



# United for Lewy: Strength in Togetherness



2024  
Impact Report



To optimize the quality of life for those affected by Lewy body dementia, we accelerate awareness, advance research for early diagnosis and improved care, and provide comprehensive education and compassionate support.

Together, we will make a positive impact on the 1.4 million people living with Lewy body dementia.

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# A Message from the CEO

2024 was a year of growth for the Lewy Body Dementia Association (LBDA), achieving new milestones and embarking upon the path with clarity and purpose towards a future where living with Lewy body dementia (LBD) is the same as living well.

We were honored to welcome over 13,000 registrants to our Community Webinar Series, and humbled to provide compassionate support services to over 10,000 people in the U.S.

We know the research on Lewy body dementia must never end, and LBDA is steadfast in our commitment to accelerating awareness and advancing science by supporting recruitment for clinical trials and studies. This year, we helped multiple studies reach their recruitment goals, including two drug trials in LBD funded by the National Institutes of Health (NIH).

LBDA, in collaboration with the Alzheimer's Association, hosted the first-ever Externally-Led Patient-Focused Drug Development meeting on dementia with Lewy bodies. This pinnacle event of 2024 was a crucial and unique opportunity for the FDA, drug developers and other key stakeholders to hear directly from you, the LBD community, about the impact of the disease and what you need from current and future treatment options. Thank you for showing up, sharing your stories, and being the collective voice for those living with Lewy for safe, effective and better treatments.

We completed the first year of our 2024-2026 Strategic Plan, which was developed with the insights you shared about ways we can better meet your needs. We look forward to sharing our progress over the next two years and continuing to be a trusted source of information, support and education wherever you may be on your LBD journey.

We are incredibly grateful for your generous philanthropic support, for our amazing volunteers who graciously share their time and personal experiences to help others, for the guidance provided by our Board of Directors and Scientific Advisory Council, our partners and for the enduring spirit of the LBD community.

As we reflect upon our accomplishments, our moments of hope, the meaningful connections and new partnerships we made in 2024, we are reminded of our purpose - to ensure that no one faces this disease alone and together, we are improving the lives of those living with Lewy.



**Allison Feldman, CEO**



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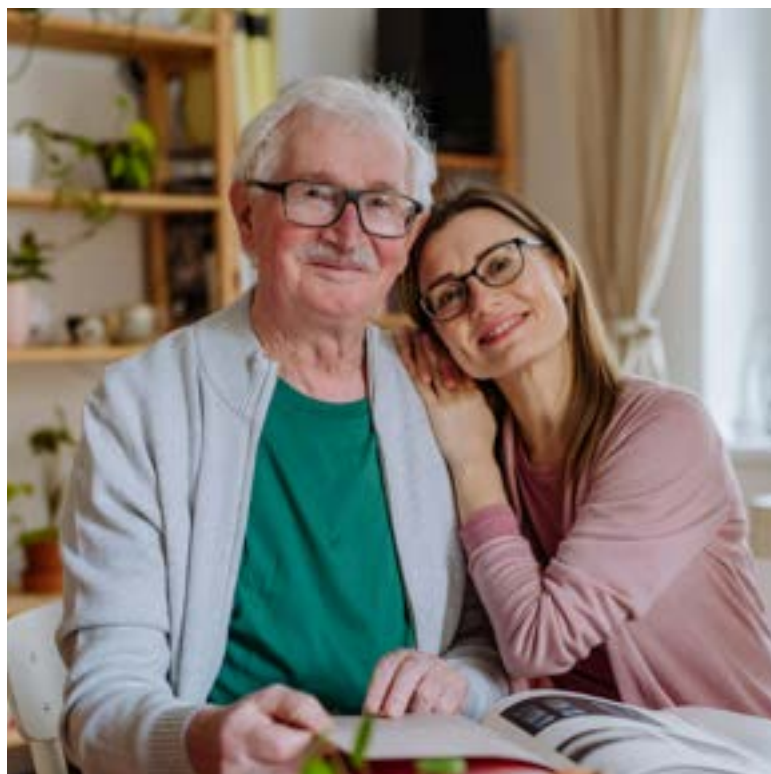
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Director at Large

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# Scientific Advisory Council (SAC)

The LBDA Scientific Advisory Council (SAC) members are internationally recognized leaders in LBD research and clinical management.

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**Daniel Weintraub, M.D.**  
University of Pennsylvania

**Cyrus P. Zabetian, M.D., M.S.**  
University of Washington School of Medicine

# Research Centers Of Excellence (RCOE)

The RCOE program and its investigators are collectively making remarkable contributions to our understanding of LBD and related disorders

**Arizona Collaborative RCOE**

**Barrow Neurological Institute in Phoenix, AZ**

**Cleveland Clinic in Cleveland, OH**

**Columbia University in New York, NY**

**Emory University in Atlanta, GA**

**Houston Methodist in Houston, TX**

**Johns Hopkins University in Baltimore, MD**

**Massachusetts General Hospital in Boston, MA**

**Mayo Clinic in Jacksonville, FL**

**Mayo Clinic in Rochester, MN**

**Oregon Health & Science University in Portland, OR**

**Rush University Medical Center in Chicago, IL**

**Stanford University in Palo Alto, CA**

**The Medical University of South Carolina**

**The Ohio State University in Columbus, OH**

**University of California, San Diego in San Diego, CA**

**University of Colorado Anschutz Medical Campus in Aurora, CO**

**University of Florida in Gainesville, FL**

**University of Miami in Miami, FL**

**University of Michigan in Ann Arbor, MI**

**University of North Carolina, Chapel Hill in Chapel Hill, NC**

**University of Pennsylvania in Philadelphia, PA**

**University of Pittsburgh, PA**

**University of Washington in Seattle, WA**

**UT Health in San Antonio, TX**

# Centering the Voices of Those with Lived Experience



442

Registered



2,100+ Views

On YouTube @LBDAtv

On October 15, 2024, the Lewy Body Dementia Association, in collaboration with the Alzheimer's Association, hosted the first-ever Externally-Led Patient-Focused Drug Development (EL-PFDD) Meeting on dementia with Lewy bodies (DLB). The patient perspective is critical in helping the FDA understand the context in which regulatory decisions are made for new drugs.

EL-PFDD meetings give the FDA and other key stakeholders, including medical product developers, health care providers, federal partners, an important opportunity to hear directly from patients, their families, care partners and patient advocates about the symptoms that matter most to them, the impact the disease has on their daily lives, and their experiences with currently available treatments.

Scan the QR  
Code to Watch  
the EL-PFDD  
Meeting on  
DLB on LBDAtv







# United through Research



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Strength in Togetherness

# Successfully Supporting Clinical Trial Recruitment

One of the key barriers to developing effective treatments for Lewy body dementia (LBD) is finding volunteers to participate in clinical trials. Dementia trials often accept only people without other significant health concerns—a challenge among older adults; further, they typically require a study partner such as a caregiver. So for every person in the trial, the need for volunteers is actually doubled. In 2024, LBDA helped multiple studies reach their recruitment goals, including two drug trials in LBD funded by the National Institutes of Health: the SHIMMER trial of CT1812/zervimesine and the RewinD-LB trial of neflamopimod.

Our approach to supporting recruitment is to inform people with LBD, care partners and families about active studies, how the study will advance science, and where they can find centers participating in the study. This includes layers of community outreach and educational initiatives such as webinars, disseminating print materials, reporting on research news, and creating study visibility through LBDA's communications channels like our website, email and social media.

**Both SHIMMER and RewinD-LB met their recruitment goals and are working toward Phase 3 trials.** We are eager to see what new research opportunities 2025 will bring, so LBDA can continue helping families find more hope and empowerment by participating in research.



# Focus for Impact: Defining LBDA's Research Priorities

Recent changes in the LBD scientific landscape are creating new opportunities for LBDA to advance its mission. These include:

- The **development of biomarkers** that allow for highly accurate identification of people with Lewy bodies (brain changes associated with LBD and PD) during life, potentially many years before the onset of measurable symptoms.
- **FDA approval of medications for Alzheimer's disease** that can reduce the amount of amyloid in the brain. More than half of people with LBD also have co-existing Alzheimer's disease. This is linked to earlier onset of cognitive decline, faster progression, and decreased lifespan.
- The scientific community is shifting its approach to LBD, moving closer to defining it by its biology and **focusing attention on treatment approaches that target the earliest stages of the disease.**

In addition, LBDA's research programs have matured significantly since 2017 when we established the LBDA Research Centers of Excellence (RCOE) program.

In light of these advances, LBDA research staff surveyed our scientific advisors for their guidance on which areas of research LBDA could make the most impact over the next five years. In making their recommendations, the advisors took into account our strengths and capacity, current and emerging gaps and opportunities in the field, and the needs of people with LBD and their care partners.



"As the premiere national nonprofit in the United States devoted to improving the lives of people with Lewy body dementia, LBDA has a unique and powerful role to play in research. LBDA's new research priorities will maximize the impact of its research programs to advance scientific discovery on behalf of people living with Lewy body dementia and their care partners."

Kejal Kantarci, MD, MS  
Professor of Radiology, Mayo Clinic  
Chair, LBDA Scientific Advisory Council (SAC)

## Understanding the Biology of LBD

**Priority: Longitudinal cohort studies.** Without a better understanding of how LBD develops and evolves over time, scientists will be unable to efficiently discover new drug targets and how and when to intervene to slow or stop the disease process. Longitudinal cohort studies follow groups of people over time, providing critical information to guide drug discovery and development.

**Priority: Biomarkers.** People living with LBD often struggle to get an accurate and timely diagnosis. Furthermore, misdiagnosis creates problems for clinical trials, slowing progress toward effective treatments. A critical tool in diagnosis and drug development are biomarkers, which are medical tests that can reveal the presence or absence of a disease process or measure the progression of a disease. For example, cholesterol levels are a biomarker for heart disease. Biomarker research will lead to advancements in early and accurate diagnosis in LBD and in clinical trial design.

## Treatment and Intervention

**Priority: Clinical trials.** Clinical trials are the most important kind of research to test new therapies for their safety and effectiveness. Working with the LBDA Research Centers of Excellence, a clinical trial network of more than 25 of the nation's leading academic medical institutions, LBDA is helping to advance the study of potential treatments for individuals with LBD and their caregivers.

**Priority: Patient/caregiver-centric outcomes.** Many outcome measures that are used in clinical trials for LBD today are "borrowed" from other diseases, such as Parkinson's disease and Alzheimer's disease. Repurposing these tools means clinical trials are not as relevant to the lived experience of LBD and slows scientific progress. This priority will advance the study of outcome measures that are more specific to the experience of people living with LBD and their care partners.

**Priority: Caregiver interventions.** LBD is a uniquely challenging disease for caregivers, so more research is needed to develop interventions that will provide them meaningful tools and improve caregivers' quality of life.







# United through Support



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Strength in Togetherness

# Strengthening Hope through Support and Connection

In 2024, the Lewy Line and Support email continued to serve as lifelines for those facing the complexities of Lewy body dementia (LBD). With **1,712 individuals** reaching out to our Support team across **45,695 minutes**, the power of connection has never been more evident. Each touchpoint represents not just a number, but a moment of hope, reassurance, guidance, and shared understanding.

Care partners and those diagnosed remain at the heart of these interactions. Notably, an increasing number of individuals reached out on behalf of siblings and friends, demonstrating the widening network of care and advocacy. The need for bereavement support also grew, with **66 individuals** seeking guidance after losing a loved one to LBD—**more than double** from the previous year.

Professional engagement expanded (particularly in fields like hospice, home health, and assisted living) reinforcing the importance of collaboration in care. The reach of support connected people from all **50 states** - further underscoring the essential role of these resources.

**Support is here—and it's growing stronger.**



# Support Volunteers

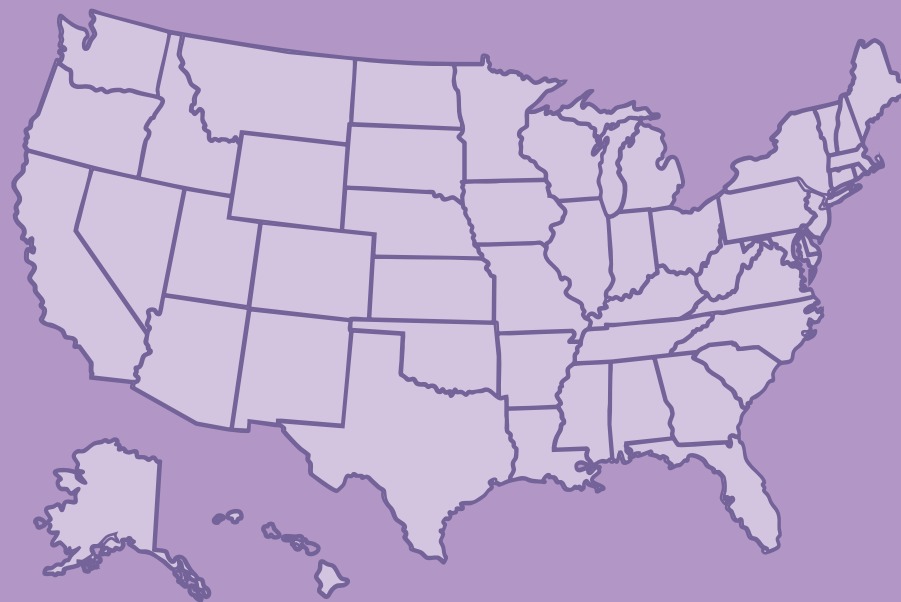
In 2024, LBDA's Support volunteer network demonstrated the incredible power of unity and resilience. Through compassionate connection, our Lewy Buddies and support group facilitators strengthened a foundation of care, ensuring that no one faces Lewy body dementia (LBD) alone.

At year's end, **43 Lewy Buddies** provided vital telephone-based mentoring offering understanding, guidance, and a sense of hope to those symptomatic, diagnosed, caregiving or grieving. Their outreach proved invaluable in fostering comfort and confidence during uncertain times.

Additionally, **92 support groups** operated nationwide, led by **81 dedicated facilitators** who created safe spaces for care partners and those living with LBD to share experiences, process emotions, and build relationships. These groups reinforced a collective strength, turning shared challenges into opportunities for growth, knowledge, and healing.

More than numbers, this work reflects the undeniable power of coming together. In each call, meeting, and conversation we see the resilience of the human spirit—supporting one another, lifting each other up, and proving that strength is found in community. As we move forward, we carry this commitment, ensuring that connection remains at the heart of LBD support.

LBDA's Support Services received at least one call from EVERY state in the US in 2024.



Support groups are a great way to connect with others affected by LBD. They provide a non-judgmental space to process emotions, reduce isolation, develop realistic expectations, share resources and practical tips, and brainstorm ways to continue to live well with Lewy.



# Building Community and Togetherness within LBDA Support Facebook Pages

In 2024, LBDA's Facebook Support communities reached a record **8,581 participants** across four dedicated pages: Care Partner, Living with Lewy, Beyond Lewy, and Newly Lewy. These pages serve as vital lifelines, offering peer connection and shared insight.

The continued growth of our Support Facebook platforms underscores a powerful truth: community matters. The journey of those diagnosed with Lewy body dementia (LBD), their care partners, and bereaved loved ones is marked by challenges that require understanding, connection, and shared wisdom.

Beyond numbers, the heart of our impact lies in the unity cultivated within these pages. The challenges of LBD are complex, and together, we have fostered a culture of resilience, understanding, and compassion. Whether through discussions on grief, navigating caregiving struggles, or finding moments of joy amid hardship, the spirit of this community continues to deepen.





# LBDA's Support Facebook Pages

LBDA offers four Facebook groups to support the LBD community. These groups are closed, so you can choose to share your story, ask for the opinions of the other group members, and read about the experience of others.



## [LBDA Care Partners](#)

is specific to care partners of those living with LBD.



## [Living with Lewy](#)

is for those living with LBD with a possible/probable diagnosis.



## [Newly Lewy](#)

is for those newly diagnosed and/or those caring for them.



## [Beyond Lewy](#)

is for those coping with the loss of a loved one to LBD.

An elderly couple is shown from behind, embracing each other in a park. The man, on the right, has white hair and wears glasses, a white long-sleeved shirt, and light-colored trousers. The woman, on the left, has short blonde hair and wears a light blue t-shirt and jeans. They are standing on a grassy area with a body of water and lush green trees in the background. The scene is bathed in warm, golden light, suggesting late afternoon or early morning.

**No one should have  
to face LBD alone.**

**Together, we will improve the  
lives of those living with Lewy.**



# United through Education



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# LBDA's 2024 Community Webinar Series: Growth, Innovation and Impact

In 2024, LBDA's Community Webinar Series saw remarkable growth. With **20 dynamic webinars** on crucial topics, the series attracted over **13,000 unique registrations**, with nearly half of participants joining live. The recorded sessions on LBDA's YouTube channel, LBDAtv, have garnered over **30,000 views** to date, amplifying our reach and extending the LBD community's access to essential insights.

Collaboration played a vital role, both within LBDA and the broader LBD community. Our webinars often feature leaders from LBDA's Research Centers of Excellence. Dr. Kathleen Poston's "Introduction to Synuclein Biomarkers: How Researchers Are "Seeing" Lewy Bodies in the Living Brain" had the highest number of registrations in 2024, followed by Dr. Melissa Armstrong's webinar "Navigating End-of-Life Challenges in Lewy Body Dementia". Both Dr. Poston and Dr. Armstrong are Primary Investigators at LBDA Research Centers of Excellence, highlighting LBDA's cross-functional collaboration to provide the greatest impact.

Beyond the numbers, the Community Webinar Series profoundly impacted all who participated.

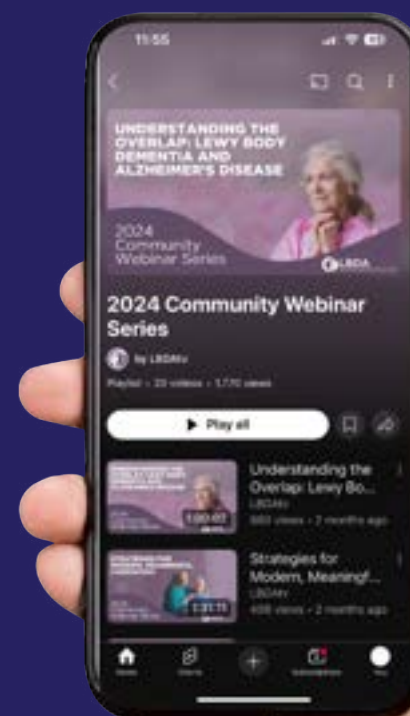
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watch LBDAtv



**20**  
Expert-led sessions

**13,000**  
Unique Registrants

**30,000+**  
Views on YouTube @LBDAtv





# Expanding LBD Education: New Courses on the Lewy Learning Center



In 2024, LBDA expanded its educational reach with **five new courses** on the Lewy Learning Center, a free platform offering on-demand learning for both the LBD community and healthcare professionals. Enrollment surged, with new student accounts rising from **201** in 2023 to **1,246** in 2024.

Four of the new courses fall under the Community Education series, designed for individuals with LBD, their families, and care partners. Unpacking Parkinsonism: Understanding Movement Changes in LBD and Unpacking Psychiatric Symptoms present complex topics in easily digestible lessons, with the latter already seeing over **500 enrollments**.

LBDA also introduced The Tip Jar, a community-driven course where LBD experts answer frequently asked questions through short videos and supplemental resources. Dr. Melissa Armstrong's concise and compassionate video response to the question, "What do people with Lewy body dementia usually die from?" perfectly demonstrates the effectiveness of this format.

Additionally, LBDA launched its **first Professional Education course**, Caring with Confidence: Understanding Lewy Body Dementia. This course covers effective caregiving strategies, communication techniques, and individualized care approaches that enhance quality of life.

Through these initiatives, LBDA continues to provide accessible, high-quality education, in a format that was most requested by our constituents.

# Strengthening the Community of Care: LBDA's Breakfast Symposium at AAGP 2024

At the 2024 American Association for Geriatric Psychiatry (AAGP) Annual Meeting, the Lewy Body Dementia Association (LBDA) hosted a pivotal Breakfast Symposium, bringing together over **200 geriatric psychiatrists** for an in-depth exploration of Lewy body dementia (LBD) diagnosis, management, and case studies. This gathering underscored the power of community-driven education, fostering collaboration among specialists dedicated to improving care for individuals with LBD.

The symposium featured expert presentations from Jennifer G. Goldman, M.D., Parichita Choudhury, M.D., and Chiadi Onyike, M.D., all leading voices in LBD research and clinical management. Their insights helped attendees deepen their understanding of the complexities of LBD, from diagnostic challenges to best practices in treatment and patient care.

A highlight of the event was the premiere of the U.S. Based DIAMOND Lewy™ Management Toolkit, a groundbreaking resource designed to standardize and enhance LBD care. Attendees received printed copies and access to a downloadable version, ensuring that the toolkit's impact extended beyond the walls of the annual meeting. By equipping geriatric psychiatrists with evidence-based strategies, LBDA strengthened a network of informed providers, empowering them to deliver more precise and compassionate care to patients and families affected by LBD.

This initiative was made possible through the generous grant funding of GE Healthcare and Acadia Pharmaceuticals, whose support enabled LBDA to expand access to critical educational resources. Their investment in community-driven learning ensures that geriatric psychiatrists nationwide can integrate best practices into their clinical work, ultimately improving patient outcomes.

The symposium reinforced the importance of collective expertise, demonstrating that education, collaboration, and shared knowledge are essential in advancing LBD care. Together, we are building a stronger, more connected community for those impacted by LBD.



# United through Development



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# Honoring Tim Perkins

Tim Perkins was a vibrant spirit who filled every room with warmth, creativity, and color—often in his favorite tie-dyed shirt, surrounded by his beloved family, dog, garden, and handmade creations.

After being diagnosed with Lewy body dementia (LBD), Tim faced the fear and uncertainty with courage and determination. He found support through the Lewy Body Dementia Association and soon began giving back as a volunteer. In just a year, he was named Volunteer of the Year—an honor he never sought, but deeply earned.

Tim devoted himself to helping others navigate LBD, offering comfort through peer support, outreach, and education. “I want to make their travels a bit better,” he once said—and he did. His impact grew through art, advocacy, and even co-authoring a children’s book to help young people understand dementia.

Tim gave generously of his time, creativity, and heart—not for recognition, but because helping others was simply who he was.

In May 2025, Tim’s journey came to an end. But his legacy of compassion, courage, and kindness lives on. He will be deeply missed, and forever remembered.

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**“I cannot imagine going through something like this and not using it to help others.”**

**- Tim Perkins**





# Mike Madness VI

This year, we returned to Birmingham, Alabama for the 6th annual Mike Madness 3-on-3 basketball tournament—a day filled with energy, music, community and remembrance – all in tribute to Mike Oliver.

Mike was a devoted husband, proud father and grandfather, gifted writer, and friend to many. After being diagnosed with Lewy body dementia (LBD), he faced the disease with honesty, humor, and purpose. Through his blog, My Vinyl Countdown, Mike shared his journey with LBD while reviewing his 678 vinyl records—blending music, memory, and advocacy.

"It probably will not be a pretty end," he wrote, "but I'm hoping, while I can, to build awareness and raise research funds for this complex and often misdiagnosed disease."

Mike Madness was born from that vision. Created by those who loved him, the tournament and music-filled after-party honor his competitive spirit and commitment to advancing LBD awareness and research.

This year's event broke participation records, sparked powerful connections, and reaffirmed our shared mission. Though Mike is no longer courtside, his legacy lives on in every game, every song, and every dollar raised. LBDA is proud to carry his mission forward—and grateful to the Mike Madness community for showing what one voice and one community's love can do.



# Finding LBDA and Hope

## Krissan Lutz Moss

After years of navigating a maze of confusing symptoms, Krissan Moss, an experienced nurse with a bright and tenacious spirit, finally found answers through a clinical study at LBDA's Research Center of Excellence at the Mayo Clinic. That diagnosis marked a turning point in her journey.

With determination, Krissan embraced LBDA resources. She immersed herself in educational webinars, used printed materials to educate her family and care team, and became a powerful advocate for others facing Lewy body dementia. Today, she proudly says, "I'm not losing to Lewy, I'm just living with Lewy."

Thanks to supporters like you, Krissan didn't have to face her diagnosis alone. Your generosity helped provide the education, support, and connection that gave her clarity, strength, and a renewed sense of purpose.

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"LBDA was my first real source of support. The support groups gave me the gift of normalcy and words to explain my situation to others."

– Krissan Lutz Moss





# Thank You, LBDA Volunteers

As we reflect on 2024, the Lewy Body Dementia Association's (LBDA) staff are filled with deep gratitude for the unwavering dedication of our volunteers.

Thank you for your bravery and being an advocate for yourself and others by sharing your lived experience with Lewy body dementia.

Thank you for providing guidance, comfort and connection to countless individuals during their journey.  
Thank you for being our advisors and partners in stewarding the mission of LBDA and helping us to help others live well with Lewy.

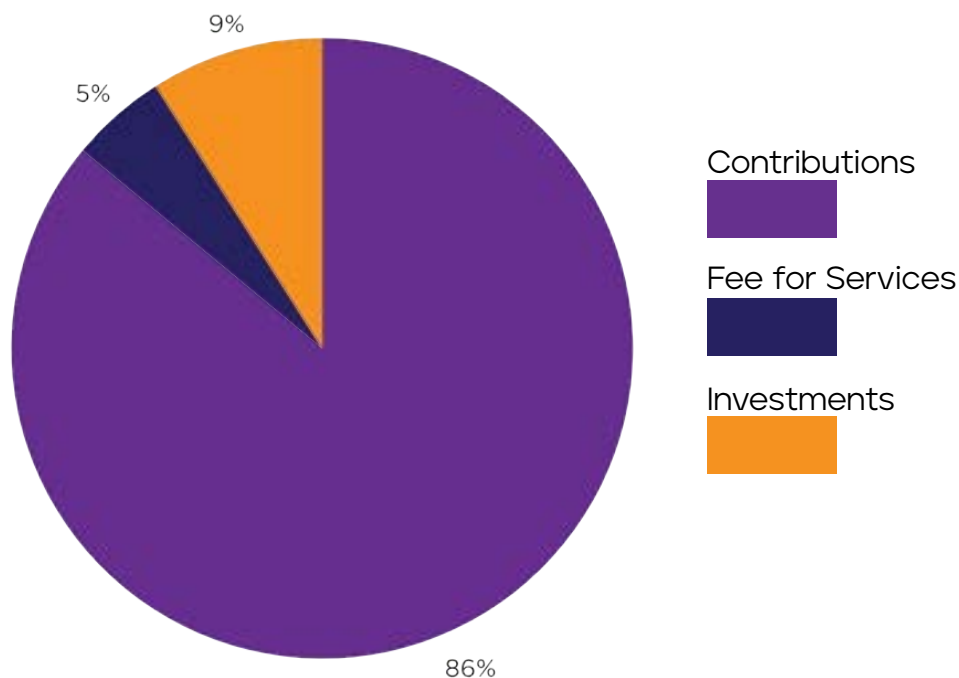
Thank you for raising awareness of LBD in your communities by contributing your time or making a philanthropic gift to sustain our program provision.

Thank you for being the heart of our community and for walking with LBDA in service, advocacy, and hope. Your compassion, time, and energy continue to make a meaningful difference in the lives of individuals living with Lewy and those who care for them.



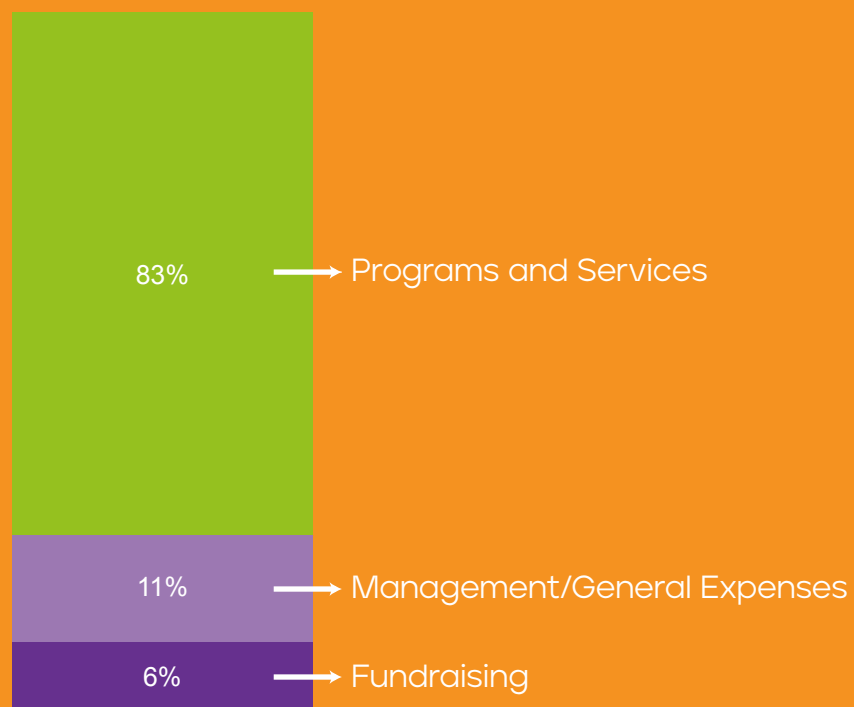
## Total Revenue

LBDA is committed to being vigilant stewards of the funds you have so generously given to support our programs and advance LBD research. We are dedicated to efficiency, accountability and maximizing every gift to continue to provide the education, information and support needed.



## Total Expenses

Your belief in our mission and generous contributions enable us to continue to expand the depth and breadth of our support and advocacy for LBD patients, their care partners and families. Thank you.





## Find LBDA's Free Resources



### The Lewy Digest

Receive the latest information on Lewy body dementia care and support, research advances, upcoming events, and community resources for people living with the disease and their care partners.



### The Lewy Learning Center

The place for free, on-demand learning on Lewy body dementia (LBD) offering community education courses designed for those living with Lewy, their families and care partners.



### Lewy Trial Tracker

Sign up for the Lewy Trial Tracker to receive a quarterly e-newsletter with new and ongoing clinical trials and studies looking for volunteers.

## Join Our Online Community

YouTube: [@LBDAtv](#)

X (Twitter): [@LBDAAssoc](#)

Facebook: [Facebook.com/lewybodydementia](https://www.facebook.com/lewybodydementia)

Instagram: [@lewybodydementiaassociation](#)

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