



Lewy
Body
Dementia
Association Inc.

2005 ANNUAL REPORT

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

OUR INSPIRATION

“Thank you so much for the comfort discovering this site has just given me. I found it especially helpful to know that others find it frustrating that friends and family do not understand the changes and fluctuations. Some times I wonder who is 'losing it'! WE have lived with LBD for 7 years and I am thankful that it has moved so slowly with us - but it is exhausting for all concerned. Thank you for the reminder that now is to be appreciated, however hard now seems.”

*Pat Prestney
LBD caregiver*

“...My husband does have LBD rather than vascular dementia. While I know that a diagnosis of LBD is not a good thing, at least now we know what he has. And now we can treat him with the right medications and take him off the wrong ones...”

“Your detailed and caring response to my original inquiry helped us get the right diagnosis, and you've made me feel better about it. Being a caregiver for my husband, like you have been with your parents, is a little easier for me when I know what I'm dealing with, and I find someone like you who understands. Thank you from the bottom of my heart.”

*Sandy Burnett
LBD caregiver
(in respose to LBDA Helpline assistance)*

“There are great benefits for people with LBD and their families if the condition is recognized early and treated effectively. The LBDA is playing a key role in increasing the awareness of this generally unrecognized disease and make a real difference in patient outcomes.”

*Dr. Ian McKeith
LBDA Scientific Advisory Council Member,
Professor of Old Age Psychiatry and Head of
Brain Ageing & Dementia Research Group
Institute for Ageing and Health
University of Newcastle upon Tyne, UK*

A LETTER FROM THE PRESIDENT

Patients, families and caregivers face far too many 'bad days' on the road with Lewy body dementia (LBD). Not just bad days from symptoms of the disease, but from other preventable causes.

We hear from families who have been given two or even three different diagnoses over several years and they just don't know what to believe any more. Some are worried about serious and possibly irreversible side effects from medicines their loved ones have been prescribed. Others still haven't seen the doctor and are frightened by hallucinations or the specter of the word dementia.

And when families do get an LBD diagnosis, nobody seems able to tell them what to expect next. Their friends haven't heard of LBD. Family members who visit wonder what all the fuss is about, because the patient seems just fine to them on that particular day. But caregivers see the day after the visit, when their loved one's exhaustion, confusion and hallucinations are worse than ever. When LBD patients find themselves in the emergency room, they are commonly greeted by medical staff unfamiliar with the existence of LBD and the potentially fatal risks of certain medications.

And then there are the good days. Caregivers share stories of simple yet beautiful moments of love and joy that sneak in when they weren't expecting it. And they talk of times where silliness is inescapable and it's great to laugh at LBD. And of the blessings that come from unexpected moments of clarity and recognition in their loved one's eyes.

There is life with LBD, but it isn't easy. That's why we are here. We have a dedicated team of medical advisors, tireless volunteers, and the commitment to make Lewy body dementia a household word.

We look to 2006 with great anticipation and are encouraged by the many new people joining us on the journey to bring LBD out of the shadows. We'd like you to join us too.

In hope,

Angela Taylor
President
LBDA Board of Directors

A LETTER FROM THE CEO

Dear Friends;

This past year was an exciting and pivotal year for the Lewy Body Dementia Association (LBDA). As you review this Annual Report you will see that 2005 was a year of firsts:

- § First year LBDA exhibited at a medical conference;
- § First year LBDA received grants thus recognizing the need for our services and our ability to deliver them;
- § First year an LBDA local support group was formed;
- § First year LBDA produced an LBD publication in Spanish;
- § First year LBDA employed professional staff to help expand our outreach.

2005 was also a year of significant growth in the demand for LBDA services as the awareness of our organization and the disease we fight grew. Visits to our Web site averaged 12,000 a month as people desperate for information found us. Our online and toll-free helplines saw steady growth as individuals looked to make a personal contact with other caregivers. Requests for our publications by individuals and organizations grew on a monthly basis. And interest by other communities to start an LBDA local support group increased as well.

Lewy body dementia takes an emotional, physical, financial and social toll on American families. Our Scientific Advisory Council estimates that over 800,000 families are affected by LBD and the numbers grow daily as our older population swells with the aging of the baby boomer generation.

As you can see, we have come a long way but have a long way to go. Next year our focus will be on building awareness of this relatively unknown, but certainly not rare, dementia. We will also be focusing on building the infrastructure needed to meet the growing demand for our services. If your family is affected by LBD, seek out our services and let us help you improve the quality of life of your loved one. If you are seeking an opportunity to make a significant difference in people's lives, contact us. We need all the volunteer help we can find. And, if you want to support an organization that is dedicated to helping those who have spent their whole life providing for others then call us, we need your help, too.

Sincerely,

Bob DeBusk
CEO

OUR VISION

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

OUR MISSION

Through education and outreach we support those affected by Lewy body dementias, and promote research for a cure.

OUR PURPOSE

The Lewy Body Dementia Association (LBDA) is a 501(c)(3) nonprofit organization dedicated to raising awareness of the Lewy body dementias (LBD); supporting patients, their families and caregivers; and promoting scientific advances. The Association's purposes are charitable, educational, and scientific.

Lewy body dementia is not a rare disease, and accounts for up to 800,000 cases in the United States alone. Medical studies indicate up to 70% of LBD cases go undiagnosed. The Lewy Body Dementia Association (LBDA) calls for increased research funding, increased awareness, and centers of excellence in LBD diagnosis and treatment.

LBD caregivers report the majority of primary care physicians are unable to recognize the symptoms of LBD. The most frequent incorrect diagnoses include Alzheimer's disease and Parkinson's disease. Thus, far too many primary care physicians do not refer their patients to specialists for diagnosis and treatment. This fact highlights the need for further research for symptom differentiation.

Compounding this situation, there are currently no *medications approved by the US Food and Drug Administration for treatment of LBD. Off-label prescribing is the only option for physicians. Further funding for clinical pharmaceutical studies is desperately needed to identify safe treatment options suitable for LBD.*

Patients, families and caregivers are often left without accurate diagnosis, inadequate treatment, lack of understanding and support from their primary doctors, and a sense of isolation and abandonment. Caregivers are turning to the LBDA because many doctors cannot meet their diagnostic and informational needs.

Through education and outreach, LBDA supports patients and caregivers affected by Lewy body dementias. We participate in two online caregiver support groups that total over 1,100 caregivers from countries around the world, including the United States, Canada, the United Kingdom, Australia, and New Zealand.

OUR HISTORY

The LBDA was formed in 2003 by a group of caregivers who met in an online LBD caregiver support group. Discussions about the need of support for LBD caregivers and the lack of public awareness about LBD led to the organization's incorporation. The Directors of the LBDA Board are located throughout the US, and LBDA volunteers are from the United States, Canada, and the United Kingdom. The Association consists of a dedicated group of people from all walks of life who understand the struggles of other caregivers. Many of the LBDA Board members have personal LBD experiences.

OUR MILESTONES

2005 was a year of tremendous growth for the Lewy Body Dementia Association. In August the Association was awarded its first grant -- \$500,000 from the Harry T. Mangurian, Jr. Foundation to provide funds to expand its efforts to meet its mission. Mr. Mangurian learned first-hand about the plight facing LBD patients and their families and wanted to help bring this disease out of its shadows.

"From the information available through the LBDA, I was surprised by the general lack of recognition and awareness of this disease, even within the medical profession. Hopefully, this grant will help solve this problem and will provide caregivers guidance in assisting those with this debilitating disease,"

Harry T. Mangurian, Jr.

In September, after evaluating numerous cities throughout the United States, the LBDA Board of Directors decided to locate the Association's corporate offices in Atlanta. Citing the city's ease of accessibility, its vibrant business and medical communities, and its outstanding support of the local nonprofit community, the Board moved the organization to Atlanta in the end of 2005.

In October the Board of Directors hired its first Chief Executive Officer, Bob DeBusk. Bob has over seventeen years of leadership experience in the nonprofit industry. His primary responsibility is to assist LBDA in adopting and

implementing programs that will build national awareness of LBD, provide assistance to those caring for LBD patients, and to encourage research towards a cure.

In November, LBDA received an educational grant from Novartis. The purpose of this grant is to help LBDA reach out to the medical community to raise their awareness of Lewy body dementia.

OUR ACHIEVEMENTS

The LBDA provides support to caregivers, families, and professionals through our outreach program of services. The demand for these services grew significantly in 2005:

Web site – The LBDA Web site is a repository of information and support for LBD families, caregivers, and professionals with Internet access. The Web site is constantly evaluated and refined to ensure that it is responsive to the needs of caregivers and anyone searching the Internet for information on LBD. Communication with caregivers is also enhanced through our web site by providing an e-mail helpline, copies of our quarterly newsletter, and direct e-mail inquiries with board and staff. As the awareness of the LBDA has grown, so has the demand for information from our Web site. In 2005, the LBDA website experienced a substantial amount of activity that steadily rose throughout the year. The site recorded 140,000 visits for the year -- an average of close to 12,000 a month. Visitors to the Web site averaged viewing 10 additional pages after linking to the site, indicating a desire to find as much information as possible on Lewy body dementia.

Quarterly Newsletter – LBDA's quarterly newsletter, *The Thistle*, is published quarterly to provide LBD caregivers and medical professionals with the most up-to-date information on Lewy body dementia. The newsletter draws on information from the health care industry, our Scientific Advisory Council and related organizations. Our caregivers provide us with a perspective that can only be gained by someone in the "caregiver" role. The newsletter is available free of charge and can be downloaded from the LBDA Web site or received in the mail. Interest in LBDA's newsletter continued to grow in 2005 with now more than 800 subscribers.

E-mail helpline – The e-mail helpline, staffed by experienced, LBD caregiver volunteers, provides an opportunity for individuals to seek more personalized information. Requests for assistance through the e-mail hotline increased throughout the year. When comparing the first half of 2005 with the second half, there was 32% growth in requests for assistance through the e-mail hotline.

Toll-free helpline 800-539-9767 – The toll-free helpline provides a more personal and private way for caregivers to request LBDA assistance. Our helpline volunteers are current or former LBD caregivers and are prepared to answer a wide variety of questions about LBD and caregiving. Approximately 100 caregivers a month contacted LBDA directly for assistance either through our toll-free or e-mail helplines.

Information packets – Literature is mailed to caregivers and professionals who seek printed reference materials. These information packets are either custom prepared to match an individual's specific request or for larger distribution at meetings.

Brochures – The LBDA informational brochure was designed to be used as a reference guide for either caregivers and their families or the medical professionals who are caring for their loved ones. The brochure may be printed from the Web site, and professionally printed copies are also available. Proven to be very popular, approximately 50,000 brochures were distributed during 2005.

Events – The LBDA attends local, regional, and national caregiver and medical conferences to build awareness about LBD and the Association's programs and services. A sampling of conferences attended by LBDA in 2005 are:

American Academy of Neurology Annual Conference, Miami, Fla.
Alzheimer's Educational Conference, W. Palm Beach, Fla.
American Neurological Association Annual Conference, San Diego, Calif.
Neurology Expo (American Academy of Neurology), Atlanta, Ga.

Local support groups – The purpose of an LBDA caregiver group is to provide information and emotional support for those coping with Lewy body dementia in a loved one. In September 2005, LBDA launched its first monthly local support group in Ft. Lauderdale, Fla. Interest by caregivers in other states to form LBDA-affiliated caregiver groups is growing.

OUR PLANS FOR 2006

Website

The LBDA's website:

- Is the most effective method of disseminating information to the public and medical community
- Is a major source of new volunteers
- Is becoming a major point of donor development
- Will be a key tool in advocacy for increased research funding

Because the Web site plays such a central role in our organization's growth and ability to achieve our mission, continuing to develop it further is a high-priority in 2006.

Publications

The updated version of our LBD informational pamphlet will be completed in 2006. The brochure is distributed to (1) caregivers and medical staff seeking LBD information; (2) handouts at LBD presentations; (3) visitors to LBDA's booth at trade shows; (4) donors to LBDA programming. The brochure is also made available on the LBDA Web site for downloading in a pdf format.

A wallet card is being produced for use by families in medical emergencies, warning physicians and medical staff about the dangers of antipsychotic medications.

Conferences

The LBDA will exhibit at the following national medical conferences and international congresses:

- American Academy of Neurology
- American Neurological Association
- World Parkinson's Congress
- PDD/DLB at a Crossroads Symposium

An Exhibitor's Kit will be created for volunteers who wish to exhibit at local caregiving events.

Helplines

Increased awareness is bringing about the increased use of LBDA's email and voice mail helplines. Plans are underway to expand these two critical services through the recruitment and training of more volunteer responders.

Local Support Groups

The Lewy Body Dementia Association will continue to support the efforts of LBD caregivers who want to form and operate local networks of LBD caregivers where information can be exchanged and emotional support provided to one another.

Volunteers

Volunteers are the backbone of any nonprofit organization. LBDA will continue to expand its corps of volunteers through the aggressive recruitment of highly dedicated individuals willing to commit their time and talents to help build the Association's programs and services

Board of Directors

Governing a national nonprofit organization and guiding its development is multifaceted. LBDA will continue to build the capacity of its Board of Directors through the recruitment of those possessing needed skill sets and a broad range of experiences.

LBDA SCIENTIFIC ADVISORY COUNCIL

Carol F. Lippa, M.D., Chair

Professor of Neurology
Director,
Memory Disorders Program
Drexel University College of Medicine,
Philadelphia, PA

Dag Aarsland, M.D.

Professor of Geriatric Psychiatry
Stavanger University Hospital
Stavanger, Norway

Bradley F. Boeve, M.D.

Associate Professor of Neurology
Division of Behavioral Neurology
and Sleep Disorders Center
Department of Neurology
Mayo Clinic College of Medicine,
Rochester, MN

Jeffrey L. Cummings, M.D.

Augustus Rose Prof. of Neurology
Prof. of Psych. & Biobehavioral Sciences
Dir., UCLA Alzheimer's Disease Center
Director, Deane F. Johnson
Center for Neurotherapeutics
Executive Vice Chair,
Department of Neurology
David Geffen School of Medicine, UCLA
Los Angeles, CA,

Dennis W. Dickson, M.D.

Professor of Pathology
Mayo Clinic College of Medicine
Jacksonville, FL

John Duda, M.D.

Co-Dir., Parkinson's Disease Research,
Education and Clinical Center
Philadelphia VA Medical Center
Asst. Professor, Dept. of Neurology
Univ. of Pennsylvania School of Medicine
Philadelphia, PA

Tanis Ferman, PhD

Assistant Professor, Clinical Neuropsychology
Mayo Clinic
Jacksonville, FL

Douglas R. Galasko, M.D.

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

Serge Gauthier, M.D., FRCPC.

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

Kenji Kosaka, M.D., PhD

Professor, Department of Psychiatry
Yokohama City University School of Medicine
Yokohama, Japan

James B. Leverenz, M.D.

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

Ian G McKeith M.D., FMed Sci.

Professor of Old Age Psychiatry and Head of
Brain Ageing & Dementia Research Group
Institute for Ageing and Health
University of Newcastle upon Tyne,
United Kingdom

Debby W. Tsuang, M.D., MSc

Associate Professor, Department of
Psychiatry and Behavioral Sciences
Adjunct Assoc. Prof., Dept. of Epidemiology
University of Washington
Staff Physician, VAPSHCS
Seattle, WA

2005 LBDA BOARD OF DIRECTORS

Angela Taylor, President
State College, Pa.

Micki Horst, Vice President
Okemos, Mich.

Peggy Smith, Treasurer
Cross Hill, S.C.

Sandy Shelton, Secretary
West Jefferson, Ohio

Jan Childress, Director
Sacramento, Calif.

Donna Rae, Director
Royal Oak, Mich.

Lynn Whitman, Director
Chandler, Ariz.

Jim Whitworth, Director
Mesa, Ariz.

John Young, Director
Houston, Texas

LBDA STAFF

Robert DeBusk, CEO

LEWY BODY DEMENTIA ASSOCIATION, INC.
STATEMENTS OF FINANCIAL POSITION
December 31, 2005

ASSETS

ASSETS	
Current Assets	
Cash (Note 2)	\$ 36,895
Pledges receivable	312
Investments	506,398
Other receivables	53
Prepaid expenses	3,112
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Total Current Assets	546,770
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Fixed Assets	
Computer software	4,810
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	4,810
Less: Accumulated depreciation	-
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Total Fixed Assets	4,810
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TOTAL ASSETS	\$ 551,580

LIABILITIES AND STOCKHOLDERS' EQUITY

LIABILITIES AND NET ASSETS	
Current Liabilities	
Accounts payable	\$ 2,129
Accrued expenses	380
Short term loans payable (Note 4)	27,482
Total Current Liabilities	29,991
Total Liabilities	29,991
Net Assets	
Unrestricted	510,589
Temporarily restricted	11,000
Permanently restricted	-
Total Net Assets	521,589
TOTAL LIABILITIES AND NET ASSETS	\$ 551,580

NOTE: The Association received a one time unrestricted grant of \$500,000 in FY 2005.

CONTACT INFORMATION

Lewy Body Dementia Association
PO Box 451429
Atlanta, GA 31145-9429

Web site: <http://www.lewybodydementia.org>

Caregiver Helpline: 800-LewySOS
(800-539-9767)
LBDinfo@lbda.org

Office: 404-935-6444

Fax: 480-422-5434

e-mail: lbda@lbda.org