



Increasing Knowledge, Sharing Experience, Building Hope

2006 ANNUAL REPORT

OUR INSPIRATION

“Although I just recently tapped into this wonderfully helpful website, I have always felt connected to all of you. My husband, Richard, passed away on March 13, 2007. His battle lasted 3 years. It was not as long of a battle as many I have read about, but it felt like a lifetime. I thank this site and everyone with their posts for giving me all the information and support I needed to understand what was happening....it kept me sane. It also helped me understand and accept my frustrations.”

Stephanie Ricci, California

“The LBDA is one of the best developments that has occurred in the history of the disorder... it seems barely credible that we have to struggle so hard to get it in the eye of the scientific community, health and social care providers, funders and the general public.”

Dr. Ian McKeith, Institute for Ageing and Health
University of Newcastle upon Tyne, UK
LBDA Scientific Advisory Council

“...I am glad for (my dad) to be able to forget the times I would get mad and say, ‘I hate you!’ But, I will truly be sad for him to forget any single time that I ever said, ‘I love you.’”

Amy Syx, Alabama

“Many caregivers have told me that the LBDA has been one of the biggest sources of information and comfort, when few individuals and clinicians still know so little about this disorder.”

Dr. Brad Boeve, Mayo Clinic
LBDA Scientific Advisory Council

She (my mother) had an appointment to see a neurologist due to her confusion (her mother had Alzheimer's and we thought she may have it, too), but with her falls, it confirmed the diagnosis of Lewy body dementia. Whew, we thought... thank God it's not Alzheimer's after all! Our relief was short lived however, once we learned what a diagnosis of Lewy body dementia meant. I had never heard of this Lewy before and soon learned that no one else, including those in the medical field, knew very much about Lewy either.

Gourete De Sousa Libanio Broderick, Canada
LBDA Volunteer

A LETTER FROM THE PRESIDENT

To our loyal supporters and friends,

Did you know that the majority of our programs and services are 100% volunteer driven? That's right! Volunteers are the driving force behind LBDA, contributing knowledge, experience, energy and creativity. We rely heavily on them to fulfill roles that are usually held by paid staff in larger, more mature nonprofits. **And they save us hundreds of thousands of dollars a year!**

So, what is it that they actually do?

- **Volunteers** respond to our email and toll free Caregiver Helpline to answer questions, offer emotional support, and assist families in finding resources.
- **Volunteers** distribute literature in their local communities to those in the medical and caring professions.
- **Volunteers** hold local support group meetings for LBD caregivers and their loved ones with LBD.
- **Volunteers** represent LBDA at health fairs and conferences to spread the word that LBDA is here to help.
- **Volunteers** organize educational events so that hundreds of people can learn about LBD from experts in dementia and movement disorders.
- **Volunteers** prepare educational materials that are received by thousands of people who need answers on LBD.
- **Volunteers** plan and launch fundraising campaigns and events on our behalf.
- **Volunteers** participate on project teams and committees to plan and launch new services.
- **Volunteers** serve on the Board of Directors, setting the strategic direction for LBDA
- **Volunteers** (with lots of initials after their names) serve on our Scientific Advisory Council.

That's just a taste of a long list of ways volunteers contribute to our mission. But what's the short of it? Our volunteers are:

Increasing Knowledge Sharing Experience Building Hope

These words clearly and succinctly represent what LBDA has been doing for the past 3 years. That's why we have chosen them to be our new slogan. And together with a brand new logo, our public image is undergoing a transformation that will continue to build our reputation as the premiere resource for trustworthy information on LBD.

We are excited to meet all the new volunteers who are as passionate as we are about lifting the burden that rests heavily on those who are impacted by LBD. At our current rate, our volunteer ranks should reach 50 people who are actively engaged in our mission by the time you read this report. That's a remarkable growth rate for an organization that is only 3 ½ years old! We are excited about the progress we made in 2006, not only in programs but in strengthening our leadership, clarifying our strategic goals, and setting an exciting course for 2007.

I hope you feel the contagious enthusiasm that ties us all together in our mission – from volunteers to donors, from LBD experts to LBD families. Together, we are:

**Increasing Knowledge
Sharing Experience
Building Hope**

In hope,
Angela Taylor
President, 2006 LBDA Board of Directors

A LETTER FROM THE EXECUTIVE DIRECTOR

Dear Friends,

LBDA has experienced incredible growth in the past year and stands poised to make powerful contributions to all of the communities it serves. I believe that LBDA is at the threshold of tremendous growth in programs, services, and visibility in many areas.

With a strong emphasis on strategic planning and long-range goals, LBDA is taking great strides toward a firm infrastructure and support system for its growing portfolio of offerings to caregivers, medical professionals, and the public at large. Each component of this outreach will be of great benefit to all of our communities.

The goal of LBDA in the coming year is to supplement grants and awards beyond the level of basic operating expenses. With a staffing plan in place for a fundraising professional and a program assistant, the funding and support for increased services and the reach of LBDA should grow at levels beyond the pace we have seen looking back over the last 3 ½ years. Investments such as these will support the future of LBDA and enable us to grow our relationships with a far greater number of partners.

The professional staff of LBDA will become a strong conduit for enhanced services and outreach. Each of us has an important role in advancing the knowledge of Lewy body dementia. If you are a volunteer, consider recruiting a friend who can help you help the thousands LBDA reaches each year. If you have graciously contributed as a donor, there are not enough words of thanks. If you have given once, consider becoming an annual donor.

Working together we can make a positive and enduring difference in not just thousands, but millions of lives.

Sincerely,
Samantha Spears, CAE and MBA
Interim Executive Director
Lewy Body Dementia Association

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: 10 THINGS THE PUBLIC SHOULD KNOW

Understanding Lewy Body Dementias

Lewy body dementias (LBD) affect an estimated 1.5 million individuals and their families in the United States. At the Lewy Body Dementia Association (LBDA), we understand that though many families are affected by this disease, few individuals and medical professionals are aware of the symptoms, diagnostic criteria, or even that LBD exists. There are important facts about Lewy body dementias that you should know if you, a loved one, or a patient you are treating may have LBD.

1. **Lewy body dementias (LBD) are the second most common form of degenerative dementia and is widely under-diagnosed:** The only other form of degenerative dementia that is more common than LBD is Alzheimer's disease (AD). Many individuals who have LBD are misdiagnosed, most commonly with Alzheimer's disease if they present with a memory disorder or with Parkinson's disease if they present with movement problems.
2. **LBD can have three common presentations:** Some individuals will start out with a movement disorder leading to the diagnosis of Parkinson's disease and later develop dementia. Another group of individuals will start out with a memory disorder that may look like AD, but over time two or more distinctive features become apparent leading to the diagnosis of "dementia with Lewy bodies" (DLB). Lastly, a small group will first present with neuropsychiatric symptoms, which can include hallucinations, behavioral problems, and difficulty with complex mental activities, leading to an initial diagnosis of DLB. Regardless of the initial symptom, over time all three presentations of LBD will develop very similar cognitive, physical, sleep and behavioral features, all caused by the presence of Lewy bodies throughout the brain.
3. **The most common symptoms of LBD include:**
 - a. Dementia: problems with memory and thinking
 - b. Hallucinations: seeing or hearing things that are not really present
 - c. Cognitive fluctuations: unpredictable changes in concentration and attention
 - d. Parkinson-like symptoms: rigidity or stiffness, shuffling gait, tremor, slowness of movement (bradykinesia)
 - e. Severe sensitivity to neuroleptics (medications used to treat hallucinations)
 - f. REM Sleep Behavior Disorder: a sleep disorder where people seemingly act out their dreams
4. **The symptoms of LBD are treatable:** Currently there are no medications approved specifically for the treatment of LBD. All medications prescribed for LBD are approved for a course of treatment for symptoms related to other diseases such as Alzheimer's disease and Parkinson's disease with dementia and offer symptomatic benefits for cognitive, movement and behavioral problems.

5. **Early and accurate diagnosis of LBD is essential:** Early and accurate diagnosis is important because LBD patients react to certain medications differently than AD or PD patients. A variety of drugs, including anticholinergics and some antiparkinsonian medications, can worsen LBD symptoms. LBDA has compiled a list of medications that should be avoided.
6. **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.
7. **Early recognition, diagnosis and treatment of LBD can improve the patients' quality of life:** LBD may affect an individual's cognitive abilities, motor functions, and/or ability to complete activities of daily living. Treatment should always be monitored by your physician(s) and may include: prescriptive and other therapies, exercise, diet, sleep habits, changes in behavior and daily routines.
8. **Individuals and families living with LBD should not have to face this disease alone:** LBD affects every aspect of a person – their mood, the way they think, and the way they move. LBD patients and families will need considerable resources and assistance from healthcare professionals and agencies. The combination of cognitive, motor and behavioral symptoms creates a highly challenging set of demands for continuing care. LBDA was formed to help families address many of these challenges.
9. **Physician education is urgently needed:** An increasing number of general practitioners, neurologists, and other medical professionals are beginning to learn to recognize and differentiate the symptoms of LBD from other diseases. However, more education on the diagnosis and treatment of LBD is essential.
10. **More research is urgently needed!** Research needs include tools for early diagnosis, such as screening questionnaires, biomarkers, neuroimaging techniques, and more effective therapies. With further research, LBD may ultimately be treated and prevented through early detection and neuroprotective interventions. Currently, there is no specific test to diagnose LBD.

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 for support of 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 caregiving experiences.

OUR MILESTONES

January, 2006 – Held the first annual Many Faces of LBD Symposium

February, 2006 – Attended and participated in the “PDD/DLB at a Crossroad Symposium”

May, 2006 – Testified at an FDA advisory panel meeting

Aug 2006 – Launched a website survey to gather caregiver feedback

Sept 2006 – Held our first major Strategic Planning Session

Oct 2006 – Re-staffed the Atlanta office with an Interim Executive Director and established a staffing plan for 2007

Dec 2006 - Approved new corporate branding

LBDA 2006 PROGRAM ACHIEVEMENTS

As LBDA has grown, so have the demands on us for resources and information available on LBD. The marked increase in demand for these services in 2006 over 2005 is a strong indicator of the visibility and recognition of LBDA in the public at large, and the constituencies LBDA serves.

Website – The LBDA Website is a central communication hub for information and resources to support LBD families, caregivers, and professionals. In 2006, the website received a 30% increase in visitations over 2005, and the total number of visits to the LBDA website in 2006 was 182,979. Over 10,000 unique individuals made approximately 15,000 visits to LBDA's website on average each month in 2006 and viewed an average of eight additional pages. In April, the LBDA blog was launched, and in June LBDA forums were added to the website. The blog has four contributors and the forums host 300+ users and feature over 1400 posts.

LBDA Newsletter – LBDA's newsletter (formerly named *The Thistle* and being re-launched in 2007 as the *Lewy Body Digest*), provides LBD caregivers and medical staff with up-to-date information on Lewy body dementia. Requests for LBDA's newsletter increased by 90% in 2006. There were an additional 720 requests beyond our existing 800 electronic subscribers from 2005 and we had a 42% increase in hard-copy subscription requests.

Toll-free Caregivers' Helpline 800-539-9767 – The LBDA Caregivers' Helpline is a direct and personal way for caregivers to interact with experienced LBD caregiver volunteers who are prepared to answer a wide variety of questions about LBD and caregiving. In 2006, the Caregivers' Helpline responded to 978 calls, an increase of 31% over 2005 call volume.

E-mail helpline – The e-mail helpline provides another option for individuals to seek personalized information. There were 472 requests for assistance through the e-mail hotline during 2006.

Educational Materials – LBD educational literature is mailed to caregivers, professionals and other interested parties who seek printed materials on LBD. Three different types of information packets have been designed to provide information and resources specifically focused on the needs of caregivers, professionals, and organizations. Literature and materials are also provided for distribution at conferences, within support groups and at other LBD related meetings and events.

In 2006, LBDA mailed 283 caregivers a literature packet to assist in their journey with LBD. There were an additional 88 organizations or facilities which requested materials for wider distribution and education regarding LBD. Literature supplies were also provided to 57 volunteers, who use our materials to raise public awareness on a grassroots level.

LBDA Pamphlet – The LBDA informational pamphlet is designed to be a widely distributed, introductory reference guide for caregivers and their families or medical professionals who are caring for their loved ones. This brochure was updated in 2006 and has remained very popular, with approximately 40,000 brochures distributed during 2006.

PDD/DLB at a Crossroad Symposium, Washington, DC – The staff and Board of Directors of LBDA joined with LBD caregivers from across the US to attend the PDD/DLB at a Crossroad Symposium in February, 2006. Coordinated by Dr. Carol Lippa (chair of LBDA's Scientific Advisory Council) as a satellite meeting of the World Parkinson Congress, the event was designed to bring clinical and research experts in movement cognitive disorders together to compare PDD and DLB, with the goals of identifying areas of consensus and research priorities. As planning for the event evolved, LBDA was asked to provide an added and vital communication link by bringing LBD families and researchers together. Breakout sessions for caregivers allowed time for questions and answers with leading LBD clinical experts. Most of LBDA's Scientific Advisory Council attended and presented at this major event on LBD.

LBDA Symposium and DVD: The Many Faces of Lewy Body Dementia – In January, 2006, the South Florida LBD Caregiver Support Group, Coral Springs Medical Center and LBDA produced an educational symposium on LBD. One-hundred-fifty people attended this program featuring Tanis Ferman, PhD, neuropsychologist at Mayo Clinic and Dr. Benjamin Barnea, neurologist with Coral Springs Medical Center. An LBD caregiver panel was also on hand for questions and answers. LBDA filmed the event and distributed more than 450 copies on DVD in 2006 to caregivers, physicians, facilities, and other organizations wishing to learn more about LBD. (Distribution was kept limited until a new process to order publications online could be added to LBDA's website in 2007.)

Caregiver Meet & Greet Event, Atlanta, GA – LBDA held an LBD caregiver event in September, 2006, featuring Dr. Daniel Kaufer from the Scientific Advisory Council who spoke to an audience of 50 caregivers and caring professionals about the challenges of LBD. The Atlanta LBD caregiver support group was launched by attendees of this event. Dr. Kaufer also presented on behalf of LBDA at the Alzheimer's Association's Dementia Care Conference in Atlanta that same week.

Conferences – LBDA attends local, regional, and national caregiver and medical conferences to build awareness about LBD and the Association's programs and services.

In 2006, LBDA exhibited at the following conferences:

American Academy of Neurology Annual Conference, San Diego, CA
World Parkinson's Conference, Washington, D.C.
American Neurological Association Annual Conference, Chicago, IL
Gerontological Society Conference, Dallas, TX

Local Support Groups – The purpose of an LBDA caregiver group is to provide information and emotional support for those coping with a loved one's Lewy body dementia. In 2006, LBDA began the year with four support groups, adding two additional support groups by year end. Several caregivers in other states had also expressed an interest in forming LBDA-affiliated caregiver groups.

Volunteers – The heart of LBDA is in the strength and passion of our volunteers. In 2006, LBDA added an additional 47 volunteers, bringing our volunteer numbers to 66. These volunteers contributed more than 8,180 hours, allowing LBDA to function in an effective and responsive fashion.

Donors – While volunteers are at the heart of LBDA's ability to perform and deliver many of our services, it is the generosity of donors who enable the organization to sustain itself. The increase in donor activity has been tremendous. The year 2006 brought a total of \$115,757 in contributions from individuals and corporations. This is an increase of 112% over the 2005 individual and corporate donations level of \$52,071. The tremendous growth and visibility of LBDA and knowledge of LBD is reflected in the level of increased donations.

The vast majority of donations to LBDA are made as memorials for a friend or loved one with LBD, and were the motivation behind 96% of all 2006 donations. Another 3% of donations are made 'in honor' of an individual. The remaining 1% of donations resulted from an annual campaign which generated 13% of our annual income.

2006 also received a generous grant from The Carmen Foundation in the amount of \$15,000 for white paper research.

OUR PLANS FOR 2007

With updated strategic priorities for 2007, LBDA is moving forward to strengthen our existing programs and expand our organizational capacity.

PROGRAMS:

LBD Informational Materials and Publications

A network of widely accessible white papers, written in an easy to understand style, was outlined in 2006. The first paper, Identifying Unmet Needs in LBD Diagnosis, Treatment and Research, will be the subject of a roundtable discussion of LBDA's Scientific Advisory Council at our May, 2007, meeting.

In 2006, LBDA began distributing free DVDs of The Many Faces of LBD educational symposium on LBD for the general public. LBDA is also filming additional LBD educational events for use in future educational DVDs.

LBDA's newsletter is being re-launched in 2007 with a new layout, content and name. The first issue of the *Lewy Body Digest* will be available in the second quarter of 2007.

We have developed a Wallet-sized Card for LBD patients, which can be carried by patients and/or caregivers at all times, and is designed to warn doctors and emergency room staff against the use of traditional antipsychotics in LBD care. This will be available for caregivers to order free of charge from the LBDA office.

Events

LBDA continues to expand our efforts to raise awareness about LBD and LBDA to physicians and affiliated professionals in aging. Plans are in place to exhibit at 5 national medical and aging conferences in 2007, in addition to several regional caregiver conferences.

The second annual Many Faces of LBD symposium is scheduled for January, 2007, in Coral Springs, FL.

LBDA is collaborating with Mayo Clinic to put on a multi-site educational event for caregivers and caring professionals in March, 2007. This event will be held live in Jacksonville, FL and Rochester, MN.

A live online chat event is planned to bring caregivers together with experts in movement and cognitive disorders. The pilot event is scheduled for March, 2007.

LBD Caregiver and Patient Outreach

LBDA is expanding our helpline capacity by adding more volunteer resources to answer the email and helplines, allowing for more timely responses and greater time availability per caller.

The first LBD caregiver support group was launched in 2005, and by the end of 2006 the number of local LBD support groups had grown to eight. LBDA has established a goal of helping to launch 20 LBD caregiver support groups in 2007.

A virtual support group will also be held at LBDA's website, and caregivers can soon gather in our chat room to provide direct support and share experiences.

ORGANIZATIONAL CAPACITY:

Human Resources

Volunteers

LBDA is a volunteer-driven organization, and with only one employee, we rely almost entirely on volunteers to plan, launch and maintain programming. We find experienced LBD caregivers provide the best caregiver-to-caregiver outreach and education, but by necessity they are limited in their availability due to their caregiving responsibilities. To expand our human resources, LBDA has successfully begun recruiting new volunteers from outside the caregiver network by using online volunteer matching services.

Board of Directors

The Board traditionally has been hands-on in program development and implementation, but as the organization matures we are beginning to develop a mid-level tier of volunteer leaders and project coordinators. This is allowing Directors to begin slowly stepping back from our function as a working board and begin the process of becoming a governing board.

Staff

LBDA is making a major investment in human resources in 2007 with plans to hire a Chief Advancement Officer and a Development and Program Coordinator. These two new roles will expand our focus on fundraising exponentially and will allow the Board and CEO to focus on more strategic issues.

Fundraising

Our fundraising focus for 2007 includes hiring an experienced professional with a successful fundraising track record to seek multi-year grants to: fund existing and new programs, increase organizational capacity, seek unrestricted educational grants from the pharmaceutical industry, develop corporate sponsors for national fundraising events designed to solicit donations from the general public, develop and expand relationships with our existing donor base, and to increase direct support from those receiving services from LBDA.

2006 DONORS:

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LEWY BODY DEMENTIA ASSOCIATION, INC.
Statement of Financial Position
December 31, 2006

ASSETS

Cash	\$ 46,681
Investments	427,715
Accounts Receivable	294
Prepaid Expenses	325
Property, Furniture and Equipment, net	<u>3,207</u>
Total Assets	<u>\$ 478,222</u>

LIABILITIES AND NET ASSETS

Liabilities:	
Accounts Payable and Accrued Expenses	\$ 2,868
Net Assets:	
Unrestricted	467,646
Temporarily Restricted	<u>7,708</u>
Total Net Assets	<u>475,354</u>
Total Liabilities and Net Assets	<u>\$ 478,222</u>

LEWY BODY DEMENTIA ASSOCIATION, INC.
Statement of Activities
For the Years Ended December 31, 2006

CHANGES IN UNRESTRICTED NET ASSETS:

Revenue and Support:

Contributions	\$ 141,258
Investment Income	<u>21,056</u>

Total Revenue and Support	162,314
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Net Assets Released from Restrictions	<u>3,292</u>
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Total Revenue, Support and Reclassifications	165,606
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Expenses:

Program Services	131,225
Support Services	74,824
Fundraising	<u>2,500</u>

Total Expenses	<u>208,549</u>
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Increase (Decrease) in Unrestricted Net Assets	(42,943)
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CHANGES IN TEMPORARILY RESTRICTED NET ASSETS

Net Assets Released from Restrictions	<u>(3,292)</u>
---------------------------------------	----------------

Increase (Decrease) in Temporarily Restricted Net Assets	<u>(3,292)</u>
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Total Change in Net Assets	(46,235)
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NET ASSETS AT BEGINNING OF YEAR	<u>521,589</u>
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NET ASSETS AT END OF YEAR	<u>\$ 475,354</u>
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LEWY BODY DEMENTIA ASSOCIATION, INC.
Statement of Cash Flows
For the Year Ended December 31, 2006

CASH FLOWS FROM OPERATING ACTIVITIES:	
Change in Net Assets	\$ (46,235)
Adjustments to reconcile Change in Net Assets to Net Cash used by Operating Activities:	
Depreciation	1,603
(Increase) Decrease in Accounts Receivables	72
Increase (Decrease) in Prepaid Expenses	2,787
Increase in Accounts Payable and Accrued Liabilities	<u>359</u>
Net Cash Provided (Used) in Operating Activities	(41,414)
 CASH FLOWS FROM INVESTING ACTIVITIES:	
Withdrawals from Investment Account	99,780
Purchases of Investments	<u>(21,098)</u>
Net Cash Provided (Used) by Investing Activities	78,682
 CASH FLOWS FROM FINANCING ACTIVITIES:	
Principal Payments on Notes Payable	<u>(27,482)</u>
Net Cash Provided (Used) in Financing Activities	<u>(27,482)</u>
 NET INCREASE IN CASH	9,786
 CASH AT BEGINNING OF YEAR	<u>36,895</u>
 CASH AT END OF YEAR	<u>\$ 46,681</u>
 SUPPLEMENTAL DISCLOSURE:	
Interest Paid	<u>\$ 7</u>

CONTACT INFORMATION

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Atlanta, GA 31145-9429

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support@lbda.org

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Fax: 480-422-5434

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