

“  
I'm fine...  
but how are  
all of you?  
”



Sevi Krigel

The following is a speech from A Night of Hope on April 4, 2003:

Ask my mom how's she doing and she will always say, "I'm fine... how are you, dear?" She could be lying in a hospital bed, recovering from surgery and half dazed and you could ask her how's she doing and she'd say, "I'm fine... but how are all of you?" That's the way my mom is... never paying too much attention to herself and worried more about everyone else.

So, it seemed strange to us that starting about a year ago, we'd ask my mom how she was doing and she'd say, "I'm fine... but how are you..." but the words would come out somewhat slurred. So we'd prod a bit and say, are you sure something wasn't going on? For years, Sevi had been taking medicine for one small problem or another and we figured that... maybe the doses had gotten out of whack. But, changing medicines didn't improve her articulation; in fact, it only got worse. So, last summer - in July - we made an appointment with mom's neurologist, who had seen Sevi only five months earlier.

The doctor talked to my mom and ran her through a series of strength tests, the kind that any of us who have had arm or leg injuries have performed. Sevi was asked to pull her arms apart as the doctor held them in, and move her legs up as they were being pushed down. It was as Sevi was walking down the hall and out of earshot that the doctor turned and whispered to my wife, dad and me that she thought that Sevi had something new... something not good... ALS - Lou Gehrig's Disease. She said she was going to refer Sevi to a colleague who would make a more firm diagnosis. Like most people, we had no real understanding about ALS. But we quickly learned. ALS usually doesn't strike someone as old as my mom, who at the time was 78. But it did. And while most people who were afflicted with the disease get the limb variety and have it work its way from their feet up, Sevi's was going to go from her head down.

About 25% of ALS patients get this "bulbar" variety. And I would guess that my mom's progression has been somewhat typical. In September, two months after her original diagnosis, she was still eating and talking. By December, she was no longer understandable though still eating. At the end of December, she had a feeding tube inserted. By January, choking and gagging episodes had become more common, particularly if my mom sneaked a bite of orange or tomato - two of her favorite foods. Her walking was also unsteady and she was falling more. By February, after she ate, choked and passed out on a small piece of food, it was decided that it was time for Sevi to give up eating altogether.

*Continued on page 2*

**June Happenings** - *For more information, see page 3.*

- The Joe McGuff ALS Golf Classic (Kansas City)
- Dinner with Lou (Wichita)
- Walk to D'Feet ALS (Wichita)
- The Bob Hohn/ALS Celebrity Golf Tournament (Nebraska)

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This has been really tough, because, in spite of her trim figure, she has always loved eating. She now gets 100% of her nourishment from five cans of Boost poured through her feeding tube at different times during the day. She also no longer gets up on her own and only walks with the aid of someone beside her.

Fortunately, my folks have had incredible support from our caregivers, Mimi and Jana, my brother Barry, and our wonderful cousins, all of whom have joined them for medical appointments, helped them to shop, or just facilitated communication. And all of us have marveled at the determination and strength of my mom.

As all of you know, there is no cure for ALS. If you or I were to get it, who knows how we would react. Many of us would probably try to get our affairs in order and worry about what the end would be like. That hasn't been the case with my mom, though. She has gone on living her life like there would be a tomorrow. When hospice came over to the house a couple weeks ago for their initial visit, Sevi's biggest concern wasn't whether she'd get good care, or that there would be one more nurse around. No her biggest concern was finding out when the interview would be over...because, as she struggled to write, she didn't want to be late that afternoon for her appointment...at the beauty parlor.

This is very much in character for my mom. As director of volunteer services for Western Missouri Mental Health, Sevi trained her workers on how to deal with the disabled. One of her biggest pieces of advice was also her shortest: It was...to relax. She would tell them, "If you don't know what to do or say, allow the person who has a disability to help put you at ease." Maybe that's why she still smiles so much and laughs still tries to say...she's doing fine...but how are you?

My mom would not want your sympathy. If she could, she'd tell you that ALS is a lousy disease, but she's at least glad she got it at this point of her life and not earlier. But because most others who get ALS get it at a younger age, she would also ask that you do what you can to help rid us of this illness...be it this dinner, or the auction, or to be perfectly blunt - to reach out and grab one of those silver envelopes on the table and give what you can, again.

So...on behalf of my mom, Sevi Krigel - whose name really is Sevi, by the way - thank you for helping us look for a cure for ALS and thank you for honoring her tonight.

M A Y / J U N E 2 0 0 3

## A Night of Hope Goes Broadway is a Success!

Over 550 guests came to the Sheraton Overland Park Hotel April 4th for the 14th Annual Night of Hope. Our theme this year, A Night of Hope Goes Broadway, proved to be a success raising over \$225,000! Event Chairs Lynda & Ed Connolly joined Patty & Jerry Reece, Honorary Community Chairpersons and Sevi Krigel, Honorary ALS Chair in welcoming one of Broadway's up-and-coming stars, Eric DeGray. His incredible performance was certainly the highlight of the evening. Over the past 14 years, Night of Hope has raised over \$3 million!



Patty & Jerry Reece, Honorary Community Chairpersons, Sevi Krigel, Honorary ALS Chair and her husband Melvin and Lynda & Ed Connolly, Event Chairs

The Betzelberger family and current Chairman of the Board of The National ALS Association, Bob Bjorseth, eagerly await and discuss the next item up for bid.



Gigi Winston, Emily Golson and Norma Woodard put their heated bidding on hold to pose for a picture.



Employees from North Kansas City Hospital, one of the many sponsors of A Night of Hope Goes Broadway, enjoyed the evening.

## Dinner with Lou

### Saturday, April 19, 2003

Approximately 200 people attended the premier showing of *Lou Gehrig ~ The Luckiest Man*, adapted and performed by the advanced repertory students from Shawnee Mission High School in the Kansas City area.

"The more I learn about him, the more respect I have," said Parker Reynolds who played the part of Lou Gehrig.



*Lou Gehrig - The Luckiest Man* is a story for all ages



Frank Boal, Sports Director at WDAF TV Fox 4 as the play's narrator



Hot dogs, popcorn and cracker jacks at the Stadium Club



Lou Gehrig makes his famous speech

## Upcoming Chapter Events

### The Joe McGuff ALS Golf Classic

Monday, June 2, 2003  
The Jack Nicklaus Golf Club at Lion's Gate

11:30 am Lunch  
12:30 pm Clinic presented by Tom Watson\*  
1:00 pm Tee time for each 5 person scramble  
\*Tom Watson's caddy was diagnosed in 2002.

Patients and their families are welcome to join us at this event!  
For more information, call Sarah Kerwin at 913.648.2062, ext. 209.

### Bob Hohn/ALS Celebrity Golf Tournament

Saturday, June 21, 2003  
Indian Creek Golf Course in Elkhorn, Nebraska  
Friday, June 20<sup>th</sup> - Celebrity reception and banquet -  
Holiday Inn, Lincoln, NE

For more information, call Ric Miller at 402.991.8788.

### The Wichita ALS Pro-Am Golf Tournament

Monday, September 22, 2003  
The Wichita Country Club

For more information, call Kathleen Wille at 316.612.0188.



### Walk to D'Feet ALS

For information on the Walks, contact the ALS office nearest you.

June 21	Wichita, KS
September 6	Topeka, KS - Joplin, MO - Pratt, KS
September 14	Kansas City, MO
September 20	Hays, KS - Grand Island, NE
September 27	Liberal, KS - Branson, MO
	St. Joseph, MO - Columbus, NE
October 4	Jefferson City, MO - Salina, KS
October 11	Emporia, KS - Springfield, MO
	Manhattan, KS - Omaha, NE

### Dinner with Lou in Wichita, KS

Thursday, June 19, 2003  
Wichita Wranglers' game 6 pm  
\$20 ticket includes dinner, play, baseball game and donation  
For more information, call Kathleen Wille at 316.612.0188.

## MAY IS ALS AWARENESS MONTH

- Every 90 minutes someone is diagnosed with ALS
- Over 5,000 new cases of ALS are diagnosed each year
- 300,000 people alive today in the United States will develop ALS
- There are more than 30,000 ALS sufferers in the United States at any given time
- ALS affects males and females in equal numbers
- One in every 50 families is affected by ALS
- Sporadic ALS (strikes randomly) affects the majority of ALS patients
- Familial ALS (inherited) affects about 5-10% of all ALS patients
- Half of all offspring of familial ALS patients inherit the gene and develop ALS

The ALS Association (ALSA) is the only not-for-profit organization dedicated solely to the fight against ALS against ALS and the support of ALS patients and their families. ALSA's key responsibilities are research support/funding, patient/family support, information, and education. The national headquarters are in Calabasas Hills, California.

The ALS Association, Keith Worthington Chapter provides information, referral, counseling, support groups, and special equipment to individuals with ALS and their families in Kansas, Nebraska, and Western Missouri. There are no charges for these services. The Chapter also raises money for research into the cause and cure of ALS.

The ALS Association Keith Worthington Chapter would like to thank



for sponsoring the May/June issue of Dialog in honor of ALS Awareness Month.

### Help promote ALS Awareness Month by purchasing an *ALS Bracelet of Hope*

Jackie Foltz has designed this beautiful sterling silver bracelet to help fight ALS. To order, fill out the form below and send your check and order form to: Silver N Stone, 12502 Jayson Lane, Wichita, KS 67235-1445.

Name: \_\_\_\_\_ Address: \_\_\_\_\_  
City: \_\_\_\_\_ State: \_\_\_\_\_ Zip: \_\_\_\_\_ Phone number: \_\_\_\_\_

The standard bracelet will have the ALS charm, the charm of Hope and the angel. The cost is \$35 plus \$2.00 shipping with the proceeds going to the ALS Association Keith Worthington Chapter.

*Select One:*

Type of bracelet:  Stretch  Clasp  Toggle  
 Wrist size:  Small  Medium  Large (most people have medium size wrists)  
 Block letters: (must be a toggle bracelet) \_\_\_\_\_, \_\_\_\_\_, \_\_\_\_\_, \_\_\_\_\_, \_\_\_\_\_, \_\_\_\_\_, \_\_\_\_\_, \_\_\_\_\_  
 Beads:  Red, silver and clear  Red, silver, gold and clear

*Payment:*

Checks only, sorry no credit cards. Make checks payable to: Silver N Stone



		# Ordered	
ALS Bracelet of Hope	\$35		
Block letters (.70 cents each)	.70		\$
Shipping	\$2		\$
Total			\$

Questions, contact Jackie Foltz at (316) 729-0273 or jfoltz1@cox.net.  
 Silver N Stone • 12502 Jayson Lane • Wichita, KS 67235-1445

## JUNE IS LOU GEHRIG MONTH



**Lou Gehrig**

2003 celebrates the 100<sup>th</sup> anniversary of an American hero

On June 19, 1903, Henry Louis Gehrig was born. He became one of the greatest players in the history of baseball. A rare combination of speed, power and consistency enabled Gehrig to capture two Most Valuable Player awards in 1927 and 1936, the Triple Crown in 1934 and six World Series titles. His single season mark of 184 RBI's still stands in the American League record books. The New York City native earned his nickname, "The Iron Horse," for his record-setting consecutive games played streak of 2,130. Yet Gehrig is often best remembered for delivering one of the greatest speeches in sports history. At Yankee Stadium on July 4, 1939, he bid a touching farewell to baseball in front of over 62,000 fans and reporters.

More about Lou Gehrig, can be found in the following books:

*Lou Gehrig ~ The Luckiest Man* (for young children)

*Lou Gehrig ~ One of Baseball's Greatest* (for older children)

*Iron Horse* (for youth and adults)

These books may be purchased at your local book store, or through Rainy Day Books in Fairway Kansas (913)384-3126, [www.RainyDayBooks.com](http://www.RainyDayBooks.com).

### Study Participants Wanted

Dr. Greg Turner from CMSU is looking for individuals with speech difficulties associated with having ALS. He is evaluating the influence slowing speaking has on improving how well a person with ALS is understood. He needs to find 30 individuals to participate in a three-hour study. Individuals meeting the following criteria are eligible for participation: 1) speaking should be your primary mode of communication and 2) you should be having difficulty being understood. The study is divided into two parts. The first part involves a basic evaluation of your speech for the purpose of describing the speech problem that Dr. Turner would travel to your home to complete. The second half would involve producing speech at different speaking rates. Dr. Turner will be able to pay participants \$50 for being involved in the study. If you are interested please contact Dr. Turner via email [turner@cmsu1.cmsu.edu](mailto:turner@cmsu1.cmsu.edu), or at 660-543-8799 or Betsy Sylvester via [tweety2301@msn.com](mailto:tweety2301@msn.com) or 816-847-0335. Please pass on the word about the study to your fellow support group members. Until a cure can be found, I hope my work can help to improve the quality of life for individuals with ALS. Thank you for considering participation and best wishes.

Greg Turner Ph.D.  
 Professor of Communication Disorders  
 Central Missouri State University

## Support Group News

### *Kansas City Support Group*

The Kansas City Night support group met May 6<sup>th</sup> at the Second Presbyterian Church in the Brookside area. Patients, families and friends, Dr. Barohn and Laura Herbelin were present to hear Clint Merrick from the Kansas Foundation for Medical Care talk about patient's rights. In very clear terms, he explained a Medicare beneficiary's four basic rights and steps to take to initiate an immediate appeal if a person feels those rights are violated in regards to hospital stays, nursing home care, home health care and outpatient ambulatory care centers. Mr. Merrick distributed helpful materials along with phone numbers and web sites. The topic for the June 3<sup>rd</sup> KC Night Support Group will be the health benefits of therapeutic massage.

### *Omaha Support Group*

The April Omaha support group meeting was Thursday, April 10<sup>th</sup> with fourteen people in attendance. The speaker was Lisa Oberg from Assistive Technology Partnership who presented information on the programs and services they provide. These services include assessments and possible funding for assistive technology and home modification alternatives, vehicle modification, and equipment for daily activities. Lisa answered questions, provided information on resources, and demonstrated some equipment that she brought with her. She also informed us of their upcoming Ability Quest conference and exhibit hall on May 8<sup>th</sup> & 9<sup>th</sup> at the Cornhusker Hotel in Lincoln. After Lisa's presentation, the group had open discussion and sharing. The May meeting was held on Thursday, May 8<sup>th</sup>. Eight people attended the meeting and Laura Ball, Ph.D., University of Nebraska Medical Center, Munroe Meyer Institute presented on Speech and Language Considerations for Persons with ALS. She shared her research with us and demonstrated a variety of augmentative and alternative communication devices. The next meeting will be on Thursday, June 12<sup>th</sup>.

### *Springfield Support Group*

The Springfield support group met on April 8<sup>th</sup> with nine in attendance. Our guest speaker Donna Willoughby RN, PCS, serves as Palliative Care Nurse Coordinator for Cox Health Systems. The Palliative Care Nurse assesses and documents the patient and family needs as related to end-of-life cares. The Palliative Care Nurse offers recommendations to the patient's physician as indicated for interdisciplinary team care that best meets the patient's expressed goals and values. Donna provided a "Durable Power of Attorney for Health Care Choices and Health Care Choices Directive" from the Community Alliance for Compassionate Care. Following the in-service, attendees shared concerns on difficult issues dealing with the ALS disease process and tried to problem solve. At the next meeting on May 13<sup>th</sup>, a guest speaker from the Southwest Missouri Office on Aging will be presenting.

### *Hutchinson Support Group*

The Hutchinson support group met on Wednesday, April 2<sup>nd</sup>. Those who attended heard an enlightening and encouraging talk by the pastor of the Grace Episcopal Church, Rev. Michael Milliken. This church family has been a gracious host to the monthly meetings. Rev. Milliken spoke about the powerful ways in which we can all learn to cope with adversity, especially devastating illness. The focus was not only on our common humanity, but reliance on a Higher Power to carry us over the rough spots. Everyone was in agreement that there was no greater support than from each other and that is one of the most effective aspects of having a support group in the community.

### *Wichita Support Group*

The Grace Presbyterian Church played host to 26 ALS patients and family members Thursday evening April 3<sup>rd</sup>. Rev. George Gardner, Pastor of the Unity Church of Wichita, spoke on life issues. He emphasized that NO ONE was a victim or was being victimized. He went on to explain that life was neither fair nor unfair, it was just difficult. He pointed out that the greatest heroes were not on the battle field of Iraq, but rather were amongst us all in the arena of ALS. He gave many tools to survive the slings and arrows of disappointment and frustration that we have all come to know all too well in our search for a CURE. It was a very uplifting and educational evening. Kathleen Wille and Jeff Severt (family member of a former ALS patient) spoke about the upcoming Walk to D'Feet ALS in June 2003 and how to form a team. The petition for National ALS Advocacy Day was signed and endorsed by all attendees. Kerry Gray introduced us to the President of the TV Health Channel in Wichita and the plans to create a documentary on ALS as a source of community awareness. It was pointed out that last year's Walk had limited media exposure, something that will be rectified for Year 2003 Walk to D'Feet ALS. Everyone was invited to attend the Dullea (Phi Delt sponsored) Memorial Auction at the Boathouse in Wichita at 7 PM, Friday April 4<sup>th</sup>. The proceeds will benefit ALS research and programs.

### *Wichita Caregiver Support Group*

The caregiver support group potluck luncheons take place in the parlor of the Grace Presbyterian Church in Wichita one Saturday of each month from 11 am - 2 pm. See the last page of this newsletter for exact dates. All caregivers are cordially invited to attend and share experiences whether or not they have time to prepare any goodies. There is always ample food for all.

## Research - Joint Initiative

*Consortium undertakes collaborative initiative to screen FDA-approved compounds for treatment of ALS in mice*

A pilot study has been launched to test three FDA-approved compounds for their effect in treating ALS to help determine whether clinical trials are warranted. The two-phase study is a collaboration of The ALS Association (ALSA), The Robert Packard Center for ALS Research at Johns Hopkins and Project A.L.S.

The unprecedented effort to screen drugs in the mutant G93A SOD1 mouse follows a 2002 study in which ALSA partnered with The National Institute of Neurological Disorders and Stroke (NINDS) to screen a set of over 1000 FDA-approved compounds, termed the NINDS collection, in neurodegeneration assays (models).

"This is an important follow-up to the previous study as it will show whether the compounds with an apparent effect in those assays will increase the lifespan of the ALS mouse model. This investigation will provide strong support for moving to clinical trials," said Dr. Lucie Bruijn, Science Director and Vice President of ALSA.

"Project A.L.S. is pleased to join forces in screening these promising drugs aggressively and thoroughly, with the necessary scientific oversight--which is crucial. Our goal is to work together intensively, as committed organizations, build on the initial findings of the NINDS screening, and identify medicine that will make a difference to ALS patients," said Jenifer Estess, chief executive officer of Project A.L.S. Estess has ALS.

The three test compounds chosen for this animal study are among those that show a significant effect in assays representing various potential disease mechanisms in ALS (models in a dish).

**Phase 1.** Three test compounds and one control compound will be screened in mice beginning at five weeks of age.

**Phase 2.** Compounds that show a significant effect will be tested in mice beginning at 12 weeks when animals begin to show signs of disease progression.

"We were eager to get on with this next phase of testing," says Dr. Jeffrey Rothstein, who directs the Packard Center. "It's certainly the best way we know to determine whether these drugs should move on to clinical trials."

The ALS Association's Greater New York and Bay Area Chapters along with The Robert Packard Center for ALS Research at Johns Hopkins and Project A.L.S. are providing support for the study, which will be conducted by New York-based PsychoGenics Inc, an independent testing facility.

The ALS Association (ALSA) is the only national not-for-profit voluntary health organization dedicated solely to the fight against ALS. Its mission is to find a cure for and improve living with ALS.

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## Research News Update from ALSA's National Office

*March 31, 2003*

Many of you may have read or heard the news about an "experimental drug" for Parkinson's disease that showed positive results in a very small Phase 1 clinical study. The study, being published in today's Nature Medicine, is co-authored by Dr. Clive Svendson, University of Wisconsin-Madison. The "experimental drug" is GDNF, a glial-derived neurotrophic factor previously studied as a potential treatment for ALS.

The study by Dr. Svendson and colleagues in the U.S. and Britain is considered a "prelude to the dream solution: engineering stem cells to produce the protein on their own and transplanting them into the brains of Parkinson's patients," as stated in the article from the Milwaukee Journal Sentinel. (<http://www.jsonline.com/alive/news/mar03/129848.asp>)

This study (using stem cells as a delivery system) mirrors an ALSA-funded study by Dr. Svendson currently underway through our Lou Gehrig Challenge research effort ([http://www.alsa.org/research/awardlgc\\_svend.cfm](http://www.alsa.org/research/awardlgc_svend.cfm)). This project began in February 2002.

Eat Great Food and Support a Great Cause  
in the Kansas City area!

**The ALS Association**

and

**BAJA FRESH®**

**FUND RAISER**

**Earn dollars for The ALS Association**

Get together with family and friends from  
our local community on the night and  
time listed below and **BAJA FRESH®** will  
donate **15% of sales** to **The ALS Association**

**Enjoy great Baja Fresh® food,  
while benefiting The ALS Association**

**DINE IN OR TAKE OUT**

**Organization: The ALS Association**

**Date: Wednesday Night  
June 4<sup>th</sup> and June 11<sup>th</sup>, 2003**

**Time: 4:30 pm to 8:30 pm**

Important! Bring this flyer to the  
event and present when ordering.

©2000 Baja Fresh



**Location**

<b>North Regency Park</b>	<b>7301 W. 91<sup>st</sup>, Overland Park, KS</b>	<b>(913)901-8600</b>
<b>Ward Parkway Mall</b>	<b>8600 Ward Parkway, KC, MO</b>	<b>(816)444-7500</b>

## Advocacy Update

### *Reporting Fraudulent Claims*

In January of this year Steve Gibson, The ALS Association's Vice President, met with the new FDA Commissioner Dr. Mark McClellan. One of the issues he addressed with him was the problem of hoax cures and treatments that confront many patients and families. Commissioner McClellan offered the services of one of his staff to develop a procedure that all patients and families can use to report these incidents. We would like to share with you their guidance.

To avoid becoming victims of health fraud, it is important for consumers to learn how to assess claims and seek the advice of a health care professional. The underlying rule when deciding whether a product is authentic or not is for the consumer to ask "Does it sound too good to be true." If it does, it probably is not true.

Consumers can learn whether the Food and Drug Administration (FDA) or the Federal Trade Commission (FTC) have taken action against the promoter of a product they may be considering by visiting <http://www.fda.gov/oc/enforcement.html> or <http://www.ftc.gov> A list of dietary supplement ingredients for which the FDA has issued warnings for can be accessed at <http://www.cfsan.fda.gov/~dms/supplmnt.html>.

The FDA defines "health fraud" as the deceptive promotion, advertisement, distribution or sale of articles, intended for human or animal use, that are represented as being effective to diagnose, prevent, cure, treat, or mitigate disease (or other conditions), or provide a beneficial effect on health, but which have not been scientifically proven safe and effective for such purposes. Such practices may be deliberate, or done without adequate knowledge or understanding of the article. FDA has Health Fraud Coordinators and/or Public Affairs Specialists located in its district offices. For a contact in your area, please check the blue pages of your phone book for the local FDA telephone number or the FDA website for a directory of local offices: [http://www.fda.gov/ora/inspect\\_ref/iom/IOMORADIR.html](http://www.fda.gov/ora/inspect_ref/iom/IOMORADIR.html). You can find tips and warnings about buying medical products online, as well as some articles on topics such as "How to Spot Health Fraud" on the FDA's website at <http://www.fda.gov/oc/buyonline/>.

The FDA, FTC, Health Canada, and various state Attorneys General have joined together to crack down on unscrupulous marketers who use the Internet to prey on the sickest and most vulnerable consumers. The FTC is targeting false and unsubstantiated health claims on the Internet through Operation Cure All - a law enforcement and consumer education campaign. FTC's Virtual Treatment website <http://www.ftc.gov/bcp/conline/edcams/cureall/index.html> offers information for consumers on how to recognize health fraud, tips on buying healthcare products on the Internet, and guidance for businesses on how to market health products and services truthfully, and information about the FTC's initiatives.

The FDA and FTC are encouraging people to report suspicious health claims. To file a complaint regarding a possible fraudulent, deceptive, or unfair business practice, call toll-free, 1-877-FTC-HELP (1-877-382-4357), or use the complaint form at <http://www.ftc.gov> If you find a website you think is illegally selling human drugs, animal drugs, medical devices, biological products, foods, dietary supplements, or cosmetics over the Internet, use the complaint form at <http://www.fda.gov/oc/buyonline/buyonlineform.htm>. The FDA and FTC do not resolve individual consumer problems, your complaint helps them investigate fraud, and can lead to law enforcement action. The FTC enters Internet, telemarketing, identity theft and other fraud-related complaints into Consumer Sentinel <http://www.consumer.gov/sentinel/>, a secure, online database available to hundreds of civil and criminal law enforcement agencies worldwide.

Suspicious promoters of fraudulent health care products often use similar claims and practices to lure consumers into buying their goods. The FDA and FTC advise consumers to be suspicious of: claims that the product is "natural" or "non-toxic," suggesting it does not have side effects. "Natural" or "non-toxic" does not necessarily mean safe. Some "natural" supplements contain potent stimulants; others can result in negative interactions with medicines.

It is important to be careful to scrutinize testimonials from people who claim amazing results. Testimonials often are undocumented and are not a substitute for scientific proof. Some examples are: claims that a product is a "scientific breakthrough," "miraculous cure," "secret ingredient" or "ancient remedy," as well as claims that the product is an effective cure for a wide range of ailments. Other examples include: claims that use impressive-sounding medical terms; claims that the product is available from only one source; products that require advance payment; claims of a "money-back" guarantee; and websites that fail to list the company's name, physical address, phone number or other contact information.

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 webpage at: [http://www.alsa.org/serving/adv\\_update.cfm](http://www.alsa.org/serving/adv_update.cfm). You can also contact Ted Burnes toll-free at: 877-444-2572 or via e-mail at: [ted@alsa-national.org](mailto:ted@alsa-national.org).

# FOR SALE

## VANS

**1989 Dodge Caravan** handicap equipped with rear entry ramp, hand driving controls, 61,000 miles. \$5,500 or best offer. Call 913-782-6756.

**1992 Dodge IMS Wheelchair Van** 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.

**1994 Dodge Handicapped Modified Van** 89,000 miles. Great condition. Asking \$10,000. Contact Diana @ 316-775-7701.

**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, call 913-469-4188.

**2000 Dodge Caravan IMS Rampvan** 18,500 miles, fully loaded, lock down for wheelchair, still under warranty. Call Jeaneene @ 417-466-2907 or 417-466-1471 or email GRANEENE1@aol.com.

## WHEELCHAIRS

**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.

**2002 Pride Jazzy 1122 2** remotes, onboard battery charger, lifting leg rests & head rest. Owner's manual included. Asking \$2800 or 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.

**2002 Permobil Red Electric Wheelchair** joystick, toggle switch with seat control. Positioning belt and chest strap, laptray, Roho cushion, battery charger & instructions included. Only used 6 weeks. Call Anna @ 573-437-7586.

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

**Invacare Ranger X Wheelchair** 18" seat with Ishdish pad, power reclining back & legs, 2 new batteries, charger & additional 16" molded back & seat. \$5,000. Call Bob @ 573-592-4013 or 573-659-6692 or email btphillips1@mchsi.com.

**Invacare Solara Wheelchair** adjustable headrest, arm rests & leg supports. Tilt positioning chair with Avanti Curve Back & air inflated seats. Used only 6 weeks. Asking \$1600 or best offer. Contact Don @ 402-488-5387 or dwoodbu@lps.org.

**Jazzy Red Electric Wheelchair** can be disassembled and put in car. One year old, valued at \$6000.00. Best offer. 913-772-7071.

**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. Call 573-636-2550 or email jselbold@mchsi.com (Jefferson City area).

**Bruno Power Chair - PWC 2300** 350 pound weight capacity, drop down controller, long trailing arm suspension, carry-along charger. 90 degree swivel seat, adjustable armrests, security key lock system, curb climbing height: 1:25", turning radius: 22". Used for only 3 months. Asking \$4,000.00. Contact Jeff Blair @ 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 Electric 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 and mirrors. 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 Electric Wheelchair** fully adjustable. As new. Appointment only, 913-469-4188.

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

**Invacare Storm Wheelchair** headrest, tilt, recline, a gel cushion seat, an oxygen holder and is set up for a vent tray. Call Jeaneene @ 417-466-2907 or 417-466-1471 or email GRANEENE1@aol.com.

## 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 box. \$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.

## CHAIR GLIDES

**2 Chair Glides** for 12-13 steps. Manufacturer will re-install in the purchaser's home for approx. \$300. One and a half years old. Best offer. 913-772-7071.

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

Please notify Suzanne at 913-648-2062, ext. 209 or sfrye@alsa-midwest.org if your item has been sold or should be removed.

# June Birthdays

Bill Grimm	June 2	Stephen Lundholm	June 24
Terry Olson	June 4	Paul Rose	June 25
Dale Magnusen	June 4	Dick Spittles	June 26
Kay Nichols	June 9	William Williamson	June 26
Myron Thiessen	June 9	Kerry Gray	June 26
Tony McGrath	June 13	Jeanette Flint	June 26
Randy Pilcher	June 13	Carl Walker	June 29
Bob Hohn	June 14	Marilyn Cunningham	June 29
Gertrude Cundiff	June 14	Pedro Guiao	June 29
Sam Williams	June 19	Tamara Perry	June 30
Gilmer Krehbiel	June 20		

## Memorials

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

*Eric Chollet      Margaret Hanzlick  
Dennis Havranek      Reggie Thompson*

## In Memorium

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

*Mary Bennett      Dennis Havranek  
Donald Chastain      Robert Holmberg  
Eric Chollet      Gerald Katz  
Patrick Coyle      Eileen Mercer  
Philip Graves      Reggie Thompson*

## National ALS Advocacy Day

May 1, 2003



Kim & Jeff Julian (l) along with Steve Eiken (rt) met with Chris Huff, Senior Legislative Director for Congressman Roy Blunt, and later with the Congressman.



Mary Martin, RN from the ALS Clinic at KU Medical Center, and Sally Dwyer, Program Director for the ALS Association met with Congressman Dennis Moore.

The Keith Worthington Chapter delegation joined other ALS Association representatives from across the country for National ALS Advocacy Day. The Chapter met with senators and representatives from Kansas, Nebraska, and Missouri to ask for support for the following:

- Inclusion of ALS specific research in the fiscal year 2004 Dept of Defense Appropriations bill (DOD) Peer Reviewed Medical Research Program (PRMRP).
- Increase in funding in the National Institutes of Health (NIH) budget in fiscal year 2004 by 8%-10% for ALS within the National Institute for Neurological Disorders and Stroke (NINDS).
- Eligibility for individuals to receive Social Security Disability after they receive an ALS diagnosis by their primary neurologist. This type of coverage is called presumptive eligibility.
- A prescription drug coverage plan, even without a complete overhaul of the Medicare system, that includes a provision for catastrophic coverage without co-pay, and that will ensure the continued vitality of the drug discovery process and development of new and better pharmaceutical treatments.

### ALSA's 2003 Leadership Development and ALS Clinical Conference

May 2 and 3, 2003

Conference participants attended presentations and workshops on ALS, research, and the work of the ALS Association.

#### Clinical Management Track Sessions Included:

Sexuality and ALS  
Addressing Communication Needs  
NIPPV for People with Bulbar Symptoms  
Unorthodox Therapies, Unproven Claims  
Medicare Reimbursement for Palliative Care  
Improving Cultural Awareness and Sensitivity  
Clinical Issues in the ALSA Centers and ALS Clinics  
Genetics: Implications for ALS Patients and Families  
Use of Home Adaptations and Technology for Independence in the Home  
Bereavement: Supporting Those Affected by the Death of Someone with ALS

#### Leadership Track Sessions Included:

Walk "U"  
Human Resources  
Case Studies in Major Gift Fundraising  
A Successful Volunteer Program to Meet Chapter Needs  
How to Develop a High Performance Entrepreneurial Board  
Chapter Treasurer/CFO/Bookkeeper Financial Roundtable  
Education and Awareness: Branding and Marketing The ALS Association

Dr. Jim LeBow, Chapter President and Sally Dwyer, Program Director receive a Chapter award from Bob Bjorseth, Chairman of ALSA's Board of Directors, at the ALS Conference in Washington, D.C.



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

##### Directors

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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

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

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M A Y / J U N E 2 0 0 3

### May Support Groups

- 1 Wichita 7 p.m.
- 6 KC Night 7 p.m.
- 6 Salina 7 p.m.
- 7 Hutchinson 2 p.m.
- 8 Omaha 7 p.m.
- 9 KC Caregivers 12:30 p.m.
- 13 Springfield 7 p.m.
- 19 Topeka 7 p.m.
- 21 KC Day 2 p.m.
- 21 Lincoln 6:30 p.m.
- 24 Wichita Caregivers 11 a.m.

### June Support Groups

- 3 KC Night 7 p.m.
- 3 Salina 7 p.m.
- 4 Hutchinson 2 p.m.
- 5 Wichita 7 p.m.
- 10 Springfield 7 p.m.
- 12 Omaha 7 p.m.
- 13 KC Caregivers 12:30 p.m.
- 18 KC Day 2 p.m.
- 18 Lincoln 6:30 p.m.
- 21 Wichita Caregivers 11 a.m.
- 23 Topeka 7 p.m.

### July Support Groups

- 1 KC Night 7 p.m.
- 1 Salina 7 p.m.
- 2 Hutchinson 2 p.m.
- 8 Springfield 7 p.m.
- 10 Wichita 7 p.m.
- 10 Omaha 7 p.m.
- 11 KC Caregivers 12:30 p.m.
- 16 KC Day 2 p.m.
- 16 Lincoln 6:30 p.m.
- 21 Topeka 7 p.m.
- 26 Wichita Caregivers 11 a.m.

**KC Night SG**  
2<sup>nd</sup> Presbyterian Church  
55<sup>th</sup> & Oak

**KC Caregivers SG**  
ALS Office - Must RSVP  
8340 Mission Rd., Ste. B-4

**Hutchinson SG**  
Grace Episcopal Church  
20<sup>th</sup> & Main

**Salina SG**  
Christ the King Lutheran  
111 W. Magnolia Street

**Omaha SG**  
St. Pius X Parish Center  
6905 Blondo Street

**KC Day SG**  
Village Presbyterian Church  
66<sup>th</sup> & Mission Road

**Wichita SG & Caregivers SG**  
Grace Presbyterian Church  
5002 East Douglas

**Topeka SG**  
Topeka Assoc. for Retarded  
Citizens - main entrance  
2701 SW Randolph

**Lincoln SG**  
Tabitha Health Center  
4720 Randolph St.  
Johnson Wing Conf. Rm.

**Springfield SG**  
Cox Medical Center South  
3801 South National Avenue

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

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

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

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