

A stylized brain with a large red 'A' overlaid on it. The brain is rendered in a dark blue color with white outlines of the gyri and sulci. The letter 'A' is a solid red color and is positioned centrally over the brain. The text 'The Disease' is written in a white serif font, centered within the 'A'.

The
Disease

B



Behind the ALS Challenge

Last year, many people across the world took part in the Ice Bucket Challenge that brought increased awareness to ALS. While those with the disease try to live their lives to the fullest, the illness remains a great mystery to those in the medical profession

By Savita Iyer-Ahrestani

Every year, when hunting season comes around, Scott Morgenweck can't help but feel really down. The Altoona-area resident and Army veteran had always been an avid hunter and a keen fisherman, but some years after he was diagnosed with Amyotrophic Lateral Sclerosis (ALS) and lost the use of his limbs, he was forced to give up, among many other things, both of the sports he loved. And yet, he is not one to feel down for long.

Morgenweck has been living with ALS, a degenerative disease that progressively destroys the motor neurons in the brain, for 12 years. And though he needs a power wheelchair to get around, requires 24/7 help from his wife, Vicki, for just about everything, and, above all, knows that there is no cure for his illness, he's an incredibly upbeat, larger-than-life person with a seemingly innate *joie de vivre*, and he's quick to crack a joke — even about his own condition.

He is extremely fortunate, he says, that he can still talk and laugh, since many ALS patients lose these faculties fairly early in their illnesses. He's happy that even after more than a decade with ALS, he doesn't require a feeding tube and he can breathe without assistance (doctors put the average lifespan of a person with ALS at between two and five years after diagnosis, though there are exceptions such as Morgenweck and theoretical physicist Stephen Hawking, who has lived with ALS for 50 years). At the same time, however, Morgenweck doesn't know how long he has before he's going to need either or both of those.

"I guess that's when I will start eating vegetables, because I'll have no choice but to eat what they give me through that tube," Morgenweck jokes. "I hate vegetables, and as long as I don't have to eat them I won't."

ALS is an illness whose progression is impossible to determine medically, and doctors cannot tell whether a patient who has been diagnosed with ALS will lose their faculties slowly over time or whether the disease will cause them to deteriorate rapidly.

It goes without saying that this lack of clarity is a huge source of frustration and anguish for ALS sufferers and their families, but it's an equal challenge for medical professionals, says Brian Hyman, MD, a neurologist at the Mount Nittany Physician Group in State College. Also, because ALS affects such a small percentage of the



Scott Morgenweck, shown with his wife, Vicki, was diagnosed with ALS 12 years ago but has maintained an upbeat attitude about life.

population (about six in every 100,000 people), research has not yet been able to pinpoint any clear causes for the disease, Hyman says, and there's still no conclusive data to show whether there are any specific triggers for it, whether certain people are more prone to get it than others, or whether genetics plays a role.

This makes the quest for treatments and for a possible cure even more difficult.

"With diseases like Huntington's and Alzheimer's, we can give people a pretty decent idea of how they're going to progress and what will happen to them. But with ALS, which is such a devastating disease, there is nothing right now to predict its progression," says James Connor, professor and vice chair of neurosurgery at Penn State Milton S. Hershey Medical Center.

He says research is moving forward in several directions, and he and Hyman are among many in the medical profession who are hoping that last summer's Ice Bucket Challenge will help push things along even further. The online challenge, where people dumped buckets of ice water over their heads and which went viral very quickly and became a must-do for celebrities, politicians, and

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Fighting for Family: Penn State football sees ALS hit two former players

By Savita Iyer-Ahrestani

A few months ago, when Tim Shaw, former linebacker for the Tennessee Titans, publicly announced that he had ALS, he felt a sense of relief. Shaw, who played for Penn State between 2002 and 2006, had been diagnosed a couple of months before his announcement. It had taken a “monumental effort” to be able to declare his illness publicly, he says, but he was both overwhelmed and strengthened by the outpouring of support he received from so many different quarters.

“I have been given a platform that I’m going to take advantage of in order to really spread awareness of this disease and to help raise funds, and I plan to speak publicly about ALS whenever I can,” he says. “I’m beyond supported and loved, and I consider myself lucky to be young, active, and fit compared to so many others. Those things are really helping me now.”

All the same, having to prepare for the inevitable effects of having ALS demands extreme strength of mind, and it’s as difficult for Shaw as it is for anyone else with the disease to see their faculties deteriorate and to realize “that you’re just not going to be able to do the things you used to do.” For others, he says, “this happens over the course of your life. For people with ALS, it all happens a lot quicker. It’s like getting old, but a lot faster.”

For families of ALS patients, the ordeal is just as painful.

“I have seen a man who has been a great husband, father, and son to our family progressively go from a muscular, well-built man to one who has lost most of his muscle mass and all of his strength, and now lies almost fully paralyzed and on a feeding tube and ventilator, in bed 24/7, unless he’s



Smith surrounded by his family – (from left) Jazmin, Dante, and wife, Chie.

getting out for doctor appointments, occasional family outings, or physical therapy,” says Chie Smith, wife of former NFL player Steve Smith, who was first diagnosed with ALS in 2002.

A captain on Penn State’s 1986 national-championship team, Steve Smith requires around-the-clock care. This is extremely tough, Chie says, and oftentimes is as frustrating for her and the couple’s children, Jazmin and Dante, as it is sad.

“But we have learned to adjust as Steve’s illness progressed, and I felt that it was very important that the kids be hands-on with their dad — helping in ways like learning how to suction his trachea to figuring out how to communicate with him when he lost his voice,” she says. “I don’t think anyone realizes their source of strength or resolve in a difficult situation until it happens.”

Steve himself has no illusions about his illness, but he refuses to give up.

“I just know that this is the biggest fight for my life,” he writes in an e-mail, “but you just have to keep fighting every minute of the day.”

Shaw takes comfort in knowing that he’s surrounded by family and friends, and is confident that with many hands joined together, research and medicine can continue to work toward finding treatments for ALS.

Soon after Shaw’s announcement, Penn State athletics announced that it would partner with the Best Man Tim campaign that Shaw’s friend and former Penn State soccer player Paul Omekanda set up to raise awareness and funding for ALS research.

In a released statement after the partnership had been announced, Shaw said, “I will always consider Penn State home. It feels great to have family support me in the fight.” **T&G**

Contributed photos (2)



Shaw (left) and his father took a mission trip to Brazil two months ago.



Amy and Mike Strouse at the Nittany Lion Shrine in 2006, six months before Mike began to show signs of ALS.

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thousands of regular citizens alike, not only greatly increased awareness about ALS — an illness that, Connor says, “so many only had a vague idea about and knew only as Lou Gehrig’s disease” — but also raised more



The Strouses in Beaver Stadium celebrating Mike’s 37th birthday in 2010.



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than \$100 million for the ALS Association. He's hoping that some of that money will be channeled into furthering research efforts into the causes of and possible treatments for ALS. He is even hopeful that one day there may be a cure, but that's still a long way into the future, he says, and, for now, sadly, the only sure thing about ALS is that those who have it have only a finite period in which to live.

A life, not a death, sentence

Knowing that greatly helped people such as Amy and Mike Strouse. Mike, a 1995 Penn State graduate and former resident of Dover, was 34 when he was diagnosed with ALS (he died in 2013 at the age of 40), and, like most others, his initial symptoms were innocuous.

"Mike noticed his voice was cutting in and out," Amy Strouse says. "He'd always loved singing — he'd been in many choirs while he was at Penn State — but he noticed that he couldn't project his voice, and he felt like he had to keep clearing his throat all the time, but we thought it was just allergies."

An astute family doctor thought otherwise,

however, and sent Strouse to a neurologist, who, after conducting a series of tests to rule out other possible illnesses, finally determined that Strouse had ALS (as yet, there is no independent test for ALS).

"Even before we got the official diagnosis, we knew," Amy says. "We'd been online and researched, and we had been prepping ourselves. During the test time, Mike was also progressing like a typical ALS patient — his speech was worsening, his hands were becoming weaker. So we already knew even before we were told."

The finality of things almost made it easier for the couple, though.

"We let ourselves have a pity party for a time, and then we turned it around," Amy says.

In the following year, Mike and Amy Strouse reorganized their lives and did a lot of things — from what was necessary (selling their house and moving into one that was wheelchair accessible and equipped to deal with Mike's worsening condition) to what gave them pleasure (taking their dream trip to Italy). They became very close, Amy says,

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Mike Strouse with his newborn daughter, Ella, who was born in 2012.

savoring every moment they had together, and they even had a child — a girl, Ella, born the year before Mike passed away.

For Jim Knudson, an IT professional in Mechanicsburg who was diagnosed with ALS in 2013, the illness is a “life sentence, not a death sentence.”

“We must realize that we’re all dying every day that we are alive, and our focus should be on life not death,” Knudson, who used to live in State College, says. “You also can’t wait to do things in the future because none of us know what the future holds.”

Knudson, who blogs about his illness at dailylifewithals.blogspot.com, is candid about his frustrations over losing his speech (he now uses an iPad with inbuilt communications software, and he answered questions for this article via e-mail). Because of the increasing weakness in his tongue and jaws, chewing and swallowing are a real challenge, and “it may take me about 45 minutes to finish what a normal person can finish in 15,” he says.

Although he does have a trip planned to the Caribbean island of Bonaire, he wonders whether he will ever be able to scuba dive again — something he greatly enjoys. To friends and family members, with whom he’s now starting to spend much more time than in the past, he’s giving away the bottles of fine wine he has collected over the past 20 years because he can’t really tolerate wine anymore.

Nevertheless, he continues to travel and to

enjoy many things about life, including books, music, and art. He’s still working, he can move about independently, and he’s still able to drive.

He is prepared for the loss of these abilities, of course, but “I am not the kind of person that is going to sit around and wait to die,” he says. “I want to accomplish as much as I can and live life fully with whatever time remains.”

In his role as director of Penn State Hershey’s ALS Clinic and Research Center, a multidisciplinary facility

that ALS patients in Centre County also are patients of, Zachary Simmons, MD, has come across patients such as Knudson many times.

“There’s a concept associated with people who are terminally ill called a ‘frame’ or ‘response’ shift, whereby they are often able to maintain a good quality of life by shifting their expectations to better match reality, so they are much better able to deal with a more physically limiting status than others may think,” he says. “People in good health frequently underestimate the way those who are ill would rate their own quality of life. Working here has been a real learning process for me.”

Toward effective treatment

But their ability to reframe their lives to fit in with the realities of an incurable illness doesn’t mean that ALS patients don’t wish fervently for a cure, or even for effective treatments to increase their lifespans and slow down the degeneration of their faculties. To that end, researchers at Penn State Hershey are making advances in a couple of important areas, Connor says, notably in assessing the protein profiles of individuals with ALS.

“We showed in a small study that we could really identify a protein profile that’s different for a slower progression of the disease than it is for a more rapid progression,” he says. “If we’re able to infuse the spinal chord of ALS patients with a protein cocktail that’s associated with

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slower progression, we'd be able to slow down the illness in patients. That's a huge step, and we should be able to go to the FDA soon to request approval to try it out."

Currently, there is only one FDA-approved drug available for ALS patients, which Connor says is not particularly effective as it only increases a patient's lifespan by two or three months. It also does not work for all ALS patients.

"We're not looking at a drug with what we're doing, we're talking about using a naturally occurring trophic solution that's bathing the spinal chord," he says.

Whether these or other possible treatments will be available in either Knudson's or Morgenweck's lifetimes remains to be seen. But the Ice Bucket Challenge also has given them and others with ALS a new avenue of hope that research into probable causes will eventually lead to new treatments.

Above all, they're not giving up on themselves.

While he's waiting for new treatments and a possible cure, Knudson is trying out an alternative therapy, the Deanna Protocol,

invented by a doctor and named for his daughter who had ALS. The treatment aims to provide energy and stimulation, through various supplements, to the nerve and muscle cells to prevent them from dying, and it also involves regularly massaging the muscles with coconut oil, believed to be extremely therapeutic. Knudson tries to eat as healthy as possible to remain fit and in good shape, and, above all, to try his best to maintain a positive mental attitude, no matter how hard that may be.

As for Morgenweck, his greatest wish is to be able to do things on his own again.

"If I could just be a little more independent," he says, "that would be great." **T&G**

Savita Iyer-Ahrestani is a freelance journalist who has worked as a full-time business journalist in New York, and, as a freelancer, has reported from both Europe and Asia. Her features on a variety of topics have appeared in many publications, including Business Week, Vogue (Mumbai, India edition), and on CNN.com.



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