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On World Lewy Body Dementia Day

California nonprofit releases documentary film on YouTube to shed light on Lewy body dementia, second most common dementia after Alzheimer's yet little-known

SAN JOSE, Calif., Jan. 28, 2025 /PRNewswire/ -- Today, the Susan and Charles Berghoff Foundation announced the public release of its award-winning documentary film, *Sue's Story: A Journey with Lewy Body Dementia*, in recognition of World Lewy Body Dementia Day. Affecting an estimated **11 million people worldwide**¹, Lewy body dementia (LBD) is a challenging and fatal neurodegenerative condition that as yet has no cure.



Sue Berghoff

Sue's Story: A Journey with Lewy Body Dementia has been presented in Continuing Medical Education programs offered by Kaiser Permanente and other health systems; in nursing programs offered by University of California, California State University, and California Community College systems; and in community education programs offered by organizations such as AARP.

Now on YouTube, the film centers on Sue Berghoff who was diagnosed with LBD in 2017. As Sue explains in the film, she decided to transform her diagnosis into something positive to help others living with LBD, starting with advocacy. Also in the film: Sue's husband/caregiver Chuck Berghoff; and neurology and neuroscience experts Dr. Kathleen Poston (Stanford Medicine), Dr. Geoffrey Kerchner (Roche), and Dr. Elena Call (Kaiser Permanente).

Lewy body dementia (LBD)² is an umbrella term encompassing two different but related diagnoses: Dementia with Lewy bodies (DLB) and Parkinson's disease dementia (PDD). Historically, LBD has not been sufficiently prioritized, described or supported in research funding; Continuing Medical Education; public health initiatives; or the general media.

The Berghoffs established the Sue Berghoff LBD Research Fellowship at Stanford (2019), formed the **Susan and Charles Berghoff Foundation** (2021), and launched an LBD caregivers support group (2024). *Sue's Story: A Journey with Lewy Body Dementia* won "Best Documentary Film" at the Poppy Jasper International Film Festival (2018).

About LBD

Lewy body dementia is the second most common neurodegenerative dementia, a leading cause of mortality in the U.S. LBD is characterized by cognitive decline, behavioral changes, hallucinations, sleep and movement problems and autonomic system dysfunction. LBD has two diagnoses: Dementia with Lewy bodies (DLB) and Parkinson's disease dementia (PDD). Currently there is no cure for LBD.

About the Susan and Charles Berghoff Foundation

We provide dementia education, funding for research, and caregiving resources for families living with LBD. [Watch the film on YouTube](#). Connect with us online: berghoff-foundation.org, [LinkedIn](#), [Facebook](#) or [Twitter/X](#).

¹Source: [Lewy Body International](#)

²Source: [National Institute of Neurological Disorders and Stroke](#)