



For Families, Caregivers, and Medical Professionals

### LBDA Exhibits at Neurology Convention

The American Academy of Neurology (AAN) held its annual meeting and convention in Miami Beach, Florida on April 11-15. Advances in research were presented by world-renown scientists to over 8,000 clinicians and researchers. A significant number of exhibit posters and discussions included the Lewy body dementias.

The Lewy Body Dementia Association's first exhibit at a medical conference introduced an 'eye-catching' poster with statistics emphasizing that LBD is not a rare disease. It is estimated that up to 800,000 people in the US have LBD, and only 30-50% are currently diagnosed. A small version of the poster is available for printing online at [www.lewybodydementia.org](http://www.lewybodydementia.org) or by calling: 1-800-LEWYSOS.

While visiting the LBDA booth, medical professionals expressed an interest in the

Association's mission of providing caregiver support and raising awareness of the Lewy body dementias. Several hundred copies of LBD literature, brochures and scientific articles, were provided to clinicians for their families and caregivers. Information was exchanged with organizations involved with other neurological diseases, government agencies and pharmaceutical companies.

One of the unexpected benefits of exhibiting has been that our web site and organization has more Internet exposure. The National Institutes of Health (NIH) now has a link to our web site where we provide both LBD and caregiver information. We would like to acknowledge the AAN, the largest neurologist organization in the US, for providing an exhibit area for non-profits attending the conference.

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[www.lewybodydementia.org](http://www.lewybodydementia.org)

### Caregivers' Meeting in Ft Lauderdale, Florida

The staff at HCR-Manor Care (Heartland of Lauderhill) provided meeting space and refreshments for the caregiver's meeting on Sunday afternoon April 10th. It is the only 100% dementia facility in Broward County. Carol did a wonderful job planning the meeting. Her father, 90, was spending his final week at Heartland in the end stage of LBD. LBD caregivers, spouses, patients and LBDA Board members joined together to share hugs in person and munch on goodies. A highlight of the gathering was signing LBD brochures as a memento of the event. The LBD support group will meet on September 15th, 12:30-2:00 PM, Coral Springs Medical Complex, Ft. Lauderdale and meet monthly on the third Thursday of each month. For info email [Outreach-SouthFlorida@LBDA.org](mailto:Outreach-SouthFlorida@LBDA.org) or 1-800-LEWYSOS to leave Carol a message.



Pictured left to right, top to bottom are: Jim (AZ), Peggy (SC), Gail (CO), Jacqui (FL), Micki (MI), Jan (CA), Donna (MI), Sandy (OH), Carol (FL), Ginnie (OH), John (TX), Janet (TX) and Angela (PA). Hensha (FL) was not present for the photo.

## Ask the Experts:

A caregiver sent us the following question:

***“We read recently that REM sleep behavior disorder (RBD) can be a symptom of LBD. What is it?”***

We asked Dr. Brad Boeve of the Mayo Clinic to share his thoughts:

*Rapid Eye Movement (REM) sleep behavior disorder (RBD) is a common feature of LBD and can cause injury not only to the patient but also his/her bedpartner.*

*A person’s body is nearly entirely paralyzed when dreaming during REM sleep. In a person with RBD, the normal paralysis is lost, and they physically appear to act out their dreams. Unfortunately, those dreams frequently include being attacked or chased by someone or something, and so violent physical movement often occurs.*

*RBD tends to affect more men than women, especially those over 50, but can affect people of all ages. It usually begins years, sometimes decades, before the cognitive or physical symptoms of LBD appear. An evaluation with a physician who specializes in sleep medicine and*

*parasomnias is recommended to confirm a diagnosis of RBD. Some patients who are thought to have RBD turn out to have obstructive sleep apnea (OSA), and their “RBD features” disappear once OSA is effectively treated. It is an important step because the medication commonly used to treat RBD, clonazepam, can cause unwanted side effects such as cognitive impairment and morning drowsiness. Also, clonazepam can worsen OSA, so evaluation by a sleep medicine clinician with knowledge and expertise in the parasomnias is important to determine the correct diagnosis and determine the best course of treatment.*

*All individuals with RBD should improve safety in the sleep environment by taking safeguards against injury. These include placing padding on the floor next to the bed, moving furniture with sharp edges away from the side of the bed, and putting padding on the headboard. Some bedpartners may even need to move to a separate bed or bedroom to avoid injury. Plus, spouses should avoid attempting to waken the patients while they are acting out their dreams since their shaking and commands are often woven into the*

*patients’ dreams, putting the spouses at risk for injury.*

*Clonazepam has been effective in controlling the unpleasant dreams, and many people are able to use it without side-effects. Melatonin has also proved helpful in some cases, but is not regulated by the Food and Drug Administration, and does not have to conform to the same testing standards as prescription drugs. For that reason, it is recommended that patients and caregivers first discuss the pros and cons with a physician well-versed in treating sleep disorders before taking melatonin.*

*More information on RBD can be found from these websites:*

<http://www.mayoclinic.org/news2003-rst/1936.html>

<http://www.parasomnias.com/html/rem-sleep.php3>

<http://sleepdisorderchannel.com/rem>

To “Ask the Experts?” a question about LBD email [sac@lbda.org](mailto:sac@lbda.org) or leave a message for Angela at 1-800-LEWYSOS. We will pick one or two to submit to the SAC for publication in the next newsletter!

## West Palm Beach Alzheimer’s Meeting

The Alzheimer’s Community Care organization of West Palm Beach, Florida held an Alzheimer’s Educational Conference titled “Unlocking the Mystery” on May 19<sup>th</sup> and 20<sup>th</sup>. Over 300 LBD brochures and educational materials were distributed to caregivers and professionals attending the conference. Caregivers were provided information about the on-line LBD support groups and other LBD caregivers in South Florida.

The conference sessions on dementia and caregiving were excellent. It is encouraging to note that four speakers mentioned LBD in their presentations. One physician, in particular, discussed LBD at length during his presentation on psychotropic medications.

Olga Brunner, founder and president of the geriatric care management company, A Good Daughter, Inc., Margate, Florida, donated booth space to the LBDA.

Carol Caughran, who invited the LBDA to attend, is an independent contractor with A Good Daughter, Inc. Carol currently cares for her mother with Alzheimer’s and was also caregiver to her father who passed away from LBD in April.

Photo left-right: Peggy Smith, LBDA; Olga Brunner, MaryLynne Beringer, and Carol Caughran

For newsletter comments, questions, article requests or submissions please send email to: [Sandy Shelton, Editor newsletter@LBDA.org](mailto:Sandy.Shelton@LBDA.org)



# LBDA Volunteer of the Year

At the LBDA Annual Meeting in April, Gourete Broderick was unanimously selected the Association's first Volunteer of the Year. We first met her when she joined the online LBD Caregiver's Yahoo support group in the fall of 2002, after learning that her mother, Olivia, now age 69, has Lewy body dementia.

Gourete's nickname in the group is Courage, and it describes her well. Her sharing of not only the difficult, but also the tender moments experienced while caring for Olivia serves as a reminder of why the thistle was chosen as the LBD logo, recognizing both the beauty and thorns of LBD. Shortly after joining the caregiver's group, she created online polls to identify similarities and differences in the caregiver's loved ones, and initiated discussions on difficult caregiver topics like post-mortem autopsies and the dying and grieving processes.

Gourete also enlightened the caregivers group with descriptive walking tours of Toronto that she and her mother took after Olivia became wheelchair bound. Her article titled "Olivia and LBD" was published on several websites, including the



Courage and Olivia

Caregiver's Words section at [www.lewybodydementia.org](http://www.lewybodydementia.org).

Shortly after Gourete joined the LBD online caregiver's group, she utilized skills acquired during her advertising career to e-mail LBD information to over 4,000 medical professionals world wide, and to date has funded and mailed over 1,000 LBD brochures in the Toronto area. Her personal mission is to continue the LBD awareness campaign throughout Canada, until LBD is a household word.

## We just call her "Courage."

She was born and raised in Toronto, Ontario, Canada by parents, Olivia and Domingos, who moved to Toronto from Santa Maria, Azores (Portugal) in 1960. She shares caregiving responsibilities, for both her father and mother, with her sister Susan Libanio. Olivia is now in the late stages of LBD. Domingos has had Parkinson's for seven years and was diagnosed last year with Alzheimer's. In spite of his illness, Domingos, now 73, faithfully visits Olivia 7 days a week where she now resides in a nursing home. Gourete is the proud mother of two children, Andrew, 21, and Andrea, 24, and enjoys spending time with her beautiful new granddaughter, Katelyn "Katie".

## Comments from a Caregiver

Posted recently to the Yahoo LBD Caregivers Group — re: LBD

"What a tough disease....but thank goodness for this group. This past couple of years have been hell on earth at times - filled with depression, confusion, fear, tears, laughter etc. I've shared with friends who have all listened and supported me - I've seen a therapist - I've written in my journal - you name it - I've done it... but nothing has helped me like this group. It's amazing. The people are wonderful - the information is of the utmost help - this group has been my life saver....."

You can find a link to the LBD Caregivers Support Groups on our website at :

[www.lewybodydementia.org](http://www.lewybodydementia.org)

## Caregiving Tips

Caring for a person with LBD is often difficult due to the fluctuating cognition, visuospatial difficulties and movement problems. Lifelong relationship dynamics change. Creative thinking is often necessary on the part of family and caregivers in order to find ways to relate to an LBD person's world and provide much needed assistance while allowing them to maintain dignity. Similar concerns may arise for caregivers who are unfamiliar to the LBD person or when LBD people are in new surroundings.

**Example:** Reluctance to bathe.

**Considerations:** Review environmental and other factors: Is the room cold or unfamiliar? Is the lighting in the room poor? Is the person embarrassed by the need to have someone help with personal

care issues? Are different times of the day better for different types of tasks? Is there a fear of falling? Would it help to allow the person to take a more active role in the task?

## Creative approaches that have made caregiving easier.....

**Approaches:** When these and other questions are answered, it is often easier to approach the situation creatively seeking solutions that work well for both the LBD person and the caregiver. The room can be warmed ahead of time. A towel can be placed over a persons shoulders to alleviate feelings of embarrassment or cold. Consider handing the LBD person a wash-

cloth and ask them to help in the bathing process. If there is a fear or danger of falling shower bars may be installed and long bench seats that straddle the side of the tub are available. An explanation of what is coming next may be helpful in many situations. Alleviating fears and concerns often make the caregiving job easier by providing a higher comfort level for the person with LBD.

If you have a caregiving question that you would like to see in our newsletter you can e-mail questions or comments to: [newsletter@lbda.org](mailto:newsletter@lbda.org).

**About the Author:** Cindy Keith, RN, BS and Certified Dementia Practitioner is owner of M.I.N.D. or "Moving in Nurturing Directions in Memory Care"



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## “HOOFBEATS”

*The following was written by caregiver Dann Johnson explaining his view of why LBD is so often misdiagnosed. Providing physicians with complete accurate description of symptoms may assist them to make an accurate diagnosis. Unfortunately there isn't a test to give readings of "normal."*

Following a trail from another caregiver's web links, I developed my own mental picture of Lewy, Parkinson's (PD), Alzheimer's and other degenerative diseases of the brain, like Creutzfeldt-Jakob Disease. My mental picture of Lewy imagines a brain as a densely populated apartment building. Each brain cell is an individual apartment in the building/brain something goes wrong with the waste/plumbing system in a number of apartments and won't flush properly.

Our Lewy neurons are kind of like that. To survive and function for a while, they clump up the badly folded waste proteins so that the cell can continue to function. As the waste proteins can't get out, the clumps (Lewy bodies) get bigger and bigger eventually causing the death of the cell. Whole groups of neurons begin dying. These different diseases, like Lewy bodies and Alzheimer's may attack different parts of the brain first, but in common, they have clumped / malformed protein waste that plug up and eventually kill neurons. Doctors often use the phrase "hearing hoofbeats." I have heard half a dozen medical doctors express the following sentiment: "If someone is in

South Africa and hear equine hoofbeats, they suspect Zebra. If they are in Wyoming and hear equine hoofbeats, they suspect Mustangs/wild horses."

Similarly, LBD people are sometimes diagnosed with Alzheimer's rather than Lewy body dementia, because the doctors commonly are looking for "Wild Horses rather than Zebra."

If someone in Africa hears hoofbeats, they expect zebra.

One GP and two Neurologists diagnosed my mother with Parkinson's Disease because she had mild dementia, and a slow, shuffling walk. Mom had no PD tremors and never has. The doctors told us that PD affects people differently, but that she definitely had PD.

After a while, when it felt that Mom had more or less been abandoned by doctors at our regional hospital, I took her to Mayo clinic in Rochester, MN. After more than 3.5 years on PD Meds, the doctors at Mayo said otherwise. The neurologists there did their own tests

and explained to us, using the MRI of Mom's brain, how Lewy looks different than Alzheimer's, different from NPH, etc. I explained how certain meds made Mom "goofy" and that the Parkinson's medicine didn't seem to help anything. The doctor asked about her hallucinations. He suggested that I read up on LBD. We have since completely discontinued the PD meds, with no symptomatic changes other than *fewer/less severe hallucination*.

People have been diagnosed with both Parkinson's Disease AND Lewy body dementia. Or both Parkinson's AND Alzheimer's. However, science teaches us to look for the simplest solution as the most likely one. So if a person has symptoms of PD AND Alzheimer's, they may just have LBD.

Until I got to Mayo Clinic / Rochester, very few neurologists, and none of the General Practitioners that I have spoken with, seemed to have much of an understanding of LBD. They weren't expecting to see Zebra when they heard hoofbeats. So they diagnosed the equine shadows as horses.

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## Middle Tennessee Alzheimer's Association Caregiver of the Year

Bob Winstead, Middle Tennessee Alzheimer's Association Caregiver of the year, accepted the award on behalf of his late wife Judy. He was nominated by the staff at Waterford Assisted Living and Dr. William Petrie for his dedication to his wife. She was diagnosed with LBD in 2001.

Bob provided 24/7 care for 4 years and in his acceptance speech he credited Judy with "instilling love in him to care for her making the best of a grave situation and live it to the fullest one day at a time." He added, "Caregiving is plural. You can't be a caregiver unless you have someone being your caregiver, so I would like to thank my caregivers for they deserve this award as much or more than

I do." He expressed his appreciation to family, friends and medical professionals who provided support thru the difficult times.

The Alzheimer's association described Bob's devotion to his wife as bringing a whole new meaning to the phrase "in sickness and in health." He was constantly by her side yet it was common to see him coaxing another resident to eat, help them walk down the hall or even replace a doorknob.

"Caregiving is plural not singular."

Bob spent years researching Lewy Body Dementia, meeting with local professionals, and actively participated with

LBD Caregiver's groups worldwide via the internet. He explained to attendees at the event, "Most all Lewy body patients are first diagnosed with Alzheimer's or Parkinson's. Judy was first diagnosed with Alzheimer's.... Even last November I had to take Judy to one of the largest hospitals in Nashville. I had to explain to the emergency room doctor, her doctor that was assigned to her even to what medicines she could take."

Bob said "Some 40 years ago, I stood in front of God and Judy and pledged to take care of her in good times and bad times till death do us part. I am here to say I have fulfilled that commitment."

## Scientific Advisory Council



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and Dementia Research Group  
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**Please join us in welcoming the  
newest members of the  
Scientific Advisory Council.**

**Dag Aarsland, M.D.**  
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Stavanger, Norway

**Jeffrey L. Cummings, M.D.**  
Augustus Rose Professor of Neurology  
Professor of Psychiatry and Biobehavioral Sciences  
Director, UCLA Alzheimer's Disease Center  
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Staff Physician, VA Puget Sound Health Care System,  
Seattle, WA, USA



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## Letter from the President

Greetings from the LBDA!

You might be saying to yourself, "That's not the same face that was on the last newsletter." You are right! At the Board of Director's meeting in April 2005, new officers were elected. Jim Whitworth is enjoying a much-deserved break from the rigors of officer-duty and remains an active, vibrant part of the LBDA. We would like to express our sincere appreciation to Jim for his leadership during the first two years of our organization.

The new officers and directors for 2005:

Angela Taylor, President  
Micki Horst, Vice President  
Peggy Smith, Treasurer  
Sandy Shelton, Secretary  
Donna Rae, Director  
Jim Whitworth, Director  
John Young, Director

During the first quarter of 2005 the board was busy preparing for a week of activities in Miami, FL. What an outstanding week it was! We held our annual Board of Directors meeting, met with our Scientific Advisory Council (SAC), and exhibited for the first time at a medical conference (the American Academy of Neurology's annual meeting). This provided the opportunity to introduce the LBDA to neurologists from both across the US and around the world.

The second quarter of 2005 focused on existing programs such as the caregiver helpline, web site content development and brochure distribution. Over 50,000 brochures have been distributed to caregivers, dementia clinics, family physicians, neurologists, other medical specialists, support organizations like Alzheimer's Association and more!

Additional focus was placed on building the internal infrastructure and creating a strategic plan to define goals expanding outreach programs. Plans for the remainder of 2005 include creating more LBD publications and launching new outreach programs with continued effort to increase LBD awareness among the public and medical communities.

Keep an eye on our website and future issues of the newsletter for many other exciting developments!

Angela Taylor  
President



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## Call for Support

Did you know that there are over 800,000 patients in the US alone with LBD? Did you also know that it's the second most common type of dementia in the elderly, after Alzheimer's? That's right! LBD is NOT a rare disease, but because the diagnostic criteria was only established in 1996, it is a relatively unrecognized disease.

There is much to be done to bring LBD out of the shadows and into the awareness of the public and medical

communities, so that family doctors readily recognize the symptoms of LBD.

Without that ability patients are often not diagnosed, leaving families to struggle without adequate treatment and feeling they are facing the disease alone.

By making a contribution today to the LBDA, you help launch more caregiver support programs, create more publica-

tions on LBD, and achieve our mission:

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

Please send tax-deductible donations to:  
LBDA, PO Box 11390, Tempe, AZ  
85284-0024

### Vision Statement

**We envision a cure for Lewy Body Dementias and quality support for those still living with the disease.**

**Lewy Body Dementia Association, Inc.  
P O Box 11390  
Tempe, AZ 85284**

**Business Phone: 1-480-894-1100  
Help Line 1-800-LEWYSOS (539-9767)  
Web: [www.lewybodydementia.org](http://www.lewybodydementia.org)**