



Metric Anderson's Homecoming

by Cathy Sherman

This article appeared in an ALS insert in the June 29th Wichita Eagle.

For two and a half years, Metric Anderson was Melba Madden's caregiver. Madden, who had ALS, died in June of 2002. In May 2008, Jean Haley, the patient services coordinator for The ALS Association Keith Worthington Chapter in Wichita, received a call from a hospice nurse in Connecticut. The reason for the call? Anderson, a woman with ALS, wanted to return to Wichita. "The name was so familiar to me," Haley said, "but I found it hard to believe. Metric had ALS? I've never heard of an unrelated caregiver also getting ALS."

Haley called Melba's husband, Norval, who was "just flabbergasted" at the news. Norval Madden immediately volunteered to pay for Anderson's return, as well as a hospice nurse to accompany her. Anderson returned to Wichita on May 19. "Metric was an integral part of our family," Madden said. "She cared for my wife all day, six days a week for two and a half years. We owe her a great debt."

Anderson, 60, traveled to Hartford, Conn, in December 2006. She wanted to see her brothers and sisters while she could still travel. She had been suffering muscular problems since 2004, and had first received a diagnosis of myasthenia gravis and then carpal tunnel disease. She was diagnosed with ALS in 2006 and her disease progressed so rapidly that she needed hospice care by April of 2007. "But by the time she left for Connecticut for her extended visit, she could only swallow pureed foods and was choking frequently -- definitely more than carpal tunnel symptoms," Haley said.

ALS can mimic many diseases. It can also be mistaken for stroke and MS. "Many times, ALS is misdiagnosed in the early stages," Haley said. "There's no test for it. When you rule out everything else, ALS is the one that's left."

Continued on page 2

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We owe her
a great debt.
”



The 1st Walk to Defeat ALS™ 2008 is in August.

See page 4 for all Walk locations and dates in

August, September & October.

Continued from page 1

Helen Kingstorf, her hospice nurse in Connecticut, said Anderson is a fighter. "She'd lost a lot of weight, but when she got a feeding tube she bounced back," she said. But Anderson's disease continued to progress, and she wanted to return to her home in Wichita, to be near her son and five grandchildren. Kingstorf accompanied Anderson on the flight to Wichita Mid-Continent Airport, where Madden and Haley greeted her.

"Norval called Metric before our trip," Kingstorf said.

"He was so excited. He told her 'I'm going to pay for the whole thing. We're going to be at the airport with a wheelchair. We're going to have a balloon with your name on it.'"

Is Anderson happy to be home?

"Oh, yes, I am," she said.

Kingstorf stayed overnight to help Anderson get situated in her home. "We started getting ready at 4 a.m. today," Kingstorf said, describing their long day of travel to Wichita. Anderson said she understands and appreciates that devotion. "We nurse from our hearts," she said, patting her chest.

Madden, who was a teacher and administrator in the Wichita schools for 25 years before retiring, said he hoped to spend a lot of time with Anderson. Elvira Martin, one of Anderson's cousins from Jamaica, is caring for Anderson. Hospice Care of Kansas and Haley of the ALS Association Keith Worthington Chapter are following Anderson's care in Wichita.

* * *



Casey and Spike, mascots of the Omaha Royals show their team spirit for the Omaha Walk to Defeat ALS™ at the ALS Day at the ballpark on July 28th. Mr. Peanut tries to figure out how he can get in on the fun.



An Outstanding Partnership

The ALS Association Keith Worthington Chapter's partnership with KU Medical Center doesn't end at clinical trials and the Center of Excellence. (See next page -->.)

The University of Kansas Medical Center is also a major supporter of this year's Walk to Defeat ALS.



Executive Vice Chancellor, Barbara Atkinson, MD, is serving as the 2008 Corporate Recruitment Chair for the Walk To Defeat ALS.

Dr. Atkinson hosted an informational breakfast for 40 local business leaders to generate new support for the walk. So far \$5,000 in new money has come out of the breakfast!

KU Medical Center has its own corporate walk team; Dr. Atkinson, Dr. Kirk Benson (Professor and Senior Associate Dean for Clinical Affairs), David Adkins (Vice Chancellor of External Affairs) and staff are heading up the effort to raise \$30,000 at the Medical Center alone for the Walk in September.

Departments all over the campus will be contributing to the effort through letter writing campaigns and fundraising events.

The Keith Worthington Chapter thanks The University of Kansas Medical Center for all they do in the fight against ALS!

AUGUST 2008

The ALS Association Center of Excellence

Eight years ago, on August 6, 2001, The University of Kansas Medical Center and The Keith Worthington Chapter opened the doors of the ALS clinic located just north of the medical center in the Landon Center on Aging. On August 12, 2002, a year later, after meeting rigorous clinical care standards and passing a comprehensive site inspection, the clinic was certified as The ALS Association Center of Excellence. Currently there are only 32 in the country.

The ALS Association selects, certifies and supports distinguished regional institutions recognized as the best in the field with regard to knowledge of and experience with ALS. The clinic neurologists are Dr. Richard Barohn, Chair of KU Medical Center's Department of Neurology and Dr. April McVey, the current clinic director. They are national experts in the field of ALS. The clinic has grown from approximately 75 clinic visits to 325 this past year -- the current year looks to increase even more.

"I feel privileged to work with our ALS patients and their families, and the team is populated by the most caring, dedicated, and experienced health care professionals," says Dr. McVey.

Neurological diagnostics and imaging are available, and the following licensed and certified ancillary services make up the multi-discipline team and are on-site on clinic days:

- Physical therapy
- Occupational therapy
- Respiratory therapy
- Registered dietician services
- Ph.D. psychology or psychiatry
- Speech and language pathology
- MSW social work services
- Nursing

The ALS Center has many strengths: a large comfortable and accessible rehabilitation facility in which to examine and treat those with ALS, dedicated neurologists and other professional team members, and a strong cooperative KU Medical Center-ALS Association partnership. On clinic days, members of the Chapter Patient Services staff serve on the multi-discipline team.



Research

In addition to the clinic, which meets every Monday morning, the Center is actively involved in clinical research and drug trials. Here is a list of current ALS research at the Center:

1. Clinical trials of
 - a. celebrex in subjects with ALS
 - b. creatine in subjects with ALS
 - c. minocycline in subjects with ALS
 - d. ceftriaxone in subjects with ALS
2. Study of TCH345 versus placebo for ALS
3. Randomized, double-blind, placebo-controlled study of safety and efficacy of botulinum toxin type B (myobloc) for sialorrhea in ALS
4. Intravenous glutathione for ALS
5. Combination therapy selection trial to study the combination of minocycline and creatine or CoQ10 and creatine on slowing the progression of subjects with ALS
6. A multicenter, dose ranging safety and pharmacokinetics study of arimocloamol in ALS
7. Collection of data and biomaterial for repository banking to facilitate research into etiology of ALS and related motor neuron diseases.
8. QALS clinical trial of high dose CoQ10 in ALS
9. Neuroimaging markers of ALS
10. Resequencing the variable human genome in ALS: A necessary prelude to diagnostics and drug development
11. A multinational, multicenter, randomized double-blind, placebo controlled, parallel group study to assess the efficacy, tolerability, safety of talampanel in subjects with ALS
12. A double-blind, randomized, placebo-controlled, multicenter study to assess the safety and efficacy and to determine the pharmacokinetics of two doses of AVP-923 (dextromethoophan/quinidine) in the treatment of pseudobulbar affect (PBA) in patients with ALS and multiple sclerosis
13. A 2-part, randomized, double-blind, safety and tolerability study evaluating KNS-760704 in subjects with ALS
14. A multi-center controlled screening trial of safety and efficacy of lithium carbonate in subjects with ALS

Get Ready for This Year's Walk to Defeat ALS™



2008 Walk Schedule

08/02/08	Kearney, NE	Univ of NE Kearney, Ockinga Center
08/23/08	Omaha, NE	Elmwood Park
08/23/08	Emporia, KS	Jones Park
09/13/08	Branson, MO	Stockstill Park
09/14/08	Joplin, MO	Cunningham Park
09/20/08	Kansas City	Corporate Woods (Overland Park)
09/20/08	Springfield, MO	Chesterfield Park
09/27/08	Topeka, KS	Lake Shawnee
09/27/08	Salina, KS	Bill Burks Park
09/28/08	Columbia, MO	Stephens Lake Park
10/11/08	Wichita, KS	Lawrence Dumont Stadium
10/11/08	Lincoln, NE	Antelope Park
10/11/08	Richmond, MO	Richmond High School

Great Weather and Delicious Food Bring Over 55 to the Kansas City Support Group Picnic



Photos Courtesy of Myron Cramer

Trusts and Estate Planning

Part One

A popular tool in estate planning is trusts. One reason for this is the fact that there are many different types of trusts that can serve a variety of purposes. It would be impossible to give even a brief explanation of the many types of trusts available; the advice of an attorney and qualified financial planner is necessary to assess your situation and decide which trust might best serve your goals. However, there are two types of trusts that are often used by those wishing to include a charitable gift in their estate plans. In this issue, a brief overview of the popular living trust is included. Next month, we will include information about charitable remainder trusts.

Many people are choosing to distribute their property after death through a revocable living trust. If properly established, this trust can minimize or avoid probate costs for the estate. In some cases, the living trust may also help keep your estate affairs private, and will allow you to appoint someone to handle your affairs if you should become incapacitated. However the attorney fees to draft a living trust are generally higher than those for a will and the costs to actually distribute your property after death may be comparable to what it would be through the probate process. There is also the necessity of re-titling all your assets into the name of the trust. Many people fail to complete this process, which means that probate will still be necessary with the estate along with the administration of the trust. It is important to work with a qualified professional who can help ensure that your trust is properly established and implemented.

If you use a living trust in your estate plans, it is easy to include a gift to The ALS Association Keith Worthington Chapter by using the following language (this language can also be used in wills):

I give the sum of \$ _____ (or _____% of my estate) to The ALS Association Keith Worthington Chapter to be used for its general purposes.

You may also give a particular asset ("my shares of XYZ stock...") or a portion of the residue of your estate after other gifts have been paid ("50% of the rest, residue and remainder of my estate...").

If you have included the Chapter in your estate plans, please contact the office at (913)648-2062 so we can send you information on joining The Lou Gehrig Legacy Society.

The above information is of a general nature only and the services of qualified legal counsel or a financial planner should be sought for specific advice pertaining to your estate plan.

Walk to Defeat ALS™ Fundraising Tips

Check out these tips from Walk participants around the Keith Worthington Chapter:

TIP #1

Letter writing campaign – Raise 5-10 times more by sending out emails/letters to everyone & anyone you know.

Start with your Holiday card list & add any businesses you frequent often.

Contact your local office for sample letters to get you started. Better yet, send out emails from your personal fundraising web page.

Not sure how? Go to www.alsa-midwest.org, click on the Walk logo, select the city in which you would like to Walk and follow the steps to register.

Once you have registered, you can personalize your web site and send out emails!

TIP #2

Don't do it alone – get co-captains to help recruit more walkers for the team.

TIP #3

Ask 10 people for \$10.

TIP #4

Have a silent auction or a bake sale (or both!) at your office.

TIP #5

Host a barbecue for family and friends and ask for donations at the door.



Defeating ALS One Step At A Time...



Advocacy Update

ALS Association Wins Fight for Power Wheelchairs

(July 9, 2008)

AUGUST 2008

Thanks to the outreach of ALS advocates in key states across the country, the U.S. Senate this afternoon passed legislation (HR 6331) that would exclude power wheelchairs from Medicare's new competitive bidding program. The bill, which passed by a 69-30 vote, also would delay implementation of the program for 18 months. This is a tremendous victory for people with ALS and their families and helps to ensure PALS will continue to have access to needed power wheelchairs!

For nearly two years, The ALS Association has worked with Congress to exclude high-end power chairs from the new program for fear that it would limit the types of chairs available to PALS, reduce services and force PALS to obtain chairs from suppliers who do not know the unique medical needs of people with ALS.

The Association held a breakout session on competitive bidding during our Advocacy Conference in May and worked closely with PALS and Chapters to educate Congress on the unique needs of people with ALS, making it clear that one-size-fits-all policies like competitive bidding are not appropriate when it comes to this disease. In fact, the participation of PALS at a press conference on competitive bidding last year helped to highlight the concerns of the ALS community and clearly demonstrated that the chairs needed by PALS are much different than those used by most Medicare beneficiaries.

With today's vote, we are one step closer to ensuring that competitive bidding will not limit the ability of PALS to access to the power chairs they need when they need them.

The House of Representatives already has passed HR 6331 with broad support so the bill now heads to the President for his signature. The President has signaled that he may veto the bill due to concerns about other unrelated provisions. However, both the Senate and House passed the bill with enough support to override a veto and enact HR 6331 into law.

If you have any questions about today's vote or would like additional information, please contact the Advocacy Department at advocacy@alsa-national.org or 1-877-444-ALSA. *(PALS = People with ALS)*

Programs & Services Update for FY09	In June	Fiscal Year
(from the June 2008 report)	2008	'09 to Date
New patients	12	54
Number of patients who have died	5	41
Consultations made by Service Coordinators	448	2126
Number of clinics held	5	19
Patients attending clinic	29	145
Number of support group meetings	10	57
Patients attending support group meetings	22	106
Total number attending support group meetings	116	535

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

In Memoriam

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

Luanna Leichliter
Denise Stice
Paul Stone
Carl Walker

Memorials

Thank you to the families of the following for designating our Chapter for donations:

Jeanne Browning
Donna Carr
Luanna Leichliter

EQUIPMENT EXCHANGE

ITEMS FOR SALE

VANS

2003 Dodge Grand Caravan, Rampvan. Perfect condition, 98,000 miles, new tires, new rear shocks, serviced Feb 06, asking \$26,000. Call (888) 386-1200 or e-mail djmathis1@alltel.net for details.

1995 Ford Econoline 150 full-size van. Leather interior, Braun lift, 113,000 miles. Call Pam Garcia (402) 345-0879 or 402-917-6478 (cell).

'2000 Dodge Grand Caravan. Lower conversion, auto ramp and door, tie downs, p-windows and door locks, cruise, tilt, cold air, Beautiful condition. Call (913)205-2848. \$14750

2007 Honda Odyssey. <7000 Miles. New May 07. Used only 6 months. Autoslide out ramp-VMI-Power all-TV's Stereo Navigation Ron (913) 660-0587

'98 Town and Country Handicap Conversion Van. Wheelchair locks and side ramp. Removable front seats. 40,000 miles. New Battery. \$14,000. Alice Zavcek Alice.B.Zavcek@usace.army.mil

2000 Chrysler Town & Country. One owner Lower conversion, auto ramp and door, tie downs, p-windows and door locks, cruise, tilt, cold air, Beautiful condition. Call (913)205-2848. \$14750

Chrysler Town & Country, 2001, 65,000 miles. Comes with Bruno transfer chair installed. New tires. Light blue. \$10,000. Call 1-417-683-6854 or 1-417-880-4161. Ava, MO area.

WHEELCHAIRS

Permobil C300 Wheelchair with Gelseat, tilt/recline, legs raise, height adusts, <1 year old. \$5000. Contact Don Green at (417)781-8262 (work)

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

ALL POWER Permobil wheelchair. Slightly used (approximately 6 months). Some surface scratches, otherwise in perfect shape. \$2,500. (816) 377-4351.

InvaCare Chairman Power Wheelchair. Incl. ventilator tray, head controls. Like new, used only 5 times. \$6,299 or best offer. Call Fernando (816) 213-0607.

InvaCare Storm Series TDX4 Power Wheelchair. Storm Series TDX4 incl Formula Invisible Super Low Tilt, tilt/recline/elevate, Formula PTO Plus & joystick controller. 2 yrs old. Pickup or delivery available in Springfield/ Joplin. List price \$10,305; asking \$6,200. Call Francine (636)530-6001.

Quantam 600 series power chair. Reclines to lay down w/ legs up. Call Pam Garcia or (402)917-6478

Wheelchair, sized for a woman. Excellent condition. \$125. Call Melvin (913) 498-3129.

Hoveround power chair w/battery pack and charger. Excellent condition. \$1550. Call Melvin (913) 498-3129.

Like new Merit Red Power Wheel Chair with large rear wheels. Model #2005. Asking price \$23,000.00. Used only a few times. Call:Mrs. J. J. Wyatt (316) 207-8186 or Pamela Rayer (316) 721-0939.

Wheelchair, Permobil C300. Reclines, Joystick. \$6500. Call Linda at (816) 238-3991

Electric Wheelchair, Permobil, Tilt, recline, RoHo seat, red. Needs batteries. Call Cherri at 1-417-658-6858. Neosho, MO area.

PLATFORM LIFTS

Access Industries Indoor/Outdoor Vertical Platform Lift, Model PLS 96. Used little 750 lbs. capacity. \$5,500 - . Call (314) 374-4480.

MISCELLANEOUS

NEW DINAVOX MAX, blue Never used \$3000 Contact Susan Smith (816) 943-9654.

INVACARE HOSPITAL BED. Full electric hospital bed, 88" x 36". Split springs to ends. \$1,000. Call Eileen at (913) 888-9998.

SCOOTER, Pride Shuttle Mobility Scooter, variable speed control; 2 batteries, 110v built-in charger; baskets. Good condition. \$550.00 Call Sharon (417) 276-3363.

SCOOTER LIFT. Bruno electric swing arm scooter lift. \$550.00 (Installation not incl.) Call Sharon (417) 276-3363.

CHAIR GLIDE, Summit Stairway, installed Nov. 2006. Straight stairway. Incl. all paperwork and instructions. New \$2926, asking \$1900. Please call Chelly (913) 661-0374.

LIFT CHAIR, beige power recliner, grea t condition. \$550. Call Melvin at (913)498-3129.

SCOOTER CHAIR. Never used. Pd \$6,000, asking \$3,500. Call Darlene (402) 352-2083.

LIFT SYSTEM Sure-Hands Patient Lift System w/ 3-room access. \$7000 or reasonable offer. Contact Marilyn Gray (316) 831-0123.

WHEELCHAIR TUB BASE. 30x60 Barrier Free. Only used twice. Cost \$515, asking \$200. Please call George (816) 461-0980.

SHOWER CHAIR PVC. Call Pam Garcia (402) 345-0879 or (402) 917-6478 (cell).

SEVERAL ITEMS AVAILABLE:

- Sure Hands lift system, \$6,000
- Deluxe Wheelchair - \$12,000
- Portable commode chairs, walkers, plastic ankle supports, size large

Call Margie Lafevers (870) 424-6325.

FULL ELECTRIC HOSPITAL BED. 88'X 36'. Asking \$800. Call Donna at (620) 232-2357.

Dynovox V, complete with mini-mdia keyboard, typewriter keyboard, mouse, carrying case with shorlder strap, blue, charger, User & Resource Manuals, Purchased 11/07, used under 2 mos. Asking \$3,000. Call Connie at 816-233-8903.

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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 Jennifer at (913) 648-2062 or jmiller@alsa-midwest.org.

CONTACT INFORMATION

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Walk Website
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National Website
www.alsa.org

THE DIALOG

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8 • THE DIALOG

August Support Group Dates

*Phone RSVP's are requested if marked with *
Toll-free phone numbers are listed below.*

AUGUST 2008	5	*Kansas City Evening	7:00 p.m.
		<i>(Catherine Goodson - a representative from The Elder & Disability Law Firm)</i>	
	6	Jefferson City	1:30 p.m.
	6	Hutchinson	2:00 p.m.
	7	Wichita	7:00 p.m.
	8	*Kansas City Caregivers	12:30 p.m.
	12	*Omaha	6:30 p.m.
	12	Springfield	6:30 p.m.
	12	*Kansas City Men's	12:00 p.m.
	16	Wichita Caregivers	11:00 a.m.
	20	*Kansas City Yoga	1:30 p.m.
	21	Salina	7:00 p.m.
	28	*Carl Junction	11:00 a.m.
28	Nebraska Phone Group	7:00 p.m.	

Support Group Locations

<p>Hutchinson, KS Grace Episcopal Church 20th & Main</p> <p>Salina, KS Church of the Cross Methodist Corner of W. Claflin & Rush St.</p> <p>Topeka, KS Shawnee Co. Public Library 1515 SW 10th Avenue * Meets every other month</p> <p>Wichita, KS Caregivers ALSA Office- 3450 N. Rock Rd, Bldg 200, Ste 211 No need to RSVP</p> <p>Wichita, KS Grace Presbyterian Church 5002 East Douglas</p>	<p>KC Caregivers/Survivors ALSA Bldg - 2nd Floor Mtg Rm Please RSVP</p> <p>KC Day (YOGA) ALSA Bldg - 2nd Floor Room</p> <p>KC Men ALSA Bldg - 2nd Floor room Please RSVP * Meets every other month</p> <p>KC Evening 2nd Presbyterian Church 55th and Oak</p> <p>Lawrence Bert Nash Comm Health Ctr 200 Maine St., 1st floor rm * Meets every other month</p>	<p>Richmond, MO Call Lea 816-776-6007</p> <p>Jefferson City, MO Southridge Baptist Church 1815 Vieth Drive</p> <p>Springfield, MO Cox South Hospital Meeting Room #3</p> <p>Carl Junction, MO Gambino's Pizza 1304 Pennell Street</p> <p>Omaha, NE Millard Library 13214 Westwood Lane</p> <p>Nebraska Phone Group Call Shannon 866-762-6361</p>
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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