



**Lewy  
Body  
Dementia**  
Association, Inc.

## **More than the Sum of our Parts**

Collaborating with LBDA

Learn more about **LBD** at [lbda.org](http://lbda.org)



# Introductions

Lewy  
Body  
Dementia  
Association, Inc.

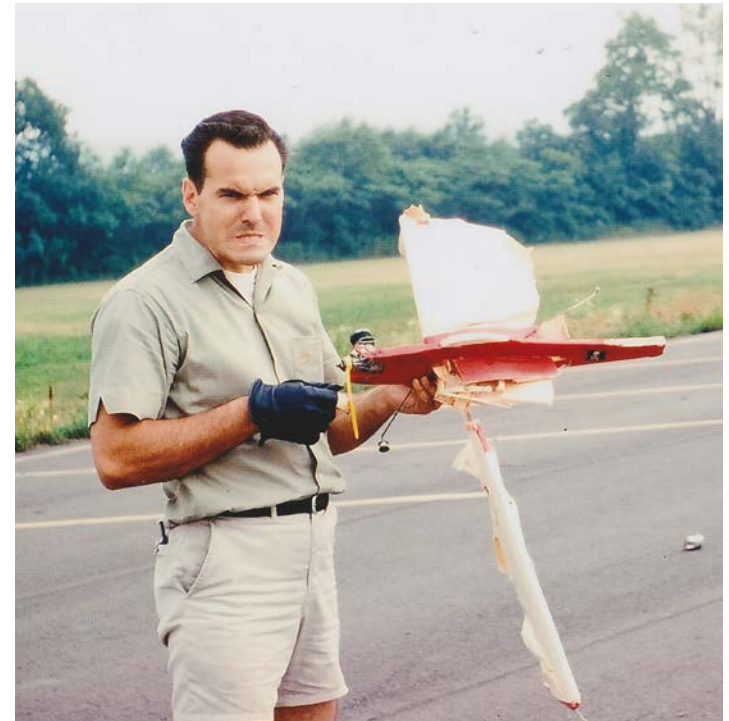
- James E. Galvin, MD, MPH
  - Professor of Neurology and Psychiatry
  - Director of Clinical Operations, Comprehensive Center on Brain Aging and Ed Core Leader/Associate Director, Alzheimer Disease Center at New York University Langone School of Medicine
- Angela Taylor
  - LBD family caregiver
  - President of LBDA Board of Directors, 2005-2007
  - LBDA's Director of Programs since 2008



# This Can Be Fixed

Lewy  
Body  
Dementia  
Association, Inc.

- Misdiagnosis and delays in diagnosis are common.
- Families have to educate healthcare providers
  - Primary care, RNs, emergency room physicians, anesthesiologists, etc.
- Many symptoms go untreated or are mistreated
- No public awareness about LBD leads caregivers to feel isolated





# Help is Available at LBDA

Lewy  
Body  
Dementia  
Association, Inc.



- Family Services
  - Support Groups
  - Caregiver Link
  - Online communities
- Education/Awareness
  - Print and online educational resources
  - LBD Awareness Month
  - Speaker's kit for raising public awareness
  - Campaigns to healthcare providers
- Research Collaborations
  - Guided by LBDA's Scientific Advisory Council



# Mission, Vision and Structure of LBDA

Lewy  
Body  
Dementia  
Association, Inc.

- Vision
  - A cure for Lewy body dementias and quality support for those still living with the disease.
- Mission
  - Through outreach, education and research, we support those affected by Lewy body dementias
- Structure
  - Board of Directors
  - Scientific Advisory Committee
  - Staff
  - Committees
  - LBD Community Discussion Panel



# Mutual Benefits to Families and Scientists

Lewy  
Body  
Dementia  
Association, Inc.

- Collaboration on research, programs
  - Co-branding/cross-promotion
- Public awareness of non-AD dementias
  - Outreach to LBD community
  - Education programming
- Educating Neurologists and Internal Medicine
- Posting medical-scientific advances in LBD
- Interactive Blogs for Caregivers and Patients
- Advocates for those who can't advocate for themselves



# Examples of Research Collaborations

Lewy  
Body  
Dementia  
Association, Inc.

- Co-sponsoring scientific meetings
  - LBD Biomarker Symposium, coordinated jointly with NINDS
    - Over 40 speakers from around the globe
      - Keynote speakers – Bernard Ravina, Dag Aarsland
      - Sessions
        - » Biological Fluids - blood, urine, CSF...
        - » Clinical Markers - neuropsych, sleep, olfaction...
        - » Other Modalities – electrophysiology, genetics, proteomics, pathology,
        - » Neuroimaging - PET, MRI, MIBG
        - » Update from Complimentary Efforts – ADNI, PPMI
        - » Hot Topic Session
- Co-sponsored LBD biomarker pilot grants with ADDF
  - 2010 – one grant of \$125K
  - 2012 – two grants of \$100K each



# Caregiver Research Collaborations

Lewy  
Body  
Dementia  
Association, Inc.

- Two large surveys to explore impact of LBD on patients and caregivers
- **Survey 1:** 962 respondents to explore diagnostic experience and caregiver burden
  - Leggett AN, Zarit SH, Taylor A, Galvin JE. Stress and burden among caregivers of patients with Lewy Body Dementia. *The Gerontologist* 51:76-85, 2011
  - Galvin JE, Duda JE, Kaufer DI, Lippa CF, Taylor A, Zarit SH. Lewy body dementia: The caregiver experience of clinical care. *Parkinson Rel Disord*, 16:388-392, 2010
  - Galvin JE, Duda JE, Kaufer DI, Lippa CF, Taylor A, Zarit SH. Lewy body dementia: Caregiver burden and unmet needs. *Alz Dis Assoc Disord*, 24:177-181, 2010
- **Survey 2:** 736 respondents to examine caregiver grief, quality of life and well-being
  - 4 manuscript under development
  - GSA presentation (Nov 2013)



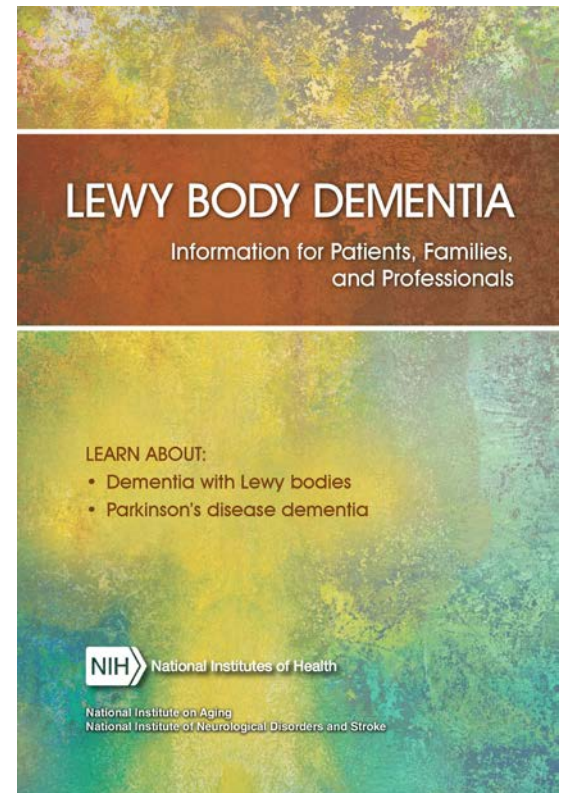


# Other Collaborations

Lewy  
Body  
Dementia  
Association, Inc.

- Webinars featuring expert speakers
  - Research updates, clinical care, caregiving
- Local educational events
  - Collaborating with academia
- Educational resources
  - NEW: Comprehensive symptom checklist

COMING SOON: 40 page booklet  
by UCSD, LBDA, NIA, NINDS





# Join Us in Raising Awareness

Lewy Body Dementia Association, Inc.



Click here to learn more about Lewy Body Dementia

A STARZ ORIGINAL SERIES  
**BOSS**



Lewy Body Dementia Association, Inc.

**A MONTH TO REMEMBER**  
Standing Strong with LBDA

**Stand Strong with LBDA and help make October a Month to Remember**

# Contact Us!

[www.lbda.org](http://www.lbda.org)

Angela Taylor  
Director of Programs  
[ataylor@lbda.org](mailto:ataylor@lbda.org)

Or find us on social media!

