



**Keith Worthington
Chapter**

The Dialog

A Monthly Newsletter

February 2009

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*You're
invited to
the 20th
annual
NIGHT
OF
HOPE.*

Details on page 3.

Passing the Gavel

From out-going president, Pete Story:

It has been my honor and privilege for the past two years to serve as president of The ALS Association Keith Worthington Chapter. During this time, we have seen incredible support of our mission to find a cause and a cure. We would not be where we are without our magnificent staff. I have never been involved with a group so incredibly dedicated. My hat is off to all of them.

I am thrilled to turn the gavel over to my good friend David Wurth. In the short time David has been on our board he has shown enthusiasm, passion and professionalism in joining our fight.

As we go into 2009, like so many other non-profits, we are faced with economic uncertainty. Our challenge as a board is to continue to raise money and to provide the services and support the ALS community has grown to expect. I would like to reach out to you, our PALS, caregivers, and friends, to join us in our fundraising efforts. Please ask your friends, relatives, co-workers and anyone you come into contact with to open their hearts and wallets and give to The Keith Worthington Chapter. No donation is too small (or too large).

I have always been uncomfortable asking for money. It is difficult for most of us. However, that all changed when I expressed this to a friend whom I was asking for a contribution to ALS. He told me there is an old Jewish proverb that states, "He who asks for a gift to benefit humanity will receive a higher place in heaven than the one who gives." He then signed up for Circles of Giving.

I urge you all to keep these comforting words in mind as you make those calls on behalf of our fine organization.

From in-coming president, David Wurth:

I am in awe of the honor to serve. We all have a huge job to do during this TOUGH year ahead, beginning with Night of Hope in February. Pete Story left us with a great motto and understanding of asking people to give.

Believe me when I say that humility will be my byword, but courage is what I see from those living with ALS. So, thanks in advance for your support, your service and your courage.

Research News from The ALS Association

November 25, 2008

Disappointing Results from IGF-1 Clinical Trial

By Richard Robinson, Science Writer

Subcutaneous (under the skin) delivery of insulin-like growth factor 1 (IGF-1), known as the drug Myotrophin, does not benefit people with ALS at a dose of 0.5 milligrams per kilogram of body weight, according to a large clinical trial whose results were announced.

IGF-1 is a substance the body produces to sustain motor neurons, the nerve cells that die in ALS. Experiments in animal models of the disease suggested IGF-1 treatment may delay death of motor neurons. IGF-1 was tested in ALS a decade ago in two trials, but the results of the two were inconsistent, with one suggesting treatment was beneficial, and the other showing no benefit.

“These results are deeply disappointing to all of us in the ALS community,” said Lucie Bruijn, Ph.D., senior vice president, research and development, The ALS Association. “The subcutaneous delivery route may be the key problem, or it may be that IGF-1 alone is not sufficient to rescue motor neurons.”

The current trial involved 330 people with ALS from 20 ALS treatment centers across the United States. Patients were randomly assigned to receive either IGF-1 or a placebo, injected under the skin twice a day, for two years. The dose used was the highest tolerated dose from previous studies. Neither doctors nor patients knew which treatment the patient had received until the end of the study.

At the end of the two-year treatment period, there were no differences between people with ALS who received IGF-1

and those who received placebo in muscle strength, the need for a tracheostomy for breathing, or survival, indicating that IGF-1 provided patients no benefit.

The ALS Association is the only national, not-for-profit voluntary health organization devoted solely to fighting ALS through research, patient services, advocacy and public education and information. The Association is currently exploring multiple new avenues for treatment through its TREAT-ALS (Translational Research Advancing Therapies for ALS) drug discovery program and clinical trials process.

For more information about The ALS Association’s research program, visit www.alsa.org/research.



Chapter Web site
www.alsa-midwest.org

Walk Web site
<http://walkkwc.alsa.org>

National Web site
www.alsa.org

Now on Facebook!

The Keith Worthington Chapter is now on Facebook at www.tinyurl.com/fbalsakwc. If you’re already on Facebook, simply become a fan of the page. If not, you’ll first be prompted to sign up for Facebook (it’s free and easy).

Do we have your current E-mail address?

Please provide us with your current E-mail address so that we can be more efficient and “green” in our communications with you.

E-mail us at: info@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.

Mary Chadwick
Doris Cole
Ed Finley
Bertie Hood
Lanny Lenker

Memorials

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

Mary Chadwick
Bertie Hood

You're Invited to the 20th Annual Benefit for
The ALS Association Keith Worthington Chapter!



Jazz at the Gem, A Night of Hope



Join us at two of KC's most notable landmarks, The American Jazz Museum and Gem Theatre, as we travel back to the Roaring '20s for a night of food, fun and entertainment!

Help celebrate the people who make the Chapter's programs and services possible.

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.

Visit www.alsa-midwest.org for more info and event registration. Remember, tickets are limited and available on a first-come, first-served basis.

"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

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



Walk to Defeat ALS™ Corporate Support Needed!

If your company or the company of a loved one is interested in learning more about partnering with the Walk to Defeat ALS™, please contact the people below:

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

In Nebraska
Sherrie Hanneman
 (402) 991-8788
 shanneman@alsa-midwest.org

In Springfield
Clark Snyder
 (417) 886-5003
 csnyder@alsa-midwest.org

In Wichita
Colleen Wachter
 (800) 533-9056
 cwachter@alsa-midwest.org

We offer many wonderful ways for companies to support the Walk to Defeat ALS™ and would be happy to discuss the opportunities.

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.



**The Joe
 McGuff
 ALS GOLF
 CLASSIC**



**For more information
 please contact:**

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

Advocacy

THE ALS ASSOCIATION ADVOCACY SUCCESSES HAVE INCLUDED:

- **Veterans Benefits**

Helped to secure more than \$500 million in benefits for military veterans with ALS, their families and survivors as the Veterans Administration implemented historic new regulations in 2008 to designate ALS as a service connected disease. Veterans with ALS and their survivors are now eligible for full health and disability benefits, regardless of where or when they served in the military and regardless of how soon after discharge they were diagnosed.

- **24-Month Medicare Waiver**

Eliminated the 24-month waiting period that people disabled with ALS had to endure before they could start receiving Medicare benefits.

- **Presumptive Disability**

Orchestrated Social Security rule change under which people with ALS automatically meet the medical eligibility requirements

for SSDI and SSI payments. This ruling allows people with ALS to access their benefits months or even years sooner than before.

- **Generated more than \$365 million for ALS research over the past ten years**

Increased government funding from \$15 million per year in 1998 to more than \$60 million in 2007.

- **National ALS Registry**

Enacted the ALS Registry Act in 2008 to establish the first nationwide ALS patient registry, which may become the single largest ALS research project ever. The Association also has worked with Congress to secure nearly \$5 million for registry pilot projects, including \$3 million in FY 2008. The registry will be administered by the Centers for Disease Control and Prevention.



- **Department of Defense/ Department of Veterans Affairs Research Funding**

Worked with Congress to appropriate \$5 million in FY 2009 for the ALS Research Program at the Department of Defense. The ALSRP is the only ALS specific program at DOD and is focused on translational research, leading to new treatments for the disease. The ALSRP was initially launched in 2007 when The ALS Association partnered with DOD to bring new focus to their ALS research portfolio, which, combined with the VA, has provided over \$25 million in funding for ALS research in recent years.

HOWEVER, THERE IS MORE WORK TO BE DONE!

Save the Date!

The 2009 National ALS Advocacy Day/
Public Policy Conference
May 11-13, 2009
Washington, D.C.

For additional information, 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

Become an ALSA Advocate!

As an ALS Association Advocate, you can help change the laws and policies that affect thousands of persons with ALS and their families.

To sign up, visit The ALS Association Web site at www.alsa.org/policy

Look for the button:

“Sign up to be an ALSA Advocate”

The Keith Worthington Chapter Board of Directors

At the January 6th Board of Directors meeting, President Pete Story passed the gavel to the new president, David Wurth, and swore in the new officers (below, left to right) David Wurth, *President*, Emily Jennings, *Vice President*, Ron Edelman, *Secretary*, and Pete Hartweger, *Treasurer*.

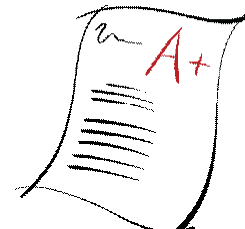
Also welcomed to the Board are new members (left to right) Matt Brane, Richard Ehlers and Keith Gary.



PROGRAM REPORT

Programs & Services Update for FY09 (from the December 2008 report)	Dec 2008	Total 2008
New patients	6	119
Number of patients who have died	4	97
Consultations by Service Coordinators	522	4950
Number of clinics held	5	47
Patients attending clinic	27	341
Number of support group meetings	13	142
Patients attending support group meetings	48	223
Total attending support group meetings	361	1480

(The Chapter's fiscal year runs from Feb to Jan of the following year. Fiscal year 2009 is Feb '08 - Jan '09.)



In our effort to provide quality services to the ALS community, we need your input. If you or a loved one either currently receives or has recently received services from the Chapter, please complete the evaluation form located on our Web site at: www.alsa-midwest.org

If you can't access the internet, but would like to fill out an evaluation, please call the office nearest you, toll-free numbers are located on page eight of this newsletter.

If you have equipment you would like to donate, please contact Sarah Tucker at (913) 648-2062 or stucker@alsa-midwest.org

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 mi, \$35,000 or best offer, Dolly Humes H (417) 781-2506 or (417) 529-0785

2004 Chev 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

2000 Chrysler Town & Country. One owner Lower conversion, auto ramp and door, tie downs, \$12,500, (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 Zavcek at Alice.B.Zavcek@usace.army.mil

Chrysler 1995 Town & Country, all leather interior, 187,000 miles, Bruno Lift & 2 docking units. \$2,500.00 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. \$5000. Don Green W (417) 781-8262

Invacare Pronto Sure Step Wheelchair. \$1000. Don Green (417) 781-8262 work number

Permobil C300, ALS options, \$7500, Sheryl (620) 276-6527

MISCELLANEOUS

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. \$1000. Call Linda Edwards (316) 755-3121

Dynovox, \$4000 & Hoyer Lift, \$750, Sheryl (620) 276-6527

DynaVox, Series 4." Used for six months, excellent condition. table top mount, wheel chair mount, and joystick. \$3000.00 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 Sarah at
(913) 648-2062 or
stucker@alsa-midwest.org.**

Contact Information

Directors

Kansas City (913) 648-2062
Beckie Cooper, Ext. 210
Executive Director
bcooper@alsa-midwest.org
Sally Dwyer, Ext. 212
Program Director
sdwyer@alsa-midwest.org
Colleen Wachter, Ext. 221
Director of Events
cwachter@alsa-midwest.org
David Wurth
President
info@alsa-midwest.org

Patient Services

Kansas City (800) 878-2062
Linnea Brandt, Ext. 206
lbrandt@alsa-midwest.org
Nancy Lindquist, Ext. 204
nlindquist@alsa-midwest.org
Sarah Tucker, Ext. 202
stucker@alsa-midwest.org
Nebraska (402) 991-8788
Shannon Todd
stodd@alsa-midwest.org
Springfield (888) 386-1200
Debra Harlan
dharlan@alsa-midwest.org
Wichita (800) 553-9056
Jean Haley
jhaley@alsa-midwest.org

Fundraising

Kansas City (913) 648-2062
Sally Roberts, Ext. 209
sroberts@alsa-midwest.org
Kristin Spence, Ext. 211
kspence@alsa-midwest.org
Nebraska (402) 991-8788
Sherrie Hanneman
shanneman@alsa-midwest.org
Springfield (417) 886-5003
Clark Snyder
csnyder@alsa-midwest.org
Wichita (800) 878-92062
Colleen Wachter
cwachter@alsa-midwest.org

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

February Support Group Dates

Support Group Locations

PHONE RSVP IF MARKED WITH *		
TOLL-FREE NUMBERS LISTED BELOW.		
3	*KANSAS CITY EVENING <i>(LATEST RESEARCH FROM ALSA NATL CONF.)</i>	7:00 PM
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
26	*CARL JUNCTION	11:00 AM
26	NEBRASKA PHONE GROUP	7:00 PM

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 * Every other month	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