

NEWSLETTER

North of Scotland Parkinson's Research Interest Group
(NoSPRIG)

Compiled by Andrew Grant

IN THIS EDITION:

New Local Research Opportunity!

Parkinson's Beats is Drumming Up a Worldwide Following!

An update from founder, NoSPRIG's **Jo Holland**.

New Exercise Video Features People with Parkinson's from the Highlands.

.... but first....

Can you help with this study?

The Neuroprogressive & Dementia Network have a new Parkinson's clinical trial taking place in Aberdeen which is looking for local participants.

To take part you have to meet various criteria including:

- Over 40 years old
- Experienced symptoms of psychosis for at least 1 month
- Been taking PD medication for at least 1 month

There are sites in Aberdeen, Dundee, and Edinburgh so you can choose the one closest to you. For more information please visit the website:

<https://www.parkinsons.org.uk/research/can-pdp-cannabidiol-cbd-people-parkinsons-who-experience-hallucinations-or-delusions>

The best way to be considered for current or future trials is to join the 'Permission to Contact' scheme for the Neuroprogressive and Dementia Network. This will allow the research team to access your medical records

and check whether you are eligible for studies. To find out more click on the link below:

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

Signing up for the 'Permission to Contact' scheme is easy. You can do it by completing this online form:

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

Alternatively email:

tay.ndntayside@nhs.scot or call 01382 423086 to have a paper form sent out.

PARKINSON'S BEATS: by Jo Holland

Things certainly don't get any slower with our drumming group! Here's a round-up of what we've been doing...

December '23: Discussions began on how best to expand Elgin-based Parkinson's Beats to other venues throughout Scotland. A grant application to the National Lottery was planned so other activity providers could get accredited training to help them start their own drumming groups.

15th February '24 – Julie Jones and I met with Emma Rodgers, Communications Officer for Parkinson's UK. Emma wanted to use the story of Parkinson's Beats in a number of planned research campaigns.

14th March – Our class was joined by Brian Campkin from Toronto, who's keen to start up a Canadian group, so came to try it out!

19th March – Then came an enquiry from Spain! Silvia contacted me requesting details of the methodology of exercise drumming and details of any studies published on its effectiveness.

5th April – I sat my level 2 fitness instructor exam for exercise drumming and passed! This means I can now run classes myself!

11th April – World Parkinson's Day and Parkinson's Beats was featured in the open day in Elgin. Sharon led the drumming.

And.... a new drumming group has been formed in Northern Ireland with assistance from Parkinson's Beats, Amanda Mckay (Physical Activity Delivery Manager Scotland) and Lifedock Training!

18th April – I led my first solo drumming class when Sharon was on holiday!

19th April – Our research paper was finally published in the International Journal of Environmental Research and Public Health. This was a joint submission with Yoon Irons, Alison Williams, Julie Jones and me – here's a link to the paper:

<https://www.mdpi.com/1660-4601/21/4/514>

10th May – Sharon and I were invited back to the Archiestown BALL Group to give an update on Parkinson's Beats along with a second drumming session. This group is fast becoming very proficient and is keen to have regular drumming sessions. Unfortunately we are not currently in a position to enable this.

Archiestown BALL Group in action.



28th May – Parkinson's Beats was invited to a Parliamentary reception to demonstrate their drumming skills, unfortunately, due to election time restraints, this had to be postponed.

9th June – Ed Davey was on the BBC in Romsey having a go at exercise drumming. Finally the rest of the country is beginning to wake up to the benefits of having drumming in their lives!



12th June 2024 - Verity Willcocks from Parkinson's Europe published an article about Parkinson's Beats on their webpage.

<https://parkinsonseurope.org/2024/06/11/5-unconventional-exercises-for-parkinsons/>



18th June 2024 – Parkinson's Beats were invited to attend the Movement for Health Conference.

<https://www.movementforhealth.scot/>

There were 10 of us involved and what a great day we had introducing drumming to the delegates there. It was exhausting but great fun! Hopefully we'll have more converts as a result of our efforts. The group, as always, were magnificent!



Then came another international enquiry: Ilene from Israel wanted to know how to start up a group there, so I put her in touch with Karen Case from Lifedock Training, who offer an online course for teaching exercise drumming.

This was followed by yet another enquiry: Adrian from the north-east of England wanted advice on setting up a group, backed by Kirsty Mcdowell of Parkinson's UK with confirmation that they are interested.

Meanwhile... our Facebook page is gaining new followers from all over the world! Edinburgh, Glasgow, Middlesborough, Israel, Kentucky and California.

If you're on Facebook, you can easily find us by typing 'Parkinson's Beats into the search bar and then follow us so you keep up to date with what we're up to!

Future plans:

- Amanda McKay and I are to meet Ann Hay of Moray Council to consider the best way to involve people with other neurological conditions and to reach even more people with Parkinson's.
- We await news of the application to the National Lottery for significant funds to aid the expansion of the project.

Parkinsons Exercise video in association with NHS Highland and High Life Highland.

With the summer starting to recede (did it even start?!) it's time to start thinking of our exercise routines in the shorter days ahead.

To encourage you, we'd like to highlight this great new video produced thanks to joint working between Parkinsons, High Life Highland and NHS Highland.

They've been able to train instructors to deliver classes that specifically meet the needs of people with Parkinson's

This wonderfully uplifting production lets you hear firsthand from participants in the north of Scotland about how physical activity helps them live better with their condition.

Watch here – the enthusiasm is great!

<https://www.youtube.com/watch?v=WN5-x9NhFAk>

Annual Edinburgh Parkinson's Lecture

Just a reminder that booking is now open for this. The lecture will take place on the evening of Tuesday 17th September at the Royal College of Physicians of Edinburgh.



This year's presentation is by Richelle Flanagan – an Irish Dietician, person with Parkinson's and a World Parkinson Congress Ambassador.

The title of the lecture is; How Nutrition and Diet can help you live better with Parkinson's. We know it will be fascinating as Richelle has been a guest in not one but two of our research podcast series!

<https://www.nosprigpod.podbean.com>



For more information about the Edinburgh Lecture and to register to attend in person, or watch online, please go to:

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

Our Future Health; Developing new ways to prevent, detect and treat illnesses

Our Future Health is the UK's largest-ever health research programme, aiming to help everyone live longer and healthier lives. The programme plans to collect health and lifestyle information from up to 5 million adults across the UK. Researchers will then be able to apply to study the information to make discoveries about health and conditions.

Researchers need 5 million volunteers aged over 18 and living in the UK to take part. Volunteers are required to;

Participation will require you to attend a clinic appointment to have physical measurements taken including: blood pressure, height and weight, a cholesterol test and a blood sample.

Other requirements are that you:

- Complete a questionnaire about yourself.
- Allow researchers to link to and analyse health records.
- Allow the information to be studied for health research.

Click on the link below if you are interested in taking part:

<https://www.parkinsons.org.uk/research/our-future-health-developing-new-ways-prevent-detect-and-treat-illnesses>