



THE LBD DIGEST

Norman Fixel Institute for Neurological Diseases at UF Health

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Welcome to Our Inaugural Issue

Melissa Armstrong, MD, MSc, FAAN

I am excited to welcome you to the first edition of our quarterly Lewy body dementia newsletter. In this newsletter, we hope to provide useful local and national resources for living with Lewy body dementia, highlight information from recent support groups, and inform you about research studies looking for participants at the University of Florida. If there's something that you want to see in this space, please let us know!



Support Group Recap

Jacqueline Baron-Lee, PhD gave an informative presentation on Advance Directives during our January Support Group. Advance Directives are written statements of a patient's goals for receiving medical treatment, allowing them to articulate decisions when they cannot make decisions for themselves. They promote person-centered care by allowing the care team to incorporate patients' end-of-life goals into their treatment plan.

These documents also take the stress off of patient, family and healthcare providers by outlining the patient's desires for things such as life-support treatment, pain medications, religious or personal beliefs and practices, where or how to spend their final days or who they would like to designate as a healthcare surrogate. If you need any advice or assistance with filling out these documents for you or your loved one, please contact

Dr. Jacqueline Baron-Lee at jbaronlee@ufl.edu or 352.273.6961.



LBDA Learning Links

The LBDA Lewy Line

The Lewy Body Dementia Association (LBDA) is an organization dedicated to raising awareness of the Lewy body dementias (LBD), supporting people with LBD, their families and caregivers and promoting scientific advances. Their LBDA Lewy Line is a resource for both families and caregivers connecting them with "Lewy Buddies," experienced LBD caregivers, who can share their time and experience, but cannot provide medical advice. They are well-informed individuals who may help you identify information or community resources improving your LBD caregiver journey. You may connect to this resource by: (1) calling and leaving a message at this toll-free access line (800) 539-9767 or (2) emailing support@lbda.org where you may ask questions and connect with a Lewy Buddy.

The direct link to this information is here (<https://www.lbda.org/go/lbd-caregiver-link>).

Research Corner

For more information, please email DLB-support@neurology.ufl.edu

1. **The PRESENCE Study:** The purpose of this research study is to evaluate the safety and efficacy of three doses of the study drug LY3154207 treated for 12 weeks in participants with mild-to-moderate dementia associated with LBD (PDD or DLB). Please find more information [HERE](#).
2. **Implicit and Explicit memory Differences in Patients with Mild Cognitive Impairment (MCI) and Mild Dementia:** The purpose of this research study is to understand how different aspects of thinking abilities are affected in older adults with MCI and dementia due to probable Alzheimer's, Parkinson's, and Dementia due to Lewy Body Disease. Please find more information [HERE](#).
3. **PEACEOFMND: Physical Exercise and Cognitive Engagement Outcomes For Mild Neurocognitive Disorder:** Over the two weeks of the PEACEOFMND study training, participants will engage daily in individual memory compensation training as well as group supportive therapy. In addition, participants will be randomly assigned to 1 of 3 program components: yoga, computer brain fitness or wellness education. Please find more information [HERE](#).
4. **Accurate WiFi-Based Localization of Dementia Patients For Caregiver Support: Phase II** The goal of this study is to fully evaluate the efficacy of the Activlink system by offering localization and wandering status of a dementia patient to improve caregiver quality of life. Please find more information [HERE](#).

Lewy Body Dementia (LBD) affects an estimated **1.4 million** Americans.



LBD is often misdiagnosed as a **mental disorder** or another form of **dementia**.

Did you know?



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!

HOW TO CONNECT:

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