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Finding hope where there is no cure - (References to Dr. Young & Carecure)

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Finding hope where there is no cure

By Russell Nichols

DEMOCRAT WRITER

Pieces of Michael Thomas began to die the day of his mother's funeral.

It was a crisp autumn afternoon in New York. Thomas watched his mother's body disappear into the ground, relieved that her suffering from cancer had finally ended.

After the funeral, he climbed into the passenger seat of the silver Acura with wife Kim in the driver's seat and daughter Mandy behind him. They had a 20-hour drive to Tallahassee ahead of them.

As he sat in the car wearing cargo shorts, the muscles in his right thigh started jumping. His leg didn't hurt, but it looked as if small snakes were slithering beneath his skin.

"I wonder what's causing that?" he asked.

"Probably just nerves," his wife said. "You've been through a lot."

That was in August 2003. Four seasons have passed. Now, the 47-year-old sits at home with a burgundy shawl draped across his lap watching ABC's "Extreme Makeover."

Amyotrophic lateral sclerosis, the disease that killed Lou Gehrig in 1941, has come to claim him.

He can't wiggle his toes or lift his right foot. He has lost about 30 pounds.

He can't walk across the living room without support.

He has three to five years left, doctors say.

But Friday - thanks to the contributions of countless people known and unknown - he flew across the globe to Beijing. There Dr. Hongyun Huang, using a technique clouded with controversy, may be able to answer the question that has lingered since the day his mother was buried: Do I have to die so soon?

Searching for answers

The numbness kicked in a few months after the funeral.

Thomas went to his family doctor and a local neurologist. The doctors said it was too early to tell what was happening.

Thomas, who works as the supervisor for the city utilities department, got time off in April to go to Shands Hospital in Gainesville. There, specialists conducted biopsies to see whether any of the motor neurons in his leg were dead. Still, no conclusions.

Thomas saw three doctors, had three EMGs and three MRIs. But he was still in his preliminary stages, so it was hard for doctors to say whether he had ALS.

"The most difficult (diagnosis) to make is when the ALS starts in one leg," said Dr. Winston Ortiz, a neurosurgeon at the Tallahassee Neurological Clinic. "Most of the time, even though I think they have ALS, I don't make the diagnosis the first time. As they progress, you can make the diagnosis because the patient is deteriorating."

Thomas suspected the doctors knew what was wrong. He also knew why doctors were hesitant to tell him.

"It's not your everyday disease," he said. "To give you a diagnosis of ALS is to give you a death sentence. Doctors don't want to tell you you're going to die."

In June, after consulting with his family doctor, he drove to Emory University in Atlanta for help.

In a cramped exam room at the ALS Center, neurologist Dr. Jonathan Glass and two assistants hovered over Thomas.

They checked his breathing: 85-percent normal.

They stuck an electrode and needles in him, puncturing parts his feet. His hands. His arms. His chin. His tongue.

His wife and daughter watched Thomas' body jolt after each prick.

"Sorry," the doctor kept repeating. "Sorry."

On June 7, Glass told him the news.

Controversial treatment

ALS destroys motor neurons, the cells that deliver red-light/green-light messages to muscles. As they deteriorate, it becomes harder and harder to move and breathe. Patients become paralyzed and usually wither away within five years. The disease is random and rare. It's estimated that 30,000 U.S. citizens have it. And there are about 5,000 new cases a year, according to the 2004 ALS Association report.

There is no cure.

But for some, there is new hope.

Huang, a neurosurgeon at Beijing's Chaoyang Hospital, has been operating on patients who have spinal-cord injuries, Parkinson's disease and ALS. He said he has performed more than 400 surgeries in the past three years. About 45 of those patients had ALS, said Dr. Wise Young, chairman of cell biology and neuroscience at Rutgers University in New Jersey - where Huang did postgraduate work four years ago.

In his new procedure, Huang injects millions of olfactory ensheathing glia (OEG) cells - the cells that help determine smells - from second-trimester aborted fetuses into the brain and spinal cord. These cells, in theory, swarm the injury site and wake up their lifeless cousins.

No clinical data support transplanting OEG cells, there have been no tests on animals, and Huang's findings have not been published, Young said. He trained Huang for two years in the Rutgers lab, analyzing olfactory cells and their ability to regenerate. Young thinks the procedure has potential. But "I've been advising people not to go," Young said. "There's just not enough data to say yes or no. It's still very experimental."

Young said the Chinese government supports the procedure.

Here, Huang's operations would be illegal, said Kristyn Newhall, research coordinator for the Neurology Clinical Trials Unit in Charlestown, Mass. Because there have not been documented tests, the practice has not been approved by the U.S. Food and Drug Administration.

Some of Huang's patients with ALS have died or had significant complications after the surgery, Young said. Some haven't changed at all. And others, Young said, have seen improvements in movement and speech within days after the operation.

The rapid recoveries might be a placebo effect, he said, but the real question is whether the treatment has long-lasting benefits. Still, for people diagnosed with ALS, the three- to five-year countdown already has begun. Desperation narrows options.

"They cannot wait for data to come out. They cannot wait for therapies," Young said. "Because it's a progressive disease, time is of the essence." In the past three years, ALS patients from all over have flocked to Beijing.

Steve Byer, a Dodgeville, Wis., resident whose son had the surgery in July, has become the middleman for American patients who want to go overseas.

There are about 300 Americans scheduled for operations through October 2005, Byer said, and 600 others waiting to mark their calendars. ALS progressively paralyzes patients, so Byer said he doesn't schedule surgeries more than a year in advance.

But because Thomas found out about Byer early on, he beat the rush. He's next in line.

Bound for China

In July, Thomas heard that Huang had been featured on a CBS News program about the operation on Byer's son, Ben. Thomas did more research.

On the Internet, he found the Care Cure Community Forum, where about 8,000 registered members read and post messages about ALS. The site, moderated from Rutgers, also provides a link to Huang, who responds to questions from spinal-cord and ALS patients. There are updates from patients back from China and questions from those on their way.

Ben Byer, 33, came back in August. Little has changed in his day-to-day life. Still, he doesn't regret the trip.

"There's no way to prove definitively that this operation does what we would like it to do," Byer said from his home in Chicago. "But people need to take a risk. Otherwise they will stay home and die."

Thomas had no money and no idea how to get to China until one afternoon after speaking with his friend Juhan Mixon.

Mixon, a managing partner in a Tallahassee lobbying firm, met Thomas on a soccer field 11 years ago. Their daughters played in the same league. Thomas told him about Huang's method.

"It's just so expensive," he said.

"How much is it?" Mixon asked.

"Thirty thousand dollars," Thomas replied.

Mixon was silent for a moment.

"Mike," he finally said, "you're going to China.... We'll find a way. If I can raise money for people running for office, I can raise \$30,000 for you."

Within the next few days, Mixon drafted an e-mail letter and set up a Mike Thomas Trust for contributions. (Thomas doesn't have direct access to it.) They sent the e-mail to friends, who sent it

to friends. In about six weeks, \$10,000 had been deposited.

Mixon used some of his frequent-flier miles and purchased a ticket for Thomas to go to China. Other friends did the same for his wife. They applied for visas.

On Oct. 8, Thomas returned to Atlanta for a checkup. He sat with Kim in an exam room waiting for Glass, the neurologist at Emory. Glass had heard about the procedure. Thomas was going to be his first patient to go to China for the operation.

Glass' words still echo in Thomas' head.

"You know, Mike," he said, "there's no magic."

"I know," Thomas replied.

"There's been no follow-up with what Huang's doing in China," Glass said.

Kim recalled staring at the wiry doctor.

"Dr. Glass," she interjected, "what do you have for us?"

"I have nothing," Glass admitted.

"Then we're going to China," she said.

'To stay alive'

The day after the 19th anniversary of his marriage to Kim, Thomas sits with the burgundy blanket draped across his lap. It's a prayer shawl. His second cousin, who's a nun, made it for him, and he carries it everywhere.

"I'm trying every avenue there is," he said. "I'm going with the medical and I'm going with the mysterious."

Thomas has been on sick leave since the end of September. He swims every day at his southwestern Leon County home to strengthen the muscles that are slowly deteriorating.

"I will do whatever I have to do to stay alive," he said.

The trust now has a balance of \$27,000. Thomas has heard from five ALS patients who had the surgery, telling him how they can speak more clearly. How they're walking a little better than before. How they can clench their fists. Twist their wrists.

Thomas hopes that one day their stories become his story.

HOW TO HELP

If you would like to be informed of Michael Thomas' progress, e-mail Mixon and Associates at leslie@mixonandassociates.com.

Make your donation to
Mike Thomas Trust
c/o Wakulla Bank
2101 Capital Circle N.E.
Tallahassee, FL 32309