

## QUOTES REVISITED

Compiled by Sally Dwyer, Program Director

This year, as we recognize The Keith Worthington Chapter's 30th year of providing services to those with ALS, we have an opportunity to look back at the people, places, and events that make up the Chapter's history. What a perfect opportunity to do so through the words of people who have been on the journey.

Quotes from past issues of Dialog -- by individuals living with ALS, caregivers, family members, friends, Chapter staff, and volunteers -- reflect the spirit, courage, insight, determination, love and care that is so much a part of the ALS community.

Here is a small sampling along with a brief byline of who said them and the surrounding circumstances. Because we have 10 years of quotes, look for others in future issues and on our web site at [www.alsa-midwest.org](http://www.alsa-midwest.org).

One more thing -- if YOU have a story, please share it through this newsletter. Your story may inspire others!



*Standing still...  
is not an option.*

By: Jim Barb, Springfield Family Walk Chair, whose son, Eric, was living with ALS.  
From: We Can't Stand Still...We Must Walk to D'feet ALS (Sept. 2004)

*I hope I'm a pioneer for other women.*

By: Pamela Rayer, who is living with ALS in Wichita.  
From: A Pioneer for Disabled Women: One Woman's Fight with ALS and Medicare (May 2007)

*Some day I wish we could go back to  
turtle searches, basketball games...  
My grandpa's life will never be the same,  
nor will my time spent with him.*

By: Amy Barrett, age 13  
From: My Grandpa (Sept. 1999)

*Attitude  
goes a long way...*

By: Wayne Osterhout whose dad, brother and sister also lived with ALS.  
From: An "ALS" Family (Jul 2001)



continued on page 2

SEE PAGE 2 FOR DETAILS ON THIS YEAR'S HOLIDAY PARTIES!



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Continued from page 1



*After all, LIFE is a FATAL disease.*

By: Kerry Gray, who lived with ALS in Wichita  
From: Kerry Gray's ALS Update - Part II (Jan. 2005)

*There are moments of laughter, intimate conversations and discovery.*

By: Darlene Nikkel, who died of ALS in 1997  
From: The Mystery Trip, a 2-part story (Mar. 1998)

*"Job" doesn't really seem to define what I do.*

By: John Hill, Chapter Information Technologist  
From: Committed to the Cause (Feb. 2005)

*I grabbed his helpless hand and told him I loved him. That week I really got to know another side of my only brother.*

By: Jean Harrison, whose brother was diagnosed with ALS at age 55  
From: The Lilac Bush Bloomed (Oct. 1999)

*We are brain power, muscle and talent. We are the medicine the doctors don't have.*

By: Cary Marriott, who formed an ALS caretiver group for her sister  
From: Share the Care, November is National Family Caregiver Month (Oct/Nov. 2003)

*When you're dealt the joker you play it the best way you know how.*

By: Don Brockmoller of Ogallala NE who was diagnosed with ALS in 2000  
From: Facing Life's Challenges (Jul. 2002)

*James Warren Woodard, roller of great times, prince of clowns, champion of all things gentle and kind and above all most excellent of warriors, had had enough of the dragon.*

By: Wendell Woodard, brother of Jim Woodard  
From: Eulogy to James Warren Woodard (Nov. 1999)

*I never realized before how much I could take for granted. The little things never meant that much until I was the one doing them.*

By: Wendi Savage, age 18, who took care of her mother with ALS.  
From: The Day the Music Stopped and Reality Began (Sept. 1998)



OCTOBER 2008



*Mark your calendars now for your area holiday party and let it snow. . . . .*

- Kansas City** Tuesday, Dec. 2 at The Sylvester Powell Conference Center, 6:30 - 8:30 pm
- Springfield** Tuesday, Dec. 2 at Cox North Fountain Plaza Room, 6:30 pm
- Wichita** Thursday, Dec. 4 at St. Joseph Hospital, in the McNamara Room, 6:30 pm
- Jefferson City** Thursday, Dec. 4 at Southridge Baptist Church, 12:00 noon - 2:00 pm
- Omaha** Tuesday, Dec. 9 at The Regency Lodge., 6:30-8:00 pm



## RESEARCH NEWS FROM THE ALS ASSOCIATION

August 25, 2008

### The ALS Association to Support Trial of Lithium

By Richard Robinson

The ALS Association is funding a major clinical trial to determine if lithium can slow disease progression in patients in the early stages of ALS. The study builds on earlier promising results from preclinical research and a small, open-label investigation in ALS patients.

“Lithium has generated a lot of interest in the ALS community,” according to Lucie Bruijn, Ph.D., Senior Vice President, Research and Development of The ALS Association. “This trial is vital for testing the efficacy of lithium in a well-controlled way. It’s the crucial next step for investigating the potential of this drug.”

The trial is being supported through The Association’s TREAT ALS (Translational Research Advancing Therapies for ALS) initiative, and will use the TREAT ALS/NEALS Clinical Trials Network. Lead investigators for the study will be Merit Cudkowicz, M.D., and Swati Aggarwal, M.D., of Massachusetts General Hospital, Lorne Zinman, M.D., from the University of Toronto, Petra Kaufman, M.D., from Columbia University, and Jeremy Shefner, M.D., of SUNY Upstate Medical University.

In addition to The ALS Association, funding partners for the new study include the National Institutes of Health / National Institute of Neurological Disorders and Stroke and ALS Society of Canada. Investigators worked together with the funding agencies to design the most appropriate study within the shortest possible time frame. “Collaboration among researchers and funding agencies makes this trial possible,” Dr. Bruijn said. “All of us are working together to support this important research to find a new treatment for ALS.”

Lithium is a simple chemical substance approved for use in humans and prescribed as a mood stabilizer. Lithium protects neurons in the brain in animal models of neurodegenerative diseases, including Alzheimer’s disease and Parkinson’s disease, and has been recently shown to do the same in a mouse model of ALS. In that study, lithium prolonged survival and protected cells in both the brain and spinal cord. While the exact mechanism of lithium’s effect is unknown, researchers have proposed it promotes clearance of toxic protein accumulation.

A study in a small number of ALS patients compared lithium plus riluzole (an approved treatment for ALS) to riluzole alone. After 15 months, no deaths occurred in the

16 participants treated with lithium plus riluzole, while 29% of those taking riluzole alone had died. Patients on lithium also had a markedly lower decline in disease-related disability. However, the trial was limited by the small numbers of patients and the absence of a placebo treatment—both the patient and the doctor knew whether the patient was taking lithium or not, which may have influenced the response to treatment or interpretation of disability. Due to diagnostic and prognostic variability in persons showing symptoms of ALS, the small numbers in this study were not sufficient to know whether lithium was indeed an effective treatment. Many apparently effective treatments in open trials (trials lacking a concurrent placebo group) fail in larger double-blind trials, in which neither doctor nor patient knows whether the patient is receiving the study drug.



The new trial will be a double-blind, placebo-controlled trial with 84 patients, who will be randomized to either lithium or placebo. A review of data will occur after the 84th person is enrolled, and then a decision will be made on whether to expand to 250 patients.

Patients may be included if they are within three years of their diagnosis and are not already taking lithium. Treatment will be for up to one year. The disease course and safety assessments will be measured at regular intervals over that time. Further details including trial sites, enrollment criteria and start dates will follow shortly. “We formed a collaboration with Canadian and US sites to perform a study that will provide an answer quickly on whether lithium is effective in the treatment of ALS. The study is designed to answer this key question definitively and with appropriate monitoring of safety,” commented Merit Cudkowicz, M.D., one of the lead investigators on the study.

Denise Figlewicz, Ph.D., Director of Research at the ALS Society of Canada says, “We welcome this opportunity to support the lithium clinical trial. The promising results from the Italian study data serve as the impetus for new research and new treatment strategies. This is very exciting news for the ALS community. We also welcome this opportunity to work together with our American colleagues. This collaborative approach between Canada and the United States will serve as a model for subsequent clinical trials.”

For more information on ALS research, go to [www.alsa.org](http://www.alsa.org).

# OCTOBER 2008 WALKS TO DEFEAT ALS™

OCTOBER 2008



10/11/08	Wichita, KS	Lawrence Dumont Stadium
10/11/08	Lincoln, NE	Antelope Park
10/11/08	Richmond, MO	Richmond High School
10/12/08	Lawrence, KS	Student Union

## THE OMAHA WALK

Over 350 people celebrated the annual Walk to Defeat ALS™ in Omaha's Elmwood Park on Saturday August 23rd.

Special guests at the event included Carrot Top the Clown and Casey from the Omaha Royals Baseball team.



Top fundraisers for the event included Rob Freeman, top individual fundraiser, P Squared, top friends and family team, and MAC ATTACK, top corporate team.



## FUNDRAISERS COME IN SMALL PACKAGES!



Pat Tvrdik was a Major in the United States Army, serving his country in Iraq when he first noticed a twitching sensation in his shoulders and weakness in his arms. His condition worsened. When his tour was up he returned to his base in Germany where he got the news. On September 11, 2007, Pat Tvrdik was diagnosed with ALS.

Recently Pat and Pam Tvrdik received a letter from several of their young friends who wanted to do something special for Pat that would raise both awareness and funds for the Omaha Walk.

The kids decided on a lemonade stand where they gave away lemonade and animal crackers, told people about ALS and Pat, and then asked for a donation.

They raised \$172.50 that they donated to the P Squared Walk team's efforts.

\* \* \*



Big (above) registered for the Walk in May of 2008.

Through his Walk website he was able to raise \$60 for the Omaha Walk.

Big also was present to participate in the Walk as part of the Carin' for Sharon team.

# THE ALS ASSOCIATION RESEARCH GRANTS ARE ANNOUNCED

August 2008

Research grants by The ALS Association will support investigations of new disease models, pathogenesis of ALS, biomarkers of disease progression, and development of new treatments. The research portfolio supported by the Association is designed to speed therapy development by attacking ALS on all fronts, from basic research to clinical trials. Each year the Association funds the most promising research from hundreds of investigator-initiated proposals. In addition, it actively seeks researchers to undertake studies identified by the Association as critical for filling gaps in knowledge of ALS. The Association also gives the Milton Safenowitz post-doctoral fellowship award for ALS research to encourage young scientists to focus their research efforts on ALS.

Newly funded investigator-initiated research will study the following important questions:

Why do motor neurons die in ALS?

Why is mutant SOD1 toxic?

What can we learn from new animal models of ALS?

Can imaging be used to track disease progression?

How can transplanted motor neurons be optimized for therapy?

## IT'S A HOME RUN

*Leave A Legacy of Hope*



Make a gift to The ALS Association that pays you or your loved ones an income for life. The principal goes to The ALS Association later to create a **legacy of hope** for others.



For more information on how you can leave a legacy of hope, please contact our chapter office at (913) 648-2062 or e-mail [info@alsa-midwest.org](mailto:info@alsa-midwest.org)

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## JOIN THE ALS ASSOCIATION ADVOCATE TEAM

Speak out for those who have lost their voice.

Step up for those who can no longer walk.

Fight for those fighting ALS.

Join the fight against ALS today and help strike out this devastating disease.

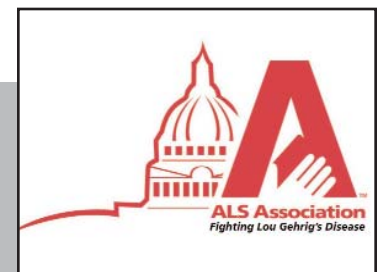
Become an ALS Advocate today!

ALS Advocates are empowered with information and tools to make a difference in the lives of those living with ALS. They are informed and prepared to reach out to their elected officials.

ALS Advocates receive legislative alerts via email, as well as federal and state updates on priority issues.

In joining with other ALS Advocates across the country, you too can help educate Congress about the urgent need to find a treatment and cure and show them why they should join our fight.

Sign-up (<http://www.alsa.org/policy>) to help us continue to light the way for a treatment and cure for ALS.





## JOIN A WORKPLACE GIVING PROGRAM

Workplace giving programs allow employees to direct a portion of their paychecks to a charitable organization.

Community Health Charities is a federation of health organizations working to improve the health and well-being for people right here in your own neighborhood.

When donations go to a member charity, it is used to provide patient services, education and medical research. These charities are connecting passions and creating hope for a healthy America.

Federal employees, members of the US Military and other government employees can direct donations through their respective employee charitable campaigns.

To find out if your workplace participates in an employee giving campaign or if your favorite health charity is part of Community Health Charities, go to [www.healthcharitiesksmo.org](http://www.healthcharitiesksmo.org).

Let's build that bridge of hope together and make this community a healthier place to live.

<b>Programs &amp; Services Update for FY09</b>	<b>In August</b>	<b>Fiscal Year</b>
(from the August 2008 report)	<b>2008</b>	<b>'09 to Date</b>
New patients	17	84
Number of patients who have died	13	64
Consultations made by Service Coordinators	382	3013
Number of clinics held	4	27
Patients attending clinic	31	208
Number of support group meetings	12	80
Patients attending support group meetings	28	165
Total number attending support group meetings	107	843

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

### IN MEMORIAM

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

- |                    |                  |                   |
|--------------------|------------------|-------------------|
| Robert Bischoff    | Herbert Hemmila  | Angie Smith       |
| Mary Jane Faessler | Cuma Jameson     | Mary Tunnell      |
| Henry Geeska       | Marvin Kriley    | Sydney Uhr        |
| Deborah Gregg      | Mabel Ortiz      | Beulah Woodmansee |
|                    | Marge Plagmann   |                   |
|                    | Eugene Schlabach |                   |

### MEMORIALS

Thank you to the families of the following for designating designating The Keith Worthington Chapter for donations:

- Mary Jane Faessler
- Herbert Hemmila
- Deborah Gregg
- Mary Tunnell

## EQUIPMENT EXCHANGE

## ITEMS FOR SALE

## VANS

**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

**2005 Pontiac Montana Van,** fully loaded, 7000 mi, \$35,000 or best offer, Dolly Humes (417)781-2506 H or (417)529-0785

**2004 Chev Venture-rampvan,** 101k mi but excel mech and appear, top notch condition all svc records, \$19,000 or best offer call (316)729-8815  
2004 chev van, Braun conversion, all maint records, 102k miles but excel appearance and condition in and out, \$16000 or best offer. 316-729-8815

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

**Chrysler Town & Country, 2001,** 65,000 miles. Comes with Bruno transfer chair installed. New tires. Light blue. \$10,000. Call 1-417-683-6854 or 1-417-880-4161. Ava, MO area.

**'2000 Dodge Grand Caravan.** Lower conversion, auto ramp and door, tie downs, p-windows and door locks, cruise, tilt, cold air, Beautiful condition. Call (913)205-2848. \$14750

**2000 Chrysler Town & Country.** One owner Lower conversion, auto ramp and door, tie downs, Beautiful condition. Call (913)205-2848. \$14750

1999 Plymouth Voyager Rampvan with EZ lock for front passenger. 76,200 miles. \$11,500. Call Lisa (913)397-8180.

**'98 Town and Country Handicap Conversion Van.** 40,000 miles. New Battery. \$14,000. Alice Zavcek Alice.B.Zvacek@usace.army.mil

**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).

## WHEELCHAIRS

**Permobil C300 Wheelchair** with Gelseat, tilt/recline, legs raise, height adusts, <1 year old. \$5000. Contact Don Green at (417)781-8262 (work)

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

**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.

**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 w/ legs up. Call Pam Garcia or (402)917-6478

**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 \$2,300.00. Used only a few times. Call:Mrs. J. J. Wyatt (316) 207-8186 or Pamela Rayer (316) 721-0939.

**Invacare Pronto Sure Step Wheelchair.** \$1000. Contact Don Green at (417)781-8262 (work)

Wheelchair, Permobil, new 1/2008. pwr with multiple speeds and elect display/joystick, aircushion seat, pwr tilt,relaine, and legrest, best offer. 316-729-8815

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

**Electric Wheelchair,** Permobil, Tilt, recline, RoHo seat, red. Needs batteries. Call Cherri at 1-417-658-6858. Neosho, MO area.

## PLATFORM LIFTS

Access Industries Vertical Platform Wheelchair Lift, Model PL-RA 36, 550 lb. capacity, 36"x54" platform, used in garage, excellent condition. \$2250, (402) 490-0799. Omaha area.

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

## MISCELLANEOUS

**NEW DINAVOX MAX,** blue Never used \$3000 Contact Susan Smith (816) 943-9654.

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

**SCOOTER,** Pride Shuttle Mobility Scooter, 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, grea t condition. \$550. Call Melvin at (913)498-3129.

**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.

**FULL ELECTRIC HOSPITAL BED.** 88'X 36'. Asking \$800. Call Donna at (620) 232-2357.

**Dynovox V,** complete with mini-mdia keyboard, typewriter keyboard, mouse, User & Resource Manuals, Purchased 11/07, used under 2 mos. Asking \$3,000. Call Connie at 816-233-8903.

INCLUSION IN DIALOG IS NOT AN  
ENDORSEMENT OF THESE PRODUCTS.

## CONTACT INFORMATION

## Directors

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Walk Website  
http://walkkwc.alsa.org

National Website  
www.alsa.org

# THE DIALOG

Keith Worthington Chapter  
6950 Squibb Road, Suite 210  
Mission, KS 66202

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### OCTOBER SUPPORT GROUP DATES

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

OCTOBER 2008	2	JEFFERSON CITY	1:30 P.M.
	2	HUTCHINSON	2:00 P.M.
	2	WICHITA	7:00 P.M.
	7	*KANSAS CITY EVENING (CARE OF THE PATIENT & CAREGIVER -TURNING POINT)	7:00 PM.
	10	*KANSAS CITY CAREGIVERS	12:30 P.M.
	14	*OMAHA	6:30 P.M.
	14	SPRINGFIELD	6:30 P.M.
	15	*KANSAS CITY YOGA	1:30 P.M.
	16	SALINA	7:00 P.M.
	18	WICHITA CAREGIVERS	11:00 A.M.
	23	*CARL JUNCTION	11:00 A.M.
	23	NEBRASKA PHONE GROUP	7:00 P.M.
	27	TOPEKA	4:00 P.M.

### SUPPORT GROUP LOCATIONS

<p><b>Hutchinson, KS</b> Grace Episcopal Church 20th &amp; Main</p> <p><b>Salina, KS</b> Church of the Cross Methodist Corner of W. Claflin &amp; Rush St.</p> <p><b>Topeka, KS</b> Shawnee Co. Public Library 1515 SW 10th Avenue * Meets every other month</p> <p><b>Wichita, KS Caregivers</b> ALSA Office- 3450 N. Rock Rd, Bldg 200, Ste 211 <b>No need to RSVP</b></p> <p><b>Wichita, KS</b> Grace Presbyterian Church 5002 East Douglas</p>	<p><b>KC Caregivers/Survivors</b> ALSA Bldg - 2nd Floor Mtg Rm <b>Please RSVP</b></p> <p><b>KC Day (YOGA)</b> ALSA Bldg - 2nd Floor Room</p> <p><b>KC Men</b> ALSA Bldg - 2nd Floor room <b>Please RSVP</b> * Meets every other month</p> <p><b>KC Evening</b> 2nd Presbyterian Church 55th and Oak</p> <p><b>Richmond, MO</b> Call Lea 816-776-6007</p>	<p><b>Jefferson City, MO</b> Southridge Baptist Church 1815 Vieth Drive</p> <p><b>Springfield, MO</b> Cox South Hospital Meeting Room #3</p> <p><b>Carl Junction, MO</b> Gambino's Pizza 1304 Pennell Street</p> <p><b>Omaha, NE</b> Millard Library 13214 Westwood Lane</p> <p><b>Nebraska Phone Group</b> Call Shannon 866-762-6361</p>
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THE KEITH W ORTHINGTON CHAPTER HAS OFFICES IN THE FOLLOWING CITIES :

<b>KANSAS CITY</b> (800) 878-2062	<b>NEBRASKA</b> (866) 762-6361	<b>SPRINGFIELD</b> (888) 386-1200	<b>WICHITA</b> (800) 553-9056
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