Tech-Savvy Hero

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Forever famous in New Orleans Saints' lore, Steve Gleason (B '11) never backs down from a challenge, not even a diagnosis of ALS. He now strives to find and develop new technologies to live life fully. (Photo by Jackson Hill)

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The average person types about 40 words a minute, fingers clicking on a keyboard to produce every word. Steve Gleason (MBA '11) can type about 20 words a minute, an incredible speed when you consider how he does it. Gleason's eyes search for each letter on a digital keyboard, the words become letters, the letters sentences, no fingers involved.

Steve Gleason isn't the average person.

The former New Orleans Saint can be found on the sidelines at most home games. The documentary about his battle with ALS, Gleason, debuted at the 2016 Sundance Film Festival, and he's been touring film festivals and awards shows across the country for the last year.

Gleason's biggest job is keeping up with his 5-year-old son, Rivers.

"I want to experience everything I can with him," says Gleason. "He is incredibly active, so sitting idly is not an option."

But ALS robs its victims of the ability to move, speak, even breathe without assistance.

The neurodegenerative disease affects nerve cells in the brain and spinal cord, leading to weakness and eventually paralysis. Many ALS patients only have three years of life beyond diagnosis. There is only one Food and Drug Administration–approved drug to treat ALS right now. The medicine modestly slows progression of the disease in some people.

Until a cure is found for ALS, Gleason is tackling it the only way he knows how, using technology.

EYE-TRACKING INNOVATIONS

Immediately after being diagnosed in 2011, Gleason researched communications devices. What he could find was outdated and expensive.

"They were still the equivalent to 1990s' technology with costs up to $20,000," he says.

Gleason reached out to communications device manufacturers with suggestions and began using a tablet that connects with eye-tracking controls. A sensor followed his corneas to control the cursor on the screen.

The makers of the tablet, Microsoft, heard Gleason's story and put him in a Super Bowl commercial. He began working with Microsoft to improve the tablet. It's now used by a number of ALS patients and costs less than $3,000.

The company also invited Gleason to participate in a hackathon competition. Employees worked to develop technology that would enable him to play with his

son, talk more easily with his wife and move his wheelchair independently.

“Losing the ability to move on my own was difficult,” says Gleason. “For a long time, I had use of one finger or limited knee or head movement to control my chair. When that was finally lost, I felt discouraged and completely helpless to engage with my son and others.”

The hackathon team developed an eye-tracking wheelchair and now, with Gleason’s help, a powerchair EyeDrive system with Microsoft is making its way to the FDA for approval.

“Developing the system has been entirely and completely liberating,” he says. “I can now drive my chair without the help of others when using the eye-tracking interface.”

A ‘BANKED’ VOICE

Gleason says losing his voice was, by far, one of the most difficult things to process. Soon after his diagnosis, Gleason “banked” his voice. Most augmentative communications devices use a computerized voice. Voice banking allowed Gleason to record his own voice so it sounds much like the way he used to speak. He says the technology wasn’t new when he used it but voice banking wasn’t well known and was also cost-prohibitive.

“I was one of the first with ALS to bank my voice and now many groups offer this service at a reduced cost,” says Gleason.

The technology allows people to bank recorded phrases or even create synthesized speech using a computer file of all the sounds a voice makes from the alphabet and combinations of letters. The key phrases give a baseline for how a person says and speaks certain words. Gleason was given a few options after making recordings to select what sounded like his own voice. He still has to change some words to sound phonetically correct, important in a city that pronounces street names like Burgundy and Calliope with emphasis on different syllables. As one example, Gleason types “New Orleens” so it will sound correct.

CAPSTONE PROJECTS

Shortly after his diagnosis, Gleason visited the Steve Saling ALS Residence near Boston. The residence has 10 private bedrooms, each with a full, private bathroom. The bedrooms share a living room, kitchen and dining area so residents, staff and guests can gather like families. The entire home is fully automated and accessible.

After returning from the trip, Gleason had the idea to build a similar residence in New Orleans. The result is Team Gleason House for Innovative Living at St. Margaret's at Mercy Skilled Nursing Residence on Bienville Street, which opened in 2014. Four residents currently live in the home and they can control everything from the thermostat to the blinds using their communication devices or computers.

Gleason is also working with a group of Tulane biomedical engineering seniors on their final project. The students spent two weeks last summer following residents of Gleason House, interacting and working with them. They then returned to campus to brainstorm ideas that would help address some of the unmet needs they observed. The students will present their project in the BME Senior Team Design Show later this spring.

This so-called Capstone project enables biomedical engineering students to use the knowledge and skills acquired in earlier course work. Teams incorporate appropriate engineering standards and realistic constraints while they produce designs that address healthcare-related needs.

PURPOSE AND PRODUCTIVITY

Gleason has always challenged life. An unlikely hero on a football team with stars like Drew Brees, it's Gleason who is immortalized in bronze outside the Mercedes-Benz Superdome, the statue version showing him stretched out to block a punt during the Saints' first home game following Hurricane Katrina on Sept. 25, 2006.

He sees ALS as another challenge.

"I'm like everyone else who loves life and wants to experience it," he says. "I need help doing those things but am fortunate to have an excellent care crew."

Gleason hopes to help other patients with ALS live with purpose and remain productive. Improving technology, he says, is key.

“We hear constantly how the devices we provide and have helped improve have led to many choosing to live, and live fully, despite ALS,” says Gleason.

“I believe, by expanding capabilities and reducing the need for assistance, others can be motivated to continue pursuing the things they love.”

For Gleason, that means a full schedule, whether he’s taking the family to Audubon Park or introducing his favorite band, Pearl Jam, at a concert. The Gleason documentary is still making the rounds at awards shows and is now available to watch through Amazon Prime, gaining Gleason more fans every day. His annual Gleason Gras events and fundraisers throughout the year raise thousands of dollars for the Gleason Initiative Foundation, which helps provide cutting-edge technology to ALS patients and spread awareness about the disease.

Gleason says his MBA from the A. B. Freeman School of Business at Tulane University provided valuable knowledge for running a foundation.

“I learned a lot about leadership,” he says. “I have to manage a team of caretakers as well, so I definitely use techniques and strategies that came from Tulane.”

“I was also taught how to manage change and I certainly have experienced enormous amounts of change in the past six years. Thanks in part to my Tulane MBA, I seem to be as productive as ever.”

A football player, a businessman, an inventor, a movie star, a husband and a father, Steve Gleason could never be considered average.

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