#### 144<sup>TH</sup> ANNUAL MEETING OF THE AMERICAN NEUROLOGICAL ASSOCIATION



OCTOBER 13-15, 2019 · MARRIOTT ST. LOUIS GRAND · ST. LOUIS, MO · 2019.MYANA.ORG

### **For Immediate Release**

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# A Musical Journey with Alzheimer's Disease: Kim Campbell Gives Caregiver Perspective at ANA2019



Photo credit: Robb Cohen Photography

**(ST. LOUIS, MO, October 13, 2019)** — Kim Campbell, Alzheimer's disease (AD) advocate and widow of Grammy Hall of Fame and Award-winning music legend Glen Campbell, recounted both the toll that the disease took on her husband and the musical talent that sustained him.

With a combination of video and stories, Ms. Campbell addressed hundreds of academic neurologists and neuroscientists gathered at the Marriott St Louis Grand for the <u>American Neurological Association's 144<sup>th</sup> Annual Meeting.</u> In a standing-room-only convening, she followed groundbreaking science presented in the <u>Presidential Symposium</u> on "Dominantly

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Inherited and Late-Onset Alzheimer's Disease," offering the caregiver perspective. Ms. Campbell described the insights gained during her family's extraordinary journey, as her husband of 34 years defied the limitations of his Alzheimer's diagnosis by traveling across America on a Farewell Tour, documented in the acclaimed 2014 documentary <u>Glen Campbell: I'll Be Me</u>.

"We started out aiming to do a five-week tour, and I was so afraid that people wouldn't want to see the show," Ms. Campbell said. "But was the opposite. It was completely sold out, standing room only, they were just cheering for him and rooting for him. He was enjoying it so much, making music and being with his family on the road. Instead of five weeks it was a year and a half." Doctors said that his music and touring probably helped delay the progression of his disease, she added.

"We got Glen into the studio, and he had never painted in his life, and he painted and had a great time. People with Alzheimer's disease can still learn new things."

Her husband became "childlike" in many ways in the middle stages of his disease, Ms. Campbell said. "Every sunset he saw was the most beautiful sunset he'd ever seen in his life. Every hamburger he ate was the best he'd ever tasted."

Sometimes, those childlike moments were devastating. Ms. Campbell described a moment on tour in which she stopped Glen from buying an unneeded bottle of Pepto-Bismol at a gift shop. She later discovered that it had been



intended as a Mother's Day present for her, because, he'd said, "Kim loves pink." When she found out, "It broke my heart in two. I missed a chance for him to show his love for me. I urge caregivers to take the time to find out what your loved one is thinking so that you don't miss a moment."

And people with Alzheimer's can surprise you, Ms. Campbell said. The actress Jane Seymour, who was the executive producer of *I'll Be Me*, is also a painter. "We got Glen into the studio, and he had never painted in his life, and he painted and had a great time. People with Alzheimer's disease can still learn new things," she said.

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In the late stages of the disease, Glen Campbell lost the ability to understand speech or communicate beyond a few repeated phrases. He became erratic, aggressive, and afraid. "I couldn't drive him anywhere because he would try to jump out of the car while I was driving. He'd panic. It was exhausting. It is so depressing to lose someone you love to this disease."

Despite being surrounded by their children, caregiving for Glen began to take a noticeable toll on Ms. Campbell's physical and emotional health. "Forty percent of caregivers die before the person they're caring for does," she noted. "It can take years off your life because of the strain, fatigue, and depression." Finally, Glen's physician recommended a memory care community in Nashville, where he lived until his death in 2017 at age 81. "I didn't even know these places existed," Ms. Campbell said. The community provided the kind of care her husband needed, as well as a community of support for the whole family.

Also therapeutic was the launch of a blog, CareLiving.org, with advice for other caregivers. Since then, Ms Campbell has established the <u>Kim & Glen Campbell Foundation</u> for the research of music as medicine; lobbied for additional funding for neurological research at the national level; and became an honorary faculty member of the University of Maryland, Baltimore County's Erickson School, connecting aging services research with industry leaders.

"I am so proud of my husband for inviting filmmakers to document his Farewell Tour, because I think it helped break the stigma of an Alzheimer's diagnosis," Ms. Campbell said. "Hopefully it encourages people who are having cognitive decline to see a neurologist and get checked."

The Presidential Symposium, chaired by ANA President David Holtzman, MD, Professor and Chairman of the Department of Neurology at the Washington University School of Medicine, featured leading researchers sharing new insights on the mechanisms of neurodegeneration underlying Alzheimer's disease; the emerging role of the innate immune system in AD expression; and the use of biomarkers in clinical characterization, as well as their contributions to current therapeutic trials.

A full Q&A interview with Kim Campbell can be found here.

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#### About ANA2019

The 144<sup>th</sup> Annual Meeting of the American Neurological Association (ANA) will be held October 13–15, 2019 at the Marriott St. Louis Grand, with a Pre-Meeting Symposium on October 12 on Brain-Computer Interfaces in Neurological Disease. More than 900 of the nation's top academic neurologists and neuroscientists, as well as students, trainees, and international professionals, will convene to share three days of research at the forefront of neurology and neuroscience. A "Highlights of the Meeting" roundtable will be held for media at 11 a.m. Central on October 15, with option to call in. A detailed Meeting Program is online. Follow the meeting live using #ANA2019 on Twitter @TheNewANA1, on Facebook @AmericanNeurologicalAssociation, or on Instagram @ananeurology.

### **About the American Neurological Association (ANA)**

From advances in stroke and dementia to movement disorders and epilepsy, the American Neurological Association has been at the vanguard of research since 1875 as the premier professional society of academic neurologists and neuroscientists devoted to understanding and treating diseases of the nervous system. Its monthly *Annals of Neurology* is among the world's most prestigious medical journals, and the ANA's *Annals of Clinical and Translational Neurology* is an online-only, open access journal providing rapid dissemination of high-quality, peer-reviewed research related to all areas of neurology. The acclaimed ANA Annual Meeting draws faculty and trainees from the top academic departments across the U.S. and abroad for groundbreaking research, networking, and career development. For more information, visit <a href="https://www.myana.org">www.myana.org</a> or follow @TheNewANA1 on Twitter, @AmericanNeurologicalAssociation on Facebook, or @ananeurology on Instagram.