



**Lewy
Body
Dementia**
Association, Inc.

Bringing LBD Out of the Shadows:

**Increasing Knowledge,
Sharing Experience,
Building Hope.**

Annual Report for 2009-2010

What is Lewy body dementia?

Although still largely unknown by the general public, Lewy body dementia (LBD) devastates the lives of an estimated 1.3 million individuals and their families. A degenerative dementia that dramatically affects not just thinking, but also movement, behavior, sleep, and mood, LBD eventually robs individuals of their ability to perform the most basic tasks of everyday life.

LBD is a spectrum disorder and includes the clinical diagnoses, dementia with Lewy bodies (DLB) and Parkinson's disease dementia (PDD). While the earliest symptoms of these two diseases differ, they reflect the same underlying biological changes in the brain; over time, people with LBD will all develop very similar cognitive, physical, sleep, and behavioral symptoms.

DLB is most frequently misdiagnosed as Alzheimer's disease. In LBDA's recent online survey of almost 1,000 LBD caregivers, over 75% said that LBD was *not* the first diagnosis they received. Two out of three DLB cases may not be detectable on clinical examination alone. And at least 70% of people with DLB also have some changes related to Alzheimer's co-existing in their brains, though they may not necessarily display the clinical symptoms of Alzheimer's. Research demonstrates these individuals have a more aggressive disease course, making early diagnosis essential to prepare families for the road ahead of them.

Our Mission

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

Our Vision

We envision a cure for Lewy body dementias and quality support for those still living with the disease.

About the Lewy Body Dementia Association

The Lewy Body Dementia Association (LBDA) is a 501(c)3 nonprofit organization providing outreach and education to families facing the challenges of living with LBD. Last year, LBDA provided over one million points of service across all of our programs and services to caregivers and individuals with LBD, as well as primary care physicians, specialists, nurses, and allied health professionals.

We are dedicated to raising awareness about LBD until it becomes a household word, and through the guidance and engagement of our Scientific Advisory Council, we are committed to building a bridge between movement and cognitive disorder researchers and clinicians, industry, governmental agencies, and other nonprofits to the ultimate benefit of all LBD families.

We support those affected by Lewy body dementias — those living with the disease, their caregivers and medical professionals — in these ways:

- **Outreach** – providing families with reliable sources of information about LBD and caregiving, as well as access to supportive people (especially other experienced LBD caregivers) who understand the challenges they may be facing and can offer constructive problem-solving suggestions.
- **Education** – providing up-to-date educational resources for families and medical and caring professionals on LBD diagnosis, treatment, and behavioral issues, and increasing LBD awareness among the general public.
- **Research** – engaging federal agencies, industry, dementia and movement disorder clinical experts and scientists in dialogue and collaborative efforts to advance the growing body of knowledge about Lewy body dementia.

Letter from the President



Dear Friends,

As we mark LBDA's eighth year as a nonprofit organization, I think about those who Stand Strong with us in the fight against Lewy body dementia.

Individuals like former board member and past president, John L. Young, under whose leadership LBDA's Strategic Plan was developed. I think about Volunteers of the Year, Ronnie Genser and Irene Selak, whose tireless efforts and dedication have benefited so many. I think about the inspirational vision of Coleen Greco and the many hundreds of participants involved in awareness raising efforts across the country. Most especially, though, I think about the countless thousands of individuals who make a difference every day, one person at a time, by helping to educate others about LBD and to support those who are affected by this devastating disease.

Together, these individuals are the heart of LBDA.

In the past year alone, LBDA provided more than one million points of service across all of its programs and services to caregivers and individuals with LBD, as well as primary care physicians, specialists, nurses, and allied health professionals. The Biomarkers in Lewy Body Disease Conference was held in partnership with the National Institute of Neurological Disorders and Stroke. The first, national grassroots LBD Awareness Movement was launched, and LBDStories.com was created to help put real faces and stories of LBD in the public eye.

Because we believe that no one should have to make this journey alone, we strive to be a Beacon of Hope for the many faces of LBD and for you, the heart of LBDA. On behalf of the Board of Directors, we invite you to continue with us on the journey. Together, we are *Increasing Knowledge, Sharing Experience, Building Hope!*

Most sincerely,

A handwritten signature in black ink, appearing to read "Angela J. Herron".

Angela J. Herron
President, Board of Directors

2010-2012 Strategic Plan

In 2009, LBDA adopted a Strategic Plan to guide the Association through 2012. The Plan responds to the needs expressed by many caregivers, particularly those who participated in LBDA's Caregiver Survey. The Survey measured the impact of LBD on over 900 families. Their needs provide the call to action to overcome the challenges encountered by individuals with LBD and their caregivers. The Strategic Plan responds to the issues identified in the survey and serves as the foundation for annual planning and budgeting. LBDA's defining visions and goals are articulated in the Plan along with strategies to achieve them.

The Plan is fueled by the mission statement that unites each of us in our work with the Association:

***Through outreach, education and research,
LBDA supports those affected by Lewy body dementias.***

LBDA will strategically leverage resources to maximize its capacity to deliver its mission by focusing on three key areas: empowering grassroots volunteer activities through local support groups; expanding LBD resources and dialogue through Internet-based technology; and leveraging clinical and scientific knowledge and networks of the Scientific Advisory Council.

Defining Visions for 2010-2012:

LBDA's three defining visions through 2012 will successfully serve the medical and scientific community engaged in LBD-related research and clinical practice and will provide support and educational materials for LBD patients, caregivers, and the general public, while increasing public awareness of this disease.

- **To improve the understanding of LBD by reducing the mean time to accurate diagnosis and delivery of appropriate treatments for LBD.**
LBDA's recent survey of over 900 LBD caregivers indicated that it takes, on average, 18 months and at least three different doctors to receive a diagnosis of LBD. Since the time to diagnosis is extremely stressful for both patients and caregivers, LBDA considers reducing the time to accurate diagnosis in LBD to be of primary importance. Even now, when knowledge and options for treatment are limited, it is important that the available treatments are appropriate for those with LBD.
- **To be the recognized leader for information about LBD for the medical community and consumers.**
LBDA is the only organization in the United States that provides comprehensive information, education and support for the 1.3 million people affected by Lewy body dementias. By building on our current reputation, as LBD awareness grows so will LBDA's capacity to serve more families through our programming in outreach, education and research.

- **To improve quality of life for people with LBD and LBD caregivers through increased LBD awareness, education and support.**

LBD is a multi-system disease with a dramatic impact not only on the person with LBD but also on their primary caregiver. Research shows LBD may be a more difficult disease to manage and for which to care than Alzheimer's disease.

Accomplishing the following key Goals and Strategies by the end of 2012 will serve as LBDA's indicators of success:

1. Increase clinical knowledge about LBD among physicians.

LBDA will seek to raise awareness of LBD among primary care physicians, promote the development and use of LBD diagnostic tools and resources within the medical community, and deliver clinical information to generalists and specialists.

2. Increase scientific knowledge about LBD.

LBDA will encourage the development of biomarkers to improve the diagnostic rates and the treatment of people with LBD. We will foster interaction between individuals and organizations with a vested interest in LBD, including the scientific community, pharmaceutical and technology industries, and government agencies.

3. Raise awareness about LBD in the general public.

LBDA will put a "face" on LBD, and the families affected by LBD, by collecting their stories and making them available in print, electronic and broadcast media. We will empower LBD families and volunteers to raise awareness in their communities, and maximize the use of the Internet to raise awareness about LBD and to build LBDA's reputation as the leader in consumer information on LBD.

4. Deliver outreach and education resources to families affected by LBD.

LBDA will foster interaction between LBD families online and at the local level, and will deliver educational resources for LBD families.

Expanding Our Reach

In the past two years, LBDA expanded its reach through new programs and services, serving LBD families, individuals with LBD, and the medical professionals who care for them. Here are some of the ways LBDA was Increasing Knowledge, Sharing Experience, and Building Hope in 2009 and 2010.

2010

December 2010 – LBDA's national support group network climbs to 97 groups in 36 U.S. states and one Canadian province

October 2010 – LBDA observes “LBD Awareness Week: Standing Strong with LBDA,” the first nationwide, grassroots LBD awareness movement, October 10-16



LBDA on Today: (L to R) Meredith Vieira, Jennifer Brookman, Norma Loeb, Angela Taylor, Marta Mooney.

September 2010 – A national press release is issued on the new report, Caregiver Burden in Lewy Body Dementias.

August 2010 – LBDstories.com is launched, allowing families affected by LBD to share their personal stories and photos.

July 2010 – A third scientific paper on the findings from the survey on Caregiver Burden in Lewy Body Dementias is published in *The Gerontologist*.

July 2010 – A second scientific paper on the Caregiver Burden in Lewy Body Dementias is published in the July, 2010 issue of *Parkinsonism & Related Disorders*.

April 2010 – A scientific paper on the findings from the survey on Caregiver Burden in Lewy Body Dementias is published in the April-June, 2010 issue of *Alzheimer Disease & Associated Disorders*.

April 2010 – The Biomarkers in Lewy Body Disease Conference, jointly sponsored by LBDA and the National Institute of Neurological Disorders and Stroke, is held in Washington, D.C., bringing together leading LBD researchers in academia, industry, voluntary health organizations and federal agencies.

April 2010 – The Alzheimer's Drug Discovery Foundation and LBDA announce the recipient of their collaborative research award through the Lewy Body Dementia Biomarker Research Program, Lawrence Honig, M.D., of Columbia University in New York.

March 2010 – A virtual support group is launched for men who are caring for a loved one with LBD.



LBD book signing event: (L to R)
Vicki and Tom Graboys, M.D., and
Cathy Flanagan, LBD support group
facilitator, at Dr. Graboys' book signing
event in Boston.

2009

December 2009 – LBDA's National Support Group Network climbs to over 63 support groups in 25 states and one Canadian province.

October 2009 – Two families run in marathons to support LBDA; Boston-area volunteers hold 5K for LBDA

September 2009 – The Alzheimer's Drug Discovery Foundation submits a joint RFP for a collaborative research grant entitled Lewy Body Dementia Research Award

August 2009 – LBDA staff, elder law lawyer Sean W. Scott, and LBDA support group facilitator Karen Karle produce a podcast on Lewy body dementias available at no cost on iTunes

August 2009 – Neurologists campaign concludes with more than 500 new contacts with neurologists and 170 requests for educational material

June 2009 – National Institute of Neurological Disorders and Stroke approves \$150,000 in funding for Biomarkers in Lewy Body Disease Conference, to be held in April 2010

May 2009 – A Physicians Resources section, including an online publications ordering page, is added to the Web site

April 2009 – Research collaboration with Alzheimer's Drug Discovery Foundation is launched

April 2009 – Results of LBDA Caregiver Survey is presented at a poster session of the annual meeting of the American Academy of Neurology

March 2009 – Nearly 3,000 general practitioners are contacted by direct mail through the Neurologist Outreach and Education Initiative

Our Programs: Serving Those Affected by LBD

Biomarkers in Lewy Body Disease Conference

The Biomarkers in Lewy Body Disease Conference, held April 25-27, 2010, in Washington, D.C., engaged governmental agencies and researchers, in academia, voluntary health organizations and industry, at an academic level. LBDA, in collaboration with National Institute of Neurological Disorders and Stroke (NINDS), held the conference to identify promising avenues for diagnosis and new treatments and to create a research agenda to accelerate discovery.



Lewy Body Disease Conference: (L to R) SAC Member Dr. Howard Hurtig, LBDA Program Director Angela Taylor, and Dr. Gary Romano of Johnson & Johnson.

This was the first scientific meeting designed to discuss the current state of imaging, cerebrospinal fluid, and other biological markers for both Lewy body dementia and Parkinson's disease dementia. A biomarker is a biochemical indicator that can measure the progress of a disease or the effects of treatment (e.g., high cholesterol levels are a biomarker for heart disease). Biomarkers are essential not only for improving diagnostic accuracy, but also for monitoring treatment response and for the development of novel targets for treatment.

LBDA recognized that a concerted effort was needed to bring researchers and industry representatives together at scientific meetings on LBD, to share information and explore progress into the basic sciences and translate these findings into novel diagnostic methods and treatment options.

The development of biomarkers for LBD will also provide greater information on disease prevalence, the lack of which largely inhibits pharmaceutical companies from studying efficacy of medications currently used off-label in LBD, and inhibits the exploration of new therapeutic treatments for LBD. With better diagnostic tools and the ability to accurately measure disease progression, the pharmaceutical industry can better identify appropriate doses, assess safety, and allow for comparisons among drugs, as well as evaluate the effects of drugs on disease progression.

LBDA is grateful for the generous support of the following partners, without whom this conference would not have been possible.

- ✓ National Institute of Neurological Disorders and Stroke (NINDS)
- ✓ Alzheimer's Drug Discovery Foundation
- ✓ Alzheimer Research Forum
- ✓ "DLB/PDD as a Crossroads" conference
- ✓ The Jerry Carpenter Lewy Body Disease Fund of the Turner Family Foundation, Foundation For The Carolinas
- ✓ Johnson & Johnson Pharmaceutical Research & Development
- ✓ The Movement & Disorder Society
- ✓ Parkinson's Disease Foundation
- ✓ PD Online Research

Collaborating for LBD Biomarker Research



SAC Chair, Dr. Jim Leverenz (center), is pictured here with Dr. Howard Fillit and Diana Shineman of ADDF.

In 2010, the Alzheimer's Drug Discovery Foundation (ADDF) and the Lewy Body Dementia Association announced the recipient of their collaborative research award through the Lewy Body Dementia Biomarker Research Program. The goal of the program is to catalyze the discovery of innovative biomarkers that aid in early diagnosis, detection and disease monitoring of Lewy body dementias. Lawrence Honig, M.D., of Columbia University in New York, was awarded \$125,000 for his cutting edge research for LBD.

"The development of reliable biomarkers for LBD is essential for both early diagnosis and the future development of new LBD treatments. This award is part of LBDA's commitment to improving the rate of early and reliable diagnosis in LBD. We are proud to be partnering with the ADDF and welcome their involvement in lifting the burden from LBD families and building hope through research."

-Angela Herron, president, LBDA Board of Directors

Caregiver Burden

Disabling diseases like LBD affect not only the individual diagnosed with the illness, but also caregivers, families, and friends. In 2010, LBDA released its second white paper, *Caregiver Burden in Lewy Body Dementias*, a report providing a quantitative overview of LBD's impact on caregivers as assessed by a survey of almost 1,000 caregivers.

Delayed diagnosis and caregiver emotional burden are common in Lewy body dementia, and survey findings include:

- ✓ Nearly 80% of people with LBD received a diagnosis for a different cognitive, movement or psychiatric disorder before ultimately learning they had Lewy body dementia.
- ✓ LBD caregivers face a number of challenges: social, medical, functional and financial. LBD caregivers feel particularly isolated and often have to respond to crises, but may not be receiving adequate support from family, friends or healthcare providers because of the lack of LBD public awareness. These features have the potential to lead to adverse outcomes for LBD family caregivers, including "burnout", stress, depression and poor health.

Caregiver Burden in Lewy Body Dementias accomplishes several objectives. It allows the families and friends of people with LBD to compare their experiences in caring for loved ones with LBD. Additionally, it provides other interested lay readers, policymakers, and researchers with an overview of LBD and the effect it has on families. Finally, it serves as a blueprint for action to overcome some of the challenges encountered by LBD caregivers.

Scientific Papers on LBD

In 2010, three scientific papers were published on the findings from the survey on Caregiver Burden in Lewy Body Dementias:

- ✓ *Lewy Body Dementia: Caregiver Burden and Unmet Needs* – A scientific paper was published in the April-June, 2010 issue of *Alzheimer Disease & Associated Disorders*.
- ✓ *Lewy Body Dementia: The Caregiver Experience of Clinical Care* – A second scientific paper was published in the July, 2010 issue of *Parkinsonism & Related Disorders*.
- ✓ *Stress and Burden Among Caregivers of Patients with Lewy Body Dementia* – Penn State University doctoral student Amanda Leggett, under the supervision of Dr. Steven Zarit and in collaboration with Dr. James Galvin of New York University and LBDA's Scientific Advisory Council, was the lead author of a third paper published in *The Gerontologist*, and also presented the data in Vienna, Austria at the International Conference on Alzheimer's Disease and at the Gerontological Society of America's annual conference.

The primary investigator, Dr. James Galvin, and LBDA are planning to conduct a second caregiver survey in 2011. The survey will explore grieving experienced during the caregiving process and caregiver knowledge about Lewy body dementia, Alzheimer's disease and Parkinson's disease.

Dr. James Galvin, member of LBDA's Board of Directors and Scientific Advisory Council, is the primary investigator for the caregiver survey.



Physician Outreach Initiative

Recognition of LBD as a common form of dementia grew to prominence among neurologists only within the past 5 years; general awareness of LBD as a disease has yet to make its way to the majority of primary care physicians.

Physicians play a key role in the diagnosis and treatment of those with LBD. Often, families learn about LBD only after a loved one has been diagnosed with the disease by a neurologist. LBDA recognizes the importance of providing essential resources and services to physicians treating those with LBD. In 2009 and 2010, our Physician Outreach Initiative offered information and resources to thousands of doctors across the U.S. in a new way.

Nearly 3,000 general practitioners across the country received LBDA's latest publication, *An Introduction to Lewy Body Dementia*, which was developed especially for the person newly diagnosed with LBD. This mailing was made possible by a grant from Novartis Pharmaceuticals Corporation.

Another 5,000 internists received an invitation to participate in an online survey about their routine practices to evaluate patients reporting cognitive changes. While internists that participated in this survey indicated they are familiar with Lewy body dementias, the majority admitted they do NOT know the diagnostic criteria for dementia with Lewy bodies. Additionally, internists do not routinely screen for all LBD symptoms when diagnosing dementia and nearly half did not know that Parkinson's disease dementia is a form of LBD. As a result of this survey, LBDA will be distributing materials as part of 2011 LBD Awareness Month to help increase the reporting of LBD symptoms to primary care physicians, in the form of posters for physician waiting rooms and examination rooms.

More than 12,000 neurologists also received information on LBD and LBDA's services. Neurologists were invited to contact LBDA for additional information and free resources on LBD to share with their patients. This effort was made possible by a generous grant from The Jerry Carpenter Lewy Body Disease Fund and the Lewy Body Advisory Committee, a subcommittee of the Turner Family Foundation, Foundation For The Carolinas.



A WEEK TO REMEMBER

OCTOBER 10-16, 2010

Standing Strong with LBDA

Beacons of Hope: Raising Awareness about LBD

To raise awareness about LBD in the general public and in the medical profession, the Lewy Body Dementia Association led the first national, grassroots LBD awareness movement, culminating with “**A Week To Remember**,” October 10-16, 2010.

Thanks to the tireless and creative efforts of our awareness volunteers, great gains were made in LBD awareness. LBD awareness events took place in 34 U.S. cities and six locations outside the U.S. and Canada. Determined not to sit on the sidelines and watch, LBD families took action, finding new ways to promote awareness and bring Lewy body dementia out of the shadows and into the public eye. Fundraising and awareness raising events ranged from a 5k run/walk to a dog show, presentations made by LBD specialists to book signings, and from a pumpkin carving contest to a pancake breakfast.

Al Morrison, who is living with LBD, medals in his age group at the **2nd Annual Allan D. Morrison 5K Run/Walk** – an event in Melrose, MA, organized by his daughter Coleen Greco to benefit LBDA.



Volunteers were especially motivated to increase LBD awareness among physicians, due to their own difficult experiences seeking a diagnosis. Through this awareness movement, hundreds of medical professionals across the country received hand-delivered LBDA materials for their medical practices from LBD families in their communities.



Boy Scout Liam Vaughn (pictured here with his parents, Celeste and Paul) was inspired by his father's battle with LBD and decided to take action by organizing a silent auction fundraiser for LBDA.

When LBDA volunteers were on hand with LBDA signs for the outdoor audience segments of two morning television shows, Dave Price of CBS' The Early Show and Al Roker of NBC's Today show stopped by to chat with them about their efforts to raise LBD awareness. As a result of the national television visibility, LBDA's homepage welcomed six times the average daily number of visitors.

There was such a positive response to Awareness Week in 2010 that we're expanding our awareness raising efforts in 2011 to the entire month of October!



LBDA volunteer and professional soprano, Ilana Davidson, and The An Beal Bocht Radio Workshop Players presented *The Big Murder Mystery Broadcast of 1943* in Manhattan, benefiting LBDA.

Our Volunteers

Volunteer of the Year Awards

LBDA was pleased to recognize Irene Selak as the **2010 Volunteer of the Year**. In addition to serving as moderator of LBDA's discussion forums, Ms. Selak also served as a primary contact for telephonic and electronic support of LBDA's Caregiver Helpline. She first came to LBDA through an LBD support group while serving as a caregiver for her husband, Jim. As she became an active participant in the LBDA forums, her natural desire to help others became evident through the information and resources she provided to other forum users.

Ms. Ronnie Genser was recognized as LBDA's **2009 LBDA Volunteer of the Year**. For 4-1/2 years, Ms. Genser volunteered as the Support Group Coordinator for LBDA's national support group network. Through her leadership and expertise, the network grew from just six support groups to more than 95!

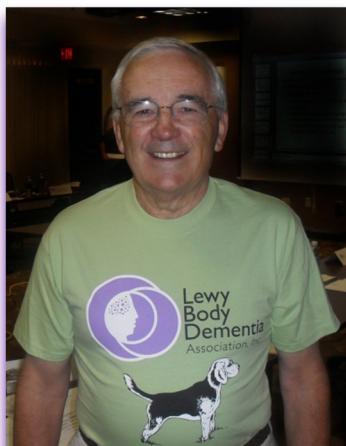
On behalf of LBDA and all the families we serve, we extend our deepest gratitude to Irene Selak and to Ronnie Genser for their tireless efforts and their heartfelt and passionate service for our mission to support those affected by Lewy body dementias.

Caregiver Support

In 2010, more than 3,000 people received one-to-one services through LBDA's telephone and email helpline, as well as literature requests from caregivers and medical professionals.

National Support Group Network

LBDA's national support group network continues to see significant growth. At the end of 2010, there were 97 support groups in 36 U.S. states and the Canadian province of Ontario. This represents a substantial increase, up from 68 support groups in 2009 and 45 groups in 2008.



Virtual Support Group Organized for Male Caregivers

Board member Steve Lamb believes that "Sharing is relieving." In 2010, he founded a virtual support group for men who are caring for a loved one with Lewy body dementia. The group meets monthly by teleconference and is available to anyone with access to a phone. This group is tailored for men caring for a wife, parent, or loved one with LBD, where there is no support group in their area, or for men who cannot regularly attend support group meetings due to caregiving responsibilities.

LBD Online Resources

In 2009 and 2010, the Lewy Body Dementia Association continued to enhance its web presence and online programming for LBD families and medical professionals.

LBDA Online

- ✓ 1,000,000 page views on LBDA's website, www.lbda.org
- ✓ 345,000 unique visitors to our website each year
- ✓ 75,000 impressions each year with the *Lewy Body Digest*, LBDA's e-newsletter
- ✓ 3,000 followers on Facebook: www.facebook.com/LewyBodyDementia
- ✓ Over 1,700 current members participating in LBDA's Discussion Forum online

LBD Stories

LBDstories.com was launched to help put real faces and stories of LBD in the public eye. LBD families are bringing this disease out of the shadows by telling the world a story about life with LBD and putting a face on LBD by including a photo.

Lewy Body Digest

Through its e-news publication, LBDA delivered updates on LBD clinical and research advances, stories about LBD families, and educational resources on LBD to 5,000 inboxes last year!

New Online Resources

LBDA issued its second white paper, "Caregiver Burden in Lewy Body Dementias", based on LBDA's survey of over 900 LBD caregivers.

LBDA provides summaries on relevant news stories of LBD research, clinical or caregiving interest to LBD families. Nearly 35 news articles were highlighted on the LBDA website. We also introduced a new educational resource for LBD families who want to understand more of what they read about research news, entitled "How To Read A Research Paper," by Debbie McCoy-Massey.

Another new resource included 40 answers to common caregiver questions. Nearly 400 caregivers listened in on a scientific webinar, hosted by the Alzheimer Research Forum and promoted by LBDA, to hear the answers to pressing questions regarding dementia with Lewy bodies. Before and after the event, LBD caregivers submitted more than 100 questions to the panel, which included Dr. Ian McKeith, Dr. James Galvin, and Dr. James Leverenz, members of LBDA's Scientific Advisory Council. Due to the tremendous caregiver response, the Alzheimer Research Forum turned to LBDA to provide answers to a broad assortment of caregiver questions. We were pleased to provide answers to frequently asked caregiver questions, available on our website.

Our Leadership



Board Officers: Angela Herron,
LBDA Board President, and Debbie
McCoy-Massey, Vice President

2010 Board of Directors

The governing board of directors is comprised of individuals whose lives have been touched by LBD as well as professionals with a deep dedication to our mission.

Angela Herron, President
Dallas/Fort Worth, TX

Joe Whiteis, Vice President
Minneapolis, MN

Debbie McCoy-Massey, Vice President
Atlanta, GA

Nancy Silverman, Secretary
Fort Lauderdale, FL

Stephen Lamb, Treasurer
Huntington, WV

Barbara Ann Bush, Director
Dunwoody, GA

James E. Galvin, MD, MPH, Director
New York, NY

Coleen Greco, Director
Boston, MA

Miles Hurley, Director
Atlanta, GA

Mike Koehler, Director
North Wales, PA

Alan Lerner, MD, Director
Shaker Heights, OH

Terms of service for the following board members ended in 2009:

John L. Young, President
Lake Tahoe, CA

Jim Whitworth, Secretary
Mesa, AZ

Carol Caughran, Director
Jacksonville, FL

Steve Stevenson, Director
Atlanta, GA

2010 LBDA Scientific Advisory Council (SAC)

The LBDA Scientific Advisory Council (SAC) is comprised of international leaders in LBD research and clinical management. The SAC helps to formulate recommendations for diagnosis, treatment and prevention of LBD, and fosters research in the Lewy body dementias.

The SAC provides LBDA with strategic input on programming and participates in LBDA-initiated research projects. The SAC also reviews the Association's educational materials for clinical and scientific accuracy and SAC members serve as LBD experts to the media on behalf of the organization.



SAC Members: Dr. Tanis Ferman and Dr. Bradley Boeve at the Biomarkers in Lewy Body Disease Conference in Washington, D.C.

James B. Leverenz, M.D. , Chair
VA-PSHCS, Parkinson's Disease and Mental Illness Research, Education, and Clinical Centers
Associate Professor, Neurology and Psychiatry and Behavioral Sciences
University of Washington
Seattle, WA, USA

Bradley F. Boeve, M.D.
Professor of Neurology
Division of Behavioral Neurology and Sleep Disorders Center
Department of Neurology
Mayo Clinic College of Medicine
Rochester, MN, USA

Dennis W. Dickson, M.D.
Robert E. Jacoby Professor of Alzheimer's Research
Departments of Pathology and Neuroscience
Mayo Clinic
Jacksonville, FL, USA

John Duda, M.D.
Director, Parkinson's Disease Research Education and Clinical Center
Philadelphia Veterans Affairs Medical Center
Assistant Professor, Department of Neurology
University of Pennsylvania School of Medicine
Philadelphia, PA, USA

Tanis Ferman, Ph.D.
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Joseph H. Friedman, M.D.
Professor and Chief, Division of Movement Disorders, Department of Neurology
Warren Alpert Medical School of Brown University
Providence, RI, USA
Director, Movement Disorders Program
Butler Hospital NeuroHealth
Warwick, RI, USA

Douglas R. Galasko, M.D.

Professor In Residence
Department of Neurosciences
University of California
San Diego, CA, USA

James E. Galvin, M.D., M.P.H.*

Professor of Neurology and Psychiatry
Director of Clinical Operations, Center of Excellence on Brain Aging
Director, Pearl Barlow Center for Memory Evaluation and Treatment
New York University Langone School of Medicine
New York, NY, USA

Serge Gauthier, M.D., FRCPC

Professor, Depts. of Neurology & Neurosurgery, Psychiatry, Medicine
Director, Alzheimer's Disease Research Unit
McGill University
Montreal, Canada

Howard Hurtig, M.D.

Chair, Department of Neurology
Co-Director, Parkinson's Disease and Movement Disorders Center
Pennsylvania Hospital
Frank and Gladys Elliott Professor
University of Pennsylvania School of Medicine
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Daniel Kaufer, M.D.

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Director, UNC Memory Disorders Program
University of North Carolina at Chapel Hill
Chapel Hill, NC, USA

Kenji Kosaka, M.D., Ph.D. **

Professor Emeritus, Yokohama City University School of Medicine
Director, Yokohama Houyuu Hospital
Yokohama, Japan

Virginia M.-Y. Lee, Ph.D.

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Director, Center for Neurodegenerative Disease Research
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Oscar L. Lopez, M.D.

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Director, Alzheimer's Disease Research Center
Chief of Cognitive and Behavioral Neurology Division
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Ian G. McKeith M.D., F.Med Sci.

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Director, MIND Unit
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Andrew Singleton, Ph.D.

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Laboratory of Neurogenetics and Molecular Genetic Section
National Institute on Aging
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Debby W. Tsuang, M.D., M.Sc.

Professor, Department of Psychiatry and Behavioral Sciences
Adjunct Professor, Department of Epidemiology
Adjunct Professor, Division of Medical Genetics, Department of Internal Medicine
University of Washington
Staff Physician, VAPSHCS
Seattle, WA, USA

Daniel Weintraub, M.D.

Associate Professor of Psychiatry, University of Pennsylvania
Parkinson's Disease Research, Education and Clinical Center
Mental Illness Research, Education and Clinical Center
Philadelphia Veterans Affairs Medical Center
Philadelphia, PA, USA

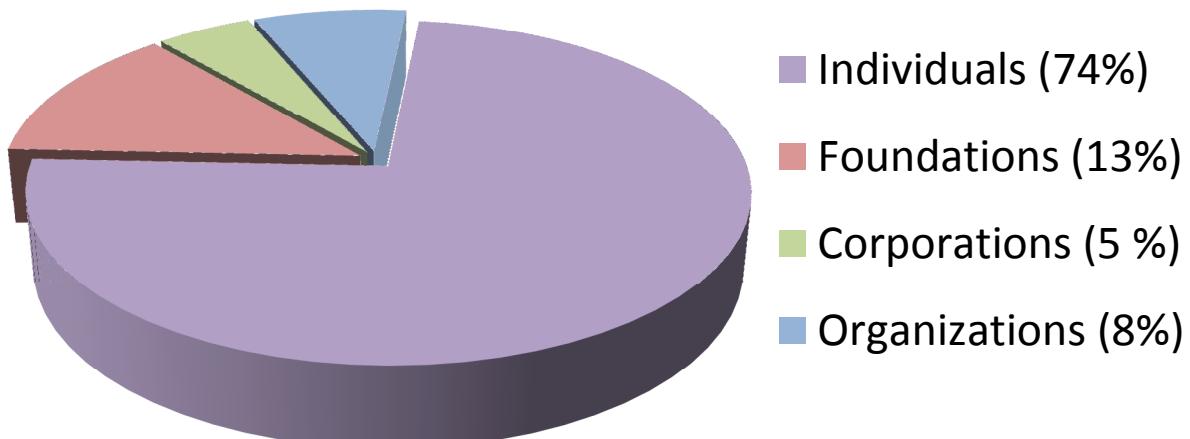
*LBDA Board of Directors

**Honorary SAC Member

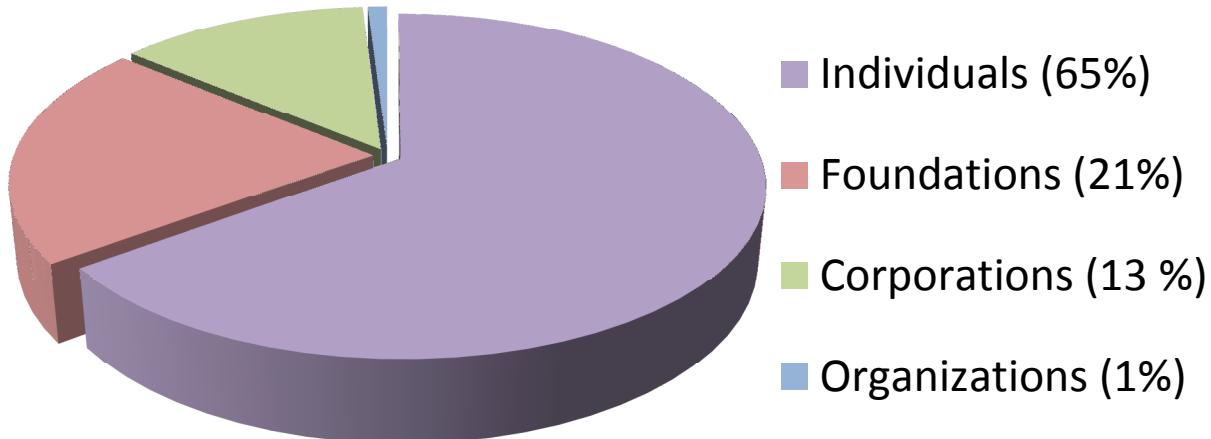
Support for LBDA

The Lewy Body Dementia Association is a 501(c)3 nonprofit organization and relies on the support of its generous contributors in order to provide programs and services to the 1.3 million families affected by LBD in the U.S. We are grateful for your continued support of LBDA's mission.

2010 Contributions By Source



2009 Contributions By Source



Financial Information

The complete, audited financial statements for 2009 and 2010, as well as IRS Form 990, are available on LBDA's website, www.lbda.org, under "About Us." Or, you can request a copy by contacting our national office at 404-935-6444.

LEWY BODY DEMENTIA ASSOCIATION, INC.

Statement of Financial Position December 31, 2010 and 2009

Assets	<u>2010</u>	<u>2009</u>
Cash and Cash Equivalents	\$ 205,050	\$ 193,683
Investments	50,878	50,254
Prepaid Expenses	1,853	2,507
Property, Furniture and Equipment, net	<u>4,088</u>	<u>6,730</u>
 Total Assets	 <u>\$ 261,869</u>	 <u>\$ 253,174</u>
Liabilities and Net Assets		
 Liabilities:		
Accounts Payable	\$ 6,514	\$ 3,257
 Net Assets:		
Unrestricted	242,350	249,917
Temporarily Restricted	<u>13,005</u>	<u>-</u>
 Total Net Assets	 <u>255,355</u>	 <u>249,917</u>
 Total Liabilities and Net Assets	 <u>\$ 261,869</u>	 <u>\$ 253,174</u>

LEWY BODY DEMENTIA ASSOCIATION, INC.
Statement of Activities
For the Years Ended December 31, 2010 and 2009

	<u>2010</u>	<u>2009</u>
Changes in Unrestricted Net Assets:		
Revenue and Support:		
Contributions	\$ 252,288	\$ 278,414
Special Events	84,239	48,232
Investment Income	<u>2,366</u>	<u>2,850</u>
Total Revenue and Support	338,893	329,496
Net Assets Released from Restrictions	<u>13,900</u>	<u>10,424</u>
Total Revenue, Support and Reclassifications	352,793	339,920
Expenses:		
Programs	215,111	295,059
Support Services	85,629	112,307
Fundraising	<u>59,620</u>	<u>57,552</u>
Total Expenses	<u>360,360</u>	<u>464,918</u>
Decrease in Unrestricted Net Assets	(7,567)	(124,998)
Changes in Temporarily Restricted Net Assets:		
Contributions	26,905	
Net Assets Released from Restrictions	<u>(13,900)</u>	<u>(10,424)</u>
Increase (Decrease) in Temporarily Restricted Net Assets	<u>13,005</u>	<u>(10,424)</u>
Change in Net Assets	5,438	(135,422)
Net Assets at Beginning of Year	<u>249,917</u>	<u>385,339</u>
Net Assets at End of Year	<u>\$ 255,355</u>	<u>\$ 249,917</u>



**Lewy
Body
Dementia**
Association, Inc.

Contact Us at LBDA's National Office

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