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## Alzheimer's Community Mourns Mrs. Reagan

The Alzheimer's Association was saddened to learn of the passing of former First Lady and Alzheimer's advocate, Nancy Reagan. Mrs. Reagan was a long-standing honorary member of the Alzheimer's Association National Board of Directors, and her involvement in the cause inspired the Alzheimer's community of families, caregivers and researchers.

In 1994, U.S. President Ronald Reagan shared that he had been diagnosed with Alzheimer's disease in an open letter to the American people writing, "In opening our hearts, we hope this might promote greater awareness of this condition. Perhaps it will encourage a clearer understanding of the individuals and families who are affected by it." Following this brave announcement, Mrs. Reagan used her own voice to represent families and increase public awareness of Alzheimer's disease.

"The Alzheimer's Association mourns the loss of First Lady Nancy Reagan. Mrs. Reagan and President Reagan bravely shared his diagnosis of Alzheimer's disease with the world in 1994. This was at a time when Alzheimer's disease was truly in the shadows and together they began to change the conversation about Alzheimer's disease for millions," said Harry Johns, president and CEO, Alzheimer's Association. "The public disclosure of their Alzheimer's experience created an enormous, and much needed upsurge of interest in the disease from the general public and government officials. It was our honor to work with Mrs. Reagan over the years to raise awareness and inspire progress in Alzheimer's research."

### Local caregivers, researchers say Nancy Reagan helped the country face Alzheimer's

Bill Lindemann trembled as Ronald Reagan announced in a hand-scrawled letter he had been diagnosed with Alzheimer's, the disease that would ultimately end Lindemann's life. "He sat and cried and said 'he's a wonderful man. He didn't deserve that,'" said Sue Lindemann of Thousand Oaks, remembering her husband watching on television. "The tears were just coming down his cheeks."

Nancy Reagan, who died Sunday morning in Bel Air, spent 10 years taking care of her husband as the disease engulfed him. Publicly, she championed caregivers and lent her name to fundraising efforts. She pushed for embryonic stem cell research



Nancy Reagan (1921- 2016)

cloaked by controversy that silenced others.

She shoved a disease that triggers isolation and shame into the limelight.

"Because of them, people started paying attention," said Lindemann, an Alzheimer's support group leader whose husband died in 2005, nearly 20 years after he was diagnosed.

"They had the single greatest impact," she said of the Reagans. "Most people will not go public and I understand it."

In his letter dated Nov. 5, 1994, President Reagan worried the burden of his care would fall on his family.

"I only wish there was some way I could spare Nancy from this painful experience," he wrote. "When the time comes, I am confident that with your help she will face it with faith and courage."

Dr. James Sutton of Oxnard reads the letter every time he visits the Ronald Reagan Presidential Library & Museum in Simi Valley.

"It kind of chokes me up," he said Monday. "It's emotional ... It's inspiring."

Sutton is a neurologist who helps evaluate peo-

*Continued from previous page*

ple who may suffer from Alzheimer's and other conditions that steal away memory. As a researcher, he tests medications including the high-profile Alzheimer's drug, aducanumab, currently in clinical trials.

Sutton talked about research and Nancy Reagan's persistent support for federal funding.

Mostly, he talked about her decision to publicly confront a disease that affects 5 million people across the country, including at least 14,000 in Ventura County.

"To me, it's basically sharing with the world that Alzheimer's is not something to fear, not something to hide, not something to be ashamed of but something you deal with," Sutton said.

And Nancy Reagan dealing with it resonated with people because she was Nancy Reagan.

"They were a beloved couple. ... They spoke to what America was," said Rhonda Spiegel, executive director of the association's California Central Coast Chapter. "I think it gave the American people permission to talk about it."

At UC Santa Barbara, Dr. Ken Kosik uses stem cells - some from embryos, some converted from skin cells - to create aspects of Alzheimer's in a Petri dish.

After her husband was diagnosed, the former first lady jumped into the raging debate over embryonic stem cells. According to a 2002 story in The New York Times, a Republican lawmaker told Reagan adviser Michael Deaver the former president



Nancy and Ronald Reagan, 1964

would not have supported the research.

"Ronald Reagan didn't have to take care of Ronald Reagan for the last 10 years," Deaver said.

Kosik credited the former first lady with tilting public opinion.

"Research is driven by public consciousness," he said. "The public needs to understand the gravity of this problem. Nancy Reagan brought that home."

*Written by Tom Kiskien of the Ventura County Star*

## Tips & Tools: Respite Grants Available

The toll of caring for a loved one suffering from dementia builds up gradually. To help avoid becoming overwhelmed, include as many people as you can in the care of your loved one earlier, rather than later. Respite care can come in different forms:

**In your home:** A friend, other family member, volunteer or paid service can offer companionship, assistance with personal care such as bathing, dressing, laundry and shopping. Skilled care can also be provided at home, such as assistance with administering medication.

**Adult day centers:** These centers offer the person with dementia a safe place to socialize and participate in directed activities. Transportation and meals are often provided.

**Residential facilities:** Options may include an overnight stay, a few days, or a few weeks, allowing the caregiver a chance to take an extended break or vacation.

There are costs involved. Consider asking about financial

assistance, which may come in the form of scholarships, sliding-scales, or government programs.

Respite Care Grants are available to low-income family caregivers in need of respite care for their loved ones with Alzheimer's disease or other forms of dementia. Funds received through our grants are restricted, intended solely to help caregivers obtain a much needed break from caregiving duties.

These grants are made possible by the Mary Oakley Foundation and the Alzheimer's Association California Central Chapter. To find out more about our grants and to learn if your family qualifies, please contact:

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