



Photo: Patrick W. Boyer with his mom, Margie Boyer. This story was written by Patrick for his English class.

Living with ALS

By Patrick Boyer

CRASH!!!! The sounds of bending metal and sirens light up the night on August 17, 1990. Even though I was not old enough to fully understand, it is a night I will never forget. August 17, 1990 is the night that my mother, Margie Boyer, was involved in a car accident. A drunk driver ran a red light and my mother and her friend Darla could not stop in time.

A little under a year later my mother was diagnosed with Amyotrophic Lateral Sclerosis, also known as ALS. It seemed to us that ALS was a gene that you are born with and lies dormant until a traumatic event activates the gene. For my mom, it was hitting her head on the windshield. For the first four years my mom fought the symptoms and did what she could to stay healthy but in the summer of 1995 she started using a wheelchair. By fall of 1998 she had had an operation to put a feeding tube into her stomach and for the most part has been off solid foods since 2004. In 2001 I was at Howe Military Academy in Howe Indiana, and received a phone call that my mom was in the Intensive Care Unit at St. Joseph Hospital in Kansas City, almost 600 miles away. I was on the first plane there.

When I arrived she had a tube running down her throat and it looked like she had been crying. I tried to comfort her and it helped quite a bit for her to see me there. Still the fact that she would have to go on a ventilator was still something that she did not want to do. A week later when she left the hospital she had a ventilator hooked up and was headed home to make a lot of changes.

Throughout my short life I have had my emotional and physical battles that I have fought my way through. Many of my friends have met my mother and like her very much. After a new friend meets my mom the first thing they ask is, "What happened," or "What's wrong with your mom." I would give them just a short story of what happened and they would say, "Oh, I'm sorry," not knowing how it really has changed my life.

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“
I hope that one
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a cure for
ALS...
”

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Over the years I have become more and more independent, self reliant, and compassionate because of my mother's disability. I have had to learn and do things on my own that normal kids wouldn't have to because I didn't have a mom that could stand by my side, hold my hand and guide me. Now don't think that my mom hasn't helped me at all because between her and her caregiver Sherrie, they have both filled my brain with more knowledge than I know what to do with sometimes. I have, throughout my life, learned how to help, understand, and know what my mom needs when she asks for it or even when she doesn't. I have had to learn how to get my mom out of bed and into the wheelchair, get the ventilator hooked up the right way so that she can breathe, get her feeding tube going, set her up in her wheelchair when needed and countless other tasks that need to be done from time to time.

Friends ask my how I feel about my mom being in a wheelchair and all I can say is that I don't know any other way. My mom has been in her wheelchair for longer than I remember. Truthfully I can't remember seeing my mom stand except for in pictures. I can't remember her voice,

except for one recording that my grandmother has. So I don't really know what it is like to have a "regular" mom or a "regular" family. I'm ok with that because I'm pretty happy with how things have turned out. I am lucky to have a family like mine that has gone through the trials of life and came out on top. Having a mom like mine gives me a bigger perspective into how other people that have to use a wheelchair or that have other illnesses feel.

I feel like I am more compassionate towards people because I know what they're going through. I hope that one day they will find a cure for ALS, not just for my mom but for people with ALS all over the world. Even if they don't find a cure before my mom, my family, or even I am gone, it will still be the best thing that could happen for anyone with ALS, or any other disease.

So that fateful night in 1990, my life along with my mother's and everyone in my family's has been forever changed. One final note; my mom's knowledge and guidance even though in a wheelchair, has helped shape and mold who I am today.



WE LIGHT THIS CANDLE TO REMEMBER THOSE WHO HAVE LOST THEIR BATTLE TO ALS.

WE LIGHT THIS CANDLE TO HONOR THOSE WHO LIVE EACH DAY WITH ALS.

WE LIGHT THIS CANDLE FOR HOPE - HOPE TO FIND A CURE.

On Sunday, May 11, 2008, thousands will gather in Washington, DC,
for a candle lighting ceremony in honor of those fighting ALS.

Please join us as we light our candles of hope.

May 15, 2008

OMAHA

Picnic 6:30 pm; Candle lighting 8:00 pm
Elmwood Park at the Pavillion

RSVP: Shannon or Sue - 402.991.8788

WICHITA

7:00 pm
Home of Pam & Randy Rayer

RSVP: Jean or Kathy - 316.612.0188

ALS Research

The following research information is from The ALS Association web site - www.alsa.org.

Environmental Factors

Overview Summary

Researchers are looking for aspects of lifestyle that can interact with genes to cause or contribute to ALS. The notion that ALS could be linked to viral infection is a concept that reappears periodically when researchers focus on the issue. Exposure to toxins, or the influence of intense exertion, are ideas researchers consider as possible reasons for the finding that some veterans and some athletes have increased incidence of ALS. ALSA will continue to support investigations into the way that environmental factors may interact with genetics to produce ALS.

What Environmental Factors Are Suspect in ALS?

Toxins

After finding the mutated gene for SOD1 (see also SOD1) in some inherited cases of ALS, researchers continue to search for additional factors that can cause or contribute to the disease. Toxins encountered in the environment have been examined as possible factors in producing the disease. As yet no conclusive proof exists for any toxin as a causative factor in ALS. Suspects that scientists have researched include heavy metals, solvents, radiation, and electromagnetic fields.

As no one would propose to give a known or potentially toxic substance to people on purpose, any study of the potential role of environmental or dietary factors in ALS must be by the methods of epidemiology. These studies look at populations of people and use answers to questionnaires or information collected from patients and stored in databases to investigate what common factors among people with ALS could provide a link to the disease. Such studies can only reveal a potential association and can never prove cause.

Warfare

As well as the Chamorro of Guam, U.S. veterans are another group of people who appear to develop ALS more often than the general population. A recent study found that the relative risk of dying from ALS for veterans was 1.5 times that seen for the men who did not serve. The increased risk was apparent for veterans of World War II, the Korean War, and the War in Vietnam. A prior study had found that the rate of ALS in young Gulf War veterans was more than two times greater than expected for the general population.

Scientists have expressed concern that the degree of excess risk is not convincing because of the small number of total ALS cases documented in these studies of veterans. Statistical theory says that such small numbers may not be able to provide reliable answers to questions about associations between diseases and their causes. Larger sample sizes are needed for better certainty.

See next month's Dialog for information on other environmental factors such as exercise, pesticides, diet and trace minerals in soil and viruses, or visit the national website www.alsa.org.

Upcoming 2008 Events

Mark Your Calendars

Casino Night, Springfield - April 4, 2008

Night of Hope, KC - May 3, 2008

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

**Oasis Convention Center, Springfield MO
\$50 per person in advance, \$60 at the door
and \$500 for a table of 8**

For more information, contact Mindy Wallace at
417-886-5003 or mwallace@alsa-midwest.org.





**Keith Worthington
Chapter**

1978 30th 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 with the following information:

Name

Age

Date of diagnosis

Hobbies

A little about your family (spouse, kids, grandkids...)

How has ALS affected your life? (100 words or less)

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

Research Update from The ALS Association's National Office - Feb. 28, 2008 ⁴³

New ALS Gene Paves the Way for Better Understanding, New Treatments - By Richard Robinson, Science Writer

The discovery of a new gene that causes some forms of ALS will enable the development of new model systems to understand the disease and open the way for development of new treatments. The discovery, to be published today in the journal *Science*, links mutations in the TDP-43 gene to cases of both familial and sporadic ALS.

The research was led by Professor Christopher Shaw, M.D., at the Department of Clinical Neuroscience, King's College London, United Kingdom, in collaboration with Jemeen Sreedharan, MRCP and Vineeta Tripathi, Ph.D., Department of Clinical Neuroscience, King's College London, United Kingdom, and Ian Blair, Ph.D., and Garth Nicholson, Ph.D., Northcott Neuroscience Laboratory, ANZAC Research Institute, Concord, NSW, Australia.

These investigators have been funded by The ALS Association over the past years in their efforts to identify new genes linked to ALS.

"These exciting findings open up new avenues for ALS research, enabling us to develop new models for testing therapies. This is a much-needed resource for drug discovery in ALS, which has to date focused largely on mutations in superoxide dismutase 1," commented Lucie Bruijn, Ph.D., science director and vice president of The ALS Association.

TDP-43 (TAR DNA binding protein 43) has been previously identified (see previous article) as a major component of the "inclusions," or protein clumps, found in the motor neurons of ALS patients. Motor neurons die off in ALS. Until now, however, it was unknown whether TDP-43 contributed to the disease, or was an innocent bystander. The normal function of TDP-43 is unknown.

The researchers found single base changes (mutations) in the TDP-



gene (formally known as TARDBP) in 5 affected members of 1 family, versus none of the unaffected members. They also found mutations in 2 ALS patients with no family history of the disease (sporadic ALS). No mutations were found in 1,262 unaffected controls, or in 523 other ALS cases. In all, 3 mutations were found, all affecting one region of the protein. In the familial case, the mutation was inherited in an autosomal dominant fashion (1 mutant copy was sufficient to cause the disease).

The discovery confirms that in at least some cases of ALS, TDP-43 is playing a direct role in causing the disease.

When the researchers placed the mutant gene into chick embryos, they observed abnormalities in limb development and premature cell death, although the relation of these changes to the ALS disease process is still unclear. Further work to understand the protein's functions will lead to clues that will aid in therapy development.

"The identification of TARDBP gene mutations in ALS places TDP-43 at center stage as a potential cause of motor neuron degeneration. Critically, these mutations will give scientists around the world a new tool to explore the disease process and hopefully accelerate drug discovery," Dr. Shaw said.

A second study, published online by the journal *Annals of Neurology*, identifies TDP-43 mutations in another ALS family. TBP-43 was first found in ALS inclusions in 2006. While TBP-43 mutations appear to be a rare cause of ALS, their discovery should lead to a deeper understanding of the protein's role in the majority of ALS cases.

2008 Golf Tournaments



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 Michelle at (316) 612-0188



\$\$\$ Free Money! \$\$\$

That's right - The ALS Association Keith Worthington Chapter receives "free money" when those who make a contribution participate in their company's matching gift program. With this type of program, a company will match a certain percentage of their employee's gifts to charity. The amount of the "match" varies but can often mean that your gift amount will be doubled!

Here's how it works: You make a donation to the Chapter - the contribution can be in memory or honor of a loved one, for the Walk or just because you know that giving to the Chapter will help those affected by ALS. You will then want to check with your company (often the Human Resources department) to see if they have a matching gift program. If they do, they will give you very simple paperwork to complete. This

will be sent to the Chapter and we will verify your gift and return the form to the company. They will then send a check to the Chapter for the match amount. That's it! The process is easy and allows your single gift to turn into even more funds to support the Chapter's programs and services.

More and more companies are implementing this type of giving program so we encourage you to check to see if this is an option for you. Increasing the financial resources the Chapter receives will help all those dealing with ALS receive the support they need. If you have questions about the matching gifts program, please call the Chapter at 913-648-2062 for more information.

Somewhere Over the Rainbow

Night of Hope 2008

May 3, 2008

Overland Park Sheraton

Please join us in celebrating our 30 year anniversary by inaugurating two new awards to be presented at our annual Night of Hope. These awards are inspired by two major contributors to our community, Tom Watson and George Brett.



The Tom Watson Award for Courage

When Bruce Edwards, Tom Watson's caddie and friend for 30 years, was diagnosed with ALS, Tom witnessed first hand the courage it takes to face this disease. This year we are honoring Cyndi Starke, who is facing this disease with the same courage and who continues to support our mission by fundraising and being an inspiration to everyone she encounters.

The George Brett Award for Commitment

George Brett has been a part of our ALS community fighting this disease for over 30 years. His commitment is unsurpassed when it comes to fundraising and awareness. This year, we present the Honorable Jay Daugherty with this award because of his commitment as a part of our Keith Worthington Chapter Board of Directors as well as the National Board of Trustees.

For more information about attending the event,
please contact Laura at 913-648-2062 or lball@alsa-midwest.org



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	Nebraska	Central/Southwest Missouri	Wichita
Kristin Spence	Sherrie Hanneman	Mindy Wallace	Michelle Masood
(913) 648-2062	(402) 991-8788	(417) 886-5003	(316) 612-0188
kspence@alsa-midwest.org	shanneman@alsa-midwest.org	mwallace@alsa-midwest.org	cwachter@alsa-midwest.org

Symposiums Scheduled in April

Wichita

Help for Today ~ Hope for Tomorrow
Lunch and Learn

April McVey, MD, Director of The ALS Association Certified Center, Associate Professor of the Dept of Neurology and Associate Program Director of Neurology Residency at The University of Kansas Medical Center, will speak on:

ALS Symptom Management, Research and Drug Trials

Wednesday, April 29 - 12:00 noon
Grace Presbyterian Church
5002 E. Douglas
(Between Edgemoor and Oliver)

R.S.V.P. to the Wichita Office (316)612-0188
Jean or Kathy

R.S.V.P. needed for ordering lunches

Nebraska

Help for Today ~ Hope for Tomorrow
ALS Information for the Healthcare Professional

Vahid Taghavi, MD, Dept of Neurological Sciences, The University of Nebraska Medical Center, will speak on:

* Symptom Recognition, Diagnostic Criteria & Tools, Disease Management

Sharon Matland, RN MBA, VP of Patient Services with The ALS Association National Office will speak on:

* Research Updates & Breakthroughs, Clinic Trials & Results

Sally Dwyer, MA, BS Ed, Program Director with The Keith Worthington Chapter will speak on:

* Programs Available to People with ALS

Shannon Todd, MSW, MPA, Patient Services Coordinator, The Keith Worthington Chapter Nebraska Office will speak on:

* Local Programs & Available Resources for Patients in Nebraska.

Wednesday, April 23, 2008 - 8:00am to 11:15 am.
Fee is \$20 which includes Continuing Education Credits through UNMC College of Nursing.
For more information please contact:
Shannon Todd or Sherrie Hanneman at 402-991-8788

APRIL 2008

Programs & Services Update for FY09

(from the February 2008 report)

	In February 2008	Fiscal Year '09 to Date
New patients	8	8
Number of patients who have died	10	10
Consultations made by Service Coordinators	444	444
Number of clinics held	4	4
Patients attending clinic	24	24
Number of support group meetings	9	9
Patients attending support group meetings	14	14
Total number attending support group meetings	65	65
Number of equipment items on loan	391	391

(The Chapter's fiscal year runs from Feb to Jan of the following year. Fiscal year 2009 is Feb '08 - Jan '09.)

Call for email addresses!



Please send an email to Laura at lball@alsa-midwest.org with your name, home address and email address.
Email addresses will remain the sole property of the Keith Worthington Chapter.

In Memoriam

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

James Bolt	Mary Evelyn Jones
Jack Conrad	Howard Mangels
James Giesler	Shirley Smith
Melvin Hammeke	Dian Frank-Wilburn
Mary Lou BrownMary Allen	James Womelsdorf

Memorials

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

James Bolt
Jack Conrad
James Giesler
Melvin Hammeke
James Womelsdorf

EQUIPMENT EXCHANGE

ITEMS FOR SALE

VANS

1999 Ford Econoline Conversion Van. Has lift and many extras. 86,000 miles. \$10,500. Call Bruce at 402-291-1697.

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

2006 Toyota Van. Dark blue, excellent condition, only 1,700 miles with Braun Lift and Easy Lock tie-down system. Asking \$40,000. Call Wayne Ryherd at 620-365-5485 and leave message. All calls returned.

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

2007 Honda Odyssey. <7000 Miles. New May 07. Used only 6 months. Autoslide out ramp-VMI-Power all-TV's Stereo Navigation Ron 913-660-0587

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.

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

Hoveround power chair w/battery pack and charger. Excellent condition. \$1550. 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

PLATFORM LIFTS

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

MISCELLANEOUS

NEW DINAFOX MAX, blue Never used \$3000 Contact Susan Smith 816-943-9654.

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.

INVACARE HOSPITAL BED. Full electric hospital bed, 88" x 36". Split springs to ends. \$1,000. Call Eileen at 913-888-9998.

DYNAFOX SERIES 4. Less than 1 year old. Asking \$2,200. Call Daphne at 417-844-4814.

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.

DYNAFOX 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 Lafeyers 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

nlindquist@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

cwachter@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

Michelle Masood

mmasood@alsa-midwest.org

Jo Harris

jharris@alsa-midwest.org

Chapter Website

www.alsa-midwest.org

Walk Website

<http://walkkwc.alsa.org>

National Website

www.alsa.org

THE DIALOG

Keith Worthington Chapter
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Mission, KS 66202

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8 • THE DIALOG

April Support Group Dates

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

1	*Kansas City Evening <i>(Perri Cagle P.T. "Exercise Dos and Don'ts")</i>	7:00 p.m.
2	*Jefferson City	1:30 p.m.
2	Hutchinson	2:00 p.m.
3	Wichita	7:00 p.m.
8	*Omaha <i>(please note new location)</i>	6:30 p.m.
8	*Springfield	6:30 p.m.
11	*Kansas City Caregivers	12:30 p.m.
15	*Kansas City Men's	12:00 p.m.
16	*Kansas City Day (yoga)	1:30 p.m.
17	Salina	7:00 p.m.
18	Wichita Caregivers	11:00 a.m.
16	*Carl Junction	11:00 a.m.
24	Nebraska Phone Group	7:00 p.m.

APRIL 2008

Support Group Locations

Hutchinson, KS Grace Episcopal Church 20th & Main	KC Caregivers/Survivors ALSA Bldg - 2nd Floor Mtg Rm Please RSVP	Richmond, MO Call Lea 816-776-6007
Salina, KS Church of the Cross Methodist Corner of W. Claflin & Rush St.	KC Day (YOGA) ALSA Bldg - 2nd Floor Room	Jefferson City, MO Southridge Baptist Church 1815 Vieth Drive
Topeka, KS Shawnee Co. Public Library 1515 SW 10th Avenue * Meets every other month *	KC Men ALSA Bldg - 2nd Floor room Please RSVP * Meets every other month *	Springfield, MO Cox South Hospital Meeting Room #3
Wichita, KS Caregivers ALSA Office- 3450 N. Rock Rd, Bldg 200, Ste 211 No need to RSVP	KC Evening 2nd Presbyterian Church 55th and Oak	Carl Junction, MO Gambino's Pizza 1304 Pennell Street
Wichita, KS Grace Presbyterian Church 5002 East Douglas	Lawrence Bert Nash Comm Health Ctr 200 Maine St., 1st floor room * Meets every other month *	Omaha, NE Millard Library 13214 Westwood Lane
		Nebraska Phone Group 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