

ALS

Volume V

Issue 7

Ceremonies to Honor Gehrig's 100th Birthday



. . .but who can
tell that it might
not lead to
greater things?



Harry Warriner grew up a baseball fan. His favorite player was Lou Gehrig. In January 2000, at the age of 70, Harry was diagnosed with ALS - the disease that bears Lou Gehrig's name.

Had he lived, Gehrig would have turned 100 years old on June 19th, 2003. Supporters of the ALS Association gathered in Cooperstown, New York - home of the Baseball Hall of Fame - and in ballparks around the country, to celebrate Lou Gehrig's birthday.

Harry was fortunate enough to be included as a key player in the festivities. Harry and his former neighbor and baseball fan, Danne Webb, represented the Midwest at the celebration.

The ALS Association had made arrangements for two Baseball Hall of Famers to participate in the events of the week. Robin Roberts and Gaylord Perry represented the players in the Hall of Fame, and throughout the events, shared stories and anecdotes on all kinds of topics, baseball and non-baseball.

Neither Harry nor Danne had ever been to the Hall of Fame, and the Hall exceeded their expectations. Harry posed for pictures next to the Hall of Fame plaques of Lou Gehrig, Stan Musial (also one of Harry's favorite players), and Jim "Catfish" Hunter, who died of ALS. Danne enjoyed the displays featuring his favorite player - George Brett.

ALSA had arranged for a private viewing of many of Lou Gehrig's personal artifacts, including his 1939 Yankees uniform, a bat he used in the 1937 All Star Game, and a glove that was presented to him during a barnstorming tour of Japan with Babe Ruth.



Harry Warriner with
Gehrig's Hall of Fame
Plaque in Cooperstown

Continued on page 2



Don't forget that you can register online and
make donations for all 16 Walks to D'Feet ALS
in Kansas, Missouri and Nebraska!

See page 11 for more information.

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Living with ALS - Continued from page 1

The head librarian of the Hall of Fame, Jim Gates, had also arranged for some very special documents to be available. One of those documents was a handwritten letter from Lou Gehrig to his wife, Eleanor, which he wrote in May of 1939. Historians originally thought the letter was written after Lou Gehrig was diagnosed with ALS; however, further research has indicated that the letter probably predates his diagnoses and relates to his decision to take himself out of the lineup following his remarkable consecutive games streak of 2,130 games. In the letter, Lou wrote:

My Sweetheart - and please God grant that we may be ever such - for what the hell else matters - That thing yesterday I believe and hope was the turning point in my life for the future as far as taking life too seriously is concerned - It was inevitable, although I dreaded the day, and my thoughts were with you constantly - How would this affect you and I - that was the big question and the most important thought underlying everything - I broke just before the game because of thoughts of you - Not because I didn't know you are the bravest kind of partner, but because my inferiority grabbed me and made me wonder and ponder if I could possibly prove myself worthy of you - As for me, the road may come to a dead end here, but why should it? - Seems like our backs are to the wall now, but there usually comes a way out - where, and what, I know not, but who can tell that it might not lead to greater things? - Time will tell -

The Hall of Fame also presented the original letter from the Mayo Clinic dated June 19th, 1939, where the Mayo Clinic advised the world that Lou Gehrig should not play baseball anymore because he had to conserve his energy and his muscle strength. Ironically, that letter is dated on Lou Gehrig's 36th birthday.

One of the other highlights of that presentation was the opportunity to spend some quality time with Helen Hunter, Jim "Catfish" Hunter's wife. She had not been back to the Hall of Fame since Catfish was enshrined in 1987. A delightful woman from North Carolina, Mrs. Hunter shared stories of her husband's baseball career and private life.

The Baseball Hall of Fame keeps archives of articles, photographs and documents for every member of the Hall of Fame. At Mrs. Hunter's request, the library staff brought up Jim Hunter's files. Watching her leaf through volumes of articles, some of which she had never seen before, was a true privilege. In an ironic twist, Harry pointed out to Mrs. Hunter that several of the early articles had been written by Joe McGuff, Kansas City's fabled sportswriter who, himself, has been diagnosed with ALS.

For Harry, although the Cooperstown trip had ended, his involvement in the Lou Gehrig celebration had one piece remaining. The Keith Worthington Chapter had made arrangements with the Kansas City Royals for an on-field ceremony on June 19th, 2003 before the afternoon game between the Royals and the Minnesota Twins. Although ALS has left Harry with restricted range of motion in his arms, he was able to throw a Dan Quisenberry-like sidearm strike to his catcher, ALS Board Member Dan Winter. The pitch followed a public service announcement by Bob Costas about the disease and the efforts being made to find a cure.

Harry and those who accompanied him remained on the field while Grammy Award Winner Larry Gatlin sang the National Anthem. Immediately following the Anthem, Larry Gatlin shook Harry's hand and said, "You are an inspiration to us all."

ALS is not just Lou Gehrig's disease.

Bigger Than the Sky

The True Love Story of Emilie and Her Grandfather

By Helene E.D. Nichols - Published June 2003

Paperback \$20.99, Hardback \$30.99

130 pages

Available at any major bookstore or online at

Amazon, Barnes & Noble,

Borders or Xlibris.

In October 1994 Steve Nichols was diagnosed with ALS. In March of 1997 his life was turned around again with the birth of granddaughter Emilie. Despite his inability to walk or talk, Steve and Emilie have found their own ways to interact, communicate and have fun together. Having inherited her grandfather's undaunted spirit as well as his drive, Emilie declared recently, "When I grow up, I want to help people with ALS, and plain people too."

Bigger Than the Sky, written by Steve's wife, Helene, is an endearing tribute to the extraordinary little girl and the incredible man who happen to belong to each other.

Advocacy Alert

From Steve Gibson, ALSA's Vice President, Government Relations & Public Affairs

Presumptive Eligibility Announced for Persons with ALS

The ALS Association is very pleased to share with you today that Social Security Commissioner Jo Anne Barnhart announced the inclusion of a presumptive eligibility ruling for persons with ALS. This is a monumental breakthrough for ALS patients, as they will automatically gain disability status at the time of their diagnosis from their primary neurologist. This disability status will make receiving disability benefits far less tedious and frustrating. In fact, it can help an ALS patient receive disability benefits months, and even years before patients might have received benefits prior to this ruling. Upon gaining disability status, persons with ALS must still wait the 5-month period before they will receive their benefits.

The Office of Management and Budget (OMB) must give its final approval of this rule making before it officially becomes law. While the OMB review process can take as long as 90 days, we are hopeful that this new ruling will be approved in a shorter period. The Advocacy Department will continue to monitor this process and will give you an update as soon as OMB gives its final approval of this ruling.

Thank you to the hundreds of ALSA Advocates who reached out to their Members of Congress during National ALS Advocacy Day. Due to your efforts, 82 Members of Congress sent a letter to Commissioner Barnhart requesting this important change. Please thank your Member of Congress for their assistance.

A special thanks also goes to Mr. and Mrs. John Hunter from our Northeast Ohio Chapter and Duane Pohlman, chief investigative reporter for Channel 5 News in Cleveland, OH. This effort began by their initiative when John Hunter applied for but was denied disability benefits by his local Social Security Office because the office said that Mr. Hunter "could still walk with a normal gait." This outraged the Hunters and with the assistance of Mr. Pohlman, made the story public. They then traveled to Washington, D.C. last February, and we met with Members of Congress from the Ohio Delegation and made the claim for presumptive eligibility for ALS patients nationwide.

Please remember, in order to get up-to-date information about ALSA's 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. If you have any questions, please contact Ted Burnes toll-free at: 877-444-2572 or via e-mail at: ted@alsa-national.org

The Bob Hohn/ALS Celebrity Golf Tournament Raises Approximately \$100,000 For the Fight Against ALS in Nebraska

Gayle Sayers joined Frank & Pam Solich as Chairs for this year's second annual golf tournament hosted by The ALS Association Keith Worthington Chapter and the Bob Hohn ALS Foundation. Together they made a difference!



Rotzin & Sayers



Lansing Grain Team



Hohn & Solich



Williamson Auto Team



Former Senator Bob Kerry

The ALS Association and U.S. Department of Veterans Affairs establish registry of veterans with ALS; data may provide platform for future studies

Nationwide effort underway to enroll all living veterans

Calabasas Hills, CA (July 10) - The ALS Association (ALSA) is collaborating with the U.S. Department of Veterans Affairs (USDVA) in a nationwide effort to enroll all living veterans with amyotrophic lateral sclerosis (ALS) in the National Registry of Veterans with ALS, the first registry to identify and track the health status of veterans with this progressive neurodegenerative disorder.

"The purpose of this registry is to identify veterans with ALS, make them aware of emerging treatment studies and offer them the opportunity to participate in research into potential causes of the disease," said Dr. Eugene Oddone, co-principal investigator of the health-tracking project.

Veterans of any era who have ALS are eligible to enroll. They will complete an initial telephone interview, covering their health and military service, and will be interviewed twice yearly thereafter. Enrollees may be contacted regarding clinical trials and other studies related to ALS, but are under no obligation to participate.

"We hope the registry will provide the systematic information that researchers require to develop new studies focused on any potential relationships between military service and ALS," said Dr. Lucie Bruijn, science director and vice president of ALSA.

ALSA, which is advising the registry study leaders, has played a lead role in advocating for the registry, boosting public awareness and in ascertaining prospective enrollees. In addition, ALSA is working closely with researchers in exploring the potential for an array of additional basic science and genetic studies.

"One of the main goals of the registry is to be able to inform veterans about clinical trials, both by VA and non-VA investigators," Oddone said. "We have a scientific review committee of ALS experts who will evaluate potential studies. If they think a particular study has merit, we will inform registry members about it."

The ALS registry will be directed by the Epidemiologic Research and Information Center (ERIC) at the Durham VA Medical Center, with cooperation from the VA Medical Center in Lexington, Ky. Oddone and Edward Kasarskis, MD, PhD, are co-principal investigators of the registry.

Known as Lou Gehrig's disease, ALS kills the brain and spinal cord cells that control muscle movement, resulting in gradual muscle wasting and loss of movement. Only 20 percent of ALS patients live beyond five years. ALS affects as many as 30,000 Americans at a given time. The disease usually strikes those between ages 40 and 70.

In preliminary findings announced by the VA in December 2001, a higher incidence of ALS was noted among veterans who had been deployed to the Persian Gulf region during the Gulf War than among those not deployed. This study, funded by the VA and the Department of Defense and involving ALSA and other health agencies, has resulted in the discovery of the first possible link between Gulf War service and a specific disease. A final report on this study is expected to be published in 2003.

"The ALS Association is committed to assisting the Department of Veterans Affairs in identifying this distinct group of veterans who have ALS and who may become the key to a deeper understanding of any links between the military and this disease," said Mary Lyon, vice president of patient services for ALSA.

For more information about the ALS Registry, eligible veterans or their family members or friends can call 1-877-DIAL-ALS or e-mail als@med.va.gov.

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

Scientists Announce Two New Genetic Sites Linked to Familial ALS

July 22, 2003

Three independent groups of researchers have identified families with linkage to chromosome 16, providing strong evidence that another gene associated with familial ALS is close to being identified. There are four families linked to chromosome 16. The affected family members exhibit both upper and lower motor neuron involvement - classical ALS. In addition, one of the studies identified linkage in another family to chromosome 20.

These independent studies provide a powerful foundation from which to move in on the next ALS gene. This study has been greatly helped by the collaboration that has been of enormous value in consolidating the finding, according to Dr. Jackie de Bellerche, Imperial College London.

These findings are reported in three articles published in the August 2003 edition of the American Journal of Human Genetics. Among the research teams are currently ALSA-funded researchers Drs. Robert H. Brown, Massachusetts General Hospital, Jackie de Bellerche, Imperial College London, Charing Cross Hospital, and Christopher E. Shaw, King's College in London.

"The next step -- identification of the mutant gene -- will have an enormous impact on ALS research, similar to that of the SOD1 discovery in 1993," said Dr. Lucie Bruijn, science director and vice president, The ALS Association. "Because there is some overlap in linkage to a region on chromosome 16 in the four families, the region of special interest is reduced. That should expedite gene identification."

Several aggressive approaches are already underway to identify the specific gene. The ALS Association's Gene Identification Project is an accelerated approach. This \$1.5 million collaborative study, launched last summer, is focused on chromosome 16. That project led by Drs. Robert Brown, Jackie de Bellerche, Guy Rouleau, Teepu Siddique, Eric Lander and Pieter de Jong applies techniques used in the Human Genome Project. In parallel, investigators are using the standard "candidate gene" approach, selecting genes in the area and sequencing them.

The ALS Association's interest in and support of ALS genetics studies dates back to the mid-1980s when other entities thought it too high risk. The payoff came in 1991 and 1993 with the discoveries of linkage of familial ALS to chromosome 21 and the mutant SOD1 gene respectively. Those discoveries have provided invaluable information about both familial and sporadic ALS, including models to study disease onset and progression as well as to test potential therapies.

Thank You Sprint!

Over 50 PALS, caregivers, family members and friends enjoyed a pot luck picnic with food, fellowship and fun at Shawnee Mission Park on Saturday, June 21st. This event was part of the United Way Annual Day of Caring that partners companies with charitable organizations. This year Sprint was our partner and provided a team of individuals who helped with picnic set up, cooking and clean up. Cathy Casto from Horizon Bank, a previous Day of Caring partner, applied her art expertise in face painting. Thanks to all who helped make this day a success!



The Fritzs



The Barbs



The Murrays



The Manfords



Sprint Volunteers

3 New Data Implicates Abnormalities in VEGF Gene as a Risk Factor for ALS

July 14, 2003

A new study by a group of European researchers has produced data that strongly implicates the VEGF gene as a risk factor in ALS. The study, in the current issue of Nature Genetics, reports that VEGF (vascular endothelial growth factor) may be a modifier gene associated with motor neuron degeneration. This finding could be significant for sporadic ALS, which accounts for 90 percent of ALS cases and for which a specific contributing factor has not been identified. However, it is not clear whether these variations themselves or other genetic contributors or other factors in combination with these variations are the important link to the disease. Further work needs to be done to establish this question.

Among the findings in the study: individuals carrying any one of three variations in the VEGF gene had a 1.8 times greater risk (than the general population) of developing ALS. Associated with these variations was a lower level of plasma VEGF.

"The finding that VEGF may be a risk factor for sporadic ALS is an extremely exciting one and may provide a potential new target for therapy. Important follow up studies are now underway," comments Dr. Lucie Bruijn, science director and vice president of The ALS Association (ALSA).

About the study

The European study, involving more than 30 investigators, was very thorough and included detailed follow-up to verify the validity of the associations with ALS. Some 1900 individuals in Sweden, Belgium and England were studied - patients with familial ALS without the SOD1 mutation, sporadic ALS, along with healthy individuals of similar age, geography and ethnicity as control groups.

The investigators also generated these variations in a cell system and showed that introducing these variations resulted in low VEGF levels. Further evidence of the role of abnormal VEGF in ALS came from their mouse studies -- cross breeding mice with low levels of VEGF with SOD1G93A mutant mice. The disease progressed more rapidly in mice with mutant SOD1 and lower levels of VEGF than in mice with the mutant SOD1 gene alone. Individuals with ALS (those that the investigators were able to study in the Swedish population) had lower plasma levels of VEGF providing strong support for a possible involvement of VEGF in the disease. Again, the caution is that altered levels of VEGF and the variations in the gene may be associated with other more important gene changes. VEGF may be a modifier of ALS whose influence may depend on genetic background, the presence of additional modifiers, environment or lifestyle. This is highlighted by the fact that a subpopulation in England showed no association with these mutations.

It is important for other groups to replicate the data and to look for similar or other mutations in VEGF in the U.S. population, according to the researchers. Studies are now underway in the United States to determine whether a similar increased risk can be identified in the U.S. population.

Researchers are using both mouse models and cell culture studies to identify the role of VEGF in motor neurons in Dr. Wim Robberecht's current ALSA-funded study, performed in collaboration with Dr. Peter Carmeliet's research group. "Our results suggest that VEGF has direct trophic effects on motor neurons, but more studies are needed to establish the mechanism through which VEGF may form a risk factor to develop ALS," said Dr. Robberecht.

The serendipity of scientific research

VEGF is best known for its role in development and maintenance of the vascular system (blood vessels) and response to oxygen deficiency. Dr. Peter Carmeliet of Belgium was conducting studies associated with the vascular system. He engineered a mouse model such that it could not up-regulate (turn on or raise) VEGF levels during hypoxia. Quite unexpectedly, this mouse model showed motor neuron degeneration and became paralyzed. This was the first indication that VEGF might play an important role in motor neurons. Dr. Carmeliet turned to investigators involved in motor neuron degeneration research and the new study was launched.

"Our ongoing studies using additional transgenic and pharmacological models further underscore the role of VEGF in motor neuron degeneration," said Dr. Carmeliet. "We are therefore now intensively studying whether VEGF has any therapeutic potential to delay or slow down ALS in animal models, using various protein delivery, gene transfer and cellular transplantation methodologies, and expect to have conclusive answers very soon. Moreover, we are pursuing additional studies to better understand the molecular and cellular mechanisms whereby VEGF affects motor neuron survival in stressed conditions. Such insights should be helpful to design future therapeutic strategies."

Workplace Giving

Did you know that you can donate to The ALS Association Keith Worthington Chapter through payroll deduction? ALS participates in the following workplace donation campaigns:

- Community Health Charities of Kansas and Missouri through United Way Campaigns
(We will also be included in the Combined Health Agencies Drive of Nebraska (CHAD-NE) in 2004!)
- Combined Federal Campaign with a Local Listing and a National Listing
- Missouri Employee Charitables Campaign
- National Private Sector Campaigns

If you are employed by:

- the federal government, you can support ALS through the Combined Federal Campaign.
- Aetna, American Airlines, C.N.A. Insurance, Pitney Bowes, Sears, UnitedHealth Group, USA Today or the GAP you can contribute through your workplace giving campaign.
- the state of Missouri you can support ALS through the Missouri Employees Charitable Campaign.

The beauty of all these campaigns is that YOU can decide how your contribution is spent. Know your options. There are two ways to give through the campaigns:

1. DONOR CHOICE*

You choose where your money goes! If a specific agency or agencies have helped you or a loved one you can designate your money directly to them. Request a DONOR CHOICE FORM and fill in the number of the charity of your choice listed on the back of the form.

** Donor Choice may not be available in every United Way Campaign but please inquire.*

2. GENERAL OR COMMUNITY CARE FUNDS*

Your gift is a general gift to the campaign. Your money is given to agency/committee and they determine where it will be best spent in the community.

** Community Health Charities agencies do NOT receive any funds from these funds.*

The key to DONOR CHOICE is to **ask** for the DONOR CHOICE FORM, without this form your gift will not reach ALS. Make sure to fill out the DONOR CHOICE FORM in its entirety and KEEP A COPY for your records, when your designation reaches ALS we will send you a thank you letter with the amount pledged listed as a check and balance for you.

We appreciate your contributions; they are vital to the survival of our mission.

VEGF Gene - *Continued from page 6*

Questions & Answers

1. Is there a test to see if I have abnormalities in the VEGF gene?

The European study suggests that VEGF abnormalities may be a risk factor. It is important for other researchers to replicate the data and to look for similar or other variations in the VEGF gene in the U.S. population. It is too soon to consider any testing until we can, at the very least, repeat the results. Also, as the study described above indicates, the variations in VEGF may be a risk factor -- variations in the VEGF gene may need to be in combination with other gene changes, or may be dependent on environment and lifestyle. The technique used in the research study is neither available nor indicated for ALS at this time.

2. Is VEGF available as a treatment?

No. VEGF is a protein that is rapidly degraded and present normally in the body (like BDNF and GDNF). Delivery is a challenge as it is for GDNF and IGF-1 so it would likely be a good candidate for gene therapy, where it would be delivered with a viral vector. Also, we do not have enough evidence that VEGF levels alone are indeed a factor in ALS. Studies to confirm the European research team's findings are needed.

3. Since VEGF is best known for its role in the development of blood vessels and response to oxygen deficiency, does this mean blood supply to the nerves and low oxygen levels have a role in ALS?

It is not clear that there is any association with the blood supply to the nerves and low oxygen levels leading to ALS. VEGF may play a very different role in motor neurons. In fact, in the European study, there were no variations in the region of the gene that is responsive to oxygen levels. More research is needed to determine what role VEGF may have in ALS and what therapies might be developed.

ALS Association Participates in the Kansas City Wellness Fair

St. Joseph Health Center • I-435 & Stateline • September 27th, 2003 • 10 a.m. to 2 p.m.

Information on complementary and alternative therapies:
Yoga • Aroma therapy • Music therapy

Free blood pressure screening, equipment evaluations and nutritional samples will be available along with special services and information for people with disabilities. Free prizes to the first 100 people.

Participants include:

American Red Cross - will give free blood pressure testing.

Carondolet Health - information on stress.

Mobility Center - will give free equipment evaluations.

Hollister Inc. - will have a display and info on intermittent catheters

Depends and Poise have sent literature and \$2 off coupons for display

Department of Housing and Urban Development

Kansas State SRS and Vocational Rehabilitation

Johnson County Human Services

Barrier Removal Programs

Foresters - will talk to people about financial planning, long term care and retirement.

Carondolet Health - will have info on Lifeline and caregiver program.

Lawyer Yvonne Ernzen will answer legal questions about disability and social security.

Boost will be there giving free samples.

Nutrijoy will be there giving free samples of Cal-C drinks.

Wild Oats will be there talking about nutrition.

Liz Brown - information on Feng Shui, aromatherapy and massage.

Healing Heart - information on herbalism, energy work and yoga.

Complete Mobility Systems will bring 2 vans with a variety of lifts for display in the parking lot

SUCCESS IN ADVOCACY

Many of you may have met or heard about David Jayne from time to time. David is a PALS who has battled ALS for over 15 years. He lives outside of Atlanta and is involved with the ALSA Georgia Chapter. In the fall of 2000, David attended a football game with his caregiver and a college buddy. About this same time, a full two page article was written on him in the Atlanta Journal and Constitution. This article mentioned that he had attended a Georgia football game! Long story short, his home health care provider informed him they were dropping him from their care since he was no longer considered "homebound" - this decision was based solely on him attending a football game. There is no question that David is homebound! For a mental picture of David, he is totally paralyzed from ALS, except for the blinking of his eyelids and the movement of a few of his fingers. He is vent dependent, has a feeding tube and speaks thru his computer. It takes two people over two hours every day to get him out of bed, showered, shaved, and dressed for the day!

Within two days, the reporter that wrote the original story the week prior, put another article about David on the front page of the Atlanta newspaper - this article stated that David had been released from his home health care. The city of Atlanta was outraged! Many calls were made to Georgia Senators and Congressmen. Thankfully, Congressman Mac Collins met with the Medicare office in DC and David's services were restored. However, David had to supposedly remain under "house arrest" because of the antiquated laws regarding Medicare services.

David felt compelled to fight Medicare and started an online petition that gathered over 20,000 signatures. David has two young children and wanted the freedom to attend their sporting events, school programs, even go to a movie with them. From the petition, he heard many heart-wrenching stories, including one from a severely disabled woman that did not attend her own child's funeral because she was told she would lose her Medicare services if she left her home. Another severely disabled woman wrote that she also had a child die, did attend the funeral and lost her services. This same woman filed an appeal to have her services restored, but lost the appeal. This hit David in his heart and he knew this Medicare rule had to change!

David has fought this issue in DC for three years. For the past three years, David has made the great trek to DC in May to help bring awareness to ALS. He has also traveled to DC a couple of other times for press conferences, meetings with CNN and meetings with countless Congressmen and Senators. For David to travel to DC, he is lifted via a forklift to the rear cargo door of a small plane, then he is rolled into place and tied down in the back of the plane. It involves tremendous effort from many people to arrange his travel. But David is a man on a mission and there is no stopping him!

Today in DC, David's efforts paid off! His amendment was passed in the House and in the Senate. It is anticipated that Bush will sign this bill and Bob Dole wants David present to meet the President. Once this is signed into law, Medicare will do a two year demonstration project to see if the costs of allowing those receiving their services will add costs to the Medicare system. David has had the help of Senator Bob Dole, countless "new" lobbying friends in healthcare fields in DC and Susan Constantine in the ALS Georgia chapter. It is truly unbelievable that he could change Medicare with just two fingers!

Support Group News

Kansas Support Groups

The **Hutchinson** support group was held on June 4th with 10 in attendance to hear Vicki Hoelting of Lifeline offer a variety of assistance resources to keep ALS patients safe in their homes. A discussion followed regarding the latest research. There were nine attendees at the July 2nd **Hutchinson** support group who listened to Linda Brown from the Medicare office in Topeka speak about the new Medicare changes. It was followed by a vigorous question and answer period.

The **Wichita** support group met June 5th with 32 attending. The speaker did not show up so the group shared ideas and information on the upcoming Walk To D'Feet ALS and the enthusiasm of the teams, the Wichita Wrangler's baseball game, buffet and Lou Gehrig play on June 19th. The **Wichita** Caregiver support luncheon was held on Saturday, June 28th. The second in the series of Caring for the Caregiver was shown. The July **Wichita** support group took place on July 10th. Larry Bohlen, Producer, and his television staff from our local Health Channel joined the group for the evening. There was a half hour interview with Jean Haley, Patient Services Coordinator, prior to the meeting and then they filmed the featured speaker, Vicki Hoelting, Director of Wichita Lifeline, Inc. Larry and his crew did spontaneous interviews with the majority of the 19 attendees concerning their views on the benefits of attending the ALS support groups on an ongoing basis and the positive effects it had on them and their family members in coping with the disease progression. The film, when edited, will be a 1-hour special airing throughout the state of Kansas. The focus surrounds the diagnosis, onslaught and progression of ALS in Kerry Gray of Associated Advertising in Wichita. It highlights the effects not only on Kerry himself, and the way it has impacted his very public career, but also the emotional effects on his family. It spotlights the ALSA Clinic at the KU Medical Center along with Dr. Richard Barohn and his staff. The show aired in July and will air every 3rd Sunday until September.

The **Kansas City** support group met on July 1st. There were approximately 25 in attendance to hear Jennifer Becker from The Rehab Institute who demonstrated various pieces of equipment that help make activities of daily living more manageable for those with ALS. Chapter President Jim LeBow spoke on the ALS Association's Conference and Advocacy Day.

Missouri Support Groups

The **Springfield** support group was held on July 8th with nine in attendance. Guest speaker, Jan Dickensheet, a volunteer with The American Red Cross, spoke about "Caring for the Caregiver." Jan interacted with the group in discussing and validating the varied feelings one experiences in the process of caring for someone they love. We discussed the importance of the care provider's having someone with whom to share and verbalize those feelings. Other topics discussed included upcoming ALSA Walks, support group meetings, and research and clinical trial news from the ALSA national website. The next support group meeting will be held August 12th and the topic will be seating and mobility.

The first meeting of the **Joplin** support group was held on Tuesday, July 15th at the Joplin Family YMCA. There were 12 in attendance. The group discussed possible topics for future meetings and exchanged phone numbers and addresses. The services of the ALS Association and where ALS information can be found on-line was discussed. The group was updated on the Joplin Walk to D'Feet ALS scheduled for Saturday, September 6th in Cunningham Park. The next meeting will be Tuesday, August 19th at 1p.m. at the Joplin Family YMCA, South Branch, Meeting Room A.

Nebraska Support Groups

The **Omaha** support group met on July 10th with nine people in attendance. The group shared information on resources that have helped them and a list of other community resources was distributed. Next month the group will meet on August 14th and Mark Zach from Schrier Ford will present information on adaptive equipment for vehicles and wheelchair accessible vans.

The **Lincoln** support group met on July 16th. Six people attended and enjoyed sharing information. We hope to have a mobility expert join us next month to present on mobility options.

The **Norfolk** support group met on July 22nd at the Faith Regional Hospital West Campus with 12 people in attendance - most of whom live in Norfolk, several from Columbus, and one from Newman Grove. It was an opportunity for people to get acquainted with one another before the upcoming Walk to D'Feet ALS in Columbus. The first part of the meeting was open discussion and sharing, and then the group viewed the new ALS Association video on mobility. Glenn Suhr brought his camera and took several pictures. As for future meetings, the Chapter is looking for possible support group facilitators for meetings in Columbus or Norfolk. One of the Chapter goals is to find a person to facilitate and a place to hold regular meetings - meetings could alternate from Columbus to Norfolk month to month if there is someone in both places interested in helping.

FOR SALE

VANS

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.

1996 Ford Econoline with lift, extended roof. 50,000 miles. Call Joan @ 913-385-1259.

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 @ 417-466-2907/417-466-1471. 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, chest strap, laptray, Roho cushion, battery charger. Only used 6 weeks. Call Anna @ 573-437-7586.

Quantum Jazzy 1400 Power Wheelchair 4 months old, great condition. \$3,000 obo. 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 @ 402-488-3387 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. Email sjsbold@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.

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

Electric Wheelchair 2 yrs. old. Like new. Asking \$1000. Call 913-362-2354.

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. 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. 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

Ricon S-Series Wheelchair Lift for van rear access. Load capacity 800 lbs. Weight 325 lbs. Remote control with manual backup. Call 417-865-1977.

Silver Glide Stair Lift with battery pack back up. 18 foot track. Manufacturer - American Access Ind. Like new. Asking \$1200. 816-943-8334.

MATTRESSES & CUSHIONS

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

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.

August & September Birthdays

Harry Warriner	August 1	Lorene Stone	September 4
Earl Waddill	August 1	Wilma Kruger	September 4
Margie Wedekind	August 1	R.J. Roper	September 5
Ed Carpenter	August 3	Clyde Smith	September 7
Elaine Foster	August 6	Henry Geeseka	September 11
Barbara Liger	August 8	Harold Jones	September 15
Gayle Simons	August 8	Barbara Rohrman	September 15
Ruth Bowker	August 8	Joan Wetovick	September 16
Wade Nyberg	August 15	Lee Razak	September 18
Robert Holmberg	August 16	Opal Poorbaugh	September 19
Ellen Wright	August 18	Julian Nunez	September 20
Ron McCormick	August 18	Sue Fox	September 20
Earl Sanders	August 21	John Main	September 21
Judith Barton	August 21	Melvin Jackson	September 21
Harold Bruce	August 24	Ramona Mitchell	September 21
Carolyn Bork	August 26	Harold Zug	September 23
Larry Murdock	August 26	Joyce Brannan	September 25
John McClure	August 27	Jamie Brooks	September 28
Joseph Downs	August 29	Lonnie Trotter	September 28
Kenneth Huntley	August 29	Connie Bullard	September 28
Al Ybarra	August 31	Don Hunter	September 29
Mike Georges	August 31		

Memorials

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

Bernard Arzu

Mel Meineke

Michael Maier

James Mason

In Memorium

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

Bernard Arzu

Marian Davis

Claudia "Tom" Gussey

Dorothy Hager

James Mason

There's a Walk to D'Feet ALS in Your Area!

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



For more information or a registration form visit www.alsa-midwest.org or contact Emily Marsh at 913.648.2062, ext. 221 regarding walks in Topeka, KS, Kansas City, MO, St. Joseph, MO or Manhattan, KS.

Contact Kathleen Wille at 316.612.0188 regarding walks in Pratt, KS, Hays, KS, Liberal, KS, Salina, KS or Emporia, KS.

Contact Sarah Kerwin at 913.648.2062, ext. 223 regarding walks in Joplin, MO, Branson, MO, Jefferson City, MO or Springfield, MO.

Contact Ric Miller at 402.991.8788 regarding walks in Grand Island, NE, Columbus, NE or Omaha, NE.

Holiday Parties - Save the Date!

Kansas City - Wednesday, December 3rd
Omaha & Wichita - Thursday, December 4th
Springfield - Tuesday, December 9th

Raise Money for ALS While Shopping at Kansas City Metro Price Choppers and Hen House Stores

Price Chopper and Hen House grocery stores have again announced two exciting programs we would like to tell you about. They are programs that you can use to help The ALS Association financially while doing your weekly grocery shopping!

Every time you use your Price Chopper Shopper Card or your Hen House Rewards Card from September 1, 2003 to May 31, 2004, each store will donate 1% of your net purchase to the organization you designate (hopefully The ALS Association).

If you enrolled in either of these programs last year, you must re-enroll to designate ALS again. You can do this a few ways. For Price Chopper, you can register online at www.mypricechopper.com. You can also download the forms for both organizations off of The ALS Association's website www.alsa-midwest.org. If you don't have access to the internet, please call the ALS office and a form will be mailed to you. If you have questions regarding either of these programs, please contact Suzanne Frye at 913.648.2062, ext. 209.

EMAIL ADDRESSES AND PHONE EXTENSIONS TO BETTER SERVE YOU:

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Mac McCartney and

Larry Freund

Wichita (316) 612-0188

Kathleen Wille

kwille@alsa-midwest.org

Chapter Website

www.alsa-midwest.org

National Website

www.alsa.org

THE DIALOG

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Prairie Village, KS 66206

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AUG / SEPT 2003

August Support Groups

- 5 KC Night 7 p.m.
- 6 Hutchinson 2 p.m.
- 7 Wichita 7 p.m.
- 8 KC CG 12:30 p.m.
- 14 Omaha 7 p.m.
- 12 Springfield 7 p.m.
- 19 Joplin 1 p.m.
- 20 KC Day 2 p.m.
- 20 Lincoln 6:30 p.m.
- 23 Wichita CG 11 a.m.
- 25 Topeka 7 p.m.

September Support Groups

- 2 KC Night 7 p.m.
- 3 Hutchinson 2 p.m.
- 4 Wichita 7 p.m.
- 9 Springfield 7 p.m.
- 11 Omaha 7 p.m.
- 12 KC CG 12:30 p.m.
- 15 Topeka 7 p.m.
- 16 Joplin 1 p.m.
- 17 KC Day 2 p.m.
- 17 Lincoln 6:30 p.m.
- 20 Wichita CG 11 a.m.

October Support Groups

- 2 Wichita 7 p.m.
- 7 KC Night 7 p.m.
- 8 Hutchinson 2 p.m.
- 9 Omaha 7 p.m.
- 11 KC CG 12:30 p.m.
- 14 Springfield 7 p.m.
- 15 KC Day 2 p.m.
- 15 Lincoln 6:30 p.m.
- 19 Wichita CG 11 a.m.
- 20 Topeka 7 p.m.
- 21 Joplin 1 p.m.

KC Night SG
2nd Presbyterian Church
55th & Oak

KC Day SG
Village Presbyterian Church
66th & Mission Road

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

Wichita, KS SG & Caregivers SG
Grace Presbyterian Church
5002 East Douglas

Hutchinson, KS SG
Grace Episcopal Church
20th & Main

Salina, KS SG
Christ the King Lutheran
111 W. Magnolia Street

Topeka, KS SG
Topeka Association for Retarded
Citizens - main entrance
2701 SW Randolph

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

Omaha, NE SG
St. Pius X Parish Center
6905 Blondo Street

Springfield, MO SG
Cox Medical Center South
3801 South National Ave.

Joplin, MO SG
YMCA - 3404 W. McIntosh Circle
Room A, South Branch

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

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

Nebraska
Sonya Glenn
(866) 762-6361

Springfield
Dorothy Foulk
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