Letter from the Board of Directors

Dear Friends,

What makes ordinary people respond in extraordinary ways to a call for action? It's usually the knowledge that what they do has the potential to make a dramatic difference in the life of someone else. That's what everyone at LBDA - from our national program volunteers and our staff in Atlanta to the Board of Directors and international Scientific Advisory Council - has been doing every day since 2003.

Together, we are **Increasing Knowledge** every time we develop educational material that is read by tens of thousands of people via our website and printed literature. We are committed to **Sharing Experience** when we connect thousands of LBD caregivers to others who are also walking in their shoes, and when we spend one-on-one time with those who bring us LBD questions to which they haven’t found answers. And we are **Building Hope** by exploring the state of LBD research with those who do the research and those who fund it, in the hope of seeing the research community grow and thrive in the years to come.

We encourage you to read our annual report through the eyes of those who had to face LBD alone - before LBDA was founded. Before there was widely available information on LBD. Before they had support from others who knew just what they were going through. Imagine the encouragement they now feel by reading how many people LBDA is serving. Can you envision their satisfaction when they see the places LBDA plans to go in 2008 and beyond? And do you sense their relief that, thanks to our thousands of supporters, no person will ever have to face LBD alone again?

Because LBDA continues to respond to the call for action, we are very proud of the accomplishments our team of dedicated volunteers and staff made in 2007. But there is still so much to be done. To effect deep and lasting change, we need to make LBD a household name by reaching not just LBD families, but doctors, nurses, social workers, hospice agencies; scientists and researchers; industries like long term care, pharmaceuticals and imaging technology; public policy makers, and the general public.

The call for action has been sounded. Will you join us in answering the call?

Sincerely,

Angela Taylor  
President  
2007 LBDA Board of Directors
An Inside View

“This disease is fraying my communication with those I love, the connections scratchy with interference caused by the Lewy bodies. I mourn what’s already lost and fear the losses still to come, wondering if and when the connection, like a phone line gone down in a storm, will sever the bond forever.”

From book “Life in the Balance” by Dr. Thomas Graboys with Peter Zheutlin

A Caregiver’s Call

I would like to have patience for all the times I need to stop what I am doing to focus on listening to and deciphering the vanishing voice of my husband. I need patience for finding the lost things: my glasses that show up on his face, his wallet that surfaces in his underwear drawer, his glasses that lived for weeks with his boots in the garage. Just wrap up patience and give it to me, please, with a bow that promises tranquility on those days when I seem to run out of the inner resources that being a caregiver requires.

I would like before-breakfast endurance. When I want only to put my feet to the morning floor and stretch toward the day, but need to bolt into attentiveness and vigilance to avoid messes, misses, and moroseness. Then I need endurance. When I get up in the morning and want to remember my dreams, but instead am instantly needed for untangling his day, that’s when I need endurance.

I would like to live with hope again instead of this gnawing knowing that nothing I do is going to bring back my husband’s vitality, and nothing is going to stop this slow shuffle of loss.

I fantasize that ABC would do a show called “Extreme Care for the Caregiver.” I see a crew of resources coming to the doors of caregivers and announcing, “help is on the way!” We caregivers are tired though, and most of us are old enough that we wouldn’t be able to jump up and down and scream our delight for the cameras. We could faint though.

Since no one can grant me the wishes on my list, and ABC is not at my door, I will ask for hugs. Nelson’s hugs are diluted by dementia and need, and his strong arms are weakened by disease. I miss those attentive hugs. Just give me hugs for Christmas, strong reassuring hugs that tell me someone close to me cares.

An excerpt by Ginny Burkholder on LBDA’s caregiver blog
LBD – The basic facts

While many people never have heard of LBD, it is not a rare disease and affects an estimated 1.5 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 currently widely under-diagnosed. There are even many doctors and other medical professionals who are not familiar with LBD at all.

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 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.
Brief history of LBDA

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

The Lewy Body Dementia Association was formed 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 Association consists of a growing, dedicated group of people from all walks of life, many of whom understand the struggles of other caregivers due to their personal LBD experiences.

Memorial donations from the general public provided funds for basic programs and operations when LBDA was 100% volunteer driven. Our first major grant was received in 2005 and has provided basic office and staff infrastructure. New donors, foundation grants and corporate support are now allowing us to expand our programs and services in 2007 and beyond.

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.
THE URGENCY OF OUR CAUSE

A Growing Picture of Family Burden

LBD affects every aspect of a person – their mood, the way they think, and the way they move. It presents a triple threat of cognitive, motor and behavioral symptoms early in the course of LBD which quickly creates a highly challenging set of demands for continuing care. However, early recognition, diagnosis and appropriate treatment of LBD can significantly improve the patients’ and family caregivers’ quality of life.

Recent studies demonstrate that LBD families need considerable resources and assistance from healthcare professionals and other health-related agencies. Possibly even more than with Alzheimer’s. LBDA was formed to help families address many of these challenges.

- One recent study concluded that patients with DLB were more functionally impaired in activities of daily living (eating, dressing, bathing, etc.) than patients with AD with similar cognitive scores. (McKeith IG, Rowan E, Askew K, Naidu A, Allan L, Barnett N, Lett D, Mosimann UP, Burn D, O’Brien JT.; More severe functional impairment in dementia with Lewy bodies than Alzheimer disease is related to extrapyramidal motor dysfunction. Am J Geriatr Psychiatry. 2006 Jul;14(7):582-8.)

- Another study concluded that LBD progresses more rapidly than AD to specific clinical endpoints such as nursing home placement or death. The study revealed that individuals with LBD were 2 times more likely to die at comparable ages compared with people with AD. The average survival time for LBD was 78 years of age and for AD was 85 years of age. (Williams M, Xiong C, Morris JC, Galvin JE. Survival and mortality differences between dementia with Lewy bodies versus Alzheimer’s disease. Neurology, 67:1935-1942, 2006.)

- And a third study compared the resource use and cost in patients with DLB and AD and assessed determinants in costs of care in DLB. In this study, DLB patients used more than double the amount of resources compared to AD patients. (Boström F, Jönsson L, Minthon L, Londos E.; Patients with Lewy body dementia use more resources than those with Alzheimer’s disease. Int J Geriatr Psychiatry. 2007 Aug;22(8):713-9.)

I knew nothing about LBD, till the caregivers group that I attend, mentioned it. WOW, those symptoms matched my husband’s, who was diagnosed with Alzheimer’s. I made an appt. with a neurologist, and sure enough, LBD was diagnosed. Your group has sent me info that I am now sharing with everyone, especially the Home Care Group that come in to help with my husband. Not one of them had ever heard of LBD. They are now taking all the info and printing it out for each employed person of their group.

an excerpt from a caregiver message on LBDA’s online discussion forums
Too Many People Must Face LBD Alone

Despite its common prevalence, most health care providers simply aren’t adequately informed about LBD. While increasing numbers of neurologists and other specialists are beginning to recognize and differentiate the symptoms of LBD from other diseases, many primary care physicians and allied healthcare professionals remain largely unaware of LBD. Because it is an unfortunate reality that most people with dementia are never referred to a specialist for diagnosis and treatment of their specific type of dementia, increased education of medical and caring professionals on LBD is essential.

LBD families are also not being referred by their physicians to other resources where they can learn more about LBD. Combined with low LBD awareness in the medical profession, the majority of families are not prepared to face LBD’s unpredictable course.

LBD caregiving can also be socially isolating. Friends and acquaintances typically know nothing about LBD and the challenges it places on families. Even close family members who don’t live with the person with LBD can’t understand the waxing and waning cognitive abilities or the unpredictable behavioral changes. This frequently leads friends and relatives to underestimating the significant caregiving burden or the emotional toll on the primary caregiver.

… LBD patients seem to become more alert when other people, besides the caregiver, are present. My husband seems to do better when our children are around. My oldest son seemed to think I was exaggerating his (father’s) symptoms and "couldn’t see it" as bad as I told them. Then this past summer we went for a visit to their house for about six days. He saw a lot of the things I see daily and he now knows I am not exaggerating. He still can’t seem to realize it is as bad as I tell them. I think a lot of this is because he can’t believe his dad would ever get like this.

He was a good dad and was very intelligent all the growing up years of our children. Now he can’t use a remote or feed himself. That is hard for a son to accept. He hallucinates a lot and tells stories all confused. And, of course, they all wonder if they will have it some day. It is very terrifying to them.

(an excerpt from a caregiver message on LBDA’s online discussion forums)
It’s Taken Research Nearly 200 Years to Put the Lewy/Parkinson’s/Alzheimer’s Pieces Together

First came Parkinson’s Disease.
In 1817, Dr. Parkinson first reported on the “shaking palsy” that “spared the intellect.” Sixty years later, a French neurologist name Jean Martin Charcot recognized the significance of Dr. Parkinson’s work, and named the disease after him. In the early 1900’s, the pathology of Parkinson’s disease is documented, specifically the abnormalities in the area of the brain called the substantia nigra. The National Parkinson’s Foundation was eventually founded in 1957 by a family caregiver. In the 1960s, researchers developed the first approved treatment for motor dysfunction in Parkinson’s disease, but it wasn’t until 1979 that the first diagnostic criteria for PD were formally accepted. In time, it also became widely acknowledged that a large proportion of individuals with PD also developed cognitive impairment that progressed to dementia. In 2006, the FDA approved the first drug to treat the cognitive symptoms of the disease which Dr. Parkinson said ‘spared the intellect’ and, in 2007, the criteria to formally diagnose Parkinson’s disease dementia were established.

Then came Alzheimer’s Disease.
In 1906, Dr. Alzheimer first described a ‘peculiar disease of the cerebral cortex’ in a 54 year old woman. He went on to describe the two major brain abnormalities associated with Alzheimer’s – amyloid plaques and neurofibrillary tangles. In 1979, the Alzheimer’s Association was formed by representatives of five family support groups in consultation with Alzheimer’s experts and the National Institute of Neurological Disorders and Strokes. It wasn’t until 1980 that the first diagnostic criteria for Alzheimer’s were established. Fourteen years later, in 1994, the first treatment was developed and approved for Alzheimer’s. Today there are two classes of medications approved and widely used in the U.S. to treat the cognitive symptoms of Alzheimer’s.

Even later came Lewy Body Dementias.
In 1912, Dr. Lewy reported microscopic protein accumulations in the brainstem of autopsied Parkinson’s patients. In 1961, the protein deposits (now called Lewy bodies) were linked to progressive dementia and, by 1990, researchers across the world were using different names to describe a single disease that had motor, cognitive, and psychiatric symptoms. In 1996, an international consortium established a single set of diagnostic criteria for the disease now known as Dementia with Lewy Bodies (DLB). The Lewy Body Dementia Association was soon formed in 2003 by five family caregivers who met online. The diagnostic criteria were updated again in 2005 by the international consortium, to reflect additional symptoms and severe, potentially fatal medication sensitivities.
The Missing Piece Falls into Place

In 2007, researchers and clinical experts in both dementia and movement disorders established a new consensus that Parkinson’s disease with dementia (PDD) and dementia with Lewy bodies (DLB) shared the same underlying disease mechanism. This new consensus established four important priorities for future research:

1) Continued communication between experts who specialize in PDD and DLB;
2) Research studies to validate the diagnostic criteria;
3) The development of tests using blood, urine, or brain imaging to diagnose LBD, instead of relying only on symptom reporting by patients and caregivers;
4) Accelerated efforts to find more effective treatments for these diseases.

The Challenges Facing LBD Researchers

The lack of awareness of LBD’s prevalence, burden and costs to patients, caregivers and society has major implications for public policy and funding for research. The LBD patient population (DLB and PDD combined) is estimated to be approximately the same size as that of Parkinson’s.

There are two institutes at the NIH largely responsible for funding research in LBD. The National Institute on Aging (NIA) has, as part of its mandate, funding for dementia research as well as other disorders of older adults. The National Institute of Neurological Disorders and Stroke (NINDS) is largely responsible for research funding for neurological disorders including Parkinson’s disease. However, with NIA and NINDS both funding degenerative neurological conditions related by symptoms or biology to LBD, neither institutes are the clear leader in LBD research funding in the United States. This leaves researchers unsure where to find optimum funding.

Between 2000 and early 2007, the National Institutes of Health (NIH) funded 2,895 projects directly related to AD, including 29 Alzheimer Disease Centers through a number of earmarked funding programs (Source: http://crisp.cit.nih.gov). In contrast, during this same time period, NIH funded only 29 grants directly related to clinical, basic science and educational projects related to LBD.

This disparity impedes progress in LBD research and leaves patients with LBD with a host of unmet needs. Although the LBDA exists to promote awareness and support for patients and families, we are not yet in a position to fund a research portfolio. Until that time, LBDA advocates for increased LBD research funding by those already funding research into neurodegenerative diseases.
Answering the Call For Action in 2007

Until mid 2007, LBDA’s programs and services were heavily volunteer driven, and we are extremely proud of the work that our volunteers were able to accomplish with the support of a single employee. In the summer of 2007, LBDA hired two additional full time staff people, enabling us to transition leadership of most programs and services to our office in Atlanta, GA. LBDA’s transition to a staff-driven organization has allowed the Association to meet the growing volume of demand for LBD information and support, while become more efficient in managing programs and preparing to offer more extensive resources to even more people in 2008.

Increasing Knowledge

www.lbda.org

Our largest and most cost effective method of providing outreach and education to LBD families is our website. This year, we served an average of nearly 500 unique visitors every day, an increase of 45% over last year. This translates into many thousand unique visitors to our website every month. The growth isn’t limited only to visitors to our homepage. For example,

- The number of posts to the LBDA discussion forum has tripled over 2006 numbers, with the number of registered users more than doubling. There are now more than 680 users and over 4,400 messages posted by individuals with LBD and caregivers. There are also occasional posts from LBD experts.
- LBDA added a live online chat feature to our website, allowing for live caregiver interaction, and the first LBDA Live Chat with Dr. Stephen Gomperts of Massachusetts General Hospital. (The transcript from this event is available on our website.)

DVDs, Literature and More

In addition to the tens of thousands of website visitors each year, LBDA also provides printed and multimedia educational materials to those without Internet access.

- We fulfilled requests for literature packets from nearly 2,000 individuals, medical professionals, institutions and organizations, as opposed to 740 in 2006.
- LBDA re-launched our quarterly newsletter, which is both educational and focused on caregiver support. Approximately 2,300 people subscribed to the Lewy Body Digest in 2007.

The LBDA has provided me the opportunity to get information, check in with others and know there exists a place where someone knows what LBD means… And, the folks from the LBDA have been supportive in their discussing this process with me, and support of any kind is very much appreciated. In short, all of this keeps me moving forward in as positive and helpful manner as possible and focus the good things that can happen even during difficult times. So, thanks LBDA and thanks to those members who have taken the time to communicate with me.

(an excerpt from a message by a man diagnosed with LBD, posted LBDA’s online discussion forums)
We distributed over 1,000 copies of the “Many Faces of LBD” symposium DVD to caregivers and caring professionals.

**SHARING EXPERIENCE**

Someone to Listen
LBDA’s volunteer team of experienced LBD caregivers provides one-on-one support via telephone and email to LBD caregivers across the United States and internationally. In 2007, we responded to 1,500 caregiver inquiries through our telephone and email Caregiver Helplines.

LBDA and its growing network of local volunteers collaborate regularly with other nonprofit organizations and healthcare providers on LBD educational events.

- Approximately 450 individuals participated in 18 LBD-related support groups across the country.
- We collaborated with Mayo Clinic on a multi-site LBD educational event, reaching live audiences with presentations by LBD experts at Mayo Clinic locations in Jacksonville, FL and Rochester, MN.
- LBDA presented the second annual “Many Faces of LBD” symposium in Coral Springs, FL., in collaboration with the Coral Springs Medical Center.

**BUILDING HOPE**

One Small Step into Research, One Giant Step for LBDA
In a first-of-its-kind survey, LBDA launched an online LBD Caregiver Survey with the help of Dr. Steven H. Zarit of Penn State University. Using scientifically-sound methods, this survey will assess LBD caregiver burden and establishes LBDA as a national leader on LBD caregiving issues. Nearly 1,000 caregivers participated in this survey, also indicating LBDA’s potential for becoming a viable referral resource for studies seeking LBD research participants. While a full report will be issued in 2008, we learned a tremendous amount about LBD caregivers. This information is being translated into programs to benefit both families affected by LBD and the medical professionals who treat...
hospital-based internists, to collaborate on providing educational information for their audience.
LBDA coordinated an interview between Dr. Carol Lippa, Chair of our Scientific Advisory Council, and the magazine editor.

- Staff collaborated with Emory University on a presentation for the Georgia Association for Social Workers.

LBDA reached out to physicians at national and regional medical conferences, offering free literature for medical professionals and individuals with LBD. LBDA exhibited at the following events:

- American College of Physicians, San Diego, CA, April, 2007
- CaregiverEXPO, Chicago, IL, June 2007.
- 15th Annual Dementia Care Conference, Chicago, IL, August 2007.
- NASW Workshop, Atlanta, GA, October 2007.
- Texas Alzheimer’s Association events, Fall and Spring 2007.

In May, 2007, our Scientific Advisory Council held a roundtable discussion on current unmet needs in LBD diagnosis, treatment and research. Out of that discussion, a physician-oriented paper began to form and is nearing completion. Featured in this report is the new consensus that LBD is a spectrum disorder, the diagnostic criteria for both PDD and DLB, and a review of scientific literature on LBD treatment options. The report also underscores the substantial gap in LBD funding when compared to other neurological disorders like Alzheimer’s and Parkinson’s.
Our First Time in the Media
As LBDA’s staff grew, so did our focus on preparing for media attention as LBD awareness grows. Our first step was to develop an online press kit, complete with a list of “The 10 Things You Should Know about LBD.” This provides a simplified, high level overview of the most pressing issues on LBD. Other early forays into the media are as follows:

- LBDA facilitated a television interview of Barbara and Bill Hutchinson (LBD caregiver and patient) and LBDA’s Interim Executive Director on The Norma Sherry Show, shown locally in FL.
- LBDA’s 2007 Board President appeared by invitation on a local PBS station’s talk show on dementia caregiving in State College, PA.

Our list of loyal supporters keeps growing!
In the same way we’ve provided services to more and more people in 2007, so has our list of loyal supporters grown! Supporters come in two forms – those who contribute their time and talents and those who contribute financial resources. Both have grown considerably in 2007!

LBDA’s total sources of income jumped more than 70% over 2006 figures, largely due to our newly-expanded staff’s ability to reach out to foundations and corporations. The support coming from individuals making donations in memory of loved ones who passed away from LBD has also steadily increased.

Furthering our efforts to raise funds in support of our mission, LBDA launched an online store to allow LBD families to purchase LBDA-branded items. LBDA receives 20% of the profit from all purchases through our online vendor. Awareness wristbands are also available for purchase from our Atlanta office and have become a favorite item of LBD caregivers across the country.

Our volunteers, whose ranks increase steadily, continue to amaze us with their energy, dedication and creativity. In 2007, we had 57 people register to volunteer in some capacity. That’s a 146% increase over the year before!
A Glimpse into 2008

LBDA is very excited about our continually expanding capabilities, and staff and volunteers are already hard at work on a host of new programs, publications and resources for our various constituencies. Below are just a few of the many programs and projects planned for 2008 and beyond.

Increasing Knowledge

Building an Army of Doctors

One common challenge shared by those with LBD and their caregivers is the difficulty finding a physician experienced in diagnosing and treating LBD. In response to these needs, LBDA is preparing a multi-pronged approach to reach neurologists to provide them with valuable information on LBD for their practice, and printed literature for both individuals with LBD and their caregivers.

Starting with a direct mail campaign to attendees of the annual conference of the American Academy of Neurology, LBDA will promote the availability of a new publication especially for physicians. “Current Issues in LBD Diagnosis, Treatment and Research” is being developed by members of our Scientific Advisory Council and will bring key issues of LBD to the forefront of the doctors who most often diagnose and treat LBD.

This will be followed by a much larger direct mail campaign to thousands of neurologists across the country, offering patient-oriented publications and physician-oriented literature. This campaign will also invite neurologists to list themselves in a database of LBD-experienced clinicians on LBDA’s website.

And in the first major sign that LBDA is viewed as an international leader in LBD advocacy, LBDA has been invited to present on the topic of LBD caregiver issues at the 6th International Congress on Mental Dysfunctions & Other Non-Motor Features in Parkinson’s Disease in Dresden, Germany, from October 16-19, 2008. There, LBDA will reach an international array of scientists and physicians who specialize in movement disorders.

Sharing Experience

A New Publication especially for Those Diagnosed with LBD

A recent grant from Novartis Pharmaceuticals Corporation has provided funding to develop and nationally distribute a new publication, especially for people who are newly diagnosed with LBD and for those still seeking a diagnosis. Written in easy-to-understand language, this pamphlet provides an
introduction to LBD, its symptoms, and unique treatment issues. The pamphlet also provides short
overviews of other common types of dementia and helpful first steps for those who are newly-
diagnosed with LBD. A Medical Alert wallet card will be inserted into each brochure, providing LBD
families with a readily-available resource to warn emergency room personnel of the medication
sensitivities in LBD. A Spanish version will also be available.

This new publication and wallet card will be distributed to all 655 Area Agencies on Aging, 230 Title VI
American Indian Aging Programs, as well as 12,000+ neurologists and general practitioners. In addition,
LBDA will promote the availability of the brochure by submitting an announcement to the Connections
newsletter, issued by the federally-funded Alzheimer’s Disease Education and Referral Center (ADEAR),
which has a circulation of approximately 10,000. This magazine goes out to long-term care facilities,
social workers, and other allied healthcare professionals working in the field of aging.

BUILDING HOPE

Expanding our Focus on Research
In our first major contribution to advancing LBD research, LBDA will collaborate on a Lewy Body
Disease Biomarker Symposium in partnership with Washington University, St. Louis. This
scientific meeting, slated for late 2009 or early 2010, will be solely designed to explore the current state
of imaging, cerebrospinal fluid and other biological markers for LBD. This is essential for determining
what may be responsive to disease modifying interventions.

An international panel of clinical and scientific experts in LBD will join with representatives from the
biotechnology industry in closed door sessions to review and discuss unpublished LBD research findings
to identify new insights into LBD. Open sessions are also planned to bring LBD researchers together
with relevant governmental agencies for broad academic dialogue.

LBDA has established two major outcomes from the conference: first, to publish an LBDA supplement
in the American Academy of Neurology’s journal, Neurology; second, to establish a research agenda.
### 2007 Donors of $100 or More

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<td>Howard and Barbara Hoover</td>
</tr>
<tr>
<td>Cindy Bault</td>
<td>Paul Demou</td>
<td>Herb and Barbara Hoover</td>
<td>Howard and O’Brien Associates</td>
</tr>
<tr>
<td>Edward and Myra Bell</td>
<td>Heidi Dempsey</td>
<td>Mitzi and Red Howard</td>
<td>Mitzi and Red Howard</td>
</tr>
<tr>
<td>Carl Bennett</td>
<td>Deutsche Bank of Americas</td>
<td>William and Roula Hunter</td>
<td>William and Roula Hunter</td>
</tr>
<tr>
<td>Carol Bennett</td>
<td>Foundation</td>
<td>Richard and Karen Hyde</td>
<td>Infantine Insurance, Inc.</td>
</tr>
<tr>
<td>Anne Bernstein</td>
<td>Sandy and Bill Doer</td>
<td>Irving Noon-Day Lions Club</td>
<td>J B Arnovitz Foundation Inc</td>
</tr>
<tr>
<td>Mary Besser</td>
<td>Suzanne Douglas</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bestway Copy Center, Inc.</td>
<td>Loretta Dufresne</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Blackcap Holsteins</td>
<td>Rosemary Dyslin</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ramona and Jesse Blake</td>
<td>E.I. DuPont DE Nemours and Co.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Howard and Karen Blechman</td>
<td>East Tennessee Children’s Hospital</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Judith Block</td>
<td>Marsha and Bob Eccleston</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Borough of Bogota</td>
<td>Edwards and Jennings</td>
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<td></td>
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<tr>
<td>Noel Bouquet</td>
<td>Kathleen Edwards</td>
<td></td>
<td></td>
</tr>
<tr>
<td>George and Maria Brent</td>
<td>Len and Babs Eichorn</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Michael Brune</td>
<td>Elizur</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Paul and Joan Buechner</td>
<td>Roy Elliott, Jr.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Donnalee Bushey</td>
<td>Emerald Home Furnishings</td>
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<td></td>
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<tr>
<td>Alfred Butzbaugh</td>
<td>Tom and Doris English</td>
<td></td>
<td></td>
</tr>
<tr>
<td>CSJJJ Litt Foundation</td>
<td>Michelle Erp</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Kurt and Marcia Carlisle</td>
<td>Estate of Howard C. Corey</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diane Caswell</td>
<td>Andrew and Wilma Eubank</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Laura Caswell</td>
<td>Tsui Family</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Paul Caswell</td>
<td>Nancy and Bill Farrar</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Century 21 Department Store</td>
<td>Bill, Georgina and Daniel Farris</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Michael and Christy Chamish</td>
<td>Tanis Ferman</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Zhiqiang Chen</td>
<td>Mitzi Filson</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Edward Jaeger  
Jeffries and Company, Inc. 
Mary Lou Johnson  
Peggy Joslin  
Harvey and Freddi Kadden  
Suzanne and John Kannarr  
Herschel Kanter  
Karen and Eric Pulaski  
Philanthropic Fund  
Elliot and Donna Katzman  
Marion and George Kelley  
Kennestone Hospital Pre-Admission Testing and Teaching  
Roger and Deborah Kirkman  
Arlene Koch  
Maureen Kodweis  
Inge Kress  
Barry and Christina Kringstein  
Matthew and Mara Kveton  
La-Z-Boy, Inc.  
Leslie and Mark Laven  
Thomas Lawrence  
Rod Lee  
Bill and Karen Lenker  
Nancy Lewitz  
Lipton Family Foundation  
The Topscene Group and Friends  
Lockheed Martin Missiles and Fire Control  
Norma Loeb  
Mary Beth Ludington  
MNP Corporation  
James MacCormack  
Coletta MacGregor  
Lynn and Eva Maddox  
Bob Winstead and Linda Major  
Carl Mann  
Alice Marold  
Hermojino Martinez  
Martha Maso  
Catherine Mathis  
Lael and Charlene Mathis  
Ed Maxwell  
Patricia and Paul McCormick  
Mary McEvoy  
Ruth McHugh  
Helen and Ralph Medsgen  
Barry Mertz  
Microsoft Giving Campaign, The JK Group Inc.  
Microsoft Matching Gifts Program  
Germaine Miklos  
Shirley Mitchell  
Charles and Jerrie Moffat  
Monroe Wee Hornets and Monroe Sports Association  
Louise Mormon  
Eric Mugele  
Florence Munat  
NYC and Company, Inc.  
National Philanthropic Trust  
Nadine Nelsen  
Marcia Nelson  
New Hampshire Charitable Foundation  
Newforma Employees  
David Newman  
Orpha Nicholson  
Heather Nicholson  
Rich and Dari Norman  
Novartis Pharmaceuticals Corporation  
John O’Keefe  
Jennifer Oloughlin  
Gregory and Barbara Ott  
Pacific Diversified Insurance  
Mike Padden  
Dan and Theresa Palmer  
Kimberly Park  
Robyn Parket  
Gwen Paulson  
Judy Pearson  
Dianne Penson Lerner  
Marci Pere  
Lisa Kinney Perugi  
James L. Perzik  
Carleton Plummer  
Gerri Polo  
Susan Porfert  
Lawrence and Mary Potter  
Publishers Printing Company  
Michael and Rita Radovic  
Anne Rahal  
Michael L. Ramatowski  
Jeffrey Ravel  
Harlan Rector  
Rehs Galleries, Inc.  
Peg Reiterman  
Evelyn Reviere  
Mary Robinson  
Michael Rubin  
James Saitz  
Robert Saltzman  
Scandinavian Airlines of North America  
Joe and Aine Schenk  
Doug and Linda Scherf  
Sherry Schwartz  
SciClone Pharmaceuticals, Inc.  
Edward and Evelyn Scibek  
Stephen Scott  
George and Ruth Shambough  
Madeline Shanken  
Robert Sheldon  
Gabriela Shelley  
Sheresky Aronson and Mayefsky, LLP  
James Shilcock  
Jane Siegrist  
Joe Sigler  
William Silvis  
Emmett W. Sims  
Jeanne and Chesley Singleton  
Janet Smith  
June Smith  
Alan and Dottie Snitzer  
Maria Soares  
Richard Soble  
Murray Somerville  
South Central VA Health Care Network  
Southern University  
Anthony Spalla  
Specialized Transport and Logistics  
Mel and Rita Spira  
Spring Lake Consulting  
Gwen Stafford  
Edie Stark  
Patrick Sullivan  
Marion, Jerry, Jodi, Andrew Sussman  
Joanne Suter  
Robert Sweeney  
Karen Taft  
Bob and Barbara Tallman  
The David and Susan Strauss Foundation, Inc.  
The Dubofsky Family Foundation  
The Harvey and Phyllis Sandler Foundation, Inc.  
The Lake Family Fund  
The Lubrizol Foundation  
The Ritchey Family  
The Sherry-Netherland, Inc.  
The Strickland Group, Ltd.  
Jo-Ann Thomas  
Alicia Tillman  
Times Square District Management Assoc., Inc.  
Tolliver and Curl Paving Contractors, Inc.  
Robert and Sandra Toulouse  
Bruce Tremayne  
Triton Container International, Inc.  
Lorraine Turcotte
United States District Court  | Richard Welch  | Cynthia Wozniak
Universal Home Lending Corp.  | Lorri Wetzel  | Jim Wright
VFW  | Robert and Christine Wiggins  | Doug and Lynn Yaeger
June Vaseen  | George and Rhonda Wilcox  | Mari Yamaguchi
Virginia International Terminals, Inc.  | Danese Williams  | Alice Marie Young
John Virmig  | Aileen, Ann and D. D. Wilson  | Carrie Young
Gus Vlahos  | Don Wiltfong  | Cathy Young
Koula Vlahos  | Rachel Wist  | Richard Zepernick, Jr.
Debbie Ward  | Thomas Witthoft  |

We are grateful to the following for their very generous gifts

Novartis Pharmaceuticals Corporation
The Carmen Foundation
Turner Family Foundation, Jerry Carpenter Lewy Body Disease Fund
LBDA Scientific Advisory Council

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

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University of California, San Diego, California

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Director, Memory Diagnostic Center and Alzheimer Treatment Unit
Director, Education and Community Outreach, Alzheimer's Disease Research Center
HOPE Center for Neurological Disorders
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St. Louis, MO

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Stavanger University Hospital
Stavanger, Norway

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Dir., Alzheimer's Disease Research Unit
McGill University, Montreal, Canada

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Pittsburgh, PA

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Prof. of Psych. & Biobehavioral Sciences
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Los Angeles, CA

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University of Pennsylvania
Philadelphia, PA

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Seattle, WA

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Philadelphia, PA

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Yokohama, Japan

Tanis Ferman, PhD
Assistant Professor, Clinical Neuropsychology
Mayo Clinic
Jacksonville, FL
INDEPENDENT AUDITORS’ REPORT

To the Board of Directors of
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, 2007 and 2006 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, 2007 and 2006, 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.

May 7, 2008
LEWY BODY DEMENTIA ASSOCIATION, INC.
Statement of Financial Position
December 31, 2007 and 2006

<table>
<thead>
<tr>
<th>Assets</th>
<th>2007</th>
<th>2006</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cash</td>
<td>$96,401</td>
<td>$46,681</td>
</tr>
<tr>
<td>Investments</td>
<td>353,653</td>
<td>427,715</td>
</tr>
<tr>
<td>Unconditional Promises to Give</td>
<td>5,240</td>
<td>294</td>
</tr>
<tr>
<td>Prepaid Expenses</td>
<td>2,750</td>
<td>325</td>
</tr>
<tr>
<td>Property, Furniture and Equipment, net</td>
<td>7,966</td>
<td>3,207</td>
</tr>
<tr>
<td><strong>Total Assets</strong></td>
<td><strong>$466,010</strong></td>
<td><strong>$478,222</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 and Accrued Expenses</td>
<td>$2,001</td>
<td>$2,868</td>
</tr>
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</table>

**Net Assets:**

<table>
<thead>
<tr>
<th>Unrestricted:</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Undesignated</td>
<td>390,073</td>
<td>467,646</td>
</tr>
<tr>
<td>Designated</td>
<td>20,000</td>
<td>-</td>
</tr>
<tr>
<td><strong>Total Unrestricted</strong></td>
<td>410,073</td>
<td>467,646</td>
</tr>
<tr>
<td>Temporarily Restricted</td>
<td>53,936</td>
<td>7,708</td>
</tr>
<tr>
<td><strong>Total Net Assets</strong></td>
<td><strong>464,009</strong></td>
<td><strong>475,354</strong></td>
</tr>
</tbody>
</table>

| **Total Liabilities and Net Assets**      | **$466,010** | **$478,222** |

See accompanying notes to the financial statements.
**LEWY BODY DEMENTIA ASSOCIATION, INC.**

Statement of Activities
For the Years Ended December 31, 2007 and 2006

<table>
<thead>
<tr>
<th></th>
<th>2007</th>
<th>2006</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Changes in Unrestricted Net Assets:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Revenue and Support:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Contributions</td>
<td>$ 191,230</td>
<td>$ 141,258</td>
</tr>
<tr>
<td>Investment Income</td>
<td>20,962</td>
<td>21,056</td>
</tr>
<tr>
<td>Total Revenue and Support</td>
<td>212,192</td>
<td>162,314</td>
</tr>
<tr>
<td><strong>Net Assets Released from Restrictions</strong></td>
<td>13,008</td>
<td>3,292</td>
</tr>
<tr>
<td><strong>Total Revenue, Support and Reclassifications</strong></td>
<td>225,200</td>
<td>165,606</td>
</tr>
<tr>
<td><strong>Expenses:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Program Services</td>
<td>196,917</td>
<td>131,225</td>
</tr>
<tr>
<td>Support Services</td>
<td>83,690</td>
<td>74,824</td>
</tr>
<tr>
<td>Fundraising</td>
<td>2,166</td>
<td>2,500</td>
</tr>
<tr>
<td><strong>Total Expenses</strong></td>
<td>282,773</td>
<td>208,549</td>
</tr>
<tr>
<td><strong>Decrease in Unrestricted Net Assets</strong></td>
<td>(57,573)</td>
<td>(42,943)</td>
</tr>
<tr>
<td><strong>Changes in Temporarily Restricted Net Assets:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Contributions</td>
<td>59,236</td>
<td>-</td>
</tr>
<tr>
<td>Net Assets Released from Restrictions</td>
<td>(13,008)</td>
<td>(3,292)</td>
</tr>
<tr>
<td><strong>Increase (Decrease) in Temporarily Restricted Net Assets</strong></td>
<td>46,228</td>
<td>(3,292)</td>
</tr>
<tr>
<td><strong>Change in Net Assets</strong></td>
<td>(11,345)</td>
<td>(46,235)</td>
</tr>
<tr>
<td><strong>Net Assets at Beginning of Year</strong></td>
<td>475,354</td>
<td>521,589</td>
</tr>
<tr>
<td><strong>Net Assets at End of Year</strong></td>
<td>$ 464,009</td>
<td>$ 475,354</td>
</tr>
</tbody>
</table>

See accompanying notes to the financial statements.
# LEWY BODY DEMENTIA ASSOCIATION, INC.

Statement of Cash Flows
For the Years Ended December 31, 2007 and 2006

<table>
<thead>
<tr>
<th>Cash Flows from Operating Activities:</th>
<th>2007</th>
<th>2006</th>
</tr>
</thead>
<tbody>
<tr>
<td>Change in Net Assets</td>
<td>$(11,345)</td>
<td>$(46,235)</td>
</tr>
</tbody>
</table>

Adjustments to reconcile Change in Net Assets to Net Cash used by Operating Activities:
- Depreciation                     | 3,283    | 1,603    |
- Net Realized and Unrealized Gains on Investments | (20,938) | (21,098) |

Changes in Operating Assets and Liabilities:
- (Increase) Decrease in Accounts Receivables | (4,946)  | 72       |
- Increase (Decrease) in Prepaid Expenses     | 2,425    | 2,787    |
- Increase in Accounts Payable and Accrued Liabilities | (867)    | 359      |

Net Cash Used in Operating Activities     | (37,238) | (62,512) |

<table>
<thead>
<tr>
<th>Cash Flows from Investing Activities:</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Withdrawals from Investment Account</td>
<td>95,000</td>
<td>99,780</td>
</tr>
<tr>
<td>Purchase of Equipment</td>
<td>(8,042)</td>
<td>-</td>
</tr>
</tbody>
</table>

Net Cash Provided by Investing Activities | 86,958 | 99,780   |

<table>
<thead>
<tr>
<th>Cash Flows from Financing Activities:</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Principal Payments on Notes Payable</td>
<td>-</td>
<td>(27,482)</td>
</tr>
</tbody>
</table>

Net Cash Used in Financing Activities | -      | (27,482) |

<table>
<thead>
<tr>
<th>Net Increase in Cash</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>49,720</td>
<td>9,786</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Cash at Beginning of Year</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>46,681</td>
<td>36,895</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Cash at End of Year</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>$96,401</td>
<td>$46,681</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Supplemental Disclosure:</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Interest Paid</td>
<td>$</td>
<td>$7</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 non-profit organization established to provide information on the Lewy body dementias. The Organization assists, informs and supports families, caregivers and medical professionals. Outreach services include caregiver helplines, support groups, quarterly newsletters, brochures, educational seminars. The Organization is funded through individual contributions and grants from foundations.

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 nets 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.

Cash

Cash represents funds without legal restrictions on hand or in demand deposit accounts with financial institutions.

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 is 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 non allowance for uncollectible promises was necessary.

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.

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.
Note 2 - Investments

Investments, at December 31, 2007, consist of a money market account held at an investment brokerage and reported at fair market value.

Note 3 - Unconditional Promises to Give

Unconditional promises to give at December 31, 2007 totaled $5,240 and are expected to be received within one year.

Note 4 - Fixed Assets

Fixed assets at December 31, 2007 and 2006 consist of software at a cost of $11,249 and $4,810, respectively and accumulated depreciation of $3,283 and $1,603, respectively.

Note 5 - Designated Net Assets

The Organization has chosen to designate $20,000 for operating expenses in future years.

Note 6 - Temporarily Restricted Net Assets

Temporarily restricted net assets are available for the following purposes:

<table>
<thead>
<tr>
<th></th>
<th>2007</th>
<th>2006</th>
</tr>
</thead>
<tbody>
<tr>
<td>Capital acquisitions</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Educational materials</td>
<td>$49,236</td>
<td>$2,798</td>
</tr>
<tr>
<td>Website redesign</td>
<td>$4,700</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>$53,936</td>
<td>$7,798</td>
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</table>

Note 7 - 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 amount the programs and supporting services benefited.
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