

Building Hope: The Right Treatment Makes All the Difference

It was one of the saddest days in Margaret Boehne's life. Her husband Art, diagnosed with Lewy body dementia (LBD), was in a nursing home. Margaret was forced to sell their home and move 60 miles to live alone in a senior apartment close to the nursing home.

Everything started with what appeared to be some memory changes. Then one day Art laid down for a nap, but when Margaret tried to wake him up several hours later he was in distress. He had a high fever, severe confusion, hallucinations, and couldn't walk.

Margaret called 911 and Art was taken to a community hospital, where a simple bladder infection diagnosed. He was treated with antibiotics and sent home a week later with a walker. Things went from bad to worse. Art didn't recognize the family home, got progressively more confused and paranoid.

Margaret tearfully called their daughter who lived out of town. She dropped everything and arrived 3 hours later, to find her mother exhausted and her father terribly confused. The family doctor acknowledged that Art needed more help than he or the community hospital could provide. The family headed to the Mayo Clinic in Rochester, MN.

Ten days of hospitalization and medical tests led to a diagnosis of hypertension and LBD. Margaret was stunned by the diagnosis, having never heard of LBD. She was told by the doctor that LBD was the likely cause of Art's earlier memory problems and was fully revealed by the bladder infection. She and her daughter later went to the library to learn about LBD.

During the hospitalization, Art continued hallucinating, and was very anxious and paranoid. He resisted help at every

turn. The doctors treated his psychiatric symptoms with an atypical antipsychotic medication.

Margaret was told that Art needed to be placed in a nursing home. In November, 2004, Margaret, her son and daughter took Art to a highly rated nursing home and he was soon moved into the Alzheimer's Care Unit.



Art & Margaret Boehne

Margaret and her daughter continued their education on LBD and learned that the antipsychotic medication might be contributing to Art's continued high level of confusion, and conferred with Art's local doctor. Having never had an LBD patient before, he cut Art's dose in half instead of reducing it slowly. Art reacted to the lower dose with high anxiety, and was quickly returned to the original dosage.

One day Margaret's daughter found an article on LBDA's Web site by Dr. Brad Boeve, entitled "A Comprehensive Approach to Treatment Can Significantly Improve the Quality of Life of Patients with the Lewy Body Dementias." Margaret immediately sensed that they had found somebody who could at last help Art.

Dr. Boeve first saw Art at the Mayo Clinic on June 4, 2004 and agreed that Art's symptoms were most consistent with LBD and prescribed a dementia

medication called a cholinesterase inhibitor. Within 5 days, Art told Margaret he felt he was able to express his thoughts better and that his words now flowed freely. Art's anxiety also began to decrease sharply. Finally they were able to enjoy drives in the country and eat out at restaurants.

A month later, Art and Margaret met again with Dr. Boeve. Because Art was responding nicely and making solid gains in everyday functioning, Dr. Boeve gave Margaret exciting news — Art could return home very soon.

On July 26, 2005, Margaret brought Art home after a very long and difficult 8½ months. Margaret told LBDA, "So many people gathered around to wish us well as we walked hand and hand out of the nursing home. A nurse later told

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10 things you should know about LBD:

#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.

To read more, please visit us on our Web site at www.LBDA.org. Online you can subscribe to this newsletter, join a support group, research, learn, or just connect with someone who understands what you're going through.

From the President

My Compelling Journey



I have been on a compelling journey this year, traveling more than 30,000 miles on behalf of the Lewy Body Dementia Association. I quickly came to realize how many people have impacted LBDA and helped us reach new heights.

I think of people like Barbara and Bill Hutchinson, delivering their personal message about Lewy body dementias as they drove across the country for more than a year. I think of Dr. Tom Grayboys describing his personal journey with LBD on national television during his book tour. And, I think of Jim and Helen Whitworth who are traveling through the West holding LBD Seminars for medical professionals.

I have met with medical professionals, caregivers and volunteers in a variety of settings. I am encouraged every time I hear more and more people, includ-

ing medical professionals, say they are aware of LBD and the work of LBDA. At a mid-summer trip to Ann Arbor, Michigan, I met old friends and made new ones at the 5th Anniversary of the Yahoo LBD Caregivers Group gathering. I have such profound feelings when meeting with others touched by LBD. I am again reminded this is, "the best group of people you never wanted to meet." My thanks to all in Ann Arbor for the warm welcome I received!

I met Mr. Harry Mangurian in the spring. I felt a unique bond with Mr. M. in the unfairness and frustration that we have both experienced having a spouse stricken with this dread disease. We also share the hope to build a better future for others in our situation. Without his very generous support LBDA would not be as effective making a difference in the lives of people touched by LBD.

My travels included participation in two fundraisers for LBDA, Project 57, an art auction organized by Melissa Walker, and the 2nd Annual LBD

Volleyball Tournament, organized by Kristine Spencer, both in memory of their fathers. Although I did not attend, The Mickey Gaynor Family held a golf tournament in his memory. All three events heightened awareness of the impact of LBD and raised significant funds for LBDA. No one left any of these incredible events without gaining special knowledge of LBD.

I invite each of you to join me on this all-important journey. Your continued financial support and volunteer efforts will enable LBDA to provide services to families impacted by LBD. Together we can continue increasing knowledge, sharing experience and building hope.

John L. Young
President, Board of Directors

In Rememberance

The Lewy Body Dementia Association mourns the passing of Harry T. Mangurian, Sunday, October 19, 2008. Mr. Mangurian was a true friend and supporter of LBDA in myriad ways.

Harry Mangurian was an early supporter of the LBDA at a stage when we needed it most. He will always be remembered for his immense contributions. Financial contributions of course, but also contributions of ideas, support, and energy.

Harry was a man who filled a room.

Filled it with big ideas, enthusiasm, and a desire to make a difference. I had the pleasure to meet him twice and immediately felt a bond I have seldom experienced. That of a caregiver, spouse, and a joy of life. I feel his loss profoundly as well.



Harry T. Mangurian, Jr.

Everyone at LBDA offers best wishes to his family during this difficult time.

John L. Young
President, Board of Directors

(To learn more about Mr. Mangurian, visit <http://www.lbda.org/feature/1860/lbda-receives-mangurian-grant.htm>.)

LBDA Caregiver Helpline: 1-800-LEWY-SOS (1-800-539-9767)

This toll-free helpline provides a link to experienced LBD caregivers who provide information on LBD and can also share their personal experience and compassion. Or you may email support@lbda.org to ask questions, seek information, and connect with other experienced LBD caregivers.

2nd Annual Friends Asking Friends! Campaign

As members of LBDA's extended family, you are too familiar with the fear and sense of isolation that everyone faces with a diagnosis of Lewy body dementia.

Since our founding five years ago, LBDA has been the nation's only source for comprehensive information, education and support for the 1,500,000 women and men affected by this staggering disease.

Due to increased demand for LBDA's programs and services, the cost of providing these programs has increased by 119% since last year. Now, we need your help so that we can continue to respond with support, compassion, information, and answers to tough questions.

Please join us in the 2nd Annual Friends Asking Friends Campaign. This initiative calls on each of us to make a personal gift, to reach out to our friends and family, and to encourage them to support

LBDA's mission through their personal gifts.

We know many of you have recently made a generous contribution to LBDA. And, we know that many of you continue to donate your time and energy towards achieving the mission we all share. We are forever appreciative. Thank you!

Please invite your friends and family to join you. You'll find a sample letter and email to use at www.lbda.org/go/friends, or you may choose to personalize it. If you would like a copy of the letter mailed and/or faxed to you, simply call 404-935-6444 or send your request to LBDA@lbda.org.



Please join the other LBDA family members who are making a difference in the fight against this devastating disease.

With sincere thanks for all you do for those served by LBDA and its many volunteers!

In hope,

LBDA's Board of Directors

John Young
Joe Whiteis
Jim Whitworth
Jim Galvin, MD
Ronnie Genser
Debbie McCoy Massey
Nancy Silverman
Steve Stevenson
Angela Taylor

Building Hope

Continued from p. 1

me that she couldn't believe the change in Art since he started on the cholinesterase inhibitor. She also said that there wasn't a dry eye among the group watching us leave."

Dr. Boeve suggested lowering the atypical antipsychotic medication dose by small increments in July 2006 and by mid-September, Art was entirely off of it. Art and Margaret still go for annual visits as a participant in Mayo Alzheimer's Disease Research Center (ADRC) program, which also follows a number of LBD patients. Now, two years later, Art still walks with a cane, but his mind is clear.

A decorative sign that reads "NEVER GIVE UP" hangs in their apartment. True to that motto, Art and Margaret, now 75 and 71 respectively, are planning a vacation with their children so that they can all celebrate their 50th wedding anniversary on February 14, 2009 — Valentine's Day, of course!

Three Events a Success

Three families recently raised over \$30,000 for LBDA in separate events. We would like to offer a very special "Thank You!" to Mark Gaynor, Melissa Walker, Kristine Spencer and their families for their tireless efforts that made each of these special events possible.

In July, 2008, the Gaynor Family hosted the Michael "Mickey" Gaynor Golf Tournament in Northborough, MA. More than 200 people came out for a day of golfing and a cookout to honor the memory of Mickey Gaynor and his battle with Lewy body dementia. The tournament raised more than \$15,000 in proceeds for LBDA.

Distinction Art Gallery in Escondido, California hosted Project 57 from August 9 - September 6, 2008. Owner Melissa Walker organized the event, which featured pieces by more than 100 artists. LBDA received \$15,000 in proceeds to establish the Charles "Chuck" Leslie Walker Fund, dedicated to raising awareness of LBD.



LBDA President John Young with the folks at Project 57. (Photo: Kurt Lightfoot)

Kristine Spencer hosted the 2nd Annual LBD Awareness Volleyball Tournament

See "Events" on p. 6

Increasing Knowledge: Publication for Those Newly Diagnosed with LBD

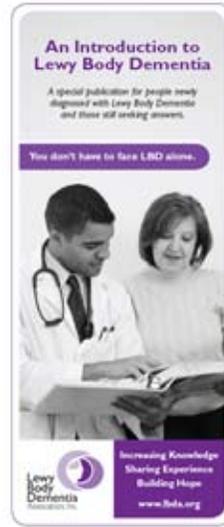
An Introduction to Lewy Body Dementia

A special publication for people newly diagnosed with Lewy Body Dementia and those still seeking answers.

An Introduction to Lewy Body Dementia provides easy-to-read clinical information on Lewy body dementia in a patient-friendly manner. This booklet was made possible by a generous grant from Novartis Pharmaceuticals Corporation and through the guidance of LBDA's Scientific Advisory Council.

According to Carol F. Lippa, M.D., Chair, LBDA's Scientific Advisory Council,

“Our increased longevity is associated with a greater number of individuals who develop dementia. These individuals experience a wide variety of cognitive and behavioral symptoms, and caregivers and physicians are often at a loss for the safest and most effective management strategies. Millions of individuals are affected with Lewy body dementia, yet it is amongst the hardest of these dis-



orders to manage. The LBDA's patient booklet summarizes clinical features and some key points regarding LBD which will lead to improved care and reduced disease burden.”

To download a copy, visit www.lbda.org. For a printed copy, please send a self-addressed, stamped envelope with first class postage with your request to LBDA, PO Box 451429, Atlanta, GA, 31145-9429. For multiple copies, please contact the National Office at lbda@lbda.org or 404-935-6444.

Ask the Expert

Q. What is fluctuating cognition – is it the same as sundowning? My husband is always more confused at home than at the doctor's office, so how can the doctor know if he has fluctuating cognition?

A. The experience of having your loved one “rise to the occasion” in the doctor's office can be frustrating for the caregiver. It may reflect fluctuations in Lewy body disease if variability in skills, communication and alertness are also evident at home.

The fluctuations in LBD can be distinguished from sundowning. In sundowning, a worsening of one's cognition or behavior occurs in the evening or night. Just like many of us, persons with dementia are not as sharp at the end of the day. Since persons with dementia have very little cognitive reserve, they

may seem more impaired and problem behaviors (e.g., greater frustration) may surface. The fluctuations in LBD may occur at any time of day or night, and represent a waxing and waning of alertness and abilities. It is often mistaken for delirium, stroke or even seizures and tests are often done to rule out those other conditions.

The fluctuations of LBD can be distinguished from the “good days and bad days” observed in other types of dementia, such as Alzheimer's disease. When patients with LBD experience fluctuations, they tend to have episodes of drowsiness and lethargy, may stare into space and seem somewhat zoned out (but responsive to their name), and their speech may be out of context or may not be logical. In general, fluctuations are more apparent early in the

disease course, but with progression of the dementia, family members often describe less variability over time. Cholinesterase inhibitors may be helpful in treating fluctuations.

One of the more frustrating aspects of fluctuations for caregivers is that they may observe that their loved one cannot do a task, such as use the microwave, only to find that later, they use the microwave easily. By understanding that fluctuations are a common symptom of the disease, family members can identify and understand fluctuations when they occur.

Tanis J. Ferman, Ph.D.
Dept. of Psychiatry & Psychology
Mayo Clinic, Jacksonville, FL
Member of LBDA's Scientific Advisory Council

Have you seen a great article that would be of interest to other LBDA community members? Let LBDA know how to find the article so that it can be reviewed for the LBDA Web site and/or future editions of Lewy Body Digest.

Contact LBDA: lbda@lbda.org or by calling the office at 404-935-6444.

Caring for the Caregiver

By Lyn Roche

This new column will be all about YOU — a caregiver of someone with Lewy Body dementia.

First, please allow me to introduce myself. I was a caregiver for my father and mother-in-law, who were both diagnosed with Alzheimer's disease, and for my grandmother who lived to age 95 and did not have dementia. That was in the 1980's, when I still had teenage children at home — long before the term 'sandwich generation' came about. I humbly learned a lot during those full and challenging years. Mostly, I learned that caregiving is all about love and that I had to love myself enough to care for me as well as I did for my family members.

Attending a caregiver support group was a lifesaver for me and made a lasting impression. Caring about my fellow caregivers became permanently etched on my heart and ultimately led me to write a book called *Coping with Caring*, a book of daily caregiver reflections and practical caregiving tips. My husband Bill and I have traveled extensively, organizing events for caregivers and making presentations at countless faith-based and civic organizations. In 2000, we organized a local caregiver support group, which has met every week since then. I also write a syndicated newspaper column, *The Caregiver's Caregiver™*, in the *Tampa Tribune*.

About a year ago I was asked where to find reliable resources on Lewy Body dementia, so I called LBDA. They sent me some excellent materials on LBD, and while studying them I realized my own father most likely had LBD, not Alzheimer's. I wondered how many

other caregivers had loved ones who also might have been misdiagnosed. Bill and I immediately made all the LBDA resources available to every caregiver in our support group. Our relationship with LBDA has become a blessing to families in our support group, their doctors, and many home health providers in our area.

One support group member, Jean, realized that many of her husband's symptoms resembled LBD. (He had been diagnosed with Alzheimer's several years ago.) I asked her recently how she approached her husband's neurologist with her new suspicions. She asked the doctor if there could be a chance her husband has LBD, not AD. The doctor responded with a question, "What do you know about Lewy Body?" She told him she'd been reading information from the LBDA and handed him everything.



With one computer screen open displaying her husband's records, and LBDA materials in hand, he turned another computer on and began scanning all LBD factors. He remarked that her husband didn't have PD, but his stoop and shuffle were "PD like."

He pored over past medical records too, including her husband's "allergic reaction" to morphine after back surgery in 2000. His behavior required that he be "restrained." Similar medication reactions occurred after subsequent surgeries too. Jean related that during

those episodes her husband was a "total terror" and didn't resemble the gentle man she'd married.

After an hour of investigation on his computers and discussion with Jean and her husband, the neurologist changed the diagnosis to LBD and adjusted current medications.

Since her husband suffers from severe back problems, pain medications present a challenge. I asked Jean what the new diagnosis means to her as a caregiver. She said she now considers any new medication as being possibly life threatening. She strictly monitors medicines, even over-the-counter products. She added, "Everything is a fine balance and maintaining that balance occupies my every thought. But, I'm so glad to know what we're really dealing with now."

She says she tells everyone about LBD. She's made copies of LBDA's "Message to Physicians Treating LBD." She gives them to the home health nurses and her husband's physical therapist. The physical therapist has distributed copies of LBDA information to all her co-workers.

I asked Jean what she'd like to tell others caring for a loved one diagnosed with LBD? She eagerly replied, "Go on a computer. Visit www.lbda.org often. Learn as much as you can about LBD — especially about medications and finding a proper balance that works for your loved one. Take advantage of the LBDA online discussion forums. And, find a local support group where you can share in person and get those hugs we all need!"

Send your LBD caregiving questions to Lyn via e-mail at lyn@thecaregiverscaregiver.com or write to Journey Publications, PO Box 433, Sebring, FL 33871.

Volunteering comes from the heart. If you would like to volunteer with LBDA, please visit our web site and click on volunteer opportunities to see how you can help LBDA as we are increasing knowledge, sharing experience, and building hope. Go to <http://www.lbda.org/category/3459/volunteer.htm>.

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Victoria Ruff Named 2008 Volunteer of the Year

Every year LBDA recognizes one volunteer who has gone above and beyond the call of duty — someone who demonstrates innovation and dedication and who contributes to building awareness about Lewy body dementias and who enhances the efficiency of LBDA. This person is a trailblazer — innovative, and a self-starter, someone who has exceeded the expectations of their role as a volunteer. This year LBDA is proud to name Victoria Ruff as its 2008 Volunteer of the Year.

Victoria became involved with LBDA after her mother passed away from LBD in 2006. Victoria faced many challenges in finding the best care and treatment

for her mother. She says, “I learned so much during my mother’s journey...I have to share it with others.”



Victoria Ruff with her husband, Michael Bright.

After joining the LBDA family in 2006, Victoria quickly became an integral part of our volunteer team. She sits on the Out-

reach Committee where she helps to shape and grow many of the programs and services that help families affected by LBD. She has made the LBDA Chat Room a valuable resource for caregivers and others affected by LBD. Victoria leads an LBD support group in Boston and has helped to bring information and resources on Lewy body dementias to local facilities like Sherrill House, a non-profit skilled nursing and rehabilitation center near Boston. Most recently, Victoria designed and led a project which reached out to hundreds of doctors and facilities across the United States, inviting physicians to self-report to LBDA if they treat Lewy body dementias.

Victoria doesn’t limit her volunteer work to LBDA. She plays a vital role with the LBD Caregiver Group on Yahoo, continues to be involved with many organizations in her local community, and participated in Memory Walk 2008 in Cambridge, MA. Victoria also chairs a holiday event in Boston that raises funds for children’s charities, something she has been involved with for the past 13 years.

Victoria’s dedication and generosity has helped countless families who are battling this terrible disease and who need information and support. “I’m just giving back to those caregivers that [helped] me,” Victoria says. “I do a lot of volunteer[ing], that’s who I am.”

Congratulations to Victoria Ruff, LBDA’s 2008 Volunteer of the Year!

Honorable Mentions

LBDA is proud to recognize the other nominees for Volunteer of the Year, for their tremendous contributions which have helped so many LBD families.

Robin Riddle for her work as an LBDA support group facilitator and her tremendous contributions as a member of the Science Committee.

Gwen Ross for her devotion to the Caregiver Helpline as Helpline Coordinator. Her efforts have built this service as a resource for hundreds of families affected by LBD each year.

Irene Selak for her incredible dedication on the E-mail Helpline, for moderating all of the LBDA forums, participating in special projects and being an active member of the Outreach Committee.

Kristine Spencer for her tireless efforts in raising awareness through the planning and hosting of the Annual LBD Awareness Volleyball Tournament and for coordinating an educational symposium with local Alzheimer’s and Parkinson’s and other organizations.

in Loomis, California on August 16-17, 2008. More than 50 volleyball teams participated in the tournament, held in association with AAU Volleyball and covered by ESPN Radio. The tournament included educational presentations on LBD and a public honoring of caregivers. This event succeeded in raising LBD awareness for more than 5,000 people in the Loomis, California area.

The Gaynor Family, Melissa Walker and Kristine Spencer dedicated their time, effort and creativity in planning these events to make a difference in the lives of the families we serve. Thank you for your incredible dedication and your generosity!

If you are interested in planning a special event to honor a loved one and help support the families we serve, contact Caite Schulz, Development and Program Manager today at cschulz@lbda.org.

Special Thanks To...

LBDA offers our deep appreciation to the following foundations and individuals for their generosity. Thank you to...

- The Turner Foundation for their support of LBDA’s new Web site which was made possible by a generous grant from the foundation.
- The Carmen Foundation for their ongoing support of LBDA’s programs and services, helping millions of families and medical professionals find the information and support they need.
- Dr. Tom Graboys for his incredible efforts in raising awareness of Lewy body dementia and his generous support of the cause as he continues on his own journey living with LBD.

Lewy Body Digest Changing for 2009

LBDA is revamping the Lewy Body Digest in 2009 to make it faster and easier for you to get the information you want on Lewy body dementia! With the growing demand for up-to-date information, we are changing the format of the Lewy Body Digest into an e-newsletter delivered directly to your inbox every two months.

If you currently subscribe to our print newsletter you can continue receiving the Lewy Body Digest by registering online at www.lbda.org for the electronic copy delivered via e-mail.

Scientists Claim Breakthrough

In August, 2008, the Journal of Neuroscience reported a new mouse model for LBD. Scientists at the University of Nottingham Medical School showed that this mouse model exhibits Lewy-like deposits in the brain.

A team of scientists led by Dr. John Meyer set out 8.5 years ago to determine whether specific gene malfunctions would cause the formation of protein deposits in brain cells of mice that model Lewy bodies in people with LBD. By manipulating the 26S gene sequence, one of machinery that eliminates unwanted protein "trash" in cells, researchers created a line of mice with defective trash removal ability resulting in the formation of deposits which resembled early Lewy bodies.

This is the first mouse model demonstrating that clogging up the trash removal system by deleting the 26S gene can lead to the accumulation of Lewy-like deposits, and it provides an opportunity to understand the role that the 26S gene might play in Lewy body disease. Understanding this process in mice should help identify ways to define, interrupt or prevent the same kinds of processes in humans.

While this research advance is a big step forward, the search for a mouse model with actual Lewy body disease is still underway. An LBD mouse model will provide new avenues to investigate and allow the testing of potential therapeutic approaches to prevent neurodegeneration in the brain.

Visit http://www.lbda.org/index.cfm?fuseaction=feature.display&feature_id=1766 to learn why a mouse model is important in LBD research.

Lynn Bedford, David Hay, Anny Devoy, Simon Paine, Des G. Powe, Rashmi Seth, Trevor Gray, Ian Topham, Kevin Fone, Inooshin Rezvani, Maureen Mee, Tim Soane, Robert Layfield, Paul W. Sheppard, Ted Ebendal, Dmitry Usoskin, James Lowe, and R. John Mayer 2008, *Depletion of 26S Proteasomes in Mouse Brain Neurons Causes Neurodegeneration and Lewy-Like Inclusions Resembling Human Pale Bodies*, The Journal of Neuroscience, 28(33):8189–8198.

Caregiver Corner

A "Proem" by Marjorie Carmen

There is an advertisement
A Dead Zone
Then, all of a sudden
A massive group of folks
Show up

Supporting the Verizon customer
Reminding me of the power
Of support on our
LBDA forums.



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for detailed bios, visit us online

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Vision Statement

We envision a cure for
Lewy body dementias and
quality support for those still
living with the disease.

Mission Statement

Through outreach, education and
research, we support those affected
by Lewy body dementias.

Lewy Body Digest

A publication of the Lewy Body Dementia Association

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DISCLAIMER: This newsletter is compiled by the LBDA. Articles contributed by caregivers are based on personal experience. As such, the information may not reflect opinions of LBDA or the medical community. Every effort is made to review all content for accuracy and accepted practices. Please consult your professional before acting on any legal or medical information posted herein.

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