

## Instant images, enduring frustrations

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### Exhibit exposes brain injury woes

By Irene Sege, Globe Staff | March 12, 2009

When Judy Szczeblowski enrolled in a photography project for survivors of brain injury in 2006, her chin-length hair hid the scar and bald spot that dominate the back of her head, artifacts of the surgery and radiation used to treat a life-threatening brain tumor in 1990. By the time the project ended 10 weeks later, Szczeblowski had cut her hair short enough to expose the entire bald spot.

The photograph Szczeblowski asked her mother to take of the back of her head is on display this week at the State House, part of an exhibit called "Brain Injury X-posed" that features the work of Szczeblowski and seven other long-term survivors.

"I am no longer shamed by lack of hair and scar," Szczeblowski wrote in her caption. "It represents a new freedom, pride in what I have overcome."

At a time when as many as one of every five US service members returning from Iraq and Afghanistan has suffered a traumatic brain injury, the exhibit provides a glimpse of what could lie ahead for some of them. It highlights not only the photographers' new limitations, but also the resilience of their spirits and the brain itself. It offers personal testimony to scientists' emerging understanding that the brain can rebuild cognitive and motor function much longer after the original insult than once believed.

Szczeblowski, who lives in Medfield, was the executive chef at Boston's Algonquin Club when doctors found her brain tumor. Today she works part time at the Sherborn Library. Scott Davis of Natick was a Babson College freshman when he lost control of his car in 1978 and slammed into a tree. He didn't understand his lingering brain injury until 2003, when he lost his job of 18 years at a financial firm for mistakes that could have proved costly if not caught. Today he's a part-time supermarket cashier. Peggi Robart of Newton was a respiratory therapist and clinical educator when a sign on a rental car shuttle bus hit her on the head in 2002. Today she's a volunteer.

Kathleen Donovan, 51, of Natick was assistant manager at a camera store when she suffered a stroke while doctors probed an inoperable brain tumor in 1999. After awakening from a three-month coma needing to relearn how to walk and talk, and spending a year and a half in a wheelchair, she now works part time taking tickets in a movie theater.

Their disabilities are not immediately apparent. Davis, 49, didn't discover until almost two decades after his accident that he has a mild seizure disorder, which he controls with medication. Robart still has trouble reading. Szczeblowski battles daily headaches. They all developed strategies to organize their thinking and master new tasks. They tire easily.

"We don't have crutches or wheelchairs," Davis says. "You can't necessarily look at us and say this person's disabled."

"It's a daily challenge," Robart says, "to push your own envelope but not so much you get a horrible headache or get overwhelmed."

The participants belong to a larger support group sponsored by the Brain Injury Association of Massachusetts. In PhotoVoice, they got disposable cameras, then talked and wrote about the images they made. "We ended up communicating much deeper emotions," says Szczeblowski, 53.

"Not only did we become closer as a group, but we could do more," says Robart, 50. "I could organize better."

In an act of triumph, Robart wore a dress to the exhibit Tuesday. The wounded left side of her brain no longer transmits impulses to her right foot, so for years Robart wore a brace to keep her foot in place and clunky walking shoes, hardly the footwear for dresses. In November, Robart got an electrical device that she straps below her right knee. Whenever she steps with her left foot, the device signals her lamed foot. Robart hopes it will eventually retrain her brain so she will be able to walk without it or her cane.

"In the past we thought people only recovered in the first three to six months. Now we believe people can recover for the first 18 months to two years," says Dr. Ross Zafonte, vice president of medical affairs at Boston's Spaulding Rehabilitation Hospital. "We're finding that isn't even the limit. What if you intervene for a specific deficit? We're showing some of that can be improved."

Robart photographed a ladder resting beyond a patch of mud. "It's a muddy, rutty, hands-and-knees crawl up to the first rung of the ladder that begins to make some semblance of sense - and then you get to begin to really struggle," she wrote.

The group has displayed pieces of their work in a few libraries. In November, 200 people attended a PhotoVoice program at the Newton Free Library that focused on veterans. The State House exhibit marks the first showing of the entire project.

Davis's photo of ducks is the first picture the group discussed, and he likes to think it set the tone for the project. Ducks, Davis wrote, "likely don't have things they can't do that they could do before, and, if they do, they probably don't have near-constant thoughts about them."

Photographs of people who helped her and correspondence with legislators document Donovan's 2 1/2-year struggle to get the one-bedroom apartment she shares with her two cats after living in a nursing home. "I'm tenacious," Donovan says. Her next goal is to become a physical therapy assistant. "Make my life count," she says.

Szczeblowski snapped a picture of her shelf of cookbooks to illustrate what she's lost. A photograph of a perennial garden she's planted outside her apartment captures what she's found.

"Judy the chef. Those words were always together. With PhotoVoice I really cut that cord," Szczeblowski says. "I was happy and content and had built a life as good as the one I'd had." ■

1