

Features

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****Temporal lobe surgery leaves
young woman seizure-free

DALLAS -- Pam Perkins has something really special to celebrate this holiday season. The 28-year-old Dallas wife and mother is celebrating a full year without an epileptic seizure.

This time last year Pam had just come home after neurological surgery at Parkland Memorial Hospital. On Nov. 19, 1990, Dr. Robert Leroy, assistant professor of neurology and a faculty member of the Clinical Center for Neurologic Diseases at The University of Texas Southwestern Medical Center at Dallas, located the source of Pam's lifelong seizures in her left temporal lobe. The next day Dr. Sam Finn, now a clinical assistant professor of neurological surgery, did a temporal lobectomy and hippocampectomy, excising that portion of her brain.

Epilepsy, which has been a fact of life for Pam since she was very young, is not a disease, Leroy explains. It is a syndrome of chronic, recurring seizures. Some epilepsy is genetic; some is caused by injury, often during birth; in other cases, such as Pam's the exact cause is unknown.

When Pam was just 14 months old, her parents found her in her crib, not breathing, her lips turning blue. Her father gave her mouth-to-mouth resuscitation and rushed her to a hospital, where she remained in coma for three days.

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"The doctor gave me Phenobarbital (a conventional treatment for epileptic seizures), so I have to think he knew it was epilepsy, but he never told my parents that's what it was," says Pam.

Then, when she was two, the family car slid off an icy road into a ditch in Michigan, where Pam's parents lived, and the toddler hit her head on the windshield. From then on, every so often Pam would come in from playing, sit down on a chair and stare off into space. "After a few minutes, I'd jump up and go back out and play," Pam says. "Now, I'm sure I was having seizures."

Pam was almost 6 when a seizure put her in a hospital emergency room again. This time the doctor did an electroencephalograph (EEG) and diagnosed Pam's problem as epilepsy. It could be controlled, he said, with oral phenobarbital twice a day.

Taking her medication, the child rarely had seizures during the day. Most were at night, "and we thought they were just nightmares," Pam recalls. At the age of 12 she started having occasional daytime seizures, which made her feel dizzy and black out for a minute or so.

Although they rarely, if ever, saw her having a seizure, Pam's schoolmates were afraid of her condition. "I was dumb enough to tell them I had seizures," she says, "and they backed right off."

Pam married Mike Perkins--the boy next door--and when she was 20, their daughter, Brandy, was born. Then Pam's seizures started getting worse. By the time the family moved to Dallas in 1984, Pam was having seizures almost every day.

Brandy has grown up with an awareness of her mother's epilepsy. "When she was just a little thing, I'd say, 'Brandy, Mommy's having a seizure,' and she'd run right to me and stay by my side, stroking me

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until it was over. It had to be scary for her." Brandy nods solemnly.

Pam tried to work as a file clerk, but "it's hard to keep a job when you're having seizures." And the seizures were getting worse. "I knew I needed to see a doctor, but I don't trust doctors," says Pam.

Finally she did go to a physician who did nothing to improve her attitude toward the medical profession. "He trashed my phenobarb prescription and wouldn't give me any more until I got an EEG and a CT (computed tomography) scan," she says. "I guess he didn't believe I was taking it for epilepsy."

For 10 months Pam went without medication. "I was having five or six seizures a day, seven days a week. I had to do something."

Finally, in 1986--hesitant but desperate--she made an appointment to see Leroy at UT Southwestern's comprehensive epilepsy unit which has components at Parkland, Zale Lipshy University Hospital, the James Aston Ambulatory Care Center, Children's Medical Center of Dallas and the Department of Veterans Affairs Medical Center in Dallas.

Epilepsy affects an estimated 350,000 adults in the United States. Eight out of 10 can control their seizures with medication. Leroy, who spearheaded the development of UT Southwestern's epilepsy program, specializes in working with the 20 percent whose seizures are not well controlled by medication. He and his colleagues in the center follow approximately 5,500 "problem patients," mostly from Texas and surrounding states.

UT Southwestern is a referral center for these problem cases.

About half the patients who come to UT Southwestern with uncontrolled seizures wind up having surgery, and 90 percent of those patients experience a significant reduction in number of seizures and a significant improvement in quality of life. For seven out of 10, a temporal lobectomy totally controls their seizures. About 50 percent who undergo surgery also are able to stop taking medication and are considered cured.

When Pam first visited Leroy, he prescribed Tegretol, another anticonvulsant often used in treating epilepsy. "It helped for a little while," says Pam. "Then I started having seizures again."

Leroy then switched Pam to Dilantin, another medication commonly used to control epileptic seizures. It didn't work. Pam shudders at the memory. "I was having up to 10 seizures a week. I couldn't work. The seizures were wearing me out; the medication was wearing me out. It was hard for me to even get up."

Next the neurologist tried Dilantin with Mysoline. "That did control the seizures," says Pam, "but within a month, I dropped from 116 to 104 pounds. I had to force-feed myself to get down one meal a day."

The neurologist took her off Dilantin to see if the Mysoline would work solo. It didn't, and when Pam went back on both drugs, they no longer worked together either.

Then Leroy tried Depakote. It was a short-lived experiment. "For two days, everything I ate came right back up," Pam recalls. "That's when they offered me the operation."

At first she said no. "Nobody's touching my brain!" she said.

Leroy did talk Pam into checking into the epilepsy unit at Parkland to try to locate the source of the seizures. "She had the type of seizures that come from the temporal lobes, but we couldn't prove it without seizure monitoring," he explained.

In Pam's case, they couldn't prove it with seizure monitoring either. She underwent a veritable alphabet soup of measuring and monitoring: EEG, MRI (magnetic resonance imaging), CT and SPECT (single photon emission tomography). Leroy and his team even implanted electrodes into her frontal and temporal lobes to monitor the seizures.

"We felt pretty sure, but we still were not 100 percent sure, that her seizures were coming from the left temporal lobe," says Leroy.

Finding the exact site in the brain where seizures arise is this difficult in only one case in 10. After depth electrodes failed to pinpoint the seat of her seizures, Pam's only remaining option was double surgery: a craniotomy and electrocorticography to definitively locate the seizures, followed by removal of the offending brain tissue.

"I didn't want to do it," Pam recalls. "It was bad enough that they went into the top of my head (with depth electrodes), but now they wanted to cut my head open and sew those things (cortical arrays) into my brain. I was scared, but not of dying. I was scared they would make a little slip while they were sewing, just one little 'whoops!' and I'm a vegetable for the rest of my life."

Actually Pam's fears were groundless, Leroy says. "We were nowhere near that part of the brain."

She had come to trust Leroy and Paula Tosch, an epilepsy nurse specialist in Parkland's epilepsy unit. "They listened to me," she explains. "They showed that they cared." So when Leroy told Pam he felt confident that the surgery would make her seizure-free, she agreed.

The neurologist warned her that there was a slight chance of speech impairment, memory loss or paralysis on her right side. "I chose not to think about that," she says. "I went into that hospital with a totally positive attitude, because if I didn't, I wouldn't have gone at all."

She even managed to joke about her upcoming ordeal. "What are those doctors going to do when they cut open my head and find out there's no brain in there?" she asked two startled friends. They, in turn, bought her a model of the scarecrow from "The Wizard of Oz," captioned "If I only had a brain." The scarecrow accompanied her to the hospital and stood guard by her bedside until she went home a week after the operation.

Pam hasn't had a seizure since. To her, that's nothing short of a miracle. She's able to drive a car now, and she's making plans to go back to school to become a registered nurse.

"I finally know what I want to be when I grow up," Pam says with a grin, "an epilepsy nurse." And she's sure she'll be a good one. "I've been there, she says. "I know what it feels like."

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