



2022

ANNUAL REPORT

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

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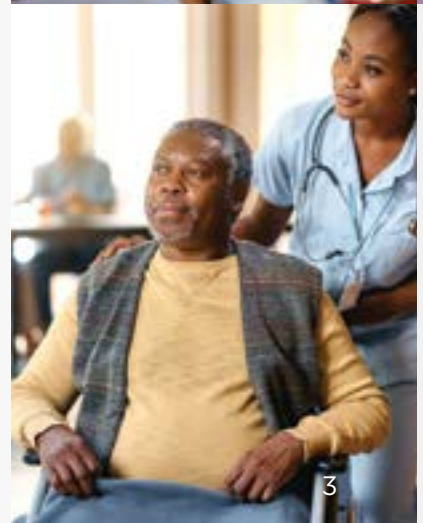
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The Lewy Body Dementia Association (LBDA) is the leading national organization solely dedicated to improving the lives of LBD families.





OUR MISSION

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.

OUR VISION

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

A MESSAGE FROM ALLISON FELDMAN, CEO

Every year since 2002, the Lewy Body Dementia Association (LBDA) has been meeting people affected by Lewy body dementia (LBD) where they are at every point in their journey. We provide education to our community and healthcare professionals. We pick up the phone when someone who is newly diagnosed calls with questions and uncertainties. We connect care partners with our wonderful Lewy Buddy volunteers who have walked a mile in their shoes and can reassure them that they are not alone. We provide up-to-the-minute information on the latest research and opportunities to participate in LBD clinical studies and trials.



Today, LBDA is the leading national organization solely dedicated to improving the lives of LBD families.

When I was brought onboard in June 2022, I knew that LBDA had cultivated a stellar reputation as a reliable resource for information, a safe place to find support and community, and as a vital partner for clinical research. What I quickly realized is that we could not have built our reputation or served our community for all these years without the people who comprise LBDA. We are very lucky to be guided by a passionate board of directors. Our staff are talented and experienced professionals who understand that we are all honored to serve the LBD community. Our team is supported by compassionate, dedicated volunteers who give their time and generously share their first-hand experiences with LBD.

As I look to the future, I am excited to position LBDA to be even more responsive and effective to help more people impacted by LBD. In 2023, as we mark our 20th anniversary, we are working hard to create our 2024-2026 Strategic Plan, incorporating your feedback about ways we can better meet your needs. We will expand our Research Centers of Excellence, build new bridges with researchers and cultivate new collaborative relationships with other organizations. We will re-dedicate ourselves to the mission of LBDA and thoughtfully expand our program provision. We will ensure that we are being vigilant stewards of the funds you have so generously given to support our programs and advance LBD research. And we will be transparent about the impact your gift makes on the LBD community we serve.

Warm Regards,

Allison Feldman
Chief Executive Officer

A MESSAGE FROM TINA CHRISTIE

2022 marked a year of progress, growth and change for the Lewy Body Dementia Association (LBDA) some of which is highlighted in this annual report. Through our outreach, education, advocacy, and the generous and enthusiastic support from donors like you, LBDA continues to make a positive impact on the lives of those living with Lewy and their families and communities which support them.

LBDA's Research Centers of Excellence was a powerful force advancing research for LBD and related disorders with its investigators publishing nearly 140 manuscripts. You will read the inspirational story of Helen Medsger, LBDA's Volunteer of the Year and an integral part of our Lewy Buddy volunteer program. As the cornerstone of our organization, volunteers not only aid our staff in achieving the mission of LBDA, but they are also at the heart of the LBD community, locally and nationally. They are fundraising, building awareness of LBD in their neighborhoods and communities, and facilitating safe, informative, and compassionate conversations within our support groups. We are so grateful for you, our volunteers!

To continue the momentum we have built over the last 20 years, we welcomed new leadership this year with the appointment of Allison Feldman as CEO who will further amplify LBDA as the leading national organization solely dedicated to improving the lives of LBD families. Shannon McCarty-Caplan, who joined the LBDA Board of Directors in 2012, will assume the role as Board President in 2023. Though I am transitioning off the board, my involvement with LBDA will not end. I am looking forward to hosting the 10th Anniversary of the Lewy Body Dementia Walk for Awareness in September 2023 to raise crucial funds to support the mission of LBDA. I hope you share in my excitement about the amazing work and undeniable transformative positive impact LBDA will continue to have in the next 20 years.

Warm Regards,

Christina Christie

LBDA Board President





IMPACT SPOTLIGHT

You Make it Possible

Because of your generous support we continue to expand our reach to the LBD community by offering support, education and advocacy for those living with Lewy, their care partners and health care providers. Here is a snapshot of the meaningful impact you made possible!

■ 19,600+ received clinical care at LBDA's Research Centers of Excellence

Individuals with LBD and their families were connected with highly-specialized physicians and leading LBD academic medical institutions across the country.

■ 9,600+ healthcare professionals trained

LBDA's Research Centers of Excellence provided training in clinical management of LBD to healthcare professionals nationwide.

■ 7,800 LBD Educational Publications Delivered

LBDA offers free educational resources and publications through an easy, online request form to anyone seeking information on LBD.

■ 8,000+ Community Connections

The LBDA Support team is a conduit to connect members of the LBD community such as those who are symptomatic, diagnosed, care partners, bereaved and allied health professionals to additional resources and other support services.

■ 100+ Support Groups

Occurring monthly, support groups provide free and confidential support to individuals affected by LBD.

■ 2,500+ attendees for screenings of SPARK: *Robin Williams and his Battle with Lewy Body Dementia*

LBDA hosts screenings of this compelling documentary with Q&A sessions to provide a deeper dive into LBD, its biology, symptoms and impact on patients and care partners.

■ 10% Growth in Online LBD Community

LBDA actively engages our online community by sharing research news, educational resources and promoting upcoming events to keep our community well-informed and supported.

Funding the Next Generation of LBD Researchers

LBDA's newest research grants provide essential seed funding for emerging LBD investigators. These funds support the development of preliminary data needed to apply for much larger grant awards from the National Institutes of Health (NIH). Awards such as these are a key part of a healthy research ecosystem, as they support the ability of researchers interested in the field to establish a sustainable career path.



Ece Bayram, M.D., Ph.D., University of California, San Diego (UCSD), received LBDA's inaugural **New Investigator Pilot Study Award** in 2022. Dr. Bayram studies the impact of biological sex and gender on risk for developing neurodegenerative disease. LBD is more common in men than women, but women more frequently have more co-existing Alzheimer's disease. Even in 'pure' cases, the risk factors for LBD may vary between men and women. Dr. Bayram's study explores the interplay between sex and risk factors for LBD. Developing a better understanding of how LBD impacts men and women differently may ultimately provide important insights that guide criteria for predicting and diagnosing LBD.

LBDA: A Valued Collaborator

LBDA plays a vital role in research by representing the needs of LBD families. We are increasingly approached to collaborate on NIH-funded LBD studies and invited to serve on study teams and external advisory committees.

In 2022 LBDA personnel served on external advisory committees to the North Atlantic Prodromal Synucleinopathy (NAPS) Consortium study and the LBD Center Without Walls (LBD CWOW). The goal of the NAPS Consortium is to study potential disease-modifying treatments in people with REM sleep behavior disorder, a risk factor for LBD and related disorders. The LBD CWOW seeks to understand how proteins implicated in LBD and Alzheimer's disease may interact and affect how each disease may unfold.

The Power of the LBDA's Research Centers of Excellence

The LBDA's Research Centers of Excellence program and its investigators are collectively making remarkable contributions to our understanding of LBD and related disorders. For example, just in over a year the investigators had nearly 140 manuscripts published.

“The LBDA’s RCOE program is a nationwide consortium of healthcare professionals devoted to LBD clinical care and research,” stated Brad Boeve, M.D., primary investigator for the RCOE Coordinating Center at Mayo Clinic. “This is and will continue to be the foundation for major LBD work in the future.”



- 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 (Coordinating Center), Rochester, MN
- 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
- University of California, San Diego, San Diego, CA
- University of Colorado Anschutz Medical Campus, Aurora, CO
- University of Florida, Gainesville, FL
- University of Miami, Miami, FL
- University of Michigan, Ann Arbor, MI
- University of North Carolina, Chapel Hill, Chapel Hill, NC
- University of Pennsylvania, Philadelphia, PA
- University of Washington, Seattle, WA

EDUCATION

LBDA responds to the needs of our community

We learned via calls to the Lewy Line and reports from clinicians at our Research Centers of Excellence that accessing person-centered care from allied health professionals was often difficult. People with LBD were often refused therapy services, or people felt the services they received were not satisfactory. To address this need, we developed a continuing education course for occupational therapists (OT), physical therapists (PT), and speech language pathologists (SLP).

Lewy Body Dementia: The Role of OT, PT, and SLP in Person Centered Care is a 4.5 hour masterclass offered on ContinuED.com. The course launched in September and has been viewed by 5,500 clinicians and has a 5-star review.

In this masterclass, the complexity of Lewy body dementias and evaluation and intervention approaches are examined. Case studies emphasize opportunities and approaches for interprofessional collaboration to provide comprehensive, person-centered care.

Upon completion, participants are able to describe the symptoms LBD and how it differs from other forms of dementia, as well as describe physical therapy, occupational therapy and speech-language assessment and treatment techniques when working with people with dementia.

The syllabus includes:

- <https://www.speechpathology.com/slp-ceus/course/lewy-body-dementia-role-pt-10308>
- <https://www.occupationaltherapy.com/ot-ceus/course/lewy-body-dementia-role-pt-5719>
- <https://www.physicaltherapy.com/pt-ceus/course/lewy-body-dementia-role-pt-4536>

“ TESTIMONIAL ”

March 10, 2023

I have had two friends with this diagnosis and no treatment program was established for them. It was very frustrating for the carer, the patient, and me as their friend to watch. I feel like this information will help me encourage the interventions and treatments with evidence you presented.

Cheri

EDUCATION

The Power of Sharing a Lived-Experience with LBD

Premiering in 2020, *SPARK: Robin Williams and His Battle with Lewy Body Dementia* continues to be a sought-after educational resource. With its raw and honest story as told by Susan Schneider Williams, wife of actor and comedian Robin Williams, *SPARK* reveals the struggle those living with LBD face—the quest to understand, detect and diagnose the disease.

Over 15 educational events featuring the documentary were hosted nationwide this year.

Since its debut on [LBDA's Mediflix Channel](#), *SPARK* remains one of the most watched videos on the platform. In 2022, the documentary and its trailer were viewed over 7,500 times generating over 32,000 impressions. Inspired by its reach, Mediflix now provides promotional support to bring awareness to the documentary on behalf of LBDA.



SPARK: Robin Williams and His Battle with Lewy Body Dementia is funded by the Lewy Body Dementia Association and its partner, ACADIA Pharmaceuticals, Inc.

SUPPORT

We Are Here When You Need Us

LBDA's Support Team provides direct-care support to individuals who are symptomatic or diagnosed with LBD, and their care partners both current and bereaved. We assist families with a host of different needs such as connections to others with lived-experience, information and education about LBD, guidance and advocacy.

We connect with the LBD community on an ongoing basis in various ways including answering calls on the Lewy Line and responding through our dedicated Support email. This year alone we spoke with over **1,250 individuals with LBD and their care partners**, gladly investing **over 37,000 minutes addressing questions and concerns**, sharing resources and often just lending a compassionate ear.

Our nationwide network of compassionate volunteer Lewy Buddies and Support Group Facilitators are a critical and valued extension of the support team. We are incredibly grateful for their generous contributions of time and for providing comfort and guidance to others by sharing their lived experiences with LBD. Not only do they lead support groups across the country, but they also help support the growing community within our closed, support-specific Facebook groups, now with over 7,000 members.

LBDA's support extends beyond those living with Lewy and their care partners. Education and resources were provided to over 100 allied health professionals and service providers in multiple care settings such as homecare, Area Agencies on Aging, hospice, care management and long-term care communities in 2022.



VOLUNTEER OF THE YEAR

Helen Bundy Medsger

Helen's story is a unique one. Helen has had three first-degree relatives impacted by LBD throughout her life and was the primary caregiver of two of these relatives.



Her first encounter with Lewy came early in life, as she supported her father through his challenging journey with the disease at a time when LBD was still widely unknown. In fact, the diagnostic criteria for LBD was not released until the year he passed. Helen experienced the struggle that so many face as they seek an accurate diagnosis for their loved ones. Wading through complex conversations with healthcare professionals, she fought to advocate for his needs and quality of life at a time when his needs were not generally understood by those in the medical field. Six years later, her sister Maureen began to show signs of the same terrible disease.

Professionals assured Helen that Maureen's changing behaviors were likely attributed to the 'nature of growing older as a woman' - menopause, and subsequently, depression. She was prescribed anti-depressants, and instantly saw adverse side effects. Helen and Maureen began "pounding at the health system - [Maureen] needed more testing."

Their efforts were not in vain. With neuropsychological testing approved, they could move forward. The results were anything but positive. Now, officially diagnosed with Lewy body dementia, Maureen would turn once more to Helen just as their father had. She asked, "Will you walk this path with me?"

For Helen, this was not even a question. She knew that something needed to change, though. Her first experience as a caregiver had taken a toll on her, and she knew she couldn't do it the same way again. "By the time my dad passed, I was not in good shape at all." She told herself, "You've got to do this differently, Helen," and she made sure to create a village of care, mentorship, and support around she and Maureen as they navigated their journey together.

Helen's experience as a caregiver and advocate for LBD coupled with Maureen's keen ability to articulate what she was experiencing; whether it be hallucinations, delusions, or another symptom of the disease, empowered the sisters in their 15-year walk with Lewy. After their father, the two knew that the best medicine for Maureen was to stay physically and mentally engaged. They became involved with the University of California San Francisco Memory and Aging Center, participating in invaluable research and sharing their story to help raise awareness of the disease and its management amongst others.

Helen would coordinate transportation with her sister's neighbors so that she and Maureen could participate in activities outside the house, such as water aerobics. They attended water aerobics three days a week until she went into care, where Maureen would reside for the last three years of her life.

Even as Helen speaks about her efforts in the Lewy body dementia space, she reflects on the power of Maureen's continued influence. Helen knew from caring for her father what the future held in store for Maureen, and she decided early on to focus on creating moments of joy for the two of them during the time they had together. Every research trip was coupled with one for pleasure, and the photos from these trips remain some of her most cherished. "Every day my role is to bring her joy. If I can make her smile, that is a gift, but if I can make her laugh? That is the best thing I can give her, and it is a gift to me at the same time. We laughed a lot."

She advises others living with Lewy to find happiness in the little things. "I stress to people; this is going to be a marathon. There is no sprint in this – you have to pace yourself. There are going to be hills and valleys, and they are going to be rocky." Focusing on the wins when they come, and ensuring you have a community there to support you when it feels like there are none, are imperative as a caregiver. The importance of support cannot be overstated.

In 2004, Helen met The Whitworths, early founders of the Lewy Body Dementia Association, and became heavily involved in the organization and its forums. She remains engaged in the community to this day, amassing an incredible network of those in the community whom she supports through education, awareness, and advocacy efforts as a volunteer. Although Helen has expanded her impact to other dementia-focused organizations, she continues her work with LBDA even still.

Helen's world has grown large in the time since her sister's passing. Quickly becoming a part of the international conversation surrounding LBD, she is now a member of the National Alzheimer's Project Act (NAPA) Council on Research, Care, and Services along with other advisory boards, and a nationally recognized resource on Lewy body dementia caregiving. She has commented on a World Health Organization (WHO) paper, edited a book on LBD, created webinars and presentations alongside the University of California San Francisco, and spoken on podcasts.

Helen continues to participate in research and promotes the inclusion of those with lived experience of dementia in research development, manages support groups, and provides one-on-one support through the LBDA Lewy Buddy program. The impact of her tireless efforts is felt the world over.

Helen is an exemplification of LBDA's mission to support those living with Lewy body dementias, their families, and caregivers. We are beyond grateful for her dedication and continued work helping others navigate their own journey with Lewy.



COMMUNITY SPOTLIGHT

Too Young for Lewy?

As an academic with a 3.73 GPA in his doctorate program, JR Pagan was worried when he started failing courses. His instructors blamed it on stress, but JR felt it had to be something more.

Proving everyone wrong

At age 46, JR was initially diagnosed with a mild cognitive impairment. But he was assured that he was too young for dementia. Unsatisfied with his diagnosis, JR used his research skills to find more answers. He spent hours poring over resources on the LBDA website. His efforts helped convince his doctor that he might have LBD. Sadly, he was proven right and was ultimately diagnosed with LBD.

JR knew that life with LBD would be difficult, but as an openly gay Hispanic man he had never been one to shy away from adversity. Prior to his career in academia, JR served in the U.S. military, and had faced many life challenges that prepared him to accept his diagnosis with grace and determination.

He resolved to do just that as he left San Diego with his pup to return to the first caregivers he had ever known – his mother and father. The move put JR in the unique position of being both caregiver and cared for, at times assisting his 70-something parents with their own cognitive decline issues.

Choosing a positive path

Today, JR is a passionate advocate for those with dementia, working with LBDA support groups and the Dementia Action Alliance. He encourages others to advocate for LBD awareness and support in any way they can, from making posters to talking to their doctors to supporting those who were recently diagnosed and their families. He also refuses to let LBD change his positive outlook. Whether gardening, going to the gym, or serving others, JR chooses to live well with Lewy for as long as he can and find happiness in every day.

“ Throw away the timeline. Being newly diagnosed with LBD, learn to find hope in the small things. Stay one day at a time and enjoy the moment. ”



Community Fundraising Events



Mike Madness

Mike Madness honors award-winning journalist, Mike Oliver, who was diagnosed with LBD in 2016. The event started as a way for family, friends and colleagues to show Mike their support and has grown substantially. Taking place in Birmingham, AL and now in its fourth year, Mike Madness has raised funds for LBD research and awareness of the disease.



The Lewy Body Dementia Walk for Awareness

Started by LBDA Board President, Tina Christie, in honor of her late father James Christie, the Lewy Body Dementia Walk for Awareness ushers in its 9th year of impact in the Jamison, PA community and beyond. This walk, held both in-person and virtually, has brought hundreds of individuals together over the years.



Picklin' for a Cure

The second annual pickle ball tournament celebrated the lives of TK Warfield and Tony Gomez, beloved members of the Tucson, AZ community. This three-day event was filled with competitive play and education, as attendees learned about LBD and all that LBDA is doing to combat the disease and support the LBD community.

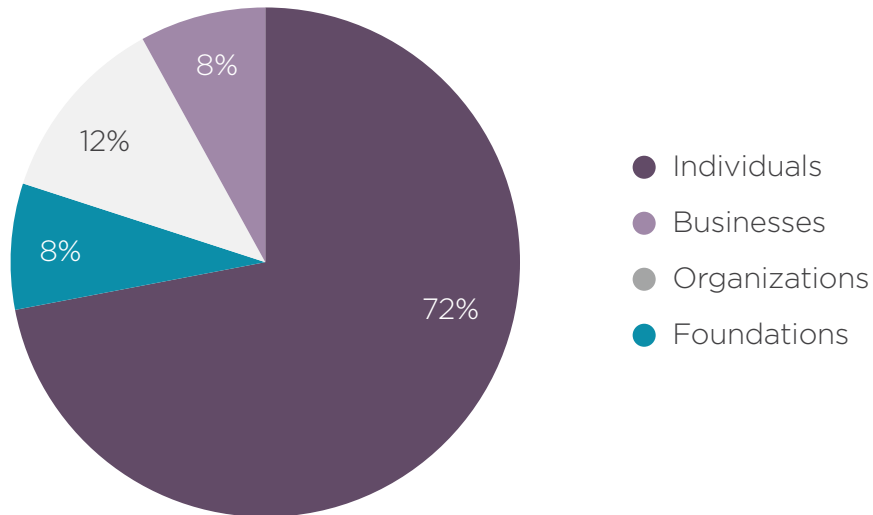


LBD Luncheon and Fashion Show

This annual event is hosted by LBDA's 2021 Volunteer of the Year, Barbara Levine, and the Robert H. Levine Foundation whose mission is to raise awareness of Lewy body dementia and funds to support the research of LBD. Initially started as an instore fundraiser, this event has developed into an exclusive fashion show and luncheon

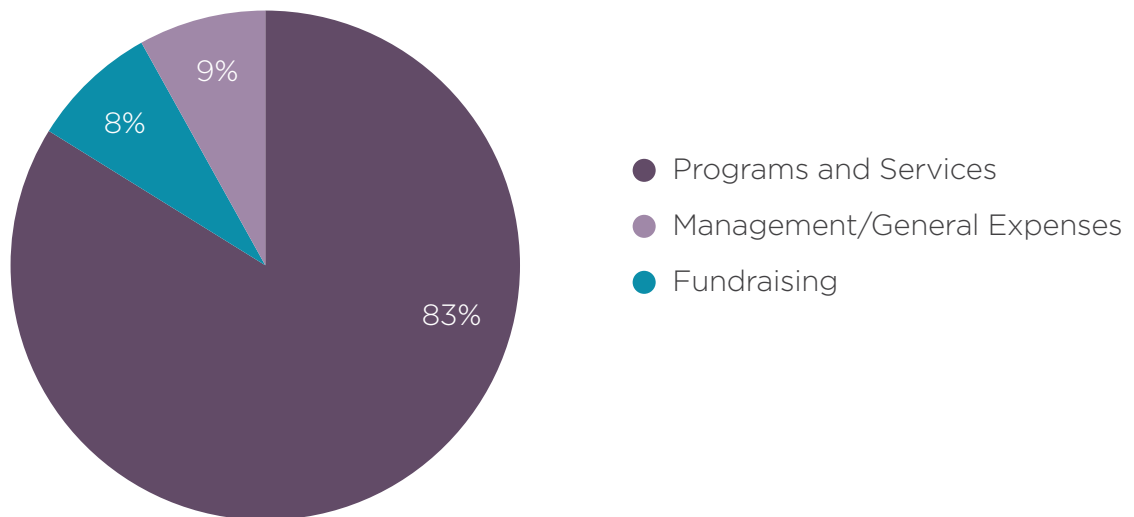
Revenue by Category

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.



Expenses by Category

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.





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