

# 2017 Update

**Bethany Peterson, PhD**  
**Director of Project Management**

# Research Centers of Excellence Program

- **Aims**

- Increase patient access nationwide to experts in the diagnosis and management of LBD, and
- Create a clinical trials-ready network of nationally-recognized research centers for trials in LBD.

- **Coordinating Center**

- PI: Brad Boeve, Mayo Clinic, Rochester, MN



# Nationwide Interest

- 25 applications received
- Review meeting held Sept, 2017
- Public announcement coming soon



# Next Steps

- **Working groups**
  - Clinical Care and Professional Education
  - Community Education and Support
  - Clinical Trial Design
  - Industry Engagement
- **Scientific Oversight Committee**
  - Doug Galasko, MD, chair
- **Planning Meeting**
  - December 14, 2017 in New Orleans, LA



# End of Life Study

- **PI-initiated collaboration**
  - Melissa Armstrong, MD
- **Aims**
  - To understand the experiences of people with dementia with Lewy bodies (DLB) and their families at the end-of-life, and
  - To identify ways that end-of-life care can be improved
- **Features a national online survey and phone interviews**
  - Nearly 900 respondents in 30 days
  - Over 100 volunteered for interviews



# 2018 Educational Conference

## Early Diagnosis: The road to better therapies and LBD care


- May 4, 2018, Philadelphia, PA
- Co-Sponsored by University of Pennsylvania
- Intended for:
  - LBD families
  - Allied healthcare professionals
  - Primary care physicians, hospitalists, general neurologists
- CME and CEs provided



# New LBDA Publication

## Professional Brief: Updated DLB Diagnostic Criteria

- Key changes in the criteria
- Core and supportive clinical features of DLB
- Indicative and supportive biomarkers of DLB
- Criteria for probable and possible DLB
- Exclusion criteria
- Tips for assessing symptoms of DLB in the primary care setting



Professional Brief: New DLB Diagnostic Criteria

In June, 2017 the International Dementia with Lewy Bodies (DLB) Consortium published updated diagnostic criteria for dementia with Lewy bodies in the journal *Neurology*.

Compared to the previous criteria, the new criteria now distinguish between **clinical features** and **diagnostic biomarkers** and provide guidance on how to establish and interpret them to make a DLB diagnosis.

Based on the diagnostic specificity, clinical features are divided into **core** and **supportive** categories and biomarkers are divided up into **indicative** and **supportive** categories. These revised categorizations provide greater weight to those features and biomarkers that are highly associated with the presence of Lewy body pathology.

**KEY CHANGES**

- Biomarkers are divided into the categories 'indicative' and 'supportive.'
- Compared to previous criteria, greater weight is now given to the presence of rapid eye movement (REM) sleep behavior disorder and iodine 123 - metaiodobenzylguanidine (MIBG) myocardial scintigraphy.
- Hypersomnia and hyposmia are new supportive clinical features.

*As DLB is a heterogeneous disorder, this new diagnostic construct allows healthcare providers the ability to diagnose the disease based on the patient's individualized clinical presentation and biomarker profile.*

Reference: (OPEN ACCESS)  
McKeith IG, Boeve BF, Dickson DW, et al. Diagnosis and management of dementia with Lewy bodies: Fourth consensus report of the DLB Consortium. *Neurology*. 2017 Jul 4;89(1):86-100.

Patient Resource:  
Patient Checklist for Diagnostic Symptoms: <http://www.lbda.org/content/lbda-diagnostic-symptoms-checklist>

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