

# NEUROPROGRESSIVE AND DEMENTIA

Neuroprogressive & Dementia Network October 24

# **Forewords**





# Jacqui Kerr - Network Manager

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

In our Summer 2024 newsletter Dr Tom Russ our Network Champion spoke about our very long name and was seeking any bright ideas and suggestions for a new 'catchy' but informative name to identify us and the wonderful work we do. Unfortunately, despite our best efforts, we are unable to go ahead with our name change following guidance from NRS Scotland, thank you to everyone who gave us some great suggestions there really were some good ones!!

Colleagues from the NDN and ENRICH are all looking forward to attending the Alzheimer Europe Conference in a few weeks. Dr Rosalie Ashworth will be presenting on Wednesday October 9th – 'Coresearch as part of patient and public involvement: NRS Neuroprogressive and Dementia Network Partners in Research and ENRICH Scotland RICH Voices' and Dr Emma Law will be presenting on Thursday October 10th – 'Underserved Populations in Dementia Research in Scotland'. We also have poster presentations to showcase all the amazing work we do within the NDN and ENRICH. I am sure we will be updating you in our next newsletter about the interesting presentations we were fortunate to listen, learn and be part of at the Alzheimer Europe Conference.

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

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Welcome to our latest newsletter. We're very excited at everything that's happening at the moment. We're looking forward to the READ-OUT study of blood-based biomarkers from the University of Oxford starting. This will be happening in six health boards across Scotland – Tayside, Greater Glasgow & Clyde, Lanarkshire, Ayrshire & Arran, Dumfries & Galloway and, most exciting of all, NHS Western Isles! This will be swiftly followed by the ADAPT trial of blood-based biomarkers from University College London which we hope to run at multiple sites too.

The drug selection for the MASTODON-AD platform trial (the same kind of trial as MND-SMART) continues and we are contributing to this process and look forward to supporting the development of this trial, looking at repurposing existing drugs to treat Alzheimer dementia.

I'm just back from speaking at the International Dementia Conference in Sydney, where I found a very warm welcome and wonderful examples of good practice I'm bringing home to Scotland. We are grateful to everyone who supports the NDN, in whatever form, and I hope you enjoy reading this newsletter.

# **National NDN Information**



# Permission to Contact Research Database



We now have over **850 participants** signed up to our Permission to Contact scheme. From as north as Shetland to as west as Stornoway and all over the mainland. Signing up to our Permission to Contact scheme allows people THE OPPORTUNITY to take part in research.

To sign up please click on link: <a href="https://www.nhsresearchscotland.org.uk/research-areas/dementia-and-neurodegenerative-disease/patient-signup-form">https://www.nhsresearchscotland.org.uk/research-areas/dementia-and-neurodegenerative-disease/patient-signup-form</a>

# **Text Message Pilot**

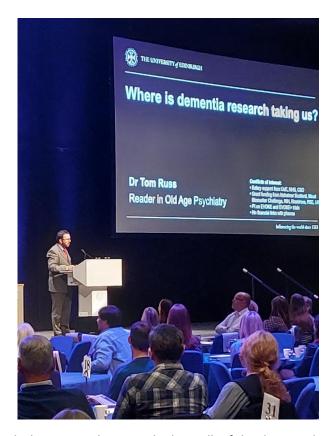
We have been working with GP practices in north-west Edinburgh (where the majority of older adults in the city live) to see whether sending a text message to highlight the possibility of taking part in NHS research at the local hospital is a good way of getting the word out. We have learned that it certainly is! We've had well over 100 people sign up to Permission to Contact to say they are interested in hearing about research opportunities (without any obligation to take part). We are going to explore if this would be possible elsewhere in the country as we really want everyone to be offered the opportunity to take part in research





We attended the excellent Alzheimer Scotland Conference on Friday 20th September at the Edinburgh Conference Centre. The programme was very varied and really interesting. We were delighted we got a mention from the Minister for Social Care, Mental Wellbeing and Sport, Maree Todd, when she was talking about the new studies coming along for dementia.

Our stand at the conference was really busy in all the breaks with lots of people interested in joining our research database 'Permission to Contact' and also to know more about our 'Confident Conversations' Training programme for those who work with people with dementia.



Dr Tom Russ, our network champion, also gave the last talk of the day on where dementia research is taking us and some of the exciting developments happening. The recordings of the day are on the Alzheimer Scotland website and worth a watch: <a href="https://www.alzscot.org/conference24">https://www.alzscot.org/conference24</a>

# Royal Society of Edinburgh 'Curious' Festival 2024



As part of the RSE 'Curious'Festival 2024 (which is described as 'a vibrant celebration of learning, inviting diverse minds to come together to learn, discuss big ideas, ask questions, and get curious), we joined with the Small Vessel Diseases Research team from Rowfogo centre at Edinburgh University and Prof Terry Quinn from Glasgow University to highlight the research going on at the NDN

The title of the event was 'Blood Flow & Brain Health: Understanding Dementia through Vascular Research' and one of our Partners in Research, Willy Gilder, talked about his experience of navigating the healthcare symptoms after getting is diagnosis.

# Red for Research day - Friday 20th September

A number of our sites took part in 'Red for Research' day on Friday 20th September.

In Dundee we joined the other NHS Research depts to hold an information stand in Ninewells Hospital concourse. Teams interacted with the public and offered NDN information about local research opportunities, as well as the opportunity to sign up to our Permission to contact database.

https://www.nhsresearchscotland.com/news/red-alert-edinburgh-castle-set-to-be-lit-up-for-red4research-day<sup>1</sup>

# **Partners in Research**



# **Partners in Research Update**

We have recently published our latest newsletter which you can view here<sup>2</sup>. Our Partners in Research groups have been really busy so far this year with lots of exciting projects happening.

¹https://eur01.safelinks.protection.outlook.com/?url=https%3A%2F%2Fwww.nhsresearchscotland.com%2Fnews%2Fred-alert-edinburgh-castle-set-to-be-lit-up-for-red4research-

 $<sup>\</sup>frac{day\&data=05\,|\,02\,|\,helen.davidson4\%40nhs.scot\,|\,9f709e166ac34eb3574c08dcdd2ffbfb\,|\,10efe0bda0304bca809c\,b5e6745e499a\,|\,0\,|\,0\,|\,638628445356914791\,|\,Unknown\,|\,TWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luM\,|\,2liLCJBTil6lk1haWwilCJXVCl6Mn0\%3D\,|\,0\,|\,|\,&sdata=Ul4yydk\%2BzwlvWq\%2FFqiZ4hyjDNJ5nZC00tKnTRA9KzcE\,|\,30\&Teserved=0$ 

<sup>&</sup>lt;sup>2</sup>https://www.nhsresearchscotland.org.uk/uploads/tinymce/Autumn 2024 Newsletter (1).pdf

# Would you like to join Partners in Research? Not sure what it involves

Some members of our group have put together a video talking about why they joined Partners in research. Watch it here<sup>3</sup>

We will also soon be launching a buddying scheme, pairing up new faces with established members to help answer questions and support getting involved in group activities. If you are interested in having an introduction to the buddying process get in touch

Contact us on tay.ppipartners@nhs.scot4

# **Tayside Information**





# Abbvie M15-737 study

Study:An extension of Study M15-741 evaluating the safety and tolerability of ABBV-951 in subjects with Parkinson's disease

<sup>&</sup>lt;sup>3</sup>https://youtu.be/JUr4nzwVwu0

<sup>&</sup>lt;sup>4</sup>mailto:tay.ppipartners@nhs.scot

Our participants have now completed their final study visits and have successfully transitioned over to the new Abbvie pump.

ABBV-951 is the first-and-only subcutaneous 24-hour infusion of levodopa based therapy for the treatment of advanced Parkinson's disease available for commercial use

One of our patients was interviewed on BBC News: Click here to see the full story<sup>5</sup>



# NHS Tayside Clinical Fellow

Dr Joe Farrimond believes in the need to strengthen the research culture in the NHS and increase capacity so was delighted to join the Network in August 2023 following the completion of his foundation training at NHS Tayside. He has now completed a year in the role and wrote a blog on it:

https://www.nhsresearchscotland.com/news/clinical-research-fellow-recommends-extremely-rewarding-opportunity-of-working-with-network<sup>6</sup>

<sup>5</sup>https://www.nhsresearchscotland.org.uk/news/groundbreaking-parkinsons-treatment-features-on-bbc-news-thanks-to-scottish-study-efforts#:~:text=Produodopa has now been approved,results" after being taken orally.
6https://eur01.safelinks.protection.outlook.com/?url=https%3A%2F%2Fwww.nhsresearchscotland.com%2Fnews%2Fclinical-research-fellow-recommends-extremely-rewarding-opportunity-of-working-with-network&data=05|02|helen.davidson4%40nhs.scot|9f709e166ac34eb3574c08dcdd2ffbfb|10efe0bda0304bca809cb5e6745e499a|0|0|638628445356954308|Unknown|TWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzliLCJBTil6lk1haWwiLCJXVCl6Mn0%3D|0||&sdata=RXPCKrd3UJ%2Be4cAHxYwNKatbT7dkWipoO2U80iL4Aok%3D&reserved=0



# **New Clinical Fellow**

We would like to welcome our new Clinical Fellow, Dr Emma Mair who started with us in August 2024.

My name is Emma Mair and I am a Clinical Fellow Doctor. I have just completed my two years of Foundation Training here in Dundee and I am very excited to join the team here. Since I was in medical school, I have always been very interested in Neurology as a specialty and I am keen to learn more about a wide range of neuroprogressive conditions through this role. It is a privilege to be involved in research and to become a key part of the search for novel advancements in treatments for our patients.



# Successful use of interpretation and translation services in Tayside

Historically, much of the research that we have been involved with in Tayside has been restricted to participants who are fluent in the English language. This is primarily due to protocol requirements for cognitive testing in Dementia trials in particular. However, with greater involvement now in trials in

the other neuroprogressive disease areas, such restrictions no longer apply and we can include participants for whom English is not the first language.

Recently, we were referred an MND patient from the Polish community, whose English is very limited. We approached the sponsor in the first instance to check how to proceed and how to support this person's inclusion in the trial. We then discussed the study with the participant via telephone and email and sent the English version of the study information (as no Polish version approved for use). For screening, we arranged for a Polish interpreter to be present for the full 90 minutes of the appointment while consent and eligibility/medical history were discussed to ensure that we did not misinterpret any of the important medical information and to ensure that the participant was appropriately informed about the study. The study doctor and interpreter read the information sheet verbatim to ensure the information was given in a manner the patient could understand. The patient was deemed eligible to participate in the trial and we invited him back for a baseline visit with the interpreter present again to ensure that important drug information was communicated and understood. Amusingly, the patient understands the term "placebo" as "like Tic-Tacs", which has now become a running joke at each of the study visits! For future shorter telephone visits, we decided that we could continue without the support of the interpretation service but know how to access support if required.

The patient is now doing well 2 months into the trial and when I call he always reminds me that he is "on the Tic-Tacs"!

Our ability to overcome language barriers and include a participant into this trial has been hugely rewarding and satisfying. It is very important to our team and our network as a whole that we can continue to break down barriers to research and be as inclusive as possible. Our positive experience with the NHS Tayside Interpretation and Translation Service gives me confidence that we can engage further with under-represented communities and rely on the support of this service to promote equal access to research and further engage with NHS Tayside patients from all backgrounds

# **Lothian Information**



We have been very busy recently promoting NDN Lothian at local events.



We were at the Euan MacDonald Centre for the Anne Rowling Clinic's Spring 2024 Research Open Evening in May this year. It was really busy and we had lots of interest from patients, relatives, researchers and clinical scientists. The event was organised by the Euan MacDonald Centre and Anne Rowling Clinic to showcase current research into a wide range of neurodegenerative conditions including multiple sclerosis (MS), motor neuron disease (MND) and Parkinson's Disease (PD). Dr Duncan and Jessica were pleased to be involved as Edinburgh NDN continue to develop their collaboration with the Anne Rowling research team



We also had a stand at the excellent Parkinson's Edinburgh Branch lecture in September. We spoke to so many people who wanted to take part in research and have since signed up for our 'Permission to Contact' scheme. Richelle Flanagan, who is a registered dietician and a person living with Parkinson's disease, delivered a fascinating lecture on the effect of diet and Parkinson's. You can view the lecture from our Edinburgh Parkinson's YouTube Channel (https://www.youtube.com/watch?v=NG3OzH\_PWYI<sup>7</sup>)

<sup>7</sup>https://eur01.safelinks.protection.outlook.com/?url=https%3A%2F%2Fwww.youtube.com%2Fwatch%3Fv%3D NG3OzH PWYI&data=05|02|helen.davidson4%40nhs.scot|4c153b2dfd3444f185af08dce2e89515|10efe0bda0 304bca809cb5e6745e499a|0|0|638634735755325082|Unknown|TWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLC JQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D|0||&sdata=JklECqYEAFkBT1DNvBX7Vf07hUxfLwxTGtgqQT ZRQXc%3D&reserved=0



Lastly, at the end of September, 2 team members attended the Foundation Parkinson's Masterclass by the Neurology Academy. It was a jam packed 2 days with a fascinating programme that helped develop their Parkinson's Disease knowledge on physical symptoms, medications and the role of the wider multi-disciplinary team. We learnt so much during the masterclass and networked with other clinical colleagues in the UK. We would recommend this masterclass to our fellow CSOs in the NDN.

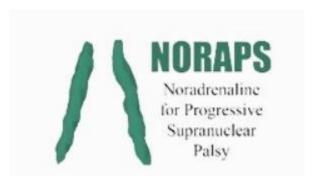
# **Glasgow Information**





### Parkinson Disease Excellence Network

Catriona McNeill -NDN Glasgow Senior Clinical Studies Officer and Jacqui Kerr — Network Manager were fortunate to be invited along to the Parkinson's Excellence Network meeting in August hosted in the Teaching Learning Centre of the Queen Elizabeth University Hospital in Glasgow. There were many interesting topics on the agenda including speakers from Parkinson's UK. Catriona and Jacqui also had the opportunity to talk about the NDN and how take part in our research. Catriona talked about local research opportunities and the current studies open to participation in Glasgow. The day was very informative with much interest in the NDN and our research.



### **NEW STUDY ALERT - PSP**

In Glasgow we are the only site in Scotland to be doing this study - Noradrenaline for Progressive Supranuclear Palsy Syndromes (PSP)

It will look at whether Atomoxetine is safe and well tolerated in patients with PSP and if it will reduce apathy and impulsivity

# **Grampian Information**





We had an invitation from Joy Doorghen, to attend The Garioch support group for Parkinson's meeting at the Acorn centre Inverurie on Tuesday 27th August 2024. We spoke about

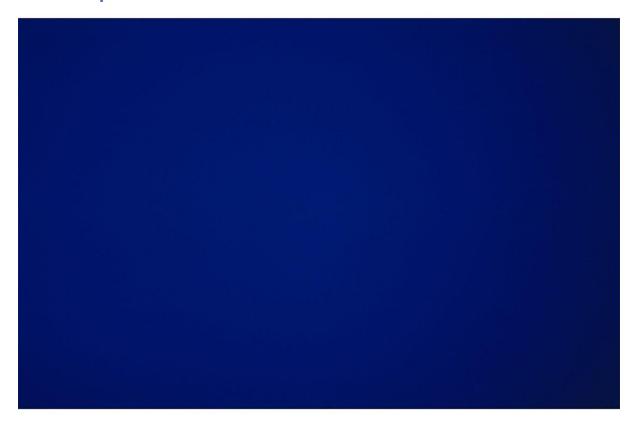
 $<sup>{\</sup>it 8} \underline{\it mailto:} \underline{\it ggc.glasgowresearchndn@ggc.scot.nhs.uk}$ 

our Permission to Contact research database and the CAN-PDP study that we are currently recruiting to.

We also attended a Parkinson support group meeting at Craigie-Buckler Church. Thursday 26th Sept2024. The organiser Barbara Webster, Chair of the Aberdeen Branch Parkinson's UK kindly allowed us to speak about the same topics.

Both Meetings were well attended and welcoming.

# Studies open to recruitment



# **Alzheimer's Studies**

**The Dreamer Study:** This is taking place in Grampian, in conjunction with the University of Aberdeen. This study is investigating a new MRI method for detecting Alzheimer's disease in people over 60, who do not have diabetes or have had a major stroke.

This study is being run in NDN Grampian - contact gram.sdcrn@nhs.scot<sup>9</sup> or tel 01224 557941 for more information

**Deep and Frequent Phenotyping for Experimental Medicine in Dementia:** This is taking place in Lothian. This study is using many different types of tests and assessments to see how Alzheimer's develops over a 12 month period. This study is for people who HAVE NOT been diagnosed with dementia and are over 60 years old.

Contact loth.sdcrn@nhslothian.scot.nhs.uk10 or tel 0131 537 3804

<sup>9</sup>mailto:gram.sdcrn@nhs.scot

<sup>&</sup>lt;sup>10</sup>mailto:loth.sdcrn@nhslothian.scot.nhs.uk

### **Parkinson Disease Studies**

### 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<sup>11</sup> or tel 01224 557941

For Lothian contact loth.sdcrn@nhslothian.scot.nhs.uk<sup>12</sup> or tel 0131 537 3804

For Tayside contact tay.ndntayside@nhs.scot<sup>13</sup> or tel 01382 423086

**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 taking place in NDN Fife, Lothian and Glasgow

For Fife contact fleur.davey@nhs.scot14 or 01383 623623 ext: 24364

For Lothian contact loth.sdcrn@nhslothian.scot.nhs.uk<sup>15</sup> or tel 0131 537 3804

For Glasgow contact ggc.glasgowresearchndn@nhs.scot<sup>16</sup> or tel 0141 451 8945

**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.scot<sup>17</sup> 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.

This is currently being run in NDN Lothian. Contact loth.sdcrn@nhslothian.scot.nhs.uk<sup>18</sup> or tel 0131 537 3804 for further details

<sup>11</sup>mailto:gram.sdcrn@nhs.scot

<sup>&</sup>lt;sup>12</sup>mailto:loth.sdcrn@nhslothian.scot.nhs.uk

<sup>&</sup>lt;sup>13</sup>mailto:tay.ndntayside@nhs.scot

<sup>&</sup>lt;sup>14</sup>mailto:fleur.davey@nhs.scot

<sup>&</sup>lt;sup>15</sup>mailto:loth.sdcrn@nhslothian.scot.nhs.uk

<sup>&</sup>lt;sup>16</sup>mailto:ggc.glasgowresearchndn@ggc.scot.nhs.uk

<sup>&</sup>lt;sup>17</sup>mailto:tay.ndntayside@nhs.scot

**PD Frontline:** This allows participants to undertake genetic testing which may make people eligible for drug trials

This study is taking place in NDN Tayside, Lothian and Glasgow

For Tayside contact tay.ndntayside@nhs.scot<sup>19</sup> or tel 01382 423086

For Glasgow contact ggc.glasgowresearchndn@nhs.scot<sup>20</sup> or tel 0141 451 8945

For Lothian contact loth.sdcrn@nhslothian.scot.nhs.uk<sup>21</sup> or tel 0131 537 3804 for further details

#### Parkinson's UK study:

My name's Anita Jefferies and I'm an Area Development Manager (Scotland) with Parkinson's UK. I am undertaking some work surrounding Parkinson's related dementia and am looking for insights from people with Parkinson's, their family / friends / carers and relevant health professionals such as Parkinson's Nurses and AHPs. These insights will then inform what is explored and potentially developed which could be anything from developing further support, better access to information, improved awareness etc... As part of this work I have established a working group to support and inform the development of the work and would be really keen to hear from anyone who might be interested. If you would be willing to speak with me about your experience of living with Parkinson's related dementia, or that of a loved one, or would be interested in finding out more about the Parkinson's and dementia working group, I would love to hear from you!

Anita Jefferies - Area Development Manager (Scotland)ajefferies@parkinsons.org.uk<sup>22</sup>07876 135817"

# **Huntington Disease Studies**

**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 Fife, Grampian & Tayside

For Fife, contact nicola.johns@nhs.scot<sup>23</sup>

For Grampian contact gram.sdcrn@nhs.scot<sup>24</sup> or tel 01224 557941

For Tayside contact tay.ndntayside@nhs.scot<sup>25</sup> or tel 01382 423086

# **Motor Neurone Disease studies**

**MND SMART:** The purpose of this clinical trial is to test how effective two different drugs are at slowing down the progression of MND. These drugs are already approved to treat other medical conditions.

This is currently being run in NDN Grampian & Tayside

<sup>&</sup>lt;sup>18</sup>mailto:loth.sdcrn@nhslothian.scot.nhs.uk

<sup>19</sup> mailto:tay.ndntayside@nhs.scot

 $<sup>^{20}\</sup>underline{mailto:}ggc.glasgowresearchndn@ggc.scot.nhs.uk$ 

<sup>&</sup>lt;sup>21</sup>mailto:loth.sdcrn@nhslothian.scot.nhs.uk

<sup>&</sup>lt;sup>22</sup>mailto:ajefferies@parkinsons.org.uk

<sup>&</sup>lt;sup>23</sup>mailto:nicola.johns@nhs.scot

<sup>&</sup>lt;sup>24</sup>mailto:gram.sdcrn@nhs.scot

<sup>&</sup>lt;sup>25</sup>mailto:tay.ndntayside@nhs.scot

For Grampian contact gram.sdcrn@nhs.scot<sup>26</sup> or tel 01224 557941

For Tayside contact tay.ndntayside@nhs.scot<sup>27</sup> or tel 01382 423086

**OPTICALS:** This research is about improving nutritional management in people living with ALS by using a support package (OptiCALS) developed for this trial. The OptiCALS intervention has been designed to help people with ALS receive the best diet at the most appropriate time, in the most cost-effective manner.

This is currently being run in NDN Tayside - contact tay.ndntayside@nhs.scot<sup>28</sup> or tel 01382 423086 for more information

# **Contact Us**



### **Neuroprogressive & Dementia Network**

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Website: Neuroprogressive and Dementia | NHS Research Scotland | NHS Research Scotland<sup>30</sup>

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