LEWY BODY DEMENTIA ASSOCIATION

2020 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,

As was true for people and organizations around the world, 2020 presented a unique set of challenges for the Lewy Body Dementia Association (LBDA). Thanks to friends and partners like you, the momentum of the LBDA mission has continued to grow. Your support advanced the care, awareness, understanding, and treatment of those affected by the complex and debilitating disorders under the Lewy body dementia umbrella.

You’ll see your life-changing work detailed in this annual report. More than ever before, your partnership made it possible to extend greater care to more families in more places who are facing Lewy body dementia. From launching virtual events to expanding online resources, to increasing email and phone support for families, to passing key legislation and increasing healthcare professional training, to producing memorable, educational films—together we have provided a network of strength for those with Lewy body dementia, their families, and their caregivers.

The care and growth you’ve championed is making a significant difference in lives across the country. I can attest to this firsthand, as my father had Lewy body dementia. His journey is like so many others: first diagnosed with Alzheimer’s (for my father, it was around 2008) before later discovering it was in fact Lewy body dementia (two years later, in 2010). Our family walked with him on that difficult journey from 2008 until his passing in 2011. We’ve gained so much from LBDA, and I know other families are also finding the strength needed for this difficult journey.

Thank you for ensuring care to all those with Lewy body dementia and their caregivers through the LBDA during this challenging year. We look forward to sharing the continued impact your faithful support and giving is making in the year to come.

Christina Christie
LBDA Board President
LBDA’S MISSION

Our Work Together

Through outreach, education, and research, we support those affected by Lewy body dementias.

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 caregivers.

OUR 2020 IMPACT SUMMARY

The Difference You Are Making

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 2020.

17K+ received clinical care

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

7.5K+ professionals trained

healthcare professionals trained in clinical management of Lewy body dementia at the LBDA’s RCOE

4.9K+ caregivers supported & trained

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

150+ support groups

up from 75 groups in 2019! providing free and confidential weekly support to individuals affected by Lewy body dementia

8K+ connected to professional care

individuals connected to licensed professionals through the LBDA support channels
IMPACT SPOTLIGHT
Meet Lisa Kelly, LBDA Volunteer of the Year

Volunteers are the cornerstone of our organization and are vital to raising awareness. Each year, we bestow a Volunteer of the Year Award recognizing a special volunteer for: valuable and selfless commitment to innovation and dedication, impressive contributions to awareness, and significant enhancement of efficiency. **We are pleased to announce Lisa Kelly as our 2020 recipient!**

Lisa’s father was diagnosed with Lewy body dementia seven years ago. Though the experience has been difficult, it has brought her family closer together. And Lisa has become a true champion for the cause!

Her father’s diagnosis inspired her to couple her passion for health and her personal fitness goals with advocacy by participating in the prestigious Ironman Triathlon. To prepare, Lisa trained 10–12 hours a week, waking up at the crack of dawn to complete rigorous workouts. She rotated between swimming 2–2.5 miles, biking 20–60 miles, and running 5–20 miles. To raise awareness and to support more families like hers, she launched the annual event called the Lisa Kelly Ironman Challenge and has hosted annual Facebook birthday fundraisers. So far, she has raised over $20,000! Lisa’s passion and commitment are truly inspiring.

Lisa’s advice for those affected by Lewy body dementia is to learn everything about the disease, plan for the future as early as possible, and spend time with the people you love. She also advises that caregivers encourage their loved ones living with Lewy body dementia to stay active and healthy.

Volunteers like Lisa make a tremendous difference for the LBDA community. Thank you, Lisa!
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.

With the Research Centers of Excellence network, the LBDA collaborates with 26 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 leading to a cure.

**RESEARCH CENTERS OF EXCELLENCE NETWORK**

- Mayo Clinic, Coordinating Center (Rochester, MN)
- Barrow Neurological Institute (Phoenix, AZ)
- Cleveland Clinic – Nevada (Las Vegas, NV)
- 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 AbilityLab (Chicago, IL)
- Stanford University (Palo Alto, CA)
- The Ohio State University (Columbus, OH)
- Thomas Jefferson University (Philadelphia, PA)
- 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 Rochester Medical Center (Rochester, NY)
- University of Virginia Health (Charlottesville, VA)
- University of Washington (Seattle, WA)
IMPACT SPOTLIGHT
Leading the Way to a Cure

Three 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. RCOE is a collaboration between the LBDA and 26 of the nation’s leading Lewy body dementia academic medical institutions. This year, all sites have demonstrated the capabilities to do Phase 1, 2, and 3 clinical trials in Lewy body dementia, resulting in the RCOE program becoming a critical piece of the infrastructure needed to study potential new treatments for the disease. In 2020, more than 17,000 people with Lewy body dementia received clinical care via RCOE and more than 7,500 healthcare professionals were trained in clinical management of Lewy body dementia.

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.

Two key pieces of legislation were passed in 2020, thanks to your support and direct efforts. LBDA volunteers joined with veterans and Parkinson’s disease advocacy groups to contact their legislators in support of the Fair Care for Veterans Act (H.R. 5610/S. 3444). With its success, Vietnam veterans with parkinsonism now have a pathway to VA benefits. This represents a huge boon for Vietnam veterans with Lewy body dementia, as parkinsonism is a very common symptom. With the passing of the Promoting Alzheimer’s Awareness to Prevent Elder Abuse Act (S. 3703/H.R. 6813), the Justice Department must bolster its efforts to protect people with Alzheimer’s disease and related dementias. It requires greater emphasis on engaging people with dementia as witnesses and to review/refine best practices and training materials for law enforcement and judicial officials.

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, you are supporting the Dementia with Lewy Bodies Consortium Study, a 10-site research network led by the Cleveland Clinic, which is running a 5-year study to assess people with Lewy body dementia over time. Researchers collect and analyze their clinical information, brain imaging scans, and biological samples.
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. Your generous support and giving through the LBDA have accelerated education about Lewy body dementia, directly advancing care for the wider community.
IMPACT SPOTLIGHT

Expanding Knowledge through Healthcare Education

This year the LBDA became a joint provider of continuing medical education (CME) through a new collaboration with Medscape, a global leader in healthcare professional education. Thanks to an unrestricted educational grant from ACADIA Pharmaceuticals, Inc., over 5,100 physicians and allied healthcare professionals obtained CME credit through this new educational activity on the diagnosis and management of Lewy body dementia.

The LBDA also organized a webinar in collaboration with the Association for Frontotemporal Degeneration and the American Society on Aging covering practical strategies for care in Lewy body dementia and frontotemporal degeneration. This event offered continuing education units through ASA to the 527 healthcare professional learners who attended. Later in the year, we joined forces with the Accelerating Treatments and Cures for All Dementias (ACT-AD) coalition to develop a webinar on Research and Clinical Development in LBD for member organizations in the ACT-AD coalition.

Scientific and educational offerings in early 2021 include the LBDA Research Centers of Excellence symposium on blood and tissue biomarkers in Lewy body dementia and a CME-accredited webinar series on performing Lewy body dementia assessments virtually. These events were recorded and can be viewed on demand at the LBDA YouTube page, LBDAtv.

All of these training opportunities have better equipped professionals to deliver quality care to those affected by Lewy body dementia. Thank you for supporting educational advances like these!
AWARENESS PROGRAM
Raising Awareness for Lewy Body Dementia

Lewy body dementia affects an estimated 1.4 million individuals and their families 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. Through your support, 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 Susan Schneider Williams were on a quest to understand the inexplicable 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 someone with Lewy body dementia, and SPARK: Robin Williams and His Battle with Lewy Body Dementia, a 45-minute educational adaptation of Robin’s Wish, which was funded by the LBDA and 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.

Through the LBDA—thanks to you!—SPARK is now freely available to all academic medical research institutions and organizations involved in Lewy body dementia and related neurodegenerative diseases. Your generous support is driving greater understanding, detection, diagnosis, and quality care management of Lewy body dementia to lead to better outcomes for individuals and families.
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. Our Support Program provides both individual and group services every step of the way.

Living with Lewy Facebook Group offers two-hour support meetings led by the LBDA Support Services staff; some experienced volunteers also assisted with group moderation and communications. The 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. Through the Lewy Line, individuals are able to connect directly to the LBDA licensed professionals. Additional care comes from Lewy Buddies who are the LBDA’s volunteers offering support and guidance using their own lived experience. Through your partnership, those affected by Lewy body dementia are receiving the care they need.
IMPACT SPOTLIGHT
Your Amazing Support for Bonnie & Mary Alice

Bonnie Roache and her mother, Mary Alice, have always enjoyed a warm, loving relationship. So, when her mother’s behavior began to turn from affectionate to agitated, Bonnie knew something was wrong. She remembered the neurologist’s numbing words: “Your mother has Lewy body dementia.”

Bonnie became her mother’s caregiver, first helping her find an apartment in Atlanta so they could be closer together. But as Lewy body dementia started to swallow Mary Alice’s independence, she was forced to move into a memory care facility. Bonnie visited her daily and often needed to educate the staff about Lewy body dementia issues, including Mary Alice’s agitation. Eventually Mary Alice moved into a nursing home, but the pandemic isolated her from her family which accelerated the progression of Lewy body dementia. When her mother’s disease was in the final stages, Bonnie decided to bring her mother home to be with her loving family. They enjoyed five months together, until Mary Alice began fading at year’s end. She passed on January 5, 2021. Bonnie says, “People with LBD do not remember a lot, but they understand what makes them feel safe. Even when Mom no longer knew I was her daughter, she knew I was someone she loved.”

Because of your generous support and giving, Bonnie and Mary Alice found the lifeline they needed. Bonnie is grateful for how the LBDA shaped her understanding of the disease, and she is now passionate about sharing her experiences to help raise awareness in the healthcare community and beyond.
OUR GROWTH

Annual Revenue by Year

Over the past five years, generous partners of the LBDA have spurred on significant growth of support, care, research, and education for those affected by Lewy body dementia.

FY 2020 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 2020 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 TODD & MARK

Looking Ahead: Our Future Impact

Your impact this past year on the lives of those affected by Lewy body dementia is remarkable. Because of your investment and commitment through LBDA, medical research, professional education, caregiving support, and public awareness have all grown. 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 and caregivers to enhance understanding of all aspects of Lewy body dementia

• Grow awareness within the Lewy body dementia community across the nation to better assess and utilize the full spectrum of LBDA resources

• Ensure patients, families, and caregivers receive personal, advanced care each step of their journey

These robust growth initiatives include many exciting new offerings. For example, this year we’re launching a new app to empower patients and their care partners. And in-house, to support future growth and better meet the needs of our constituents, we’re enhancing our internal organizational structure. This includes new team members 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.

Todd Graham & Mark Wall
Co-Executive Directors
Lewy Body Dementia Association, Inc.