



THE LBD DIGEST

Norman Fixel Institute for Neurological Diseases at UF Health

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LBDA Learning Link: LBDAtv

The Lewy Body Dementia Association (LBDA) compiles and creates LBD-related videos to better educate and support the LBD community. Part of this effort includes the creation of the 2023 Community Webinar Series. This series showcases experts who discuss topics like vision changes in LBD, using palliative/comfort care, research priorities of those living with LBD and their carepartners, and how to cope with cognitive challenges. The Lewy Briefs series are summarized educational videos lasting a few minutes.

The most recent Community Webinar video, “You Spoke, We Listened,” presented a summary of results from an online survey the LBDA shared with people living with LBD, current carepartners and former carepartners. The survey spearheaded by the University of Florida asked questions about what they felt were the most important things to research. The speakers shared the top three priorities across all respondents were finding a cure, improving diagnostic testing and figuring out underlying causes. When asked about the impact of LBD symptoms, cognitive changes, cognitive fluctuations and daytime sleepiness/fatigue were ranked as the most bothersome. If you are interested in reading the paper, use the following link: <https://pubmed.ncbi.nlm.nih.gov/36821177/>.

The LBDAtv YouTube channel (<https://www.youtube.com/user/LBDAtv>) also compiles conversations that are great to explore like tips for oral health and basic estate planning. The best part of this YouTube channel is all videos are free to view and are presented by trustworthy sources so you know you are getting the most accurate and up-to-date information.

Identifying Factors Predicting Accurately End-of-Life in Dementia with Lewy Bodies and Promoting Quality End-of-Life Experiences: the PACE-DLB Study: Study recruiting people with moderate to severe dementia with Lewy bodies (DLB). The person with DLB and their caregiver must participate together. Find more information here: <https://ufhealth.org/research-study/pace-dlb>. Call 352-733-3004 or email PACE-DLB@neurology.ufl.edu for more information.

Research
Corner

Visit this website if you are interested in participating in other research studies: <https://lbd.neurology.ufl.edu/participate-in-a-study/>

Meet Our Team: Stacey White, MS



Stacey is a research coordinator with the Alzheimer's Disease Research Center (ADRC). She received a Master of Science degree from Florida Atlantic University and is currently a doctoral candidate at Concordia University. Prior to working for the University of Florida Department of Neurology, Stacey spent 15 years working in the areas of dysphagia and cognitive disorders within the acute care hospital setting. She has presented at several national and international conferences on the subjects. Stacey enjoys being part of the ADRC team and is excited to continue working with those involved in the study.

We hope you have a wonderful
holiday season!

CONTACT US



To contact your UF Health Lewy Body Dementia Support Team call (352) 733-2419 or email us at DLB-support@neurology.ufl.edu.



Are you a caregiver in need of support?

Join our monthly Virtual Lewy Body Dementia Caregiver Support Group!

- Every 4th Friday of the month from 2-3PM
- Connect by telephone:
 - Call the toll-free number
 - +1 (646) 558-8656
 - Input Meeting ID: 540-200-2903
- Connect online:
 - <https://uflphi.zoom.us/j/5402002903>

