

Facing Life's Challenges

The following contains excerpts from a story in *The Keith County News*,
March 27, 2002, by Mary Pierce



When you're dealt
the joker you play
it the best way you
know how.



It crept into his life - a silent unseen force. Occasionally he'd feel its presence when loosening a bolt, holding something up with his right arm, or climbing into his back hoe. "I thought it was bad rotator cuffs," Don Brockmoller of Ogallala said. A trail of doctors agreed. Specific exercises and physical therapy were prescribed, yet there was no improvement. In fact, Don continued to lose strength in his arms and eventually his legs. "When I started having trouble running my back hoe I knew something was wrong," he said. It's got to be Parkinson's disease he thought - a disease which had afflicted his father.

Doctors did an electromyogram (EMG) test, which measures the activity of the muscles. "I can tell you right now it's not Parkinson's disease," North Platte neurologist Ashok Narayan told Brockmoller. A spinal tap was done a week later bringing Don and Phyllis Brockmoller news that would change their lives. "I hate to tell you this, but you have ALS," Narayan said. ALS was not an unknown disease to the couple. Phyllis' uncle had died from it. "We both knew what it was," Don said. "It sure knocks the props out from under you."

"Naturally the news broke up both of us," Don said. The doctor was compassionate, crying right along with the couple. And just like how September 11 is now engraved in many American's minds as one of tragedy and sadness, for the Brockmoller's, the date that is etched in their memories is September 2, 2000. "Everybody remembers September 11. We remember September 2," Phyllis said.

"The first year was miserable," he recalled. "After the diagnosis we both were broken-hearted. We sat around crying. We didn't know what to do." Dr. Narayan had been open in his prognosis of the disease. The couple knew there was no known cure, and the disease can progress rapidly.

Continued on page 2



Don Brockmoller, right

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WICHITA/HUTCHINSON SUPPORT GROUP NEWS

The Hutchinson Support Group met Wednesday June 5, 2002 at the Grace Episcopal Church with 11 family and patients in attendance. The speaker was Cindy Jones from Assistive Technology for Kansans with a demonstration and presentation on computer speech software. There were a lot of questions from the group and a hands on opportunity for them to practice.

The Wichita Support Group met Thursday evening June 6, 2002 at the Grace Presbyterian Church with 14 patients and family members in attendance. Cindy Jones from Assistive Technology for Kansans again gave a lively presentation and hands on opportunity for the patients to try their skills at the latest in software devices. Also, as part of the presentation was Julie Scherz, Associate Professor in the Department of Communicative Disorders and Sciences from Wichita State University. She answered many questions from the audience and offered to evaluate any patient whose speech was slowing, to qualify for Medicare coverage. She spent considerable time detailing the Medicare coverage changes. It was not only an interesting but very informative evening. Next month the dates will change slightly due to the Fourth of July week-end. The Hutchinson Support Group will meet Wednesday, July 10th and the Wichita Support Group will meet Thursday, July 11th.

The July Caregiver's Support Group Pot-Luck Luncheon will be held Saturday, July 27th. All caregiver's and family members are invited along with any surviving caregivers with deceased family members. If you make your mind up at the last minute feel free to join us because there is always plenty of additional food. Next month's Support Group Focus will be "The Benefits of Therapeutic Massage in ALS".

SPRINGFIELD SUPPORT GROUP NEWS

The Springfield support group met Tuesday, May 21. The speaker, from SOMA Wellness Center, spoke to the group about Wellness & Prevention and tips to caregivers on ways to decrease stress. Everyone received a "chair massage" from students at the Massage Therapy School. The next meeting will be Tuesday, June 18. Cheryl Needham and Dr. Coulter will speak on Benefits of BiPAP.

Narayan said Don could stay home as long as someone could care for him there. "We decided we better do something about the house," Don said. And so it was action time. He was no stranger to the construction business after having owned his own back hoe business for 32 years. "I loved to run my back hoe," Don said, having worked on projects from basements to bridges. "I made him promise he'd retire at 75," Phyllis said, noting Don was 73 when he was forced to quit working because of the disease. "I didn't want him to quit this way."

On his last major project, Don drew out plans for an addition to his own home which would contain everything he'd need. The couple visited hospitals to check out room designs and equipment. Construction started in April 2001 and was completed in October 2001. The 20-foot-by-24-foot addition to the back of the couple's Ogallala home includes a handicap-accessible bathroom. The family room portion contains a battery-operated gas fireplace, which can be used as a heat source in case of a power outage. There is a desk under the bay window where Don can sit in his wheelchair and see the outdoors. The couple's bedroom, now moved to the corner of the new addition, is equipped with Don's electric bed. Located against the wall, yet in the center of the room, is Don's chair, an electric lift chair which assists him in standing up. From this vantage point, Don can see the comings and goings in his house, and is an integral part of the communication. A lift system was added to the ceiling, in preparation for the time when Don will not be able to walk or stand.

In the 18 months since diagnosis, Don's condition has steadily deteriorated. "I've lost probably 25-30 pounds since I was diagnosed," he said, attributing this to loss of muscle mass. Don said he often finds himself short of breath these days, too. "The last month's really taken a hold of my legs," he said. While he can still walk short distances, he has fallen numerous times. "I'm just lucky I haven't broken anything." Because Phyllis is no longer able to help him up, she calls 911 for assistance from Ogallala Police officers. "They just come and help pick him up," she said. Don has little hand function left, and must have help with most daily tasks including eating and brushing his teeth. Though his appetite is still good, Don said he has to eat smaller meals more frequently and eat at a slower pace. Treatments and medications were prescribed.

Because of the high costs associated with the disease, the Brockmollers went to the Veterans Association for help. "They've helped me a lot," he said. Twice a week he attends physical therapy to help keep his joints from seizing. Don also relies heavily on daily care from home health aide Sally Corfield and nurse Leann Hinrichs. "They're super," he said. While the disease continues to rob Don of his body functions, his spirit remains strong. "His attitude is tremendous," said Phyllis. "He makes it a joy to care for him." "There's no use being grumpy about it," he said, admitting being mad or upset about the disease would not change it. "I just take every day one day at a time." The love and support from his wife has also helped Don a lot. "The best caregiver I've got is sitting right here," Don said, looking at his wife of almost 54 years. "Even when I cry a lot?" she asked. "Even then," Don said. Phyllis admitted the diagnosis was hard to hear. "But you deal with it. He's still the same Don he has always been," she said. The devoted love and care from their four children and their families have helped Don immensely. "I'm not walking alone," he said. Son Jerry and wife Sandy of Gillette, Wyo., Kim and wife Darla of Lexington, daughters Cindy and husband Bob Lungrin of Kearney, and Cathy and husband Lonnie Logan of Grand Island each visit one weekend a month. "That's been good," Don said. "I have a really nice family." "They do all the dirty work," Phyllis said. She used to worry about the house always being clean, dishes always washed, laundry always folded and put away. "No more," she said. Caring for Don, being a companion to him is her No. 1 priority. "Sure, we have our

ups and downs. But mostly ups because of happiness," she said. The couple also has eight grandchildren and five (almost six) great-grandchildren who occasionally visit. Don's five sisters also come and lend their support and love.

Phyllis' brother, Jack Gammell, provides Don with something he values a lot in his life these days, a daily outing. Each afternoon Gammell picks Don up and takes him for coffee at Arby's. There they meet a large group of friends, who dole out free advice, laughs and hearty conversation. Each Wednesday, Phyllis' sister, Carol Olson, comes from her Brule home to be with Don so Phyllis can work at Trail's End. The couple said their neighbors have been kind to them as well, coming either by an urgent phone call from Phyllis to help her husband up from a fall, to shovel snow from their walks, or just to visit with Don. The couple has also been showered with support from their other friends. Each day someone comes to visit - visits that sustain the couple in their journey. Don said some people were shy to visit with him at first, afraid they wouldn't know what to say. "I'm not afraid to talk about this," he said. "If people feel comfortable, the best thing they can say is, 'Hi, Don.' If you don't know what to say, come see me, I'll make you comfortable."

Don's next challenge is learning to operate a voice-activated computer, which will become his voice once the disease robs him of his own. "We're excited to try it," he said. The project after that will be purchasing a van with a wheelchair lift because Phyllis can't load Don's wheelchair anymore. As ALS continues to throw the couple new challenges each day, Don remains cheerful, and surprisingly content. "Before this happened we took so much for granted," he said. Now they take nothing as a given, not Don's fragile health, their family or friendships. These are gifts. "It was hard on all of us when he was first diagnosed," said son Jerry. "But we're all card players, and this is the hand we were dealt." "When you're dealt the joker you play it the best way you know how," Don said.



Board President Elect, Dr. Jim LeBow graciously accepts the Chapter of the Year Award.

The Keith Worthington Chapter Wins The ALS Association Chapter of the Year

The Keith Worthington Chapter received the Chapter of the Year Award at the conclusion of The ALS Association's 2002 Leadership Development and ALS Clinical Conference in Washington, DC. The award is based on performance and adherence to standards in the areas of administration, patient services, public education and awareness, marketing, advocacy, and fundraising during the past year.



KANSAS CITY SUPPORT GROUP NEWS

The Kansas City support group met on Tuesday, June 4. The speakers included Terry Betzelberger, Board President, Jim LeBow, President-Elect, and Emily Marsh, Event Coordinator for the Kansas City Walk to D'Feet ALS. Terry detailed the year-long Chapter accomplishments and presentation of the Chapter of the Year Award at the recent ALSA Conference in Washington, D.C. Jim discussed current ALS research presented at the conference. Emily informed the group of the dates, times and locations of the ALS walks taking place this fall, and that there will be a new walk in Manhattan, Kansas. Linda Dost talked about ALS advocacy efforts. Everyone was reminded of the up-coming family picnic and barbeque on Saturday, June 22 from 10:30am to 1:30pm, Shelter 8 at Shawnee Mission Park. The next meeting will be on Tuesday, July 9. Susie Wiley of the Rehab Institute will discuss communication devices.

TOPEKA SUPPORT GROUP NEWS

There were 7 people in attendance at the April 22 support group meeting. Russ Hedge, speech pathologist, discussed swallowing issues and communication devices. The May 20th meeting consisted of open discussion with 11 people in attendance.

OMAHA SUPPORT GROUP NEWS

There were 10 in attendance at the Omaha Support Group on Thursday, May 9th. Although there was no speaker, attendees viewed a video on end of life issues. An open discussion followed. Ric Miller, Awareness and Development Coordinator in the Omaha office, discussed the upcoming Bob Hohn Celebrity Golf Tournament and the need for volunteers to help with the tournament. Ric also shared information about two other activities: The Omaha Royals have designated June as ALS Month. They are broadcasting 15 and 30 second public service announcements about ALS at all games. At the June 30th game, we will have a table with information about ALS and someone from the Chapter will throw the first ball in the game. Clear Channel Communications (KAT Radio) will host a concert at WestFair in Council Bluffs, IA on Saturday, July 27 from 12:00pm to 11:00pm. ALS will have a booth at this event also.

The 13th Annual "NIGHT OF HOPE AUCTION FOR ALS"

was held on Saturday, May 4th at the Hyatt Regency Crown Center. Event Co-Chairs, Leslie and George Brett and Laurie Ingram coordinated the Spanish-themed Salsa for ALSA, which raised \$275,000 to help people with ALS. Honorary Chair Deborah Gregg, her mother Rosemary, and son, Jeramie, enjoyed the fiesta as well. Over the last 13 years, the auction has raised over 2.75 million dollars. For more information about the auction visit our website at www.alsa-midwest.org.



Deborah Gregg, Honorary Patient, with her mother, Rosemary Gallup and George Brett



Bob and Mary Jo Loyd sport festive fiesta attire.



Event co-chairs Laurie Ingram and Leslie Brett with Terry Betzelberger and Patron's Party Host, Ron Reck



Terry and Sharon Betzelberger and Karen Kerr milled over the 600 plus silent auction items.

JULY BIRTHDAYS

Gwendolyn Chenoweth	July 5
James Wiseman	July 8
Mary Kay Stilwell	July 12
Nora Lee McIntosh	July 12
Jacquelynne Krug	July 13
Howard Coffman	July 15
Eric Barb	July 17
Clemens Mann	July 17
Patricia Smith	July 18
Jerry Berkheimer	July 18
Jason Nothstine	July 21
Margaret Boyer	July 24
Darnell Phillips	July 28
Greg Honas	July 29

Memorials

Thanks to the following families for designating our Chapter for donations:

Ruth Hughey	Jacquelynne Krug
Beatrice Roever	Martha Stewart
John Thompson	Jay Waltz
Jay Wooten	

In Memorium

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

Charles Driscoll	Colleen Dunn
J.W. Haupt	Ruth Hughey
Jacquelynne Krug	Beatrice Roever
Frank Shelburn	John Thompson
Elvira Winkler	Nora Webster
Jay Waltz	

**19th ANNUAL
GEORGE BRETT CELEBRITY GOLF TOURNAMENT**

**MONDAY, AUGUST 12th
MILBURN COUNTRY CLUB
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This year the fun begins on Sunday night, August 11th with the Pairings Party at Old Ballgame Training Academy. Participate in friendly athletic competition, win prizes through raffles and enjoy food and beverages.

On Monday, the day kicks off with 32 five-person teams playing in a shotgun start, scramble format.

TEAM & INDIVIDUAL SPOTS AVAILABLE!

For Information Contact Kristine at 913.648.2062
ext. 223 or ktarwater@alsa-midwest.org



Left to right: Virginia Zamzow, Libby Heinz, Dan Larson, Sarah Tucker (staff), Margaret Dack, Polly Gallant, and Dean Heinz

On the third or fourth Monday of every month, a cheerful corps of volunteers prepares the Dialog newsletter for the monthly mailing. Sorting, labeling, and delivery to the post office are all in a day's work. We thank these volunteers for their continued help.

FOR SALE

1992 Dodge Conversion Van, Power locks and windows, Ricon lift. 10,500 miles, Call Pat 816-567-4200

1989 Dodge Caravan, 61K, handicap equipped with rear entry ramp and hand driving controls, \$5,500 obo. Call 913-782-6756

2002 Jazzy 1113 Sip & Puff Power Chair, tilt back control, red. Never used. Original price \$17,000, will negotiate. Call Linda at 913-334-2476

Dodge 1999 conversion van, RAM 1500, w/ wheelchair lift and lock. 11k miles, perfect and loaded. Appt only, 913-469-4188

Ranger 2 electric wheelchair, fully adjustable. As new. Appt only 913-469-4188

Invacare all electric, tilt wheelchair, red with removable ventilator shelf, lap tray, battery included, roho cushion, Best offer, Call 918-337-3577

Invacare manual wheelchair, black with roho cushion, barely used, \$300. Call 918-331-3577

Invacare Power Rolls Arrow Xt, Joy stick, indoor/outdoor modes, deluxe padded automotive style seat with pivot arms for easy transfer, battery charger included. Excellent condition, Best Offer, Jefferson City Area. 573-636-2550 or email sjseibold@mchsi.com.

Rascal 200 Three-Wheeled Scooter, red, slightly used. Swivel seat and flip up armrests. Battery operated. Retailer new for \$1500. Asking price \$600 or best offer. Inquiries may call (913)341-5174.

Bruno Power Chair - PWC 2300, 350 pound weight capacity, drop down controller, long trailing arm

suspension, carry-along charger, 90 degree swivel seat and adjustable armrests, security key lock system, tote pouch, curb climbing height: 1:25", turning radius: 22", speed up range up to 3.5 mph. Operators manual included purchased new for \$6,000.00, used for only 3 month months. Asking \$4,000.00, contact Jeff Blair at 402- 614-5516

1997 Ford Pinnacle Motor Home, Ford F53 Chassi V8 7.5 liter gas engine, double rear end axle, new batteries, good generator, 22,250 miles, 33 ft. long. Blue interior with queen size bed. Call Chuck after 6 p.m. @ 785-459-2281.

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).

Handicapped equipped 79 Chevrolet van, 34,000 original miles, Ricon rear lift, \$2000. Please call for 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.

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

1997 Ford Econoline 150 custom van with raised roof and new side entry Ricon wheelchair lift (\$5000). 26,000 miles. Loaded, new tires, TV, and 4 wheelchair lockdown units. Like new condition, engine well maintained. See to appreciate. \$20,000. Call 816-822-8274.

1998 Elec. Wheelchair Invacare Action Ranger II Storm Series, Loaded with Jell seat, Remote Programmer, 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 \$350.00. 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. Includes new batteries and charger. Arm rests pivot or remove and foot rests swing out. Call 816-257-0641.

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8 • **The Dialog**

JULY 2002

9	Tues	<p>Kansas City Support Group 7 - 8:30 pm Second Presbyterian Church, 55th & Oak Susan Wiley, Rehab Institute, Seating Mobility and Augmentative Communication</p>	17	Wed	<p>KC Day Support Group 2 - 3:30 pm Village Presbyterian Church 6641 Mission Rd. Prairie Village, Kansas</p>
10	Wed	<p>Wichita Support Group 7 pm Grace Presbyterian Church 5002 E Douglas</p>	22	Mon	<p>Topeka Support Group 7pm Topeka Assoc. for Retarded Citizens 2701 SW Randolph, Topeka,KS</p>
11	Thu	<p>Hutchinson Support Group 2 pm Grace Episcopal Church, 20th & Main</p>	24	Wed	<p>Lincoln Support Group Madonna Rehab Hospital 5401 South St., Rm. Sheridan C</p>
11	Thu	<p>Omaha Support Group 7pm St. Pius Parish Center 6905 Blondo Street, Omaha, NE</p>	27	Sat	<p>Wichita Caregivers Support Group Grace Presbyterian Church 5002 E Douglas</p>
12	Fri	<p>KC Caregiver Support Group 12:30 -1:30 pm ALS Office 8340 Mission Rd. B4, Prairie Village, Kansas Must RSVP! (913) 648-2062</p>			<p>Jefferson City Support Group No meeting this month</p>
16	Tues	<p>Springfield Support Group 7pm Springfield ALS Office 1447 - F S. Enterprise Augmentative Communication</p>			<p>“What is ALS” Orientation Series By appointment. Please call (913) 648-2062</p>

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