



2004 Annual Report

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Letter from the President

2004 Focus

We entered 2004 pleased with our initial accomplishments from 2003 of incorporating the organization, electing officers, applying for IRS tax-exempt status and beginning the process of state registrations toward our goal of being allowed to solicit donations in all 50 states.

2004 Highlights

February 19, 2004. The IRS has approved our 501(c)(3) charitable tax deductibility status.

May 1-2, 2004. At our Board of Directors meeting held in Brooklyn, New York, the following board changes were made. Citing personal reasons, the board accepted the resignation of Vice President Betty Wittenberg. Imelda Fagin was elected Vice President and Lynn Whitman was elected as a Director.

May 12, 2004. We completed our goal of being authorized to solicit donations in all fifty United States and the District of Columbia. Donors in all states can now make tax deductible contributions to the Association.

The 'Make a Donation' page was added to our website and describes the three ways of making a tax deductible donation to the Lewy Body Dementia Association, Inc.

1. A donation can be made in the name of the donor.
2. A donation can be made to honor someone for some deed or event in their life.
3. A donation can be made in memory of someone who has passed away.

June 1, 2004. The headquarters of the association was relocated from Greenwood, South Carolina to Tempe, Arizona. The move was prompted by the need to be in a large, metropolitan area. Tempe is a suburb of Phoenix, the fifth largest US city, and the home of Arizona State University. The area is home to one of the three Mayo Clinics in the US. There are several other medical centers in the area and a local consortium of neurologists that keep informed of the latest developments affecting the areas large retirement-age population.

July 19, 2004. The President and Secretary/Treasurer met with a group of seven doctors attending the World Alzheimer's Conference in Philadelphia. This was the formation meeting for our Scientific Advisory Council. The council appointed Dr. Carol Lippa of Drexel University, Philadelphia as their chairperson. See the article in the first issue of The Thistle for biographies of the council members.

September, 2004. The premier issue of our newsletter, **The Thistle**, was released. We received publicity about it from an Alzheimer's newsletter and our website access counter logged a 60% increase in people coming to the website. The website continues to receive from 10,000 to 15,000 "hits" per month as people come looking for LBD information and how to cope with the disease from the caregiver's point of view.

December, 2004. Our first professionally designed informative brochure was printed and is now available for world-wide distribution. The wording was approved by our Scientific Advisory Council.

At our annual Board of Directors meeting in Tempe, Arizona, citing her increased caregiver workload, Vice President Imelda Fagin asked not to stand for reelection as a director. Sandy Shelton was elected as a director in her place. The LBDA officers for 2005 are: Jim Whitworth, President; John Young, Vice President; Sandy Shelton, Secretary; Peggy Smith, Treasurer. Jan Childress, Lynn Whitman and Donna Rae continue as directors.

Respectfully,

James A. Whitworth
President

LBDA Programs - Website

The LBDA website was the original program for supporting caregivers. It has been expanded and refined over the past year to make it even more responsive to the needs of the caregivers and anyone searching for information about LBD. The contents of the Caregiver Tips page have been expanded to include more of the 'nuts and bolts' of daily caregiving. Caregivers Words contain some of the thoughts of caregivers about their ways of coping with the daily stresses encountered while caring for their Loved One.

The premier edition of The Thistle, our newsletter is available. It can be downloaded for printing by individuals. In addition, future editions of the newsletter are available by subscription as well. (A subscriber has the option to 'opt out' at any time, thus we comply with federal laws regarding a persons right to cancel a subscription at their request.)

The LBDA brochure is also available on the website. It is the same one that we have printed and are distributing to other interested nonprofits, individuals, nursing homes, hospitals, doctors, etc. The brochure is the only readily available reference about LBD that puts a wealth of information at the reader's fingertips.

The 'Links to Other Sites' has been expanded. Of particular note is the article by Dr. Bradley Boeve of Mayo Clinic, Rochester, MN. This article appeared on the website at the same time it appeared in print in a well-respected publication on neurology. This was made possible by Dr. Boeve asking for and receiving permission from the publication for the LBDA to post it on the website.

As with most nonprofit organizations, donations are our life-blood, enabling us to provide program services to the caregivers and the medical and caring professions. To this end, a 'Make a Donation' page was added to the website to make it easy for individuals to make tax deductible donations to the LBDA. Donations may be made in an individual's name, in honor of, or in memory of someone.

The website has always had the means for anyone to email us with a question or concern. The 'Contact Us' page is where anyone coming to the website can email us for assistance with a LBD problem. Questions run the gamut from asking for help in finding a qualified neurologist, to advice on medications. Of course, we don't give medical or medication advice, but attempt to steer the person to information on the 'links' page or to their own doctor or pharmacist regarding medical questions.

LBDA Programs - Helpline

A companion to the website's email function, the helpline was established to provide caregivers with a toll-free telephone number (1-800-LEWYSOS) where they can call for any sort of help or advice. Here again, we can't give medical advice, but often times find a caregiver just needs someone to talk to that 'understands' what they are experiencing in their daily battle with LBD and it's effects on their Loved One.

2004 Financial Summary

The following pages show that we're making progress in our mission to support and educate. 2004 was our first full year of operation and while we haven't yet reached our goal of having over 90% of donations go directly to our programs, we're making progress in that direction.

LEWY BODY DEMENTIA ASSOCIATION
Statement of Financial Position
1/1/2004 – 12/31/2004

	<u>Unrestricted</u>	<u>Temporarily Restricted</u>	<u>Permanently Restricted</u>	<u>Total</u>
Assets				
Checking / Savings	\$ 12,872.00	\$ 0.00	\$ 0.00	\$12,872.00
Other Current Assets	\$ 0.00	\$ 0.00	\$ 0.00	\$ 0.00
Other Assets	\$ 0.00	\$ 0.00	\$ 0.00	\$ 0.00
Total Assets	\$ 12,872.00	\$ 0.00	\$ 0.00	<u>\$ 12,872.00</u>
Liabilities				
Accounts Payable	\$ 10.00	\$ 0.00	\$ 0.00	\$ 10.00
Other Current Liabilities	\$ 9,710.00	\$ 0.00	\$ 0.00	\$ 9,700.00
Total Liabilities	\$ 9,710.00	\$ 0.00	\$ 0.00	<u>\$ 9,710.00</u>
Net Assets				
Net Assets	\$ 0.00	\$ 0.00	\$ 0.00	\$ 0.00
Change in Net Assets	\$ 3,162.00	\$ 0.00	\$ 0.00	\$ 3,162.00
Total Net Assets	\$ 3,162.00	\$ 0.00	\$ 0.00	<u>\$ 3,162.00</u>
Total Liability & Net	\$ 12,872.00	\$ 0.00	\$ 0.00	<u>\$ 12,872.00</u>

LEWY BODY DEMENTIA ASSOCIATION
Statement of Activities
All Programs
1/1/2004 – 12/31/2004

	<u>Unrestricted</u>	<u>Temporarily Restricted</u>	<u>Permanently Restricted</u>	<u>Total</u>
Income				
Support and Revenues				
Contributions (general)	\$ 19,992.00	\$ 0.00	\$ 0.00	\$ 1,9992.00
Contributions (corp.)	\$ 50.00	\$ 0.00	\$ 0.00	\$ 50.00
Total Support and	<u>\$ 20,042.00</u>	<u>\$ 0.00</u>	<u>\$ 0.00</u>	<u>\$ 20,042.00</u>
Total Income	<u>\$ 20,042.00</u>	<u>\$ 0.00</u>	<u>\$ 0.00</u>	<u>\$ 20,042.00</u>
Expenses				
Program Services				
Education	<u>\$ 9,035.00</u>	<u>\$ 0.00</u>	<u>\$ 0.00</u>	<u>\$ 9035.00</u>
Total Program Services	<u>\$ 9,035.00</u>	<u>\$ 0.00</u>	<u>\$ 0.00</u>	<u>\$ 9,035.00</u>
Supporting Services				
Management and	\$ 6,073.00	\$ 0.00	\$ 0.00	\$ 6,073.00
Fundraising	<u>\$ 495.00</u>	<u>\$ 0.00</u>	<u>\$ 0.00</u>	<u>\$ 495.00</u>
Total Supporting	<u>\$ 6,568.00</u>	<u>\$ 0.00</u>	<u>\$ 0.00</u>	<u>\$ 6,568.00</u>
Total Expenses	<u>\$ 15,603.00</u>	<u>\$ 0.00</u>	<u>\$ 0.00</u>	<u>\$ 15,603.00</u>
Changes in Net	<u>\$ 4,439.00</u>	<u>\$ 0.00</u>	<u>\$ 0.00</u>	<u>\$ 4,439.00</u>

Lewy Body Dementia Association, Inc.

2004 Directors and Officers

James A. Whitworth

120 N. Val Vista Drive, #19
Mesa, Arizona 85213
United States

President

John Young

3231 Allen Parkway, #1202
Houston, Texas 77019
United States

Vice President

Sandy Shelton

310 Georgesville - Plain City Road
Galloway, Ohio 43119
United States

Secretary

Peggy M. Smith

200 Drawdy Road
Cross Hill, South Carolina 29332
United States

Treasurer

Jan Childress

5701 Derwent Alley
Sacramento, California 95835
United States

Director

Donna Rae

900 N. Connecticut
Royal Oak, Michigan 48067
United States

Director

Lynn Whitman

1318 N. Los Feliz Drive
Chandler, Arizona 85226
United States

Director

LBDA Scientific Advisory Council

Carol F. Lippa, M.D, Chairperson

Professor of Neurology

Director, Memory Disorders Program

Drexel University College of Medicine, Philadelphia, PA

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

John Duda, M.D.

Co-Director, Parkinson's Disease Research, Education and Clinical Center

Philadelphia VA Medical Center

Assistant Professor, Department of Neurology

University of Pennsylvania School of Medicine, Philadelphia, PA

Dennis W. Dickson, M.D.

Professor of Pathology

Mayo Clinic College of Medicine, Jacksonville, FL

Douglas R. Galasko, M.D.

Associate Professor In-Residence, Department of Neurosciences

University of California, San Diego, California

Serge Gauthier, M.D., FRCPC.

Professor, departments of Neurology & Neurosurgery, Psychiatry, Medicine.

Director of the Alzheimer's Disease Research Unit

McGill University, Montreal, Canada

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 and Dementia Research Group

Institute for Ageing and Health

University of Newcastle upon Tyne, UK