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NEUROPROGRESSIVE  
AND DEMENTIA

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Neuroprogressive & Dementia Network  
November 23

## Forewords



**Jacqui Kerr - Network Manager**

Welcome everyone to the Neuroprogressive and Dementia Network October newsletter, which will be my inaugural introduction to you all as the new Network Manager.

Firstly, I want to thank Dr Emma Law for her devotion and development of the Network over the years, your drive and commitment to ensure the success of the Network is evident on how we (the Network) are all striving and committed to our research. Happy retirement Emma...well deserved!

Who am I, I hear you all ask!

I began my nursing career in 2000 as a Mental Health nurse in Ayrshire and Arran caring for older adults in hospital and community based settings and so early into the journey of my nursing career, I knew then working in the field of older adult mental health nursing would be my passion.

My journey into clinical trial research began in 2006 within the field of Alzheimer Disease research and then in 2015, I joined the Network as a Senior Clinical Studies Officer for NHS Lothian. In 2021 I went back to studying and have been fortunate to have had the full support from the Network to complete my Master of Science in Global Issues of Gerontology and Ageing and I have never looked back, still here in 2023 but now the Network Manager. It is a cliché...but I do love my job!

I look forward to developing my role as the incoming Network Manager and hope that I can carry on the work that Emma has been doing with the same drive, commitment and success!

Best wishes

Jacqui Kerr



### **Dr Tom Russ - Network Champion**

The whole Network met in Perth recently for our annual get-together. It was great to welcome Jacqui – who introduces herself above in this newsletter – as Network Manager. However, it was bittersweet as we said goodbye to Emma Law who, for many of us, has **been** the Network since it began. Emma's contribution to the Network is difficult to overstate and she has met every obstacle with determination and good humour. Thankfully, we're not really saying goodbye to her as – despite officially retiring – she'll still be working with the Network one day a week focusing on raising our profile and making sure that we work towards our aim of offering everyone in Scotland with a neuroprogressive condition or dementia the opportunity to take part in research

## Neuroprogressive & Dementia Network Information



On Thursday 5th October 2023 we kick started our Partners in Research webinar series with an Introduction to the Neuroprogressive & Dementia Network. Dr Tom Russ, Network Champion, and Jacqui Kerr, Network Manager, presented what the NDN Network is all about, what clinical trials we are involved with and how to get involved in a trial.

We had good attendance with some great discussions. If you would like to watch the recording please click here<sup>1</sup>

Our next webinar is taking place on Thursday 16th November at 11am. The topic is on ENRICH (Enabling Research in Care Homes) Scotland. To sign up please click here<sup>2</sup>

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<sup>1</sup><https://www.youtube.com/watch?v=hjmhCzU-cg8&t=9s>

<sup>2</sup><https://www.eventbrite.co.uk/e/introduction-to-enrich-scotland-tickets-739255792977>

## Permission to Contact

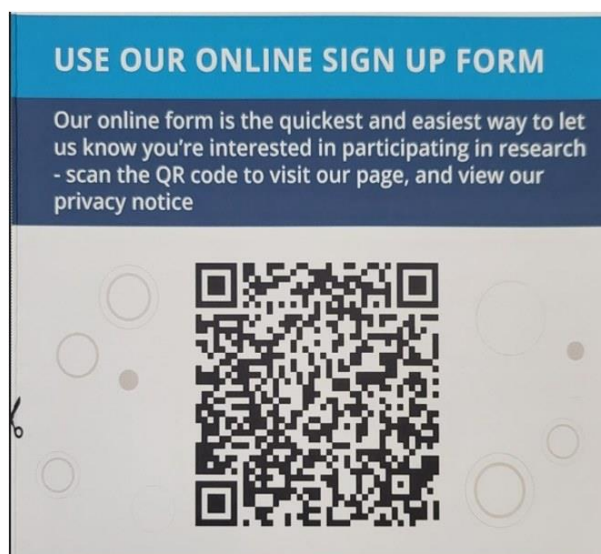


We have over 400 people in Scotland signed up to our Permission to Contact scheme. These are from all over Scotland including Shetland.

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 now 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](mailto:tay.ndntayside@nhs.scot).

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.



## Spotlight - Parkinson's disease research



The Neuroprogressive and Dementia Network supports several clinical research studies and trials focused on Parkinson's disease or Dementia with Lewy bodies. These chronic progressive neurodegenerative disorders include a broad spectrum of movement problems, autonomic dysfunction, sleep disturbances, neuropsychiatric symptoms, dementia and falls. These have a significant negative impact on the health and wellbeing of the person and their family.

In the NDN we are committed to supporting studies that seek to improve symptoms such as hallucinations (the TOP HAT trial), dementia symptoms (COBALT trial), falls (CHIEF-PD) and wearing off (ABBVIE). In addition it is important to conduct trials of potentially disease modifying therapies to slow the progression of Parkinson's (Exantide-PD3, PADOVA and LUMA). We also support studies to better understand the genetics and natural history of PD (PD FRONTLINE, ROPAD, LiPAD)

Efficient and timely recruitment processes for clinical research studies are vital and this is increasingly supported by the growing adoption of the NDN Permission to Contact leaflet which we are working hard to promote to patients and clinical colleagues such as Parkinson's Nurse Specialists, geriatricians, neurologists and old age psychiatrists.

We are also now well represented at the UK Parkinson's Disease Clinical Studies Group which is supported via Cure Parkinson's.

There are three active patient led Research Interest Groups covering Scotland and PI's affiliated with the NDN regularly engage with these groups for presentations and discussions.

We will continue to raise our profile with Parkinson's UK and Cure Parkinson's so that they can sign post people with Parkinson's to us or facilitate relationships and collaborations.

Dr Gordon Duncan: Consultant Physician - Medicine for the Elderly & Parkinson's disease Lothian

## What's happening around the NDN network



### Lothian



#### **New Senior Clinical Studies Officer**

We would like to welcome Jessica Crossan, who has recently joined the network as a Senior Clinical Studies Officer in the Lothian team.

Prior to this role, her research nurse career began in the Clinical Research Facility where she learnt the fundamental principles of clinical research. She has always had a passion for the speciality of Neurosciences as she obtained a degree in Neuroscience from the University of Dundee before she started her nursing career. Jessica moved from the CRF to the Emergency Medicine Research Group in Edinburgh to specialise on neurosurgery and stroke research. She spent her time recruiting patients with acute neurological illness to a variety of clinical studies in the emergency department and integrated stroke unit. Her most recent role was in the Edinburgh Critical Care Research Group where she led on neuro-ICU studies and learnt how to successfully conduct research at a highly distressing time of life for patients and their families in the intensive care unit. Research and neurosciences have been a longstanding interest of hers as she knows that research will ultimately improve patient outcomes in the future. She is looking forward to developing her knowledge within the network and being involved in the variety of trials on offer for patients living with neuroprogressive conditions in Scotland.

### **Update on Probiotic PD Study**

We are currently running the Probiotic PD study here in Edinburgh under Chief Investigator Dr David Breen. The study is also being run in Stavanger, Norway.

The study aims to assess the effects of the probiotic Bacillus Subtilis PXN21 on gut microbiome and blood markers in patients with PD whilst also evaluating the correlation between changes in gut and blood biomarkers and motor/non motor symptoms.

Study participants are randomised to receive either Bacillus Subtilis PXN21 (the probiotic tablet) or a matching placebo, once daily, over a 24 week period. There are 3 study visits to attend in person, week 0, week 24 and week 36, with a telephone follow up at week 8. Clinical assessments and faecal and blood sampling are performed at the in person visits. The participants complete a daily diary whilst taking the probiotic/placebo.

So far in Edinburgh we have recruited 7 participants, with number 8 booked in for a baseline visit in November. We have our first week 24 visit booked in for this coming week.

Stavanger have only recently just opened as a site therefore are still to recruit their first participant. Both sites are aiming to recruit 26 participants each.

### **Edinburgh Parkinson's Lecture 2023**

In Lothian we recently attended the above lecture. It was held at the Royal College of Physicians, Edinburgh on Wednesday 20th September.

The Lecturer was Professor Camille Carroll. She is Professor of Clinical Neuroscience and Honorary Consultant Neurologist and recently joined Newcastle University, having previously been at University of Plymouth, where she led the clinical Parkinson's service to 3 national awards. Her research is focused on disease modification and the use of digital health technologies for monitoring and personalised care in Parkinson's.

The title of Prof Carroll's Lecture was: **Learning to Listen – a patient-centred approach to Parkinson's care and research.**



A recording of the lecture is available on the Edinburgh Parkinson's Branch YouTube channel and can be accessed by going to this page of their website:

<https://www.edinburghparkinsons.org/edinburgh-parkinsons-lecture/><sup>3</sup>

The lecture was well attended both in person and on-line. The Permission to Contact (PTC) Form was promoted before and after the event to Parkinson's patients, their friends and relatives and healthcare professionals who were attending the lecture in person.

## Tayside



We would like to welcome Dr Joe Farrimond to our team. He is here with us until February 2024. We have had a staffing reshuffle and the core team of Justine, Tiffany and Kate remain. We also have Lorna Gillies, our Parkinson's nurse, who works very closely with us

### Information on Studies in Tayside

We have a number of studies coming to an end soon. BIAL Epsilon (one of our Parkinson's studies) is due to finish soon as is CHIEF PD. However, we have 2 new Parkinson's studies coming on board:

- BIAL Activate: Still in the set up phase so watch this space...
- CAN PDP: we will be recruiting shortly for this

Eligibility includes:

- Participants diagnosed with idiopathic Parkinson's Disease over 40 years old, who are experiencing psychosis
- Psychotic symptoms should be secondary to the Parkinson's diagnosis, occurring regularly and have been present for >1 month (Parkinson's Disease dementia is not excluded in this trial).
- MoCA >15 on testing

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<sup>3</sup><https://eur01.safelinks.protection.outlook.com/?url=https%3A%2F%2Fwww.edinburghparkinsons.org%2Fedinburgh-parkinsons-lecture%2F&data=05%20101|helen.davidson%40nhs.scot%2Fdb97c3cca274440a893308dbdb909905%2F10efe0bda0304bca809cb5e6745e499a%2F0%2F0%2F638345186305644738%2FUnknown%2FTWFpbGZsb3d8eyJWljoimc4wLjAwMDAiLCJQljoiv2luMzliLCJBTil6lk1haWwWwIlCjXVCl6Mn0%3D%2F3000%2F%2F%2F&sdata=1jKGhtrb8KAXqaXp70VHXAFpywTq%2B%2FqSTid1hYegw1U%3D&reserved=0>

- Participants can be taking cholinesterase inhibitors, quetiapine and standard antiparkinsonian treatment as long as these are stable for >1 month.
- Participants who have had deep brain stimulation should be since months post surgery and stable for >1 month prior to baseline and throughout trial.
- Able to swallow oral medication
- Able to give their informed consent to participate and has a reliable informant/caregiver who can support their participation and provide information."

### Celebrations

- We want to celebrate that we got a bronze award for recruiting for our LUMA study – we have triple the number of participants than our original target
- Our permission to contact numbers have increased significantly recently and we are striving to have as many eligible participants on our Parkinson's trials. Currently we are sitting at 80% of our participants have signed up for a Parkinson trial
- We have made great links with the specialist Parkinsons' nurses and they are helping us with lots of referrals.
- Dr Esther Sammler, Principal Investigator for PD Studies in Tayside, recently had an article published. Please have a read here<sup>4</sup>

### Grampian

#### Staffing Information

Our Band 7 Senior Clinical Studies Officer post is advertised and can be viewed by clicking here<sup>5</sup>. Please pass on to anyone who may be interested. Closing date is 13th November 2023



#### Networking session with Grampian R&D Team

<sup>4</sup><https://www.heraldscotland.com/news/23786235.parkinsons-disease-hope-this-exciting-time>

<sup>5</sup><https://apply.jobs.scot.nhs.uk/Job/JobDetail?JobId=168468>

Many thanks to the Grampian Research and Development Team and the Grampian Neuroprogressive and Dementia Network (NDN) for welcoming Dr Tom Russ, Network Champion, and Jacqui Kerr, Network Manager, on September 19th 2023 on their visit. We enjoyed an informative conversation about research within the NDN and the wider Grampian research community. There is an impressive range of activities going on and we are proud to be part of it. We look forward to continuing to work with Grampian and hope to further expand opportunities to take part in research for the people in the North-East of Scotland.

## Greater Glasgow & Clyde



Hello from Catriona and Marion in Greater Glasgow & Clyde 😊

We are about to interview for our replacement Clinical Studies Officer after receiving a number of applications. Looking forward to having a full team.

### Information on Studies in GG&C

In Glasgow we have been busy recruiting patients to the phase 2 Multiple System Atrophy study (Alterity), which is a randomised, double-blind, placebo controlled study of ATH 434. This has been shown in pre-clinical studies to reduce iron accumulation and reduce alpha-synuclein aggregation. End points include iron content on MRI, QOL and motor scoring, and safety endpoints over 52 weeks. Recruitment is now closed for this study.

We hope to start recruiting soon for a Progressive Supranuclear Palsy study (NORAPS- Noradrenaline for Progressive Supranuclear Palsy syndromes). The background being that our brain produces noradrenaline in the locus coeruleus which is important for memory, attention and making decisions. The locus coeruleus is badly affected by PSP and is thought to cause many of the changes in behaviour, including apathy and impulsivity. NORAPS tests the drug Atomoxetine, which is already licensed for use in ADHD, which boosts the brains own noradrenaline, in a Phase 2b, randomised, controlled, crossover design clinical trial. The primary objective is to estimate the efficacy of Atomoxetine versus placebo for the treatment of apathy and impulsivity and to assess safety and tolerability.

We have been participating in recruitment for 2 large Deep brain Stimulation Registry Studies for Parkinson's, tremor and dystonia (ADROIT and VERCISE), and additionally recruited subjects to a remote programming sub-study of ADROIT named ROAM, where subjects who had recently undergone Deep Brain Stimulation for Parkinson's were randomised either to in clinic programming or remote (at home) programming.

We recently participated in EPSILON, which investigated the efficacy of adding Opicapone to levodopa and DDC inhibitor in early Parkinson's disease in subjects without evidence of motor fluctuations.

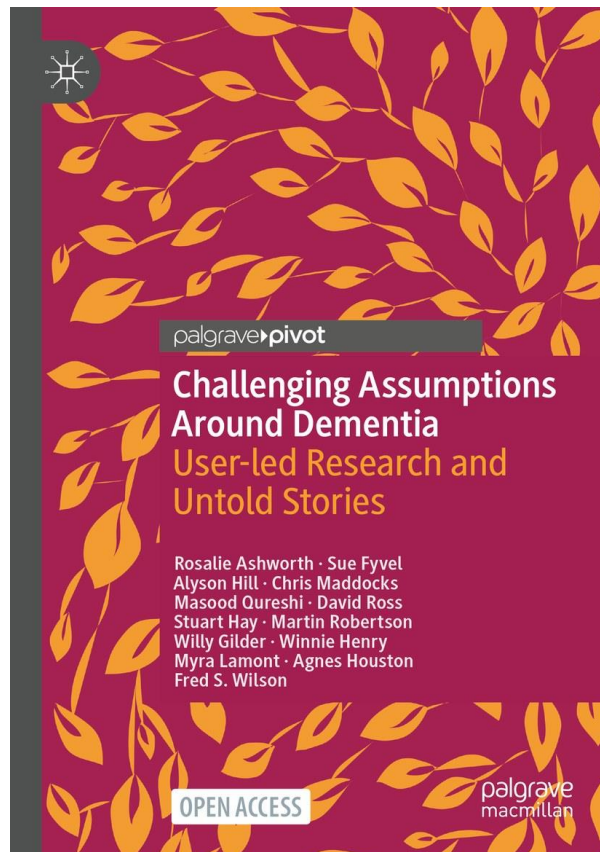
We are also a PIC site for recruiting for PD frontline/ RHAPSODI, and Molecular and Functional Imaging in Monogenic PD, which we continue to recruit to.

Dr Vicky Marshall - Consultant Neurologist GG&C

## Partners in Research



**Partners In Research Book Launch - 1st September 2023**



Our book launched on the 1st September at the V&A in Dundee. We have had over 5000 downloads of the book and had some fantastic feedback. If you have not already read it, you can download for free at <https://link.springer.com/book/9783031272226><sup>6</sup>

### Partners in Research Newsletter

If you have not already seen our newsletter, you can down by clicking here<sup>7</sup> to read all our latest news and future plans

### New Parkinson's project

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.scot](mailto:tay.ppipartners@nhs.scot)<sup>8</sup> or complete this online form<sup>9</sup>

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<sup>6</sup><https://eur01.safelinks.protection.outlook.com/?url=https%3A%2F%2Flink.springer.com%2Fbook%2F9783031272226&data=05|01|helen.davidson4%40nhs.scot|77917beea1cd4a4f72a908dbcb339293|10efe0bda0304bca809cb5e6745e499a|0|0|638327194576826332|Unknown|TWfPbGZsb3d8eyJWljoicjoiMC4wLjAwMDAiLCJQIjoiV2luMzliLCJBTil6lk1haWwiLCJXVCI6Mn0%3D|3000||&sdata=OaicROha9KtGV5wpNTEWIFd2sUJ7%2Fb5VpGxbucSQ7to%3D&reserved=0>

<sup>7</sup><https://tinyurl.com/hd7z4prx>

<sup>8</sup><mailto:tay.ppipartners@nhs.scot>

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

## Contact Us



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Website: [Neuroprogressive and Dementia](#) | [NHS Research Scotland](#) | [NHS Research Scotland](#)<sup>11</sup>

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

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