ALZHEIMER'S ASSOCIATION **Update**

Highlights of Alzheimer's Association news and events of interest to the medical and scientific community.

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Advocacy Forum breaks records, pushes for more research funding and improved access to care for people with Alzheimer's

With 1300 participants, the 2017 Alzheimer's Association Advocacy Forum held March 27–29 in Washington, D.C., was the largest gathering of Alzheimer's advocates in the 29-year history of the Forum. Advocates from all 50 states swarmed Capitol Hill for more than 500 meetings with members of Congress.

During their meetings, advocates asked their members to support increased research funding and cosponsor the Palliative Care and Hospice Education and Training Act (PCHETA) (H.R. 1676/S. 693). Many Association advocates attended a Senate Special Committee on Aging Hearing called "The Arc of Alzheimer's: From Preventing Cognitive Decline in Americans to Assuring Quality Care for those Living with the Disease."

The Forum also included featured remarks from MSNBC anchor and Association Celebrity Champion Richard Lui, who shared his experience as an Alzheimer's caregiver. Political consultant Mike McCurry, former press secretary for the Clinton White House, also addressed the Forum, speaking to advocates about how they can make their messages heard in any environment.

Impact of advocacy

Steven Osgood, member of the Alzheimer's Association National Board of Directors, chaired the Advocacy Forum. "I attended my first Forum in 1993 and have returned many times to be my 'mother's voice,' as I know she would want me to do for her in advocating on behalf of those facing Alzheimer's," said Osgood. "Like many of you, the inspiration for my passion was having a loved one who suffered and ultimately lost their life to the disease. My mother passed away in 1995 after having endured Alzheimer's for 14 years."

"Whether you're a veteran or a newcomer to advocacy, you've seen the power of our collective efforts over the past few years," commented Osgood. "Together, we've accomplished some incredible milestones, from passage of the National Family Caregiver Support Program and expedited access to Social Security Disability Insurance for younger-onset individuals to the National Alzheimer's Project Act (NAPA) and the release of the National Plan to Address Alzheimer's Disease in 2012. The inclusion of the Alzheimer's Accountability Act in 2014's Omnibus Appropriations Bill was another major victory, as was the unprecedented $350 million increase for Alzheimer's research funding at the National Institutes of Health (NIH) for FY2016.

"Following the Forum last year, we saw bipartisan support grow for two of our leading priorities. First, support for the HOPE for Alzheimer's Act grew to 366 cosponsors in Congress, which led the Centers for Medicare & Medicaid Services (CMS) to announce it would begin paying for cognitive and functional assessments and care planning in 2017. For the first time, people living with Alzheimer's will have access to care planning with a medical professional through Medicare. And second, the Senate Appropriations Committee approved our requested $400 million increase for FY2017," noted Osgood. "Our work to encourage Congress to increase federal funding is more important now than ever."

Impact on Capitol Hill

Alzheimer's is the most expensive disease in the country, costing the nation an estimated $259 billion in 2017. As the population ages, these costs will only increase—and a method of treatment that slows or stops the disease must be discovered to slow the financial and emotional toll the disease takes on people living with it and their families.

Congress has recently provided additional funding for Alzheimer's research at the National Institutes of Health (NIH), but the commitment continues to fall far short of the amount experts say is needed. The Alzheimer's Association and its advocates are asking Congress to increase funding for Alzheimer's research by at least an additional $414 million in fiscal year 2018.

With that goal in mind, Carol and Gary Hankins from Newberg, Oregon, awaited a meeting with Sen. Ron Wyden (D-Ore.) and his staff. Carol's mother died of Alzheimer's, and her father was recently diagnosed with dementia. Her work as a volunteer long-term care ombudsman, and Gary's as a psychologist, has heightened their awareness of the myriad challenges surrounding the disease. "Just being here is so inspiring," said Gary. "We can't wait to get back home to continue these efforts."

Sherry Schwarz from McKinney, Texas, has six relatives with Alzheimer's, and her husband recently died from the disease. Clad in a purple cowboy hat, Schwarz emphasized the importance of participating in Hill Day.

"I do this to honor my husband," she said. "We have to be a voice for those who longer have one. I can't imagine not coming to Hill Day. It's so important to share your story."

Schwarz was joined by Charles Assiff, a caregiver who has attended the Advocacy Forum for 13 consecutive years. They spoke to staff in the office of Sen. John Cornyn (R-Texas) about their Alzheimer's experiences and the compelling statistics behind their request for an increased federal commitment to research.

Cindy Harris from Soldotna, Alaska, met with Sen. Lisa Murkowski (R-Alaska). The senator remembered Harris' personal story about losing her mother and aunts to the disease from Harris' visit during the 2016 Advocacy Forum.

Harris, who shared caregiving responsibilities with her siblings until their mother entered a care facility, requested Murkowski's support for PCHETA. Nearly half of people with Alzheimer's and other dementias are receiving hospice care at the time of their deaths; however, less than half of surveyed nursing homes have a palliative care program. PCHETA would increase palliative care and hospice training for health care professionals, launch a national campaign to inform patients and families about the benefits of palliative care, and enhance research on improving palliative care delivery.

Murkowski shared her concerns about adequate caregiver support, especially in rural areas of her state. "Where's the help with respite care?" she asked. "Where's the help for those who have ended their careers to be caregivers? I want to push to look at that."

Senate hearing

Senator Susan Collins (R-Maine), chair of the Special Committee on Aging, began the annual hearing by welcoming advocates and renewing her commitment to the cause. She also spoke about advances made in the fight and how far there still is to go, calling for bipartisan support of the Alzheimer's disease as a national priority.

"We have come a long way in advancing research through more robust funding, yet experts have calculated that we need $2 billion a year in research funding to achieve our goal of preventing and treating Alzheimer's by 2025," Collins said. "We certainly cannot afford to go backward at a time of such great urgency and progress."

Ranking Member Sen. Bob Casey (D-Pa.) reinforced Collins' thoughts. "Despite our progress, our work is far from over, and in some ways, it is just beginning," he said. "Funding is critical. We can't look at the faces in the audience who come here year after year and not insist that more has to be done."

Collins and Casey were joined by Sens. Richard Blumenthal (D-Conn.), Catherine Cortez Masto (D-Nev.), Joe Donnelly (D-Ind.), Deb Fischer (R-Neb.), Kirsten Gillibrand (D-N.Y.), Thom Tillis (R-N.C.) and Elizabeth Warren (D-Mass.).

The panel first heard testimony from journalist, activist and author Maria Shriver, whose father, Sargent Shriver, died of Alzheimer's disease. She recalled testifying about Alzheimer's in front of a senate panel eight years earlier.

"Two years after I testified, my father died of Alzheimer's disease," Shriver said. "And now, I'm back. Back again to testify—and back again to focus your brains on this killer ravaging brains and families across this country."

Shriver emphatically urged the senators to continue their commitment to the fight to end Alzheimer's through increased research funding and the prioritization of care and support for all those affected.

"We must continue to prioritize investments in scientific research to find a disease-modifying treatment and, one day, a cure," Shriver said. "We must support caregivers of those living with Alzheimer's and provide them with the resources they need to provide care for their loved ones. And we must ensure there is a well-trained workforce ready to provide quality care to the increasing number of people living with Alzheimer's and other dementias who will need these services."

The hearing also included testimony from Phyllis Gallagher, Alzheimer's Association advocate and caregiver for her husband; Christopher Callahan, M.D., director of the Indiana University Center for Aging Research; and Kristine Yaffe, M.D., professor of psychiatry, neurology, and epidemiology and vice chair of research in psychiatry at the University of California, San Francisco.

Featured speaker presentation

On the second day of the Forum, Richard Lui shared his experience as an Alzheimer's caregiver. Lui assists his 83-year-old mother in caring for his father, also 83, who is living with Alzheimer's.

"Two years ago, I joined the ranks of the unpaid caregivers," Lui said.

Evenings can be particularly challenging for Lui and his mother, as his father sleeps fitfully, getting up around 30 times every night. Lui said that his father's Alzheimer's has brought them closer in some ways; his father tells Lui he loves him "every 30 minutes," enjoys everything Lui cooks, and laughs at all of his jokes. But being closer also includes "the tough stuff."

"I'm watching my father slowly die in front of me," he said. "At times, I'm overwhelmed with a deep, deep sadness."

To cope, Lui said he recalls experiences such as when he was 9 years old and was being bullied at school. His father said Lui had two choices: continue to be harassed or defend himself. Lui chose the latter.

"As my father struggles, I'm still that 9-year-old kid," Lui said. "I'm ready to fight, but now it's for him."

National Alzheimer's Dinner

The night before the Senate hearing, Maria Shriver received the Alzheimer's Association Lifetime Achievement Award at the National Alzheimer's Dinner. The Lifetime Achievement Award recognizes an individual who has worked