



NEUROPROGRESSIVE AND DEMENTIA

Spring 2025 Newsletter


Welcome to our Spring Newsletter




Thank you for taking the time to read our newsletter.



It is jam packed with lots of information about what the Neuroprogressive & Dementia Network have been involved with recently and also study updates


We are also on lots of social media platforms so please give us a follow us on Social Media for up to date information. You can find us on:


**Neuroprogressive & Dementia
Network**


**You can now find us on the following
social media platforms**

 **Neuroprogressive and dementia network**

 **@nrs_ndn1**  **@NRS_NDN**

And newly
arrived on  **@nrs-ndn1**

 **Tay.ndntayside@nhs.scot**





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Forewords



Jacqui Kerr - Network Manager

Welcome to the NDN Spring 2025 newsletter, as you scroll through the newsletter content you will see how busy we have been across our sites in Scotland.

Firstly, I would like to take this opportunity to say a huge thank you to everyone for their continued support of the Neuroprogressive and Dementia Network. We are grateful for everyone's contribution to our Network and the research we deliver across NHS sites in Scotland.

In our Autumn 2024 newsletter, we were pleased to share with you all that we had over 850 participants signed up to our 'Permission to contact' research interest register. Since then

our sign ups have been steadily rising and in February 2025 we were close to reaching 1000 sign ups! To help us reach our 1000 milestone, we launched a social media campaign via NRS Scotland Communications, and are excited to share that our 'Permission to Contact' reached over 1000 participants signed up. This is a fantastic achievement for the NDN. Thank you to all who have joined our 'Permission to Contact' scheme and also to the teams who have invested their time to promote our Permission to Contact to offer everyone in Scotland the opportunity to be part of our research.

At the end of February one of the NDN Lothian team Maria Dewar retired after working as a Clinical Studies Officer with the Network for 10 years. We all wish Maria a wonderful retirement and happy travels! In other Network staff news, Kirsty Kennedy will also be leaving the NDN Lothian team, she's off to explore new opportunities, and we all thank her for her hard work with the Lothian team and the NDN over the past 4 years. When one door closes another opens, our NDN team in Glasgow welcomed a new staff member Linzi McCrorie at the beginning of April – welcome to the NDN Linzi!

I hope you enjoy finding out what we have all been up to over the past few months. Please share our Spring 2025 newsletter with anyone with an interest in research.



Thank you for reading our Spring Newsletter.

There are lots of exciting developments happening in the dementia landscape and we will soon be starting our **READ-OUT** in conjunction with Oxford University. The READ-OUT Observational Study investigates blood tests in people seen in memory clinics across the United Kingdom, for a wide variety of dementias and other memory problems. It will involve everyone including people from backgrounds that are not often involved in research: very elderly, ethnic minorities, those in deprived areas or with multiple illnesses, etc. We will also

assess whether these tests are good value for money for the NHS. The project will show if blood biomarkers are useful for people attending NHS memory clinics.

This will take place in NHS Greater Glasgow & Clyde, NHS Tayside, NHS Dumfries & Galloway, NHS Ayrshire & Arran, NHS Lanarkshire and NHS Western Isles (1st dementia ever study to take place in the Western Isles!!!)

For people with Parkinson Disease, we have the **EJS-ACT-PD study** starting later this year. This looks at accelerating clinical trials by evaluating multiple treatments simultaneously. This will be taking place in NHS Greater Glasgow & Clyde, Lothian and Tayside.

We are also looking forward to visiting Orkney in June this year as part of our strategy to include remote and rural in our clinical trials.

Finally, please do have a read of the Partners in Research newsletter attached to this newsletter. Our groups are doing amazing work and we are always looking for more people to join us.

Permission to Contact Research Database





We now have over **1100 participants** signed up to our Permission to Contact register. From as north as Shetland to as west as Stornoway and all over the mainland.

This gives them the opportunity to get involved in research in all of the various forms that comes in.

Research is **NOT** just about new drugs - it can also take the form of

- Questionnaires/surveys
- Blood Tests
- Interviews
- Scans
- Patient & Public Involvement - see further down for more details on our Partners in Research groups

If you would like some forms to hand out to patients or posters to put on waiting room walls/display boards, please do not hesitate to contact us at tay.ndntayside@nhs.scot

Annual Report 2024-25



Our Annual Report has now been published and is on our website for people to read:
<https://www.nhsresearchscotland.org.uk/uploads/tinymce/Final%20Annual%20Report%202024-2025.pdf>¹

We had a very successful year in 2024-25. Our main headlines were:

- **Held a successful conference along with Scottish Dementia Research Consortium (SDRC) and Brain Health Alliance for Research Challenges (ARC) in June 2024**
- **Permission to Contact (PTC) reached over 1000 sign-ups**
- **Visit to Western Isles/Ullapool as part of our strategy for including remote and rural population in research**
- **We have been awarded the prestigious READ-OUT study from Oxford University. This will include both urban and rural participants and will include the Western Isles for the first time**

¹<https://www.nhsresearchscotland.org.uk/uploads/tinymce/Final Annual Report 2024-2025.pdf>

Research meeting with Alzheimer Scotland & Alzheimer Society



On March 12th Dr Tom Russ (Network Champion), Jacqui Kerr (Network Manager) and Jessica Crossan (NDN Lothian Senior Clinical Studies Officer) hosted visitors at our NDN/NHS Lothian site based at the Western General Hospital, Edinburgh. The purpose of the visit was to increase awareness of the NDN and our Alzheimer Disease clinical research landscape in Lothian and across Scotland.



We invited along Henry Simmons (Alzheimer Scotland Chief Executive), Alison McKean (Alzheimer Scotland Executive Lead for research), Laura Rooney (Alzheimer's Society UKDTN Lead Research Nurse) and Cat McKaskie (Alzheimer's Society Head of Strategic

Communications and News). We also invited along participants who have a lived experience of Alzheimer Disease to share their journey insights about taking part in a clinical trial.

In addition, we also had representatives from NHS Lothian and the NDN – Melanie Rowlands (Dementia Nurse Consultant) Lesley Briody (Clinical Research Nurse Manager) and Emma Fleming (NDN Lothian Clinical Studies Officer).

Our busy agenda was centred around the Alzheimer's disease research landscape in Scotland and how we (NDN) deliver our clinical research within the NHS. We also discussed the opportunities available for taking part in research. We had great discussions about our Alzheimer's disease clinical research study portfolio - past, present and future. Jess and Emma provided an insight of the journey

Clinical Trials Portfolio



Over the last year we have had 30 studies on our portfolio. They take all different forms, as explained above, and they all have different lengths of time they are open to recruitment and for the study to take place.

We have done lots of work on our website recently (details at bottom of article) and it now includes information on the studies that are open to recruitment for the following disease areas:

- Alzheimer Disease
- Parkinson Disease
- Huntington Disease
- Motor Neurone Disease

- Multiple Sclerosis

You can see which health boards are taking part in each of the studies and their contact details. Not every study runs in each area.

NEW: We have also included updates on trials, which are no longer open to recruitment, but you can see how the studies are progressing.

NEW: Finally, we have included information on trials which are now closed and results have been published

You can find all of this information at <https://www.nhsresearchscotland.org.uk/research-areas/dementia-and-neurodegenerative-disease/study-portfolio>

Partners in Research



Welcome to Partners in Research

We are the patient and public involvement (PPI) group for the Neuroprogressive & Dementia Network. Our group aims to make sure people with lived experience have the opportunity to shape research and research-related activities. We run several groups each month and are always open to new ways of helping you get involved. We look forward to meeting you



Partners In Research Newsletter

We have recently published a Partners in Research newsletter, with lots of information on what has been happening over the last few months. You can view that plus lots more information on our website page: <https://www.nhsresearchscotland.org.uk/research-areas/dementia-and-neurodegenerative-disease/get-involved>

From Around the Network



Alzheimer Disease Study update: EVOKE

The NDN Teams from Tayside, Lothian and Grampian attended an update event held by the study sponsor NOVO NORDISK on the EVOKE study. This is a research study investigating semaglutide in people with early Alzheimer's disease.



Some of the main points were:

- The UK are the 2nd highest recruiters of this study in the world
- Topline results will be published in September and we will publish them when we get them
- Future studies were also discussed

Tayside News



Alzheimer Disease/Parkinson Disease (AD/PD) Conference - April 2025

Dr Angus, Kate Fraser and Justine Hudson attended the 2025 AD/PD Conference in Vienna, which took place from 1st to 5th April. This annual conference brings together global leaders in neurodegenerative disease research, focusing on basic science, clinical research, and translational developments in the field. The theme of this year's event, "Striving for a better future for all those affected by neurodegenerative diseases," resonated throughout the

sessions, which highlighted new insights into disease mechanisms, the latest findings from clinical trials, and innovative approaches to therapy, prevention, and diagnosis.



The conference offered a diverse programme, including Forum Discussions, Symposia, Oral and Poster Presentations, all centred on the most recent breakthroughs in Alzheimer's, Parkinson's, and related neurological disorders.



Some of the topics we attended included:

- **Insights from Genetics in AD & PD**
- **Advances in PD Treatment**
- **Dementia Prevention and Treatment Strategies**
- **Diagnosis and Staging of Alzheimer's Disease**
- **Advances in Diagnosis for PD & LBD**
- **APOE: Disease Mechanisms and Biology**
- **Fluid and Digital Biomarkers & Imaging**

Dundee Research Interest Group Event - 28th February

The Tayside team were invited to attend the Dundee Parkinson's Research Interest Group (DRIG) open day at MRC PPU within Dundee University. The open day was hosted by Dr Sammler and the volunteers from the DRIG community. Research staff, university students and members of the public, including those living with PD and their carers were also in attendance.



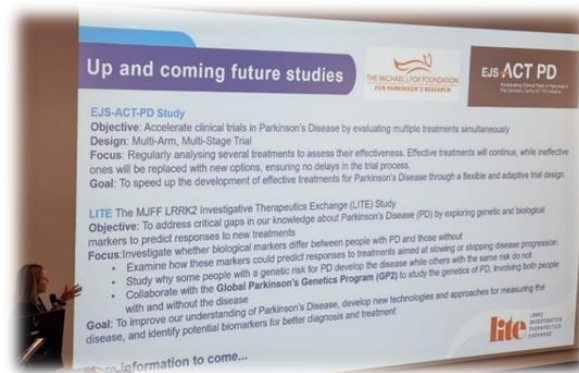
Network manager Jacqui, CSOs Kate and Tiffany and NDN administrator Helen came along and managed a stall offering information about local research, handed out approved study information and an abundance of PTCs!

Jacqui and Tiffany gave a wonderful and inspiring talk about current and future research within Tayside. Of course, the success of PTC was highlighted! Proudly mentioning our **1000 participants** on the register and our excitement to continue growing our numbers.

Some of the wonderful talks on offer included:

- Introducing LITE
- Updates from the NDN team
- Focused ultrasound in PD
- Mitophagy in PD

- Lysosomal impairment in PD
- Lived experience talks and emotive and thought-provoking poems from the Movers and Shakers group
- Group tours of MRC PPU labs and facilities



Lothian News



The team in NHS Lothian have been busy in the first quarter of the year.

Our Parkinson's study Probiotic PD closed to recruitment on 5th March after meeting the recruitment target. All participants are now in follow up and the last study visit will fall mid November.

We have recently re-opened as a site for the TOPHAT study. This study is aiming to establish whether Ondansetron will effectively treat visual hallucinations in people with Parkinson's and we are looking for Adults (over 18 years) who meet MDS criteria for Parkinson's or Revised criteria for Dementia with Lewy Bodies and have visual hallucinations at least weekly that are moderately distressing.

We are currently in the final stages of set-up for a new Parkinson's study called Aspro-PD. This study will assess whether treatment with a daily dose of oral ambroxol tablets (for 104 weeks) is associated with an improvement in motor and non-motor function compared with matching placebo. To be eligible for the study, the person with Parkinson's must have a confirmed GBA1 mutation. We hope to be open to recruitment for this study early summer. NHS Lothian are the only NDN site delivering this study.

Grampian News



Alzheimer Disease Study still recruiting



The DREAMER Study

Detecting Early Alzheimer's using MR

We invite you to help with a research study investigating a new MRI method for detecting Alzheimer's disease

IF

- You have been diagnosed with Alzheimer's disease.
- Are aged 60 years and above
- Do not have diabetes
- Have not had a major stroke
- Have no family history of Alzheimer's disease.

PLEASE CONTACT

Dr Vasiliki Mallikourti
vasiliki.mallikourti@abdn.ac.uk

We are still recruiting patients to our 'Dreamer study' for Alzheimer's Disease in Grampian. Please have a look at the criteria and if you know of anyone who meets it, please get in touch with our Grampian Team on 01224 557941 or email gram.sdcnr@nhs.scot

North of Scotland Parkinson's Research Interest Group Event - Saturday 28th June




We are looking forward to attending the North of Scotland Parkinson's Research Interest Group (NoSPRIG) event on Saturday 28th June at Robert Gordon University. We will be holding a stall with lots of information on the Parkinson's research we are undertaking. Come along and talk to us.... See you there

Greater Glasgow & Clyde News



New Multiple System Atrophy study coming soon

You could help us investigate a potential new treatment for multiple system atrophy (MSA)



Find out whether the **MASCOT Trial** could be right for you or someone you care for who is living with MSA!

If you or someone you care for has been diagnosed with MSA and it has been less than 5 years since the onset of MSA symptoms related to abnormal body movement, consider learning more about a clinical trial of an investigational drug called "Lu AFB2422". This trial seeks to determine whether the investigational trial drug is effective and safe in slowing the disease progression of MSA.



People with MSA may be able to join the MASCOT Trial if they:

- Are 40 to 75 years of age
- Have been diagnosed with MSA and it has been less than 5 years since the onset of MSA symptoms related to abnormal body movement.
- Have a reliable caregiver who will be available throughout the trial when caregiver input is needed (approximately every 4 weeks)
- Caregivers should spend approximately 3 hours or more with the participant per week and be able to tell the trial team about the participant's symptoms

Additional criteria need to be met to qualify to join the MASCOT Trial, which the trial team will discuss with those interested in participating in the trial.

Financial reimbursement of trial-related travel and expenses may also be available.

Please contact us to find out more:

MASCOT |  

204320A_Protocol_v1.0_US_Eng_24JUL2024_English (United Kingdom)_20AUG2024

We have a new trial starting soon for people with Multiple System Atrophy, which will investigate whether the drug 'Lu AFB2422' is effective and safe in slowing down the disease progression of MSA,

If interested please contact the Glasgow Team on 0141451 8945 or email ggc.glasgowresearchndn@nhs.scot

West of Scotland Parkinson's Research Interest Group Event - 7th May

WEST OF SCOTLAND RESEARCH INTEREST GROUP

We attended the West of Scotland Parkinson's Research Interest Group (WoSRIG) on Wednesday 7th May at and gave lots of information about Parkinson's research we are undertaking. The session was recorded and can be found by clicking here²

PSP & CBD Research Grants



UK charity PSPA is opening applications for funding of research studies looking into neurological conditions PSP & CBD. The funding, which will be available from late April 2025, will include Small Research Grants (up to £25,000) and Research Project Grants (up to £250,000). All scopes of research from basic science to clinical care will be considered. Applications are invited from professionals including Allied Health Professionals at all career stages, who are residents in the UK. For further information, please visit the PSPA website³ or email

²https://parkinsons-org-uk.zoom.us/rec/play/gLFjHTBI96imJo0bgdNo1z3IzNHcc1r5D4CTqXGnsJ5FtKgHVUrQd0JKbf9BtS9DQ9vewgOOoq-FDq0r.OYScrYLgxBPgTUny?accessLevel=meeting&canPlayFromShare=true&from=share_recording_detail&continueMode=true&componentName=rec-play&originRequestUrl=https%3A%2F%2Fparkinsons-org-uk.zoom.us%2Frec%2Fshare%2FcPyfNWecJ4NwrWx17yYH1eqIA6uAgqwSbWTod3Yys5rT82H1vLWbBnyuwMEanZJV.xYMCaEwuWzhZTzJK

³<https://eur01.safelinks.protection.outlook.com/?url=https%3A%2F%2Fwww.pspassociation.org.uk%2Fresearch%2Ffunding-opportunities-for-researchers%2F&data=05|02|helen.davidson4%40nhs.scot|91cb46304a684213db4c08dd71d8fded|10efe0bda0304bca809cb5e6745e499a|0|0|638791899555379660|Unknown|TWfPbGZsb3d8eyJFbXB0eU1hcGkiOnRydWUslIYiOilwLjAuMDAwMCIslIAiOiJXaW4zMilSkFOljoITWfPbClslldUljoyfQ%3D%3D|0||&sdata=BUK78Zulp24MxcMUcwfa6X4puBhNc76yv9J%2B5z7y6yk%3D&reserved=0>

You can also express your interest in taking part in PSP and CBD research with the PSPA via this online form⁴ or by calling their helpline on 0300 0110 122



Edinburgh Fringe Festival - Join Dementia Research



During the Edinburgh Fringe Festival there is going to be a show called 'The Nature of Forgetting'. The show was developed in collaboration with the Alzheimer's Society and neuroscience Professor Kate Jeffery.

At these shows there will be people there to help signpost to Join Dementia Research at the performances. You can find a link to the tickets as well as a link to the trailer for the show below:

- Link to tickets⁵
- The Nature of Forgetting trailer⁶

⁴[https://eur01.safelinks.protection.outlook.com/?url=https%3A%2F%2Fpspassociation.tfaforms.net%2F%2FExpression of Interest Form&data=05|02|helen.davidson4%40nhs.scot|91cb46304a684213db4c08dd71d8fde110efe0bda0304bca809cb5e6745e499a|0|0|638791899555404517|Unknown|TWfPbGZsb3d8eyJFbXB0eU1hcGkiOnRydWUslYiOilwLjAuMDAwMCIslAIoiJXaW4zMilslkFOljoITWfPbClslldUljoyfQ%3D%3D|0||&sdata=EtD%2Buy8vlezKYpcARiximc0tliXIOsWJS8B6u67B%2BjE%3D&reserved=0](https://eur01.safelinks.protection.outlook.com/?url=https%3A%2F%2Fpspassociation.tfaforms.net%2F%2FExpression%20of%20Interest%20Form&data=05|02|helen.davidson4%40nhs.scot|91cb46304a684213db4c08dd71d8fde110efe0bda0304bca809cb5e6745e499a|0|0|638791899555404517|Unknown|TWfPbGZsb3d8eyJFbXB0eU1hcGkiOnRydWUslYiOilwLjAuMDAwMCIslAIoiJXaW4zMilslkFOljoITWfPbClslldUljoyfQ%3D%3D|0||&sdata=EtD%2Buy8vlezKYpcARiximc0tliXIOsWJS8B6u67B%2BjE%3D&reserved=0)

⁵<https://eur01.safelinks.protection.outlook.com/?url=https%3A%2F%2Fwww.pleasance.co.uk%2Fevent%2Fnature-of-forgetting&data=05|02|helen.davidson4%40nhs.scot|fec5ade18e754653436c08dd8268e63a|10efe0bda0304bca809cb5e6745e499a|0|0|638810109227293887|Unknown|TWfPbGZsb3d8eyJFbXB0eU1hcGkiOnRydWUslYiOilwLjAuMDAwMCIslAIoiJXaW4zMilslkFOljoITWfPbClslldUljoyfQ%3D%3D|0||&sdata=MHVRXaHuTio%2BmVZ23jhqbriGjAggP8yHfQJ5svSy9Sc%3D&reserved=0>

⁶<https://eur01.safelinks.protection.outlook.com/?url=https%3A%2F%2Fwww.youtube.com%2Fwatch%3Fv%3DOg6JDL0dL9E&data=05|02|helen.davidson4%40nhs.scot|fec5ade18e754653436c08dd8268e63a|10efe0bda0304bca809cb5e6745e499a|0|0|638810109227308274|Unknown|TWfPbGZsb3d8eyJFbXB0eU1hcGkiOnRydWUslYiOilwLjAuMDAwMCIslAIoiJXaW4zMilslkFOljoITWfPbClslldUljoyfQ%3D%3D|0||&sdata=MHVRXaHuTio%2BmVZ23jhqbriGjAggP8yHfQJ5svSy9Sc%3D&reserved=0>

Contact Us



Neuroprogressive & Dementia Network

Corridor M

Ninewells Hospital

Dundee

DD5 9SY

Tel: 01382 423086

email: tay.ndntayside@nhs.scot⁷

Website: [Neuroprogressive and Dementia](#) | [NHS Research Scotland](#) | [NHS Research Scotland](#)⁸

[UsllYiOilwLjAuMDAwMCIsIIAiOiJXaW4zMilSkFOlpoiTWfPbClSlldUljoyfQ%3D%3D|0||&sdata=Qk2ldifMxeFreT7lk247fu42KiS8lCt8MDHX%2BV12wI8%3D&reserved=0](https://usllYiOilwLjAuMDAwMCIsIIAiOiJXaW4zMilSkFOlpoiTWfPbClSlldUljoyfQ%3D%3D|0||&sdata=Qk2ldifMxeFreT7lk247fu42KiS8lCt8MDHX%2BV12wI8%3D&reserved=0)

⁷<mailto:www.tay.ndntayside@nhs.scot>

⁸<https://www.nhsresearchscotland.org.uk/research-areas/dementia-and-neurodegenerative-disease>