Leading the Fight Against LBD:
Increasing Knowledge, Sharing Experience, Building Hope.
Lewy Body Dementia - The basic facts

While many people never have heard of Lewy Body Dementia (LBD), it is not a rare disease and affects an estimated 1.3 million individuals and their families in the United States. Because LBD symptoms can closely resemble other more commonly known diseases like Alzheimer’s disease (AD) and Parkinson’s disease (PD), it is widely under-diagnosed. Even many doctors and other medical professionals are not familiar with LBD.

LBD is an ‘umbrella term’ for two related diagnoses.

We use the term LBD to refer to both “Parkinson’s disease dementia” (PDD) and “Dementia with Lewy bodies” (DLB). The earliest symptoms of these two diseases differ, but reflect the same underlying biological changes in the brain. Over time, people with both diagnoses will develop very similar cognitive, physical, sleep, and behavioral symptoms.

The most common LBD symptoms are listed below:

• Dementia is the primary symptom of LBD and includes problems with memory, problem solving, planning and abstract or analytical thinking.

• Cognitive fluctuations involve unpredictable changes in concentration and attention. This means that someone’s focus and attention may fluctuate significantly from day to day, or even hour to hour.

• Parkinson’s-like symptoms include rigidity or stiffness, shuffling gait, tremor (mild to major shaking of parts of the body), and slowness of movement.

• Hallucinations are seeing or hearing things that are not really present.

• REM Sleep Behavior Disorder (RBD) is a sleep disorder where people seemingly act out their dreams. For some people, this symptom appears years before any changes in cognition. Sleep partners may be the only person to recognize this symptom, and some have reported being physically injured if this sleep disorder is untreated.

• Severe sensitivity to neuroleptics is common in LBD. Neuroleptics are antipsychotic medications used to treat hallucinations or mental disorders.

• Autonomic nervous system dysfunction causes blood pressure fluctuations, fainting, increased sweating, urinary incontinence, constipation, and sexual dysfunction or impotence.

Early and accurate diagnosis of LBD is essential because LBD patients may react to certain medications differently than AD or PD patients. Traditional antipsychotic medications may be contraindicated for individuals living with LBD. Many traditional antipsychotic medications (for example, Haldol, Mellaril) are commonly prescribed for individuals with Alzheimer’s disease and other forms of dementia to control behavioral symptoms. However, LBD affects an individual’s brain differently than other dementias. As a result, these medications can cause a severe worsening of movement and a potentially fatal condition known as neuroleptic malignant syndrome (NMS). NMS causes severe fever, muscle rigidity and breakdown that can lead to kidney failure.
About LBDA

The Lewy Body Dementia Association (LBDA) is the only 501(c)(3) nonprofit organization in the United States dedicated to raising awareness of the Lewy body dementias (LBD), supporting patients, their families and caregivers, and promoting scientific advances.

With the help of LBDA’s Scientific Advisory Council of internationally recognized leaders in LBD research, LBDA develops and distributes up-to-date and scientifically sound information on Lewy body dementias to people with LBD, their caregivers, and medical professionals.

Lifting the Burden

LBDA’s mission statement is far more than simply words on a page. It is the driving force that comes from knowing that all LBD families face a terrible and incurable disease.

LBDA is helping to lift the burden on these families by living out its mission:

• Outreach – ensuring that families can turn to someone who has first-hand knowledge of LBD with questions about the disease, caregiving challenges, and that they have someone who will listen with understanding and empathy to their fears about the future.

• Education – providing scientifically sound educational resources for families and medical and caring professionals on LBD diagnosis, treatment, and behavioral issues.

• Research – bringing together dementia and movement disorder clinical experts and scientists to advance the growing body of knowledge about Lewy body dementias.

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.
Here are some of the exciting ways your generous donations were Increasing Knowledge, Sharing Experience and Building Hope in 2008.

Publications for New Audiences

For the first time, LBDA developed resources especially for physicians and people with LBD.

• *Current Issues in LBD Diagnosis, Treatment and Research* was developed for physicians by members of the Association’s Scientific Advisory Council. LBDA received support from The Carmen Foundation for this publication, which can be downloaded from the Association’s Website at no cost.

• *An Introduction to LBD* is the first publication ever written especially for the person newly diagnosed with LBD and can be obtained online and in print through LBDA. This comprehensive publication is also available through the 890 local offices of the Area Agency on Aging and the Title VI Native American aging program. The brochure was made possible by a generous grant from Novartis Pharmaceuticals Corporation.

• *The LBD Medical Alert Wallet Card*, also funded by Novartis Pharmaceuticals Corporation, is a necessity for all people with LBD and their caregivers. The newly revised card alerts emergency room physicians to medication sensitivities in LBD and now directs them to a special Webpage for detailed information on treating psychosis in LBD. This wallet card is available by itself and is also included in every copy of *An Introduction to LBD*.

Online Resources

In an effort to make its Website more robust and user friendly, the Association launched a completely redesigned Website in June 2008. In the second half of 2008 alone, nearly 100,000 unique visitors came to www.lbda.org in their search for information on Lewy body dementias.

The following new resources and features were added to LBDA’s Website in 2008:

• LBD-related news stories in the media

• A calendar of upcoming LBD-related events

• Educational videos from past LBDA events

• A new section on LBDA Publications with up-to-date educational documents available for download or print

• Improved user interface and navigation

• Resizable text for easier readability

LBDA’s electronic newsletter continued to grow in popularity. In 2008, circulation for the bi-monthly publication reached almost 3,000.
Family Outreach and Support

Many volunteers join LBDA after benefitting from the programs and services provided by the association. They continue to impress us with their ingenuity and drive to raise LBD awareness and support in their local communities and to connect LBD families together online.

Here are some of the remarkable things our volunteers are accomplishing in their communities and across the country:

• The number of LBD support groups across the country more than doubled to 45 in 2008.

• Volunteers collaborated with LBDA and other organizations on six local events designed to raise LBD awareness within the general public.

Each year LBDA recognizes one volunteer whose contributions in service to those affected by LBD stand out for their time and dedication. LBDA recognized Victoria Ruff as our 2008 Volunteer of the Year. Victoria hails from Boston, MA, where she cared for her mother who passed away from LBD. She has made the LBD Chat Room a valuable resource for caregivers and others affected by LBD allowing them to meet online in real-time. Victoria leads an LBD support group and has helped to bring information and resources on Lewy body dementias to local facilities. She officially joined LBDA’s corps of volunteers in 2006 and currently sits on the Outreach Committee.

LBDA also has a thriving online community, which continues to grow at remarkable rates. In addition to nearly 1,000 registered forum members, more than 11,000 unique visitors used the discussion forums in 2008, gaining knowledge and support through reading about the experiences of others.

In response to popular demand, LBDA expanded our forums in 2008 as follows:

• A new, private, moderated forum for people who have LBD.

• Forums on practical caregiving tips, financial, legal and social service needs, LBD research, and member introductions.
Raising LBD Awareness Among Physicians

Despite decades of published LBD research, it is still shocking when LBD families learn that most of the medical professionals they know are unfamiliar with LBD, let alone understand the diagnosis criteria or medication sensitivities common in LBD. Out of sheer necessity most LBD caregivers quickly turn into grass roots advocates, sharing the complex world of LBD with the caregiving, aging and medical professionals they meet.

Expanded efforts to reach physicians with online and printed information on LBD included the following:

- LBDA’s first publication for physicians, entitled “Current Issues in LBD Diagnosis, Treatment and Research.”

- The newly revised “LBD Medical Alert Wallet Card,” which directs emergency room physicians to a special webpage for detailed information on treating psychosis in LBD.

- The results of our Caregiver Burden Assessment Survey were presented at the Mental Dysfunctions in Parkinson’s Disease Conference in Dresden, Germany. Several of LBDA’s scientific advisory council: James E. Galvin, MD, MPH; John E Duda, MD; Daniel Kaufer, MD; Carol F. Lippa, MD, as well as Steven H. Zarit, PhD, and the 1,000 caregivers who responded, made this possible.

- LBDA continued establishing its presence as the leader in issues facing LBD families by exhibiting at five national medical conferences and responding to requests from over 300 medical professionals and researchers.

While its Website is LBDA’s largest point of distribution of educational resources, the Association also mails printed material to individuals who don’t have Internet access and provides literature to physicians and organizations upon request. In 2008, more than 2,100 requests for publications and resources in hard copy were fulfilled.
Support for LBDA

LBDA reached new heights in 2008 through the generosity and support of its donors who contributed $400,000 for programs that serve families affected by Lewy body dementias.

In response to the nationally broadcast passing of actress Estelle Getty, who had a long battle with Lewy body dementia, LBDA’s newly launched Website proved to be extremely valuable to more than 11,000 fans who wanted to know more about this highly prevalent, yet little known disease. The average number of unique visitors to the Website daily during that same time period was roughly 500. The dramatic spike in Website traffic on the day of Ms. Getty’s passing (July 22, 2008) underscores the public’s lack of familiarity with LBD and its desire to know more.
INDEPENDENT AUDITORS' REPORT

To the Board of Directors
Lewy Body Dementia Association, Inc.
Atlanta, Georgia

We have audited the accompanying statement of financial position of the Lewy Body Dementia Association, Inc. (a nonprofit organization) as of December 31, 2008 and 2007 and the related statements of activities and cash flows for the years then ended. These financial statements are the responsibility of the Lewy Body Dementia Association, Inc.'s management. Our responsibility is to express an opinion on these financial statements based on our audits.

We conducted our audits in accordance with auditing standards generally accepted in the United States of America. Those standards require that we plan and perform the audits to obtain reasonable assurance about whether the financial statements are free of material misstatement. An audit includes examining, on a test basis, evidence supporting the amounts and disclosures in the financial statements. An audit also includes assessing the accounting principles used and significant estimates made by management, as well as evaluating the overall financial statement presentation. We believe that our audits provide a reasonable basis for our opinion.

In our opinion, the financial statements referred to above present fairly, in all material respects, the financial position of Lewy Body Dementia Association, Inc. as of December 31, 2008 and 2007, and the changes in its net assets and its cash flows for the years then ended in conformity with accounting principles generally accepted in the United States of America.

April 23, 2009
LEWY BODY DEMENTIA ASSOCIATION, INC.
Statement of Financial Position
December 31, 2008 and 2007

<table>
<thead>
<tr>
<th>Assets</th>
<th>2008</th>
<th>2007</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cash and Cash Equivalents</td>
<td>$404,311</td>
<td>$450,054</td>
</tr>
<tr>
<td>Unconditional Promises to Give</td>
<td>-</td>
<td>5,240</td>
</tr>
<tr>
<td>Prepaid Expenses</td>
<td>5,387</td>
<td>2,750</td>
</tr>
<tr>
<td>Property, Furniture and Equipment, net</td>
<td>3,818</td>
<td>7,966</td>
</tr>
<tr>
<td><strong>Total Assets</strong></td>
<td><strong>$413,516</strong></td>
<td><strong>$466,010</strong></td>
</tr>
</tbody>
</table>

Liabilities and Net Assets

<table>
<thead>
<tr>
<th>Liabilities</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Accounts Payable</td>
<td>$28,177</td>
<td>$2,001</td>
</tr>
</tbody>
</table>

Net Assets:

| Unrestricted         | 374,915   | 410,073   |
| Temporarily Restricted| 10,424    | 53,936    |
| **Total Net Assets** | **385,339** | **464,009** |

| Total Liabilities and Net Assets | $413,516 | $466,010 |

See accompanying notes to the financial statements.
LEWY BODY DEMENTIA ASSOCIATION, INC.
Statement of Activities
For the Years Ended December 31, 2008 and 2007

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Revenue and Support:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Contributions</td>
<td>$ 343,186</td>
<td>$ 191,230</td>
</tr>
<tr>
<td>Special Events</td>
<td>28,784</td>
<td>-</td>
</tr>
<tr>
<td>Investment Income</td>
<td>9,091</td>
<td>20,962</td>
</tr>
<tr>
<td>Total Revenue and Support</td>
<td>381,061</td>
<td>212,192</td>
</tr>
<tr>
<td>Net Assets Released from Restrictions</td>
<td>43,512</td>
<td>13,008</td>
</tr>
<tr>
<td>Total Revenue, Support and Reclassifications</td>
<td>424,573</td>
<td>225,200</td>
</tr>
</tbody>
</table>

| Expenses:                         |            |            |
| Programs                          | 287,163    | 196,917    |
| Support Services                  | 139,292    | 83,690     |
| Advancement - Fundraising         | 33,276     | 2,166      |
| Total Expenses                    | 459,731    | 282,773    |

| Decrease in Unrestricted Net Assets | (35,158) | (57,573) |

| Changes in Temporarily Restricted Net Assets: |            |            |
| Contributions                                | -          | 59,236     |
| Net Assets Released from Restrictions        | (43,512)   | (13,008)   |
| Increase (Decrease) in Temporarily Restricted Net Assets | (43,512)   | 46,228     |
| Change in Net Assets                          | (78,670)   | (11,345)   |

| Net Assets at Beginning of Year              | 464,009    | 475,354    |
| Net Assets at End of Year                    | $ 385,339  | $ 464,009  |

See accompanying notes to the financial statements.
LEWY BODY DEMENTIA ASSOCIATION, INC.
Statement of Cash Flows
For the Years Ended December 31, 2008 and 2007

<table>
<thead>
<tr>
<th>Cash Flows from Operating Activities:</th>
<th>2008</th>
<th>2007</th>
</tr>
</thead>
<tbody>
<tr>
<td>Change in Net Assets</td>
<td>$ (78,670)</td>
<td>$ (11,345)</td>
</tr>
<tr>
<td>Adjustments to reconcile Change in Net Assets to Net Cash Used by Operating Activities:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Depreciation</td>
<td>4,148</td>
<td>3,283</td>
</tr>
<tr>
<td>Changes in Operating Assets and Liabilities:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(Increase) Decrease in Receivables</td>
<td>5,240</td>
<td>(4,947)</td>
</tr>
<tr>
<td>(Increase) Decrease in Prepaid Expenses</td>
<td>(2,637)</td>
<td>(2,425)</td>
</tr>
<tr>
<td>Increase (Decrease) in Accounts Payable</td>
<td>26,176</td>
<td>(867)</td>
</tr>
<tr>
<td>Net Cash Used in Operating Activities</td>
<td>(45,743)</td>
<td>(16,301)</td>
</tr>
</tbody>
</table>

| Cash Flows from Investing Activities: | | |
| Purchase of Software | | |
| Net Cash Used by Investing Activities | | |

<table>
<thead>
<tr>
<th>Net Decrease in Cash</th>
<th>2008</th>
<th>2007</th>
</tr>
</thead>
<tbody>
<tr>
<td>$ (45,743)</td>
<td>$ (24,343)</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Cash and Cash Equivalents at Beginning of Year</th>
<th>2008</th>
<th>2007</th>
</tr>
</thead>
<tbody>
<tr>
<td>$ 450,054</td>
<td>$ 474,397</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Cash and Cash Equivalents at End of Year</th>
<th>2008</th>
<th>2007</th>
</tr>
</thead>
<tbody>
<tr>
<td>$ 404,311</td>
<td>$ 450,054</td>
<td></td>
</tr>
</tbody>
</table>

See accompanying notes to the financial statements.
Note 1 - Organization and Summary of Significant Accounting Policies

Nature of Business

Lewy Body Dementia Association, Inc. (the Organization) is a national 501(c)(3) non-profit organization dedicated to raising awareness of Lewy body dementias (LBD), supporting LBD patients, families and medical professionals, and promoting scientific advances. Services include the LBDA Caregiver Helpline, national support group network, bimonthly e-newsletter, educational publications and other relevant information for physicians and families in print and on the Organization's website. The Organization is funded exclusively through charitable contributions.

Basis of Accounting

Basis of accounting refers to the manner in which revenues and expenses are recognized in the accounts and reported in the financial statements. The financial statements are presented on the accrual method of accounting whereby revenues are recognized when earned and expenses are recognized when incurred.

Financial Statement Presentation

The Organization is required to report information regarding its financial position and activities according to three classes of net assets: unrestricted net assets, temporarily restricted net assets, and permanently restricted net assets.

Contributions, Support and Revenue

All grants, donations and contributions are recorded as unrestricted, temporarily restricted, or permanently restricted net assets depending on the existence or nature of any donor restrictions.

The Organization reports gifts of cash and other assets as restricted support if they are received with donor stipulations that limit the use of the donated assets. When a donor restriction expires, that is, when a stipulated time restriction ends or the purpose restriction is accomplished, temporarily restricted net assets are reclassified to unrestricted net assets and reported in the statement of activities as net assets released from restrictions. Contributions received with donor-imposed restrictions met in the same year in which the contributions are received are classified as unrestricted contributions.

The Organization records donated noncash assets at their fair value in the period received. Contributions of donated services that create or enhance nonfinancial assets or that require specialized skills, are provided by individuals possessing those skills, and would typically need to be purchased if not provided by donation, are recorded at their fair value.
Note 1 - Organization and Summary of Significant Accounting Policies - continued

Cash and Cash Equivalents

Cash and cash equivalents represent funds in demand deposit accounts with financial institutions or money market accounts held at an investment brokerage firm available within thirty days.

Unconditional Promises to Give

Contributions, including unconditional promises to give, are recognized as revenue in the year they are received or promised. Unconditional promises to give that are expected to be collected within one year are recorded at new realizable value. Unconditional promises to give that are expected to be collected in future years are recorded at the present value of their estimated future cash flows. The discounts on those amounts are computed using interest rates applicable to the years in which the promises are received. Amortization of the discounts included in contributions in the accompanying statements of activities. Conditional promises to give are not included as support until the conditions are substantially met.

The Organization uses the allowance method to determine the uncollectible unconditional promises receivable. The allowance is based on managements analysis of specific promises made. In the opinion of management, as of December 31, 2007, all unconditional promises to give were collectible and an allowance for uncollectible promises was not necessary.

There are not outstanding unconditional promises to give at December 31, 2008.

Property and Equipment

Property and equipment are stated at cost and depreciated or amortized over the estimated useful life of each asset. Depreciation and amortization are computed using the straight-line method.

Estimates

The preparation of financial statements in conformity with generally accepted accounting principles requires the use of management’s estimates. Actual results may differ from those estimates.
Note 1 - Organization and Summary of Significant Accounting Policies - continued

Tax Status

The Organization is a not-for-profit organization exempt from income taxes under the Internal Revenue Code Section 501(c)(3). Therefore, no provision for income taxes has been made.

Reclassifications

Certain accounts in the prior year financial statements have been reclassed for comparative purposes to conform with the presentation in the current year financial statements.

Note 2 - Unconditional Promises to Give

Unconditional promises to give at December 31, 2007, totaled $5,240 and were collected in 2008.

Note 3 – Fixed Assets

Fixed assets at December 31, 2008 and 2007, consist of software at a cost of $7,635 and $12,445, respectively and accumulated depreciation of $3,817 and $4,479, respectively.

Note 4 – Temporarily Restricted Net Assets

At December 31, 2008 and 2007, temporarily restricted net assets are available for the following purposes:

<table>
<thead>
<tr>
<th></th>
<th>2008</th>
<th>2007</th>
</tr>
</thead>
<tbody>
<tr>
<td>Educational materials</td>
<td>$10,424</td>
<td>$49,236</td>
</tr>
<tr>
<td>Website redesign</td>
<td>-</td>
<td>4,700</td>
</tr>
<tr>
<td>Total</td>
<td>$10,424</td>
<td>$53,936</td>
</tr>
</tbody>
</table>

Note 5 - Functional Allocation of Expenses

The costs of providing the various programs and activities have been summarized on a functional basis in the statement of activities. Accordingly, certain costs have been allocated among the programs and supporting services benefited.
LBDA Scientific Advisory Council (SAC)

The LBDA Scientific Advisory Council (SAC) members are international leaders in LBD research and clinical management. They provide the most up-to-date medical and research information, which we use to create informative publications for the general public, caregivers and the medical profession.

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Yokohama City University School of Medicine  
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Pittsburg, PA, USA

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Newcastle, England, UK

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Senior Investigator and Chief, Molecular Genetic Section, National Institute on Aging, National Institutes of Health  
Bethesda, MD, USA

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Adjunct Associate Professor, Dept. of Epidemiology  
University of Washington  
Staff Physician, VAPSHCS  
Seattle, WA, USA

Daniel Weintraub, M.D.  
Assistant Professor of Psychiatry  
University of Pennsylvania  
Philadelphia, PA, USA

*LBDA Board of Directors  
**Honorary SAC Member
2008 LBDA Board of Directors
(at December 31, 2008)

John Young, President
Lake Tahoe, CA

Joe Whiteis, President-Elect
Minneapolis, MN

Jim Whitworth, Treasurer / Secretary
Mesa, AZ

James Galvin, M.D., Director
St. Louis, MO

Debbie McCoy-Massey, Director
Atlanta, GA

Nancy Silverman, Director
Fort Lauderdale, Florida

Steve Stevenson, Director
Atlanta, Georgia

Angela Taylor, Director
State College, PA

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Fax: 480-422-5434
E-mail: lbda@lbda.org

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support@lbda.org