

# Helping to Defeat ALS



Kansas City Walk

**Everyday** hundreds of individuals battle ALS with the support of their caregivers, families and friends.

**Every fall** they join together in the **Walk to D'Feet ALS** - an event that celebrates their courage and honors their spirit.

They walk in **Omaha**.

They walk in **Salina, Emporia, Hays** and **Manhattan**.

They walk in **Springfield, Wichita** and **Kansas City**.

They walk rain or shine, wheelchairs and strollers, teams and individuals.



Emporia Walk



Springfield Walk



Wichita Walk



Manhattan Walk



Hays Walk



Omaha Walk

*Continued on page 2*



Save the date for  
**A Night of Hope Goes Broadway**  
Friday, April 4<sup>th</sup>, 2003 at the new Sheraton Overland Park Hotel  
You won't want to miss it!



## T H A N K S !

A big thank you to all of the teams that participated in the  
Walk to D'Feet ALS and a round of applause to the  
2002 Walk To D'Feet ALS Top 25 Fundraising Teams:

1	Barbs Bunch	\$9,594.00	Kansas City
2	Annies Army	\$8,652.00	Kansas City
3	Lee's Dream Team 2	\$7,905.00	Wichita
4	Landman	\$7,839.00	Kansas City
5	Golson's Greyhounds	\$6,658.00	Kansas City
6	Help Bob Strike Out ALS	\$6,625.00	Wichita
7	Team McClouds	\$6,431.00	Emporia
8	Spiegel Family	\$5,980.01	Manhattan
9	Fox Fighters for ALS	\$5,581.00	Kansas City
10	Catron's Caddies	\$4,806.00	Springfield
11	Eddie's Entourage	\$4,444.00	Wichita
12	McCarville Team	\$4,322.00	Nebraska
13	Hays Internal Medicine	\$3,970.00	Hays
14	Friends of Jim Woodard	\$3,915.00	Kansas City
15	Mill's Memories	\$3,771.00	Springfield
16	Walkin for Forrest	\$3,697.00	Kansas City
17	Doug's Dirty Dozen	\$3,695.00	Hays
18	Horizon National Bank	\$3,661.00	Kansas City
19	Younglove Team	\$3,627.00	Nebraska
20	Pam's Prize Fighters	\$3,475.00	Wichita
21	Al's Conco Construction	\$3,465.00	Wichita
22	Casey's Crazy Crew	\$3,380.00	Springfield
23	Madelyns Herd of Turtles	\$3,216.35	Manhattan
24	Harrys Heroes	\$3,213.00	Kansas City
25	Mogul's for Mary Kay	\$3,201.00	Wichita

### Plans for Our 2003 Events are Underway!

Watch for details on the web site ([www.alsa-midwest.org](http://www.alsa-midwest.org))  
and in future issues of the Dialog.

Sponsorship opportunities are available for the following events:

- ◆ **Night of Hope Goes Broadway** - Kansas City
- ◆ **Golf Tournaments** - Kansas City, Wichita, Omaha
- ◆ **ALS Survivor Challenge** - Springfield
- ◆ **Walk to D'Feet ALS** - Kansas City, Springfield (MO), Omaha (NE), Hays, Salina, Emporia, Manhattan, Wichita (KS) and new next year in Topeka, Liberal (KS), Columbus and Grand Island (NE)

## Advocacy Update - From ALSA's Washington Office

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Thanks to the efforts of our ALSA Advocates advocating to their Members of Congress, I am pleased to announce that the United States Senate and House of Representatives approved funding for ALS specific research through the fiscal year 2003 Department of Defense (DOD) Appropriations Bill. This research funding, which was finally approved late last week, will be included in a Defense Health Program called the Peer Reviewed Medical Research Program (PRMRP). ALS, for the very first time, is one of 27 diseases that will be funded through this \$50 million program.

As we wait for President Bush to sign this funding bill, we will compile a comprehensive list of our supporters in the United States Congress to thank. It is very important for all advocates to personally thank their Member of Congress for this new research funding. This research funding will be in addition to the funds which will be allocated through the National Institutes of Health. For a sample appreciation letter, please e-mail Ted Burnes, Director of National Advocacy Outreach, at [ted@alsa-national.org](mailto:ted@alsa-national.org). Please also share your communications with the Advocacy Department so we, too, can show our gratitude and compile an accurate list.

As many of you know, the Advocacy Department's top priority for this Second Session of the 107th Congress over the past ten months has been that of securing ALS specific research funding through the fiscal year 2003 DOD appropriations process. It is our hope that this funding through the PRMRP will focus on helping researchers better understand how environmental factors may be involved in ALS.

Through the work of our 600 advocates who came to Washington, D.C., on National ALS Advocacy Day last May, the Senate included ALS as one of their 43 different diseases to be funded. However, ALS was not included in the House DOD Appropriations Bill. Due to the strategic advocacy of our increasing network of ALSA Advocates, the House/Senate Conference Committee kept ALS as one of their priorities. This was a huge accomplishment since the conference committee cut 24 diseases and added eight other diseases.

The Advocacy Department, as well as ALSA's Research and Patient Services Departments, will work with the Department of Defense and Members of Congress to ensure as many dollars as possible will be allocated toward ALS specific research. We will also let you know when more details become available.

In order to get up-to-date information about our advocacy program and for more information on how to get involved, you can go to The ALS Association's Advocacy Department web page at: [http://www.alsa.org/serving/adv\\_update.cfm](http://www.alsa.org/serving/adv_update.cfm). You can also contact Ted Burnes, Director of National Advocacy Outreach, toll-free at: 877/444-2572 or via e-mail at: [ted@alsa-national.org](mailto:ted@alsa-national.org).

## Research Update - From ALSA

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### *The Lou Gehrig Challenge: Cure ALS* The Treatment of Familial Amyotrophic Lateral Sclerosis

Don W. Cleveland, PhD, Ludwig Institute for Cancer Research, University of California San Diego

An exciting new project began November 1, 2002, as part of the Lou Gehrig Challenge Initiative. Dr. Don Cleveland together with co-investigator Dr. Richard Smith propose to use a therapeutic approach to reduce levels of mutant Cu/Zn superoxide dismutase (SOD1). Since the discovery of mutations in Cu/Zn SOD1, accounting for 2% of amyotrophic lateral sclerosis (ALS), investigators have focused on how these mutations lead to toxicity and cell death. Although this remains unclear and currently several hypotheses are being proposed, there is substantial evidence that whatever the toxic property, lowering the levels of mutant protein is likely to prolong survival. Evidence for this comes from several lines of transgenic mice carrying different SOD1 mutations. In those mice expressing low levels of mutant SOD1, onset of disease is delayed and some lines of mice, expressing mutant SOD1 to levels less than 20% of endogenous mouse SOD1, do not develop disease.

Drs. Cleveland and Smith will attempt to down-regulate (reduce) the production of mutant SOD1 in a rat model of ALS to determine 1) whether one can lower levels of SOD1 and 2) whether reduction of SOD1 leads to increased survival. Once it has been demonstrated that SOD1 levels can be lowered using this approach, this effort will be expanded to produce quality reagents that can go into toxicity testing and ultimately into clinical trials. Lowering levels of SOD1 is unlikely to have adverse effects as demonstrated by a mouse model in which 50% reduction of normal SOD1 does not lead to any abnormalities.

### WICHITA SUPPORT GROUP NEWS

The Wichita support group met Thursday, November 7<sup>th</sup> at the Grace Presbyterian Church with 16 patients and family members attending. Chris Wells, Registered Dietician from the Via Christi System, St. Francis Hospital, discussed nutrition and its impact on ALS. She focused on the importance of protein stores and maintaining them in the face of the 10% increase in metabolism that is caused by the ALS process. She shared many interesting recipes and references regarding increased caloric intake without increasing volume of foodstuff consumed - very important when it becomes more difficult to eat and chew. Dysphagia and malnourishment were pointed out as problem areas to overcome. There was also a short presentation by Dennis Black of Respiroics, Inc. on the Coughlator and its benefits to assist the pulmonary toileting of the advanced ALS patient. He answered many inquiries and distributed literature, offering to make personal presentations to anyone's physician desiring it.

All patients, family and supportive friends have been invited to attend our Holiday FestivALS which will be held in the place of the Hutchinson and Wichita Support Groups for December. It will take place in the MacNamara Room (3<sup>rd</sup> floor) of Via-Christi St. Joseph Campus, Wichita. The dinner will be catered and will begin at 6 pm, December 5<sup>th</sup>. We are hoping for a festive crowd. You are encouraged to call in a rough estimate of the number in your party so we have enough turkeys in the pot! The monthly Caregiver Support Luncheon will still take place on Saturday, December 21<sup>st</sup> from 12 - 3 pm.

### WICHITA CAREGIVERS SUPPORT GROUP NEWS

Our next caregiver support luncheon will take place on Saturday, December 21<sup>st</sup> in the Church Parlor from 12 - 3 pm at the Grace Presbyterian Church, Wichita. Bring a dish to pass, but if your plans are last minute and that is an inconvenience, please come anyway, there is always a ton of extra food!

### HUTCHINSON SUPPORT GROUP NEWS

The Hutchinson support group met on Wednesday, November 6<sup>th</sup> the Grace Episcopal Church. There were 9 in attendance. The program was a demonstration of the Coughlator by Dennis Black from Respiroics, Inc. of Kansas City, Missouri. He pointed out the benefits of utilizing the Cough Assist during the cold and flu season when it becomes increasingly difficult to mobilize secretions in the ALS patient who has bulbar involvement. It is encouraging that Medicare has quadrupled their re-imbusement charges so the patient and patient's family is responsible for only a moderate amount during the 15 month rental period. The meeting was adjourned to a social gathering and discussion around punch and cookies.

### SPRINGFIELD SUPPORT GROUP NEWS

The Springfield support group was held on Tuesday, October 15<sup>th</sup>. It was attended by 17 people. The speaker was Barb Stock. She is a retired nurse that volunteers for the organization Community Alliance for Compassionate Care at the End of Life. She spoke to the group regarding Advanced Directives and end of life issues.

### KANSAS CITY CAREGIVERS SUPPORT GROUP NEWS

In honor of National Caregivers Month, the format for the November caregivers support group was changed. There was a four member panel of past caregivers, consisting of Roger Hime, who lost his wife Gin; Bill Byington (wife Patty); Emily Golson (husband John), and Reid Buturlia (wife Julia), who delivered heartfelt stories regarding all aspects of care for their lost loved ones.

We had a large group of 30 for our seminar and lunch, who listened avidly to the varied discussions pertaining to how they personally handled issues about feeding tubes, ventilation, needed equipment (and when to get it), hiring of caregivers when necessary, advanced directives, anger management, mobility, and how to address each step of the progression of the disease. These individuals shared how to incorporate friends and family into the caregiving circle: getting help with meals, bathing, respite care, shopping, chores and just basic much needed emotional support. All aspects of cost, insurance, medicaid, state programs, hospice, and end of life issues were shared freely.

They couldn't stress these wise tips enough: 1) Accept help. 2) Take time for yourself. 3) Don't spend needless energy feeling guilty about those things we have no control over. 4) Do advanced directives as soon as possible. 5) Plan ahead and be pro-active. and 6) Utilize every resource you can to help yourself and your ALS loved ones; network, and investigate support groups. And last, but certainly not least, recognize that we are all human; we will be shocked, saddened, angry, depressed, stressed, tired, and frightened at one time or another; and that is all OK, natural and normal for the journey we are on. But what we can't do! Must not do! Is give up on faith, hope, humor, love and HOPE again! It was a rewarding and informative day for all. Thanks to the panel for their unselfish, wise and caring effort!

### KANSAS CITY SUPPORT GROUP NEWS

Barbara Loveless, Nutritionist, was the speaker for the November KC Night Support Group, which had about 40 people in attendance. Discussion included ways to "boost" calories and protein for patients, whether they had a feeding tube or not, to enhance optimum dietary benefit. Thickeners, specific brand products, recipes, proper positioning, assistive devices for meals, and types of diet were evaluated and information given. Barb, who lost her husband to ALS 7 years ago, was also helpful discussing personal difficulties she encountered, and she shared those as well. There will be no December support group, but we will have a Holiday and Volunteer Recognition Party on Dec. 4<sup>th</sup> from 6:30 to 8:30 pm at the St. Joseph Hospital Community Center, food and entertainment to be included.

## Clinical Update - From ALSA

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The ALS Association (ALSA) has received a number of questions concerning, and requests for more information about, nutritional supplements purported to be beneficial for people with ALS. Recently we have been asked about a substance called Luteolin. Before deciding to take Luteolin or using any other health product, ALSA encourages people with ALS to consult with their health care professional.

Upon first hearing about Luteolin, ALSA representatives talked with individuals who have marketed the product and individuals who have done research with the product. From these efforts, and independent reference review, we have made the following observations:

- Luteolin is a flavonoid (natural product found in many plants).
- Several potential functions have been ascribed to this compound including anti-oxidant activities, anti-inflammatory activities and anti-diabetic actions. How it may play a role in ALS is unknown.
- The ALS Association is not aware of any data supporting the safety and efficacy of Luteolin in ALS.
- To our knowledge there have not been any scientific publications or presentations on the use of Luteolin in ALS.
- Some patients have reported a lessening of symptoms and improvement in physical status, however no patient data has been presented to ALSA and clinicians from ALS Centers have not reported these same results.
- There is no scientific data to support the benefit of Luteolin for people with ALS, however there is a small animal trial in process using Luteolin. Results from this research are not yet available.

The ALS Association is supportive of clinical trials with Luteolin and any other compound where there is scientific rationale for efficacy in ALS. Without the "gold standard" of clinical studies, no valid conclusions about any compound's usefulness and safety for a population of patients can be made. Ideas for ALS therapeutics are taken very seriously and the clinicians and scientists are always strongly encouraged to conduct clinical trials as soon as possible to evaluate safety and benefit.

Many people with ALS choose to take a number of nutritional supplements. When evaluating medications, treatments or nutritional supplements, it is important to be well informed in order to make educated health care decisions. It is also important to have accurate expectations about what effects the nutritional supplement may have - especially when claims are made for specific diseases. Some of the characteristics to look for and questions to ask when evaluating any potential treatment include:

- Do the claims rely on personal testimonials and not research published in a reputable medical or scientific journal?
- Is there a claim that the treatment "does it all" or "does it quickly"?
- Check the credentials of the company and individuals promoting the treatment.
- Evaluate the burden of costs or travel required.
- Reputable clinical trials do not charge patients to participate in studies.
- Ask about your rights to legal action if you are harmed by the treatment. Evaluate any consent you are asked to sign.
- Ask your health care professional to review the product and advise you.

For more information, visit ALSA's web site at [www.alsa.org/serving/careful\\_user.cfm](http://www.alsa.org/serving/careful_user.cfm)

Some patients have also had questions about nutrition and dietary recommendations for ALS in relation to dietary supplements. ALSA looks to medical and nutrition experts in the ALS community for the current clinical practice and recommendations. The ALSA publication, *Maintaining Good Nutrition with ALS*, is available free-of-charge and provides information about diet and ALS. It is available by calling ALSA's toll-free number at (800) 782-4747 or it can be ordered through ALSA's web site at [www.alsa.org](http://www.alsa.org).

ALS clinicians suggest a well-balanced diet including carbohydrates, proteins and fats along with adequate hydration. Diets that restrict any of these or recommend the exclusion of any of these nutrient groups should be discussed carefully with your ALS clinician. Although proteins are certainly important for muscles and nerves, too much protein in the diet can lead to serious kidney problems. It is important for patients with ALS to try and maintain weight and keep well nourished so that muscles are not broken down as a source of energy.

For more information about your individual dietary needs, contact your ALS clinician.

**2002 NOBEL PRIZE RECIPIENT  
H. ROBERT HORVITZ  
RECEIVED RESEARCH FUNDING FROM  
THE GEORGE BRETT ALS RESEARCH FUND**

H. Robert Horvitz, PhD, Massachusetts Institute of Technology, is one of three researchers to be awarded the 2002 Nobel Prize in Physiology and Medicine. His research linking familial ALS to the mutant SOD1 gene in the early 1990s was funded by the George Brett Research Fund of The ALS Association Keith Worthington Chapter.

The Chapter has been funding research and providing services to patients and caregivers since the mid 1980's. Robert J. Bjorseth, now Chairman of The ALS Association, served as the Chapter President from 1990 to 1993. During Bjorseth's tenure, the Chapter established the George Brett Research Fund which funded the research for which Dr. Horvitz is being recognized.

As Nobel Laureates, Sydney Brenner, John Suiston and Horvitz are being recognized for their discoveries (developing and using the round worm, *c. elegans* as an experimental model) concerning "genetic regulation of organ development and programmed cell death." Their findings have enhanced researchers' understanding of the role of programmed cell death (apoptosis) in the disease mechanisms of neurodegenerative diseases including ALS as well as in other diseases such as AIDS, cancer, stroke and heart attack.

Horvitz has been involved in ALS research for many years using the round worm, *C. elegans* as an experimental model. He is renowned for his work in human molecular genetics, with focus on the neurodegenerative disease amyotrophic lateral sclerosis. Horvitz is a past member and chair of The ALS Association's Scientific Review Committee. Currently, he is a member of ALSA's Cure ALS Advisory Committee that guides the Lou Gehrig Challenge:Cure ALS research initiative.

He was a member of the team that included Bob Brown, Teepu Siddique and David Patterson, et al, who linked familial ALS to the mutant SOD1 gene in the early 1990s. In an overview about Horvitz on the MIT web site, he states: "In collaboration with others, we showed that one gene responsible for the inherited form of amyotrophic lateral sclerosis (ALS or Lou Gehrig's disease) encodes the enzyme Cu/Zn superoxide dismutase (SOD), which catalyzes the conversion of the free radical superoxide to hydrogen peroxide. We are now seeking other genes responsible for ALS and studying *C. elegans* models of ALS and of other human genetic neurologic and/or aging disorders..."

He has organized and led ALSA Scientific Workshops including one on "Superoxide Dismutase and Motor Neuron Disease", and participated in other ALSA funded workshops focusing on cellular biology of the motor neuron, free radicals and programmed cell death.

The ALS Association and the Keith Worthington Chapter are indeed proud to have Robert Horvitz, a Nobel Laureate, as a longtime participant and leader in ALSA's research program.



**Happy Holidays!**

-The ALS Association

## Assistive Communication Software

A communication software CD, created by the Chapter with permission from the companies listed below, is available to ALS patients in Kansas, Nebraska, and Central Western Missouri at no charge.

### The CD Contains the Following:

1. ReadPlease 2002 (text-to-speech)
  - MoneyTree Software
2. Click-N-Type (on-screen keyboard)
  - Lake Software
3. Point-N-Click (virtual mouse)
  - Polital Enterprises

The 3 separate software programs may be installed on a computer and used as needed. The Chapter has included instructions and additional instructions are provided with each program.

This combination of software provides a much less expensive option for individuals to communicate using a computer with a sound card.

For more information, please contact your Patient Services Coordinator.



## Bring Joy to Those with ALS in Long Term Residential Care Facilities By Sending a Holiday Greeting

Dorothy Barth (593)  
Mission Springs Assisted Living  
5350 W. 61st Place Apt. 316  
Shawnee Mission, KS 66205

Robert Holmberg (48790)  
MO Veteran's Home  
600 N. Main  
Mt. Vernon, MO 65712

Clarice "Kay" Nichols (14169)  
Presbyterian Manor  
4712 SW. 6th, Apt. 306  
Topeka, KS 66606

Don Brower (55294)  
Willow Care  
P.O. Box 309  
Willow Springs, MO 65793



Edna Leslie (11464)  
Good Samaritan Nursing Home  
2160 Zinnia Lane, B-22  
Liberal, KS 67901

Shirley Otten (57203)  
Colonial Manor  
3207 220th Trail  
Amana, IA 52203



Harold Bruce (1206)  
Medical Lodge  
915 S. Horton St.  
Ft. Scott, KS 66701

Emma Jane Lowry (43622)  
Sandpiper Bay Health  
Care Center  
5808 W 8th St.  
Wichita, KS 67212



Charlene Parker (39436)  
Presbyterian Manor  
4712 SW. 6th Ave. #553  
Topeka, KS 66606

Dale Burns (44584)  
Ottawa Retirement Village  
1100 W. 15th St.  
Ottawa, KS 66067



Gary McCullough (56311)  
Good Samaritan Nursing Home  
22160 Zinnia Lane  
Liberal, KS 67901

Earl Porter (66173)  
Heatherwood Estates  
614 S. 8th St.  
Independence, KS 67301



Joan Cox (1846)  
HIS of Kansas City at  
Alpine North  
4700 Cliffview Drive  
Kansas City, MO 64150



Clemens Mann (42648)  
Blue River Care Center  
10425 Chestnut Ave., Room 409  
Kansas City, MO 64137

Earl Sanders (47336)  
Windsor Estates  
623 S 3rd St.  
Salina, KS 67401



Philip Graves (67249)  
Woodbine Nursing Home  
2900 Kendallwood Pkwy, 102-B  
Gladstone, MO 64119

James Mason (66882)  
Tabitha Health Care Services  
4720 Randolph St.  
Lincoln, NE 68510



Carl Walker (44498)  
Manor Nursing Home  
614 S. 8th St.  
Independence, KS 67301



## Resources

### Onmind

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Onmind is a national registry of psychological health care professionals.

As a member of Onmind, you have access to a wide range of high quality, affordable and confidential psychological health care services and treatments. These are available on line or through our toll-free number; you simply enter a zip code and select the therapeutic specialty desired to receive a listing of Onmind psychological health care professionals.

Onmind never sees your records; privacy is maintained between you and your therapist. All psychological health care professionals are licensed or certified by their state licensing boards or national professional associations. Only Onmind members benefit from its discounted fee structure based on the education and licensure of the therapist.

To contact and learn more about Onmind:

- Internet: [www.onmind.info](http://www.onmind.info)
- E-mail: [memberservices@onmind.info](mailto:memberservices@onmind.info)
- Toll free: 1-866-2onmind (1-866-266-6463)
- Fax: 1-816-412-7599

### Turning Point

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Turning Point, a new organization serving the Kansas City metro area, provides emotional and social support and educational opportunities to entire families living with serious or chronic illness.

Turning Point helps individuals who are ill understand, prepare for and respond to the physical, emotional and psychological changes brought on by illness. With lessons in coping, families can optimize not only their living with the disease, but also their relationships with each other.



TURNING POINT

Turning Point helps children with ill family members. Age appropriate activities-including art, music, relaxation, and play therapy-help kids understand and deal with the illness.

For more information on their programs and services, call Turning Point at (816)753-3075.

### Information on Stem Cells

ALSA's web site is now featuring a spotlight on stem cells, entitled "A Primer on Stem Cells". For everything you ever wanted to know about stem cells, click on [http://alsa.org/research/stem\\_cells.cfm](http://alsa.org/research/stem_cells.cfm) and you'll be directed to the article.

### Living with ALS

We are looking for "Living with ALS" articles from all over our service area for upcoming issues of the Dialog. Please send articles to:

**The ALS Association - Keith Worthington Chapter**  
8340 Mission Road, Suite B-4 • Prairie Village, KS 66206

Or email your articles to Suzanne Frye at [sfrye@alsa-midwest.org](mailto:sfrye@alsa-midwest.org).

# FOR SALE

## VANS

1989 Dodge Caravan 61K handicap equipped with rear entry ramp and hand driving controls, \$5,500 or best offer. Call 913-782-6756.

1989 Ford Van Club Wagon E150 raised roof & side door, wheelchair lift, V8, auto transmission, power windows & door locks, front & rear A/C needs charged, tinted windows, blue & white. 24,600 miles, asking \$5000. Email Jerry @ jw231@earthlink.net or call 913-856-9931.

1992 Dodge Conversion Van power locks and windows, Ricon lift, 10,500 miles. Call Pat @ 816-567-4200.

1992 Dodge IMS Wheelchair Van with side entry ramp and hand controls, 139,000 miles, new starter and muffler, runs great, looks good, \$7500. Call 402-721-3640.

1993 Ford Econoline Mark III Van raised roof, lift on side, 74,700 miles. Great condition asking \$11,500. Call Angela @ 620-763-2621.

1996 Ford Aerostar 104,000 miles, paperwork for all maintenance provided, Bruno, rear chairlift. Price negotiable. Email jerryd@aol.com or call 816-421-7545.

1997 Ford Pinnacle Motor Home Ford F53 Chassi V8 7.5 liter gas engine, double rear end axle, new batteries, good generator, 22,250 miles, 33 ft. long. Blue interior with queen size bed. Call Chuck after 6 p.m. @ 785-459-2281.

1999 Dodge Conversion Van RAM 1500, w/ wheelchair lift and lock. 11,000 miles, perfect and loaded. Appointment only, 913-469-4188.

## WHEELCHAIRS

Invacare All Electric, Tilt Wheelchair red with removable ventilator shelf, lap tray, battery included, roho cushion. Best offer call 918-337-3577.

2002 Ranger X Electric Tilt Wheelchair joystick control, several speeds, neck support, carrier on back, barely used. Owner's manual included. Call 712-527-5475.

Invacare Manual Wheelchair black with roho cushion, barely used, \$300. Call 918-331-3577.

Invacare Power Rolls Arrow Xt joy stick, indoor/outdoor modes, deluxe padded automotive style seat with pivot arms for easy transfer, battery charger included. Excellent condition. Best offer, Jefferson City Area. Call 573-636-2550 or email sjsiebold@mchsi.com.

Quantum Jazzy 1400 Power Wheelchair 4 months old, great condition. \$3,000 or best offer. Call 417-865-2911.

Bruno Power Chair - PWC 2300 350 pound weight capacity, drop down controller, long trailing arm suspension, carry-along charger, 90 degree swivel seat and adjustable armrests, security key lock system, tote pouch, curb climbing height: 1:25", turning radius: 22", speed up range up to 3.5 mph. Operators manual included purchased new for \$6,000.00, used for only 3 month months. Asking \$4,000.00, contact Jeff Blair at 402-614-5516.

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

1998 Elecetric Wheelchair Invacare Action Ranger II Storm Series loaded with gel 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).

Ranger II Storm Series Electric Wheelchair brand new, never used, loaded operation & maintenance manual, 2 batteries & charger. Paid \$18,256, asking \$12,000 or best offer. Call Loretta @ 816-370-2375.

2002 Pride Jazzy 1122 2 remotes, onboard battery charger, lifting leg rests & head rest. Owner's manual included. Asking \$2800 of best offer. Call Linda @ 402-734-2901 or 402-280-4024.

2002 Jazzy 1113 Sip & Puff Power Chair tilt back control, red. Never used. Original price \$17,000, will negotiate. Call Linda @ 913-334-2476.

Ranger II Electric Wheelchair fully adjustable. As new. Appointment only, 913-469-4188.

## SCOOTERS

Three-Wheeled Little Rascal battery operated, goes up to 5 mph, has horn, \$1900. Call 402-371-3763 and leave a message.

Rascal 200 Three-Wheeled Scooter red, slightly used. Swivel seat and flip up armrests. Battery operated. Retailed new for \$1500. Asking price \$600 or best offer. Inquiries may call 913-341-5174.

Deluxe Rascal Scooter used only 6 times, \$2000. Call 316-321-3494.

## LIFTS

Hoyer Lift brand new, never used, books & instructions included. Paid \$850, ask \$500 or best offer. Call Loretta @ 816-370-2375.

## MATTRESSES & CUSHIONS

Therapeutic Select Air Mattress has bed controls, barely used. \$1500 or best offer. Call Milli @ 316-794-8834. Goodard, KS.

Roho Air Floating Mattress brand new, still in boxes. \$1000 or best offer. Call Loretta @ 816-370-2375.

Two Roho Cushions new, still in boxes. \$250 each. Call Loretta @ 816-370-2375.

## BEDS

Hospital Bed, Serenity Home Care Bed by Medline 2 years old. Used only one year. Semi-electric. Paid \$1800, asking \$500. Call Wendy @ 913-371-2238.

INCLUSION IN THE DIALOG IS NOT AN ENDORSEMENT FOR THESE PRODUCTS AND SERVICES.

Please notify Suzanne at (913) 648-2062, ext. 209 if your item has been sold or should be removed.

The Chapter is proud to provide this newsletter and other services at no cost. Please consider a voluntary subscription fee in the amount of \$24. Thank you.

## In Memoriam

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

John Bateman	Richard Johnson	Mark Sheets
Marlene Chappell	Warren Kessler	Dale Williams
Blake Hanzlick	Arlan Reinking	Betty Wiser

## Memorials

Thanks to the following families for designating our Chapter for donations:

John Bateman	Richard Johnson
Kenneth Briggs	Mark Sheets
Blake Hanzlick	Dale Williams
Helen Hodges	Betty Wiser

Judy Oliver's husband battle ALS - amyotrophic lateral sclerosis, of Lou Gehrig's Disease. During his battle with the fatal, neuromuscular disease, Judy discovered that the experience of others living with ALS provided inspiration, courage, coping strategies and hope. Her book, capturing the experience from around the world, will inspire you, too.

For a copy of *In Sunshine and In Shadow* contact The ALS Association - Keith Worthington Chapter at (913) 648-2062, visit our website at [www.alsa-midwest.org](http://www.alsa-midwest.org) or return the below completed book order form.

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Please mail order to The ALS Association - Keith Worthington Chapter  
 8340 Mission Road, Suite B-4, Prairie Village, KS 66206

**F A R E W E L L**

It is with regret that we announce the resignation of Betty Bruce, Patient Services Coordinator in the Springfield office. Betty is working with the Chapter to prevent any reduction of services during the transition to a new staff person. The following is a copy of the letter Betty gave to the Chapter sighting her reasons for resigning:

October 23, 2002

This letter is to inform you that I will be resigning from my position as Patient Services Coordinator effective November 8, 2002. My husband's illness has made me realize that spending quality time with my family needs to be my priority.

I want to thank you for the opportunity to grow professionally and personally while an employee with the Keith Worthington Chapter. Our patients and families are fortunate to have an organization that is so dedicated to finding a cure for this devastating disease.

Sincerely,  
 Betty Bruce

**D e c e m b e r B i r t h d a y s**

John Bateman	December 1	Tom Osbern	December 10
Bill Asbury	December 1	Fred Marstall	December 13
Robert Thornton	December 2	Casey Cornelius	December 15
James Osburn	December 2	Eric Scarlett	December 17
Wayne Osterhout	December 3	Reggie Thompson	December 22
Jeff Pair	December 3	Sevi Krigel	December 22
Earl Porter	December 7	Fannie Stephens	December 26
Larry Steincamp	December 8	Marlene Fritz	December 27
Jeff McCloud	December 9	Leland Stone	December 28

**EMAIL ADDRESSES AND PHONE EXTENSIONS TO BETTER SERVE YOU:**

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 Sally Dwyer, Ext. 212  
*Program Director*  
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 Dawn Oliver, Ext. 211  
*Development Director*  
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 Terry Betzelberger  
*President*  
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**Chapter Website**  
[www.alsa-midwest.org](http://www.alsa-midwest.org)  
**National Website**  
[www.alsa.org](http://www.alsa.org)

# THE DIALOG

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Prairie Village, KS 66206

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2002  
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3 Tues  
4 Wed  
5 Thur  
5 Thu  
21 Sat

**Springfield Holiday Party**  
6:00 - 8:00 pm

**Kansas City Holiday Party**  
6:30 - 8:30 pm

**Wichita Holiday Party**  
6:30 - 8:30 pm

**Omaha Holiday Party**  
6:30 - 8:30 pm

**Wichita Caregivers Support Group** 12 - 3 pm  
Grace Presbyterian Church  
5002 E Douglas



**KC Caregiver Support Group**  
No meeting this month.

**KC Day Support Group**  
No meeting this month.

**Hutchinson Support Group Meeting**  
No meeting this month.

**Topeka Support Group**  
No meeting this month.

**Columbia Support Group**  
No meeting this month.

**Lincoln Support Group**  
No meeting this month.

“What is ALS” Orientation Series by appointment.  
Please call (913) 648-2062, Ext. 202 or 212

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

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

<b>Kansas City</b> Linnea Brandt & Nancy Lindquist (800) 878-2062	<b>Nebraska</b> Sonya Glenn (866) 762-6361	<b>Springfield</b> Sarah Tucker (888) 386-1200	<b>Wichita</b> Jean Haley (800) 553-9056
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