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Fetal tissue shows promise for ALS in study
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MILWAUKEE _ Sometimes the inspiration for scientific research comes from the most unexpected places.

Consider Jeff Kaufman's bedroom.

For much of the past 18 years, he has resided there, gradually losing the ability to move, speak or breathe on his own, as nearly all of his nerve cells that control movement have died off as the result of ALS, also known as Lou Gehrig's disease.

But the gears in the brain of the former lawyer have been turning, his ideas put into words through a novel computer device set up at his bed that allows him to communicate by grinding his teeth.

The driving force behind an annual ALS fundraiser, Kaufman and his event have generated more than $2.3 million for research, including a University of Wisconsin-Madison study published last week that could be an important development in finding new treatments for the disease.

The study, published in the journal Public Library of Science (PloS) One, found that genetically engineered fetal stem cells implanted in rats with ALS provided substantial protection for motor neurons, the nerve cells that die in ALS.

"It's clearly an important step," said Chris Henderson, co-director of the Columbia University Motor Neuron Center.

The study included techniques that have raised ethical concerns in the past _ using fetal tissue to create chimeras, creatures that contain both human and animal cells. The techniques followed National Institutes of Health guidelines and were approved by the university's institutional review board.

For the study, University of Wisconsin-Madison researchers used a type of early human brain cell known as neural progenitor cells that were obtained from fetal tissue. The tissue came from miscarriages or aborted fetuses 10 to 15 weeks old.

The cells then were genetically engineered so that they produced a protein known as glial cell line-derived neurotrophic factor (GDNF). The substance is known to protect and promote the survival of certain brain cells, including motor neurons.

The engineered stem cells then were injected into one side of the spinal cords of rats with ALS.

After transplantation, the cells migrated to areas where motor neurons were dying and began pumping out GDNF, said Clive Svendsen, a University of Wisconsin-Madison neuroscientist and the study's senior author.

More importantly, the engineered cells helped protect motor neurons.

In the early stages of the disease, nearly 100 percent of the neurons on the transplanted side of the spinal cord were protected, compared with about 40 percent on the other side of the spinal cord, he said.

In final stages of the experiment, about 25 percent to 30 percent of the neurons on the treated side survived, compared with about 11 percent on the untreated side, he said.

"They survived remarkably well," Svendsen said.

The treated nerve cells, however, were unable to maintain or establish connections to the muscles that they controlled, resulting in no improved function in the rats.

Henderson, who was not a part of the study, said it appears that GDNF was doing half of what needed to be done.

"It's keeping the cells alive, but not the muscle," said Henderson, a professor of pathology, cell biology and neurology at Columbia.

Svendsen and other researchers now are looking at other cell-based therapies that might establish connections between motor neurons in the spinal cord and the muscles they control.

Spencer Block, a neurosurgeon with Milwaukee Neurological Institute, said the study is a first step.

"Anything that can support cell health is encouraging," he said. "There are very limited treatments for ALS."

Meanwhile, ALS patient Kaufman continues to defy the odds and come up with new ideas from the bedroom of his Wisconsin home.

About 80 percent of people with ALS die within five years, according to the ALS Association. Only about 10 percent live 10 years.

Kaufman, 51, was diagnosed in 1989.

He has been hospitalized only once in the past 10 years, said his doctor, Bonnie Tesch,

an internist.

She attributed much of that to his attitude.

"He helps other people even from where he is," Tesch said.

Kaufman also gets good daily nursing care, and when it looks like he may be getting a bacterial respiratory infection, he is put on antibiotics right away, she said.

(EDITORS: BEGIN OPTIONAL TRIM)

Since losing the ability to speak, he has communicated using a computer that was activated by various body parts, such as his knee, calf and toe. As he gradually lost use of those muscles, a system was devised using a microphone that picks up the sound when he grinds his teeth. He uses that noise to pick letters and words on a computer screen.

The method can be excruciatingly slow, sometimes taking a day or two to write a two-page letter.

"I can't imagine how frustrating that is," said his wife, Jan.

The couple have four children, ages 19 to 26.

From his bed, Kaufman, a former University of Wisconsin-Madison long jumper, has kept busy devising training programs for his children's track pursuits.

He also conceived of and plans the Evening of Hope, an annual ALS fundraiser held in March in conjunction with the Wisconsin Chapter of the ALS Association.

The fundraiser provided several hundred thousand dollars in research money for the University of Wisconsin-Madison study.

(END OPTIONAL TRIM)

Using his computer device, Kaufman said he understood how some people might question the quality of life of someone in the most advanced stages of ALS.

He said that funding for the study and other research might not have come had he not been alive all these years running the Evening of Hope event.

But, he added, "I'm never the only reason people come."

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