

ALS

Volume V

Issue 3

The following poems were written in memory of
Marilyn Homan (1937-2002) & Norman Kenagy (1935-2002)
by their ministers:

“
Well done,
good and faithful
servant.
”

Wale's Tales

"Well done, good and faithful servant!"
The words ringing in my ear,
Bringing end to what has been an unbelievable year.
A life that meant so much to us has now come to an end,
And with her death, we all have lost a neighbor and a friend.
You'd find her in the kitchen
Directing volunteers,
Or working with the children's choir
Or wiping away the tears
Of grandchildren who lived with her,
Or running to and fro -
A woman with a job to do and many miles to go.
A flurry of activity from morn to setting sun,
And with the evening's coming, new tasks were then begun.
She'd sit behind the organ and fill our lives with song.
She'd do a program here and there, for groups where she'd belong.
And then, there were committees she worked on long and hard,
But rarely had the time to send that "put off" birthday card.
The PEO, the PTO, gymnastics and much more
Were only just a part of what her schedule had in store.
Suddenly there entered in an illness that was cruel,
And caused the pace to quickly cease by setting a new rule.
No Girl Scout cookies to give out. No music from her touch,
The ALS was moving fast and would not stand for much.
And death stepped in to claim her sons, a cruel and painful deed,
That only seemed to make ALS increase its dreadful speed.
In grief and sorrow, we will mourn the passing of this life,
And stand by those who now have lost a mother, friend and wife,
A co-worker, a sister, a teacher and a guide,
All left to remember who she was with pleasure and with pride.
And someday when the time is right, when our life too will cease,
We'll find her welcome there for us as we receive God's peace.

Continued on page 3



Check eBay after March 24th
for selected Night of Hope auction items.
For more information on Night of Hope, see page 5.



Support Group News

Kansas City Support Group - 1st Tuesday of each month 7 p.m.

The Kansas City night support group met Tuesday, February 4th at the Second Presbyterian Church. Patients, family members, friends, staff, Board members and five college students were present. Karen Haring, Speech and Language Clinician and graduate instructor from the University of Kansas Medical Center, and graduate student, Mary Kay Parn, spoke to the group about swallowing difficulties, practical coping techniques, and the importance of nutrition. After the presentation, there were questions, discussion, and socializing while enjoying valentine treats provided by Gretchen and Greg Courtney. The March 4th support group topic will be - Physical Therapy: How Much is Too Much and The Importance of Range of Motion.

Salina Support Group- 1st Tuesday of each month 7 p.m.

Due to sub-zero temperatures, attendance at the initial Salina support group was low. However, Norval Madden, guest speaker at both the Wichita and Hutchinson support groups, shared his presentation of the "Road To Inner Peace" which was so wonderfully received by both groups. He did tailor his thoughts for the smaller group and it became a more intimate discussion rather than a presentation.

Hutchinson Support Group- 1st Wednesday of each month 2 p.m.

The Hutchinson support group for February was a resounding success with 25 persons in attendance. They listened with rapt attention to Pamela Rayer along with her husband Randy and aunt Jeannine Rayl (hospice nurse) detail their experiences in Atlanta, Georgia receiving the Stem Cell Transplantation. There were many questions by the group about the diet that she has been placed on since the procedure that completely limits glutamate containing products and the anti-oxidant vitamin regime that accompanies it. She is very hopeful that this procedure will slow the ALS progression and it already appears to be slowing down her Lupus blood profile. We all wished her well in the coming months and will be watching her progress with eager anticipation.

Wichita Support Group- 1st Thursday of each month 7 p.m.

The support group for Wichita, scheduled for February 6th, was postponed until February 13th due to the inclement weather and snow storm. The rescheduled meeting was a rousing success. A record-breaking 46 patients, families and compassionately supportive friends were in attendance to hear Pamela and Randy Rayer speak of their recent Stem Cell Transplantation experience-sharing everything from their arrival in Atlanta, Georgia through their clinic experience, the testing, transplantation infusions, and the holistic, spiritual side of their entire trip. Pamela pointed out that they had met a couple on the plane in October when they were on their 2nd honeymoon who happened to be from Atlanta, Georgia. The husband was a magician and appearing where they were going. They proceeded to contact their only new Atlanta friend when they arrived in town this time and although this wonderful couple lived 40 minutes from the clinic they came every single day, stayed the entire time that the procedure was taking place and the husband/magician entertained the entire clinic with magic tricks to lighten their hearts.

She told of the commitment and sincerity of the entire staff and shared with us that Dr. Ghen is also an ordained Rabbi. They all prayed over Pam prior to her transplantation each day and also prayed over the Stem Cells just before the infusion began. She went on to say that Jane Reeb, Dr. Ghen's chief nurse spoke about the body, mind and spirit connection and how important it is to keep them in balance and what a powerful effect is exerted on our wellness.

The letter from Beth Bateman was shared with the group regarding the recent 2002 Drug Consortium study of FDA approved drugs and their impact on ALS. The letter from ALSA National Office was also shared in total so that they would appreciate ALSA's stand on the issue, as only one member of the entire consortium and of releasing information prematurely. There was a lengthy question and answer period and social reception following.

Wichita Caregiver Support Group

There were 10 in attendance at the luncheon on Saturday, Jan. 25th at Grace Presbyterian Church in Wichita. Many ideas were exchanged and topics discussed that were of immediate interest to all. There were many different levels of care giving represented at the meeting.

In light of the recent experience of Pamela Rayer receiving the Stem Cell transplantation in Atlanta, Georgia there was a lot of curiosity as to her progress. This spawned a discussion of excitotoxins and the role that Glutamate plays in ALS.

It was unanimously decided that it would be beneficial to have a speaker address the general patient and family support group on human sexuality and illness --- (the changes that can occur after diagnosis). It has been added to the upcoming agenda of possible topics.

The schedule for the 2003 caregiver's potluck luncheons has been set and will continue to be on Saturdays, but there has been a change in the time. The luncheons are now from 11 am. until 2 pm. This is to accommodate the church's new custodial schedule. The dates to remember are:

February 15 th	June 21 st	October 25 th
March 22 nd	July 26 th	November 22 nd
April 26 th	August 23 rd	December 20 th
May 24 th	September 20 th	

Topeka Support Group

The Topeka Support Group met on Monday, February 17th. Attendees participated in open discussions and made plans for future meetings. Please take note of the dates that have been set for the upcoming year:

March 31 st	July 21 st	November 17 th
April 28 th	August 25 th	December - No meeting
May 19 th	September 15 th	
June 23 rd	October 20 th	

Continued from page 1

A Tribute To Norman Kenagy

By Roger M. Goodwin

Norman is the kind of guy,
That pastor's really appreciate.
He's willing to serve and give,
His work is always first rate.

He was a faithful deacon,
He was a Sunday school teacher,
He knows and loves God's Word,
He could have been a great preacher.

Norman was a faithful choir member,
He loved to sing and praise the Lord,
His voice blended with the choir,
Together they sang in one accord.

Quartets were a special feature,
That the church loved to hear.
Norman's voice always blended in,
And came through sweet and clear.

A faithful witness in good times and bad,
Norman's life has left a shining light,
That has strengthened our congregation,
His lifestyle points out what's right.

A faithful friend and man of God,
His life helps us to see and know.
That no matter how hard the fight may be,
Our God will win, no matter what the foe.

So Norman, we want to let you know,
How special and loved you are.
Thank you for your love and faithfulness.
Your influence has traveled far.

I feel that one day you'll hear,
Our Lord say your name so clear.
"Well done My faithful servant,
Join those that I hold so dear."

Research Update - from ALSA National Office Creatine and Minocycline as Treatment Against ALS

Scientists report today in the current issue of *Annals of Neurology* that mice treated with a combination of Creatine and Minocycline show a greater increase in survival than either drug alone. Robert Friedlander, a professor of neurosurgery at Brigham and Women's Hospital and Harvard Medical School in Boston and his group treated mice presymptomatically with either Minocycline or creatine alone and compared them to mice treated with Creatine and Minocycline. There was 12% increased in survival in the group of mice treated with creatine and a 13% increase in survival in the group treated with Minocycline. In mice treated with the combination of the two compounds survival was increased by 25%. This is very encouraging data arguing for the value of combining drugs acting on different disease mechanisms for ALS. No adverse effects were detected in the mice treated with both drugs. Currently trials are ongoing for both Creatine and Minocycline. Although it is likely that many patients are already taking both Creatine and Minocycline, a controlled clinical trial combining these two drugs would be valuable to determine whether there is an increase in efficacy of the two drugs when given together. It should be noted that many of the compounds tested in the mouse models of ALS including this study are administered prior to onset of symptoms. This is not the case in the clinical setting where patients are already showing symptoms of the disease at the time they take the drugs and may account for the modest effect of these drugs in the clinic. This further supports the potential of combining drugs acting on different disease mechanisms to treat patients with ALS.

Stephen Scelsa, MD, Director of the Neuromuscular Division and ALSA certified Center, Beth Israel Medical Center and Associate Professor of Clinical Neurology, Albert Einstein Medical School, New York, New York, comments, "This is exciting news since many leaders in ALS research believe that progress will be made in slowing disease progression by combining less effective therapies with different mechanisms of action. It will be important first to show, through clinical trials, that each of these drugs has at least some marginal benefit in patients with ALS, before trying combination therapy, since only one drug in a combination may be effective. Fortunately, both Creatine and Minocycline have few serious side effects. I hope that the findings in clinical trials of these drugs in humans will mimic the findings in mice. We will only determine this by carefully planned, placebo-controlled trials."

"This is an important finding from animal research that may have a potential direct benefit for people with ALS," notes Mary Lyon, RN, MN, ALSA's Vice President, Patient Services. We can all be very encouraged that these two therapies had an additive effect in the mice without significant adverse events or side effects.

The next steps are to encourage and support replication animal studies and to consider clinical trials with Creatine and Minocycline in people with ALS. Although both creatine Minocycline and (physician prescription required) are currently available, ALSA stresses the importance of consulting with your ALS physician before starting any treatment.

Both Creatine and Minocycline are in clinical trials now as sole therapies. The results of these studies will be important in determining if the combination of the two may benefit people with ALS. An important distinction between the animal study and human trials is that the combination treatment was begun with the mice before the onset of symptoms of the disease.

Combination therapy for ALS has long been a goal in the ALS community and this study is an exciting sign that the hope may be realized soon. The ALS Association's Drug Company Working Group convenes researchers, clinicians and pharmaceutical companies to encourage ALS drug development and establish relationships to facilitate combination therapies in ALS.

Support Group News - continued from page 2

Springfield Support Group - 2nd Tuesday of each month 7 p.m.

The Springfield support group meeting was held on Tuesday, February 11 at Cox Medical Center South. There were sixteen in attendance. The presentation was delivered by Beth Hecker, Occupational Therapist, and her assistant. They brought a wide array of assistive devices and demonstrated the use for each of them. Attendees had questions and suggestions for adaptations. The next meeting will be held on Tuesday, March 11 in Meeting Room A next to the cafeteria.

Clinical Bulletin - from ALSA's National Office

Use of "AIDS Cocktail" in People with ALS

Last week, Canadian media released a story about a woman with ALS who has been treated for the last 18 months with an AIDS cocktail. She and her ALS physician, Dr. John Turnbull of McMaster University in Ontario, Canada, report that her disease has slowed down and some symptoms have improved or gone away. This is an encouraging report and ALSA is pleased to learn that Dr. Turnbull has begun a small clinical trial with this cocktail of AIDS drugs. Results of this trial will be available later this year.

ALSA's perspective and comments:

There is no peer-reviewed evidence at this time that indicates that the "AIDS cocktail" also known as HAART (highly active antiretroviral therapy) is beneficial to people with ALS. There can be significant side effects with this therapy. Until more is learned, ALSA is cautious about taking the report of a single case study as an indicator of what the treatment might mean to a population of people with ALS.

Two reports appeared in the medical literature in 2001 describing studies in which HIV positive patients with accompanying ALS-like syndromes showed stabilization or partial recovery of the ALS syndrome after starting antiretroviral therapy. (<http://www.alsa.org/news/news092801.cfm>)

Encouraged by these initial published reports, ALSA is sponsoring a small pilot study to test whether patients with ALS who are negative for HIV would show similar reversal of symptoms when treated with Idinavir, a protease inhibitor (different from that in the HIV cocktail, but in the same class). Idinavir was selected because it can cross the blood brain barrier. This study will be completed in May 2003 at which time results will be made available. (<http://alsa.org/research/scicur111.cfm>)

Studies to investigate whether retroviruses are involved in ALS are in progress. The protease inhibitor Indinavir and the related compound in the AIDS cocktail may be effective in preventing caspase-dependent apoptosis (a cell death pathway involved in motor neuron degeneration). More evidence from animal studies are necessary to support this hypothesis.

ALSA is currently unaware of any other trials using the AIDS cocktail. ALSA will keep the ALS community informed should we be alerted to any other ongoing efforts.

ALSA is always watching for anything that will make a difference in this horrendous illness. ALS medical literature includes reports of some cases in which the individual's disease fluctuates. The ALS community needs to have data from carefully controlled and well-designed laboratory and human studies to be confident that this or any treatment is truly safe and effective for ALS. The published results of this one case study, the pending results of the Indinavir study, and the data from the small clinical trial Dr. Turnbull has begun will provide important information to substantiate whether this therapeutic approach holds the promise for others with ALS.

People with ALS should consult with their neurologist concerning this information.

Clinical Update - from ALSA's National Office

Potential Use of Avonex and/or Antegren for People with ALS

Introduction:

ALSA's National Office and a few chapters have had inquiries from patients and family members about the potential use of Avonex and/or Antegren for people with ALS. Below is a summary of what is known at this time.

Summary:

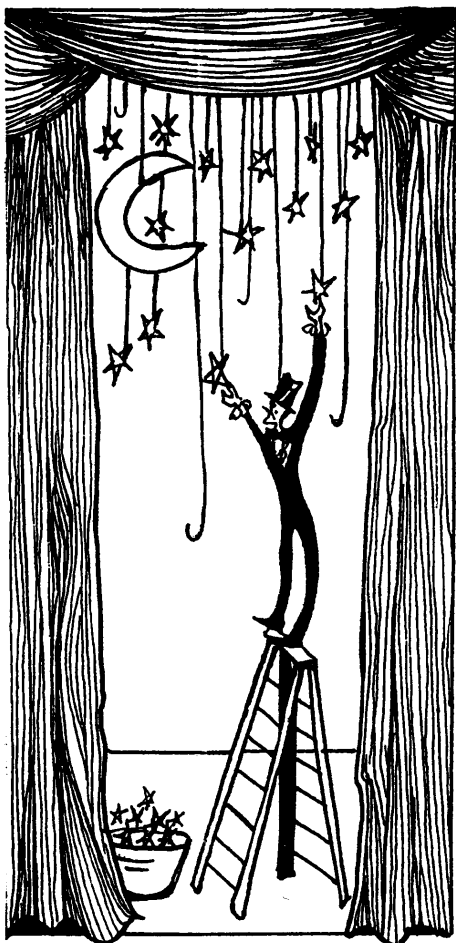
Avonex, also known as Beta-interferon-1A, is given intramuscularly to patients with multiple sclerosis (MS). The indication for Avonex in MS is for the treatment of relapsing forms of MS to slow the accumulation of physical disability and decrease the frequency of clinical exacerbations. In a laboratory culture system, Avonex has been shown to block activation of microglia. These are cells that surround motor neurons and are thought to contribute to cell death. There is a product, Rebif, which is also Beta-interferon-1A, but is administered subcutaneously. There are a few published pilot studies using beta-1a interferon in ALS, but none of them showed an effect in ALS patients.

Antegren (Natalizumab) is the first in a new class of drugs known as SAM (selective adhesion molecule) inhibitors. In MS, immune cells migrate through the blood-brain barrier into the brain leading to inflammation and destruction of the myelin sheath (the insulation for the nerves) and eventual nerve cell death. Adhesion molecules on the surface of the immune cells play an important role in the migration of these cells. Natalizumab binds to a specific adhesion molecule on the immune cell surface known as alpha-4 integrin. By binding to alpha-4 integrin, natalizumab may inhibit immune cells from leaving the bloodstream and prevent them from migrating into the brain or worsening the disease condition. A Biogen web link is included for more information http://www.biogen.com/site/content/news/pr_detail.asp?id=193.

Dr. Stan Appel, Baylor Medical Center, Houston, Texas, is conducting a small pilot study of Avonex and Antegren in ALS. Clearly, MS differs from ALS; however there are some scientists who believe that migration of inflammatory cells from the periphery may play a role in the ALS disease mechanism. The work of a number of these researchers, such as Dr. Appel's, focuses on this theory of ALS pathogenesis. Dr. Appel indicates that the pilot study is in progress and it is unclear at this point whether there is any benefit of this dual drug treatment. Should it be beneficial, he will certainly expand the study.

Both compounds described above are potentially working through an inflammation mechanism, although the specific mechanisms and how this may be beneficial in ALS patients is speculative and currently unknown. ALSA will keep you informed of any positive results or further work with these two drugs.

Upcoming April Events



A Night of Hope Goes Broadway - April 4th The 14th Annual Benefit for ALSA

Featuring "Bound for Broadway" Eric DeGray
Co-Starring Sevi Krigel and Patty & Jerry Reece

Friday, April 4th, 5:30 p.m. - Sheraton Overland Park Hotel
Cocktails, Gourmet Dinner, Entertainment,
Live & E-Bay Auctions & Raffles

Raffle Items:

A 2003 CTS Cadillac or \$10,000 cash!
Create Your Dream Vacation
Home Entertainment Package

Sponsorships \$3,000 and up
Tables \$1,750 and \$1,900
Individual Tickets \$175 and \$250

Contact Emily Marsh at 913.648.2062, ext. 221 to purchase raffle tickets, make table reservations or volunteer for the event.

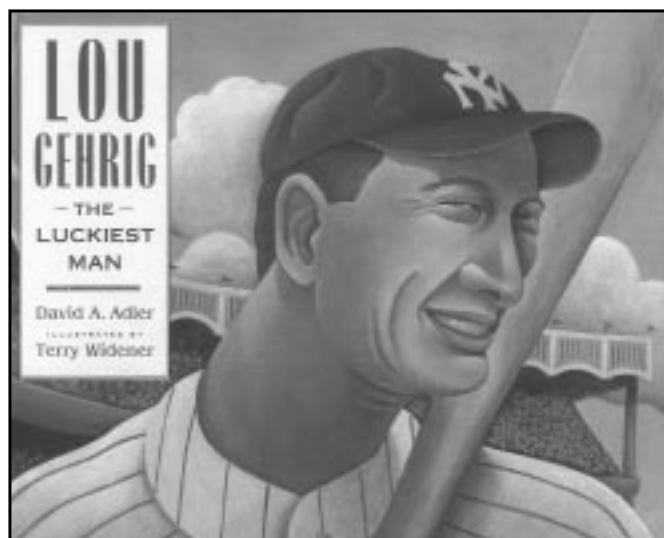
Dinner with Lou - April 19th

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 pm
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



This inspirational story has been made into a play and will be performed by the Advanced Repertory students of Shawnee Mission East High School.
WDAF-TV Fox 4 Sports Director, Frank Boal, will be the narrator.

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)

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, lap tray, 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 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 sjsiebold@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-Model 18350 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. Retail 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.

April Birthdays

Brett Zizza	April 1		Paul Palenske	April 13	
Lee Conaghan	April 1		Phillip Dick	April 13	
David Clark	April 2		Bobby Burnette	April 14	
Mel Martin	April 3		Ron Medlock	April 14	
Leonard Kewi	April 4		Terry Eason	April 14	
Jerry Katz	April 5		Marion Cox	April 16	
Bonna Hinz	April 7		Curt Brown	April 18	
Maxine Hook	April 9		Eddie Handlen	April 20	
Elizabeth Penner	April 11		Judy Suhr	April 21	

In Memoriam

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

<i>Lil Ferrell</i>	<i>Robert Hehmeyer</i>	<i>David Taylor</i>
<i>Greg Honas</i>	<i>Jeff Pair</i>	<i>Don Weigel</i>

Memorials

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

<i>Lil Ferrell</i>	<i>David Taylor</i>
<i>Robert Hehmeyer</i>	<i>Lenore Coates Vaughan</i>

New Staffing in Springfield

The ALS Association-Keith Worthington Chapter is proud to announce new staffing in Springfield. Dorothy Foulk, RN, has been hired as the Patient Services Coordinator. She served as the Director of Intensive Services and Manager of the NeuroPsych Unit at Ozarks Medical Center before moving to the Springfield area. She has extensive experience with coordination of care and services. After spending the week of January 20th in Kansas City for training, Dorothy began her position on Monday, January 27th. She will be working with patients and caregivers in Central/Western Missouri.

Mac McCartney and Larry Freund, of Development Management Services, have been hired as Awareness and Development Coordinators. Mac served as the Mayor of Springfield from 1993 to 1995 and Mayor pro-tem from 1989 to 1993. He has served on numerous local, state and national boards and councils and has extensive knowledge of the inner workings between the public and private sectors of our economy. Larry held management and sales positions with Hallmark Cards and Polaroid Corporation. He works with several charitable boards in Missouri and is a Director of Springfield Trust Company.

The Chapter is excited to have Dorothy, Mac and Larry as members of the ALS Association team!

For Those Interested in ALS Legislation. . .

On Thursday, May 1st, the Keith Worthington Chapter will be meeting with members of Congress to discuss several legislative issues of importance to ALS patients, caregivers and families. Join us as we participate, along with other Chapters across the country, in The ALS Association (ALSA) Advocacy Day/Public Policy Conference in Washington, D.C.

In preparation for National ALS Advocacy Day, there will be a strategy session and kickoff awards presentation on Wednesday, April 30th. Then on Thursday, May 1st, the Chapter will visit Senators and Representatives from Kansas, Missouri, Nebraska and Iowa.

The cost for Advocacy Day is \$50. ALSA's special rate for the hotel (Renaissance Hotel, 999 Ninth Street NW, Washington, D.C. 20001) is \$147/night (single/double) (plus tax). For more information, please call the Kansas City office at 913.648.2062, ext. 212 or email us at info@alsa-midwest.org.

Mark Your Calendars. . .

The Joe McGuff ALS Golf Classic - June 2nd

The Joe McGuff ALS Golf Classic
Monday, June 2nd, 2003
The Jack Nicklaus Golf Club at Lion's Gate

11:30 a.m. Lunch
12:30 p.m. Clinic presented by Jeff Julian
(A young PGA pro who was diagnosed with ALS in 2001)
1:00 p.m. Tee time for each five man scramble

If you have questions or would like to participate or volunteer, please call Sarah Kerwin, event director, at 913.648.2062, ext. 223.



George Brett passed tournament honors to baseball great, Joe McGuff at a press conference at the Nicklaus Golf Club at Lion's Gate on January 30, 2003.

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National Website
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THE DIALOG

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M A R C H / A P R I L 2 0 0 3

March Support Groups

- 4 KC Night 7 p.m.
- 4 Salina 7 p.m.
- 5 Hutchinson 2 p.m.
- 6 Wichita 7 p.m.
- 11 Springfield 7 p.m.
- 13 Omaha 7 p.m.
- 14 KC Caregivers 12:30 p.m.
- 19 KC Day 2 p.m.
- 19 Lincoln 6:30 p.m.
- 22 Wichita Caregivers 11 a.m.
- 31 Topeka 7 p.m.

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.

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!

Kansas City
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(800) 878-2062

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Sonya Glenn
(866) 762-6361

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Dorothy Foulk
(888) 386-1200

Wichita
Jean Haley
(800) 553-9056