



2023 Impact Report

Two Decades: Stronger than Ever



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

**Two Decades
of Service**

**Two Decades of
Propelling
Research Forward**

**Two Decades of
Empowering the
LBD Community**

**Two Decades
of Building
Community**



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LETTER FROM ALLISON FELDMAN, CEO

This year, the Lewy Body Dementia Association (LBDA) reached a significant milestone by marking our 20th anniversary of service. For twenty years we have worked tirelessly on behalf of the 1.4 million people affected by LBD.

Every day, we meet people whose lives have been changed by this disease, and we listen and respond to their needs – from providing free educational programming to picking up the phone when someone who is newly diagnosed calls with questions and uncertainties. We know that disease education is critically needed, and this year we welcomed over 5,000 registrants for our inaugural Community Webinar Series. We know living with Lewy is extremely challenging, not only for those who are symptomatic or diagnosed, but also for their care partners and family members, even after their loved one has passed away. This year, LBDA provided crucial support services to over 1,400 individuals who called the Lewy Line and saw exponential growth in participants in our in-person and online support groups.



Through our work, we honor the enduring strength and tenacity of the LBD community. We are incredibly grateful to you for providing philanthropic support and to our volunteers who graciously share their time and personal experiences to help others. We are so appreciative of the guidance provided by our Board of Directors, our advisors and partners within the research community, the members of our Scientific Advisory Council (SAC) and to all those who dedicate themselves to improving the lives of people living with LBD.

LBDA's commitment to accelerating research is unwavering. We continue to support recruitment for clinical trials through our Lewy Trial Tracker. Our Research Centers of Excellence network now includes over 20 leading academic medical research institutions across the country focusing on research to achieve better treatment outcomes and providing expert clinical care and support to LBD families.

Next year, we will embark on our 2024-2026 Strategic Plan, which was developed with the insights you shared about ways we can better meet your needs. And we will host the first ever Externally-Led Patient-Focused Drug Development meeting, a once-in-a-lifetime opportunity for the LBD community, to share their lived-experience with the FDA and other regulatory stakeholders.

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. We will expand our program provision, forge new relationships with research institutions, and reach more people affected by LBD. All of which would not be possible without your support.

Warm Regards,
Allison Feldman
Chief Executive Officer

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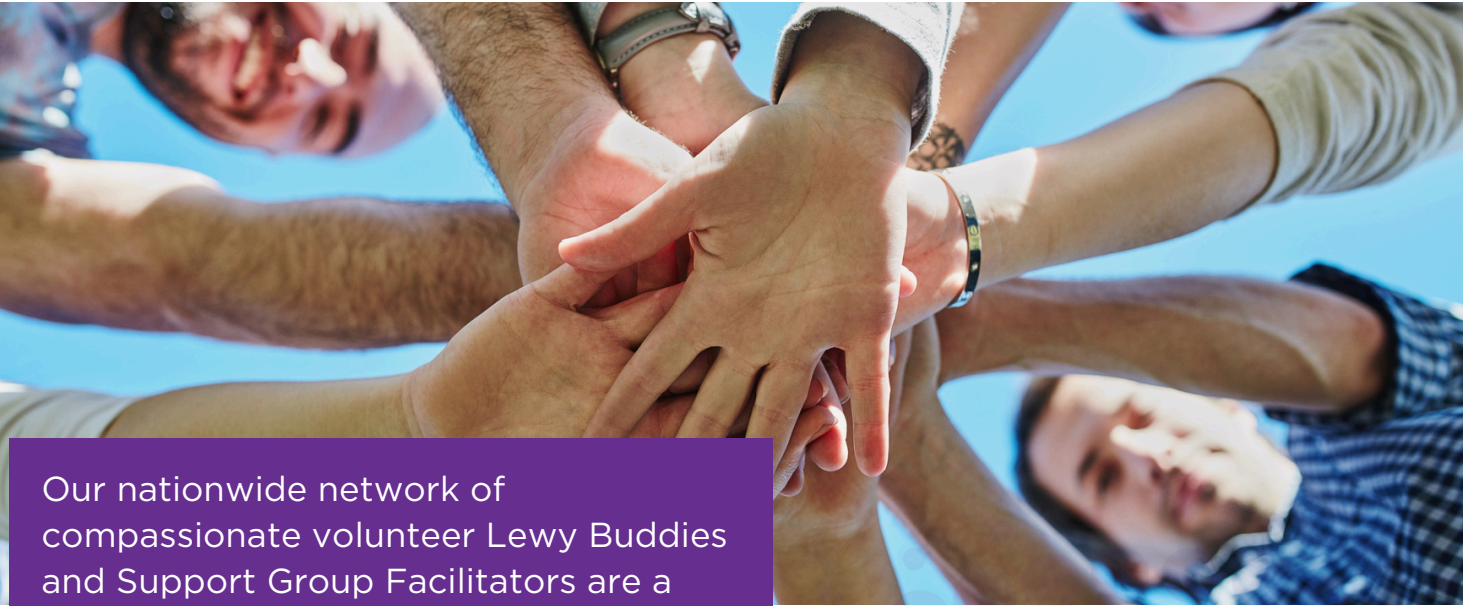
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University of Washington School of Medicine

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.



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, they actively assist with our Facebook Support Communities, which continue to grow each year. In 2023, we reached over **8,200** participants, a **228%** increase since 2020.

We served over **1,400** individuals and their care partners via the Lewy Line for a total of over **39,000** minutes addressing questions and concerns – a **14%** increase from 2022.

KEY HIGHLIGHTS

- A record-setting October Awareness Month with **174 calls** to the Lewy Line (monthly average is 120).
- Most touchpoints are care partners and most identify as spouse/partner or as adult child of someone with LBD.
- We also supported many individuals who were diagnosed with LBD or were experiencing symptoms but were not yet diagnosed, as well as **27 individuals** who had a loved one who had died with LBD.
- We received at least one call from every state except Alaska.

Learning Together

LBDA responded to the LBD community's call for accessible education by launching the 2023 Community Webinar Series and the Lewy Learning Center sharing knowledge, support and resources with thousands.



In early 2023, LBDA sent out a survey to the community to learn what their priorities were for education, support and research. Learning opportunities via video or webinar were identified as a top way in which LBDA could best support the individual and their family with **50%** of respondents identifying webinars or other live programs as their preferred format for education about LBD.

In response, LBDA launched the **2023 Community Webinar Series**. Between the months of May and November, we hosted 9 webinars on a variety of topics including vision and cognitive changes in LBD, the role of DaTScan in the diagnosis of LBD, and neuropsychiatric care. Over **5,000** people registered to attend the series, and the recordings have been viewed over **10,000** times on LBDAtv, LBDA's YouTube Channel.

The success of the 2023 Community Webinar Series offered a glimpse into the educational needs and interests of the community. Survey responses were gathered following each event regarding the presenter, content, and topics of interest for future webinars. Interestingly, the majority of respondents to the post-webinar surveys identified their relationship to LBDA as having "attended a previous webinar," suggesting the webinars have served to increase the reach of LBDA's program provision to the broader LBD community.



The Lewy Learning Center

In October 2023, LBDA launched the Lewy Learning Center, an online platform for free education courses on LBD designed for individuals with LBD, their family members and care partners. Each course offers several lessons which can be watched and re-watched on demand at any time. Courses also contain transcripts, tip sheets, and downloadable resources to provide access to more educational and support resources which complement each lesson. The first course, Living Well with Lewy, featured a faculty of presenters on a variety of topics, including interviews of those living with Lewy who shared their lived experience. A range of courses are planned for those living with Lewy and their care partners as well as healthcare professionals in 2024.

Moving the Needle: How LBDA is Advancing Scientific Progress through Our Research Grants Programs

Recognizing the need for additional research funding specific to Lewy body dementia, LBDA launched our research grants program in 2017. Since that time, we have made **\$1,284,000 of grants**, funding **40 different researchers** in at least **33 research projects**.



Jennifer G. Goldman
MD, MS,
Chair, LBDA Scientific
Advisory Council

Supporting research through grants is one of the most direct and impactful ways that nonprofit organizations can help accelerate progress in science and clinical treatments. Launched in 2017, the LBDA grants program has now funded over 20 Research Centers of Excellence, a collaborative, trial-ready network across the U.S. each year, and has expanded to support early career and other investigators through research grants. Together, these programs are creating a critical mass of activity and enabling the next stage of scientific discovery for the LBD community.

- Jennifer G. Goldman, MD, MS

The Research Centers of Excellence (RCOE) Program

Although LBD is the second most common neurodegenerative dementia, there have been few clinical trials. To develop a clinical trial-ready network of sites, LBDA in 2017 launched the Research Centers of Excellence (RCOE) program. At the end of 2023, LBDA was providing research funding to over 20 RCOEs across the country, providing a platform for research collaboration among some of the most important and productive LBD researchers in the United States. Annually, the RCOEs enroll approximately 3,000 people into LBD research studies and together publish more than 100 research papers on LBD and related disorders.

The LBDA RCOE program has changed the field. At its inception, it created a wonderful platform for world-class LBD researchers across the country to collaborate. And that builds its own kind of gravity. Now, clinical trial sponsors know where to turn when considering a clinical trial, young researchers are mentored and developed, and major research funders such as NIH can create more funding opportunities for LBD, knowing that the RCOE network is both developing a pipeline of researchers and facilitating collaborative research in this field.

- Bradley F. Boeve, MD

The Mentorship Award Program

Mentorship is a key part of the development of a researcher's career and can make the difference between a promising scientist who continues to study LBD and one who moves into a different field. In order to build a pipeline of highly qualified clinician-researchers focused on LBD, LBDA in 2021 launched the Mentorship Award program, which pairs each awardee with an internationally recognized senior researcher in the LBD field to provide guidance and mentorship. **Four young researchers were in the Mentorship Award program in 2023.**



Bradley F. Boeve, MD
*Principal Investigator
of the RCOE
Coordinating Center at
Mayo Clinic*





Jesse Cohen, MD
Mentorship Awardee
in 2023, University of
Florida

The Mentorship award from LBDA has been crucial for launching my career as a clinician-scientist studying LBD. Dr. Galasko [Dr. Cohen's mentor] provided invaluable feedback on the direction of my research and having this support has helped to connect me with other leaders in the field.

- Jesse Cohen, MD

Supporting Clinical Trial Recruitment

Most clinical trials fail to enroll enough participants, and this problem is exacerbated in dementia trials. Frequently, the trials are only recruiting people without other significant health concerns—a rarity among people with LBD—and they often also seek the participation of a care partner, meaning that for every person in the trial, the study team actually needs to recruit a pair of people. In 2023, LBDA began supporting recruitment for the RewinD-LB trial, a Phase 2 trial of the investigational drug neflamapimod in people with DLB. Together with the SHIMMER trial of the investigational drug CT1812, this means that LBDA supported recruitment for both of the most advanced trials in DLB in 2023.

We supported recruitment by educating the LBD patient and family community about the trials and about how to participate if they choose to. This took the form of community webinars, study brochures, a banner and landing page on the LBDA website, email and social media communications, targeted emails through Lewy Trial Tracker, inclusion in the Lewy Digest, and other activities. These activities were funded by NIH, the primary funder of both trials. In addition to supporting recruitment for these specific trials, these activities are also resulting in durable materials and programs that will continue to support education and recruitment for all LBD studies, such as educational materials and a volunteer research advocate program.



Tim Perkins

Each year, LBDA recognizes a volunteer who exemplifies a deep commitment to advancing our mission of education, outreach, and support for those affected by Lewy body dementia (LBD), their caregivers and families. For 2023, we are thrilled to honor Tim Perkins as our Volunteer of the Year.

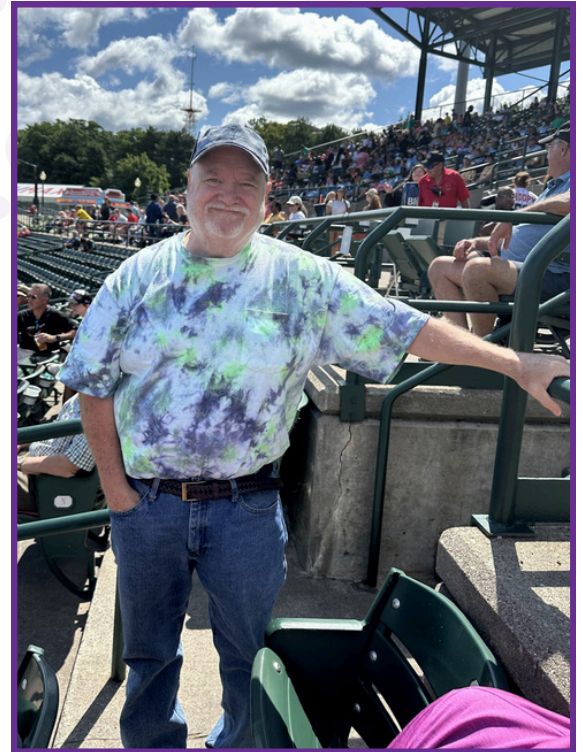
Tim has been a Lewy Buddy since 2022, offering support and guidance to many individuals navigating the challenges of an LBD diagnosis. His journey with Lewy body dementia (LBD) began eight years ago, and he vividly recalls the day his life changed. “It was a Wednesday,” Tim reflects. “Our whole world stopped.” He was advised against searching for information online, a suggestion he admits he ignored. “That was the first thing I did when I got home!” he laughs.

Tim’s initial internet search led him to LBDA’s website and eventually to attending one of the support groups. This small group of people who knew what he was facing provided him with resources, information and was a tremendous source of comfort at an uncertain time. “My whole world changed that hour...I was so scared, but by the time I left, I was no longer scared, and I have not been scared since.”

In the LBDA support group, Tim learned he could lead a full and meaningful life with Lewy body dementia (LBD). This includes maintaining a healthy lifestyle through diet, sleep, and exercise, but Tim believes having a purpose is the most important aspect of living well. “You have to have purpose!” he says earnestly.

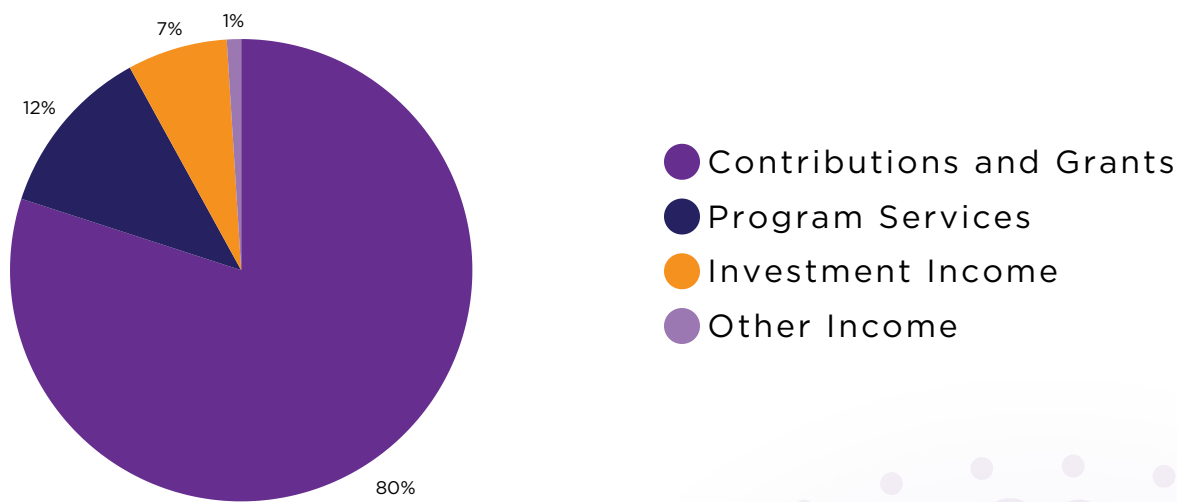
Embracing this philosophy, Tim joined LBDA as a Lewy Buddy and has helped many individuals navigate the uncharted waters of LBD. His passion for helping others is evident in his work. “I love helping people and knowing that I am making someone’s day a little easier,” he says. As if on cue his phone rings and another member of the LBDA community is calling.

Please join us in thanking Tim Perkins for his years of service and his unwavering support for LBDA. His commitment to helping others embodies the spirit of our organization and we are proud to recognize him as our 2023 Volunteer of the Year.



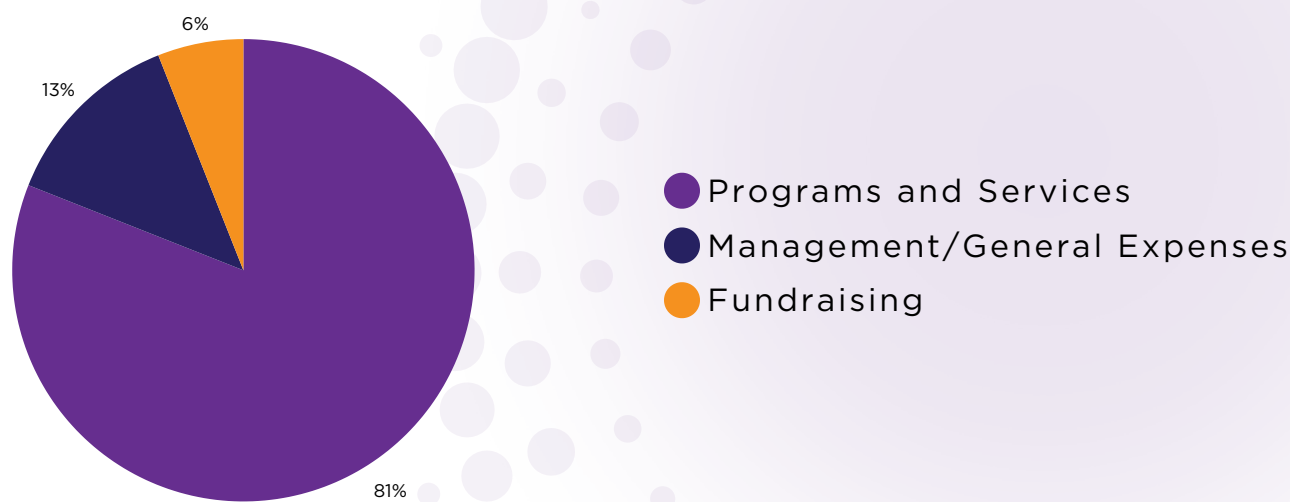
Total Revenue

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.





lbda.org

Lewy Body Dementia Association, Inc.
912 Killian Hill Road S.W., Suite 105, Lilburn, GA 30047

Headquarters
404.935.6444

Lewy Line
800.539.9767

Email
info@lbda.org