



# The Dialog

A Monthly Newsletter

March 2009

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## Jazz at the Gem

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Friday,  
Feb. 27

*It's not too late  
to register!*

*See page 2  
for details.*

## The Game for Animals Played by Gentlemen

*Bob Willson, A Gentle Giant*

Playing football at Rockhurst, an all-boys Jesuit high school known for its athletic program, had been his dream. His size, 6' 5" and 210 pounds, made him a perfect candidate. But, since his mom thought football was too dangerous, Bob Willson, class of 1984, decided instead to join the school's wrestling program in the heavy weight division.

"In high school, he was known as an egghead. During his wrestling tournaments, the whole school would stomp their feet and chant 'egghead!'" said longtime friend Dan Stolts. "He excelled in wrestling and broke several school records."

While at the University of Missouri, Bob was introduced to the game of rugby. His parents didn't know he was playing until his photo was in a newspaper article about rugby. Later Bob played for the Kansas City Blues Rugby Club.

"He was hard charging, competitive and intense," said another longtime friend, Joe Fridkin. "But beneath that veneer, he was truly a teddy bear of a guy."

Stolts, Fridkin and more than a hundred friends gathered on Friday, January 30 to celebrate the completion of the Kansas City Blues Rugby Club's 43rd season (1966-2008) and to honor Bob, the new Hall of Fame inductee, a member of the Blues brotherhood since the mid 1980s. This was a very special honor for Bob who played "second row" in the scrum from 1989 to 2003. They played all over the world -- in Europe, New Zealand, and South Africa.

"This is the biggest honor/event in my life...up there with marrying Linda and the birth of our children," said Bob at the induction ceremony. Bob spoke of his many friends who "make me feel like an all-star and inspire me every day."

Standing to accept his award he said, "For six months I've thought about what I was going to say. We get dealt some bad cards, I'm getting mine a little early and I'm going to fight it. My advice...when life hands you its worst, you have to be at your best."

*continued next page*

*Bob Willson - continued from page one*

Rugby is often called “the game for animals played by gentlemen.” Although Bob is known as “Big Bob”, he is described by his family and many friends as a gentle giant of a man -- a gentleman -- an ambassador of the game.

On Friday, February 27, at the Keith Worthington Chapter's Night of Hope, “Big Bob” Willson will receive another honor -- The Tom Watson Award for Courage.

Diagnosed with ALS in November 2007, Bob continues to display the courage and toughness it takes to face this disease and a gentle selflessness in allowing his story to be told publicly over and over so that others might join the effort.



*Bob with George Brett & Tom Watson  
at last year's Joe McGuff ALS Golf Classic.*

## Jazz at the Gem, A Night of Hope

Friday, February 27, 2009 6:30 - 10 PM

*American Jazz Museum & Gem Theater  
1616 E 18th Street • Kansas City, MO • 64108*

6:30 - 8 PM Cocktails & Heavy Hors D'oeuvres Reception  
8:30 - 10 PM Program & The McFadden Brothers

\$125 Individual Ticket  
\$75 Ages 35 and Under

Sponsorships available at  
\$5,000 \$2,500 and \$1,250 levels!

Seats are limited and available on a first-come, first-served basis so register today!

The American Jazz Museum and Gem Theatre are the perfect backdrop for a roaring good time as we travel back to the days of Jazz and Motown to honor the people who drive the Keith Worthington Chapter forward year after year.

Come enjoy complimentary cocktails & hors d'oeuvres, an exciting live auction and a performance by Kansas City's own McFadden Brothers.

Award Recipients:

Tom Watson Award for Courage - Mr. Bob Willson  
George Brett Award for Commitment - The Betzelberger Family

*"The McFadden Brothers are fantastic! From tap to Motown, they bring an energy to the stage that is very entertaining. They are always a crowd pleaser."*

*- Nancy Creasy, Current Board Member*

**VISIT [WWW.ALSA-MIDWEST.ORG](http://WWW.ALSA-MIDWEST.ORG)  
TO REGISTER ONLINE AND  
PREVIEW LIVE AUCTION ITEMS!**

**1920s-style dress is encouraged! Valet parking will be complimentary for all guests.**

Questions? Contact Sally Roberts at (913) 648-2062 ext 209 or [sroberts@alsa-midwest.org](mailto:sroberts@alsa-midwest.org)

## Research News from The ALS Association

December 9, 2008

### *ALS Association Co-Funds Study Showing Boosting the Body's Detoxifying System Counteracts Nerve Cell Loss in ALS Mice; New Therapies Suggested*

In a study that demonstrates a much-anticipated proof of principle, scientists report that raising activity of a natural detoxification system in the body can counteract the progressive loss of nerve cells that characterizes amyotrophic lateral sclerosis (ALS), significantly delaying the onset of disease and extending life.



The research, led by ALS Association-funded scientist Jeffrey Johnson at the University of Wisconsin, was carried out on two different mouse models carrying the human gene for a familial (inherited) type of ALS (Lou Gehrig's Disease) and on cultures of motor neurons at risk of death from the gene.

Studies elsewhere have shown that action of the detox system benefits models of acute injury, such as stroke. This new work, however, reveals that ramping up this system in live animals is effective against a chronic neuron-killing disease such as ALS and that the benefits can occur before its onset.

Johnson's ongoing encouraging studies of the principle in Parkinson's, Huntington's and Alzheimer's disease models suggest its broad application. The published research also verifies key parts of the protective pathway, suggesting new targets for therapies to come. "Even though we did this study in a mutant mouse model," Johnson says, "this pathway — and the reason it's needed — is the same in humans. That's true, studies show, both in patients with the familial form of ALS or with the more common sporadic form. "We believe that bodes well that our results will apply to ALS in general," Johnson says.

"We are excited about the potential new pathways for ALS therapy suggested in this research," said Dr. Lucie Bruijn, Ph.D., senior vice president for research and development at The ALS Association.

An account of the research appears this week in the *Journal of Neuroscience*. For more information on this study and others in The ALS Association's research program, visit [www.alsa.org/research](http://www.alsa.org/research).

## Every Little Bit...

Everyone knows the expression "every little bit counts." This applies to so many aspects of our lives, including charitable giving.

When you reach out your hand to help your neighbors you make a direct impact on the lives of those around you. By dedicating \$10 a month to charitable giving, you can play a significant role in improving the lives of those with ALS and their families.

If everyone who reads *Dialog* gave \$10 a month over the course of just one year, we would have more than \$320,000 to dedicate to providing vital patient services as well as funding critical research to find a cure.

Every little bit counts. Consider the impact you can make on the lives of others with just a little bit.

## Circles of Giving

Join The ALS Association Keith Worthington Chapter's Circle of Giving by making an annual pledge to help eradicate ALS.



## Lou Gehrig Legacy Society

Leaving The Keith Worthington Chapter in your will or trust is easier than you think. (You can leave percentages or even receive monthly income from making your gift.) Make the ultimate gift and leave a lasting impression on the Chapter.



For more information on giving to the Chapter, contact Sally Roberts at (913) 648-2062 ext 209 or E-mail [sroberts@alsa-midwest.org](mailto:sroberts@alsa-midwest.org).

## In Memoriam

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

Jerry Collins  
Carol Comley  
Ted Hauptman  
Nancy Laughlin  
Ron Mallory

Mark Nielsen  
Jackie Polacek  
Edward Setzler  
Valdene Veer

## Memorials

*Thank you to the families of the following for designating The Keith Worthington Chapter for donations:*

Carol Comley  
Jean Griffin  
Nancy Laughlin  
Ron Mallory  
Ed Setzler

## A Selfless Act of Kindness



“The only thing I know about Michele Clark’s story is that when our office camera was stolen several years ago, she told us that if she ever won the lottery she would buy us a new one and donate it to ALS,” said Jean Haley, Care Coordinator in the Chapter’s Wichita office.

Of course no one ever really thinks they will win, but Michele bought two tickets at the Prime Time convenience store in Newton recently and the lottery guy happened to be there at the time she purchased them.

On her way out the door she said “Well, I’ll be seeing you again when my winning ticket comes up!” Never thinking that she was holding a \$5,000 ticket at the time.

What a surprise for her and then a surprise for the Chapter! Recently Michele purchased the new camera and presented it to the staff.

“It’s a nice one,” said Jean, “a Cannon Powershot with case and all.”

Truly a selfless act of kindness!

## Advocacy

### REGISTRATION IS NOW OPEN FOR THE 2009 NATIONAL ALS ADVOCACY DAY/PUBLIC POLICY CONFERENCE

Mark your calendars for a trip to Washington, D.C. to attend the 2009 National ALS Advocacy Day/Public Policy Conference May 11 - 13, 2009.

If you are interested in:

- meeting other advocates from across the country
- getting updates on research and The ALS Association’s legislative priorities for the coming year
- visiting Senators and Representatives from your state
- making a difference in the lives of individuals, caregivers and families living with ALS,

please call the Capital Office of The ALS Association toll free at 1-877-444-ALSA or visit The ALS Association Web site at [www.alsa.org/policy](http://www.alsa.org/policy).

“LONG AGO, WHEN PEOPLE CURSED AND BEAT THE GROUND WITH STICKS, IT WAS CALLED WITCHCRAFT...

TODAY, IT'S CALLED GOLF.”

**The Joe McGuff ALS Golf Classic**  
**May 18, 2008 ~ LionsGate ~ 12:00 p.m.**

Individuals and companies are invited to join Kansas City community leaders and sports celebrities in honoring the memory of Joe McGuff while fighting the devastating disease of ALS.

This event involves an auction, lunch and dinner and a round of golf on a beautiful course. Past tournaments have included participation from celebrities such as George Brett, Tom Watson, Len Dawson, Deron Cherry and Norm Stewart – and 2009 promises even more excitement with Coach Gary Pinkel joining the effort.

**Ways to get involved:**

- Purchase a team – teams of four are available for \$4,000
- Volunteer at the event – volunteers are needed for set-up, registration, monitor games on the holes, check-out and tear down.



*For more information  
 please contact:*

*Kristin Spence  
 (913) 648-2062 Ext. 211  
 kspence@alsa-midwest.org*



We're excited to announce that the new Walk to Defeat ALS™ Web site is now open!

Register today at: [www.walktodefetails.org](http://www.walktodefetails.org)

To begin, select the state in which you would like to walk.  
 (For those interested in the Kansas City Walk, select Kansas.)

## THE ALS ASSOCIATION TEAMS WITH MAJOR LEAGUE BASEBALL IN AWARENESS INITIATIVE

“4♦ALS Awareness” to Commemorate the 70th Anniversary of  
Lou Gehrig’s Farewell Speech on July 4th



The ALS Association has joined with Major League Baseball and Minor League Baseball in the new “4♦ALS Awareness” initiative that commemorates Lou Gehrig’s dramatic farewell speech on July 4 this year in baseball stadiums across the nation, elevating awareness of the disease to an unparalleled level and raising desperately needed funds for research.

The campaign will commemorate the 70th anniversary of the speech given in 1939 and encourage contributions to The ALS Association and three other organizations involved in the fight against ALS.

“We are honored and pleased to have the opportunity to join these four important organizations in an attempt to make progress in the fight against ALS, a disease that is associated with one of the greatest players in baseball history,” said Bud Selig, Commissioner of Baseball. “Lou Gehrig displayed tremendous courage and strength in the face of a debilitating illness, and his speech 70 years ago still stands as one of the defining moments in baseball history.”

“The courage of Lou Gehrig embodies each and every service and program we offer to the brave men and women living with ALS,” said Allen L. Finkelstein, chair of The Association’s National Board of Trustees. “It is his spirit that inspires us on a daily basis to do all we can to discover new treatments and a cure.”

Players, who will wear a “4♦ALS” patch, and other celebrities, will read the speech during baseball’s traditional seventh inning stretch. MLB.com also will conduct an online auction to raise funds. Other fundraising activities are being developed as well.

WATCH FOR ANNOUNCEMENTS  
OF “4♦ALS” LOCAL ACTIVITIES  
IN FUTURE ISSUES OF DIALOG  
AND ON OUR WEB SITE.

From left, Lou Gehrig’s widow, Eleanor; catcher Bill Dickey;  
and Manager Joe McCarthy in July 1941,  
a month after Gehrig’s death.



# Equipment Exchange Items for Sale

*(Items will be listed for a maximum of 6 months.)*

## VANS

2005 Toyota Sienna LES conversion van, \$32,000 or best offer, Sheryl (620) 276-6527

2005 Pontiac Montana Van, fully loaded, 7000 miles, \$35,000 or best offer, Dolly Humes H (417) 781-2506 or (417) 529-0785

2004 Chevy Van, Braun conversion, 102k miles, \$13,500 or best offer. (316) 729-8815

2000 Dodge Grand Caravan. Lower conversion, auto ramp and door, tie downs, \$12,900, (913) 205-2848

1998 Town and Country Conversion Van. Wheelchair locks and side ramp. Removable front seats. 40,000 miles, new battery, \$14,000, Alice Zavec at [Alice.B.Zavec@usace.army.mil](mailto:Alice.B.Zavec@usace.army.mil)

Chrysler 1995 Town & Country, all leather interior, 187,000 miles, Bruno Lift & 2 docking units. \$2,500 or best offer. H (620) 254-7926 or C (620) 955-7052

## WHEELCHAIRS

Permobil power chair, air cushion, ALS options, leather, full recline, best offer (316) 729-8815

Permobil C300 with gelseat, tilt/recline, legs raise, height adjusts, <1 year old. \$5,000. Don Green W (417) 781-8262

Invacare Pronto Sure Step Wheelchair. \$1,000. Don Green (417) 781-8262 work number

Permobil C300, ALS options, \$7,500, Sheryl (620) 276-6527

Invacare wheelchair with extra cushion. \$100. Ted (316) 283-5452

## MISCELLANEOUS

Mercury II laptop computer for communication. Make offer. Ted (316) 283-5452

Hands Free Mouse Natural Point Smart NAV3, dots, and single foot switch. \$150. Call Lisa (913) 397-8180

DynaVox Handheld Impact (NEC Mobile Pro900)+ speaker with carrying case. Large keyboard with 7.5" x 2.8" touchscreen. \$2,500.

Also, HP iPAQ HX4700 Pocket PC with DecTalk software, 4" x 6" wallet case with speaker. \$1,000. Call Linda Edwards (316) 755-3121

Dynovox, \$4,000 & Hoyer Lift, \$750, Sheryl (620) 276-6527

DynaVox, Series 4, used for six months, excellent condition. table top mount, wheel chair mount, and joystick. \$3,000 or best offer Kyle Claycamp (785) 364-4216



**Inclusion in Dialog  
is not an endorsement  
of these products.**

**If your item has been sold, or if you would like to place an ad, please contact Emily at (913) 648-2062 Ext. 222 or [efuhrman@alsa-midwest.org](mailto:efuhrman@alsa-midwest.org).**

## Contact Information

### Directors

Kansas City (913) 648-2062  
Beckie Cooper, Ext. 210  
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### Patient Services

Kansas City (800) 878-2062  
Linnea Brandt, Ext. 206  
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Anne Wenger  
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THE DIALOG  
 Keith Worthington Chapter  
 6950 Squibb Road, Suite 210  
 Mission, KS 66202  
 Address Service Requested

Non Profit Org.  
 U.S. Postage  
 PAID  
 Shawnee Mission, KS  
 Permit No. 1249



Proud member of



# Support Groups

## March Support Group Dates

PHONE RSVP IF MARKED WITH *		
TOLL-FREE NUMBERS LISTED BELOW.		
3	*KANSAS CITY EVENING	7:00 PM
<i>(LATEST RESEARCH FROM ALSA NATL CONF.)</i>		
4	JEFFERSON CITY	1:30 PM
4	HUTCHINSON	2:00 PM
5	WICHITA	7:00 PM
10	*OMAHA	6:30 PM
10	SPRINGFIELD	6:30 PM
13	*KANSAS CITY CAREGIVERS	12:30 PM
18	*KANSAS CITY YOGA	1:30 PM
19	SALINA	7:00 PM
21	WICHITA CAREGIVERS	11:00 AM
23	*TOPEKA	4:00 PM
26	*CARL JUNCTION	11:00 AM
26	NEBRASKA PHONE GROUP	7:00 PM

## Support Group Locations

Hutchinson, KS Grace Episcopal Church 20th & Main	Wichita, KS Grace Presbyterian Church 5002 East Douglas	Richmond, MO Call Lea (816) 776-6007
Salina, KS Church of the Cross Methodist Corner of W. Claflin & Rush St.	KC Caregivers/Survivors ALSA Bldg - 2nd Floor Please RSVP	Jefferson City, MO Southridge Baptist Church 1815 Vieth Drive
Topeka, KS Shawnee Co. Pub Library 1515 SW 10th Avenue Please RSVP	KC Day (YOGA) ALSA Bldg - 2nd Floor Please RSVP	Springfield, MO Cox South Hospital Meeting Room #3
Wichita, KS Caregivers ALSA Office- 3450 N. Rock Rd, Bldg 200, Suite 211 No need to RSVP	KC Young Men ALSA Bldg - 2nd Floor room Please RSVP * Meets every other month	Carl Junction, MO Gambino's Pizza 1304 Pennell Street
	KC Evening 2nd Presbyterian Church 55th and Oak	Omaha, NE Millard Library 13214 Westwood Lane
		Nebraska Phone Group Call Shannon (866) 762-6361

The Keith Worthington Chapter has offices in the following cities:

**Kansas City**  
 (800) 878-2062

**Nebraska**  
 (866) 762-6361

**Springfield**  
 (888) 386-1200

**Wichita**  
 (800) 553-9056