



LSVT Global® Webinar Series

Title: Special Showing of the film SPARK: Robin Williams and his Battle with Lewy Body Dementia

Presenters: Julia Wood, MOT, OTR/L
Jennifer Tuccitto, BS, MPT, GCS
Jessica Galgano, PhD, CCC-SLP

Moderator: Laura Gusè, BSPT, MPT

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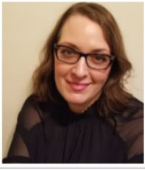
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Special Showing of the film SPARK: Robin Williams and his Battle with Lewy Body Dementia


LSVT GLOBAL Innovation in Science. Integrity in Practice.®

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Panelists



Julia Wood, MOT, OTR/L
LSVT BIG Faculty, LSVT Global, Inc.
Director of Professional and Community Education
Lewy Body Dementia Association



Jennifer Tuccitto, BS, MPT, GCS
LSVT BIG Faculty
Director of Innovation and Communications
LSVT Global, Inc.



Jessica Galgano, PhD, CCC-SLP
LSVT LQUD Faculty
LSVT Global, Inc.
Executive Director
Open Lines Communication

Moderator:
Laura Gusé, MPT
LSVT BIG Faculty & Chief Clinical Officer
LSVT Global, Inc.

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Presenter Biographies

Julia Wood, MOT, OTR/L
Ms. Wood received her Bachelor of Science in Exercise Science and Wellness from Ball State University in 1999 and Master's in Occupational Therapy from the University of Minnesota in 2013. During her career, she has specialized in interdisciplinary treatment of individuals with neurological movement disorders and has served in specialty clinics for patients with atypical Parkinsonism, Huntington's disease, ALS, and those considering Deep Brain Stimulation at a Parkinson's Center of Excellence. Ms. Wood acts as occupational therapy faculty for the Parkinson Foundation's Team Training for Parkinson's program, educating clinicians in interdisciplinary focused, evidence-based evaluation and treatment of individuals with Parkinson's disease. She received her LSVT BIG Certification in 2013 and joined the LSVT BIG faculty in 2018. She also serves on the Parkinson Foundation Rehabilitation Medicine Task Force and on the Comprehensive Care Subcommittee for the World Parkinson's Congress. She was awarded a Parkinson Foundation Community grant in 2021 to provide community engagement programming to address changes to cognition and mood related to PD & LBD. She recently co-authored the AOTA Practice Guideline for People with Parkinson's Disease. She is currently the Director of Professional and Community Education at the Lewy Body Dementia Association.

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Presenter Biographies

Jessica Galgano PhD, CCC-SLP

Dr. Galgano received her doctoral degree in the department of Biobehavioral Sciences from Columbia University in NYC. Dr. Galgano has presented at national and international conferences and has authored and co-authored publications related to neurologic communication and voice disorders. She is a faculty instructor at NYU Langone School of Medicine and is the Executive Director of Open Lines Speech and Communication in NYC, where she provides LSVT LOUD® and other types of therapy to adults and children with a wide variety of speech and language diagnoses. She is also an adjunct professor at San Francisco State University. Dr. Galgano conducted research with Dr. Ramig at Columbia University and is a clinical expert, faculty member and workshop leader for LSVT Global, Inc.

Jenny Tuccitto, MPT, GCS

Ms. Tuccitto received her Master's Degree in Physical Therapy from the College of St. Catherine in Minnesota in 2001 & received her Geriatric Clinical Specialist Certification in 2015. As a physical therapist, she has over 20 years of experience in treating a wide variety of clients with neurological diagnoses with a focus in Parkinson Disease. Ms. Tuccitto has been certified in LSVT BIG since 2009 and part of the LSVT BIG Training and Certification Faculty with LSVT Global since 2011. She now serves as the Director of Innovation and Communications for LSVT Global as well as the LSVT BIG Clinical Expert. She has assisted with the development of many LSVT BIG treatment tools & courses including the LSVT BIG Homework Helper videos, BIG for LIFE training, webinars & LSVT for LIFE. She has presented for the National Parkinson Foundation, the Minnesota Physical Therapy Association, Combined Sections for the American Physical Therapy Association and at the American Speech and Hearing Association on LSVT BIG & Parkinson Disease.

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Disclosures



Non-financial relationships include a preference for LSVT LOUD and LSVT BIG as treatment techniques.

Financial Relationships include:

- Dr. Galgano and Ms. Wood are consultants for LSVT Global, Inc. and receive lecture honorarium.
- Ms. Guse and Ms. Tuccitto are employees of LSVT Global, Inc. and receive lecture honorarium.

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Webinar Logistics

- Microphones muted
- How to ask questions
- Handouts
- Survey
- Continuing Education Units (CEUs)



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Information to Self-Report CE Activity

- Unless otherwise noted, LSVT Global webinars are **NOT** ASHA or state registered for CEUs for speech, physical and occupational therapy professionals, **but they may be used for self-reported CEU credit** as a non-registered/non-preapproved CEU activity.
- If you are a speech, physical, or occupational therapy professional and would like to self-report your activity, e-mail webinars@lsvtglobal.com to request a certificate after completion of the webinar which will include your name, date and duration of the webinar.
- Licensing requirements for CEUs differ by state. Check with your state PT, OT, or Speech licensing board to determine if your state accepts non-ASHA registered or non pre-approved CEU activities.
- Attendance for the full duration (1 hour, 30 minutes) is required to earn a certificate.



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Learning Objectives

Upon conclusion of this webinar, attendees will be able to:

1. Define Lewy body dementia (LBD) and differentiate the 2 types of dementia LBD includes.
2. Identify signs and symptoms of Lewy body dementia and understand the impact of symptoms on functional independence.
3. Name strategies to adapt LSVT BIG® and LSVT LOUD® treatment approaches to enable client centered intervention for people with Lewy body dementia.



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October is Lewy body dementia Awareness Month!

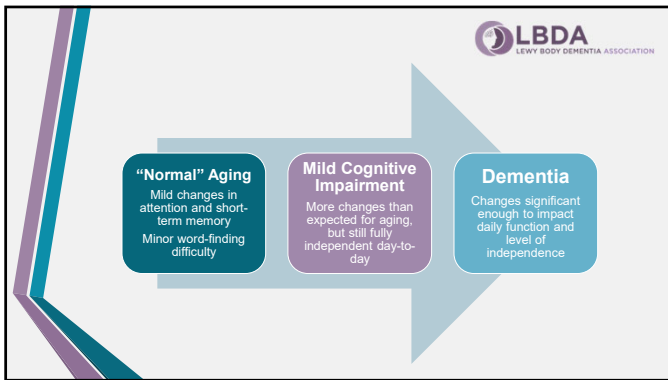
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Thank You

- LSVT Global for the opportunity to offer SPARK and share information about Lewy body dementia
- Laura Guse and Elizabeth Peterson for coordinating this event
- Jenny Tuccitto and Jessica Galgano for sharing your expertise
- Acadia Pharmaceuticals for support of the production of SPARK
- Susan Schneider Williams for sharing her story with us all



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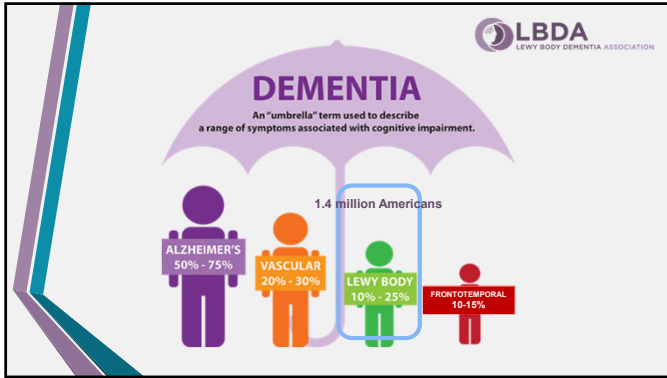
<p>“Normal” Aging</p> <p>Mild changes in attention and short-term memory Minor word-finding difficulty</p>	<p>Mild Cognitive Impairment</p> <p>More changes than expected for aging, but still fully independent day-to-day</p>	<p>Dementia</p> <p>Changes significant enough to impact daily function and level of independence</p>
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Lewy Body Dementia Statistics

LBD is the most misdiagnosed form of dementia	1.4 Million Americans affected, mostly adults over age 50
The second most common cause of progressive dementia after Alzheimer’s disease	Studies indicate that LBD is the most expensive form of dementia

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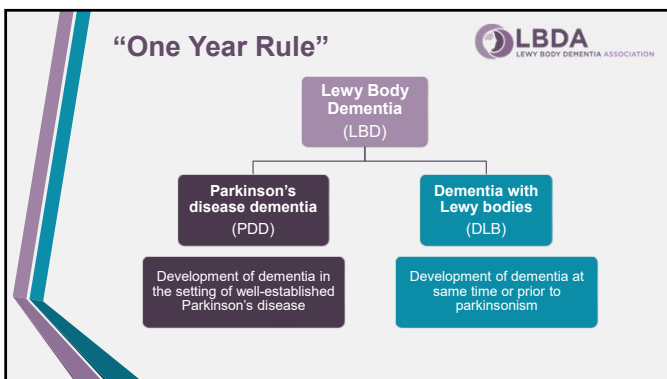


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How Is Lewy Body Dementia Defined?

- A progressive brain disorder
- Features abnormal protein deposits, called **Lewy bodies**, in the brain
- Named after Dr. Friederich Lewy, a neurologist
- Difference in diagnostic criteria based on timing of symptoms with "One year rule"

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How does DLB differ from Parkinson's?

Parkinson's Disease	Dementia with Lewy bodies
<ul style="list-style-type: none"> Always affects movement May have mild changes in thinking at diagnosis May later develop dementia 	<ul style="list-style-type: none"> Always affects cognition Will have one or several other LBD symptoms at diagnosis May not show obvious parkinsonism in early stage

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Fall Risk in DLB

- The onset of recurrent falling is much shorter in DLB than PD
- There is a far greater fall risk and shorter time period from diagnosis to recurrent falls in DLB than AD
- Those with PDD & DLB have an increased falls risk and poorer scores on walking and balance measures than those with AD
- More severe parkinsonism (slowness, stiffness, shakiness) is associated with increased falls in DLB
- Abnormalities in walking and balance are linked with increasing falls risk in DLB

(Joza et al., 2020)

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Dementia with Lewy Bodies

To diagnose someone with DLB, there **must** be enough cognitive decline to impair daily activities, plus **two** of the following features:

Parkinsonism	Visual Hallucinations	REM Behavior Disorder	Cognitive Fluctuations
<ul style="list-style-type: none"> Slowness Stiffness Shakiness 	<ul style="list-style-type: none"> Well-formed, complex visions People and/or animals 	<ul style="list-style-type: none"> Acting out dreams Can occur decades before other symptoms 	<ul style="list-style-type: none"> Changes in level of alertness or arousal "Zoning out"

All of these symptoms can also occur in Parkinson's disease

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Receiving a Diagnosis


66% required at least 3 physicians

50% of diagnoses took 12-18 months

62% of diagnosing physicians were neurologists

Less than 10% diagnosed by primary care providers

78% had been diagnosed with something else first

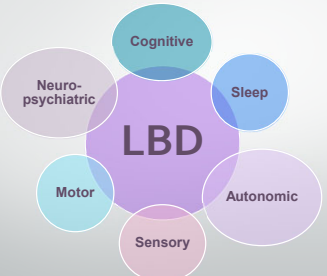


Galvin, James E., et al. "Lewy body dementia: The caregiver experience of clinical care." *Parkinsonism & related disorders* 16.6 (2010): 388-392.

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Clinical Features



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Challenges for LBD Care Partners

- **Cognitive fluctuations** make daily life challenging
- **Symptoms affect more than cognitive abilities**
 - issues walking, mobility, fall risks
 - blood pressure fluctuations, syncope
 - Sleep schedules affected for both individual and carepartner
- **Behavioral symptoms** can start in early stages and be difficult to support
- **Activities of Daily Living (ADLs)** may need support earlier

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Current Treatment Strategy

Goal: Improve quality of life

- Many symptoms can be managed or reduced with medications and other therapies
- No treatments currently available to stop LBD disease progression



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Evidence for Therapy

“There are no formal studies evaluating the efficacy of therapy in individuals with DLB, but physical therapy, occupational therapy, speech therapy, and swallow evaluations are likely beneficial clinically for helping mobility, addressing fall risk and fall prevention, identifying helpful resources to assist function (e.g. shower bars, commodes, and bed rails), and addressing dysphagia (swallowing difficulties).”

(Armstrong, 2021)

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Goal-orientated cognitive rehabilitation for dementias associated with Parkinson's disease—A pilot randomized controlled trial

(Hindle, Watermeyer, Roberts, Brand, Hoare, Martyr, & Clare, 2018)

Objective: To examine the appropriateness of goal oriented cognitive rehabilitation (CR) for people with dementia associated with Parkinson's disease.

After goal setting, participants were randomized to one of 3 groups:


1. Goal Oriented Cognitive Rehabilitation
2. Relaxation therapy
3. Treatment as usual group

Primary outcomes: Rating of goal attainment and satisfaction with goal attainment.

Secondary outcomes: QOL, mood, cognition, health status, everyday functioning.

Carer ratings: Goal attainment, QOL, and stress levels.

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Results

- At 2 months, cognitive rehab was superior to other groups for both rated goal attainment and satisfaction with goal attainment
- Cognitive rehab was superior to other groups in mood, self-efficacy, social domain of QOL and carer ratings of participant's goal attainment
- At 6 months, improved delayed recall, health status, QOL, and carer rating of goal attainment
- Care partners who participated reported improved QOL, health status and lower stress

(Hindle et al., 2018)

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It Takes a Village

- **Occupational Therapy**
 - Support independence, safety and quality of life.
- **Physical Therapy**
 - Promote mobility, safety and activity
- **Speech Therapy**
 - Facilitate communication and safe swallowing
- **Social Work**
 - Provide resources and support
- **Counseling**
 - Support coping strategies



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About LBDA

www.lbda.org

- The only national organization solely dedicated to Lewy body dementias
- Mission: Through outreach, education and research, we support those affected by Lewy body dementias

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RESEARCH CENTERS OF EXCELLENCE

- Leading research in the fight against LBD- *Lewy Trial Tracker coming soon!*
- Driving Advanced Clinical Trials
- More support for patients, families, and providers

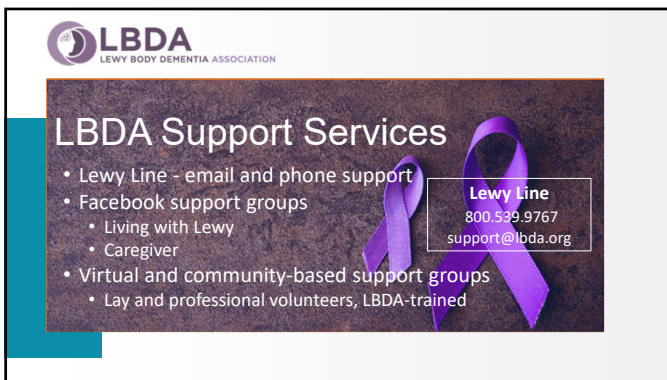
Research Centers Of Excellence

With the Research Centers of Excellence network, the LBDA has identified 22 of the nation's leading RRC clinicians to conduct RRC practice and their families can be recruited for clinical research and treatment. Through our national efforts to increase awareness and education, we hope to increase the number of RRCs and the number of RRCs that are currently conducting RRC research, providing clinical care, research, and support.

Click on the RRC location as indicated by the red pin to find out more information about that RRC site.



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LBDA Support Services

- Lewy Line - email and phone support
- Facebook support groups
 - Living with Lewy
 - Caregiver
- Virtual and community-based support groups
 - Lay and professional volunteers, LBDA-trained

Lewy Line
800.539.9767
support@lbda.org

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Publications



FACING LEWY BODY DEMENTIA TOGETHER
Increasing Knowledge, Sharing Experiences, Building Hope

MEDICAL ALERT CARD
Diagnosing and Managing Lewy Body Dementia
A Comprehensive Guide for Healthcare Professionals


IS IT LEWY?
Recognizing when it's not Alzheimer's or Parkinson's disease

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Join us after the film for a panel discussion with LSVT BIG® & LSVT LOUD® faculty for tips treating individuals with Lewy body dementia.

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How to ask questions

1. Type in the chat box on your control panel
2. Raise your hand!
3. Email info@lsvtglobal.com

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Thank you!




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Please complete the survey that will be e-mailed to you after the webinar.
It will take five minutes or less to complete!

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