



LEWY BODY DEMENTIA
R E S O U R C E C E N T E R
BRINGING AWARENESS, SUPPORTING WITH LOVE

SEPTEMBER, 2020

Dear LBDRC Friends and Caregivers,

We are aware of how difficult these past six months have been--particularly for people with LBD--as well as for persons with other dementias, the elderly population in general, and caregivers. We have received more helpline calls and emails during these months than ever before. Please know we are here to help you through our support groups, our website at www.lewybodyresourcecenter.org, and our helpline at 516-218-2026 from 8am to 8pm ET seven days a week.

MUSIC AND MIND

A wonderful one-hour segment, available for free to watch online, is led by operatic soprano Renee Fleming. It is entitled Music & Dance and Parkinson's. The first part begins with an explanation of LBD by a Nobel Laureate, followed by the program director of *Dance for PD* with uplifting dance segments of people with Parkinson's thoroughly enjoying dancing. A leading scientist then describes how important music is for people with LBD and other types of dementia. Please note two things: This is accessed through Facebook. If you are unable to watch it, consider joining Facebook for this purpose as Renee Fleming hosts this program regularly on other topics involving Music and Mind. Secondly, please note that it will take about 20 seconds to begin once you click on the page, so please be patient:

<https://www.facebook.com/ReneeFlemingMusic/videos/321715585744417>

LEWY BODY DEMENTIA IN THE NEWS

Thousands of people who never heard of Lewy Body Dementia were made aware of it this month. A major reason was the release of the new Robin Williams documentary, *Robin's Wish*. (As a reminder, it can be seen through AppleTV, Amazon, Fandango and others.) The sad passing of former New York Mets star Tom Seaver, who had LBD, brought more attention to the disease in September. Because of both of these circumstances, newspaper articles throughout the country were written, not only about the film, but specifically about LBD to bring awareness to their readers. The Lewy Body Dementia Resource Center was sought out for information for both of these excellent articles--in *USA Today* and the *Queens Chronicle*:

USA Today: <https://www.usatoday.com/story/news/health/2020/09/01/robin-williams-lewy-body-dementia-terrorist-brain/5686882002/>

Queens Chronicle: https://www.qchron.com/editions/queenswide/seaver-s-illness-is-often-misdiagnosed/article_8e4445fa-c441-512a-8e60-6522d65f98ba.html

CONNECTION

It is our pleasure to share a beautifully written poem by Vera Kewes Salter. Vera attends one of our support groups and cares for her husband who has LBD. The poem was published in Red Eft Review:

Consistent with Lewy Body by Vera Kewes Salter

Abnormal deposits of alpha synuclein in the brain

He sits with his hands in his lap
 unsure where he put them
watches two women, one tall one short
 walk through the closet door

Swollen feet shuffle soggy paper towels
 to clean droplets from
the speckled tile floor -- he showers
 I mop -- then towel water from his back

At breakfast he asks:

Why am I in Lewy's body?

we hang our answers
 on a clothesline

read the paper and pray
 for a free and fair election
together go into the garden
 turn on the sprinkler

admire the round red hibiscus
 he planted last year
watch a tiger swallowtail
 drink nectar from a tiger lily

At night he inspects the house
 turns on the porch lights
locks the terrace door
 that I left open.

Warm regards to all,

Norma

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