



## Canadian Lyme Disease Foundation

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### Show of strength

**Doctors told Steve Smith he was dying of ALS. He is now convinced that is not true.**

By FRANK BODANI

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The woman cut up the pork chops and broccoli into small pieces.

Slowly, ever so patiently, she fed them to the man sitting next to her.

Her husband. The father of her son and daughter.

The former Penn State football star.

The former NFL fullback.

Steve Smith won't turn 40 until the end of summer — and yet he cannot move his arms and hands to feed himself.

It's been two years since the captain of one of the greatest Nittany Lion teams was diagnosed with amyotrophic lateral sclerosis — Lou Gehrig's disease.

Two years since he was given a death sentence.

One year since he was given new hope.

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*"Hel-lo ... this is Ste-ven Smith. Please ... call ... me ... back."*

The words on the phone answering message were slow. Halting. Awkward, uncomfortable breaks between phrases.

Concentration needed for each word. No inflection.

But Smith pushes on, despite the muscles that have withered away in his arms, shoulders and in his throat.

Two years ago, he was diagnosed with ALS.

"I think for ... the first week ... I was ve-ry scared," Smith said. "I knew ... that Lou Geh-rig had died ... two years after he was di-ag-nosed, and that scared me. I think my ... body pro-bably ... de-ter-iorated ... more in that first week ... than in a year.

"The things you love ... the most ... seem to be slip-ping a-way from you ... and there's no-thing you can do."

He needs help standing and walking, combing his hair and brushing his teeth and using the bathroom.

And to think he was a member of the only two national championship football teams in Penn State history. He was one of the captains of the 1986 team that stunned Miami.

He was drafted in the third round by the Los Angeles Raiders. He was the guy they called "Tank" in high school and "Rhino" in the NFL because of the way he ran over defenders.

He did the dirty work, blocking for stars like Marcus Allen and Eric Dickerson, Bo Jackson and Roger Craig.

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Now, he is fighting death with day-long doses of pills, oils and intravenous medicines.

And yet, it doesn't seem to matter that his wife helps him out of a wheelchair and feeds him every meal and holds a cup to his mouth so he can sip from a straw.

Steve Smith always seems to smile the widest smiles.

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Steve and his wife, Chie (ChEE-AY) Smith, were supposed to be starting their lives over.

It was the spring of 2002 and they had just moved from Georgia to the Dallas suburb of Plano. Steve Smith had a new job, leaving behind his car wash business to take over a sub franchise.

Their two kids were growing up.

It was during games of tennis, when he noticed his legs feeling heavy for no reason.

He noticed a twitch in his neck.

He figured it had to be football battle scars. You don't play fullback for nine years in the NFL without having some kind of lasting pain.

He decided to get checked by doctors, and then neurologists, when his legs continued to weaken. There were MRIs, brain scans and spinal taps.

Then, shockingly, his world crumbled: He received an ALS diagnosis, then another. Steve's parents, Norma and Morris Smith, traveled from their home in Myrtle Beach, S.C., to hear the news.

Three times doctors told him the same thing. The last diagnosis came on Sept.11, 2002; the horrible anniversary and those horrible words crashing down together.

"Thank God for the kids," Chie Smith said. "They can even take your mind off of the worst things."

More than 5,000 Americans each year are diagnosed with ALS, which destroys specialized nerve cells called motor neurons. Life expectancy is usually 2 to 5 years.

Steve Smith seemed to be following the same awful path so familiar to ALS patients: a body steadily wasting away until the ability to move, swallow and breathe vanish — with a perfectly clear mind tortured through it all.

It didn't take long before the muscles in his hands deteriorated to the point where he could not grasp the dimes and quarters in his car change holder.

Hope, though, came unexpectedly last year when Chie Smith read a People Magazine article about a doctor in suburban Philadelphia who was making breakthroughs with ALS patients.

Actually, many of those patients, Dr. Greg Bach claimed, have severe, undetected cases of Lyme disease, which has symptoms that can mirror those of ALS.

Lyme disease usually is carried by the tiny deer tick.

And if Smith does have Lyme, there is hope. The disease can be cured, even in late stages. Aggressive antibiotic treatments miraculously seemed to rescue even some of Dr. Bach's most desperate, dying patients.

Smith has been visiting Bach every month since last July for checkups and treatments. He takes up to two dozen oral medications and is injected with other antibiotics intravenously every day.

It is somewhat of a radical medical turn. ALS doctors scoff at Bach's findings. And it can be difficult to accept Bach's talk of how tick bites can cause misdiagnosis of everything from ALS to muscular dystrophy to road rage.

He certainly has supporters, though.

"He is taking patients who are given a dead-end diagnosis ... and he's treating them and they're making recoveries," said Pat Smith, head of the Lyme Disease Association, a non-profit group based in New Jersey. "It doesn't matter what anyone thinks about it. Patients are getting help."

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based in New Jersey. "It doesn't matter what anyone thinks about it. Patients are getting help."

Steven Phillips, president of the International Lyme and Associated Diseases Society in Bethesda, Md., takes a more cautious approach.

"There is a known association between (ALS and Lyme disease). Lyme can cause these things," Phillips said.

He admitted, though, that most ALS patients treated for Lyme, while helped to some degree, do not make full recoveries.

Steve Smith is convinced he has Lyme disease. He is convinced he will recover.

"So many people have been misdiagnosed, just like Steve," his wife said. "The ALS doctors, they just shut the door on you. They don't want to hear it. It's really disgusting.

"The thing that gets to me is that we lost nine precious months."

There have been small signs of recovery lately. The muscle tone in his arms appears to be returning. His weight has remained steady when most ALS patients wither away as their muscles die. His voice, though still muddy, seems stronger.

"He's beating the odds," Bach said. "It's taken a lot of inner strength to do this. I believe he's going to be one of the ones who make it. I know he is. All the time he put in (working out for football) is what actually is saving his life."

In June, he also started an alternative medical treatment at the Haverford Wellness Center in Havertown. Five days a week, two or three times each day, his blood is drawn and mixed with amino acids and a soy-based substance, and then injected back into his system. The idea is to give the body extra material to heal damaged motor neuron cells.

On a recent visit to Haverford, Chie Smith followed her handwritten notes, and a doctor's pointers, as she learned to use the syringes. The goal is to perform the procedure at home.

They chatted and laughed a bit as they left the center. There is hope.

And yet there is still so far to go.

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The wife held her husband's hands.

The petite, 5-foot-3 woman walked backward and held both hands of the unsteady, 250-pound man.

She guided him one slow, shaky step at a time from the waiting room of the doctor's office to the black Chevy Blazer rental in the parking lot.

He smiled, as always, as he walked wearing a gray Penn State football T-shirt, green shorts and white sneakers with Velcro ties instead of laces.

His arms twitched from constant muscle spasms.

"One, two, three. I gotcha," Chie said before helping to gently push Steve into the passenger's seat. She picked up his legs and lifted them into place. She pulled the seat belt over him and locked it.

Chie leads the family for now. She is an exotic-looking beauty; Japanese on her mother's side, Navajo and Spanish from her father.

Her name means "wisdom."

But how could she know what to do now? What to say?

She was a Raiders cheerleader when she met the NFL fullback, the one who remembered the precise pronunciation of her name after hearing it only once.

He was from Clinton, Md., near Washington, D.C. He grew up comfortably (his father was a senior account executive for Xerox; his mother was a budget officer for the federal government). He grew up religiously. And he grew into a football star, first for famous DeMatha Catholic High School and then for Penn State.

Those first years of college were difficult, testing years. He struggled through Joe Paterno's strict practices and called home to complain about not being good enough. His Penn State coaches told him he wasn't dedicating himself like he should.

those last years of college were similar, losing games he struggled through for a while & called home to complain about not being good enough. His Penn State coaches told him he wasn't dedicating himself like he should.

But he learned. Smith was a redshirt freshman and a scout team member in 1982 when the Nittany Lions won their first national title over Georgia.

He started 11 times as a sophomore and ran for 126 yards against Boston College. He started the first eight games as a junior, scoring on a 63-yard run vs. Rutgers and catching the game-winning touchdown against Syracuse. He was a road grader again as a senior, plowing paths for tailbacks and catching a career-high 14 passes.

"He got so strong and so big and thick. He was a physically intimidating player," said Fran Ganter, his former position coach at Penn State. "I can picture him on the practice field with a big thing of snuff in his lip ready to go to work. Most of the guys griped about the length of practice or how much we were hitting. That never fazed him."

And yet Smith still didn't imagine NFL executives rushing after him. A no-name fullback?

So he was in the shower when the Los Angeles Raiders called during the third round of the draft.

As it turned out, he was almost an immediate success, scoring nine times in his second season with the Raiders. He ran for 471 yards in his third season. He caught 28 passes in his sixth season.

He was solid, tough and dependable. The typical NFL fullback.

The typical Penn State fullback.

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The disease has made things tough on everyone around Smith — yet another burden he must carry.

His wife said she cried constantly for the first two months after the diagnosis.

"There were some nights I couldn't stop the tears," Smith's father said. "It really takes all of the air out of me. I just feel so helpless.

"With your children you always want to be there for them. If they fall down, you want to be there to pick them up. I feel like he's going through this and I can't reach down and pick him up."

Somebody must always be near to help him if he loses his balance and falls to the floor.

Even so, the Smiths still push on to restaurants and movies, Steve always insisting on sitting in a regular chair.

At first, he didn't want anyone to know about his situation. But his wife finally decided to tell his closest friends.

Bruce Wilkerson, a former offensive lineman with the Raiders, called and cheered him up.

Then David Clark called, his former teammate and roommate at Penn State.

Then Joe Paterno.

It got Smith thinking back to Penn State again, like that time during his second year in State College when he was called into the coach's office.

Paterno told him, "Some guys you pat on the back and other guys you have to kick in the butt." And he said ... I ... was a kick-in-the-butt ... type of guy." He ... was right," Smith said.

"I ... love ... Joe. At Penn State ... you don't like him ... very much. He's ve-ry hard on you. You call him names un-der your breath. But ... when you're out in the real world ... that's when you real-ly a-pprec-iate Joe.

"That's when ... going to Penn State ... star-ted to make sense."

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His days begin simply.

Slowly, he walks down the hallway of his Texas home to build strength and balance. He does stretching exercises, even finger exercises.

His mother prays and reads the Bible with him. She massages his hands.

He still goofs around with his kids; Dante, 14, and Jazmin, 12.

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"The hardest thing for me is not ... being the husband and father I've been before ... but I know this is ... a ... temporary situation."

His wife is always there to help.

His former teammates are there, too. A Raiders' fund-raiser led by Marcus Allen will help pay his medical bills, which run more than \$6,000 a month. And that doesn't include the monthly transportation costs from Texas to Pennsylvania.

Even the specialized test to determine that he had Lyme disease cost \$800 to \$1,000.

Fortunately, it seems as if someone is always there. Bob Campbell, an uncle who lives in Los Angeles, helped start the Steve Smith Foundation. He led those Raider teammates to hold a small golf tournament and raise about \$15,000.

Campbell said ex-Raider and TV pitchman Howie Long has agreed to work the tournament next year, maybe moving it to Las Vegas, almost certainly making it a major fund-raiser.

Another golf fund-raiser is planned for Annapolis, Md., in October.

"I've tried to imagine being in his position. I don't know if I could be that tough," said Wilkerson, the former teammate. "To go from thinking you're invincible to fighting something that's the damndest thing to beat, and you don't know how ..."

Smith chooses to focus on the positive. He has his three dogs and two cats, including his prized pit bull, Shaq.

And he knows it could be worse. He doesn't have to be rolled over in bed in the middle of the night like a friend of his diagnosed with ALS.

So while Smith's goals are simple, they also are powerful, sometimes appearing to be unreachable.

Yet he smiles. He keeps reaching.

He wants to come back to Beaver Stadium. He hasn't been there in three years, since the 1986 championship team held a reunion.

He wants to move back to Maryland soon with his wife and kids to be closer to his doctors and parents.

He wants to live the life he once knew.

"I will play basketball again with my son.

"I believe ... I will be able to do a lot more ... everything I did before ... and a lot more. We will all die from something ... but I will not die from this.

"I will fight and overcome this."

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## **About Smith**

- Born Aug. 30, 1964
- Grew up in Clinton, Md., but now lives in Plano, Texas.
- Married to Chie Smith, a former Raiders cheerleader. They have a son, Dante, 14, and a daughter, Jazmin, 12.
- Graduated from DeMatha Catholic High School in Maryland.
- Attended Penn State from 1982-87, graduating with a degree in hotel, restaurant and institutional management.
- Gained a career-high 421 rushing yards as a Nittany Lion junior. He caught a career-high 14 passes for 134 yards as a senior.
- Taken by the Los Angeles Raiders in the third round of the 1987 NFL draft. The team selected superstar Bo Jackson four rounds later.
- Rushed for 1,627 yards in nine NFL seasons, averaging 3.8 yards per carry. Caught 131 passes for 1,250 yards (9.5 yards per catch). Scored nine rushing touchdowns and 12 receiving TDs.

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- Spent final two pro seasons with the Seattle Seahawks, where he combined for only 35 carries for 99 yards and two scores.
- Appeared in three NFL playoff games, winning just the first in 1990. Had 12 career playoff rushes for 43 yards and two receptions for 14 yards.

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## **Through the years**

### **1986**

- Running back Steve Smith helps lift Penn State to the national football championship, his second with the Nittany Lions.

### **1995**

- Smith concludes a nine-year NFL career.

### **2002**

- After noticing progressive weakness in his legs, Smith receives multiple diagnoses of ALS, or Lou Gehrig's disease, which can be fatal within a few years.

### **2003**

- A doctor near Philadelphia begins treating Smith for Lyme disease, which has symptoms similar to ALS but is treatable.

### **Today**

- Smith, 39, needs help to walk, dress or eat. His speech is slow and slurred. While showing slight improvements, Smith believes he suffers from Lyme disease and will make a full recovery.