

New audio technology allows ALS victim to preserve voice for his kids

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An incurable, degenerative disease slowly is robbing David Stuczynski of his ability to walk, talk and breathe.

But the Akron-area husband and father has made sure ALS will never take away his voice.

With the help of the University of Akron's Audiology and Speech Center and a research project in Delaware, Stuczynski can continue to speak with a computerized voice that sounds nearly identical to his own.

If he eventually can't talk as the disease progresses, Stuczynski can use the ModelTalker custom [speech](#) synthesizer software with a device that tracks his eye movements to let him select the words he wants to say.

Stuczynski has three important reasons for preserving his voice: his 15-year-old son, Daniel, and his daughters, Eleanor, 17, and Evie, 11.

"I want my kids to hear my voice," he said.

Stuczynski, 53, is among several hundred patients worldwide who have recorded their speech to create a unique, [synthetic voice](#) through ModelTalker, developed at the Nemours Alfred I. duPont Hospital for Children in Wilmington, Del.

The project originally started to create younger-sounding, unique voices based on a donor child's voice for children who rely on speech-

generating devices to communicate, said Tim Bunnell, director of the hospital's Center for Pediatric, Auditory and Speech Sciences.

Developers found interest in using the speech synthesis software among adults with ALS, throat cancer or other conditions that can affect speech, he said.

Participants in the ModelTalker project record themselves reading 1,600 sentences. The recordings then are shared with the Nemours Speech Research Lab, which creates a personalized database of small sound units used to form any words.

The software can be used with speech-generating devices that are controlled by typing or eye-tracking technology, depending on the patient's needs.

"People write to let us know how happy they are that they're able to preserve a voice for their children or grandchildren or to use in their profession," Bunnell said. "We had at least one minister who was delivering sermons with his voice."

Speech-generating devices, which cost about \$15,000, often are covered by health insurance.

ModelTalker can be used for free with speech-generating devices while research continues. There are plans to commercialize the product.

Stuczynski, or "Stu" as friends call him, always had been active. He played wide receiver during his college years at Case Western Reserve University and coached high school basketball and youth sports in more recent years.

A couple of years ago, he began struggling to write his players' names on

the lineup sheets before basketball games.

"I couldn't hold the pen," he recalled.

On New Year's Eve in 2012, he noticed his calves were cramping as he tried to pull on his boots.

Figuring he was suffering from a vitamin deficiency or some other minor ailment, Stuczynski mentioned the problems to his doctor. Numerous tests and a couple of months later, the devastating diagnosis was confirmed: ALS, also known as Lou Gehrig's disease, a [progressive neurodegenerative disease](#) that affects nerve cells in the brain and spinal cord.

As muscle control fades, many patients with ALS no longer can speak.

The average life expectancy after diagnosis is two to five years.

Stuczynski decided that if his voice becomes too weak, he wants his children and his wife of 18 years, Barb, to hear a computerized version similar to his own, not a generic, robotic voice.

After researching the idea online, Stuczynski called audiology and speech programs throughout the region to ask if they could help him create a custom synthetic voice.

Katie Boarman, a speech language pathologist and supervisor of clinical instruction in the University of Akron's School of Speech-Language Pathology and Audiology, knew about ModelTalker but never had helped a patient with the program before Stuczynski contacted her last year.

ModelTalker is a similar concept to voice banking but doesn't limit users

to pre-recorded sentences, she said. "You can say anything you want, and it will pull the sounds of speech that they recorded."

Over the course of several weeks last summer, Stuczynski spent hours in a soundproof booth at the University of Akron's audiology and speech center with Boarman recording the required sentences for ModelTalker.

Stuczynski recently returned to UA to try a speech-generating device with his new ModelTalker voice for the first time.

Stuczynski grinned as he heard his first words: "How are you?"

"That sounds really good," he said. "Wow! That's amazing."

Over the past year, Stuczynski has started using a wheelchair to get around and a machine to ease his breathing. He still speaks without assistance.

"Now I have my voice in a bank," he said. "If I type the words, they come out - not like a robot but my voice."

"Hopefully, I'll never have to use it too much. But if I lose my [voice](#) or it becomes too tiring to use it, I'm prepared."

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