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Margaret "Maggie" Worthen, center, with her mother, Nancy, left, and EagleEyes teacher Maureen Gates. Maggie suffered a debilitating stroke in 2006 but is trying to communicate using the EagleEyes technology developed at Boston College. (Photo by Lee Pellegrini)

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## Reaching Through the Locked Door

It looked as if her daughter's mind was closed off forever, but the Boston College EagleEyes program has given Nancy Worthen hope

By ED HAYWARD | CHRONICLE STAFF

Two years ago, Margaret "Maggie" Worthen was about to start a new chapter in her life — but not the one she envisioned.

Worthen was only a few days away from graduating Smith College in May 2006 when she was incapacitated by a stroke. In the two-and-a-half years that followed, her mother Nancy guided Maggie's rehabilitation and care, driven by a mother's instinct that inside a body rendered motionless lives the active mind of the young woman who once aspired to become a veterinarian.

Now, in the confines of Boston College's Campus School, Nancy Worthen is watching as her daughter communicates and plays games by using her left eye to move the cursor on a computer.

EagleEyes, an adaptive technology developed by Egan Professor of Computer Science James Gips, Assoc. Prof. Peter Olivieri (CSOM) and Assoc. Prof. Joseph Tecce (Psychology), has allowed Maggie to definitively communicate for the first time since she was stricken.

"There have been a few amazing moments since her stroke and the first day we came here and used EagleEyes was one of them," says Nancy Worthen, of Providence.

Nancy Worthen says her daughter's use of the technology gives her hope that Maggie can exercise her mind, master skills, play games and answer questions critical to her day-to-day care and comfort.

It is a long way from the days following the stroke, when one doctor advised Nancy Worthen to remove Maggie from life support systems. It's another step away from the diagnosis that Maggie was in a persistent vegetative state, indicating little or no brain activity. Instead, as researchers from the Weill Cornell Medical College confirmed in February of 2008, Maggie may be in a state referred to as "locked in," her mother says.

Nancy Worthen contacted Gips in March and asked if Maggie could be evaluated using EagleEyes. The initial sessions showed promise and mother and daughter returned this past fall to train with the equipment once a week, with the help of Maureen Gates, an EagleEyes teacher.

For Gips, who pioneered the EagleEyes technology a decade ago, the Worthen story struck a nerve.

"I thought, 'This could be my child. This could be me. What can we do to help this person?'" Gips says. "I think that's the same reaction anybody would have."

EagleEyes allows nonverbal and paralyzed people to play games, type words and express feelings by using their eyes to move a computer cursor. Electrodes attached around the eye detect movements and move the computer cursor to the desired location – be it a "yes" and "no" icon or a space alien that needs to be zapped. For years, the technology has been in use in the Campus School, which provides special education services to severely disabled students sent by school districts throughout the Greater Boston area.

There are approximately 50 EagleEyes boxes, or consoles, in use by individuals, families, schools and institutions. A new version of the box is slated to be produced this month. The BC technology is licensed to the Opportunity Foundation of America of Salt Lake City and produced by Sanmina, a medical manufacturer. Gips plans to provide a box to the Worthens at no cost.

In November, the Worthens and Maureen Gates traveled to the Weill Cornell Medical College in New York City for a consultation with Dr. Nicholas Schiff. A neurologist and pioneer in the use of new treatments for brain disorders and injuries, Schiff is researching diagnostic tools used to decide if a person is in a vegetative state or conscious. While Maggie completed tasks using EagleEyes, electronic impulses told Schiff and his staff that Maggie's brain was active and engaged, Nancy Worthen says. It was a landmark moment for Maggie, but also for EagleEyes, according to Gips.

"That was the first scientific validation using EEG to monitor people like Maggie while she used EagleEyes," said Gips.

Maggie works with therapists at the Middleboro Skilled Care Center in Middleboro, Mass., where she resides. There, she has worked closely with a speech therapist, learning how to communicate yes and no answers by moving her eyes. It is painstaking work and her answers must still be interpreted to some extent by the therapist, said Nancy Worthen.

Though unsure how far Maggie may continue to progress, each victory in her daughter's rehabilitation is cherished, says Nancy Worthen.

"The gifts Boston College has given Maggie have changed her life," says Nancy Worthen.

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