



THE LBD DIGEST

Norman Fixel Institute for Neurological Diseases at UF Health

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The LBD Life Lab at the University of Florida

The LBD Life Lab is an interdisciplinary team led by Melissa Armstrong, MD, MSc. This group of faculty, fellows, residents, doctoral students, and study coordinators investigates the spectrum of diseases under the Lewy body umbrella, including dementia with Lewy bodies, mild cognitive impairment due to Lewy body, Parkinson disease, Parkinson disease with mild cognitive impairment, and Parkinson disease dementia. The lab focuses on topics prioritized by individuals with Lewy body dementia and their families, including improved diagnosis, improved interactions with medical teams, quality of life, and end of life experiences. The LBD Life Lab collaborates closely with diverse researchers including neuropsychologists, pharmacists, therapists, imaging (MRI) specialists, and communication specialists.

In order to make the lab's research opportunities more accessible, we created a public website to display these opportunities. The listings include flyers, helpful study details and contact information in case you would like to connect with the study coordinators directly. You can also fill out the "participate in a study" form if you would like to hear general information or would like our staff to reach out.

LBD Life Lab website: <https://lbd.neurology.ufl.edu/>

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.

Multi-Stakeholder Engagement for Interdisciplinary Telehealth in Lewy Body Dementia: Study recruiting people with mild to moderate Lewy body dementia (LBD). The person with DLB and their caregiver must participate together. Find more information here: <https://lbd.neurology.ufl.edu/tele-lbd/>. Call 352-733-2419 or email noheli.bedenfield@neurology.ufl.edu for more information.

Characterizing FLuctuating Cognition EXperiences in Lewy Body Dementias to Improve Care and Research: Study recruiting people with LBD who experience fluctuations. The person with LBD and their caregiver must participate together. Find more information here: https://www.dropbox.com/s/zw6ss8ff5p2199d/FLUX-LBD_Flyer.pdf?dl=0. Call 352-448-8111 or email Tracy.Tholanikunnel@neurology.ufl.edu for more information.

Research Corner

DCCI: What It Is and What They Do

The Dementia Care and Cure Initiative (DCCI) is led by the Florida Department of Elder Affairs. The DCCI connects with Florida's 11 Area Agencies on Aging and 17 Memory Disorder Clinics to engage communities across the state. Each community also has a task force made up of community professionals, like social workers and occupational therapists, who are dedicated to making communities dementia and age-friendly. The goal of each task force is to increase education, awareness and sensitivity to the needs of folks affected by dementia.

The Mid-Florida DCCI Task Force members are community members from the Fixel Institute, the aging agency Elder Options, home care professionals, police officers, behavioral specialists and end-of-life experts. Their multi-disciplinary approach to engaging with the community creates lasting impact. The Task Force also offers free dementia sensitivity training to local businesses and organizations to help make their entire community dementia friendly. The Task Force is currently organizing the 2022 Dementia Resource Expo. These annual events are free to the public and feature educational sessions accompanied by an expo hall where attendees can explore local resources that may be useful to them.

<https://elderaffairs.org/programs-services/bureau-of-elder-rights/>

Be on the lookout for more information which will be sent out through the support group email list.



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>

