<b>Topeka, KS</b> Shawnee Co. Public Library 1515 SW 10th Avenue * Meets every other month *	<b>KC Men</b> ALSA Bldg - 2nd Floor Mtg Rm <b>Please RSVP</b> * Meets every other month *	<b>Springfield, MO</b> Wheeler Community Center 3800 S. National
<b>Wichita, KS Caregivers</b> ALSA Office- 3450 N. Rock Rd, Bldg 200, Ste 211 <b>No need to RSVP</b>	<b>KC Evening</b> 2nd Presbyterian Church 55th and Oak	<b>Carl Junction, MO</b> Gambino's Pizza 1304 Pennell Street
<b>Wichita, KS</b> Grace Presbyterian Church 5002 East Douglas <b>No need to RSVP</b>	<b>Lawrence</b> Bert Nash Comm Health Ctr 200 Maine St., 1st floor mtg rm * Meets every other month *	<b>Omaha, NE</b> Millard Library 13214 Westwood Lane
		<b>Nebraska Phone Group</b> Call Shannon 866-762-6361

The Keith Worthington Chapter has offices in the following cities:

**Kansas City**  
(800) 878-2062

**Nebraska**  
(866) 762-6361

**Springfield**  
(888) 386-1200

**Wichita**  
(800) 553-9056