

Table 1
Participant Demographics

	Total (n=184)	Baseline Visit 0-2 Years Prior to Conversion Group (n=68)	Baseline Visit 2-5 Years Prior to Conversion Group (n=86)	Baseline Visit >5 Years Prior to Conversion Group (n=30)
Age of Conversion to DLB	77.6 ± 8.2	75.3 ± 8.2	78.3 ± 7.8	81.2 ± 7.7
Years between Baseline and DLB Conversion	3.1 ± 2.2	1.3 ± 0.4	3.1 ± 0.9	7.3 ± 1.7
Education	15.8 ± 3.7	16.1 ± 3.4	15.8 ± 3.8	15.2 ± 4.0
Sex	71.2% Male	75.3% Male	65.1% Male	76.7% Male
Age of Cognitive Decline	71.7 ± 8.8	70.2 ± 9.0	72.1 ± 8.2	74.0 ± 9.8
Age of Behavioral Decline	71.2 ± 10.4	64.5 ± 2.6	66.5 ± 8.9	80.3 ± 8.4
Age of Motor Function Decline	72.1 ± 8.9	66.3 ± 2.9	67.8 ± 7.0	79.4 ± 7.9

DLB = Dementia with Lewy Bodies

Table 2
Neuropsychiatry Inventory Questionnaire Results for Baseline Visit*

	Total (n=184)	Baseline Visit 0- 2 Years Prior to Conversion Group (n=68)	Baseline Visit 2- 5 Years Prior to Conversion Group (n=86)	Baseline Visit >5 Years Prior to Conversion Group (n=30)
Nighttime Behaviors	41.0%	52.9%	34.9%	23.3%
Apathy/Indifference	36.0%	39.7%	37.2%	16.7%
Depression/Dysphoria	34.8%	30.9%	37.2%	30.0%
Irritability	34.3%	36.8%	33.7%	23.3%
Anxiety	33.1%	33.8%	33.7%	23.3%
Agitation/Aggression	23.0%	22.1%	24.4%	16.7%
Appetite/Eating Problems	23.6%	26.5%	26.7%	3.3%
Disinhibition	14.6%	14.7%	15.1%	10.0%
Motor Disturbances	10.1%	10.3%	11.6%	3.3%
Hallucinations	9.6%	10.3%	10.5%	3.3%
Delusions	8.4%	11.8%	7.0%	3.3%
Elation/Euphoria	3.9%	7.4%	1.2%	3.3%

*symptoms present within one month prior to baseline visit

Table 3
Clinician Judgement of Motor Symptoms at Baseline Visit

	Total (n=184)	Baseline Visit 0-2 Years Prior to Conversion Group (n=68)	Baseline Visit 2-5 Years Prior to Conversion Group (n=86)	Baseline Visit >5 Years Prior to Conversion Group (n=30)
Gait Disorder	32.6%	45.6%	31.4%	6.7%
Falls	10.9%	19.1%	8.1%	0.0%
Tremor	25.0%	29.4%	25.6%	13.3%
Slowness	39.7%	47.1%	43.0%	13.3%

O5-03-04

**THE LEWY BODY DEMENTIA
ASSOCIATION RESEARCH CENTERS OF
EXCELLENCE PROGRAM: TOWARD
OPTIMIZING CLINICAL CARE AND
CLINICAL TRIAL INFRASTRUCTURE**



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Background: The Lewy Body Dementias (LBD), which include dementia with Lewy bodies (DLB) and Parkinson's disease with dementia (PDD), represent the second most common dementia syndrome after Alzheimer's disease dementia. There are several challenges associated with LBD, which include the lack of approved medications for most clinical features, lack of evidence on management principles, and absence of infrastructure for LBD clinical trials. **Methods:** The Lewy Body Dementia Association (LBDA) oversaw the development of the Research Centers of Excellence (RCOE) program with the primary goals of 1) improving LBD clinical care and 2) developing a clinical trials-ready network and the associated infrastructure. A nation-wide request for applications and review process was performed in 2017, and the inaugural investigator meeting was held in December 2017. **Results:** Twenty-four centers were selected, and over 40 individuals participated in the investigator meeting. A survey revealed that over 1700 new and over 4800 established LBD patients are evaluated each year across the RCOE centers. The following items were identified as key objectives relating to improving clinical care: 1) identify the optimal tools for clinical diagnosis, 2) define the standards of care for management throughout the course of the disorder, 3) promote continuing medical education to health care providers, and 4) operate and maintain LBD-specific resources, support groups and programs. The key objectives relating to developing clinical trial network infrastructure include: 1) review the landscape of clinical measures and biomarkers pertinent to LBD trial methodology, 2) determine the optimal core and supplemental battery of measures for clinical trials, and develop new measures when needed, 3) expand relationships with industry partners, and 4) determine core principles for LBD trials. Several working groups and committees were established to address these objectives. **Conclusions:** These objectives address many of the priorities for LBD which were developed at the NAPA Alzheimer's Disease and Related Dementias Summit in 2016 (Corriveau et al, *Neurology* 2017;89:2381-2391) – particularly the highest priority goal of initiating more clinical trials in LBD. The LBDA RCOE investigators will update the scientific community as these objectives are addressed. Supported by the LBDA.

05-03-05 DELAYS IN DIAGNOSING LEWY BODY DEMENTIA

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Background: Lewy body dementia (LBD), consisting of dementia with Lewy bodies (DLB) and Parkinson's disease (PD) dementia (PDD), makes up >15% of cases at autopsy, however clinical prevalence rates are much lower at 5-6%. Here we review the diagnostic pathways of LBD to explore possible reasons. **Methods:** We reviewed the medical notes of 74 DLB and 72 non-DLB dementia cases matched for age, gender and cognitive performance, together with 38 PDD cases and 35 PD cases, matched for age and gender, from two geographically distinct UK regions. **Results:** DLB cases took longer to reach a final diagnosis, underwent more imaging tests, had more clinical assessments at home and had more alternative prior diagnoses, than their non-DLB counterparts (table 1). Age at referral negatively correlated with time to final diagnosis in DLB subjects (Pearson's; $R=-0.44$, $p<0.001$; see figure 1) but not non-DLB subjects (Pearson's; $R=-0.21$, $p=0.08$). Cases diagnosed in East Anglia compared to the North East had significantly more core features (as specified by the 2005 consensus criteria), but fewer suggestive features, with cases in the North East having significantly more dopamine transporter (DAT) scans performed (table 2). However there were no significant differences in the time to reach the final diagnoses between regions. For PDD, 46% (12/26 PDD cases) had impaired activities of daily living due to cognitive impairment, 57% (16/28) had cognitive impairment in multiple domains, and 38% (6/16) had both, prior to a diagnosis of dementia being recorded. 42% (10/24) of patients received treatment for dementia before a dementia diagnosis. Visual hallucinations and fluctuations were also significantly more common in the group diagnosed with dementia (table 3). **Conclusions:** Our results suggest DLB patients, particularly those on the younger end of the old age spectrum, experience delays in their diagnosis and are often misdiagnosed initially. The variation in the use of DAT scans, and the number of core features in diagnosed subjects, suggest different thresholds for clinical diagnosis between regions. This, and results suggesting that diagnosis of dementia in PD is delayed beyond the onset of symptoms, may explain the low rates of LBD diagnosis seen clinically.

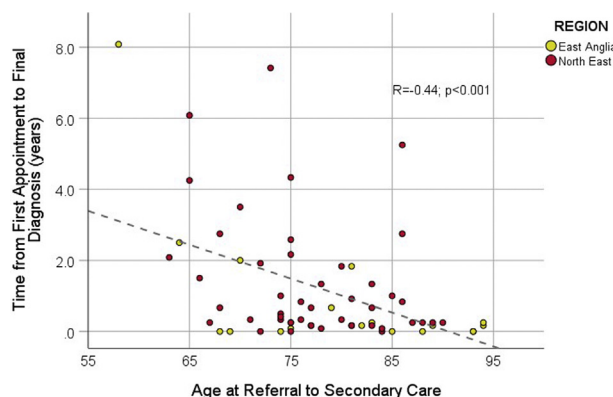


Figure 1. Correlation between Time from First Appointment to Final Diagnosis and Age of DLB subjects.