

# ASI Research Newsletter

## Autumn 2024



THE Alzheimer  
SOCIETY OF IRELAND

Dear Colleague,

Welcome to the Autumn edition of your ASI Research Newsletter!

Below you will find updates on our latest webinar series, some exciting updates from our Dementia Research Advisory Team and some new publications.

### ASI Research Webinar Series



Our second webinar in the series will take place on October 2nd at 11am in collaboration with Dementia Research Network Ireland.

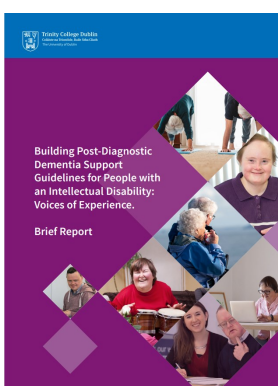
**Topic:** Disease Modifying Therapies

**Presenter:** Prof Sean Kennelly, Tallaght University Hospital & Trinity College Dublin

Prof Kennelly will present on the some of the most recent research in the area of disease-modifying therapies and updates in the field of dementia research.

To register please check out our website, or email [research@alzheimer.ie](mailto:research@alzheimer.ie)

### New Report Launch: Building Post Diagnostic Dementia Support Guidelines for People with an Intellectual Disability



In September, The Trinity Centre for Ageing and Intellectual Disabilities held their launch of the Post Diagnostic Dementia Support Guidelines for people with an intellectual disability.

This work was funded by the Health Research Board and The Alzheimer Society of Ireland, under the HRB/HRCI Joint Funding Scheme.

Research & Policy Manager, Dr. Laura O'Philbin, joined a panel as part of the online launch who shared their insights about the development and implementation of these guidelines. They will have a meaningful impact, informing care and provide insights for healthcare practitioners and providers who deliver post-diagnostic dementia support.

## Updates on disease modifying drugs: Lecanemab (Leqembi)

### European Medicines Agency

On July 25th, the European Medicines Agency said they do not recommend Leqembi (previously called Lecanemab) for approval. They believe the risks of taking Leqembi for Alzheimer's Disease are greater than the benefits. This was disappointing news in Europe, but research for other treatments is still ongoing worldwide. Also in July, another treatment called Donanemab was approved by the FDA in the United States, and there is hope it will be may be approved in Europe too.

### Medicines and Healthcare Products Regulatory Agency (MHPR) (UK)

On 22nd August, the MHPR approved Leqembi for use in the UK. However, shortly after, the National Institute for Health and Care Excellence (NICE) recommend Leqembi for use on the NHS because they deemed it to not be cost effective.

### The Alzheimer Society of Ireland's Thoughts

At The Alzheimer Society of Ireland we believe that people living with dementia in Ireland deserve the same opportunities for treatment as those in the UK and elsewhere. Fighting dementia is a global challenge, and everyone should have access to new therapies.

The Alzheimer Society of Ireland will keep supporting and advocating for people with dementia and their families to help them live well for as long as possible. You can learn more about these therapies on our website, [www.alzheimer.ie](http://www.alzheimer.ie).

## The Science of Dementia for the Non Scientist Event



In September, Dementia Research Network Ireland and The Alzheimer Society of Ireland co-hosted a conference, The Science of Dementia for the Non-Scientist in the Lexicon Library in Dun Laoghaire.

In the run up to this event, members of the Dementia Research Advisory Team worked closely with DRNI on the design & content of the event. On the day, we had members Helen give an opening speech; Carmel and Emer moderated Q&As, in conjunction with members Janice and Nuala who took part in a PPI Lived Experience panel discussion, alongside Marguerite a member of the Irish Dementia Working Group, ensuring that the lived experience remained at to the fore. We were also thrilled to see so many members in the audience cheering on the team.

The engaging and accessible format showcased a great variety of ideas and work in the dementia research space. Videos from the event will be posted soon.



## TeamUp for Dementia Research



*Photo credit: João Barbosa & Max Shulte*

Two of our wonderful members (John & Kathleen) began trekking the Camino de Santiago as part of the Walking the Talk for Dementia immersive conference.



The Walk culminated in a research conference and it was a very emotional time for everyone. Our Research & Policy Manager, Dr. Laura O'Philbin, also joined in the Walking the Talk for Dementia and took part in a panel discussion as part of the conference.



John & Kathleen also participated in this global awareness campaign as part of #WorldAlzheimersDay on September 21st to challenge stigma. A sincere thank you to everyone involved in Walking the Talk for Dementia.

We are very proud of John & Kathleen!

You can watch this video on Youtube!

The Dementia Research Advisory Team is now on X (formerly Twitter). You can find us using the handle: @DRAT\_ASI. Give us a follow to stay up to date to see what our members are up to!



🌍💜 World Alzheimer's Day | WTD 2024  
Walking the Talk for Dementia



The [Dementia Research Advisory Team](#) members continue to strengthen their skills as Person Public Involvement or PPI Contributors. In addition to collaborating with researchers throughout the universities of Ireland, the members are preparing presentations and abstract submissions for upcoming national and international conferences. We look forward to sharing updates from their work in the coming weeks so please stay tuned to The ASI's & the new DRAT social media channels.