

# Dementia with Lewy Bodies Consortium

<https://www.neurodegenerationresearch.eu/survey/dementia-with-lewy-bodies-consortium-2/>

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### Country

USA

## Title of project or programme

Dementia with Lewy Bodies Consortium

## Source of funding information

NIH (NINDS)

## Total sum awarded (Euro)

€ 5,550,755.96

## Start date of award

30/09/2016

## Total duration of award in years

5

## The project/programme is most relevant to:

Parkinson's disease & PD-related disorders|Alzheimer's disease & other dementias

## Keywords

Lewy Body Dementia, Parkinson Disease, biomarker development, progression marker, Parkinson's Dementia

## Research Abstract

Project Summary It has been estimated that 1.4 million people in the United States suffer from Lewy body dementia (LBD), including both dementia with Lewy bodies (DLB) or Parkinson's disease with dementia (PDD). Patients with LBD suffer from cognitive decline, sometimes linked to Alzheimer's disease (AD), and the motor and behavioral changes seen in Parkinson's

disease (PD). Unfortunately, the diagnosis of LBD can be difficult, particularly in those DLB patients that present with cognitive impairment prior to motor or marked behavioral changes. Biomarkers for LBD are few and their value in diagnosis, prognosis, and for treatment response is limited. Impediments to biomarker development in LBD have included small subject numbers, a lack of systematic patient characterization, and a failure to perform longitudinal follow up with autopsy. Both AD and PD have benefited from a number of large “consortiums” that have advanced research by leveraging the strengths of several groups of research centers to combine efforts with standardized approaches to the study of the disease. One good example is the Alzheimer’s Disease Centers (ADC) program, funded by the National Institute on Aging, where over 30 research centers across the United States have agreed to a standardized approach to the diagnosis and characterization of patients with AD. Other similar programs include the Alzheimer’s Disease Cooperative Study (ADCS), Alzheimer’s Disease Neuroimaging Initiative (ADNI), the National Institute of Neurological Disorders and Stroke (NINDS) Parkinson’s Disease Biomarker Program (PDBP), and the Parkinson’s Progression Marker Initiative (PPMI). Fortunately, the latter two PD programs have included more systematic clinical assessments and collection of biofluids and imaging data relevant to cognition in PD. Recently, a pathology component has been added to the PPMI project. No similar program exists for DLB. The objective of this proposal is to establish a consortium of centers for the study of DLB with a large number of subject enrolled, systematic assessments (compatible with AD and PD programs), collection of biofluids and imaging data, and ultimately autopsy. The DLB consortium (DLBC) would create the necessary foundation for biomarker development and have the secondary benefit of creating an ongoing subject sample available for additional translational and therapeutic studies. We have brought together nine centers with expertise in the Lewy body disorders and with strong connections to the Lewy body dementia research and general community to participate in the DLBC. This group of investigators has collaborated extensively together for many years and will provide the foundation for this much needed resource.

### **Lay Summary**

**Project Narrative** The Lewy body dementias are the second most common cause of dementia in the elderly. Research into this common form of dementia has been hindered by the need for large groups of patients to study in a consistent manner over time. The Dementia with Lewy Body Consortium will address this issue by bringing together a group of experts that will study a large number of patients from across the country over a two to five year period.

### **Further information available at:**

#### **Types:**

Investments > €500k

#### **Member States:**

United States of America

#### **Diseases:**

Alzheimer's disease & other dementias, Parkinson's disease & PD-related disorders

#### **Years:**

2016

#### **Database Categories:**

N/A

**Database Tags:**

N/A