



THE LEADING DISABILITY COMMUNITY

Jim Lubin: Reaching others through computer lines

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Name: Jim Lubin

Age: Lubin is 33.



Disability: Lubin has transverse myelitis, a neurological syndrome caused by inflammation of the spinal cord. He has been paralyzed from the neck and below that level since May, 1989. His neck muscles are weak. He can turn his head only a little. He can tilt his head forward, but then he is unable to return it to position. He is unable to breathe on his own and is dependent on a ventilator to breathe.

Employment: Before being diagnosed with transverse myelitis, Lubin worked at a medical manufacturer making an angioplasty device. When he first came home from the hospital, he did some computer programming projects for the same company. His previous job was not computer related. He learned enough programming for work to complete the projects. He did some tech support on the Genie online service in the early '90s, helping people with the PC front-end program and Internet features. Now he operates his own Web site and the Transverse Myelitis Association Web site.

Hobbies: Lubin enjoys using computers. He says that he had this interest even before he became paralyzed. He also likes watching movies and listening to music.

Greatest accomplishment: Lubin says starting the Transverse Myelitis Internet Club (TMIC), so people with the disability can talk with others, is his greatest accomplishment. "Since it is a rare disease, many people had never heard of or met another person with TM until meeting online," he explains.

Earning gratitude and stashing resources

Jim Lubin has a folder on his computer filled with about 500 notes of thanks he has received since 1996. It contains messages expressing appreciation for searches well-conducted and challenges "solved." He estimates that he gets one or two requests for help finding information every day. Lubin, for example, remembers a request from a mother whose child with a spinal cord injury had an irregular body temperature. The mother was wondering what products might resolve the issue, and Lubin tried searching with different keywords until he used, "personal cooling system." This search on the Web led the mother to finding clothing specifically designed for inclement conditions and people with poor circulation. Lubin not only earned the mother's gratitude for his

discovery, but he also stashed away the resource for future reference. At this point, Lubin has such a selection of useful finds, he has created his own "disABILITY Information and Resources" page. He says he wants to be remembered "as someone, who helped a lot of people in some way," and numbers indicate he is on the right track. His site averages 50,000 visits per month, with about 20,000 of those hits coming from distinct Internet addresses. The sections relating to adaptive equipment, spinal cord injuries and travel get the most hits.

Facing his disability

Lubin not only operates his own Web site, but he also runs the Transverse Myelitis Association Web site. His interest in the group is because it deals with the rare neurological disability that Lubin is facing himself.

On May 17, 1989, Lubin awoke with sore shoulders. His mild symptoms progressed rapidly to an extent where he collapsed, unable to stand or even breathe. He was rushed to the hospital and placed on a ventilator. Lubin remained in the intensive care unit until July 31. Doctors did not know what had caused his attack, and the cause of most transverse myelitis cases is usually unknown.

He gradually was able to broaden his spectrum of activities. By October, Lubin said he was able to leave the hospital and go to movies. "The nurses would try to get other patients to go out with me. I was the only one on a vent and paralyzed from the neck down," he explains. "Others didn't want to go out because they were afraid of the reaction they might get from people."

Finding a way to move beyond his barriers

In spite of the dramatic physical changes in his life, Lubin somehow concentrates on the way his life has stayed the same both before and after the transverse myelitis attack on his body. "Even before, computers were my main hobby, and now I have more time to learn and play," he says. The computer has been an interest of his since the eighth grade. He operates his machine by using a sip-and-puff device to enter Morse code patterns that input keyboard keys and mouse functions. In this way, Lubin has access to the world and to people in his same condition, who need support.

Sandy Siegel, of Columbus, Ohio, is someone who met Lubin in 1995 when his wife, Pauline, was diagnosed with transverse myelitis. When they searched the Web for information about the condition, they hit upon Lubin's "disABILITY Information and Resources" page. Today, Siegel is president of the Transverse Myelitis Association, and Lubin is the information technology director. Based on the association's Internet presence, people have questioned, according to Siegel, whether an entire staff posts information online. Lubin is the only one who does the Web work. "He has pushed me to be more creative, more efficient, more effective in what we do as an association by using technology in the most wonderful ways," says Siegel. "I hate it that TM has brought us together. I hate that Jim has this horrible condition and I hate that my wife has it, but life has a way . . . we are together only because of transverse myelitis."

Earning high praise

Lubin takes pleasure in the connections he forms on his computer. He explains that he is not able to leave the house much because being transported is so uncomfortable. "Riding in a van gives me a headache. I get bounced too much. My neck muscles are weak, so even with my head strapped to my headrest, it still bounces," he says. As secluded as his life may sound, Lubin is developing a reputation as someone who can offer comfort and compassion to people with overwhelming physical challenges. A

syndicated teen advice columnist mentioned Lubin as a resource person to a young survivor of a serious car accident. New Mobility magazine selected him as their 1998 Person of the Year. A grad student explained only last week that he found Lubin's Web site listed in his textbook, "The Teacher's Complete & Easy Guide to the Internet." The acclaim is not going to his head. Lubin says, "People are always telling me that I impress them, but unlike some people, I'm still able to do the things I enjoyed before I became 'disabled.'"

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