

## "Life is good," ALS patient tells Hingham High students

Posted May 7, 2010 11:52 AM

By Molly A. K. Connors, Town Correspondent

A dozen teenagers, rapt, stare at the electronic computerized "smart board" in front of them. A man, almost completely paralyzed by the neurologically degenerative disease ALS, has hooked up the computer attached to his wheelchair to the interactive white board so the students can see how he communicates with the world.

The students are impressed.

"That's trippy," says one.

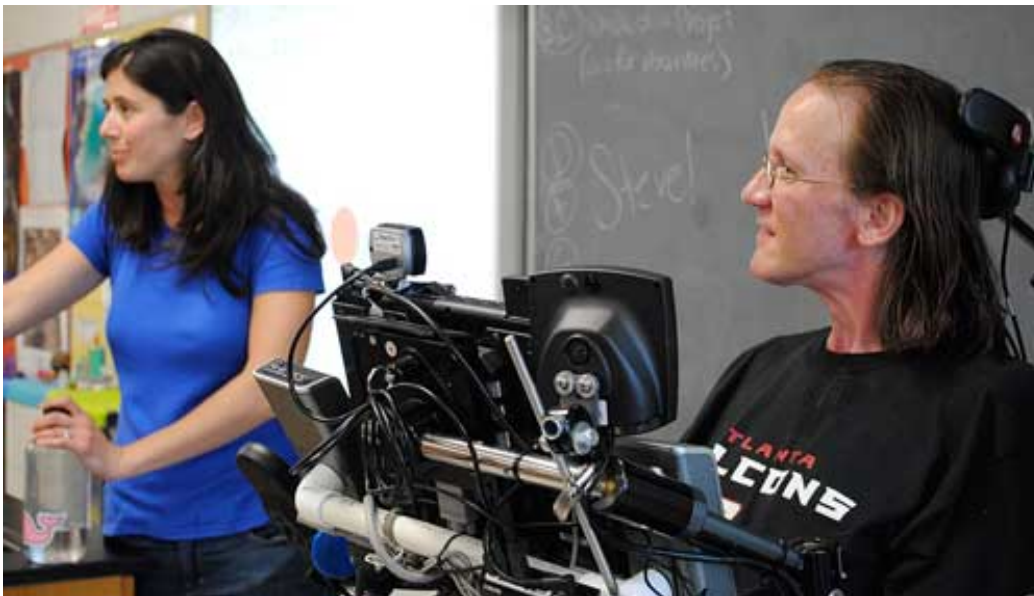
"Whaaaaa?" says another.

"Oh..My...God," says a third.

On the right of the screen, letters scroll vertically while the man selects the letters one by one with an infrared dot on the brim of his glasses. As he picks each letter, it dances to the left, across the screen, gradually forming the words he wants to say. Those words then go in a box at the top of the screen.

The room, usually a laboratory alive with students working collaboratively, is silent until a computer speaks the words Steve Saling, an accomplished architect and self-proclaimed "loud mouth," could have spoken himself two years ago.

"This is my primary mode of communication," he tells the high school seniors.



Saling, a Chelsea resident, was invited by his friend Dana Crosby {above}, a Hingham High School science teacher, to talk to her students about how technology and machines have allowed him to live a meaningful and productive life even as he feels his muscles "getting weaker almost daily."

And yet, he says, "I have never felt more vital."

Crosby says she came up with the idea to invite Saling when she was explaining to her freshman level special-needs students about basic machines.

It was a bit of a tangent, she admits, but she mentioned how her friend, Saling, who was diagnosed with ALS a month after his 38th birthday in 2006, uses machines to live and work.

“They were so interested,” Crosby says. “They had so many questions.” So, they wrote the questions down, and Crosby sent them to Saling, who came to the class less than a week later to answer them.

“Most of what ALS takes away, technology can give back,” he said.

Saling met with several classes Thursday. He told the students that no topic was off-limits.

“If you can’t move your arms, how do you eat?” one asks.

“I have to be fed,” Saling says. He also explains he has a tube in his stomach.

“How much do they know about ALS? Is it hereditary or anything like that?” asks another. Some is genetic, Saling answers, and other cases are “sporadic,” like his.

The biggest challenge of all the challenges? one wants to know.

“Not being active in conversations,” Saling types with his infrared device.

And...sex?

“I am happy to report that the important parts still work,” Saling says. Everyone laughed.

Saling showed the students pictures of the state-of-the-art, recently built facility in Chelsea that he helped to design at the Leonard Florence Center for Living in Chelsea. Saling, who had specialized in making spaces handicapped-accessible before his diagnosis, said his life will bear more fruit because of his illness.

“I ...will contribute more than I ever would have if I'd remained healthy,” he tells the students.

The students says they enjoyed their time with Saling, but wished they could have had even more time with the Atlanta native, who says doctors at first dismissed his deteriorating speech as a mere Southern drawl.

“I learned that you can still stay happy with a disease like that,” says 18-year-old Florencia Ezcurra, a senior.

“It makes me appreciate things more,” she adds.

That lesson was one of the many that Crosby was hoping her students would learn from Saling’s visit.

“I look at how he [Steve] is and then listen to my kids, who say, ‘Oh, I couldn’t get out of bed this morning,’” Crosby said. “It puts things in perspective,” she said.

But Saling’s perspective seems to need little adjustment.

“Remember,” he said, “Life is good.”

Crosby and nine friends plan to take part in a 270-mile bike ride this summer to raise money for ALS research. For more information, visit the [website](#).