



Focus on Dementia with Lewy Bodies

In our summer newsletter, we featured the introduction of the Diamond-Lewy toolkit which is used to detect symptoms of Dementia with Lewy Bodies (DLB). Recognising the signs of this challenging disease is important, because if we are to offer appropriate therapies, we must first be able to make an accurate diagnosis.

So what are the indications of DLB and how has the BDR Study, and the regional Centres supported by BDR funding, contributed to our understanding of this disease?

In many respects, the symptoms of DLB are comparable with those of Parkinson's disease dementia (PDD). Collectively, the two are known as Lewy Body Dementia (LBD) and despite being the second most frequent cause of dementia, LBD has been termed, **"The most common disease you have never heard of"**.

DLB has a range of characteristic features. This includes the core symptoms of cognitive decline, fluctuating consciousness, Parkinsonism, sleep behaviour disorder and visual hallucinations. There are also additional symptoms which may present. Notably, postural hypotension (low blood pressure), constipation, urinary problems, excess saliva, a loss of sense of smell and taste and changes in speech and swallowing. Neuropsychiatric symptoms are also commonly experienced and include, increases in anxiety, depression, apathy, and delusions. These difficulties arise when deposits of abnormal protein form into clumps inside the neurons. The clumps then damage or destroy the neurons leading to a loss of the neurotransmitters, dopamine and acetylcholine and collectively, this causes disruption to the brain's functioning.



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BDR was chosen as the focus of Adam Smith's Chatathon. For over 12 hours, Adam conversed with researchers about the use of brain tissue in their work.

If you would like to hear a recording of this chat, you can access it by going to <https://www.youtube.com/watch?>

Support for individuals and families affected by DLB

This year, the International DLB Conference was organised by the Director of BDR, Professor Alan Thomas and hosted through Newcastle University.

The Conference brought together dementia researchers from around the world and among the presenters, was Rachel Thompson, the *only* Consultant Admiral Nurse specialising in DLB. Rachel spoke about the DLB toolkit and the role of the Admiral Nurse in supporting families, by providing psychoeducation specific to DLB. She explained how this can help reduce carer distress in relation to the management of specific symptoms as well aiding the development of coping strategies.

Support for families is available by contacting the

Admiral Nurse Dementia Helpline

0800 888 6678

or Email helpline@dementiauk.org

For information about Lewy body dementia and research

www.lewybody.org

To contact the Lewy body Admiral Nurse service

Email: lewybody@dementiauk.org



What's happening in your local BDR?



Newcastle University has a long tradition of research into this dementia sub-type and recently, support by the leading UK dementia charities was awarded to two Newcastle-based early career researchers.

Funded by **Alzheimer's Research UK**, Dr Daniel Erskine (pictured right), has used BDR tissue and data to look at a specific type of fat known as **sphingolipids** which may be implicated in the development of DLB. Dr Erskine's work suggests that this fat molecule may damage certain brain cell components, causing proteins to clump together, forming the distinctive 'Lewy bodies'. This discovery may lead us to a potential new treatment for DLB and hence its potential significance cannot be understated <https://bit.ly/3FsdRKO>



Another Newcastle-based researcher is Dr Gemma Roberts (pictured left, receiving her Dementia Research Leaders Award).

Dr Roberts was funded through her PhD by the Charity **Alzheimer's Society** to work on a project which aims to improve the early diagnosis of DLB. Early damage to neurons has been shown to begin in the peripheral nervous system, rather than in the brain. It is therefore possible to detect DLB pathology in the heart as well as in the brain. Dr Roberts wanted to determine whether changes in cardiac scans could be seen in the very early (prodromal) stages of DLB. Her results indicate that indeed, using specialised imaging, DLB pathology can be detected through cardiac scans even in the very early stages of the disease process before dementia can be identified and where few clinical signs are present. This is a very promising finding because it will allow us to spot those individuals most at risk of developing the disease and determine who will benefit most from current therapies and from disease modifying treatments when they become available.

More information about Dr Roberts' work can be found at <https://bit.ly/3FtHk6U>

DLB Research at King's College, London



Newcastle is not the only BDR Centre with a special interest in DLB research. The Principal Investigator (P.I.) for the BDR Centre at King's College, Professor Dag Aarsland (pictured left), is also P.I. of the European DLB Consortium **E-DLB** and Chair of the ISTAART Professional Interest Group for Lewy body dementias. He is the Dementia theme lead at the Maudsley Biomedical Research Centre at King's College and currently, is also in charge of the multi-centre, **ENLIST-DLB Study**.

The main objective of the ENLIST-DLB Study is to improve the diagnosis and prognosis for patients with DLB. To achieve this, the team will examine if the presence of clinical core features of DLB together with specific biological biomarkers, are associated with an increased rate of cognitive decline. As a secondary objective, they plan to build up in the UK, a large cohort of people diagnosed with Dementia with Lewy bodies and from these participants, collect longitudinal clinical and cognitive data along with biological samples.

In total, there are five Centres involved in this research. Two are in London, one at King's College and another at University College and Centres are also located in Cambridge, Exeter and Newcastle.

The study team are actively recruiting and are looking for participants with a diagnosis of DLB or Parkinson's Disease Dementia (PDD). If you would like to learn more about this research, please contact the Study Manager, **Olga Borejko**, **Email: olga.borejko@kcl.ac.uk** or **Telephone: 0207 8480024**.

You can also find out more about the research by registering with the website,

Join Dementia Research

[Join dementia research - register your interest in dementia research : Login \(nih.ac.uk\)](https://www.join-dementia-research.org/)



Thank you again to all our participants and their families for your amazing support with BDR. We send you our warmest wishes from the whole team and hope that you enjoy the Festive Season.



If you would prefer not to receive future newsletters, please let us know by contacting your local study team