Robin Williams Film Draws Crowd

On March 5, 2021, viewers from across the United States and throughout the world joined the CU Alzheimer’s and Cognition Center (CUACC) virtually to watch a live showing of the film **SPARK: Robin Williams and his Battle with Lewy Body Dementia**.

**SPARK** is a 45-minute educational documentary about Robin Williams’ experience with undiagnosed Lewy body dementia (LBD) that was adapted from the documentary film **Robin’s Wish**. The Lewy Body Dementia Association (LBDA) and the producers of Robin’s Wish, with the support of Arcadia Pharmaceuticals, created **SPARK** “to promote community and professional awareness and education to those affected by Lewy body dementia.”

Before showing the film, Samantha Holden, MD, a behavioral neurologist from the CUACC who specializes in LBD, gave a brief presentation and provided some background information on topics such as the common symptoms of LBD and the differences between LBD and Alzheimer’s disease.

After watching the documentary, there was a live question and answer session with Dr. Holden together with Evan Plys, PhD, a psychologist at CU, and Karina Drake, MD, a psychiatrist at CU, both of whom specialize in geriatrics.

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SPARK Film Spreads LBD Awareness Worldwide

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and have extensive experience working with LBD patients. The questions, which were submitted prior to the event as well as throughout the presentation and film, covered a variety of topics, such as getting a diagnosis of LBD, medications and treatments, depression and suicidality, and the contents of the film relating to the Williams’ experience.

This was the largest SPARK event hosted so far by the LBDA, with over 450 people in attendance. While many of the attendees were from Colorado, people also tuned in from Florida to Alaska, and from across the globe, including attendees from Ireland, England, the Netherlands, and Canada, among others.

Robin Williams was diagnosed with LBD post-mortem, and the film’s discussion of the struggles he and his wife, Susan Schneider Williams, faced as they tried to determine what was causing Robin’s concerning behaviors in the absence of an accurate diagnosis was profoundly impactful. Susan felt compelled to share their story through films like Robin’s Wish and SPARK to help others who may be in a similar situation. The CUACC is proud to have played a part in sharing this powerful story with so many others.

Investigator Spotlight: Zachary Macchi, MD

Zachary Macchi, MD, is a behavioral neurologist and the Aging and Palliative Care Research Fellow in the Department of Neurology at the University of Colorado Anschutz Medical Campus. He received his medical degree at the University of Kansas and completed his residency and clinical fellowship in neurology here in Colorado.

Dr. Macchi has always been interested in human psychology and behavior, and is especially drawn to understanding how humans behave, perceive the world around them, and react to and interpret their own feelings and experiences. In his undergraduate program and medical school, he became increasingly interested in how brain structure and the makeup of networks and neurotransmitters shape these behaviors.

This led him to pursue training in behavioral neurology and to seek opportunities to work with people experiencing cognitive impairment with different underlying causes and neurodegenerative conditions, such as traumatic brain injuries and dementia.

Dr. Macchi has a strong interest in palliative care, which is an approach to medicine that focuses on enhancing quality of life, easing suffering, and providing support to both the patient and their caregivers and family members. He recognizes that while there may not be treatments or cures for many of the neurodegenerative conditions his patients have, such as Alzheimer’s disease, there are steps that can be taken to help manage the symptoms and behaviors, while supporting the patient and their loved ones.

As a result, Dr. Macchi’s research interests lie in developing ways to manage behaviors and provide support, not only for his patients, but also for their caregivers, while striving to take the patient’s opinions and perspectives into account when developing these practices. He also focuses on the ways in which the disease affects the caregivers and their ability to care for the patient.

Dr. Macchi is building a strong foundation for his research career as he completes his two-year research fellowship with the University, while also continuing to see patients and apply the palliative care approach in his clinical practice at the Memory Disorders Clinic. You can learn more about an ongoing research study focused on palliative care that he is helping to lead at: http://bit.ly/palstudy21
CUACC Phase II Clinical Trial Presents Results

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to the trial were discovered by CUACC researchers through their laboratory and animal research studies. It was a collaborative effort that included biologists, neuroscientists, radiologists, neurologists, and other clinicians, and, most importantly, the research participants themselves.

“We are excited by the new possibilities that this just-completed trial presents.” Dr. Potter said. “We are also very grateful to everyone who contributed to the study, especially to the participants and their family members who were involved in the trial. Without their participation, we would not be presenting to the world the results of a study that indicate a potentially new treatment approach for Alzheimer’s disease.”

While the results are promising, the study was a phase II trial, meaning that it still represents an early stage in the research process. To extend these findings, the CUACC is planning an expanded phase II trial of sargramostim in Alzheimer’s disease, which will have more participants treated over a longer period of time than in the initial trial.

The new phase II trial will be led by Dr. Peter Pressman and has been funded by a Part the Cloud grant from the Alzheimer’s Association, the University of Colorado, the Global Down Syndrome Foundation, and by a large grant recently awarded from the National Institute on Aging.

Want to know more about this trial?

Visit our website for the full press release and access to the journal article, found on the right side of the page under Clinical Trial Updates: https://medschool.cuanschutz.edu/alzheimer

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Give to Research

If you are interested in making a donation to the CU Alzheimer’s and Cognition Center, please contact Carrie Radant Flynn at 303-724-9146.

Interested in a Research Study?

Contact Neurology Research Partners at 303-724-4644 or fill out a research inquiry form at www.cumemoryresearch.org to learn more about our ongoing research studies!