

The logo for the Lewy Body Dementia Association (LBDA) features the letters 'LBDA' in a large, bold, sans-serif font. Each letter is filled with a different photograph: 'L' shows a person's hands holding a white lace garment; 'B' shows an elderly woman and a younger woman smiling together; 'D' shows a woman smiling; 'A' shows a healthcare professional in a blue uniform attending to an elderly patient. To the left of the 'L' is a small circular logo with the text 'LBDA' and 'LEWY BODY DEMENTIA ASSOCIATION' below it.

# LEWY BODY DEMENTIA ASSOCIATION

## 2021 ANNUAL REPORT

Driving awareness, education, research, and support  
for the Lewy body dementia community





## OUR VISION

A cure for Lewy body dementias and quality support for those still living with the disease.





## A MESSAGE FROM CHRISTINA CHRISTIE

Dear LBDA Community,

This past year put us to the test as we navigated through the COVID-19 pandemic. The Lewy Body Dementia Association (LBDA) is immensely grateful for friends and families like you, who have been continuously opening their hearts to help individuals and all those who have been affected by Lewy body dementia (LBD). You all came together to meet tragedy with generosity.

Because of your support, the Lewy Body Dementia Association was at the forefront of our community's response to the pandemic and was able to play a pivotal role in ensuring individuals affected by LBD had access to assistance and resources during unstable times. Your support advanced the care, awareness, understanding, and treatment of those affected by the complex and debilitating disorders under the Lewy body dementia umbrella.

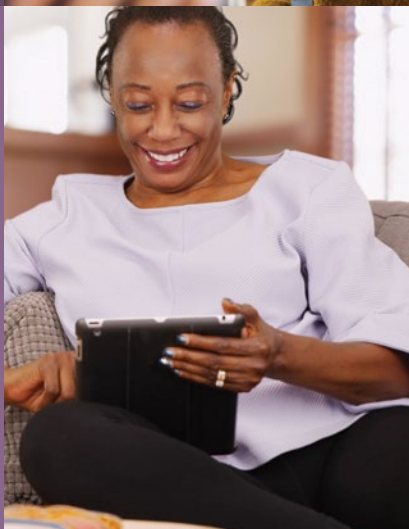
LBDA has emerged stronger than ever because of you. We remain steadfast in our mission to support those affected by Lewy body dementias, their families, and caregivers through outreach, education, and research. Many thanks from the Lewy Body Dementia Association to the friends who helped us weather this unimaginable, volatile, and still uncertain time; we greatly appreciate your generosity, your partnership, and your friendship.

Warm Regards,

**Christina Christie**

LBDA Board President





## LBDA'S MISSION

### Our Work Together

Through outreach, education, and research, we support those affected by Lewy body dementias, their families, and caregivers. We are dedicated to raising awareness and promoting scientific advances.

The **Lewy Body Dementia Association** (LBDA) traces its origins to a group of caregivers who recognized the paucity of knowledge about Lewy body dementias. Officially established in 2003, the LBDA today is the only nationwide 501(c)(3) nonprofit organization dedicated to raising awareness of these complex diseases, promoting scientific advances, and supporting those with Lewy body dementia, their families, and their care partners.

## OUR 2021 IMPACT SUMMARY

### You Make it Possible

Your partnership this year made it possible to extend greater care to more families facing Lewy body dementia. Here are just a few ways you have changed lives through the LBDA in 2021.

#### 22K+ received clinical care

Individuals with Lewy body dementia received clinical care nationwide at the LBDA's 26 Research Centers of Excellence (RCOE)

#### 12K+ professionals trained

Healthcare professionals trained in clinical management of Lewy body dementia at the LBDA's Research Centers of Excellence (RCOE)

#### 18K+ caregivers supported & trained

Educational presentations provided to improve care for those affected by Lewy body dementia

#### 100+ support groups

Support groups providing free and confidential weekly support to individuals affected by Lewy body dementia

#### 7K+ connected to professional care

Individuals connected to licensed professionals through the LBDA support channels. In 2021, we served over a thousand individuals and their supports through our Lewy Line



## RESEARCH & ADVOCACY PROGRAM

# Advances for Earlier Diagnosis, Better Care, & a Cure

Lewy body dementia is a complicated disease. It is widely under-diagnosed, exacerbating the difficulties for those affected by it. Early diagnosis is essential for providing a higher level of care and finding a cure. With your generous support and giving through the LBDA, advances are being made through research, clinical trials, and legislation. **Your giving is directly responsible for growing knowledge about Lewy body dementia in the medical field, which directly impacts those affected by the disease.**

Through the Research Centers of Excellence network, the LBDA collaborates with 22 of the nation's leading academic medical research institutions with expertise in Lewy body dementia to provide advanced diagnosis and treatment to those affected by the disease. The prestigious Mayo Clinic in Rochester, Minnesota, serves as our Coordinating Center. **Your partnership enables some of the most respected academic medical research institutions to combine efforts for greater impact.** You are connecting the Lewy body dementia community with highly specialized physicians and respected institutions that are committed to conducting needed research in advancing treatments and improving quality of life for those living with LBD.

## RESEARCH CENTERS OF EXCELLENCE NETWORK

- **Mayo Clinic, Coordinating Center (Rochester, MN)**
- Barrow Neurological Institute (Phoenix, AZ)
- Cleveland Clinic (Cleveland, OH)
- Columbia University (New York, NY)
- Emory University (Atlanta, GA)
- Georgetown University Medical Center (Washington, DC)
- Johns Hopkins University (Baltimore, MD)
- Massachusetts General Hospital (Boston, MA)
- Mayo Clinic (Jacksonville, FL)
- Oregon Health & Science University (Portland, OR)
- Rush University Medical Center (Chicago, IL)
- Shirley Ryan Ability Lab (Chicago, IL)
- Stanford University (Palo Alto, CA)
- Thomas Jefferson University (Philadelphia, PA)
- The Ohio State University (Columbus, OH)
- University of California San Diego (San Diego, CA)
- University of Colorado Anschutz Medical Campus (Aurora, CO)
- University of Florida (Gainesville, FL)
- University of Miami (Coral Gables, FL)
- University of Michigan (Ann Arbor, MI)
- University of North Carolina at Chapel Hill (Chapel Hill, NC)
- University of Pennsylvania (Philadelphia, PA)
- University of Washington (Seattle, WA)



## IMPACT SPOTLIGHT

# Engaging Federal Regulatory Agencies

Four years ago, your support enabled the launch of the **LBDA Research Centers of Excellence (RCOE)**, where people with Lewy body dementia and their families can turn for advanced diagnosis and treatment.. This year LBDA elevated the voices of LBD experts and advocates to the ears of regulators at federal agencies.

Earlier diagnosis of Lewy body dementia and the search for its cure is only possible through rigorous medical research and clinical trials. Your generous giving this year also led to key findings on the risk factors for suicidality in Lewy body dementia; the impact of dementia-related psychosis on individuals with dementia and their caregivers; the challenges and opportunities for improving the landscape for clinical trials; the use of biomarkers in diagnosis; and best practices for doing virtual clinical assessments.

The biggest dementia news in 2021 was the FDA's approval of a controversial new treatment for Alzheimer's disease. The drug, Aduhelm, is the first FDA-approved treatment with "disease-modifying" properties, meaning it has the potential to slow course of Alzheimer's disease. Unfortunately, it also has considerable risks for dangerous side effects and there are unanswered questions about whether the drug would help improve symptoms.

A third of people with dementia with Lewy bodies also have co-existing Alzheimer's disease. LBDA submitted formal public comments to the Centers for Medicare and Medicaid Services (CMS) about the importance of providing coverage for this treatment. This proactive stance helps lay the foundation for a future in which LBD will have a disease-modifying treatment available.

The controversy waged for nearly a year between the FDA's approval to CMS's final determination of coverage. Given the need for more evidence on safety and efficacy of anti-amyloid therapies, CMS ultimately limited coverage of drugs in this class to only participants of CMS-approved clinical trials.

These events are prime learnings for the LBD field; LBDA and our Research Centers of Excellence are committed to leading vital regulatory discussions. This year LBDA organized the first-ever meeting between LBD experts and the Food and Drug Administration on the urgent, unmet needs of people living with LBD. Experts in LBD presented the opportunities and challenges in designing clinical trials for a disorder that is as complex and varying as Lewy body dementia. A scientific manuscript is being developed to help inform researchers and drug companies about clinical trial design considerations.

**Your gifts are also helping to fund the discovery and development of a biomarker, or a biological test, for Lewy body dementia.** Through an annual research grant, supporting the Dementia with Lewy Bodies Consortium Study, a five-year longitudinal study assessing people with Lewy body dementia within a 10-site research network led by the Cleveland Clinic.

## EDUCATION PROGRAM

# Advancing Care for the Community

Education about Lewy body dementia is vital for early diagnosis, improved care, and a cure. Because its symptoms may closely resemble Alzheimer's and Parkinson's, it is widely under-diagnosed. LBDA is accelerating education and advancing care for the wider community.





#### IMPACT SPOTLIGHT

## Expanding Knowledge through Healthcare Education

This year the LBDA expanded education offerings to target healthcare professionals critical in the care of people with Lewy body dementia. We paired the SPARK documentary on Robin William's experience with LBD with educational content at the American Psychiatric Nursing Association (APNA) national conference and at the National Association of Directors of Nursing Administration in Long Term Care (NADONA) national conference.

In 2021, we collaborated with LSVT Global to offer webinars for clinicians and those living with LBD, reaching more than 900 attendees including physical and occupational therapists and speech language pathologists. Within this same year, LBDA offered additional scientific and educational offerings including the LBDA Research Centers of Excellence symposium on Tissue and Biofluid Biomarkers in and Digital and Wearable Biomarkers in Lewy body dementia . The LBDA also facilitated a CME-accredited webinar series on performing Lewy body dementia assessments virtually to support clinicians treating patients via telehealth. These events were recorded and can be viewed on demand at the LBDA YouTube page, LBDAtv.

**Through these training opportunities, we have better-equipped healthcare professionals to deliver quality care to those affected by Lewy body dementia.**



## AWARENESS PROGRAM

# Raising Awareness for Lewy Body Dementia

Lewy body dementia affects an estimated 1.4 million individuals in the United States alone. Because symptoms may closely resemble Alzheimer's and Parkinson's, it is widely under-diagnosed. Our Awareness Program elevates the understanding of this multi-system disease so those facing it and those treating it are better-equipped. **Awareness for Lewy body dementia is growing through the LBDA's media projects and promotional campaigns.**





## IMPACT SPOTLIGHT

### Powerful Documentaries Featuring Robin Williams

Through comedy, TV, and film, Robin Williams became a beloved source of entertainment and artistic expression. Much was lost with his tragic death in 2014. What the world didn't know was the battle Robin had endured in the two years preceding his death. Robin and his wife, Susan Schneider Williams were on a quest to understand the mystifying changes he was experiencing. The unknown enemy was named in the coroner's report months after his death: dementia with Lewy bodies.

Susan began sharing their story and raising awareness about Lewy body dementia, spearheading two films: Robin's Wish, a documentary about Robin's final days with Lewy body dementia, and SPARK: Robin Williams and His Battle with Lewy Body Dementia, a 45-minute educational adaptation of Robin's Wish, funded by LBDA and partner, ACADIA Pharmaceuticals Inc. Both films focus on their journey and provide raw insight into their agony of uncertainty. Susan sets the record straight about Robin's death and reflects on what could have been different with an early diagnosis.

SPARK continues to attract professional and community audiences throughout the world. This film has brought awareness to thousands of viewers through University Grand Rounds, Dementia Friendly community events, national conferences, and community gatherings. SPARK was recently recognized as among the top 10 most viewed videos by Parkinson and Movement Disorders (PMD) Alliance and was part of a CME course created by the Mayo Clinic which received an award of distinction in continuous professional development courses.

Through the LBDA—thanks to you!—*SPARK* is now available to all via Medflix **driving greater awareness, understanding, detection, diagnosis, and quality care management of Lewy body dementia to lead to better outcomes.**





## SUPPORT PROGRAM

### Caring for Those Affected by Lewy Body Dementia

Those affected by Lewy body dementia will face a host of physical, mental, and emotional symptoms and changes. Support for them, as well as their families and caregivers, is vital. LBDA Support Services provides both individual and group services every step of the way.

The LBDA Facebook groups are a safe space for those uniquely affected by Lewy body dementia to share their stories and discover resources while receiving support from those who truly understand. LBDA hosts four groups serving care partners, those living with Lewy, and an additional group was added in 2021 to serve those in bereavement. Our Living with Lewy Zoom Group offers two-hour weekly support meetings led by the LBDA Support Services staff.

LBDA Support Services also includes a nationwide network of support groups with facilitators who provide additional support to our constituents.

The LBDA Lewy Line connects individuals directly to LBDA licensed professionals who provide education, support options, and resources. In addition, LBDA Lewy Buddies are LBDA's volunteers who generously offer their time to provide support and guidance based on their own lived experience. LBDA is ensuring that those affected by Lewy body dementia are receiving beneficial care, education, and support.



## IMPACT SPOTLIGHT

### Gary Schmidt and His Goal to Pay it Forward

In 2018, retired primary care physician and medical director Gary Schmidt experienced a life-changing role reversal. The doctor who had spent decades serving others was now a patient taking tests in a neurologist's office. Gary's path to that life-changing appointment included several signs that he didn't realize were LBD symptoms. At the time, he had limited understanding and knowledge of LBD.

Unbeknownst to Gary, LBD reared its ugly head in the form of REM sleep disorder – a condition characterized by sudden body movements and thrashing while a person is dreaming. In time, his memory, speech, and ability to do mundane tasks declined. Depression and mood swings followed. When Gary struggled to climb stairs and lost his ability to smell aromatic coffee, he made an appointment to visit the neurologist. He was diagnosed with mild cognitive impairment and told that he had a high chance of developing LBD. The prediction was soon confirmed as Gary started experiencing hallucinations and emotional breakdowns. He felt lost and defeated. But this wasn't Gary – this was Lewy.

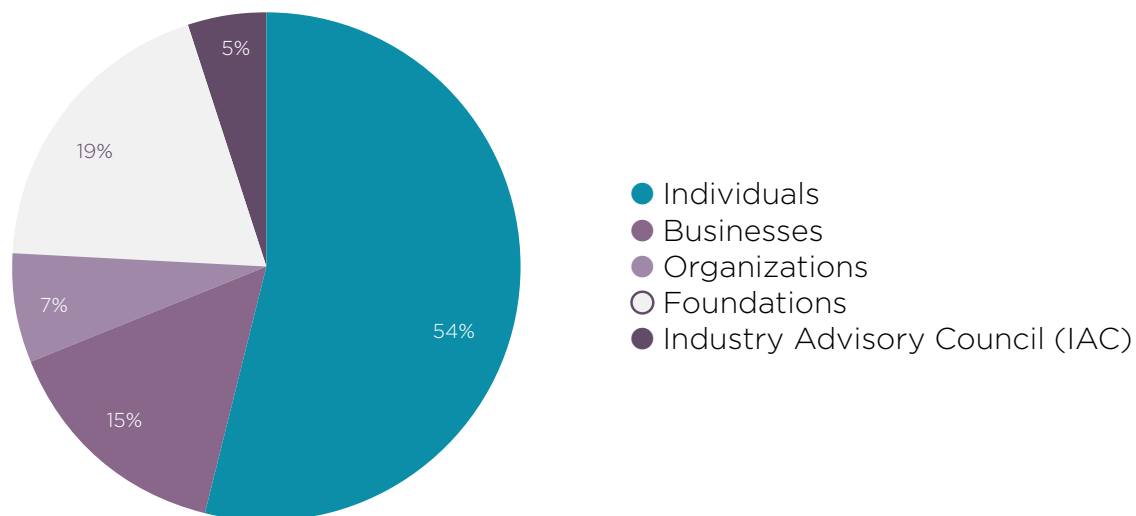
He shared his story during LBDA's weekly Facebook support group meetings, and now refers to them as "the highlight of [his] week." Gary encourages care partners and people with LBD that mistakes and blunders are the disease – not the individual. He also reminds them about the importance of raising LBD awareness and sharing their stories, especially with medical professionals.

Despite some setbacks, Gary keeps pushing forward. He has learned that even after an LBD diagnosis, life has much to offer. In Gary's case, it's the laughter, smiles and love that he shares with his family as they face the disease together.

## FY 2021 FINANCIAL RECAP BY SOURCE

### Total Funding

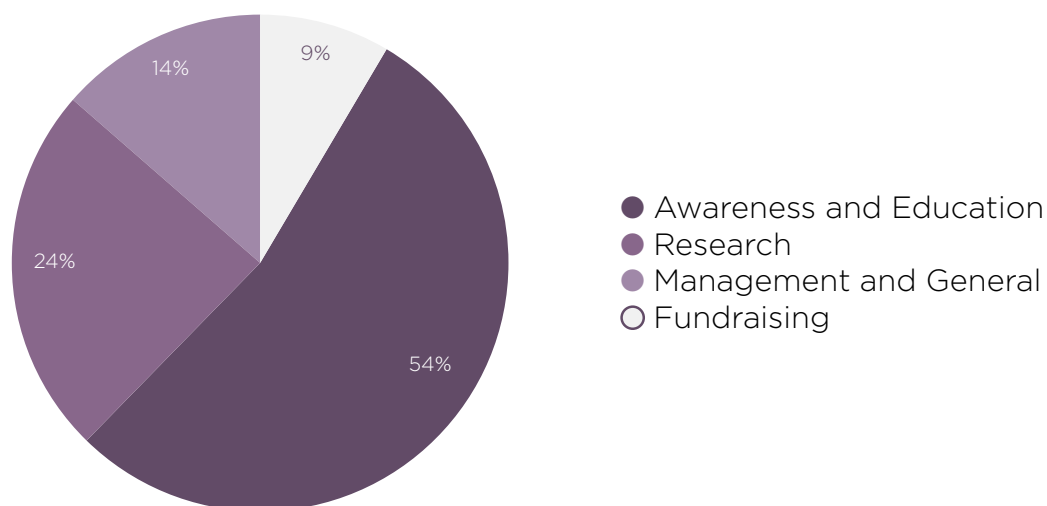
*Generous partners gave onetime gifts and multi-year commitments to move closer than ever before to a cure for Lewy body dementia and care for those affected by it. Here's a snapshot of our income:*



## FY 2021 FUNCTIONAL EXPENSES

### Highest Impact to Date

*Last year's growth enabled us to invest in our work toward a Lewy body dementia cure and care for those affected by it in the deepest way possible. Here's how the investment you made has made a life-changing impact:*



## A MESSAGE FROM LBDA

# Looking Ahead: Our Future Impact

Your impact this past year on the lives of those affected by Lewy body dementia is remarkable. Thanks to our healthcare partners, volunteers, donors, board of directors and staff, we have made real strides in medical research, professional education, caregiving support, and public awareness. The result?

We are moving closer to the day when there is a cure for Lewy body dementia.

Our strategic initiatives for the future are possible with your continued partnership. Together in the year ahead, we will:

- Advance earlier diagnosis by **catalyzing life-changing medical research** across the RCOE network and grow collaborations and projects among our key partners
- **Expand education activities for healthcare professionals, individuals with LBD and caregivers** to enhance understanding of all aspects of Lewy body dementia
- **Grow nationwide awareness** within the Lewy body dementia community and across the nation to better assess and utilize the full spectrum of LBDA resources
- **Ensure personal, advanced care** is accessible by all patients, families, and caregivers at every step of their journey

These robust growth initiatives include many exciting new offerings. For example, this year we are **launching a new app and introducing a learning management system for centralized educational programming** to empower patients and their care partners. And in-house, to support future growth and better meet the needs of our constituents, we are **enhancing our internal organizational structure**. This includes expanding our staff as well as finding new ways to highlight and incorporate our **commitment to Diversity, Equity, and Inclusion**. It's imperative our organization continues to be intentional in growing our understanding of the challenges faced by those living with Lewy body dementia. LBDA is committed to advocating for equity and inclusion in research and making access to clinical care and support accessible to all. We believe our organization is operating at its best when our staff feels supported, our volunteers feel empowered, and our community truly feels served and heard.

Your partnership in these goals is vital for advancing the LBDA mission. We're so excited to continue our work together in the years to come.









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