

ALS

Volume III Issue 2

“
Life hasn't
changed
much
”



Shadow of a Hero

*Excerpts from The Wednesday Magazine, "Run-n-Walk to D'feet ALS",
by Amy Slotemaker September 12, 2001*

Growing up, Lou Gehrig wanted to be a ball player. History tells us that he became one of the greatest ball players.

In 1939, when Lou Gehrig, the star first basemen of the New York Yankees, was 36 years old, he was diagnosed with amyotrophic lateral sclerosis, or ALS.

Growing up, Gehrig was always Harry Warriner's favorite ball player. He read articles about Gehrig and his losing battle with the debilitating disease. When Warriner was only about 12 years old, he saw "The Pride of the Yankees," which told Gehrig's story on film.

In January, 2001, when Warriner was 70 years old, he was diagnosed with Lou Gehrig's disease, or ALS.

Warriner is planning to participate in a research study being conducted at the University of Kansas Medical Center. The study will test whether creatine, a muscle-building drug, can help the body keep control of its muscles.

In December last year, Warriner realized there was something wrong one day while at the grocery store.

"I was losing strength in my hand," Warriner said. "I couldn't pull my driver's license out of my billfold. I couldn't turn the ignition."

So he went to see his doctor. After several muscle tests, doctors confirmed that Warriner had Lou Gehrig's disease.

Warriner said his life hasn't changed much yet. He still lives with his wife of 51 years, Marilyn, in their home in the Brookside/Waldo area. He still visits with his neighbors often.

"There's a lot of stuff I don't have to do now," Warriner said, smiling at his wife. "I don't walk as much."

"I think about it once in a while, but not too much," he said. "My legs cramp in the morning, but that's about the only time I really think about it."

"There isn't much I can do anyway," he said.

Sitting near him at the kitchen table, Marilyn Warriner smiled back.

"The muscles move in his arms and

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SPECIAL "DOC" EPISODE CONCERNING ALS SUNDAY, FEBRUARY 17 ON PAX TV

PAX TV will present a special episode of the hit series "Doc," starring Billy Ray Cyrus that focuses upon Lou Gehrig's disease entitled "Fearless" to air Sunday, February 17 (8:00-9:00 p.m., ET/PT). Guest-starring on this all-new episode is leading contemporary Christian recording artist Steven Curtis Chapman, who portrays a musician whose life is forever changed when he is diagnosed with ALS.

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Dear Friends,
Happy New Year!

The ALS Association, Keith Worthington Chapter is ready to begin a new fiscal year effective February 1. As is customary, in the February issue of Dialog, the Chapter President reflects back on the previous year with a report on the “state of the Chapter”. Staying with this tradition, I would like to highlight some of the accomplishments from this past year. We not only continue to see an increase in our level of services, but also an increase in the number of patients, caregivers and families we serve.

Our enthusiastic Patient Service Coordinators:

- Made 3800 significant patient contacts made through home visits, phone calls or email.
- Provided services to 380 patients throughout the year.
- Responded to inquiries from 135 new patients.
- Facilitated 8 support groups that met monthly throughout the service area.
- Provided 3 caregiver-training sessions.
- Maintained and updated the office and online reference libraries.
- Coordinated the loan of durable medical equipment to more than 200 patients at no cost.
- Presented 20 in-service training sessions for medical professionals, & service providers.

The Chapter:

- Provided information, support and resources to many patients, caregivers and interested parties through the Chapter’s redesigned and enhanced web site at www.alsa-midwest.org.
- Partnered with KU Medical Center under the direction of Dr. Richard Barohn, Head of the Dept. of Neurology, to provide comprehensive evaluations and treatment plans for patients through a multidisciplinary ALS Clinic soon to become a certified ALSA Center.
- Made 2,500 referrals to professionals and services.
- Produced and mailed *The Dialog*, an information newsletter, to more than 2,500 individuals monthly.
- Opened a branch office in South Central Missouri.
- Started a support group in Omaha, Nebraska
- Increased staffing in the Wichita and Springfield branch offices.
- Successfully advocated for ALS legislation eliminating the 24-month waiting period for Medicare benefits for people with ALS.
- Committed \$180,000 in support of cutting-edge research into the cause and cure of ALS.
- Partnered with our national organization in the Lou Gehrig Challenge-an effort to raise \$25 million in three years for research.

Our fundraising activities produced some amazing results!


- 12th Annual A Night of Hope Auction — **\$352,153**
- 18th Annual George Brett Celebrity Golf Tournament in Kansas City — **\$145,166**
- 4th Annual George Brett Celebrity Golf Tournament in Wichita — **\$130,422**
- 1st Annual Branson Golf Tournament — **\$39,419**
- 1st Annual Say It With Flowers in Wichita — **\$9,256**
- 6 Walks to D’Feet ALS (Kansas City, Wichita, Springfield, Columbia, Omaha, Hays) — **\$337,560**

In addition to the events, we raised more than \$315,000 from memorials, grants, and mailings. More than 5,000 individuals, corporations, and foundations have financially supported the Keith Worthington Chapter. Our ALS family is eternally grateful for each and every one!

Volunteer participation has been fantastic! More than 500 individuals volunteered their time by working in the Chapter office or at fundraising events, by serving on boards or committees, or by visiting with ALS patients in their homes. We are fortunate and proud to have such a tremendous corps of volunteers.

As you can see, much has been accomplished this past year in our efforts to improve living with and finding a cure for ALS. The Keith Worthington Chapter Board, volunteers and staff are filled with enthusiasm and expect great accomplishments as we continue the mission of the ALS Association in the coming year.

Sincerely,



Terry Betzelberger

The ALS Association - Keith Worthington Chapter is pleased to announce the establishment of our President's Club and Director's Club. Members of the Director's Club are those who made an event or non-event related contribution with a tax-deductible amount of \$1,000 to \$2,999 from October 1 of one year through September 31 of the next. President's Club Members made gifts of \$3,000 or more. These members will be recognized annually in our monthly newsletter, and on the boardroom's wall of honor. In addition to the recognition in our publications, they will receive the President's quarterly notes. These notes provide them with the latest activities at the ALS Association Keith Worthington Chapter. They will be one of the first to know what is happening in patient services, research, advocacy and development. Director's Club members will also be invited to the Director's reception where they will meet others who share their commitment. The President's Club members will be invited to the traditional major donor luncheon with George and Leslie Brett.

The President's and Director's Club members play a large part in allowing the ALS Association - Keith Worthington Chapter to continue improving the quality of life for persons with ALS and fund cutting-edge research into the cause and cure of this cruel, insidious disease. We are truly grateful for their support. For more information on how you can be a member of one of these clubs, please call Dawn Oliver at 913-648-2062.

PRESIDENT'S CLUB

2001

Adelphia Business Solutions
 American Century Investment Services
 Mr. & Mrs. Ed Ammon
 Ms. Bonnie Anderson
 AON Group
 Austin Hardware & Supply
 Aventis Pharmaceuticals, Inc.
 Bayer Corp, Agricultural Div.
 Ms. Jennie Betzelberger
 Ms. Sharon Betzelberger
 Mr. & Mrs. Terry Betzelberger
 Boeing Employees Charitable Fund
 Mr. & Mrs. George Brett
 Mr. & Mrs. Bruce Brown
 Cloon Law Firm
 Columbian TecTank
 Commerce Bank
 Mr. & Mrs. Edward M. Connolly, Jr.

Country Club Bank
 Custom Mobile Equipment, Inc.
 DST Systems, Inc.
 EagleMed
 Einstein Brothers Bagels
 Tom & Kyle Futo Foundation
 Heartland Corporation
 Dr. & Mrs. Steven R. Henson
 Mr. Roger Hime
 Mr. & Mrs. Robert Hoehn
 Mr. & Mrs. David Jensen
 Kansas Speedway - Nascar
 Muriel McBrien Kauffman Foundation
 Kansas City Power & Light
 Thomas B. Martin Foundation
 Don Kincaid Motors, Inc.
 Rodney Klein Golf Tournament
 Lathrop & Gage

Lee Apparel Company
 Lockton Companies
 Maritz Travel Company
 Mr. Goodcents Franchise Systems, Inc.
 Orpheum Performing Arts Centre, Ltd.
 Phi Delta Theta - KU
 Prime Health Foundation
 Quicksilver
 Price R. & Flora A. Reid Foundation
 RSM McGladrey, Inc.
 ServiceMark Telecommunications
 Mr. & Mrs. Grover B. Simpson
 Ralph L. Smith Foundation
 Sprint
 SSA, Inc.
 Superior Asphalt Company
 UtiliCorp United, Inc.
 Mr. & Mrs. David W. Wurth

DIRECTOR'S CLUB

2001

AB Sales
 Jeff & Jodi Ablah
 Aero-Mach
 American Home Patient
 American Italian Pasta Company
 American Multi-Cinema Inc.
 Andrews McMeel Universal Foundation
 Ariagno & Kerns
 Joan Camile Avery
 Babson Funds
 Bank of America
 Bartimus, Frickleton, Robertson & Obetz
 Blue Cross & Blue Shield of Kansas City
 Dr. & Mrs. Douglas Bogart
 Mr. Ferris T. Boutross
 Briman's Leading Jewelers
 Broadway Home Healthcare
 Mr. & Mrs. David W. Broderick
 Mr. Allen R. Brown
 Mr. & Mrs. Andrew Brown
 Mr. & Mrs. Bryson Cloon
 Mr. William Byington
 Candlewood Hotels
 Capitol Federal Savings
 City of Mission Hills
 Clark Rand Sales
 Commerce Bank
 Country Club Bank
 Mr. & Mrs. Marshall H. Dean
 Department of Neurology-KU SOM
 Eagle One Industries
 EdCar Safety & Lubar Chemical
 Emprise Bank
 Enright Foundation, Inc.
 Farmland Industries
 Mr. & Mrs. Jim Fassett
 First United Methodist of Emporia
 Mr. Jim Frickleton
 Dr. & Mrs. Walt Gaska
 Joseph & Mildred Gilbert

Gold Eagle Co.
 Ms. Emily Golson
 Dan Goodale
 Gorges & Company
 Mr. & Mrs. Jerome N. Gregoire
 Halls Kansas City
 Mr. Jim Hatfield
 Mr. & Mrs. Jack Henning
 Mr. & Mrs. Alfred J. Hoffman
 Mr. & Mrs. Harold S. Hook
 Mr. & Mrs. Ira J. Jackson
 JC Nichols Residential
 Edward D. Jones
 Jumper Custom Clothing
 Mr. & Mrs. Dick Kaegel
 Dr. A. Christine Kelly
 Mr. Rusty Kelley
 Mr. & Mrs. Don P. Kennedy
 Robert J. Kennedy at RJ Kennedy
 Investor Services
 Dr. & Mrs. Lynn H. Kindred
 Kindred Hospital Kansas City
 Mr. & Mrs. Bill Krueger
 Kuehn Foundation
 Lathrop & Gage
 Debbie & Dan Latta
 Mr. & Mrs. John Lavender
 Lentz Murphy & Baker OD
 Mr. & Mrs. Will Lewis
 LodgeWorks Corp
 Mr. & Mrs. Thomas Martin
 Matria Healthcare
 Mr. & Mrs. Larry Miller
 Mr. & Mrs. Don Montague
 Morgan Family Foundation
 Morrison & Hecker
 Murney & Associates
 Mr. & Mrs. Ken Oglesby
 Odyssey Healthcare, Inc.
 Mr. Gregory J. Orman

Orthopedic Clinic of Salina
 Mr. & Mrs. Steve Palermo
 Mr. & Mrs. Lawrence J. Pasquini
 Pestinger Heating & Air
 PKM Steel Service Inc.
 Preferred Health Systems
 Mr. & Mrs. David Preston
 Professional Detailing, Inc.
 Mr. & Mrs. Archie R. Provance
 QuikTrip Corp.
 Rapid Brake & Muffler
 Restaurant Management Company
 Roe Body Shop Inc.
 Russell Stover Candies, Inc.
 Sam's Club Foundation #4707
 Shamrock Self Service Storage
 Shook Hardy & Bacon
 Mr. Brad Shoup
 Tommy Simone Memorial Fund
 Jay & Carolyn Simpson
 Mr. David Skitek
 S.J. Prill Financial & Investment Planning
 Stinson Mag & Fizzell, PC
 Mr. Bob Stirton
 Ms. Leigh M. Teagarden
 Tech Inc.
 Mr. & Mrs. John Tillotson, II
 Mr. & Mrs. Roger Twibell
 Universal Lubricants, Inc.
 University of Kansas Medical Center
 Wagner Equipment Co.
 Mr. & Mrs. Gerald E. Walker
 Mr. & Mrs. Tom Ward
 Mr. & Mrs. Ronald G. Wasson
 Wichita Greyhound Park
 Mr. & Mrs. Allen G. Widner
 Ms. Pearl Mae Williams
 Winn Senter Construction Co.
 Ms. Norma Woodard
 Worthington Direct, Inc.

**KANSAS CITY
SUPPORT GROUP NEWS**

The Kansas City Night Support Group met January 8th at the 2nd Presbyterian Church in Brookside. Patients, family members, friends and Dr. Barohn were present to hear Roslyn McHenry talk about home remodeling to achieve accessibility. She shared ideas and resources that she has gathered in her 20 years of professional experience in helping people remain independent in their own homes. The topic for the February 5th Support Group Meeting will be "Pulmonary Issues."

**TOPEKA
SUPPORT GROUP NEWS**

The December meeting was a pot luck and turned into a surprise going away party for Diane Hall. Diane first hosted the ALS Support group in the same room 12 years ago. The room was a temporary placement for the speech clinic and now 12 years later we have relocated to the same room! The group enjoyed good food and lots of fellowship. An ornament exchange brought peals of laughter from all as ornaments were taken from previously selected ones. Diane was surprised with a beautiful gift and each of the members had written a card to be presented in a photo album which will contain the pictures from the party. Lots of memories were shared and hugs and tears were the fare of the evening. Diane thanked the group and ALS for allowing her to be a part of such a wonderful organization and group.

**OMAHA
SUPPORT GROUP NEWS**

The Omaha Support Group met on Thursday, December 12 with 13 people present. Martha Maurin, CNS specialist, representing Aventis, which manufactures Rilutek, spoke to the group. Support group members were able to ask questions, which was very helpful. Ms. Maurin also talked about the operation of the ALS clinic within the Kansas City area.

**SPRINGFIELD
SUPPORT GROUP NEWS**

The Springfield support group had not met at print time.

continued from page 1

legs sometimes," she said. "They have free reign."

Currently, Harry is taking the drug Rilutek, the only medication available to ALS patients.

"They say Rilutek will only prolong your life by three months," Marilyn said, "but it will improve the quality of your life."

Together, the Warriners attend group meetings sponsored by the ALS Association. The meetings often feature a speaker, usually a nurse or other medical worker familiar with ALS.

"I think those groups are important," Marilyn said. "They're just kindness and chit chat."

A Night of Hope Auction Goes South of the Border!

Mark your calendars – Saturday, May 4th it's fiesta time as we host

SALSA for ALSA. The Auction for ALS with a Cinco de Mayo flair, at The Hyatt Regency Crown Center!

Want to help? Here are some areas where you can get involved...

We are looking for:

- ◆ Auction Items
*Unique gifts with a retail value of \$100 or more.
Dining certificates valued at \$25 or more.*
- ◆ Donors interested in covering the cost of framing for donated items.
- ◆ Volunteers to work the day and evening of the event
Call Kristine Tarwater, 913-648-2062

Invitations

If you or anyone you know would like to be on the invitation list please call Keri Morrison, 913-648-2062

Auction Tickets start at \$150, Patron Tickets at \$225.

Start putting your table together.

This is going to be a fiesta to remember!

RED CROSS CAREGIVER TRAINING IN KANSAS CITY

The ALS Association, Keith Worthington Chapter is hosting, in conjunction with the American Red Cross, *Home Care - Skills for the ALS Caregiver*.

This 7-hour course will discuss how to safely care for ALS patients in the home and provide hands-on training. Guests include:

- ✓ Dietician ✓ Social Worker ✓ Physical Therapist ✓ Dr. Barohn

Breakfast and lunch will be provided. The training seminar is provided free of charge.

April 5, 2002

9 am – 4 pm

Red Cross Building
211 West Armour Blvd.
(North of the Plaza)

To register, please contact

Central Registration at the American Red Cross 816-931-6662 ext 240

TRAVELING TIPS

Hotels seem hostile? Try checking out these items before you check-in. Most hotels now have handicap rooms but not everyone has the same definition of accessibility. Your disability and needs are unique.

A few easy pre-arrangements can make your stay more enjoyable.



- ➔ Before you leave, create a checklist of things you need in your hotel room. This list might include: an accessible shower, a highboy toilet, a lift recline chair.
- ➔ Make a reservation. Let the hotel know at least 2 weeks in advance that you are a person with a disability and exactly what your needs are. Fax them a copy of your checklist and ask them to verify that they can accommodate your needs.
- ➔ When you make your reservation, ask for a ground floor room. You don't want to have to negotiate stairs and fire doors in an emergency situation. It's up to them to accommodate your safety.
- ➔ If you have special dietary needs, can the hotel provide you with a small refrigerator or can the restaurant fulfill your needs?
- ➔ When you are ready to check in to the room, ask to see the room. Have someone from the hotel go with you. Ask them to remove any furniture that is in the way and not needed. Verify that all your requested items are in place, and then finish your check-in.
- ➔ We all forget items when packing; most items can be replaced in your destination city. Check with the hotel first. They may have a relationship with a doctor or medical supply house. If they do not, then check the yellow pages under medical supply or wheelchairs. You can also try the local ALS chapter to see if they have a loan closet or a relationship that will let you borrow the needed items or at least save you some money.

Don't be afraid to travel just have your tools ready. Your best tool is planning. Your next best tool is a good recommendation! Have

Travel tips courtesy of Amigo Mobility Center

BLAKE HANZLICK CARRIED THE OLYMPIC TORCH IN WICHITA KANSAS ON FRIDAY, JANUARY 11 AT 8:18 A.M. HIS WHEELCHAIR WAS ADAPTED TO FIT THE TORCH. BLAKE WAS NOMINATED IN THE SUMMER BECAUSE HE EXEMPLIFIES THE OLYMPIC SPIRIT WITH HIS COURAGE AS AN ALS PATIENT. BLAKE'S THREE TEENS ARE VERY ATHLETIC AND BLAKE ATTENDS MOST OF THEIR EVENTS.



WICHITA SUPPORT GROUP NEWS

Wichita's Support Group was attended by 20 people eager to hear the message of "Hope for 2002" that was delivered by Melba Madden, a member of the group.

An emotional but energizing evening, the group shared hopes and dreams for the New Year. It was moderated by Melba and capped off by her sharing the 12 ways to enhance your potential for hope.

Everyone was encouraged to join us on the sidelines to cheer on Blake Hanzlick when he carries the Olympic torch through Wichita on January 11, 2002. Blake's positive attitude has been an inspiration to us all.

Next month's Wichita Support Group meeting will take place on Thursday, February 7th with Bob Collins and Barbara Whitsett from the law firm of Collins and Collins speaking on Elder Law and Advanced Directives, along with how to keep your assets from winding up in Probate Court.

A similar topic is scheduled for the Hutchinson Support Group which will meet on Wednesday afternoon 2 PM. February 6th with a local attorney speaking to them.

March 6th and 7th -- both Support Groups (Wichita and Hutchinson) will have the pleasure of hearing Lu Duerkson, MA in Gerontology, and Licensed Family Therapist from the Via Christi system address the topic of "Dealing With Family Dynamics".

HUTCHINSON SUPPORT GROUP NEWS

The "2002" Kick-off Support Group in Hutchinson took place on Wednesday, January 2. Due to the fact that the meeting was immediately following the holiday, there were only 7 people in attendance. The topic was "Hope in 2002".

We all shared our view of what made us strong and helped us in coping with ALS in our lives. The group unanimously voted to continue with the same format and meeting time. Those in attendance discussed how much they felt they received from the interaction of the group.

LINCOLN SUPPORT GROUP NEWS

The Lincoln support group had not met at print time.

News from ALSA

Call for Additional Patients for AVP-923 Trial

Clinical Trial of AVP-923 for Pseudobulbar Affect in Patients with Amyotrophic Lateral Sclerosis

Enrollment is in process at 15 U.S. sites for a multi-center study of AVP-923 for pseudobulbar affect in patients with ALS.

BACKGROUND

Pseudobulbar affect is a condition characterized by frequent episodes of uncontrolled laughing or crying that do not match a patient's underlying emotion. It is also known by other terms such as emotional lability or pathological laughing and crying. Pseudobulbar affect is a condition associated with a number of neurological disorders, including ALS.

AVP-923 is a combination of Dextromethorphan Hydrobromide and Quinidine Sulfate. Dextromethorphan Hydrobromide is a drug that is available without prescription as an over-the-counter cough suppressant. Quinidine is one of the oldest prescription drugs still in use. It is primarily prescribed to control abnormal heart rhythms (arrhythmias). The total daily dose of Quinidine in this study is less than one tenth of the dose normally used to treat arrhythmias. Preliminary data suggests that a combination of Dextromethorphan and Quinidine may reduce uncontrolled expressions of emotionality in patients with ALS.

This phase II-III study was preceded by a small phase I study.

STUDY DESIGN

The study is a double-blind, controlled, parallel, three-group study comparing AVP-923 to its individual components (i.e., Dextromethorphan alone and Quinidine alone) over a 29-day period. The total number of subjects to be enrolled is approximately 100. Twice as many subjects will receive the combination of Dextromethorphan plus Quinidine as will receive either component alone. Enrollment is expected to last until the Spring of 2002.

During the study, a small capsule is taken orally, two times a day (every 12 hours). AVP-923 is generally well-tolerated. Possible side effects include fatigue, dizziness, euphoria, confusion, rash, or diarrhea. People with a known sensitivity to Quinidine or opiate drugs (i.e., codeine) are excluded from participation in this trial.

It is hypothesized that AVP-923 will reduce the frequency and/or severity of uncontrolled laughing and/or crying episodes. Over the course of the 29-day trial, frequency and severity of pseudobulbar affect, quality of relationships, quality of life, as well as standard physical measures will be assessed. Participation in the trial will require one visit to establish eligibility for the trial and then 3 more visits during the 29-day trial period.

CAUTION

AVP-923 is an investigational drug for the treatment of pseudobulbar affect in ALS. Unexpected adverse effects can occur. If you are not enrolled in the AVP-923 clinical drug trial, do not take dextromethorphan and quinidine without consulting with your physician or other health care provider.

FUNDING

The study is funded by Avanir Pharmaceuticals.

INFORMATION AND ENROLLMENT INQUIRY

For more information about this study, visit www.clintrials.gov. If you would like to know the names of the study site locations, or to inquire about enrolling in this clinical trial at a specific site, please refer to the site contact listing at <http://alsa.org/research/drugdev25.cfm>.

ABOUT AVANIR PHARMACEUTICALS

Avanir Pharmaceuticals, based in San Diego, is a diversified biopharmaceutical company with an FDA-approved drug (Abreeva-TM) currently on the market. Avanir is engaged in research, development, commercialization, licensing and sales of innovative drug products and antibody generation services. The company's website is www.avanir.com.

February Birthdays



Brenda Christensen
Gary Battles
Donnie Rand
David Roberts
Clarence Smith
Don Hunt

February 2 Mark Sheets
February 10 Bud Short
February 11 Reba Phipps
February 16 Dixie LaHue
February 16 James Bell
February 20

February 21
February 23
February 25
February 27
February 28



IN MEMORIAM

Glenda Burbank
Diana Cone
Gail Schilke
Rosalia Whitcher





Wheelchair Care

Does your wheelchair need a pedicure? Yes, we said a pedicure. After all you care for your biological feet, shouldn't you also take proper care of your adopted feet. While you may not wish to use fire engine red polish on your tires, there are a few easy things you can do to keep your wheelchair looking like a pair of freshly polished shoes.

- Cleaning of your wheelchair is recommended at least once a week.
- Wipe off all surfaces with a clean, soft cloth.
- Clean upholstery with a mild soap solution. Rinse with clear water and wipe dry. A soft brush may be used to work out more difficult stains.
- While washing your upholstery, check for worn or torn spots. If any are found, replace the upholstery immediately as it may not support your body weight.
- Dry your wheelchair whenever it is exposed to moisture. Water + metal = rust. Use a hair dryer on low heat to get those hard to reach spots.
- Check your brakes weekly to be sure they operate easily but are snug enough to prevent your chair from rolling when you are entering or leaving the wheelchair.
- A qualified wheelchair dealer or repair center should be consulted for periodic inspections and when repairs are needed.

Use your chair safely, take a few minutes each week to give it some TLC and keep on rollin' on.

Wheelchair Care provided by Amigo Mobility Center

Order your Copy of *In Sunshine and in Shadow* TODAY!

It's About Caring, Coping, and Hope.

Judy Oliver's husband battled ALS-amyotrophic lateral sclerosis, or Lou Gehrig's Disease. During his battle with the fatal, neuromuscular disease, Judy discovered that the experience of others living with ALS provided inspiration, courage, coping strategies and hope. Her book--capturing the experience from around the world--will inspire you, too.

For a copy of *In Sunshine and In Shadow* contact the ALS Association-Keith Worthington Chapter at 913-648-2062, visit our website at www.alsa-midwest.org or return a completed Book Order Form.



NAME _____

ADDRESS _____

CITY _____ STATE _____ ZIP _____

HOME PHONE (____) _____ WORK PHONE (____) _____

Form of payment

Cash Check Visa Mastercard

Qty _____ x \$15.00 = _____

S & H per book \$3.50 _____

Total _____

Name on credit card _____

Card Number _____

Exp. _____ Signature _____

Please mail order to ALS Association - Keith Worthington Chapter, 8340 Mission Road, Suite B4, Prairie Village, KS 66206

SECOND ALS GENE DISCOVERED

A second gene mutation that causes an inherited form of amyotrophic lateral sclerosis (ALS), or Lou Gehrig's disease, has been identified by Teepu Siddique, M.D., the Northwestern University researcher who, with collaborators from Massachusetts General Hospital, discovered the first ALS gene (ALS1) in 1993. Siddique is Director of the Les Turner ALS Research Laboratory at Northwestern University Medical School in Chicago.

ALS is a terminal, progressive neuromuscular disease that renders the muscles of the body useless while leaving the mind unaffected. There is currently no effective treatment or cure for ALS.

The newly identified gene mutation is responsible for a rare, slowly progressive, early-onset form of the disease, called juvenile inherited ALS (ALS2), discovered in highly inbred populations in North Africa and the Middle East.

Siddique and colleagues discovered the gene, located on chromosome 2q33, in four Tunisian and Saudi Arabian families. They first identified the location of the gene in 1994.

Siddique and an international consortium of researchers reported the discovery of the aberrant gene in the Oct. 3 issue of *Nature Genetics*.

Their findings also clarify why clinicians previously confused ALS2 for another neurodegenerative disease called juvenile primary lateral sclerosis — different mutations in the same gene are found in both individuals with ALS2 and those with juvenile primary lateral sclerosis, indicating that these conditions have a common genetic origin.

The accompanying editorial in the journal stated that the finding by Siddique et al. represents an important advance in the field of ALS research and in studies of neurodegeneration.

The gene for ALS2 is transmitted in an autosomal recessive pattern, i.e., the individual inherits copies of the same recessive gene from both parents. Symptoms of ALS2 manifest in the first or second decade of life and progress slowly for 10 to 15 years, akin to those of Stephen Hawking, the physicist.

In patients with the better known form of inherited ALS (ALS1), symptoms generally occur age 40 to 50 and patients die within five years. This form is autosomal dominant, that is, only one copy of the gene is required to cause the disease.

In its normal form, the gene responsible for ALS2 codes for a substance named alsin, a protein that plays an integral role in signaling pathways, intracellular trafficking and the organization of the cytoskeleton. Siddique and colleagues believe that, unlike ALS1, which is caused by a novel new property in a mutated gene, called a toxic gain of function,

ALS2 results from loss of a physiologic function.

This means that the protein's functions can be predicted based on its structure, thus providing an opportunity for direct examination of the molecular consequence of the loss in model systems, Siddique said.

"The predicted sequence of the alsin protein may indicate a mechanism for motor-neuron degeneration because the predicted protein motifs are exchanges of GTP [guanosine triphosphate, a compound necessary for several important metabolic reactions] for small GTPase proteins. These GTPases are involved in cell signaling, such as transport of molecular cargo in cellular vesicles," Siddique said.

"Elucidation of protein partners interacting with alsin may inform us of basic mechanisms underlying neuronal degeneration. Identification of crucial players in this pathway may serve as therapeutic targets," Siddique said.

Siddique is the Abbott Labs Duane and Susan Burnham Research Professor, professor of neurology and of cell and molecular biology, director of the Les Turner ALS Foundation research and clinical programs in the Herbert C. and Florence M. Wenske Neurological Research Laboratories at Northwestern University Medical School and a member of the Northwestern University Institute for Neuroscience.

His collaborators on this study were Yi Yang, Afif Hentati, Han-Xiang Deng, Toru Sasaki, Makito Hirano, Wu-Yen Hung, Karim Ouahchi, Jianhua Yan, Anser C. Azim and Natalie Cole, department of neurology at Northwestern; Omar Dabbagh, King Faisal Specialist Hospital and Research Center, Riyadh, Saudi Arabia; Generoso Gascon, Brown University, Providence, R.I.; Ayesha Yagmour, King Fahad Military Hospital, Jeddah, Saudi Arabia; Faycal Hentati and Mongi Ben-Hamida, Institute of Neurology, Tunis, Tunisia; and Margaret Pericak-Vance, Duke University Medical Center, Durham, N.C.

This study was funded by grants from the National Institutes of Health, the Les Turner ALS Foundation, Grant Healthcare Foundation, the Michael Jordan Foundation and the Ralph and Marian Falk Medical Research Trust. Co-author Karim Ouahchi is a Muscular Dystrophy Association-funded fellow, and co-author Wu-Yen Hung is a Muriel Heller Fellow. [from *ALS Today*, The Les Turner ALS Foundation, Winter 2001-2002]

**We are looking for Living with ALS articles from all over our service area
for the Dialog.**

**Please send them to the ALS Association,
8430 Mission Rd. Suite B4, Prairie Village, KS 66206-
Or email your article to Nicole Reid at nreid@alsa-midwest.org**

Memorials

Thanks to the following families for designating our Chapter for donations

Glenda Burbank
Diana Cone
Rosalia Whitcher

FOR SALE

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

1998 General Motors Mobility Conversion Van (loaded); 5,000 miles. Includes Jazz Electric Wheelchair. Please call for more details: (913) 557-9212 or email emurrow@hotmail.com

Jazzy Power Chair, Model 1120, upgraded no-flat tires and joystick control. Used only 6 months. Retail is approx. \$5200. Priced at \$2000. Contact Britt at (913)681-6356 (H) or (913)341-4200 (W).

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

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

1995 Chevy conversion van ½ ton, 37,000 miles, excellent condition. Asking 15,000. Call (785)841-6937 (Lawrence, KS area) after 4:00 pm or e-mail jchime78780@aol.com for more information.

Hospital bed, Serenity Home Care Bed by Medline. 2 years old. Used only one year. Semi-electric. Paid \$1800, asking \$500. Call Wendy at (913)371-2238.

1998 Ford Econoline 150 custom van with raised roof and side entry wheelchair lift (\$5000). 25,000 miles. Loaded, new tires, TV, and 4 wheelchair lockdown units. Like new condition, engine well maintained. See to appreciate. \$22,000. Call (816)822-8274.

1998 Elec. Wheelchair Invacare Action Ranger II Storm Series, Loaded with Jell seat, Remote Joystick / Switches/ Indicator, Anti-Tippers, adjustable High Back/Headrest Recliner standard and deluxe foot/leg rests, mirrors and other add-ons. Excellent Condition. Also 2 Battery Chargers, 1 used 24 volt, Action-Model18350 Invacare and one new/unused 24 volt dual mode automatic, Lester Electrical, Model-18350. Manuals included. Best Offer. Call: (785)272-3349 (Topeka area)

1997 Power Wheelchair, Everest & Jennings, Joystick control, new seat, clean and in great working condition. Small & compact to go through most doorways as well as tight spots in bathrooms, etc., yet large enough to handle most people. Includes batteries & charger. Arm rests can pivot or remove for transfers, swing out foot rests. \$1900.00 new. Asking \$500.00. Includes books & operating instructions. Call 816-373-2215.

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

1994 Dodge Ram Van 250 Conversion Van, Crowriver Lift.74,259 miles,\$10,500 Contact Betty Owens (573)364-6017



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FEBRUARY 2002

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|----|------|---|----|-----|---|
| 5 | Tues | Kansas City Support Group 7 - 8:30 pm
Second Presbyterian Church, 55th & Oak
Dr. Amy Ladner will speak on Pulmonary Issues | 14 | Thu | Omaha Support Group 7pm
St. Pius X Parish Center
6905 Blondo Street, Omaha, Nebraska |
| 6 | Wed | Hutchinson Support Group 2 pm
Grace Episcopal Church, 20th & Main | 20 | Wed | KC Day Support Group 2 - 3:30 pm
Village Presbyterian Church
6641 Mission Rd. Prairie Village, Kansas
Topeka Support Group 7pm
Next Meeting TBA |
| 7 | Thu | Wichita Support Group 7 pm
Grace Presbyterian Church
5002 E Douglas | | | Jefferson City Support Group
Next Meeting TBA |
| 8 | Fri | KC Caregiver Support Group 12:30 - 1:30 pm
ALS Office
8340 Mission Rd. B4, Prairie Village, Kansas
Please RSVP (913) 648-2062 | | | Lincoln Support Group
Next Meeting March 27 |
| 11 | Mon | Springfield Support Group 7pm
Springfield ALS Office
1447 F. South Enterprise
(417) 886-5003 or (888) 386-1200 (toll free) | | | "What is ALS" Orientation Series
By appointment. Please call (913) 648-2062 |

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