

Increasing Knowledge Sharing Experience Building Hope

Angela Taylor
Director of Programs

Straddling the LBD Fence

LBD families

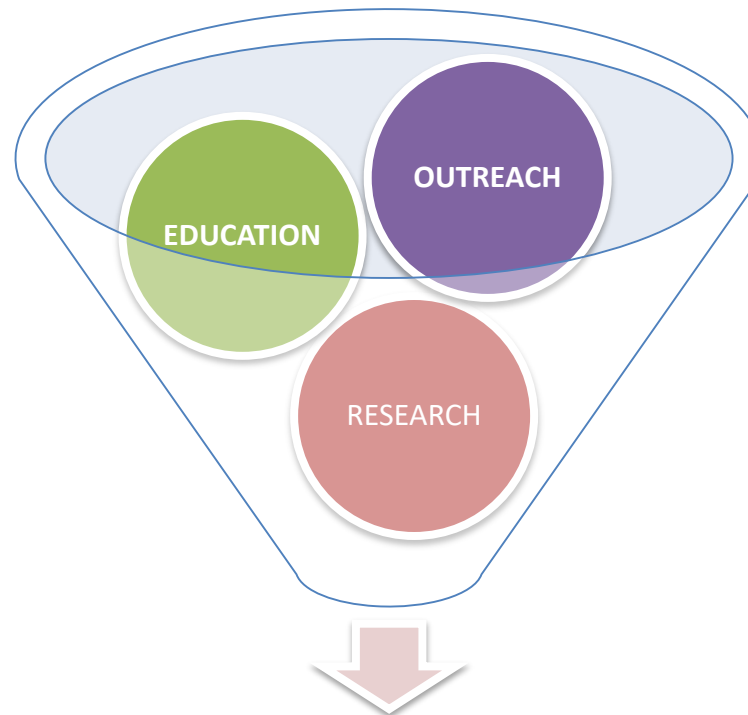


**Alzheimer's
disease**

**Parkinson's
disease**

Lewy body dementia

What We Do



**Reduce the burden on
LBD families**

Family Services

- **Support Resources**
 - **Caregiver Link**
 - Peer to peer support
 - Toll-free: 800-539-9767
 - **Support Groups**
 - Community based
 - Volunteer-driven
 - **Online Communities**
 - Forums, Facebook



Educational Programs



WATCH NOW

**ASK THE EXPERT WEBINAR:
Update on LBD Research –
A Focus on Genetics**

*This event is sponsored by an
unrestricted educational grant from* 



Next Ask the Expert Webinar:
Comprehensive LBD Clinical Care
Featuring Dr. Brad Boeve
Monday, Dec. 5, 2016
3:00-4:00 PM EDT

White Paper: State of the Science

LEWY BODY DEMENTIA: THE STATE OF THE SCIENCE

LBDA
LEWY BODY DEMENTIA
ASSOCIATION

LEWY BODY DEMENTIA THE STATE OF THE SCIENCE

WHITEPAPER BRIEF

Along with the rising tide of Lewy body dementia (LBD) diagnoses and awareness, research is entering an even more unprecedented era of opportunity.

Lewy body dementia is an umbrella term for two diagnoses: "dementia with Lewy bodies" (DLB) and "Parkinson's disease dementia" (PDD). The Lewy Body Dementia Association's report, *Lewy Body Dementia: The State of the Science*, **focuses on DLB**. Dementia with Lewy bodies impairs thinking, movement, behavior, sleep and certain automated processes in the body, such as those controlling heart rate, blood pressure, bladder and gut.

RECENT RESEARCH GAINS

DLB research has been rising steadily over the last 10 years, bringing greater understanding of its prevalence and methods to diagnose and treat the disorder.

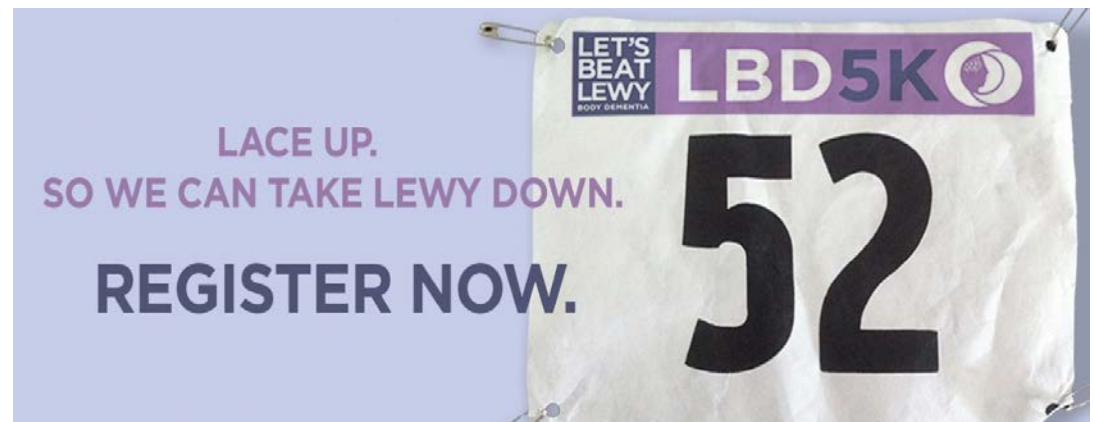
- The recent creation of an LBD research strategy as well as increases in LBD research funding from the National Institutes of Health are the direct result of LBD being included in the National Plan to Address Alzheimer's Disease.
- Autopsy studies suggest that DLB accounts for 10-25% of dementia cases.
- Cutting-edge, brain imaging tests are increasingly being used in academic research settings, such as FDG-PET, SPECT dopamine transporter scan, MIBG cardiac scintigraphy.
- A number of genes that affect the risk of someone developing DLB have been identified, including SNCA, SCARB2, GBA and APOE ϵ 4.
- For the very first time, a governmental regulatory agency approved a drug for the treatment of DLB (Aricept in Japan and the Philippines).

RISE IN RESEARCH ARTICLES INCLUDING THE TERM "DEMENTIA WITH LEWY BODIES"

Source: Medline (PubMed) Search

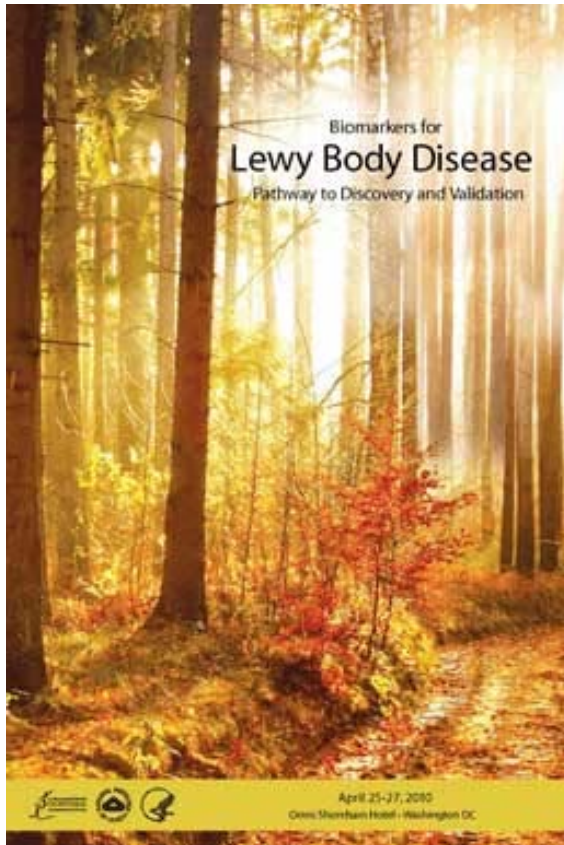
LBDA
LEWY BODY DEMENTIA ASSOCIATION

October is LBD Awareness Month



Meetings and Conferences

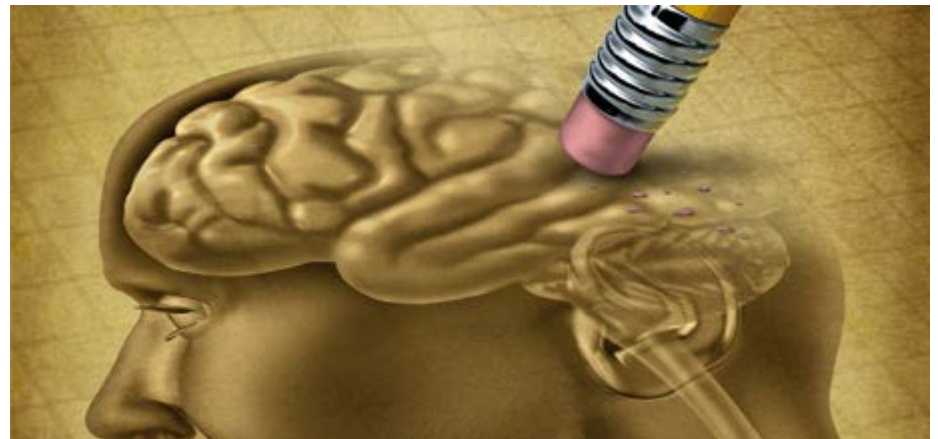
2014: LBD: Current Status, Future Directions
Convened by Cold Spring Harbor Laboratories
Co-chaired by Jim Galvin and Ian McKeith



2010: in collaboration with NINDS
Chaired by Howard Hurtig



2015 International Dementia with Lewy Bodies Conference
co-sponsored with Mayo Clinic; chaired by Brad Boeve



Patient Engagement

- Education on clinical trial participation
- Industry engagement
 - Burden of the disease on LBD families
 - Measures and study protocols
- Informing the LBD community of opportunities to participate in research

DLB Consortium

- **Houston, we have lift-off!!**
 - Funded for 5 years
 - NINDS U01 Grant
 - LBDA (annual consortium meeting)



9 Sites:

Cleveland Clinic*, Drexel, Florida Atlantic, Rush, U. of California/San Diego, U. of North Carolina/Chapel Hill, U. of Pennsylvania, U. of Pittsburgh, VA-Puget Sound/U. of Washington

*Coordinating Center

Consortium Aims

- Collect data on over 200 people with DLB or DLB-MCI
- Centralize data and samples
 - Biofluids and imaging data
 - PDBP biomarker repository
 - Clinical data
 - NACC database



PDBP
Parkinson's Disease
Biomarkers Program



NACC
National Alzheimer's Coordinating Center

- Follow them clinically for 2-5 years
- Perform brain autopsies
- Promote collaboration across consortium sites and with other international DLB consortiums

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