

Plea for Alzheimer's funds

Former Justice O'Connor shares her family's story

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Washington - Sandra Day O'Connor has said little publicly about the disease that has robbed her husband of his memory.

On Wednesday, the former Supreme Court justice broke her silence, sharing her family's personal story with Congress in an attempt to focus its attention on Alzheimer's disease.

About 5.2 million Americans live with the brain disorder, a number that is expected to grow as the baby boom generation ages.

"Our nation is certainly ready to get deadly serious about this deadly disease," she told lawmakers on the Senate Special Committee on Aging, which Sen. Herb Kohl (D-Wis.) leads. O'Connor, who stepped down from the bench in 2006 to help care for her husband, John, urged lawmakers to increase funding for research and treatment of the disease. She said her husband was not doing well.

A fatal brain disorder, the illness slowly destroys brain cells, often causing memory loss, mood swings and disorientation. It can be devastating not only for those who have it, but also for the people around them who must watch their loved ones deteriorate as the disease progresses, advocates say.

"Alzheimer's is a confusing, inconsistent and deceptive disease," said Suzanne Carbone, who also testified to the committee about how the disease has affected her husband, Bob.

Carbone, who grew up in Baraboo said she's not sure whether her husband even recognizes her anymore. Now a library manager in Rockville, Md., Carbone said she must continue to work to pay for the care her husband needs.

"Alzheimer's disease is a growing national crisis, and we must commit to addressing it in the most comprehensive way possible," Kohl said.

Study group

O'Connor is working with a group of scientists, former politicians and other public figures to boost research on the disease through a newly formed Alzheimer's Study Group. A national strategy on Alzheimer's disease could promote dramatic breakthroughs to fight the "cruel disease," former House Speaker Newt Gingrich, who co-founded the group, said during his testimony.

Alzheimer's Funds



Photo/AP
Former Supreme Court Justice Sandra Day O'Connor and former House Speaker Newt Gingrich testify Wednesday in Washington.

Dozens of patients, caregivers and their advocates attended the hearing as part of a lobbying push by the Alzheimer's Association, a nonprofit based in Chicago. Darryl White, 62, and his wife, Bridget, traveled to Washington from their Fitchburg home to attend the hearing and other events this week designed to promote more research on the disease.

They were among the roughly 600 people who descended on Capitol Hill to lobby lawmakers on the illness. Darryl White, who was diagnosed with early-onset Alzheimer's, met with members of Wisconsin's delegation Wednesday, encouraging them to increase funding for Alzheimer's research at the National Institutes of Health. His mother died of the illness, and he hopes researchers can come up with a cure or treatment before it claims him, too, he said.

The agency spends about \$644 million on Alzheimer's research each year - an amount that has remained stagnant for the past few years. Advocates say Congress should increase that funding by \$125 million a year.

They also want lawmakers to allow Alzheimer's patients younger than 65 to immediately qualify for Medicare if they are disabled. They now must wait two years before they can be eligible for the government insurance.

Waiting period a hardship

Darryl White, who said he was forced to leave his job as a parole officer in Madison, said the waiting period is a hardship for people who can no longer work.

Darryl White spoke clearly about his illness, saying he forgets things on occasion and has trouble concentrating on tasks such as paying the bills. Later, he mentioned that he recently saw the movie "The Notebook," about a man who visits his ailing wife in a nursing home and reads their love story to her even though she can't remember him. "Where was I going with that?" he said.

Bridget White shrugged but said she worries Darryl will one day forget who she is.

"I'll always know who you are," he said.