



THE LBD DIGEST

Norman Fixel Institute for Neurological Diseases at UF Health

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Understanding Clinical Research, Part 1 - Vocabulary

Whether or not to participate in research is a personal decision. As you decide whether a study is right for you, it can help to know some of the commonly used research vocabulary.

- **Informed Consent/consenting:** Before research can begin, the research team will explain the study in depth. Most research studies will then have you sign the consent form which acknowledges you understand and agree to participate in the study. Feel free to ask questions or discuss participation with trusted friends, family, or healthcare providers.
 - **Electronic consenting (eConsent):** Instead of signing paper forms, some research studies let you agree to participate online through a secure channel.
- **Randomization:** When a study participant is randomly assigned to one of multiple treatment groups
 - Usually neither the participant nor the study investigator know the assignments
- **Placebo:** A pill or treatment that mimics the experimental pill or treatment but has no true effects (“sugar pill”)
 - **Reason to use a placebo:** To be sure that any effects that happen are actually caused by the treatment and not some other factor

This website has a great list of research terms: <https://clinicaltrials.gov/ct2/about-studies/glossary>

Research Corner

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://lbd.neurology.ufl.edu/flux-lbd/>. Call 352-448-8111 or email Tracy.Tholanikunnel@neurology.ufl.edu for more information.

Meet Our Team: Amber Miller, MPH



Amber earned her Masters of Public Health with a concentration in Epidemiology from the University of Florida in 2019, and since then has pursued a career as a research coordinator at the University of Florida. Amber joined the Department of Neurology after graduating in May 2019 as the Brain Health Program Coordinator

and has recently transitioned into one of the two research coordinator roles for the Alzheimer's Disease Research Center (ADRC). In addition to the ADRC, Amber coordinates two other projects related to Mild Cognitive Impairment, Dementia and Successful Aging.

Feel free to connect with Amber to learn more about her research studies by emailing DLB-support@neurology.ufl.edu.

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>

