

ALS

Volume V

Issue 3

The following are excerpts from the book, *On Any Given Day*, by Joe Martin and Ross Yockey:

I have ALS, amyotrophic lateral sclerosis, Lou Gehrig's disease, diagnosed in October 1994. There is no cure and no significant treatment. Statistics say most people die within three to five years after diagnosis. In my case, I was told to prepare for death in less than two years.

What we have learned, my friends and I, is that it is possible to live a full, active, satisfying life despite being given a "death notice" and now despite severe paralysis. It is possible to "recover" from an incurable disease. It is possible to recover life and to remain-or become-fully engaged in life. And the techniques we have used are applicable to many of life's traumas: the death of someone close, the breakup of a marriage, the loss of a job, an unbearable disappointment, a failure in school or at work, a debilitating disease.

I am certain that life is a gift and that life is to be cherished-in the face of disappointment, in the face of disability, in the face of pain, even in the face of death. We can do that by deliberately filling our lives with "love, hope, faith, joy, laughter, festivity, sense of purpose, determination, and will to live.

- Joe Martin

Diagnosed with ALS in 1994

Joe's rule for living, for recovering and healing, is poetic in its simplicity. "This is the day the Lord has made: Get up. Go to the ballpark, and do your very best." Amen.

Some of us are more prosaic. We need things spelled out. We require detailed instructions. I believe those instructions are contained in Joe's mantra, which can be reconstructed into a "ten commandments" of living, healing, and recovering, applicable to all of us.

- Ross Yockey
Co-Author

1

LOVE life and the people important to your life without condition, without expectation.

2

HOPE in each moment of every day, because more things are possible than you can imagine.

3

Have FAITH that God will let you know about the next life when this one is done.

Continued on page 2

“
I am certain that life is a gift and that life is to be cherished - in the face of disappointment, in the face of disability, in the face of pain, even in the face of death.
”



Be sure to RSVP for:

Dinner with Lou

6:30 p.m., Saturday, April 19th, 2003

See page 4 for details.

4
Build JOY out of the materials you find within
the day, with the help of those who
are here to be on your team.

5
Let LAUGHTER embarrass fear and stupidity,
let it heal the hurt in others.

6
Insist upon FESTIVITY, and never
miss a good cause for celebration.

7
Keep your SENSE OF PURPOSE intact,
in sight, and in focus.

8
Let your DETERMINATION be contagious,
expanding geometrically as you add to it the
determination of others.

9
Make WILL TO LIVE your will to love,
creating a regenerating cycle of power.

10
Until this life truly ends, understand
That on any given day-on this day-
POSSIBILITIES ARE ENDLESS.

Permission for use of the above has been granted from John F. Blair, Publisher.

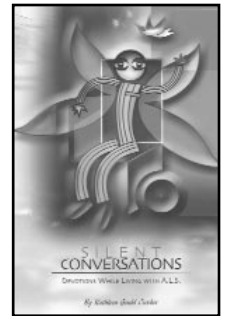
If interested in ordering a copy of the book, *On Any Given Day*,
call the toll-free number 1-800-222-9796 or visit their website at www.blairpub.com.

SILENT CONVERSATIONS

Devotions While Living with ALS
By Kathleen Gould Crocker

This is a book about how the strength and courage of
prayer and faith in God has transformed the life of Kathy
Crocker and her family. Through the struggles of living
with ALS to the most enjoyable moments of her past.

Cost of book including tax and shipping: \$13
To order send check or money order to:
Otter Creek Publications, Attn: Jerry Crocker
P.O. Box 184, Monticello, MN 55362



(Allow 2-3 weeks for delivery)

2003 National ALS Advocacy Day/Public Policy Conference

Representatives of the Keith Worthington Chapter will join other ALS Association chapters in Washington, D.C. on Thursday, May 1 to discuss the following 2003 public policy priorities with their legislators:

Issue: Complete the goal of doubling the NIH budget in fiscal year 2003, which was initially set to occur over a five-year period. Increasing NIH funding (by 15%) with specific focus on allocating funds for ALS within the National Institute for Neurological Disorders and Stroke (NINDS), is a necessary step for the ALS community in finding a cure.

Issue: Continue funding for ALS specific research in the fiscal year 2004 Department of Defense Appropriations bill (DOD) Peer Reviewed Medical Research Program (PRMRP). ALS was included as one of just twenty-eight diseases that is eligible for this funding in the 2003 fiscal year budget and researchers are currently preparing to submit applications. Continued funding for ALS specific research in the 2004 fiscal year budget will allow researchers to continue moving forward toward cause, treatment and eventual cure.

Issue: Support a prescription drug coverage plan that includes a provision for catastrophic coverage that is structured in a manner that will ensure the continued vitality of the drug discovery process and development of new and better pharmaceutical treatments and that is universal.

For those unable to travel to Washington D.C., the dates designated below as "District Work Period" are a great opportunity to meet with your Member of Congress back in the district to tell your personal story and to discuss the public policy priorities of The ALS Association.

The following is the 2003 Congressional Schedule:

January 7:	108 th Congress Convenes
February 17-21:	President's Day District Work Period
April 14-25:	Spring District Work Period
May 26-30:	Memorial Day District Work Period
June 30-July 4:	Independence Day District Work Period
July 28-Sept 2:	House Summer District Work Period
August-Sept 1:	Senate Summer District Work Period
October 3:	Target Adjournment

The District work period is when Members of Congress return back to their Congressional District to meet with constituents and to attend various local events.

Research News - from ALSA's National Office

March 10, 2003

Axonal Transport Alterations Play a Key Role in Motor Neuron Degeneration

Dr. Kenneth Fischbeck and his post doctoral fellow Dr. Imke Puls, National Institute of Neurological Disorders and Stroke, ALSA grantee, Dr. Erika Holzbauer, University of Pennsylvania School of Medicine, and Dr. Robert Brown, Massachusetts General Hospital, in collaboration with investigators at the University of Alabama and the National Institutes of Health report in the current issue of *Nature Genetics** their discovery of a mutation in dynactin linked to a human motor neuron disease. This study was funded in part by The ALS Association in support of Dr. Holzbauer's work. Funding by The ALS Association (ALSA) for Dr. Erika Holzbauer was generously provided by ALSA's Greater Philadelphia Chapter.

"The identification by Dr. Puls and her coworkers of a mutation in dynactin as the cause of motor neuron disease in a human kindred," says Dr. Erika Holzbauer, "and our ability to understand the defect at the molecular and cellular level, offers significant new insight into the importance of retrograde axonal transport to the motor neuron."

Dynactin is a protein complex that interacts with the motor protein dynein to transport important molecules from nerve endings to the cell body. This transport is required for normal functioning of the motor neuron. In an earlier study published by Dr. Holzbauer, over expression of another subunit of dynactin, dynamitin, disrupted this transport and resulted in motor neuron degeneration in a mouse model. Additional support for the critical role of this complex in the normal functioning of axonal transport comes from a recent report at the International ALS/MND symposium in Melbourne (<http://www.alsa.org/news/drugnews011003a.cfm>) where investigators showed that a mutation in dynein leads to motor neuron degeneration in mice.

The role of transport alterations as a possible mechanism for motor neuron degeneration has been described previously. Abnormal transport is seen early in disease progression in the ALS SOD1 mouse model, long before any obvious signs of hind limb weakness is detected. These studies further support this and most importantly identify a human mutation directly linking transport abnormalities to motor neuron death.

The mutation was identified in a large family from North America that show a slowly progressive motor neuron disease with onset in early adulthood. Unlike classical ALS, there is no upper motor neuron involvement. It will be important to determine whether other mutations in this transport system are linked to either familial or sporadic forms of ALS.

Dr. Kenneth Fischbeck is the co-organizer for The ALS Association's Young Investigator Workshops, hosted by ALSA's Greater Philadelphia Chapter. These workshops bring investigators together to share their data and form new collaborations. Indeed, as a result of last year's workshop, Dr. Fischbeck's post doctoral fellow Dr. Imke Puls, and Dr. Holzbauer's post doctoral fellow, Dr. Bernadette La Monte discussed the recent study showing axonal transport abnormalities in a mouse model with a dynamitin mutation, leading to the current productive collaboration to characterize the effects of the dynactin mutation in a human motor neuron disease. Dr. Robert Brown is a collaborator on the The ALS Association's Gene Identification Project to identify new genes for familial ALS (<http://www.alsa.org/news/news071502>).

*Puls, I., Jonnakuty, C., Holzbauer, E.L.F., Tokito, M., Mann, E., Kay Floeter, M., Bidus, K., Drayna, D., Oh, S.J., Brown, R.H. Jr., Ludlow, C.L., Fischbeck, K.H. 2003. Mutant dynactin in motor neuron disease. *Nature Genetics*

Assistive Communication Software

A communication software CD, created by the Chapter, is available to ALS patients at no charge. The CD contains the following four software programs:

ReadPlease - a voice program. It will read text that is typed into it.

Click-N-Type - a virtual keyboard. Displays an image of a keyboard so keys can be selected by using a mouse.

Point-N-Click - a virtual mouse. Displays a small graphic window. Mouse functions can be selected and then used on other windows application. Example: You can single click on a "click + drag" button, then move your cursor over an object and a single click will behave as if a click + drag were executed.

Dwell Pick - this is the new program. It is a virtual mouse program too. Again a small graphic window displays. From this window you can select the function that you want, then simply placing your cursor over an object for a half second will execute the function. You don't have to click, just let the cursor dwell over an object to perform the function.

For more information, please contact your Patient Services Coordinator.



Research Progress Update - from ALSA's National Office

March 3, 2003

Three-drug cocktail may represent effective strategy for ALS

In an article published on line* and appearing in print in the *Annals of Neurology*, Drs. Jasna Kriz and Jean-Pierre Julien at McGill University, Montreal, Canada describe their results of a three-drug cocktail in ALS SOD1 transgenic mice showing a dramatic increase of survival by six weeks and a delay of symptoms by one month. This study represents the second published study in the mouse model emphasizing the potential benefit of combination therapy for ALS and the first drug study in the animal model to show such dramatic benefits.

The investigators used the G37R SOD1 mouse model, not the G93A model described in the recent news item on minocycline and creatine combination therapy. (<http://www.alsa.org/news/news012303.cfm>) These mice show severe end-stage paralysis at 11 months of age. In this study, investigators started treating mice at 8-9 months of age, a time-point at which no obvious signs of paralysis are detected but disease is already in progress. The compounds of choice: minocycline, riluzole and nimodipine were administered in the diet. Previous studies, including work from this group of investigators, have shown that minocycline on its own can extend the life span of these mice by around two weeks. Although this study does not address whether the effect of either nimodipine or riluzole alone with minocycline would have effects similar to the combination of all three drugs, it does emphasize the importance of combination approaches in increasing the life span in this mouse model as compared with single drug treatments.

Detailed studies in the control and drug treated animals address the possible mechanism of how these compounds may be acting. Investigators determined that the compounds given together delay cell death mechanisms (apoptosis); axonal and motor neuron loss; and reduce the inflammation response as measured by decreased numbers of

activated microglia and astrocytes (cells surrounding the motor neurons which under conditions of stress become activated). Minocycline is an antibiotic, which has been suggested to show benefit in the mouse model of ALS by blocking inflammatory mechanisms, and inhibiting the release of important molecules involved in cell death pathways. Riluzole's mechanisms of action are not clear but believed to inhibit glutamate release. Nimodipine is a calcium channel blocker used in the treatment of acute stroke and the prevention of migraine headache. Increased calcium levels in motor neurons may activate a host of cell death cascades and it is thought that those neurons that die in ALS have reduced calcium buffering capacity. So, reducing the levels of calcium upon injury may increase cell survival.

Jean-Pierre Julien said "The benefits of the three-drug cocktail when tested in this animal model of ALS were quite remarkable. The results demonstrate the merit of a drug combination approach for treatment of a disease with complex degeneration pathways. The three drugs are currently available and we hope that our study will justify a trial on ALS patients."

Dr. Julien was the 2000 recipient of The Sheila Essey Award for ALS Research, presented by the American Academy of Neurology in partnership with The ALS Association through the generosity of the Essey Family Fund.

*Kriz, J., Gowing, G., Julien, J.P. Efficient three-drug cocktail for disease induced by mutant superoxide dismutase. Published Online: 14 Feb 2003. *Annals of Neurology* <http://www3.interscience.wiley.com/cgi-bin/abstract>

Dinner with Lou - April 19th

You're invited to

Dinner with Lou

-- a celebration of Lou Gehrig --
his modesty, his values, and his courage

When: Saturday, April 19, 2003 6:30 p.m.
Where: KC Royals Stadium Club
What: • Entertainment
Performance of the play
Lou Gehrig - The Luckiest Man
• Food
Hot dogs, popcorn, softdrinks, crackerjacks
• Raffle
Cost: Tickets are \$10, Children 5 and under are free

To purchase tickets:

- Call 913.648.2062, ext. 201
- Email to info@alsa-midwest.org
- Mail or bring your information to:
8340 Mission Road, B-4, Prairie Village, KS 66206

Be sure to include the following:

- First and last name
- # of adults & children and # of children under 5
- Method of payment: (check, cash, or credit card - number, expire date & name as appears on card)

In Memoriam

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

Milton Edwards
Lillian Harlow
Bonna Hinz

Francis G Johnson
Elwood Leach
Bob Leuck

Eileen Mee
Sandra J Sheaffer
Clarence Smith

Frances Smith
Doris Steele

Research Update - from ALSA's National Office

February 7, 2003

Nimesulide delays onset in a mouse model of ALS

In a report that appeared online this week in The Federation of American Societies for Experimental Biology (FASEB) journal (<http://www.fasebj.org/cgi/content/abstract/02-0876fjev1>), Dr. Pasinetti and his group at Mount Sinai School of Medicine, New York, in a study funded by The ALS Association, describe a significant delay in the onset of symptoms in a mouse model of ALS when treated with the compound nimesulide, a non-steroidal anti-inflammatory drug that preferentially inhibits cyclo-oxygenase-2 (COX-2).

In this study, nimesulide treatment in the mouse feed was started at 7 weeks of age. Levels of the nimesulide were measured in the blood as well as the levels of prostaglandin E2 (PGE2), a measure of how effectively COX-2 is inhibited. Motor tests including the rotarod to measure balance and a grid-walking test to measure motor strength and coordination were performed. Control mice not receiving the compound develop muscle weakness around 108 days whereas those receiving the compound developed symptoms around 120 days.

In a pilot study of nimesulide treatment in Alzheimer's patients the authors show that the compound is safe and tolerable. Besides the inhibition of COX-2 mediated inflammation (like Celebrex), nimesulide is also known to promote direct neuroprotection and may play a role in blocking activated microglia (cells surrounding motor neurons) believed to contribute to cell death mechanisms.

The data support a recent publication by Drachman et al., 2002 published in The Annals of Neurology* showing that inhibition of COX-2 delays onset of symptoms and prolongs survival in the mouse model of ALS. Clinical trials of inhibitors of COX-2 (Celebrex) are currently in progress. Dr. Pasinetti and colleagues are considering a clinical trial of nimesulide in patients with ALS.

* Drachman, B, Frank, K., Dykes-Hoberg, M., Teismann, P., Almer, G., Przedborski, S., and Rothstein, D., 2002. "Cyclooxygenase 2 Inhibition Protects Motor Neurons and Prolongs Survival in a Transgenic Mouse Model of ALS" Ann Neurol 2002; 52:771-778.

More about Dr. Pasinetti's study can be found on ALSA's web site at <http://www.alsa.org/research/scicur108.cfm>

Support Group News

Hutchinson Support Group

The Hutchinson Support Group had a smaller than average turnout with only 6 attending to hear the "Benefits of Chair Yoga and Exercise to ALS Patients," as presented by Jana Simon, certified trainer and educator from the International Institute of Yoga Studies in Wichita.

Omaha and Lincoln Support Groups

Although attendance at the March Omaha Support Group was low, there was open discussion and sharing as well as updates on upcoming events. In April, Lisa Oberg from Assistive Technology Partnership (ATP) will be the presenter and in May it will be Laura Ball, Speech Language Pathologist. Currently the plans are for a respiratory therapist to speak at the June meeting. The presenter for the April Lincoln Support Group will be someone from Assistive Technology Partnership (ATP).

Springfield Support Group

The Springfield Support Group met Tuesday, March 11th with 12 in attendance. Cari Wright of Southwest Center for Independent Living introduced attendees to the varied services provided by their non-profit organization including education, adaptive devices, telephone modifications, structural home modifications, and in-home patient support. Cari displayed a number of devices that could make simple chores such as buttoning and zipping clothing or turning a page in a book an easier task. Other topics of discussion included: The ALSA Walk to D'Feet ALS on October 11th, ALSA's Advocacy Day/Public Policy Conference in Washington, D.C., Research, Drug Trials, Identifying Resources for Medications and Updated "Living with ALS" booklets now available. The next support group meeting will be held April 8th at Cox Medical Center South, Meeting Room A next to the cafeteria.

Salina Support Group

The Salina Support Group was cancelled for the month of March due to winter weather conditions. Another Salina organizational Support Group meeting is scheduled for the 1st Tuesday of April at 7 p.m. at the Christ The King Lutheran Church on Magnolia and 9th Street across from the main shopping mall.

Wichita Support Group

The evening Wichita Support Group had 16 participants who took part in the exercises and following question and answer session with Jana Simon, International Yoga Instructor and Educator regarding the benefits of moderate exercise with the debilitated patient. Pamela and Randy Rayer attended and shared Pam's progress with the group, following her stem cell transplantation which took place this past January. We will meet at our regularly scheduled times during the month of April in both Hutchinson and Wichita.

The Caregiver Support Group Potluck Luncheon is scheduled for Saturday, March 22nd and April 26th from 11 a.m. until 2 p.m. at the Grace Presbyterian Church, 5002 E. Douglas, Wichita, Kansas.

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.

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

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. Retailer 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.

M a y B i r t h d a y s

Theresa Medellin	May 3	Paul Baker	May 16
Gary Bott	May 3	William Hisey	May 17
Rod Minniear 	May 4	Don Brower 	May 22
Mabel White 	May 8	Mary Bennett 	May 26
Betty Jo Hamm 	May 9	Gary McCullough 	May 27
Dorothy Bryan 	May 11	Joan Medill 	May 28
Eileen Leonard 	May 13	Maggie Eiken 	May 30
Allen Burnett	May 14	Carl "Duane" Davis	May 31
Sharon Dodd	May 14		

Memorials

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

<i>June Flint</i>	<i>Eileen Mee</i>
<i>Bonna Hinz</i>	<i>Sandra J Sheaffer</i>
<i>Francis G Johnson</i>	<i>Frances Smith</i>
<i>Jack Larson</i>	<i>Doris Steele</i>
<i>Elwood Leach</i>	<i>Howard L Wescott</i>
<i>Robert Leuck</i>	

ALS Association Keith Worthington Chapter

Upcoming Activities

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 *Jeff Julian & *Tom Watson

1:00 pm Tee time for each 5 person scramble

For more info call Sarah Kerwin at 913.648.2062, ext. 223.

*Jeff Julian is a young PGA pro diagnosed with ALS in 2001.

*Tom Watson's caddy was diagnosed in 2002.

Bob Hohn / ALS Celebrity Golf Tournament

Saturday, June 21, 2003

Indian Creek Golf Course in Elkhorn, Nebraska

Gale Sayers, NFL Hall of Fame Player, will join Frank and Pam Solich, Event Chairs, for the Second Annual Bob Hohn / ALS Celebrity Golf Tournament Friday, June 20th - Celebrity reception and banquet - Holiday Inn, Lincoln, NE

For more info call Ric Miller at 402.991.8788.

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

The Wichita ALS Pro-Am Golf Tournament

Monday, September 22, 2003

The Wichita Country Club

For more info call Kathleen Wille at 316.612.0188.

Request for ALS Study Participants

This case & control study will ask people with ALS located anywhere in the USA and their controls to complete an exposure assessment survey. Participants located in Iowa, Illinois and Eastern Nebraska will also be asked to provide a blood sample along with the survey. The blood sample is for testing enzyme reactivity. For more information please contact: Naomi J. Bienfang, Primary Investigator, University of Northern Iowa 239 Wellness/Recreation Center, Cedar Falls, IA 50614-0241
Phone: (319) 273-3689 Email: nomeinroma@yahoo.com

Ms. Bienfang lost her mother to ALS March 19, 2000.

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THE DIALOG

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A P R / M A Y 2 0 0 3

April Support Groups

- 1 KC Night 7 p.m.
- 1 Salina 7 p.m.
- 2 Hutchinson 2 p.m.
- 3 Wichita 7 p.m.
- 8 Springfield 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.
- 26 Wichita Caregivers 11 a.m.
- 28 Topeka 7 p.m.

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.

KC Night SG
2nd Presbyterian Church
55th & Oak

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

Hutchinson SG
Grace Episcopal Church
20th & 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
66th & 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!

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(800) 878-2062

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Sonya Glenn
(866) 762-6361

Springfield
Dorothy Foulk
(888) 386-1200

Wichita
Jean Haley
(800) 553-9056