



NEUROPROGRESSIVE
AND DEMENTIA

Neuroprogressive & Dementia Network
March 24

Forewords



Jacqui Kerr - Network Manager

Welcome everyone to our Spring Newsletter, we hope you enjoy reading it and finding out how busy we have been over the past few months with Network activities . Please share it with anyone who you think might be interested.

Across the Network and Scotland, we continue our commitment to raise our profile to ensure we are offering everyone in Scotland with a neuroprogressive condition or dementia the opportunity to take part in research. Dr Emma Law NDN Strategic Manager has been raising the Network profile by reaching out and meeting with communities to talk about our research opportunities across Scotland - see our Spotlight on Emma's strategic role to find out more!! I would also like to take this opportunity to thank all of our staff members across the Network for their continued hard work and commitment to our research.



Dr Tom Russ - Network Champion

Allow me to add my welcome to our Spring newsletter. Our field is at an exciting time for several reasons. As you know, after many years of trial failure.. two potentially disease-modifying treatments being considered by the MHRA for licensing in the UK. The NDN has the expertise in administering these treatments in NHS Scotland, having been involved in a number of clinical trials of similar agents over the last few years.

A further exciting development is closer links with our colleagues in the rest of the UK. We are delighted to join with both the Dementias Platform UK Trials Delivery Framework (TDF) led by Dr Vanessa Raymont at the University of Oxford and the NIHR Dementia Translational Research Collaboration (TRC) led by Dr Catherine Mummery at UCL. The TDF plays to our strengths, involving Phase 3 trials and the TRC – which recently benefited from almost £50Million funding from the UK Government – represents a development for us, being based around earlier, Phase 1 trials. We look forward to working with the TDF and the TRC going forward.

A final thing to mention is that I was privileged to attend a reception for the Dame Barbara Windsor Dementia Mission at No 10 Downing Street in March. That such a meeting was held shows the attention that dementia and neuroprogressive illnesses are currently getting and it was a great joy to see so many people working across the UK to make a difference to people with these conditions

Permission to Contact



We have over 500 people in Scotland signed up to our Permission to Contact scheme. These are from all over Scotland including Shetland.

We are looking for people interested in participating in research to sign up. They don't need to have a diagnosis but are also looking with people with all types of dementia, Parkinson's, Huntington's, MND and Multiple Sclerosis.

Our Permission to Contact QR code is live. These can be found on the back of our leaflets, on posters that can be displayed in waiting rooms and on our website. If you would like any leaflets or posters please do not hesitate to email tay.ndntayside@nhs.scot.

Once a person signs up for Permission to Contact, they will receive a welcome pack outlining opportunities they can take part in whilst waiting for appropriate studies. We have a number of Partner in research projects that people with lived experience, carers and family members can join - see more details in the Partners in research section

Our main aim is to ensure everyone in Scotland has 'THE OPPORTUNITY' to take part in research. The best way to do is by signing up to our Permission to Contact scheme.

USE OUR ONLINE SIGN UP FORM

Our online form is the quickest and easiest way to let us know you're interested in participating in research - scan the QR code to visit our page, and view our privacy notice



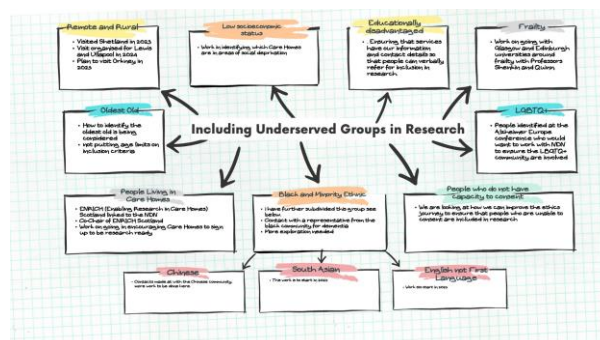
Spotlight - Strategic Network Role



I am very pleased and proud to be leaving my managerial role in the expert and capable hands of Jacqui Kerr and I will describe in more detail what my new role in the NDN is to be.

My title has change to ‘Strategic Manager’ and for one day per week, this means that all promises we made in our strategy from 2022 -2027 (<https://www.nhsresearchscotland.org.uk/research-areas/dementia-and-neurodegenerative-disease>) are acted upon and followed through.

As you will see in the diagram, I have been concentrating on some of the ‘easy wins’. In 2023 Tom Russ and I visited Shetland to discuss how to include areas which are remote and rural, such as our Island communities, in our research studies. It was pushing against an open door and we were welcomed and had a fantastic attendance, especially when we included the care homes on the island to talk about Confident Conversations. Tom, Jacqui and I are visiting Lewis and Ullapool in the summer of 2024 and we hope that we will make further progress in including our remote and rural populations in research.



Confident Conversations – I continue my work in delivering our Confident Conversations package to a variety of staff which has so far included Alzheimer Scotland link workers, NHS dementia link workers, the Scottish Dementia Working Group and staff from The Stand working in Kirriemuir Connections. We have delivered this to more than 180 people with excellent feedback.

Increasing our reach – Bernie McInally - one of our Clinical Studies Officers - did our first meeting with the Men’s Shed movement and we will be included in their Men’s Shedder publication (link) which goes to 4500 people. We reached out to the University of the Third Age (U3A) and they have asked the NDN to speak at their AGM. I am currently in negotiations with Age Scotland and the Cyrenians about how we can work together. Plenty to keep me busy!

Congratulations to Dr Rosie Ashworth



Congratulations to Dr Rosie Ashworth who won the NRS Scotland PPI Impact Award for commitment to supporting, delivering and sustaining Patient and Public Involvement, and positively impacting activity across Scotland.

New Studies



We have a number of new studies which have just commenced and are actively recruiting for participants:

Cannabidiol for Parkinson's Disease Psychosis (CAN-PDP):

This is a research study to test an investigational medicine called cannabidiol (CBD). Previous studies not only suggest that CBD may be useful in treating psychosis, they also suggest that it is safe to use in older adults.

The purpose of this trial is to look at how safe and well CBD works in patients with Parkinson's disease psychosis, and how well it is tolerated. The investigational medicine is not expected to modify the progression of Parkinson's disease.

This study is currently being run in NDN Grampian, Lothian and Tayside

For Grampian contact gram.sdcrn@nhs.scot or tel 01224 557941

For Lothian contact loth.sdcrn@nhslothian.scot.nhs.uk or tel 0131 537 3804

For Tayside contact tay.ndntayside@nhs.scot² or tel 01382 423086

BIAL Activate: The main purpose of this study is to investigate the effects, safety, and tolerability (whether side effects can be handled by a participant) of BIA 28-6156. This study is also meant to find out if the effects, safety, and tolerability are different in people with different forms of the GBA1 gene, which is a genetic characteristic that may be related to a higher risk for developing Parkinson's disease. Because the symptoms of Parkinson's disease usually get worse over time, effects will be measured by if and how BIA 28-6156 can slow down worsening of the disease.

This is currently being run in NDN Tayside - contact tay.ndntayside@nhs.scot³ or tel 01382 423086 for more information

²<mailto:tay.ndntayside@nhs.scot>

COBALT: This study is looking at whether the drug Memantine (added to the current Acetylcholinesterase Inhibitors -AChEI) can help people with Dementia with Lewy Bodies and Parkinson's disease dementia. We are looking for 150 patients with DLB and 150 patients with PDD, from across the UK to take part in this trial.

This study is about to start in NDN Lothian and Glasgow

For Lothian contact loth.sdcrn@nhslothian.scot.nhs.uk or tel 0131 537 3804

For Glasgow contact ggc.glasgowresearchndn@ggc.scot.nhs.uk or tel 0141 451 8945

Studies still open to recruitment



LUMA: This study is evaluating the safety and efficacy of a study medication, as compared to a placebo, to see if it may delay the progression of Parkinson's disease in people who are in the early stage of their condition.

This is currently being run in NDN Tayside - contact tay.ndntayside@nhs.scot⁴ or tel 01382 423086 for more information

PD Probiotic: This clinical research study is investigating the effects of B. Subtilis PXN21 on gut microbiome in Parkinson's disease. The study is recruiting participants with PD and randomly assigning them to either a treatment group or a placebo group. The treatment group will receive B. Subtilis PXN21 in the form of a pill supplement, while the placebo group will receive a similar-looking and tasting product that does not contain the bacteria.

³<mailto:tay.ndntayside@nhs.scot>

⁴<mailto:tay.ndntayside@nhs.scot>

This is currently being run in NDN Lothian. Contact loth.sdcrn@nhslothian.scot.nhs.uk or tel 0131 537 3804 for further details

ROstock International Parkinson's Disease Study (ROPAD): Being part of ROPAD you help to understand the prevalence of genetic causes of Parkinson's Disease (PD). The study procedure is simple with one doctor visit that involves a single blood collection and a brief clinical documentation which takes approximately 1 hour. The collected blood sample is then screened for a panel of genes associated with PD.

This is currently being run in NDN Tayside - contact tay.ndntayside@nhs.scot⁵ or tel 01382 423086 for more information

ENROLL-HD: The purpose of this research study is to collect clinical information about you and your health. We will also collect biological samples, such as blood and DNA (the genetic material in your blood). Researchers will use this information and samples to learn more about HD and to try to find new treatments for the disease. People from many countries contribute to Enroll-HD.

This is currently being run in NDN Grampian & Tayside

For Grampian contact gram.sdcrn@nhs.scot or tel 01224 557941

For Tayside contact tay.ndntayside@nhs.scot⁶ or tel 01382 423086

Partners in Research



Partners in Research Newsletter

If you have not already seen our newsletter, you can download by clicking [here](#)⁷ to read all our latest news and future plans

New Parkinson's project

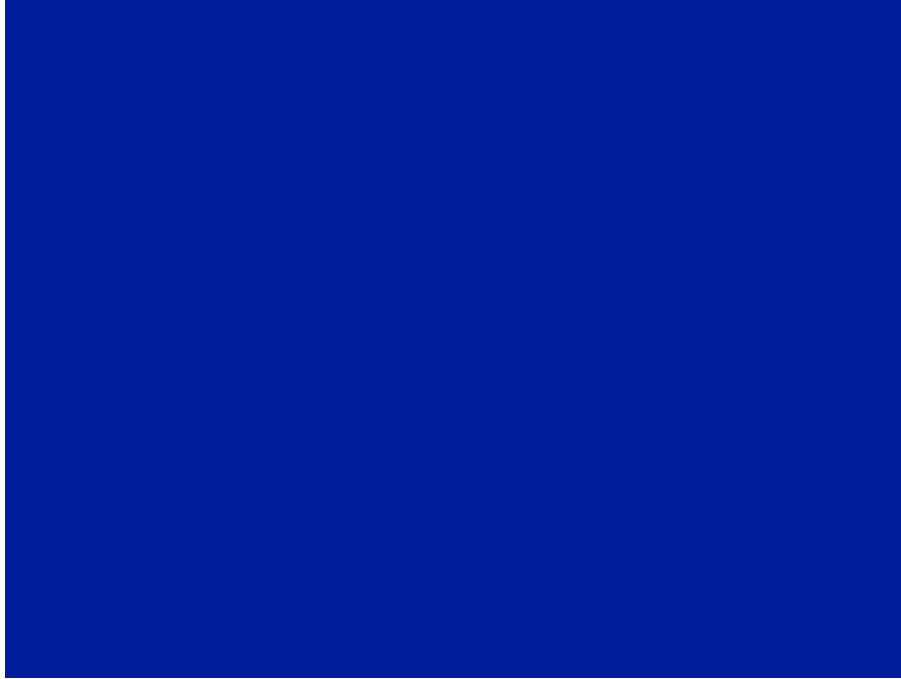
⁵<mailto:tay.ndntayside@nhs.scot>

⁶<mailto:tay.ndntayside@nhs.scot>

⁷<https://www.nhsresearchscotland.org.uk/research-areas/dementia-and-neurodegenerative-disease/get-involved>

After the success of our book, we are now looking at our next project. We are looking for people with lived experience of Parkinson's to help us in our Patient and Public Involvement activity. If interested you can either email tay.ppipartners@nhs.scot⁸ or complete this online form⁹

Contact Us



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⁹<https://forms.office.com/e/wFMp2VSBXF>

¹⁰<mailto:www.tay.ndntayside@nhs.scot>

¹¹<https://www.nhsresearchscotland.org.uk/research-areas/dementia-and-neurodegenerative-disease>