



# Duke Dementia Family Support Program


## Caregiver Connections

An Educational Webinar Series with the Experts

The presentation will begin shortly.

[dukefamilysupport.org](http://dukefamilysupport.org)


919-660-7510



# **DEMENTIA BASICS:**

## **An Introduction to Dementia with Lewy Bodies**

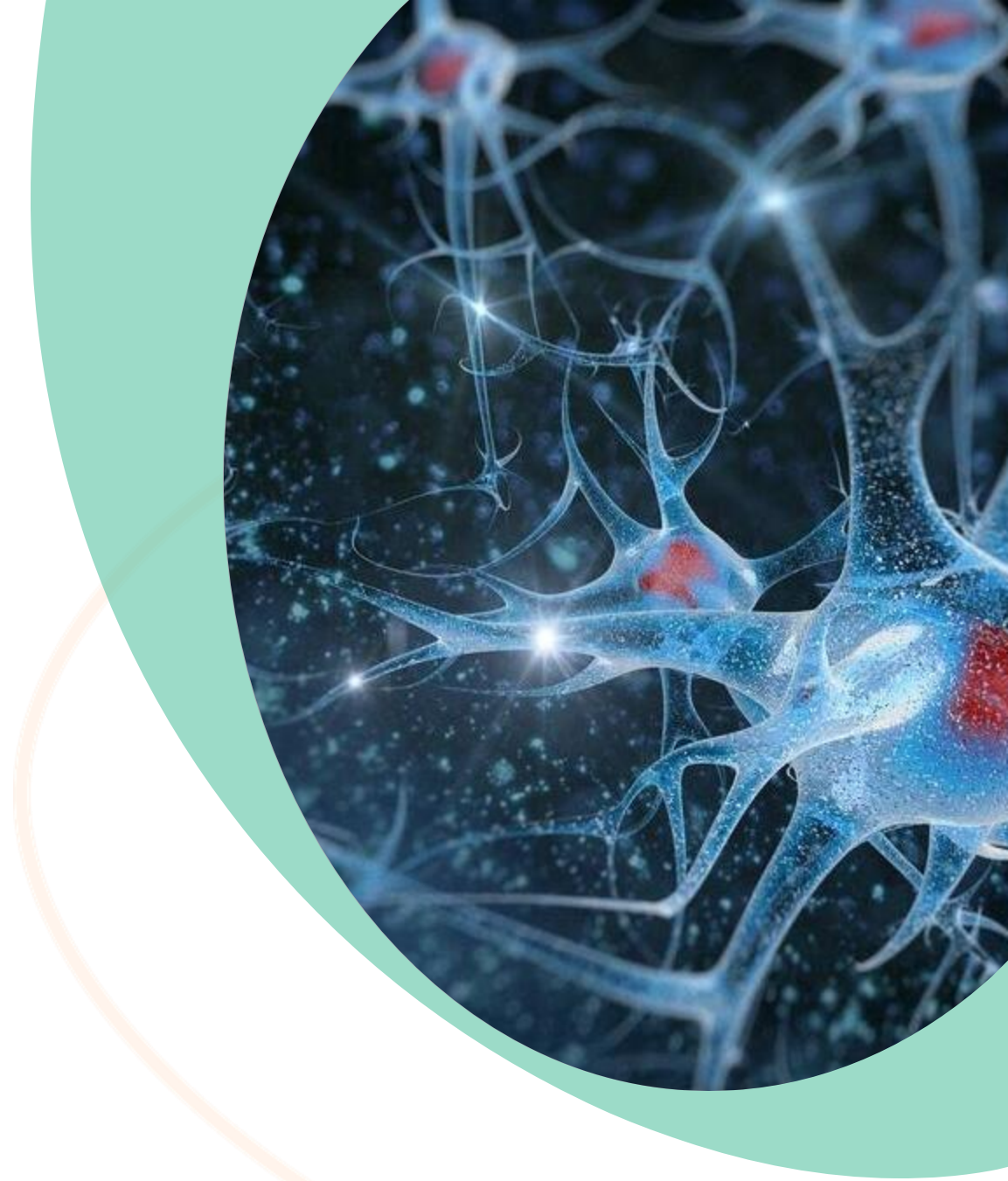
**Presented by: Erin C. Campbell, MS**  
**To: Caregiver Connections**  
**Duke Dementia Family Support Program**  
**April 9, 2025**



## PRESENTATION OVERVIEW

- What is dementia with Lewy bodies (DLB)?
- How is DLB diagnosed?
- How is DLB treated?
- How can patients and caregivers find help?

# WHAT IS DLB?



## DEMENTIA WITH LEWY BODIES (DLB)

- A neurodegenerative disease classified as a synucleinopathy.
- 2<sup>nd</sup> most common form of degenerative dementia worldwide.
- Has many symptoms, some of which are treatable.
- Traditional antipsychotic medications are often contraindicated.
- Early and accurate diagnosis is key to improved quality of life.
- Has no known “root” cause and no cure.
- DLB is one presentation of Lewy body disease.

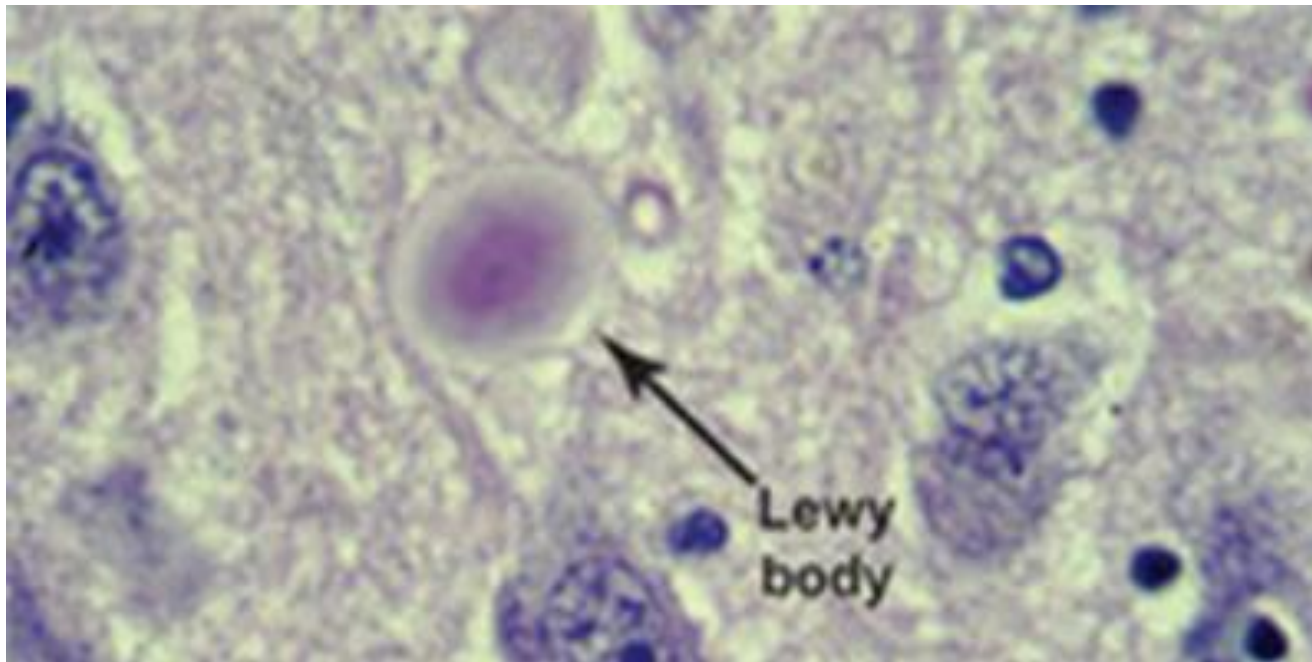
# FREDERIC LEWEY (formerly Frederick Lewy)

- 1912-1914: Worked in Alois Alzheimer's laboratory.
- 1912: First described "inclusion bodies" (now known as "Lewy bodies") in the brains of patients with Parkinson's disease.
- 1918: WWI forced Dr. Lewey to become a military medical officer for the German army.
- 1933: Forced to flee Germany because of his Jewish heritage.
- 1940: Became a U.S. citizen and changed his surname from "Lewy" to "Lewey." He served in the United States Army Medical Corps until WWII ended.
- 1947: Became a Professor of Neuropathology at the University of Pennsylvania.

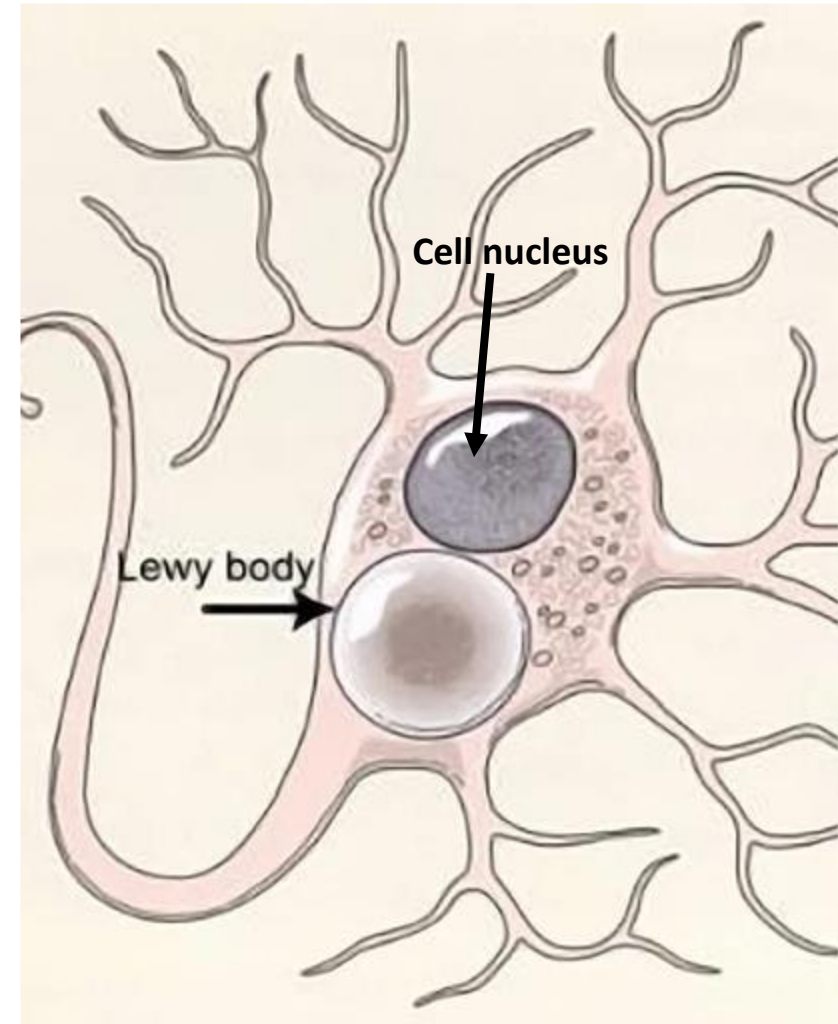


Dr. Lewey  
1885–1950

## AN INCLUSION BODY (LEWY BODY)

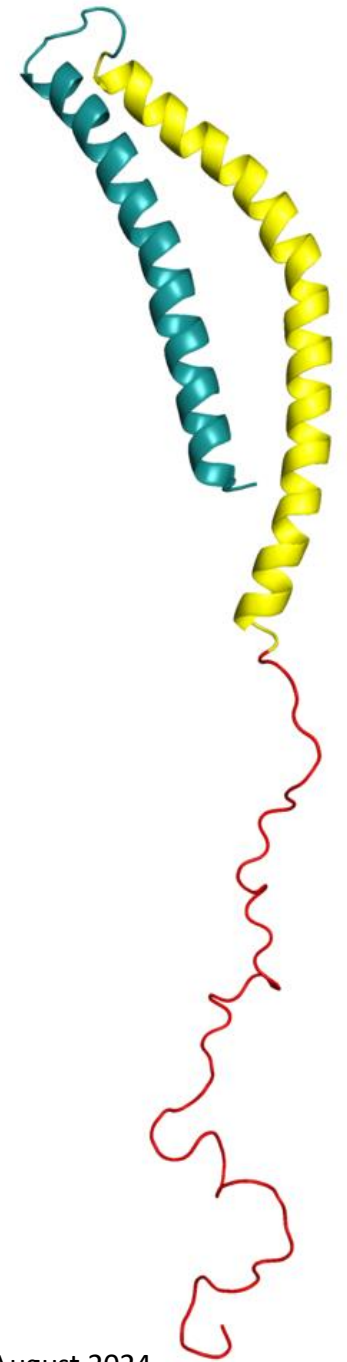


Alzheimer's Association. About dementia with Lewy bodies. Available at: <https://www.alz.org/alzheimers-dementia/what-is-dementia/types-of-dementia/dementia-with-lewy-bodies>. Accessed August 2024.



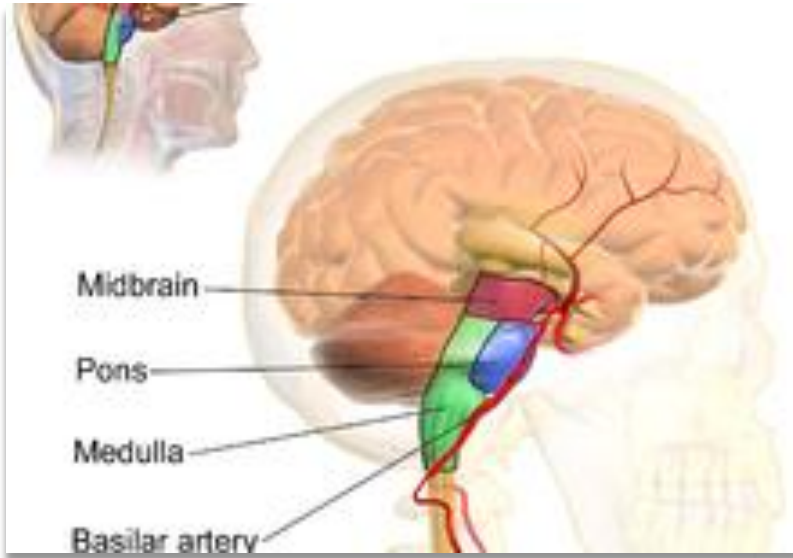
# ALPHA-SYNUCLEIN PROTEIN

- Exists naturally and is found in abundance in a healthy brain, as well as the heart, peripheral muscles, and other tissues.
- Main role: Controls neurotransmitter release.
- The existence of alpha-synuclein is not the problem: The problem is when it starts to abnormally clump.
- Why this protein clumps in synucleinopathy-related diseases like DLB is unknown.



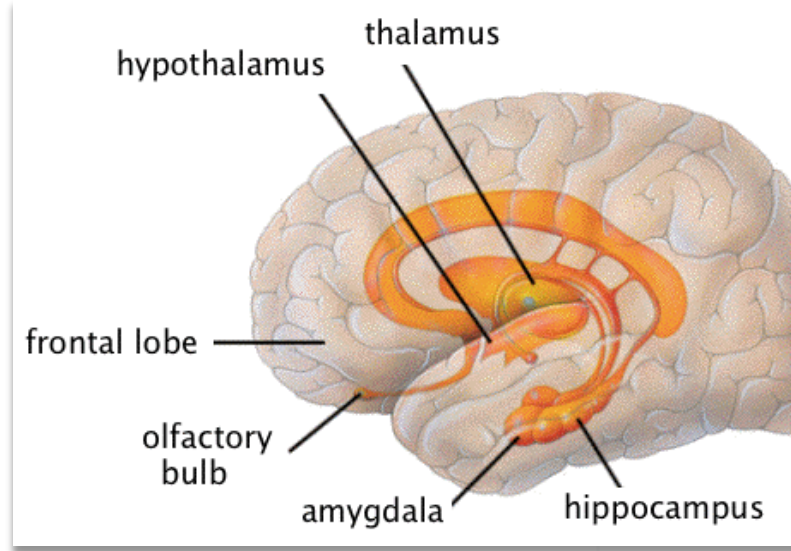


# PARTS OF THE BRAIN ASSOCIATED WITH DLB



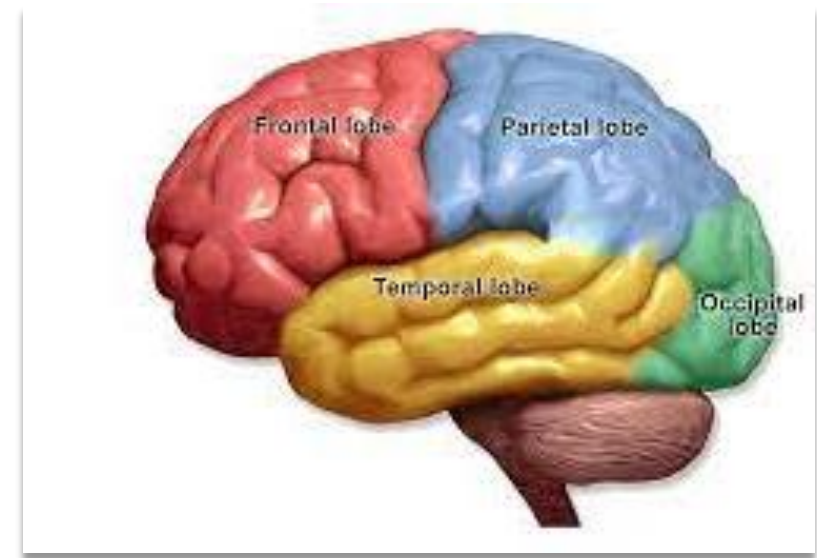
## Brainstem

- Movement control
- Blood pressure control
- Sleep/wake cycle control
- Paralysis during dream sleep
- Alertness/arousal



## Limbic

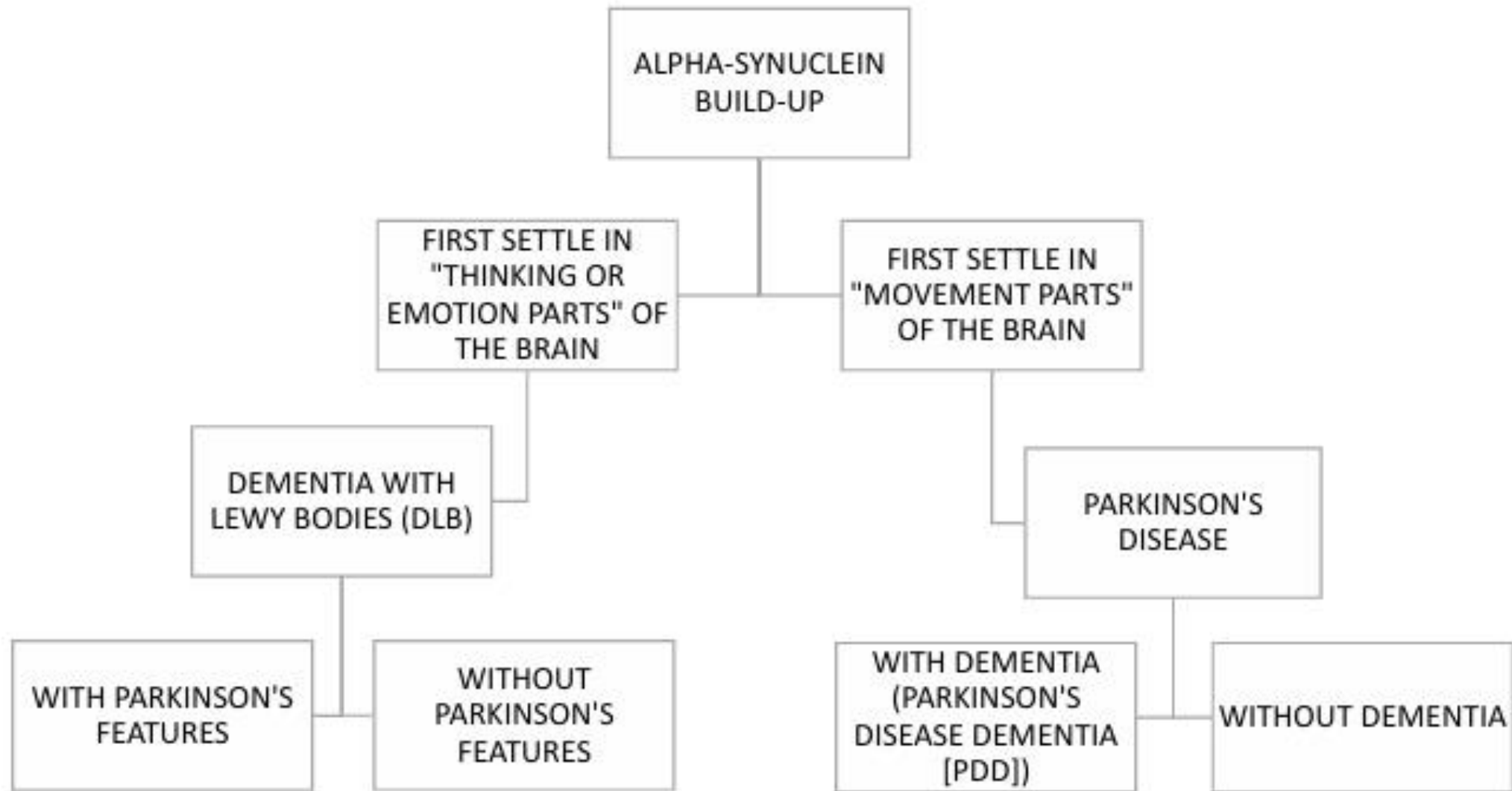
- Emotional control
- Mood control
- Sense of smell
- Reality testing



## Cortical

- Visual and spatial processing
- Judgement, reasoning
- Multitasking, attention regulation
- Memory
- Language

# LEWY BODY DISEASE

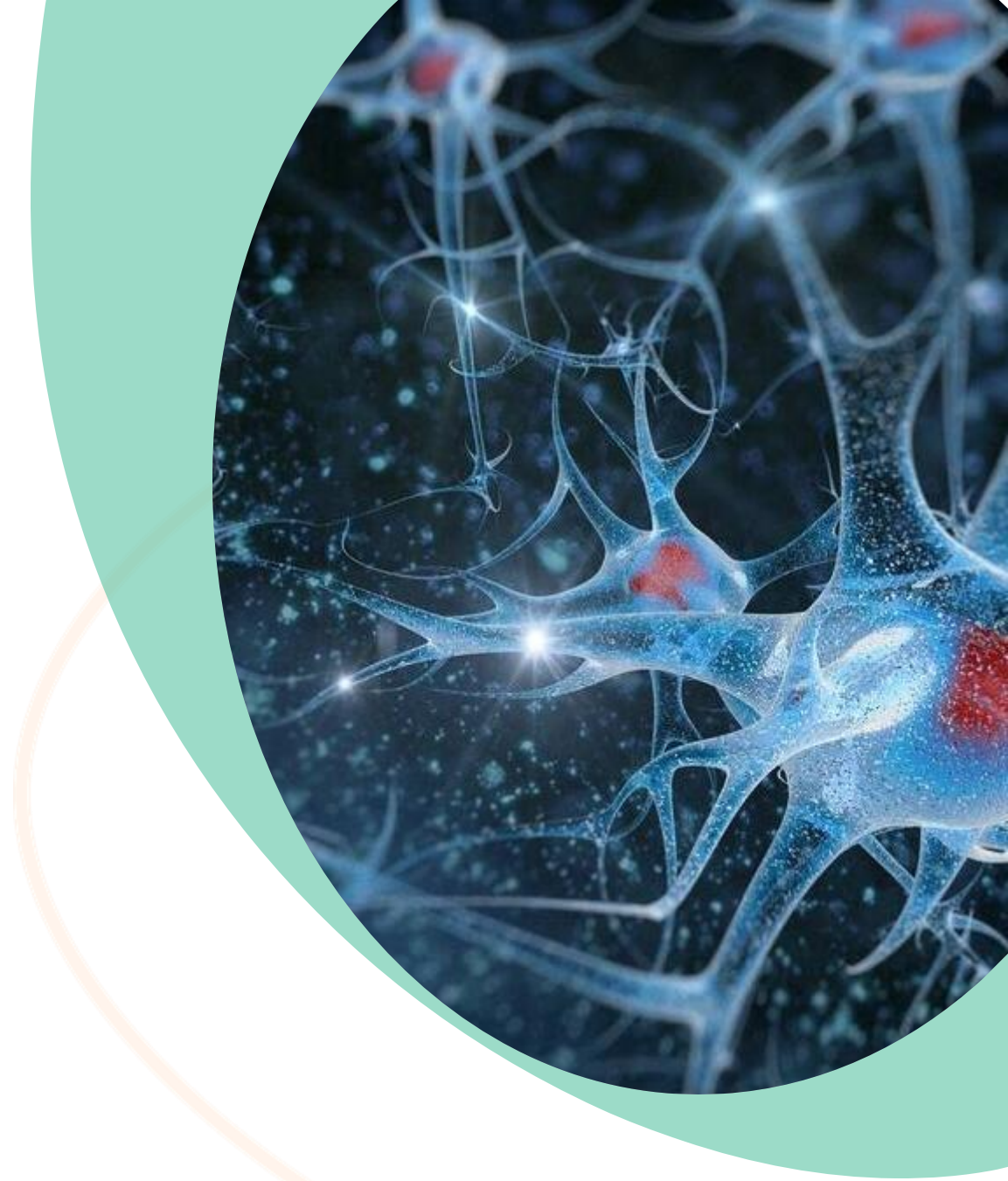


VARIABLES	DLB	ALZHEIMER'S
<b>Prevalence (United States)</b>	<ul style="list-style-type: none"> <li>• 1.4 million (diagnosed)</li> </ul>	<ul style="list-style-type: none"> <li>• 7 million (diagnosed)</li> </ul>
<b>Males vs. females</b>	<ul style="list-style-type: none"> <li>• 80% vs. 20%</li> </ul>	<ul style="list-style-type: none"> <li>• 25% vs. 75%</li> </ul>
<b>Underlying cause(s)</b>	<ul style="list-style-type: none"> <li>• Unknown</li> </ul>	<ul style="list-style-type: none"> <li>• Suspect combo of genetics, environment, and lifestyle</li> </ul>
<b>Protein that misfolds</b>	<ul style="list-style-type: none"> <li>• Alpha-synuclein</li> </ul>	<ul style="list-style-type: none"> <li>• Beta-amyloid</li> <li>• Tau</li> </ul>
<b>Cognition</b>	<ul style="list-style-type: none"> <li>• True memory loss: usually minimal</li> <li>• Increasing confusion</li> <li>• Frequent fluctuations in alertness</li> <li>• “Executive functioning” challenges: <ul style="list-style-type: none"> <li>○ Reasoning</li> <li>○ Judgment</li> <li>○ Planning</li> <li>○ Problem-solving</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• Significant memory loss early and increasing over time</li> <li>• Language difficulties</li> </ul>
<b>Recognition (people/faces)</b>	<ul style="list-style-type: none"> <li>• Remains mostly intact</li> </ul>	<ul style="list-style-type: none"> <li>• Fades as the disease progresses</li> </ul>
<b>Awareness</b>	<ul style="list-style-type: none"> <li>• Remains mostly intact</li> </ul>	<ul style="list-style-type: none"> <li>• Fades as the disease progresses</li> </ul>
<b>Hallucinations</b>	<ul style="list-style-type: none"> <li>• ~80% have hallucinations, EARLY in the disease process</li> </ul>	<ul style="list-style-type: none"> <li>• ~20% have hallucinations, typically LATER in the disease process</li> </ul>
<b>Movement</b>	<ul style="list-style-type: none"> <li>• Rigidity</li> <li>• Muscle stiffness</li> <li>• Tremors</li> <li>• Frequent falls</li> </ul>	<ul style="list-style-type: none"> <li>• Spatial awareness issues</li> </ul>
<b>Smell</b>	<ul style="list-style-type: none"> <li>• Permanent or partial loss of smell</li> </ul>	<ul style="list-style-type: none"> <li>• n/a</li> </ul>

## MIXED DLB AND ALZHEIMER'S DISEASE

- 33–50% of carefully clinically diagnosed Alzheimer's disease patients show some degree of DLB pathology upon autopsy.
- 50% of Lewy body disease patients have at least some Alzheimer's pathology.
- Patients with mixed DLB and Alzheimer's generally have more severe disease and shorter survival, but this is dependent upon the extent of each pathology in the brain.

# HOW IS DLB DIAGNOSED?



## CORE CLINICAL FEATURES

- Fluctuating cognition with variations in attention and alertness
- Recurrent visual hallucinations
- REM sleep behavior disorder
- One or more spontaneous cardinal features of Parkinsonism (slowness of movement, resting tremor, or rigidity).

## SUPPORTIVE CLINICAL FEATURES

- Severe sensitivity to antipsychotics
- Postural instability
- Repeated falls
- Transient episodes of unresponsiveness
- Severe autonomic dysfunction (e.g., constipation, blood pressure fluctuations, urinary incontinence)
- Reduced or complete loss of smell
- Excessive daytime sleepiness
- Systematized delusions
- Apathy
- Anxiety
- Depression

## INDICATIVE BIOMARKERS (per 2017 DLB GUIDELINES):

- Reduced dopamine transporter uptake in basal ganglia (on SPECT or PET imaging)
- Abnormal iodine-MIBG myocardial scintigraphy (imaging test)
- Polysomnographic confirmation of REM sleep without atonia

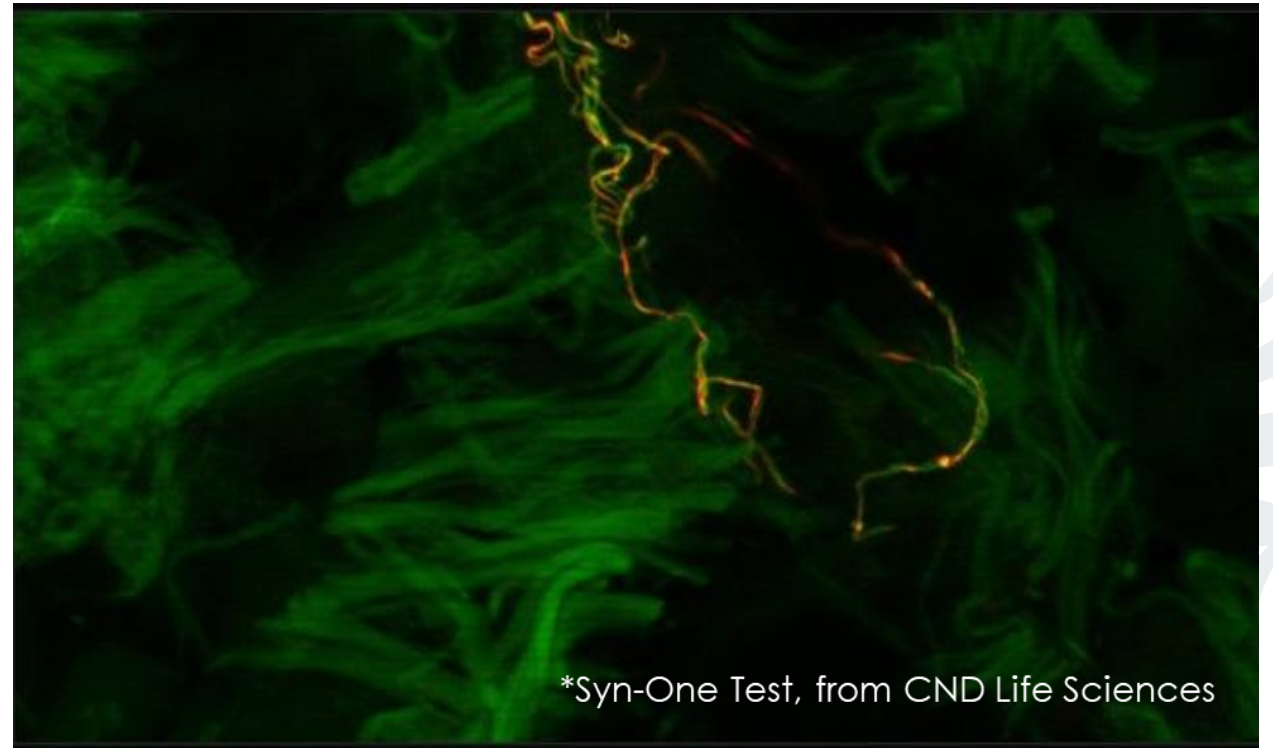
## PROBABLE DIAGNOSIS OF DLB IF:

1. Two or more clinical features of DLB are present, with or without the presence of indicative biomarkers; OR
2. Only one core clinical feature is present, but with one or more indicative biomarkers.



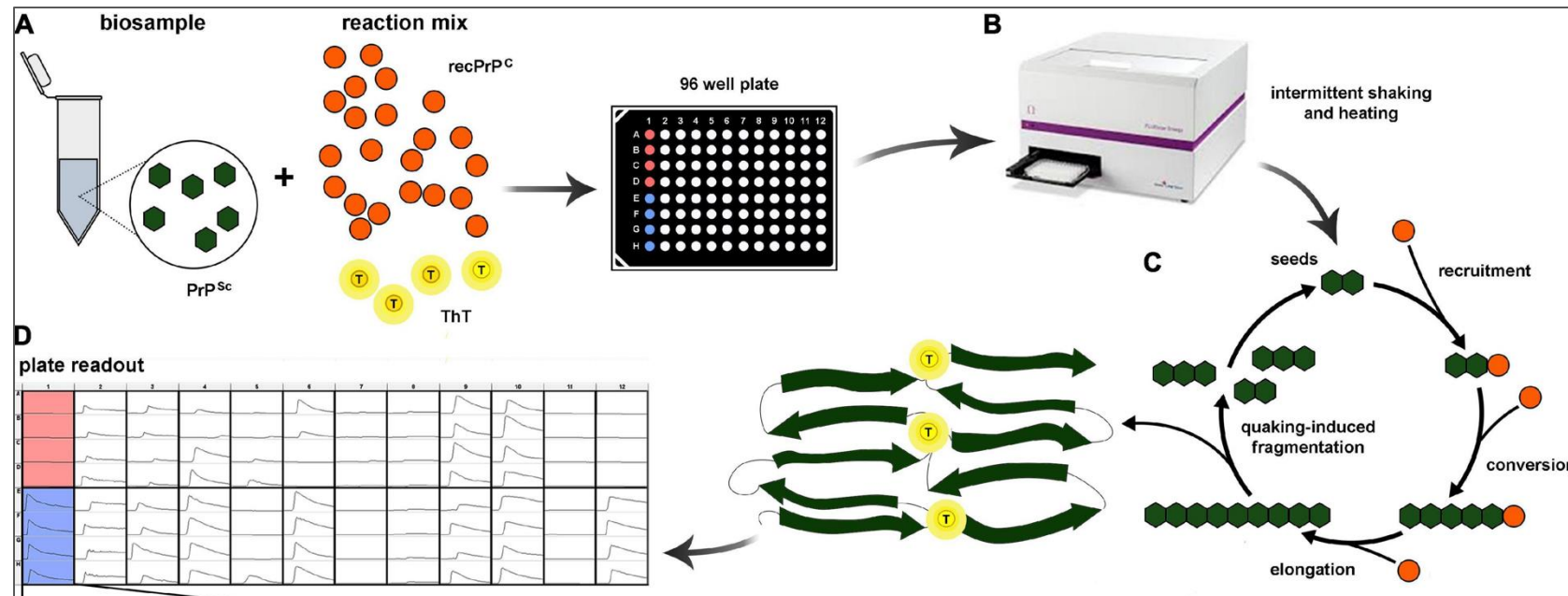
# NEW DIAGNOSTIC METHODS THAT DETECT ABNORMAL ALPHA-SYNUCLEIN: SKIN BIOPSY

- Syn-One Test (from **CND Life Sciences**)
- Detect and visualize abnormal alpha-synuclein in skin nerve fibers by immunofluorescence with 96% accuracy.
- Skin punch biopsy from 3 sites: neck, upper calf, and ankle (minimally invasive).
- Covered by Medicare.
- Patient Access Team:  
[patientaccess@cndlifesciences.com](mailto:patientaccess@cndlifesciences.com)  
480-569-2900 (ext. 2)

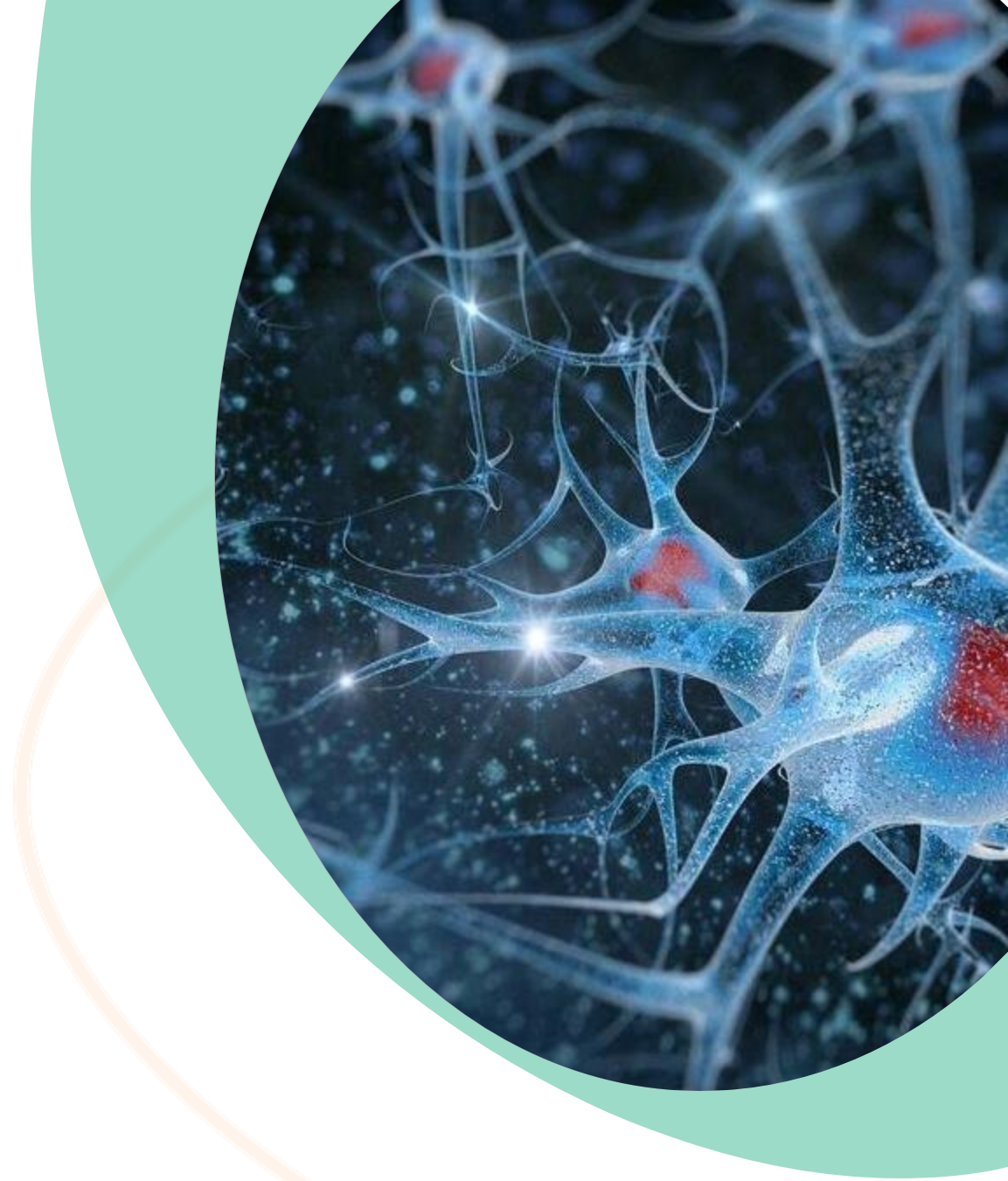


# NEW DIAGNOSTIC METHODS THAT DETECT ABNORMAL ALPHA-SYNUCLEIN: SYNTap CEREBROSPINAL FLUID TEST

- Not covered by Medicare yet
- Lumbar puncture (spinal tap)
- Detect and visualize abnormal alpha-synuclein by real-time quaking-induced conversion (RT-QuIC) and immunofluorescence



# HOW IS DLB TREATED?



# PHARMACOLOGIC INTERVENTIONS: MEDICATIONS THAT MAY HELP

May Help	Generic Name	Brand Name(s)
Cognition/behavior/mood	Donepezil	Aricept
	Rivastigmine	Exelon
Movement	Carbidopa-levodopa	Sinemet, Sinemet CR, Rytary, Duopa
Psychosis	Quetiapine	Seroquel, Seroquel XR
	Clozapine	Versacloz, FazaClo, Clozaril
	Brexpiprazole	Rexulti
	Pimavanserin	Nuplazid

# PHARMACOLOGIC INTERVENTIONS: MEDICATIONS THAT MAY HARM

**ADDITIONAL CAUTION:**  
*Be wary of anesthetics and drugs used in surgery.*

Generic Name	Brand Name(s)
Diphenhydramine*	Benadryl
Lorazepam	Ativan
Pramipexole	Mirapex
Diazepam	Valium
Alprazolam	Xanax
Haloperidol	Haldol Decanoate
Chlorpromazine	Thorazine
Fluphenazine	Prolixin
Loxapine	Loxitane
Thiothixene	Navane
Trifluoperazine	Stelazine
Risperidone	Risperdal
Amitriptyline	-
Amoxapine	-
Desipramine	Norpramin
Doxepin	
Imipramine	Tofranil
Nortriptyline	Pamelor
Protriptyline	-
Trimipramine	-
*Other over-the-counter medications contain this ingredient	

# DIET AND NUTRITION

## DO: THE MIND DIET

- Legumes
- Whole grains
- Nuts
- Fish
- Diverse fruits and vegetables
- Fats from plants rather than animals
- Low added sugars and salt
- Wine (one 5-oz glass per day)

## AVOID: ULTRA-PROCESSED FOODS

- Packaged snacks
- Cereal
- Energy/granola bars
- Fast food
- Candy
- Instant foods
- Deli cold cuts
- Store-bought bread

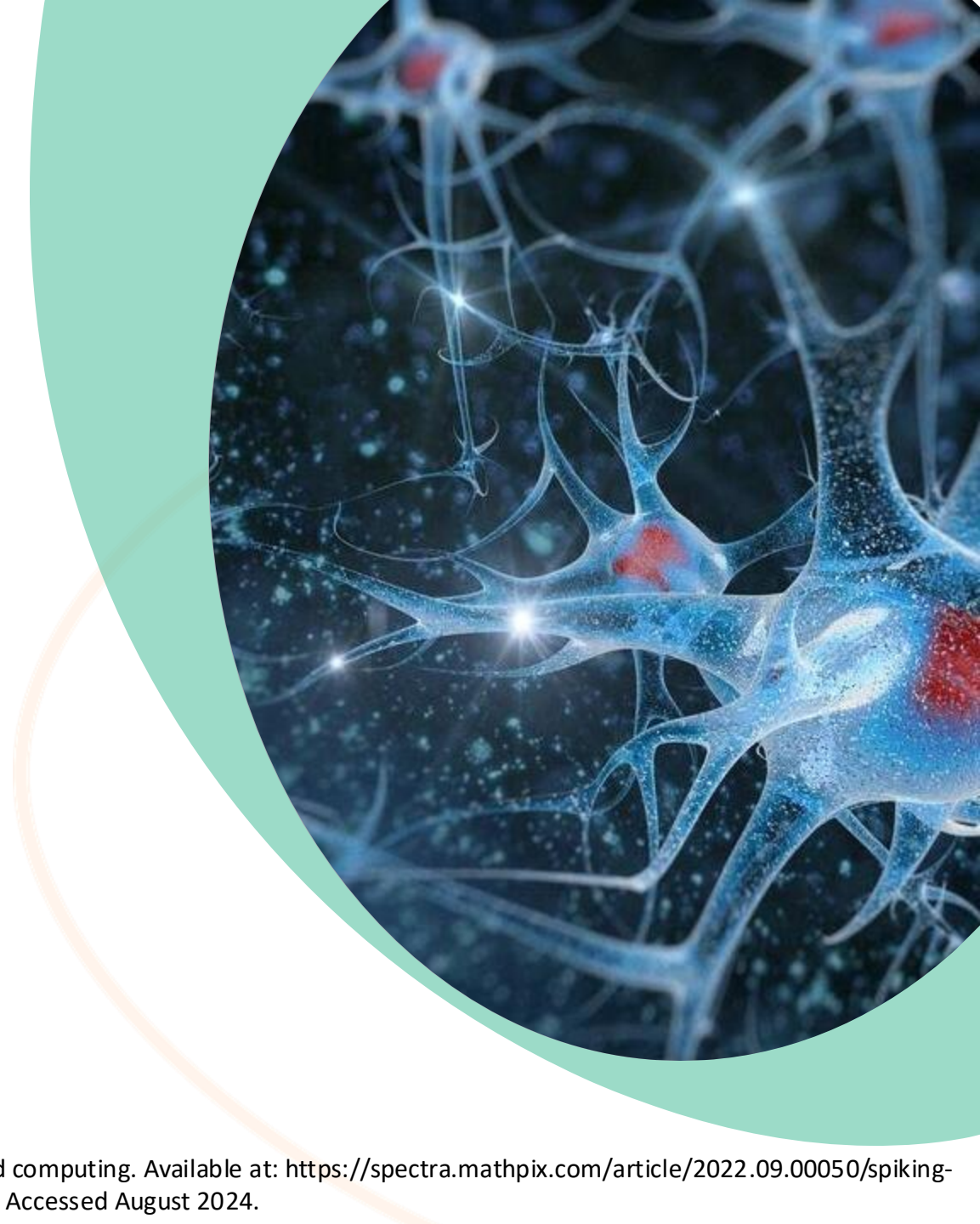
# PHYSICAL, MENTAL, AND SOCIAL

- Physical/movement therapy (e.g., walking, dancing, yoga, tai chi)
- Speech therapy
- Occupational therapy
- Mental health counseling
- Expressive art therapists
- Music and aroma therapy
- Routines are key
- Time with people you love
- **IF YOU ARE ABLE, DO WHAT BRINGS YOU JOY**

**Music imprints itself on the brain deeper than any other human experience. Music evokes emotion and emotion can bring with it memory. Music brings back the feeling of life when nothing else can.**

**- Dr. Oliver Sacks**

# RESOURCES FOR PATIENTS AND CAREGIVERS







# SUPPORT AND EDUCATIONAL OPPORTUNITIES



# ONE LOCAL SUPPORT GROUP: PAT SNYDER

Email: [patsnyder137@gmail.com](mailto:patsnyder137@gmail.com)

- Teacher for the Wake Forest Dementia Caregiver Class (in-person and Zoom)
- Moderator of LBD Caring Spouses:  
<https://groups.io/g/LBDCaringSpouses>
- Author of *Treasures in the Darkness: Extending the Early Stage of Lewy Body Dementia, Alzheimer's, and Parkinson's Disease*: <https://www.amazon.com/Treasures-Darkness-Extending-Alzheimers-Parkinsons/dp/1466428228>
- YouTube Channel:  
<https://www.youtube.com/@patsnyder9144>
- Member of the UNC Cognitive Disorders Clinic Caregiver Support Team
- National & State Caregiver Support Awards Recipient



Photo of Pat Snyder

# Duke Dementia Family Support

## A bridge to understanding your options

Services are free of charge and no affiliation with Duke Health is required. Services are available by phone, email, Zoom or in-person.

### Team can assist with:

- Understanding the basics of dementia
- Identifying necessary steps after a diagnosis
- Discussing strategies for symptom management
- Connecting families to community resources
- Coping with the emotional impact of the disease

### Educational opportunities:

- Caregiver Connections: Live monthly webinars with the experts
- What's Next: Middle-Stage Workshop
- Monthly Triangle Area E-Newsletter
- Memory Makers: Early-Stage Educational Support Group



Photo by Paul D. Jones



**Designed for family caregivers of patients with:**

- Parkinson's disease with cognitive impairment
- Parkinson's disease dementia
- Dementia with Lewy bodies

**Question:**

- Would a caregiver-centered educational intervention improve caregiver knowledge, confidence, strain, and health outcomes?
- In turn, would this type of intervention help the caregiver's patient, as well?

**If interested, please visit:**

<https://www.lbda.org/peer-mentoring-support-and-caregiver-education-persevere/>



# DEMENTIA ORGANIZATIONS





# LBDA

LEWY BODY DEMENTIA ASSOCIATION

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

## Can search by:

- Those Living with LBD
- Caregivers
- Healthcare Professionals
- Donors

## Provide free informational packets (e.g.):

- Understanding behavioral symptoms
- Comprehensive LBD symptom checklist
- NIH booklet
- Treatment summaries
- Medical alert card

## LBD Caregiver Link:

1-800-LEWYSOS (1-800-539-9767)

Email: [lbda@lbda.org](mailto:lbda@lbda.org)



# MEDICAL ALERT WALLET CARD

- Download from: [www.lbda.org](http://www.lbda.org)
- Highlights the 24/7 Lewy Help Line
- Warns about antipsychotic medication interactions
- Lists emergency contact information of loved ones and family physician information
- Encourages identification of possible etiologies causing psychosis



Lewy Line:  
**1-800-LEWYSOS**  
**1-800-539-9767**

*The information on this card is intended for general informational use only. It is not intended to be medical advice or to take the place of competent medical professionals who are familiar with a particular patient's situation. Each individual is advised to make an independent judgment regarding the content and use of this information.*

## MEDICAL ALERT CARD

I have a disorder of the brain known as **LEWY BODY DEMENTIA (LBD)** which could make me appear confused and have difficulty moving or speaking normally.

**Please call my family or my physician!**

*Thank you to the LBDA Scientific Advisory Council for their medical review in the creation of this card.*

©2021 Lewy Body Dementia Association

My name: \_\_\_\_\_  
 Address: \_\_\_\_\_  
 \_\_\_\_\_  
 Person to call: \_\_\_\_\_  
 Address: \_\_\_\_\_  
 \_\_\_\_\_  
 Phone: \_\_\_\_\_  
 Physician: \_\_\_\_\_  
 Phone: \_\_\_\_\_  
 Allergies: \_\_\_\_\_  
 \_\_\_\_\_  
 Other medical conditions: \_\_\_\_\_  
 \_\_\_\_\_

### Emergency treatment of Psychosis in LBD

Psychotic symptoms such as visual hallucinations of people or animals, or misidentifying one's spouse or one's home are common in LBD. The goal of addressing these symptoms, is to ensure the safety of the patient and others.

#### WARNING

Up to 50% of patients with LBD who are treated with any antipsychotic medication may experience severe neuroleptic sensitivity (worsening condition, heavy sedation, increased or possibly irreversible parkinsonism, or symptoms resembling neuroleptic malignant syndrome, which can be fatal).

- 1 Identify possible etiologies of delirium, e.g., pain, infection, metabolic stress, alcohol withdrawal.
- 2 Reduce or eliminate anticholinergic medications, such as over-the-counter sleep agents and bladder-control medications, and reduce dopaminergic drugs used to treat Parkinson's disease, if clinically indicated.
- 3 Consult with a doctor experienced in treating LBD. Cholinesterase inhibitor drugs may improve cognition and psychiatric symptoms, although such effects are not usually immediate.

- 4 Antipsychotic agents may be indicated if psychotic symptoms are severe and pose a significant safety risk. **AVOID traditional antipsychotic agents (e.g., haloperidol).** Newer atypical antipsychotic agents (e.g., quetiapine, clozapine) should only be used with caution at the lowest dose possible, under close supervision of a physician and a registered nurse (RN), and should be switched to a safer medication as soon as possible.

A more comprehensive physician's guide to treating behavioral disturbances in LBD patients can be found at:  
[www.lbda.org/go/ER](http://www.lbda.org/go/ER)



# LBDA

## LEWY BODY DEMENTIA ASSOCIATION



# The U.S. Based DIAMOND Lewy™ Management Toolkit

### Management Overview and Symptom Management Summaries



Used with permission from Newcastle University and Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust.



## Lewy body dementia: Management Overview

- › Identify key problems under domain headings such as cognition; gait, balance and movement; hallucinations; fluctuations; behavior and mood; sleep, and autonomic system dysfunction.
- › Establish which problems have high priority for treatment.
- › Discuss benefits and risks of treatment.
- › Be aware that symptom response is variable and that benefits in one might be at the cost of worsening of others
- › Individual treatments may have global benefits e.g. cholinesterase inhibitors.

### COGNITIVE

#### Non-pharmacological

- cognitive stimulation, use of memory aids, increased social interaction and stimulation, and exercise.

#### Pharmacological

- **Cholinesterase inhibitors** first-line.
- **Memantine** second line.

### NEUROPSYCHIATRIC

#### Psychosis

- Non-pharmacological includes orientation, validation, reassurance, distraction.
- May respond to **cholinesterase inhibitors** especially visual hallucinations.
- Be cautious in the use of antipsychotics.
- **Quetiapine and clozapine** are least apt to worsen parkinsonism. ⚠

#### Mood

- Use of **social interventions** may enhance mood.
- SSRIs or SNRIs first line ⚠
- Avoid agents with significant anti-cholinergic side effects.
- Avoid antipsychotics for non-psychotic mood disorders

### SLEEP

#### Insomnia

- Work on **sleep hygiene**.
- **Review all medications** that could be affecting sleep.
- **Melatonin** 1 hour prior to bedtime
- ⚠ **Cautious consideration for other sleep aids**

#### REM-sleep behavior disorder

- Consider **non-pharmacological** as first-line and only treat if troublesome.
- **Melatonin is first line**
- ⚠ **Clonazepam** may help although **possible** side effects

#### Motor related sleep disturbances

- May be improved with long-acting levodopa.

#### Other

Evaluation for OSA

- › Remember that LBD patients may exhibit exaggerated responses to medications.
- › Severe antipsychotic sensitivity can occur in up to 50% of patients therefore use antipsychotic agents with caution.
- › Review the need for drugs which can affect brain function and/or cause sedation and falls (see Beers List).
- › Minimize anticholinergic burden as this may worsen cognition and behavior, and counteract cholinesterase inhibitors.

### AUTONOMIC

#### Orthostatic hypotension

- **non-pharmacological** management e.g. compression stockings, fluid/salt intake, stand slowly.
- pharmacological e.g. fludrocortisone, midodrine, droxidopa
- ✗ **Reduce/remove** exacerbating drugs e.g. antihypertensives.

#### Constipation

- **Hydration and fiber intake.**
- **Stool softeners or mild laxatives** like polyethylene glycol

#### Gastroparesis

- **Non-pharmacological:** smaller, more frequent meals
- ✗ **Avoid** using metoclopramide.

#### Urinary dysfunction

- **Non-pharmacological** first-line e.g. pads, sheath catheter etc.
- Pharmacological: based on etiology. Consideration for referral to Urology. Agents like, Mirabegron can be considered. Botox may be considered for overactive bladder. Avoid centrally acting anticholinergics.

#### Sexual dysfunction

- ⚠ **Phosphodiesterase-5 inhibitors** may be considered with caution in men

#### Sialorrhea

- ✗ Anticholinergics should not generally be used
- **Botulinum toxin injections** to salivary glands is an effective treatment

### MOTOR

- Preferred pharmacological treatment of parkinsonism in LBD is **levodopa monotherapy**.
- Use **minimal dose** needed for benefit.

#### Monitor for potential neuropsychiatric side effects, if present:

- ✗ **Withdraw in order, one at a time:** anticholinergic drugs, amantadine, selegiline, dopamine agonists and catechol-O-methyltransferase inhibitors.

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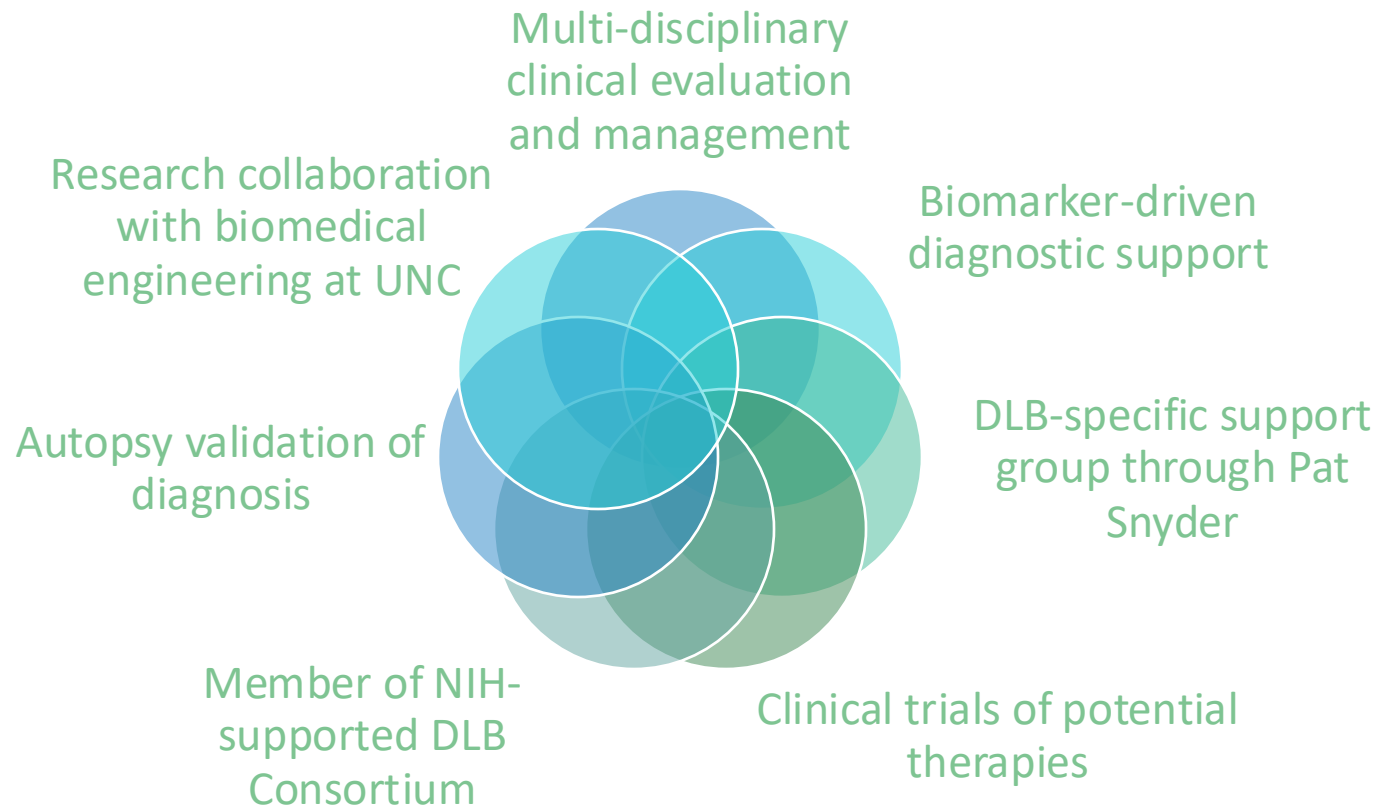


# DAN KAUFER LEWY BODY DISEASE RESEARCH CENTER OF EXCELLENCE AT UNC



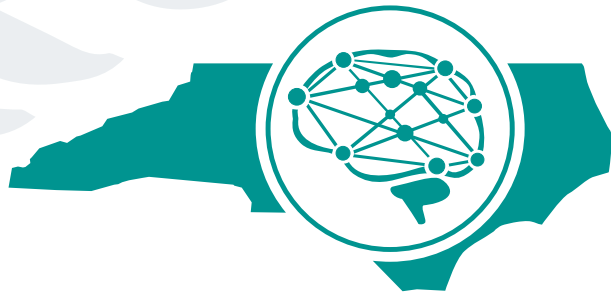
**Andrea C. Bozoki, MD**

- Division Chief, Memory and Cognitive Disorders
- Professor, Memory and Cognitive Disorders
- Outreach and Engagement Core Leader, Duke-UNC Alzheimer's Disease Research Center



## EXTERNALLY-LED, PATIENT-FOCUSED, DRUG DEVELOPMENT MEETING

- **OCCURRED:** October 15, 2024 (Washington, DC)
- **WHAT:** Patients and caregivers selected for this panel shared personal insights about DLB directly with United States Food and Drug Administration (FDA), with the goal of helping the FDA and key stakeholders better understand the implications of DLB drug-related regulatory decisions.
- **RECORDING OF THIS EVENT:**  
[https://youtu.be/\\_1pAzWSJfSQ?si=7yJTtTbt55YXIBC9](https://youtu.be/_1pAzWSJfSQ?si=7yJTtTbt55YXIBC9)



# NC Registry for Brain Health

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

## CAN SEARCH BY:

- Brain Health Tips
- Registry Studies
- What We Do
- Resources
- News
- Researchers

## PARTNERS WITH:

- UNC-Chapel Hill (Chapel Hill, NC)
- Duke University (Durham, NC)
- East Carolina University (Greenville, NC)
- Wake Forest School of Medicine (Winston-Salem, NC)
- NC A&T State University (Greensboro, NC)



# DEMENTIA ALLIANCE

of North Carolina

A STATE OF CARING

<https://dementianc.org/>

- Caregiver and support programs
- Dementia education
- Local research
- Events

# Duke-UNC Alzheimer's Disease Research Center

<https://dukeuncadrc.org/>

## Bringing Together Leading Researchers in Alzheimer's and Related Dementias

- UNC-Chapel Hill (Chapel Hill, NC)
- Duke University (Durham, NC)
- East Carolina University (Greenville, NC)
- North Carolina Central University (Durham, NC)
- UNC Pembroke (Pembroke, NC)





# ALZHEIMER'S ASSOCIATION<sup>®</sup>

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

- **24/7 Help Line: 1-800-272-3900**
- Local resources
- Help and support
- Events
- Research



# Brain Support Network™

<https://www.brainsupportnetwork.org/>

- National and International support groups for DLB and other brain-related disorders
- Educational resources
- Brain donation



# **MANAGING EVERYDAY LIFE (FOR PATIENTS AND CAREGIVERS)**





## HANDLING DIFFICULT BEHAVIORS

- Try to stay calm
- Talk slowly and reassuringly
- Do not take things personally
- Mentally separate the patient's personality from the dementia's personality
- Reassure patient of their safety
- Distraction can sometimes help
- Keep trying
- ***“Honor who they are.” –Dan Kaufer, MD***

# FOR CAREGIVERS

- Schedule small breaks
- Find someone you trust to talk to
- Get outside when the weather is nice
- Be kind to yourself
- Focus on what you can control
- Ask for help
- **IF YOU ARE ABLE, DO WHAT BRINGS YOU JOY**





# BOOKS



# BOOKS

- ***Treasures in the Darkness: Extending the Early Stage of Lewy Body Dementia, Alzheimer's, and Parkinson's Disease*** (by Pat Snyder)
- ***The Caregiver's Guide to Lewy Body Dementia*** (by Helen and James Whitworth)
- ***Managing Cognitive Issues: in Parkinson's & Lewy Body Dementia*** (by Helen and James Whitworth)
- ***Responsive Dementia Care: Fewer Behaviors, Fewer Drugs*** (by Helen and James Whitworth)
- ***Riding a Rollercoaster With Lewy Body Dementia: A Manual for Staff*** (by Helen and James Whitworth)



# CLINICAL TRIALS





# LBDA

LEWY BODY DEMENTIA ASSOCIATION

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

## LEWY TRIAL TRACKER

<https://www.lbda.org/lewy-trial-tracker/>

## CLINICAL STUDIES

<https://www.lbda.org/research/clinical-trials/>

# REFERENCES

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**THANK YOU!**







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