



The Lewy Body Society

Research Strategy 2017-2022

<http://www.lewybody.org/>

A registered charity in England & Wales (1114579) and in Scotland (SCO47044)

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1. Foreword

The Lewy Body Society is a charity registered in England and Wales (number 1114579) and in Scotland (SC047044) whose mission is to fund research into Lewy Body dementia (LBD) and to raise awareness of the disease.

Lewy Body Dementia is the second most common form of age-related neurodegenerative dementia after Alzheimer's, accounting for approximately 10-15% of all people living with dementia. We also hope to provide a community focus for those who are diagnosed with dementia with Lewy bodies as well as for their carers and families. The website provides information to help those who need to understand the disease and its impact.

Signatures of President and Chief Executive Officer

Chief Executive Officer

Chair Specialist Advisory Committee

2. Executive Summary Research Strategy 2017-22

Lewy body dementia (LBD) is the second most common cause of neurodegenerative dementia in older people yet has received less focus than other subtypes of dementia. By way of this research strategy the UK Lewy Body Society aims to

- ▶ Provide national leadership in forging and maintaining partnerships and collaborations in the UK
- ▶ Bring new people to the field
- ▶ Enable training and long-term career development of a new generation of early-career research scientists devoted to LBD research.
- ▶ Improve the understanding of the causes of LBD.
- ▶ Enhance the translation of research discoveries into better patient care.

Applications will be invited from UK universities, NHS Trusts and Statutory social care organisations or other research institutions anywhere in the United Kingdom. The types of research that will be funded include pre-clinical, clinical, and applied service / public health research, junior fellowships and collaborative projects. Project grants should be aimed at innovative studies that are designed to tackle major challenges posed by Lewy Body disorders. Grants will run for a maximum of three years.

The Specialist Advisory Committee will be responsible for reviewing the research strategy, determining the research priorities, reviewing the applications and making recommendations to the Trustees for the awards.

Up to 50% of available funds will be available for research each year; currently this would translate into a total amount of £500,000 per year. The ambition of the “Society” is to grow this fund to £1m a year within 5 years.

3. Strategic Focus

Lewy body dementia (LBD) is the second most common cause of neurodegenerative dementia in older people, accounting for 10% to 15% of all cases – about 100,000 people in the UK. It is part of a spectrum of disorders that share a similar pathology including dementia with Lewy bodies (DLB) and Parkinson's disease dementia (PDD). It is important to differentiate people with DLB from other common dementia syndromes because they have specific symptoms, impairments, and functional disabilities.

The Lewy Body Society (LBS) was founded in 2006 to support research into LBD and to raise awareness and educate the public, the medical profession and those in healthcare decision-making positions about the disease. In Table 1 there is a brief summary of the research projects that the Lewy Body Society has funded to date.

Today, a new model for disease research is evolving that involves open, coordinated collaborations between academic researchers, pharmaceutical and biotech companies, private foundations and government agencies. Vital to its success is involvement of patients, caregivers and patient advocacy groups as key collaborators, knowledge resources and decision-makers.

The research strategy will include all aspects of Lewy body dementia from bench to bedside and include considerations for families and carers. Clearly the society will need to continually tailor the available resources to where the greatest need is and where “best value” can be added. The society plans to establish a UK research network focused specifically on Dementia with Lewy Bodies.

The results of the work will hopefully contribute to finding new and improved treatments for and better ways of identifying and managing Lewy body dementia.

4. Research Strategy

4.1. Objectives

The objectives of the research strategy are to address as many of the following as possible through the UK Lewy Body Society and / or collaboration(s).

- ▶ Providing national leadership in forging and maintaining partnerships and collaborations in the UK through the organization of the Annual UK LBD scientific meeting and workshops;
- ▶ Bring new people to the field
- ▶ Enabling training and long-term career development of a new generation of early-career research scientists devoted to LBD research.
- ▶ Improve understanding of the causes of LBD.
- ▶ Enhancing translation of research discoveries into better patient care.

4.2. Types of Research

There are many types of research studies, such as those looking at:

- ▶ Prevention
- ▶ Improved animal models
- ▶ Improving diagnosis, including the development and application of biomarkers:
 - ▶ Identify and validate biomarkers for LBD, including both changes in brain structure, blood and tissue levels of specific biomolecules.
 - ▶ Defining “at-risk” stages (Mild Cognitive Impairment LBD, MCI-LBD)
 - ▶ Treatment at all stages of the disease including:
 - ▶ Non-pharmacological, pharmacological and devices
 - ▶ Disease-modification and prevention
 - ▶ Value of educational initiatives for family and professional carers
 - ▶ Surveys aiming to improve the quality of life for people with dementia and their carers.
- ▶ Developing better clinical trial enrollment criteria and outcome measures.
- ▶ Quality of care

The project grants should be aimed at innovative studies that are designed to tackle major challenges posed by Lewy Body disorders that face the scientific and patient communities. Junior Fellowships will be available for the most promising recent PhD graduates to provide a career path at this early stage and a mechanism to maintain the brightest in Lewy Body research.

Research Involving Animals

The Society funds animal research in line with policies developed by AMRC (<http://www.amrc.org.uk/our-work/animal-research/amrc-policies-on-animal-research>).

All grant holders using animals must implement the principles in the cross-funder guidance “Responsibility in the use of animals in bioscience research” (<https://www.nc3rs.org.uk/responsibility-use-animals-bioscience-research>)

Grant holders should make use of the ARRIVE guidelines when designing their experiments and should ensure that they report animal-based studies in accordance with the ARRIVE guidelines as far as possible, considering the specific editorial policies of the journal concerned.

4.3. How Priorities will be decided:

Trustees and Specialist Advisory Committee (SAC) will conduct an “in-depth” review of:

- ▶ Research to date and other LBD funding
- ▶ Areas where LBD society could “add value”
- ▶ Potential collaborations
- ▶ Grant and funding schemes

This “review” will include panel meetings with experts and other stakeholders such as pharmaceutical industry, patient / carer organisations, research organisations.

4.4. Collaborations

A challenge for many researchers today is finding appropriate patients for a study; equally people with or at risk of a condition are looking for studies to contribute to or participate in. “Join Dementia Research” (<https://www.joindementiaresearch.nihr.ac.uk/>) has partnered with National Institute for Health Research (NIHR) Alzheimer Scotland, Alzheimer's Research UK and Alzheimer's Society to promote a service which allows people to register their interest in participating in dementia research and be matched to suitable studies.

Possibilities for collaborations in the UK include the organisations mentioned above as well as MRC, Wellcome and third sector organisations such as Dementia Pathfinders, Parkinson's UK, TIDE Together in Dementia Everyday.

Possibilities for international collaboration include the Lewy Body Dementia Association (US, <https://www.lbda.org/content/research>), Michael J Fox Foundation

4.5. Proposal for a UK Dementia with Lewy body (DLB) network.

Progress in Lewy Body research has been slow, mainly because of the complexity of the underlying molecular pathology and the difficulty of studying such changes in-vivo. In DLB this has been compounded by the small number of specialist research centres focusing on the disorder, leading in turn to limited case ascertainment and small datasets. The corollary of this has been a high degree of coherence between centres that has enabled progress through collaboration and consensus, rather than competition.

The UK has a strong track record in DLB research with major contributions in clinical and neuropathological methods, neuroimaging, genetics and the basic science of LB pathogenesis. UK investigators remain at the forefront of DLB research planning and delivery and do so at a time when DLB is rising quickly up the agenda for healthcare delivery and drug regulatory authorities, for research funders, and perhaps most importantly the pharmaceutical industry.

To maximise the potential UK synergies in DLB the Society is proposing to assess the feasibility and potential of establishing a collaborative, interdisciplinary network with the primary purpose of promoting and accelerating DLB research activities. The establishment of the “Network” will require the following:

- ▶ A “scoping” event involving “known” experts across all disciplines including patient and public members.
- ▶ Definition of scientific proposals
- ▶ A funding plans
- ▶ An organisational structure.

4.6. Society Funds

Much of the Society’s funding is currently raised from donations in memorial. Other contributions come from sponsored events organized by supporters of the Society. The Society is a member of the Institute of Fundraising; therefore, all sponsored events conform to the Institute’s criteria.

The amount of funds available each year will be determined by donations the Charity receives, the performance of its investment portfolio, competing demands and the priorities set by the Trustees. Up to 50% of available funds will be available for research each year; currently this would translate into a total amount of £500,000 per year. The ambition is to grow this to £1m a year within 5 years.

5. Applications for Project Grants

5.1. Who can apply?

Applicants from the following organisations are eligible to apply:

- ▶ UK universities
- ▶ NHS Trusts
- ▶ Statutory social care organisations or other research institution.

Principal applicants should hold employment contracts that extend beyond the period of the grant or have a co-applicant that has a long-term contract with the same institution.

5.2. Process for Awarding a Grant

Grant applications submitted to the Society will be checked by the Specialist Advisory Committee (SAC) for eligibility. All eligible applications will be Peer Reviewed by a minimum of three experts each of whom will submit a written report to the SAC. SAC will choose the three experts and only ONE of the three may be a current member of the SAC.

Where appropriate the Lewy Body Society may get another AMRC registered organisation to review a proposal.

Up to 50% of available research funds (not already earmarked for research and other financial commitments) will be awarded in any one calendar year.

Invitations to submit an application will be posted on the Lewy Body Society website and other appropriate websites.

Peer review will be carried out according to the following principles:

- ▶ **Accountability:** Charities are open and transparent about their peer review procedures and publish details, including the names of members of scientific advisory panels or other decision-making bodies.
- ▶ **Balance:** Scientific advisory panels reflect a fair balance of experience and scientific disciplines.
- ▶ **Independent decision-making:** The scientific advisory panel is independent of the charity's administrative staff and trustees.
- ▶ **Rotation of scientific advisers:** Scientific advisory panel members have a fixed term of office and do not have tenure.
- ▶ **Impartiality:** Scientific advisory panels include a significant number of non-beneficiaries. There is a conflict of interest policy and potential beneficiaries are not present when decisions are made.

The Specialist Advisory Committee will:

- ▶ Check eligibility of the research applications to ensure they are within scope.
- ▶ Review the written reports from the Peer Reviewers

Following the Peer Review process the applications together with the written reports from the Experts will be reviewed by the SAC and recommendations

made to the Trustees. The Trustees will make the final decision on whether the charity should award funding to the research application(s).

Applicants will be notified of the outcome by a letter signed jointly by the CEO and Specialist Advisory Committee Chair of the Lewy Body Society.

Applicants will be expected to sign an agreement with the Society to submit an annual update report about progress and financial status of the project.

5.3. Duration:

The duration of a grant is up to a maximum of 3 years.

5.4. Further Information:

Information for applicants together with policies affecting grants is available on the Lewy Body Society website (<http://www.lewybody.org>).

6. Review of Research Strategy

The Research Strategy will be reviewed annually by the SAC to ensure that new opportunities for research and collaboration are not missed. Any proposed changes to the Research Strategy will be agreed by the Trustees and then incorporated into an updated version of the Research Strategy document.

Should a research opportunity be identified that needs urgent discussion then this will be considered jointly by the President and Chair of the SAC. Proposals considered suitable for funding will be circulated to the other SAC members for a decision about:

- ▶ Either putting forward for the Peer Review process
- ▶ Or direct recommendation to the Trustees for funding

7. Code of Conduct

The Society is firmly committed to the following practices and principles (Manifesto July 2015). That:

- ▶ We owe a duty of care to our contributors to ensure that the money they so generously send us is spent wisely and only to further the objects stated in the Society's constitution, namely to raise awareness of and fund research into Lewy body dementia;
- ▶ We do not solicit donations but are grateful to those who undertake fundraising activities that benefit the Society. The "Donate" button on the website is for the convenience of those who wish to contribute; • We will never ask a contributor for further donations;
- ▶ We do not employ paid staff but may, from time to time, buy the services of an independent contractor to augment the work of the voluntary Operations Team or provide professional expertise out with the Team's expertise and experience for a specific project and with a clear and limited remit.
- ▶ The Trustees are not remunerated for their services and the only money they receive is reimbursement for out of pocket expenses incurred on behalf of the Society,
- ▶ Repayment of all such expenses are reviewed and approved of by a different Trustee than the one submitting a request for reimbursement;
- ▶ Any investment of uncommitted funds will be with ethical companies; • We will not endorse or be associated with any commercial enterprise;
- ▶ We will not accept donations from any company or organisation which might result in fettering or dictating our activities, create a conflict of interest or that the Trustees deem to be unethical in policy or practice.

Three key principles will underpin the way in which The Lewy Body Society will conduct and oversee their research strategy and the application and review process – integrity, independence and transparency -.

Potential partnerships and / or collaborations with medical research charities, the pharmaceutical, biotechnology, diagnostic and devices industries will be conducted in accordance with the Association of Medical Research Charities (AMRC) guidances. These include:

- ▶ Principles Peer Review http://www.amrc.org.uk/sites/default/files/doc_lib/AMRC_principles_of_peer_review_April2016.pdf
- ▶ Guidance Essential Partnerships: A guide for Charities working with industry http://www.amrc.org.uk/sites/default/files/doc_lib/Essential_Partnership.pdf
- ▶ Guidance on openness on Animal Research http://www.amrc.org.uk/sites/default/files/doc_lib/AMRC-members-guide-to-the-Concordat-on-openness-on-animal-research.pdf
- ▶ Developing a Conflicts of Interest Policy <http://www.amrc.org.uk/publications/developing-conflicts-interest-policy>

- ▶ Suggested three “R”s questions in applications
[http://www.amrc.org.uk/sites/default/files/doc lib/Suggested-3Rs-questions-for-application-forms.pdf](http://www.amrc.org.uk/sites/default/files/doc_lib/Suggested-3Rs-questions-for-application-forms.pdf)

8. Acknowledgements

This strategy was developed by consulting across the dementia research and scientific communities as well as patients and carers.

We would like to thank everyone who contributed.

9. Table 1 Overview of Funded Grants 2007-2017

Awardee	Date (Start / End)	Topic	Amount	Comment
Marzena Kursawa	2007 - 2010	Role of Glucocerebrosidase mutations in Dementia with Lewy bodies and Parkinson's disease	£63,000.00	
Dr Tilo Kunath	2012-2013	Live models of cortical neurons (brain cells) affected by DLB to be used to test new drugs for DLB	£18,172.00	1-year innovation grant
Dr Jose Bras	2012-2013	Unique Genes involved in Lewy Body Dementia	£35,000.00	
Prof Alan Thomas	2015	Biomarker Research	£36,000.00	Total amount
Dr Jose Bras	06/2015 – 06/2018	3-year PhD Scholarship for familial factors of DLB	£48,000.00	
Dr Jay Amin	11/2014 – 11/2017	Investigating the role of systemic and central inflammation in Dementia with DLB	£284,000.00	Clinical research fellowship at Southampton University. Administered by Alz Research UK
Prof John O'Brien	04/2015 – 04/2018	Magnetoencephalography(MEG) Imaging in Dementia with Lewy Bodies	£82,878.00	Project started late, October 2017. £5,966.00 additional funding agreed.
Mrs Alison Killen	04/2107 – 04/2019	Feasibility and acceptance of a dementia with Lewy bodies support and information group.	£48,671.72	Co-applicants: Dr John-Paul Taylor Dr Darren Flynn Dr Nicola O'Brien