

ALS

Volume X

Issue 8

SCHLABACH'S JOURNEY INSPIRES OTHERS AS THEY HELP HIM THROUGH ADVERSITY

by Michele Clark

This story appeared in the April 9th edition of the Newton Kansan.



Karen, left, and Bob Hayes, right, are a large part of Gene Schlabach's support system.

A volunteer as defined by American Heritage Dictionary is "A person who performs or gives his service of his own free will."

This definition holds true in the life of Gene Schlabach of Newton, who is suffering from Amyotrophic Lateral Sclerosis - or ALS - more commonly known as Lou Gehrig's disease.

The debilitating and terminal illness has robbed Schlabach of the use of his limbs and is starting to affect his speech and swallowing abilities, rendering him unable to do little for himself. Yet, his mind remains active and alert, even though his body is shutting down.

Schlabach's life is chock full of volunteers and, as a result, Gene is able to remain in the comfort of his own home that until recently he shared with his late wife, Treva, the recipient of a double lung transplant who died last fall.

Friends, family and members of St. Matthew's Episcopal Church alike all pitch in to assist him in any way possible. The St. Matthew's group, spearheaded by Katie Reese, consists of about 25 people who prepare and serve meals to Schlabach three or four nights a week.

Reese cites Schlabach's sense of humor and strength as two great blessings that help him cope with his deteriorating physical condition. The group, in a sense, adopted Schlabach and his late wife as their "ministry," but Reese is quick to add Schlabach ministers to them, as well.

Continued on page 2



**You earn a living
by what you get,
but you make a life
by what you give.**



**It's not too late to form a team for Walk to Defeat ALS™ 2008.
See page 4 for Walk locations and dates.**

Continued from page 1

Volunteer Chris Simmonds affirms Reese in stating Schlabach "enriches" his caregivers' lives and does more for them than they do for him. Working with Gene helps "put life in perspective."

Also assisting with meals are eight or nine people from Prestressed Concrete who are former employees of Schlabach. Schlabach held positions as plant superintendent and operations manager for 37 years at Prestressed.

These individuals also are quick to lend a hand in any way possible, taking on such responsibilities as lawn care, home repairs and maintenance, helping Schlabach read newspapers and magazines by turning pages, or simply just paying him a visit. Schlabach remains involved in work-related happenings as his friends will, on occasion, take him to the plant for visits for a little catching up.

And there's his family. Without the help of his five children, who visit frequently, and his wife's sister and brother-in-law, Karen and Bob Hayes of Newton, Schlabach would be in dire need. The couple prepare meals, do his shopping, take him to appointments, set up and give him his medications, help with his dogs and do anything else that needs to be done. The Hayeses began by caring for both of the Schlabachs on an almost daily basis in June. Schlabach's mother, who resides in Florida, and his brother, Larry, and wife Sharon, visit as often as possible, as well.

Despite his situation, Schlabach is not one to wallow in self-pity. Notwithstanding this fatal disease, he feels he is generously blessed and is appreciative of all of the help he receives.

It was Winston Churchill who wrote: "You earn a living by what you get, but you make a life by what you give."

SHARE THE CARE



In the previous story, Gene Schlabach received on-going support from his community and family. The book *Share the Care: How to Organize a Group to Care for Someone Who is Seriously Ill* by Cappy Capossela and Shelia Warnock, a Fireside Book published by Simon & Schuster New York, is an excellent resource for learning how to turn a circle of ordinary people into a powerful caregiver team.

If you are already caring for someone who has ALS, you probably feel that you are facing what seems like an overwhelming task. It is clear that you need to start looking for support: a group of people that can help you with the care of your loved one. A Share the Care support group can help you with many of the daily chores that are involved in being a caregiver for someone with ALS. It also can give you something to fall back on when life becomes too busy, or you are in desperate need of a break.

Although people might be afraid to volunteer to help you on their own because they are unsure about what they are getting themselves into, that is not the case with people who join a Share the Care group. In Share the Care, members do not have to do it all, or do something they are not good at, afraid of, or that they simply do not want to do. Because members are part of a larger group, they only have to perform small tasks that they are suited for when they have the time. When all these small tasks get added up, a Share the Care group will make a tremendous difference to you, but not be too much of a burden on each of the group members.

If you are interested in learning more about Share the Care, contact the ALS office nearest you -- office toll free numbers are located on on the last page of this newsletter.

SHADOWS IN THE TRACKS

In February of 2007, Mary Tunnell was diagnosed with ALS. She died in August of 2008. Mary was a published author under the name M.L. Booker. Her book, Shadows in the Tracks, is available for \$16.95 paperback or for \$6.95 download through Lulu.com.

Description:

The only way to mend a broken heart was escape and that is exactly what Emma Sinclair did. This beautiful Southern Belle, who can turn heads, out fox, out shoot and out ride most men, has a secret. Finding her father in a compromising position sets the stage for a future of intrigue, secrecy, and spiring slaves in this suspenseful novel...Shadows In The Tracks.



RESEARCH NEWS FROM THE ALS ASSOCIATION

August 1, 2008

Stem Cells Generated from ALS Patients for the First Time

By Richard Robinson, Science Writer

For the first time, stem cells have been generated from individual patients with ALS. The accomplishment is likely to lead to development of new models of ALS and new understanding of disease mechanisms.

"They will also provide a potential resource for drug discovery and the development of new treatments for ALS," said Lucie Bruijn, Ph.D., science director and vice president of The ALS Association.

"Model systems to date have focused on the SOD1 mutations linked to 2% of ALS. These findings enable the development of cell lines from ALS patients, even those for which the specific causative genes remain unknown," Bruijn said. "The ability to generate human motor neurons from ALS patients carrying genes linked to the disease is a very exciting accomplishment building on novel technology and the work of several groups." Motor neurons are the nerve cells that die in ALS.

In the present study, researchers at Harvard University and Columbia University took skin cells from patients with a genetic form of ALS, caused by mutation in the superoxide dismutase (SOD1) gene. The skin cells were treated with a small set of genes that scientists have recently learned will reprogram adult cells to become stem cells capable of developing into many cell types.

The researchers showed that the genes "deprogrammed" the skin cells, reverting them to an earlier stage in their development, turning them into stem cells. Stem cells, which are formed normally during human development, have the ability to become many different kinds of cells. The researchers showed the new stem cells could transform into motor neurons.



Parallel Efforts Underway by The ALS Association

One important next step will be to make sure the motor neurons can mature, since it is mature motor neurons that are affected by ALS. Such cells could then be examined to determine what factors make them susceptible to the disease process. These studies will need to be done not only in cells from the patients in the current work, but also in cells derived from other patients, to make sure the results are widely applicable. Another important step will be to generate stem cells from patients with non-genetic (sporadic) forms of the disease. Motor neurons derived from ALS patients will be compared with those derived from people that do not have ALS. These studies are currently underway in parallel efforts funded by The Association.

Mature motor neurons would likely be useful for drug discovery, looking for compounds that improve their survival. While much publicity has surrounded the possible use of stem cells to replace dying motor neurons in ALS, the potential of such a treatment is unknown and was not attempted in this study.

More information on stem cells in ALS can be found on The ALS Association's national web site (<http://www.alsa.org/research/article.cfm?id=715>)



SEPTEMBER/OCTOBER 2008 WALKS TO DEFEAT ALS™



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	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
10/12/08	Lawrence, KS	Student Union

Photos From Walk Kickoffs Throughout the Chapter



Defeating ALS One Step At A Time...





THE TRANSITION TO HOSPICE

People dealing with ALS often wonder when it would be beneficial to enlist the support of hospice.

There is no "right" time for everyone. Rather, each person with ALS has a sense of when this transition should occur. The transition will often be considered as awareness of increasing functional decline and the need for the additional support occurs. In this decision, people with ALS are not "giving up," but are allowing themselves the opportunity to continue to live as fully as possible and in accordance with their wishes and goals of care, as their disease progresses.

Unfortunately, ALS remains a diagnosis without a cure. However, this does not mean that there is nothing that can be done to help deal with the issues and burdens that this illness presents to patients and their loved ones. Rather, much can be done to assist them as they deal with issues and persistent, long-standing symptoms, as well as the "ever new" symptoms as they emerge. In fact, aggressive symptom control and patient/family support are hallmarks of hospice care, and can augment the care provided by their primary care physician and/or ALS clinic.

While in hospice care, patients and their loved ones will receive frequent in-home monitoring and support from licensed nurses who remain in contact with the attending physician and meet regularly with the hospice medical director and the rest of the interdisciplinary team. They will also be able to enlist the support of trained volunteers, as well as licensed social workers, chaplains, bereavement specialists, and home health aides. They will receive assistance in the procurement of medical equipment needed in the home. Some hospices provide the services of registered dieticians to assist in eating, swallowing, and nutritional issues, as well as certified physical therapists. Some hospices offer additional services for comfort and enjoyment, such as certified massage and music therapists.

Medicare has established guidelines for transitioning into hospice care. Insurance companies will have their own guidelines, which often correspond to Medicare's. Strict reliance upon these guidelines can result in "late referrals" to hospice, and thus, missed opportunities. Prognosis (estimating the time course toward a future event) is an inexact science, but nonetheless remains part of the Medicare formula for hospice eligibility. The person with ALS and their physician can address this issue together as hospice is being contemplated. Regardless of "prognosis" or of current functional or clinical status, there is no harm in a hospice "information visit." The patient simply requests a visit from the hospice(s) of their choosing and, without obligation, learns about the services available and about eligibility for these services. When the patient feels ready, and their physician is in agreement, they can transition to the specialized services that hospice can offer.

From the ALS Association's Advocacy Department

Veterans Benefits Update - August 1, 2008

The ALS Association has been working to establish ALS as a service connected disease to ensure that veterans with ALS receive the disability and health benefits they need when they need them.

In July, we shared with you that the Secretary of Veterans Affairs was planning to announce that veterans with ALS will automatically be considered service connected and eligible for full VA benefits, as of August 1, 2008.

We wanted to update you that the VA has not made any announcement of a change in policy for veterans with ALS. However, we continue to anticipate that the VA will issue regulations on this issue and will establish ALS as service connected disease. The details of those regulations are still under review at the VA and it is not yet clear exactly when regulations will be officially announced.

Therefore, until regulations are released and the VA makes an official announcement, we continue to emphasize that the issue is still under review and details have not been finalized.

We also want to alert veterans with ALS and ALS Association Chapters that some organizations have released and posted on their website inaccurate and misleading information about this issue stating that veterans with ALS are considered service connected as of August 1. **THIS IS NOT TRUE.**

Unfortunately, the organizations that have shared this information have not been involved in the executive branch rulemaking process and have based their information on unsubstantiated accounts.

We encourage Chapters and veterans to share this alert with others in the veteran community so that they receive accurate information on the status of this important issue. We also encourage veterans to join our Roll Call of Veterans so that we can provide them with the latest updates on this and other issues important to veterans with ALS.

As The ALS Association and our VA Issue Team continue to work with the VA, we will keep you posted on the latest developments on establishing ALS as a service connected disease. If you have any questions, please contact the Advocacy Department of The ALS Association at advocacy@alsanational.org or 1-877-444-ALSA.



WICHITA'S NIGHT AT THE BALLPARK



A great time was had by all who attended Lou Gehrig Night at the Ballpark on Saturday, July 12th at Lawrence Dumont Stadium!

After a pregame party attended by 100 people, over 400 people attended the Wingnuts ballgame in support of The Keith Worthington Chapter, while hundreds more got to hear our message and witness a re-enactment of Lou Gehrig's famous "Luckiest Man on the Face of the Earth" speech.



PHOTOS FROM THE TRI-CITY WALK TO DEFEAT ALS™ IN KEARNEY NEBRASKA



Programs & Services Update for FY09

(from the July 2008 report)

	In July 2008	Fiscal Year '09 to Date
New patients	13	67
Number of patients who have died	10	51
Consultations made by Service Coordinators	505	2631
Number of clinics held	4	23
Patients attending clinic	31	177
Number of support group meetings	11	68
Patients attending support group meetings	31	137
Total number attending support group meetings	201	736

(The Chapter's fiscal year runs from Feb to Jan of the following year. Fiscal 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.

- | | | |
|------------------|-------------------|--------------|
| Dorothy Barth | Joan O'Connor | Roger Poulin |
| Lanny Hamilton | Robert Schneeberg | Cathy Vawter |
| Rita "Pat" Hudek | Kathleen Pelis | Carol Wagner |
| Rita Hunt | | Jack Wood |

MEMORIALS

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

- | | |
|----------------|-------------------|
| Dorothy Barth | Robert Schneeberg |
| Joan O'Connor | Cathy Vawter |
| Kathleen Pelis | Carol Wagner |
| Roger Poulin | |

EQUIPMENT EXCHANGE

ITEMS FOR SALE

VANS

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

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

2004 Chev Venture-rampvan, dual sig drs, rear air shocks, tiedowns and safety eq incl, 101k mi bu excel mech and appear, top notch condition all svc records, \$19,000 or best offer call (316)729-8815

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.

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.

'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

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

'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.Zvacek@usace.army.mil

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).

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 \$2,300.00. 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.

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

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

Pete Story

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

Sallie 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

Mindy Wallace

mwallace@alsa-midwest.org

Wichita (316) 612-0188

Michelle Masood

mmasood@alsa-midwest.org

Chapter Website
www.alsa-midwest.org

Walk Website
<http://walkkwc.alsa.org>

National Website
www.alsa.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



in Kansas, Missouri and Nebraska

8 • THE DIALOG

SEPTEMBER SUPPORT GROUP DATES

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

SEPTEMBER 2008

2	*KANSAS CITY EVENING (Bingo and Pot Luck Night)	7:00 PM.
3	JEFFERSON CITY	1:30 P.M.
3	HUTCHINSON	2:00 P.M.
4	WICHITA	7:00 P.M.
12	*KANSAS CITY CAREGIVERS	12:30 P.M.
9	*OMAHA	6:30 P.M.
9	SPRINGFIELD	6:30 P.M.
20	WICHITA CAREGIVERS	11:00 A.M.
17	*KANSAS CITY YOGA	1:30 P.M.
18	SALINA	7:00 P.M.
25	*CARL JUNCTION	11:00 A.M.
25	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>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>
--	--	---

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