

How I Came to Know ALS

The following was a speech given at the Night of Hope Auction on May 4, 2002.

My name is Rosemary Gallup.

Your honorary co-chair for tonight's auction is my only daughter — Deborah Gregg. Deborah has asked me to read this letter to you.

Good evening. Thank you for being here tonight at the Night of Hope Auction for ALS.

I want to tell you how I was introduced to ALS.

My first knowledge of this disease was in 1993 when my 2 brothers and I were told that our father had ALS. Like most people, we had not heard of it as ALS, but when Lou Gehrig's disease was mentioned, we then knew what it was.

My father was a handsome airline pilot who loved flying. Suddenly this healthy man became a man who sat in a wheelchair, getting worse with each passing day. Eventually he was unable to breathe on his own, get in and out of bed without help, or dress himself. Eventually, he needed a tube to eat.

Unfortunately, these are the things that happen to people with ALS. These are the things that happened to my dad. After 5 years he passed away in November of 1998.

In January of 2000, I began experiencing the same symptoms my father had. I began losing the muscles in my hands and arms. I could not hold anything in my hands, it was hard for me to walk. For months, I saw many doctors, endured many tests, and after about 6 months I finally called the ALS Clinic at KU Medical Center. On September 28, 2000 I was diagnosed with ALS. Mine is the inherited form which occurs only in about 5 % of ALS cases.

I can't say I was surprised, but I had hoped against all hope it was not ALS. I, like the rest of my family, could only think of the end of life - a difficult thought to deal with day after day.

Continued on page 2

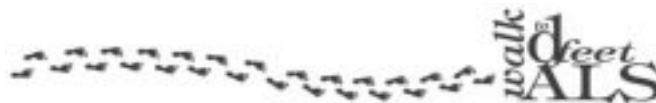
“
I have been
fortunate to see two
birthdays and two
Christmases.

”



Deborah Gregg and her mother Rosemary Gallup

**Walk to D'Feet ALS Teams Are Forming Now.
Contact Your Local ALS Office.**



HUTCHINSON AND WICHITA SUPPORT GROUP NEWS

The Hutchinson Support Group met July 10th with approximately 15 family and patients in attendance. The speaker was Reed Graber with a demonstration and presentation on therapeutic massage. The video "Thou Shall Honor", a tribute to care giving was also viewed. The Wichita Support Group met July 11th with approximately 20 patients and family members in attendance. Betty Turner spoke on the benefits of therapeutic massage in ALS such as better circulation and reduced swelling. The group also viewed the "Thou Shall Honor" video. Next month the Hutchinson Support Group will meet Wednesday, August 1st and the Wichita Support Group will meet Thursday, August 7th.

WICHITA CAREGIVERS SUPPORT GROUP NEWS

The Wichita Caregiver's Support Group Potluck Luncheon was held on Saturday, June 15th. This was a lively 3 hour interactive session with participants deriving help and encouragement from each other. Included are caregivers past, present and future which allows former caregivers to share their feelings and experiences with the ones currently going through all the stresses and demands of acute illness. The Caregiver's Support Group Pot Luckeons are scheduled for the 3rd Saturday of each month. However, due to the church's schedule, meetings have been booked for the following Saturday dates:
August 24th, September 21th, October 12th, November 23rd, December 21st

SPRINGFIELD SUPPORT GROUP NEWS

The Springfield Support Group was held on June 18, 2002 at 7 p.m. There were 15 people in attendance. The speakers were Dr. Terrence Coulter a pulmonologist from Ferrell-Duncan Clinic and Gary DuLong from Respironics. Dr. Coulter discussed the cause and effects of breathing problems in an ALS patient. He went over the symptoms of sleep apnea and the types of tests that are utilized to diagnose a breathing problem. Gary discussed & demonstrated how NPPV machines work.

However, I have been fortunate to see two birthdays and two Christmases and am looking forward to more. In the beginning I never thought I would still be as active as I am, but I feel my progression has been slow. That has given me more time to spend with my son Jeramie, grandson Jordan, and the rest of my family. In fact, I recently enjoyed a trip to the Grand Canyon with my family - a trip with memories I cherish.

I spend a lot of time on the internet gathering information, much of it sent to me from the Keith Worthington Chapter. They do a great job of keeping us all informed. They are such a marvelous group. They are always there when you need them--ready to help with information, equipment or support.

I am honored to be a part of tonight's festivities and to be among so many people who care about those of us with ALS.

I want to thank everyone for attending this auction. Thank you for caring. You DO make a difference. May God bless you.

Deborah L. Gregg

Clinical Update - From ALSA's National Office

Positive Results Reported for Emotional Lability Drug for ALS

On June 20, 2002, Avanir Pharmaceuticals in San Diego, California announced positive results from a Phase II/III clinical trial that tested the safety and effectiveness of Neurodex. The indication for Neurodex in this study of patients with ALS was pseudobulbar affect or emotional lability (exaggerated laughing or crying). Avanir reports that, in this study, the patients in the group receiving Neurodex showed a greater decline on a rating scale for pseudobulbar affect than those in two control arms, indicating greater improvement in their pseudobulbar affect.

Some people with ALS experience symptoms of pseudobulbar affect including uncontrolled laughing and/or crying in excess of the situation that prompts the laughing or crying. For many patients and their families, these symptoms are distressing and can sometimes be embarrassing. There are no medications indicated to treat pseudobulbar affect; however, some antidepressant medications are prescribed by physicians to treat pseudobulbar affect.

Neurodex is a combination of dextromethorphan and an enzyme inhibitor that allows for "sustained, elevated levels of dextromethorphan in the body." It is not approved for use by the U.S. Food and Drug Administration (FDA) at this time. Avanir plans to begin a second clinical study of Neurodex in pseudobulbar affect in patients with multiple sclerosis this year. If the results of the MS trial are positive, the company plans to present its findings and file a new drug application with the FDA as early as Spring 2004. The FDA requires positive, adequate and well-controlled studies of Neurodex before the drug can be approved for general use for emotional lability.

Avanir also plans to initiate an open label trial of Neurodex in pseudobulbar affect later this year in select locations. This will be an opportunity for some people with ALS who experience emotional lability to receive Neurodex and allow for further clinical evaluation of the safety of this drug over time.

For more information about ALS and pseudobulbar affect, contact The ALS Association toll-free at (800) 782-4747, alsinfo@alsa-national.org or on ALSA's website www.alsa.org.

For more information about treatments for pseudobulbar affect, contact your ALS neurologist or health care provider.

For more information about Neurodex or the open label trial of the drug, contact Avanir Pharmaceuticals at (858) 622-5200 or visit the web site at www.avanir.com.

The ALS C.A.R.E. Program

What is the ALS C.A.R.E. Program?

The **ALS Clinical Assessment, Research, and Education** Program was established by an Advisory Board of neurologists, other health care professionals, and ALS experts. The Program oversees projects that help doctors learn what causes ALS and develop new and effective ways to manage the care of people with ALS.

What is the ALS Patient Care Database?

The ALS Patient Care Database collects information from people with ALS, their doctors, and caregivers. Specially designed forms are filled out by you, your doctor, and, whenever possible, your caregiver. These forms ask for information about how ALS has affected you physically, emotionally, and financially, as well as the types of medications you are using.

Why should I participate?

Data provided through the database is used to promote quality of care. Information is disseminated through journal articles and by presentations at national and international meetings. The information will lead to improved patient care and greater understanding of ALS.

How often should I fill out the data collection forms?

You should fill out a Patient Form at intervals of three to six months. If you have a regular caregiver and this person accompanies you on your visit, he or she should fill out a Caregiver Form. A caregiver may be a family member, friend, or paid attendant. You will be asked to answer the same questions at each visit. Although you may find it frustrating to be asked the same questions, your answers provide critical information to help us learn what factors correlate with improved quality of life.

Will the information be kept confidential?

Absolutely. Only your neurologist and his staff have access to data.

If you have any further questions about the ALS C.A.R.E. Program and ALS Patient Care Database, please call Brian Ghafari, Nurse Clinician at the ALS Clinic at the University of Kansas Medical Center, (913)588-0648.

The Department of Defense, Department of Veterans Affairs and the Centers for Disease Control and Prevention, an agency of the Department of Health and Human Services, announced on June 21, 2002 the launch of an Internet site called Medsearch, a central repository of Gulf War-related medical research. Medsearch can be found on the Internet at:

<http://www.GulfLINK.osd.mil/medsearch>

Social Security Disability

If you have been turned down for social security disability:

- be sure you have completed and returned all forms
- include a contact name from the doctor's office or clinic on the front page of the application where there is a place to list a contact -- SSD could call the contact for information if needed and maybe prevent a denial

KANSAS CITY SUPPORT GROUP NEWS

The KC Night Support Group met July 9th. Suzie Wiley, OT, and Randy Morris, Speech Therapist from the Rehab Institute spoke to the group about adaptive computer and communication technology. Assistive Technology is a service or device that allows a person to enjoy full inclusion in their community. The staff works with the patient to help them determine what would be the best device for that individual, they assist in obtaining it for the patient, then give support and instruction in the use of the equipment. In many cases this equipment and professional assistance is all that allows a person to communicate with family, friends or co-workers. The next meeting will be August 6th. Dick Hime, pilot for Angel Flight, will explain their services.

OMAHA SUPPORT GROUP NEWS

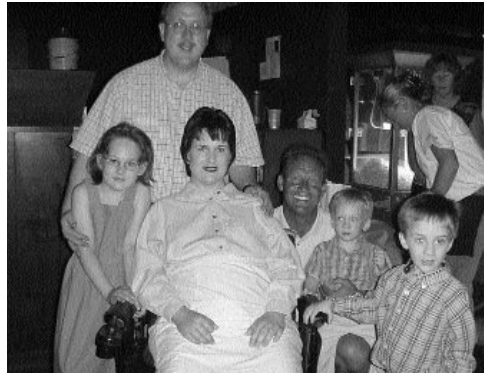
The July 11th meeting was attended by approximately 10 people with an open discussion as the program for the evening. Ric Miller reported on the success of the recent golf tournament, the music festival (where ALS was the charity of choice), and the Omaha Royals recognition of ALS in June. Four new teams were signed up from those in attendance! The program for the August 8th meeting will the video from Dr. Robert Brown's presentation on current ALS research.

TOPEKA SUPPORT GROUP NEWS

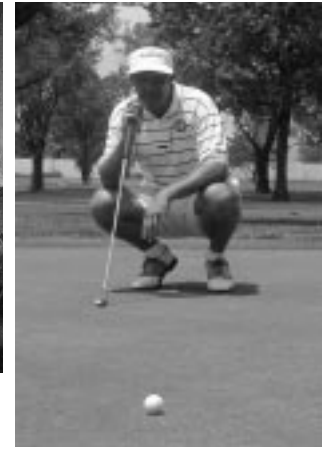
Approximately 15 people attended the July meeting. Nancy Lindquist presented in-depth information on feeding tubes, diet and nutrition. The next meeting will be on August 26. The Topeka Support Group 5th Annual Bake Sale will be held on Saturday, August 3rd from 8-3 at the WalMart on Wanamaker. For more information & donations call (785)266-5824 or email Florab29@aol.com.

2002 Adelphia George Brett Celebrity Golf Tournament

Wichita celebrated the fifth anniversary of the Adelphia George Brett Celebrity Golf Tournament in style. For the third year, Adelphia Business Solutions served as the event's title sponsor. 30 teams at Wichita Country Club raised **\$150,000!** George Brett, celebrities from the sports world like Baseball Hall of Famer, Harmon Killebrew, and actors, actresses, and country music artists joined in the celebration. Burton "Bubba" Gillian from *Blazing Saddles*, *Paper Moon* and Cinda from *Pretty Woman* and *The Young and the Restless* flew in to be a part of the weekend. They were joined by Adam Hughes & Sarah Majors from Nashville, Asleep at the Wheel and Mason Dixon, from the country music industry. The highlight of the golf tournament again was the Party Hole. This year's theme was "Brett's Diner", a 50's experience.



Honorary Chair Karen Basham and her family visit with George Brett.



George Brett lines up an important shot.

The Bob Hohn Celebrity Golf Tournament

A Huge Success!

Nebraska's beautiful Quarry Oaks Golf Club was the site of the Bob Hohn Celebrity Golf Tournament on Monday, June 17, co-chaired by Frank and Pam Solich. An autograph signing event and pairings party/auction were held the previous day at the Nebraska Champions Club. At the autograph signing, open to the general public, more than 650 footballs were signed by numerous Nebraska legends. At the Pairings Party friends helped Bob celebrate his 61st birthday with cake and singing. The next day, golfers enjoyed some great golf. Pinnacle Bank and Clear Channel Communications were the major sponsors. More than \$114,500 was raised from these three events.



Fans lined up for autographs



A foursome teeing off at Quarry Oaks Golf Club



Bob Hohn with his wife Sandy

Travel Wheelchair

In July and August, Amigo Mobility Center, has light weight travel wheelchairs available at a sale price of \$285.00 (normal price of \$425.00). There is a seat width of 17" or 19", a folding back, and swing away footrests. The chair weighs only 19 lbs. and is available in black. This sale is good through 8/31/02. It includes the ALS discount and is only available to ALS or MS patients, their caregivers and family members. Amigo Mobility Center located at 6212 Nieman Road in Shawnee, Kansas may be reached by calling (913) 631-5959.

THANK YOU HORIZON NATIONAL BANK!

On Saturday, June 22, over 50 ALS patients, caregivers, family members and friends enjoyed a day of relaxation, laughter, food and fun at the Second Annual ALS Barbecue at Shawnee Mission Park in Kansas City. This event, part of the United Way Annual Day of Caring, partners companies with charitable organizations. Horizon National Bank adopted the ALS Association Keith Worthington Chapter this year (as they did last year). The picnic was for the entire family and extended families of both the bank and the Chapter. Activities included pinatas, face painting, and a cake walk. The bank (with the help of donations from others) provided the hamburgers, hotdogs plus desserts and prizes for the cake walk and pinatas games. Through Horizon National Bank's generosity and hard work, this event was a great success!



Onlookers watch Ivan Brame swing at the pinata.



The Barb girls get their faces painted.



Jana Ruskanen helps her son Hunter.



Folks form a circle for the cake walk.

Caring for the Caregiver

Kansas Caregivers Coalition **August 16, 2002**
 Wichita 2002 8:00 am – 4:00 pm

Wichita Marriott
 9100 Corporate Hills Drive
 Wichita, Kansas

Sessions include:
 "Your Role as a Caregiver" - Dr. Ron Matson, PhD,
 Chair Dept of Sociology, Wichita State University
 "Family Dynamics" - Lu Duerkson
 "Hands on Caregiving" - American Red Cross

Break out sessions include:
 Legal & Financial Issues
 Medicare/Medicaid
 Long-term Care
 Maintaining Independence

For more information or to register,
 call the ALS office at (800) 553-9056.
Registration fee is \$5.00.

AUGUST BIRTHDAYS

Harry Warriner	August 1
Dennis Newcomb	August 3
Barbara Liger	August 8
Betty Wisler	August 13
Mickey Sparano	August 16
Ellen Wright	August 18
Ron McCormick	August 18
Earl Sanders	August 21
Judith Barton	August 21
Harold Bruce	August 24
Jacquelyn Houser	August 24
John McClure	August 27
Joseph Downs	August 29
Mike Georges	August 31

Schedule for ALS Walks

September 14 & 15, 2002	Kansas City	Theis Park
September 21, 2002	Omaha	Chalco Hills Park
September 28, 2002	Hays	Ft. Hays State Univ.
October 5, 2002	Salina	Bill Burk Park
October 12, 2002	Emporia	Jones Park
October 19, 2002	Wichita	Sedgwick Cnty. Park
October 19, 2002	Springfield	Phelps Grove Park
October 27, 2002	Manhattan	KSU Student Union

NIH Launches CAM On “Pubmed” — A Comprehensive Source Of Complementary And Alternative Medicine Information On The Internet

From meditation to magnets...the vast popularity of unconventional medical therapies has risen sharply over the past decade — to the extent that in 1997, Americans spent an estimated \$21 billion out-of-pocket for these treatments. People decide to use complementary and alternative therapies (CAM) for a variety of reasons; however, few CAM methods have been proven safe and effective.

Recognizing the need to provide authoritative CAM information, the National Center for Complementary and Alternative Medicine (NCCAM) and the National Library of Medicine (NLM), two components of the National Institutes of Health (NIH), have partnered to launch a new CAM subset of a larger medical literature database that will provide free, web-based, access to CAM sources of information.

“CAM on PubMed” is a new subset or part of PubMed, which is a free system offered by NLM that provides an easy way to access over 11 million citations and abstracts in the MEDLINE database and additional life science journals. MEDLINE currently covers nearly 4,500 journals published in the United States and more than 70 other countries. Approximately 60% of the indexed journals are published outside of the United States. In addition, “PubMed” links to over 1,700 journals for full text of articles (some publishers may require a subscription or fee) and provides links to citations of relevant MEDLINE articles. “CAM on PubMed” provides direct access to more than 220,000 references and abstracts related to CAM, as well as provides access to many full text articles.

“This joint venture will offer health professionals, CAM practitioners, researchers, educators, and consumers, ready access to a comprehensive database of journal citations directly related to complementary and alternative medicine,” said Donald A.B. Lindberg, M.D., NLM Director. “Through “CAM on PubMed”, NLM and NCCAM are providing a highly visible, easily identifiable portal to the evolving field of CAM research publications.”

The “CAM on PubMed” subset currently contains over 220,000 citations (records) of journal articles related to CAM research. As the field of research in complementary and alternative medicine grows and more articles are published in peer-reviewed journals, the service will greatly expand. “This is an important and exciting undertaking,” said Stephen E. Straus, M.D., NCCAM Director. “The opportunity to join forces with the world’s largest resource for biomedical literature represents a major step in mainstreaming CAM research information. The NLM possesses unparalleled expertise and experience to create and maintain this unique service,” Dr. Straus concluded.

“CAM on PubMed” offers literature and retrieval services, as well as article titles and abstracts related to CAM, and entire research reports. It is a service we hope will greatly benefit researchers, CAM practitioners, health care providers, students, and patients and their family members. For additional information about “CAM on PubMed” a question and answer fact sheet is provided at <http://www.nih.gov/news/pr/feb2001/nccam-05a.html> (and is included below).

NLM technical staff will maintain and evaluate the CAM subset of PubMed, as well as review CAM-related journal articles on a regular basis, and provide customer service to users.

The National Center for Complementary and Alternative Medicine (NCCAM) is dedicated to exploring complementary and alternative medical (CAM) practices in the context of rigorous science, training CAM researchers and disseminating authoritative information. For additional information, including fact sheets, press releases, and other information about NCCAM, please visit our Website at <http://www.nccam.nih.gov>.

The National Library of Medicine is the world’s largest library of the health sciences. The Library has an extensive Website at <http://www.nlm.nih.gov> that provides a great variety of information for the general public and for health professionals.

Memorials

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

*Ronald J. Bennett
Melba Madden*

In Memorium

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

*Ronald J. Bennett
Melba Madden
Gerald Woods*



PHONE SYSTEM CHANGE

IN THE KANSAS CITY OFFICE

In order to provide the most efficient and cost effective service, the Kansas City office has updated its phone system. Effective July 10, 2002, callers, during the hours of 8:30 to 5:00 Monday through Friday, will receive the following instructions:

- "If you know your party's extension dial it anytime, or to hear a directory of personnel press 3."
- "If this is a patient service related call, please press 1 to reach patient services staff."
- "Other wise dial 0 or hold the line."

FOR SALE

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

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

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

Dodge 1999 conversion van, RAM 1500, w/ wheelchair lift and lock. 11k miles, perfect and loaded. Appt only, 913-469-4188

Ranger 2 electric wheelchair, fully adjustable. As new. Appt only 913-469-4188

Invacare all electric, tilt wheelchair, red with removable ventilator shelf, lap tray, battery included, roho cushion, Best offer, Call 918-337-3577

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. 573-636-2550 or email sjseibold@mchsi.com.

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.

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

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.

Quickie II, adult, lightweight (27 lbs) titanium wheelchair in good condition with padded, swing-away arm rests, 8" pneumatic casters for easy ride on rough surfaces, 24" rear wheels with wheel locks and aluminum hand rims; 17" frame width, medium backrest with 8 degree bend and rear anti-tip tubes. The Jay seat, lumbar support and foot pedals easily disassemble for easy transport. Only used 10 months. Purchase price was \$1,784 (reduced from \$2,095). Sale price is negotiable. Call 573-445-2451 (Columbia MO area).

Handicapped equipped 79 Chevrolet van, 34,000 original miles, Ricon rear lift, \$2000. Please call for details. 913-789-8451 or email maryc@kcnet.com

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

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.

1998 Elec. Wheelchair Invacare Action Ranger II Storm Series, Loaded with Jell 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)

1997 Power Wheelchair, Everest & Jennings, Joystick control, new seat, clean and in great working condition. Small & compact to go through most doorways as well as tight spots in bathrooms, etc., yet large enough to handle most people. Includes batteries & charger. Arm rests can pivot or remove for transfers, swing out foot rests. \$1900.00 new. Asking \$350.00. Includes books & operating instructions. Call 816-373-2215.

1998 Power Wheelchair, Everest & Jennings, Joystick control, like new condition. \$2,500 new. Asking \$900.00. Used approximately 6 months. Small & compact. Includes new batteries and charger. Arm rests pivot or remove and foot rests swing out. Call 816-257-0641.

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

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

EMAIL ADDRESSES AND PHONE EXTENSIONS TO BETTER SERVE YOU:

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THE DIALOG

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AUGUST 2002	1	Thu	Wichita Support Group 7 pm Grace Presbyterian Church 5002 E Douglas	14	Wed	KC Day Support Group 2 - 3:30 pm Village Presbyterian Church 6641 Mission Rd. Prairie Village, Kansas	
	6	Tues	Kansas City Support Group 7 - 8:30 pm Second Presbyterian Church, 55th & Oak Dick Hime from Angel Flight	20	Tues	Springfield Support Group 7pm Springfield ALS Office 1447 - F S. Enterprise Scott Lopez Speaks About Wheelchairs	
	6	Tues	Columbia Support Group 1 pm Jack's Gourmet 1903 East Business Loop I-70, Columbia, MO	26	Mon	Topeka Support Group 7pm Topeka Assoc. for Retarded Citizens 2701 SW Randolph, Topeka,KS	
	7	Wed	Hutchinson Support Group 2 pm Grace Episcopal Church, 20th & Main	24	Sat	Wichita Caregivers Support Group Grace Presbyterian Church 5002 E Douglas	
	8	Thu	Omaha Support Group 7pm St. Pius Parish Center 6905 Blondo Street, Omaha, NE			Lincoln Support Group No meeting this month	
	9	Fri	KC Caregiver Support Group 12:30 -1:30 pm ALS Office 8340 Mission Rd. B4, Prairie Village, Kansas Must RSVP! (913) 648-2062				
							"What is ALS" Orientation Series by appointment. Please call (913) 648-2062

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

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

<p>Kansas City/Nebraska Linnea Brandt & Nancy Lindquist (800) 878-2062</p>	<p>Wichita Jean Haley (800) 553-9056</p>	<p>Springfield Betty Bruce (888) 386-1200</p>
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