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----- **ALS Interest Group** -----  
**ALS Digest #1151 (18 March 2003)**

*Amyotrophic Lateral Sclerosis (ALS); Motor Neurone Disease (MND)  
Lou Gehrig's disease, maladie de Charcot*

This e-mail list has been set up to serve the world-wide ALS community. That is, ALS patients, ALS researchers, ALS support/discussion groups, ALS clinics, etc. Others are welcome (and invited) to join. The ALS Digest published (approximately) weekly. Currently there are 5600+ subscribers in 80+ countries. Please be advised, the editor is not a medical doctor and the Digest not peer reviewed. This newsletter is not intended to provide medical advice on individual health matters. Any such advice should be obtained personally from a physician.

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**Positive Spin for ALS**

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Date : 15 Mar 2003

>From: *Christine Joy* [christine\\_joy@trinitynet.com](mailto:christine_joy@trinitynet.com)

About the Positive Spin for ALS

The Positive Spin for ALS is an annual cycling event and fund raiser, held in Wayland, MA, consisting of four concurrent bike rides designed for riders of any ability. The routes are 10, 25, 50 and 100-miles in length, and each is named in honor of a local person stricken with ALS.

Money raised through this event finances programs such as a durable equipment loan program and respite care, for 200 local patients and their families through the ALS Association, MA Chapter. The money also supports national research to find effective treatments and ultimately a cure for ALS.

For more information about the ride, visit [www.positivespinforals.org](http://www.positivespinforals.org). Please forward this link to anyone who may have an interest in riding or volunteering in any way for this event. Thank you.

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**Family helps ALS victim get life back**

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Date : 13 Mar 2003

>From: [George Parker](mailto:George Parker) [george\\_parker79924@yahoo.com](mailto:george_parker79924@yahoo.com)

SOURCE: El Paso Times ([www.elpasotimes.com](http://www.elpasotimes.com))

DATE : 11 February 2003

TITLE : Healthy haven

: Family helps ALS victim get life back

AUTHOR: Louie Gilot, El Paso Times ([lgilot@elpasotimes.com](mailto:lgilot@elpasotimes.com))

Army veteran George Parker, in probate court, sat in a wheelchair, his skin gray from poor circulation and his head slumping. He looked at the judge who would decide where the 54-year-old victim of Lou Gehrig's disease would die.

To communicate with the judge, a social worker held up a board inscribed with the alphabet and ran her finger from one letter to another, stopping each time George blinked. One letter at a time, George painstakingly spelled out his opinion.

"DON'T SEND ME TO A NURSING HOME."

Probate Judge Max Higgs was to decide where George would spend his last days. Doctors gave George two weeks to live. But because of his condition, it was doubtful that any place would take him.

He was on a ventilator, a machine to help him breathe, and nursing homes, as well as foster homes, would probably see him as a liability.

Higgs knew George was running out of time, so he called his friend Cruz Carder.

Cruz was 46, married, and had three children. She had left her job as a massage therapist to take care of her husband, Lloyd Carder, himself a Vietnam War veteran with heart problems and post-traumatic stress disorder.

Would Cruz and her family give George, a complete stranger, a comfortable place to spend his last days?

The Carders agreed.

That was seven years ago. Now, George is not only alive, but healthier and happier with his adopted Northeast family.

"It's a unique arrangement," Higgs said. "I don't know many families who'd want to do that."

The first meeting

Cruz and Lloyd first met George at the Beaumont Army Medical Center intensive care unit in the fall of 1995, but they had already made up their minds. They would take George home no matter what his story was.

"Nobody would turn down a child," Cruz said. "Why can't we do it with adults? We're all getting (older)."

The Carders learned later that George was born in East Texas. At 16, he dropped out of high school. A year later he joined the Army. He was still in the Army in the early 1970s when he noticed he was becoming clumsy. Things slipped out of his hands. Often, he fell down for no apparent reason.

These changes were especially traumatic to a man as active as George, who, after leaving the Army as a major, worked for federal agencies, opened a trucking business and started a North Carolina pig farm, yet still found time to indulge his passion for flying small airplanes.

But his body kept acting up. In particular, his left leg was dragging. In 1988, he was tested at a Norfolk, Va., clinic. The diagnosis: amyotrophic lateral sclerosis, or ALS, the scientific name for what most people call Lou Gehrig's disease.

The cause of ALS is unknown. What is known is that it attacks nerve cells controlling voluntary movement. The heart, sexual organs, eyes and eyebrows are usually spared. But patients soon lose movement in all other muscles. Their minds stay sharp, and most of the time they can still feel. But they can't move limbs, can't walk and can't talk. Half of them die within three to five years. Only 10 percent live more than a decade.

The ALS Association, a national organization based in Calabasas Hills, Calif., reports that ALS is diagnosed in 15 Americans every day, and about 30,000 are now affected by the disease.

George became its newest victim. He moved to El Paso in 1991 as the disease progressed, paralyzing him. In early 1995, he was admitted to Beaumont in respiratory arrest. Medical personnel revived him, condemning him to live in a body whose only possible movement was the blink of an eye.

George was left with his fantasy: a retirement without ALS.

"Life on the farm with a slotted wing, big wheeled bush plane outside the door, perhaps with amphibian floats. The farm would be active at least until my death," he spelled out.

That's when he was told that the Carder family had volunteered to take care of him for a while.

In late September 1995, Cruz walked into his hospital room. Her cascading, brown hair, her delicate wire glasses and her air of boundless patience contrasted with George's gray hair and frowning, emaciated face. Cruz walked around the hospital bed and took George's stiff hand in hers. "I'm going to have to give you a massage," she said.

George blinked once for "yes."

The first night

George arrived at the Carders' home on Texarkana Place in October 1995.

He was 6-foot-4 but weighed only 100 pounds. His unsupported head would fall limp on his chest until someone would notice and pick it up again. The rest of him was so stiff from lack of exercise that the hospital had his arms and legs propped up with pillows, as if he were in a full body cast. His limbs were dark brown because of poor circulation, but the worst of his illness was the ache in his hardened joints.

Cruz and Lloyd put his hospital bed in a wood-paneled den overlooking the kitchen and the living room. They pinned his framed military certificates to the walls, and Cruz wrote the alphabet on a notebook so George could communicate.

The first night, Cruz turned George onto his side so bed sores wouldn't break out on his body. But something was wrong. George wouldn't blink and looked angry. Cruz fetched the notebook and George spelled out: "YOU HURT ME."

That night, Cruz made the first of many deals with George.

"I said, 'Look, George, stick with me and I'll help you,' " she said.

It was a lonely job.

Cruz's husband was sick and her at-home children were only 13 and 16. She hadn't yet found her way through the bureaucracy to get agencies to pay for a nurse and medical equipment. Veterans Affairs, for instance, would not pay for a new ventilator, so the Carders rented

one. But the machine, which delivers air to the lungs through a dime-size tube in the throat, kept going out at night. Cruz would have to disconnect the tube from the machine and reattach the tube to a rubber bag. Then she would squeeze the bag rhythmically, using her own breathing as a guide, until the respiration therapist could come fix the ventilator.

One night, Cruz pumped for three hours straight.

George's throat had to be suctioned every 10 minutes because mucus would accumulate and obstruct his breathing. He would become upset if Cruz left his side. He could not sleep at night, so Cruz, who slept in a recliner at the foot of his bed, couldn't sleep either.

"It's the same feeling of having a brand-new baby," Cruz said.

Finally, George confessed he was afraid to fall asleep because he thought he would never wake up.

So Cruz made him another deal.

"I said, 'Look, George, I'll make you a promise. I'll never leave the room at night,' " she said.

And she never did, she said.

It took six months, but George finally closed his eyes to sleep.

Accustomed to home

As the months went by, George and the Carders gradually became accustomed to living with one another.

At Thanksgiving, the Carders gathered around George's bed to pray. That day, George, who was fed 10 cans of Ensure daily, a nutritional shake, directly into his stomach through a plastic tube, asked for mashed potatoes and gravy. He says he can taste the food by manipulating saliva glands in his mouth.

The Carders enlarged the den by knocking down the wall to the garage. They installed French doors in place of the garage doors so George could see the street.

Jason Carder, then 16, would run his car in the driveway for George to listen to.

George, who had dabbled in mechanics all his life, could tell what was wrong by the sound of it alone. George also helped Tiffany Carder, then 13, and her schoolmates with their math homework.

A year later, Tiffany, then 14, first suctioned his throat. She was

baby-sitting George, and there was nobody else to perform the daunting process that sends George into convulsions. The teenager did her best and asked George if she had done it right. He blinked, "yes."

Later, "He wrote me a letter saying that he was proud of me that I didn't panic," recalled Tiffany, who is now an 18-year-old nursing student.

George, in a special wheelchair, joined in on family outings to the zoo, to weddings and to their favorite Chinese restaurant.

Although the Food and Drug Administration approved its only ALS drug in 1995, Rilutek, George opted not to use it. The drug prolongs the life of ALS patients for about three months, but is expensive at more than \$600 a month.

Besides, Cruz's regimen of vegetables, medicinal herbs and massages was already changing him beyond his expectations.

He gained weight and regained color in his face and flexibility in his joints. Early in 1996, he could move his tongue.

Such small things were nothing less than miracles to a man trapped in his body.

In March, 1996, George had Cruz write a letter to a friend.

"Do you know what it's like not to be able to yawn?" he wrote. "I can yawn again."

The pain in his joints went away that year, and he could bring his knees together. Later he could hold up his head and shake it from side to side to indicate "no."

"It was a very exciting time," Cruz said. "It's like a baby learning to crawl."

Cruz enthusiastically called a research center to ask them if they wanted to study George. They told her ALS patients just didn't rebuild muscles. George must have been misdiagnosed, they decided. So Cruz took him to Texas Tech University where he was diagnosed again -- with ALS.

Today, despite several reported cases, ALS experts are still incredulous about such progress.

"It's really bizarre," said Sydell Chaiet, a spokeswoman for the ALS Association in California, when recently told about George. "With ALS, what's gone is gone."

Chaiet said the joint stiffness might have masked the muscle abilities that were there all along. Either that, or George was misdiagnosed, she said.

George smiles and spells out, "I'M 500 PERCENT BETTER."

### Small breakthroughs

George will never walk out of his bed. But he continues to enjoy small breakthroughs. Since 1997, he has gained the ability to move his right index finger half an inch, up and down, which allows him to use a computer mouse. The Texas Rehabilitation Commission paid for a computer that lets George write. It has an electronic eye that tracks down a sticker dot on George's chin and translates the movements into an arrow on the screen. When George settles on a letter, he clicks the mouse with his finger.

Cruz laments the new computer because George doesn't need her as much.

Now he writes letters to Veterans Affairs, faxes his nursing service, looks into business endeavors and e-mails ALS patients around the country. It takes a long time. George, an avowed perfectionist, won't use contractions, takes punctuation seriously and hunts down typos.

These days, George is writing letters trying to get someone to donate a van to replace his 1989 Dodge Caravan. The old, leaky minivan makes traveling to the Veterans Affairs Medical Center in Albuquerque a dangerous proposition, he said.

So far, nobody has taken him up on the offer, and George gets frustrated.

"No one will help when you have ALS because you are going to die," he spells on the computer for Cruz. "Now many years have passed and the 'Old Veggie' has outlived some of those who knew that I wouldn't make it. Still, people say I'm going to die."

"Not me," Cruz said, fluffing his pillow. "I think you're going to outlive me."

### A day in the life

Since the Carders "adopted" George Parker, a veteran with ALS, Cruz Carder, her 18-year-old daughter, Tiffany Carder, and a hired nurse are his primary caretakers. This is a typical day:

8 a.m.: Cruz wakes up and makes George a cup of tea as he likes it -- with lemon -- and injects it in his feeding tube. She starts his stretching exercises.

9 a.m.: The nurse comes in, and Cruz spends time with her husband, Lloyd Carder, who is also disabled.

2 p.m.: The nurse leaves and Cruz takes over. She sits next to George's bed and they watch television and visit. Sometimes Cruz uses that time to fix her hair and pay her bills. Tiffany comes home from nursing school.

6:30 p.m.: Tiffany takes her turn watching George. She brushes his hair and teeth and gets him ready for bed while Cruz has dinner with Lloyd. "It makes me feel good knowing that I made him feel comfortable, that I helped him get through his day," Tiffany said.

9:30 p.m.: Cruz comes back, watches the evening news with George and goes to sleep in a recliner at the foot of George's bed. "Some people say it's like having two husbands," Cruz said.

#### Celebrities with ALS

Stephen Hawking, scientist.

Jim "Catfish" Hunter, Hall of Fame baseball player.

Michael Zaslow, actor.

Jon Stone, creator of "Sesame Street."

David Niven, actor.

Ezzard Charles, boxer.

Glenn Montgomery, football player.

Jacob Javits, senator.

#### Living with ALS

Life span of ALS patients (after diagnosis):

20 percent live up to three years.

50 percent live between three and five years.

20 percent live five to 10 years.

10 percent live more than 10 years.