**NYT writer gives voice to terminally ill during speech**

By Charlie Olsen

Across the country, thousands of people participate in clinical trials to test new medications and life-saving devices, but for five people across the country, these untested treatments and life-saving devices, but for five people across the country, these untested trials were their only glimmer of hope for surviving fatal afflictions.

Denise Grady, a reporter for the New York Times (NYT) Science News, came to Rider on Monday to tell their stories, each part of a series on the terminal illness of hope for surviving fatal illnesses.

Grady, who has written and reported over 500 stories for the NYT, didn’t always want to be a writer. When she got her undergraduate degree in biology from the State University of New York at Stony Brook in 1973, she was considering going back for a biology graduate degree.

Instead, she enrolled in a writing course at Columbia University and went to the University of New Hampshire for a graduate degree in English.

“I was thinking about [biol-] grad school, but I wasn’t much for the lab,” Grady said. “I always liked writing, but I didn’t think I was good enough or fast enough.”

Though she is writing for the NYT and has a clip-file that includes Discover, Scientific American, Tissue Magazine and The New England Journal of Medicine. She got the NYT editor’s attention by sending him 20 fully-developed pitches for stories.

But at the event on Monday, organized by the Biology Department, she wasn’t talking about her personal accomplishments, but instead about people like Stephen Neiley, who developed a form of epilepsy, not responsive to treatment last in life.

Neiley had a successful career, and liked to hunt and fish—one day while he was out at a restaurant, he opened his mouth to speak and found he couldn’t talk, Grady said. He soon found himself having very severe seizures with alarming regularity. Neiley tried all the available medications with no success and soon lost both his business and his wife, who couldn’t cope with his affliction.

He turned to a radical medical treatment, which implants a fast-firing device, similar to a pacemaker, in the thalamus—a part of the brain that regulates motor control and relays sensory signals to the cerebral cortex. The procedure involved drilling holes in the skull to insert two electrodes and tunneling wires through the scalp, under his skin down to the neuro-stimulator implanted in his chest.

The device, which fires 180 times a second (a pacemaker fires 70 times a minute), has not completely eliminated his seizures, but they occur with less frequency, he said.

The parents of infant Hannah Stimell were shocked when they learned their daughter had Niemann-Pick disease, what’s known as a storage disease.

The diagnosis was devasting because her body, lacking the enzyme to process the chemical sphingomyelin, would accumulate the chemical. Her liver and spleen would enlarge and she was only given a few years at most to live, Grady said.

Scott and Jill Stimell took Hannah to Fairview-University Children’s Hospital in Minnesota, where doctors treated her with a combination of chemotherapy and umbilical cord blood, high in stem cells. Hannah showed improvement, Grady said.

Soliciting gasps from the audience, Grady showed a picture of Hannah Stimell, who couldn’t walk or talk and was stricken with a genetic disease known as Type A Niemann-Pick disease, what’s known as a “storage disease.”

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