

# PROFILE

SSM REHABILITATION INSTITUTE

## Electronic Bulletin Board Links the Disabled Community

**P**ersons who live with disabilities often feel isolated, either because of physical restrictions on their activities, difficulty communicating, or the stigma attached to their conditions. But in the St. Louis area, disabled persons have a place to meet and exchange ideas: an electronic bulletin board system (BBS) especially for them.

SSM Abilities Re-

source Terminal (or SSMART) was put on-line in 1993 by SSM Rehabilitation Institute (SSMRI), a member of the SSM Health Care System. Currently the BBS has about 125 users; 60 percent are disabled, and the others are family or friends of disabled persons, professionals who work with the disabled, and other community members who just enjoy using the system.

The BBS's primary purpose is to provide an interactive communications forum for the disabled, but "a secondary purpose is to enable the public to interact with the disabled and find that they're real people—they live, they breathe, they have opinions," explains Rich Barbre, personal computer support analyst at SSMRI. Barbre established the BBS and serves as its "sys-op,"

or systems operator (the person in charge of a BBS).

### WHAT THE BBS OFFERS

An electronic bulletin board is, in concept, like a cork bulletin board mounted in a public place, where people can leave notices, learn about resources, and carry on discussions. Anyone with a computer and a modem can access the system at no charge. SSMART has only one

telephone line currently, so users cannot "chat" with each other in real time. But they can read and join in conversations and learn about activities and support services for the disabled.

Among SSMART's features are the following:

- A general conversation forum where any user can express views or read what others have written

- Open sub-boards on specific topics, such as the American Disabilities Act (ADA) and its impact, advertisements, employment opportunities, meeting/dating/marriage, politics and religion, and computer issues

- Sub-boards with restricted access that serve as support groups for those with disabled children, spinal cord injury, head injury, stroke, or multiple sclerosis

- Electronic mail (so users can send private messages to one another)

- On-line library of text files that users can read or download (such as the entire ADA text and a short version of the Clinton

### Notes from the Bulletin Board

Last year I felt like I aged 20 years. Get'n around is such a mess. The past few times MS struck me I did get back to normal (what's normal for me). . . . If I could make my disability go away, I'd recapture my youth (I'm only 36 in people years).

My life since I lost my sight has, without a doubt, been better. . . . I wouldn't change a thing in my life at this point. But of course I am hoping that this possible cure for retinitis pigmentosa works out. I have a child to watch grow!

I was real upset when I first had symptoms at 20 years old and then finally was diagnosed at 23 years old. I thought gosh my life had barely begun, and I just thought what is going to happen to me in the future. Now, I can honestly say I am glad I was stricken with MS because it made me realize so much and appreciate things more. I used to walk around like I was invincible, like nothing could touch or harm me. Wrong! I have grown a lot from the experience of being afflicted with the MS, and it has made me a better person.

It takes me 3 1/2 hours to fight my way around the city because Bi-State [bus system] has their famous non-workable wheelchair lifts.

I would like to see a [television] story where an individual fights back [against a disability] but enters back into life in a wheelchair or using a computer with a speech synthesizer or having a dog assist him, or other similar stories. Those of us who live with disability have a great story to tell and I would like to see more of that in the public domain.



healthcare plan)

• A "files" section where users can upload computer programs to share with others (especially programs that assist the disabled in their activities of daily living)

Future plans also include an "Ask Your Shrink" area, where people can pose questions and receive answers from psychiatrists from the institute's neuropsychiatric department. Barbre said they are trying to establish a similar area for "Ask your Doc," but because of physicians' concerns about liability, it is still under discussion.

### LAUNCHING THE BBS

When Barbre first got the idea of establishing a BBS for the disabled community, he spent a year convincing the rehabilitation institute that it would be worth the investment. First, he had to explain what a bulletin board system was and how it works. "It was hard for some people to believe that anything to do with computers was going to be easy to use."

*The bulletin board enables rehabilitation staff to keep in touch with patients after they leave.*

Initial costs of establishing the system were fairly low, Barbre says. The computer was available because somebody else in the facility got a new one; the human resources department donated the modem; the finance department agreed to pay for the phone line; and the bulletin board software—World War IV—is available free for limited uses.

"It took a lot of time and a lot of thought mainly," he said. Barbre drew largely on his experience running a bulletin board out of his home for the past seven years. And he enlisted the help of a disabled friend, Dan Garrison, a computer programmer who is active in the disabled community.

### BENEFITS FOR USERS

The bulletin board offers several advantages to its users, Barbre notes. First, traditional support groups can be a hardship for some disabled persons, requiring special transportation and adherence to the group's schedule. "With the bulletin board, you can get support group help and never leave your house," Barbre says. "And if you miss something or didn't understand it, the stuff is always there and you can go back and read it again."

Also, the participants are more diverse



**Rich Barbre (right) started the bulletin board system at SSM Rehabilitation Institute with the help of a disabled friend, Dan Garrison, who now is the co-system operator.**

than normally encountered in a support group. "A person in a wheelchair is a person in a wheelchair, whether they're in there because they have cerebral palsy or a spinal cord injury. They both have the same things to combat."

The bulletin board also allows those with communications problems to join others in general conversation—about politics, religion, or other topics. "They can take their time and type whatever they have to say," Barbre notes. "Their speech impediment doesn't come into play at all. Plus they are listened to because no one is concentrating on what they look like or on trying to understand what they're saying."

### EXPANSION PLANS

SSMRI staff are planning to buy a new computer to support a multiline environment, with four telephone

lines, and to get a toll-free number to enlarge the pool of users. Some personnel in the institute are seeking funding outside the facility, and Barbre says internal departments have also agreed to fund different aspects of the expansion.

Currently, with just one line available, access is limited, Barbre notes. Many users work during the day, and each person who accesses the system is allowed 45 minutes on line. So it can be hard to get into the system during prime time, after 5 PM. In addition, multiple telephone lines would allow people to hold conversations and receive immediate responses. And quadrupling the number who can access the system would increase the resources available.

The primary benefit for the rehabilitation facility of running the BBS is it enables staff to keep in touch with

patients after they leave, Barbre said. As the system grows, inpatients will be given free, full access so they can get used to the BBS and have a useful and therapeutic activity. Barbre noted that occupational therapists believe use of the system may get patients acclimated to using a computer, which could lead to a job.

The publicity and potential for referrals associated with the bulletin board are also benefits for the institute, Barbre said, but the most important outcome is the ability to share information and create a resource for disabled people.

—Susan K. Hume

NOTE: As Health Progress went to press, Rich Barbre joined CHA as a telecommunications specialist. For information on the BBS, call him at 314-427-2500, or call SSMRI at 314-768-5200.