

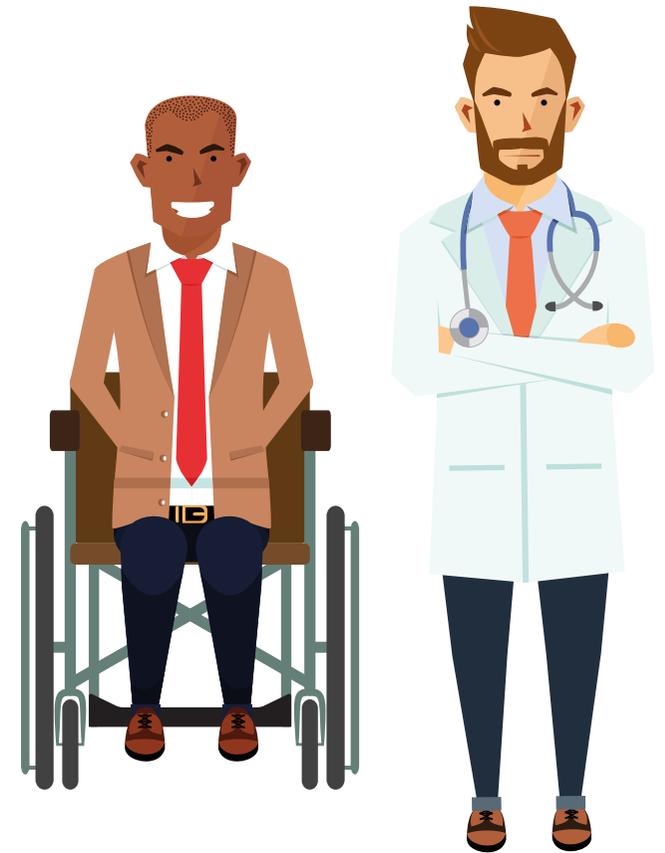
2024 RESEARCH INFORMATION SESSION 2: PROGRAMME

THURSDAY 5th SEPTEMBER 2024 – 10am to 1pm

Website zoom.us/join - Meeting ID: 842 8450 4599
Direct link - [https://us06web.zoom.us/j/84284504599?
pwd=xERbS9LwmEiGhbA8C8Buysoar84UDY.1](https://us06web.zoom.us/j/84284504599?pwd=xERbS9LwmEiGhbA8C8Buysoar84UDY.1)

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WELCOME

We are delighted to welcome you to second Research Information Session of 2024.

The event will update patients, carers, and families on ongoing research that looks to improve the quality of care and symptomatic treatments for Progressive Supranuclear Palsy and Corticobasal Degeneration (PSP & CBD).

We have a range of speakers from clinicians, researchers and PSPA staff.

The day will run from 10:00am until 1:00pm and there will be five presentations with a virtual break for tea/coffee.

We will use the Zoom platform – see page 9

Attendees will be able to ask questions writing them into a Zoom Q&A box (you will find it on the bottom of the screen). Staff will be able to see the questions and will present them to the chairs and speakers as a single question or as a theme.

Speakers will not be able to answer questions about individuals specific medical issues or medications.

All the presentations will be **recorded** so if you do miss the event or want to watch a particular presentation again you can do so at a later date. The video will be available after the event on the PSPA website.

For queries or technical issues during the day please write to researchinfoday@pspassociation.org.uk or use the “helpdesk” chat on Zoom (in the chat box, under the “to” dropdown menu).



PROGRAMME

UK TIME		
10:00am	Introduction - PSPA Chief Executive Officer	Ms Rebecca Packwood
10:05am	Welcome - Chair of the PSPA Research Committee	Prof. Karen Morrison
	Part 1: Chaired by Professor Karen Morrison	
10:15am	How to provide the best care for people with PSP and CBD	Dr Boyd Ghosh
10:45am	Treating symptoms in PSP with noradrenaline	Dr Rob Durcan
11:15am	Break	
	Part 2: Chaired by Rebecca Packwood	
11:30am	An update on OxQuip	Prof Chrystalia Antoniadis
12:00pm	Palliative Care in progressive neurological illness – experiences of people with Motor Neurone Disease and their informal carers	Prof Kate Flemming
12:30pm	Neurological Alliance’s My Neuro Survey 2024	Mark Jackson

SPEAKER PROFILES



Dr Boyd Ghosh is a Consultant Neurologist in Southampton and Salisbury. He is also an honorary clinical teacher at the University of Southampton. Dr Ghosh has a particular interest in patients with Parkinson's plus disorders such as PSP, CBD and multiple system atrophy, having previously completed research in these syndromes in his PhD in Cambridge. He trained in cognitive neurology in the Cambridge memory clinic with Professor Hodges and sees patients with cognitive disorders in the Wessex Neurological Centre. Dr Ghosh is both a PSPA Trustee and member of the PSPA Research Committee.

Dr Robert Durcan is a clinical research fellow in the Rowe group at the Cambridge Centre for Frontotemporal Dementia and related disorders. Dr Durcan is undertaking a PhD in the role of noradrenaline in neurodegenerative disease, using novel imaging techniques with MRI and PET, funded by a PSPA Fellowship. He is involved in the currently enrolling randomised control trial NORAPS, using atomoxetine in Progressive Supranuclear Palsy (PSP).



Professor Chrystalina Antoniadou is an Associate Professor of Neuroscience in the Nuffield Department of Clinical Neurosciences at the University of Oxford, and head of the NeuroMetrology Lab. Her research focuses on developing methods to accurately and objectively measure neurological disorders such as PSP and Parkinson's Disease.



Professor Kate Flemming is a highly experienced academic, internationally known for her leading research and service innovation in palliative care nursing. Kate is leading on the integration of research and teaching in our new nursing curriculum in the Department of Health Sciences, bringing together our world leading researchers with the best teachers in nurse education. Kate leads by example through her pioneering clinical leadership and research in Palliative Care within the Hospice and community settings.

Mark Jackson is the PSPA's Director of Policy and Influencing, a new role at the PSPA to increase our campaigning and influencing work to improve care and support for people living with PSP & CBD. Before coming to PSPA, Mark was a Senior Policy and Research Manager at Marie Curie, where his work focused on financial security for people at the end of life. Mark led Marie Curie's successful #Scrap6Months campaign to improve access to fast-tracked benefits for terminally ill people.



If you would like to suggest a speaker for a future research event please email research@pspassociation.org.uk

ZOOM INSTRUCTIONS

Zoom is a website that enables you to connect with people over the internet. You are able to see and hear others in the same session as you and interact in a normal conversation with them.

If you are attending an event, **you will be muted upon entry**. You will be able to ask questions or send comments via a Q&A box

“WHAT DO I NEED?”

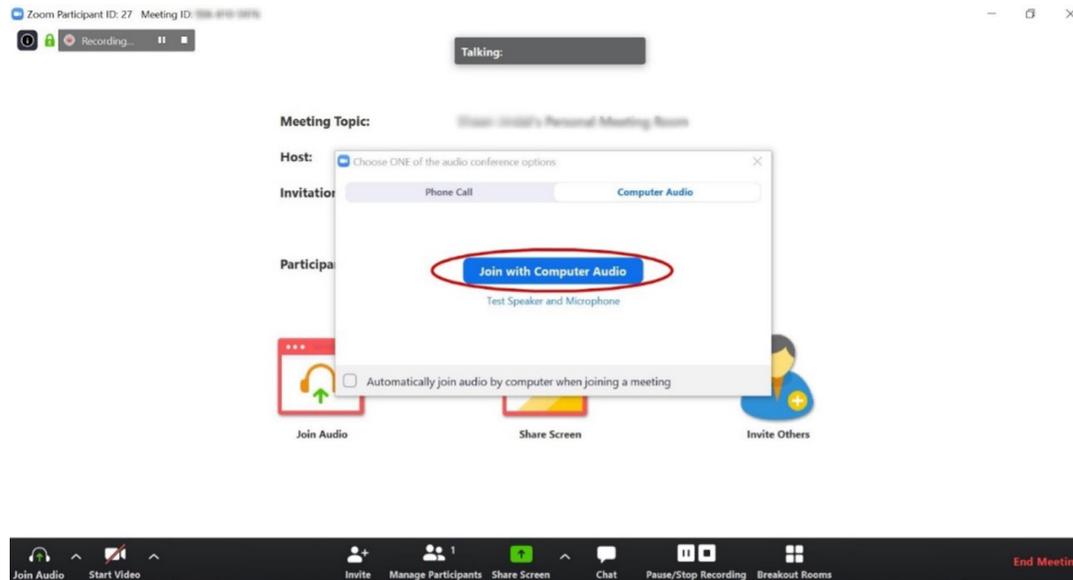
- You will need a device that is connected to the internet
- The device can be a smartphone, tablet or computer

How to join a Zoom Meeting – few options:

- On a computer, copy and paste the link below into your web browser (the browser could be called edge, chrome, safari...)

The link to paste: <https://us06web.zoom.us/j/84284504599?pwd=xERbS9LwmEiGhbA8C8Buysoar84UDY.1>

Once the meeting has started, you'll be asked how you'd like to join the meeting audio if you're on a computer. You should select 'join with computer audio' as below:



- Or if you have downloaded the Zoom app on your phone or tablet, or have the zoom shortcut on your computer use the Meeting ID: **842 8450 4599**

Downloading the Zoom app for the first time:

You can either download the app via a tablet browser or a smartphone app store.

On a tablet, go to zoom.us/download – On a phone, go to the place on your device where you normally download apps.

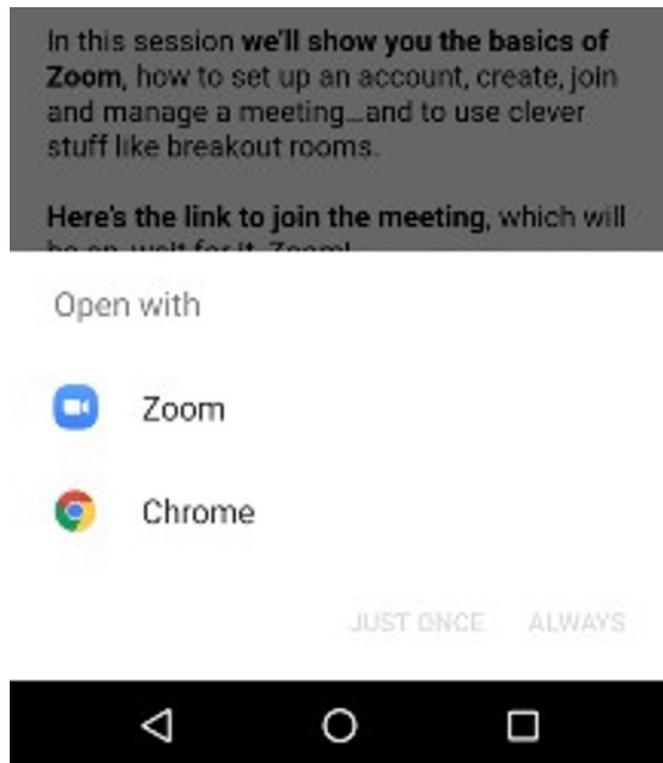


 For Apple devices, i.e., iPhone or iPad, this is the App Store

 For all other devices you download apps from the Google Play Store
Search for the word “Zoom” in your store and a few options will come up.

You need to select the **Zoom cloud meetings** option.

Download the app and complete any prompts that your store asks, you should now have the Zoom app on your device.



Joining with a smartphone or tablet, you'll see something like this if you've already downloaded the app.

When asked what you'd like to open the link with select “Zoom”.

If you haven't downloaded the app you'll be automatically taken to a webpage asking you to download it. You can't join in browser on tablets or smartphones.

Use the Meeting ID: **842 8450 4599** to join the event.

TROUBLESHOOTING

- I can't hear anything - Click the little arrow next to the microphone icon. From this menu you can select where you want your sound to come from, whether that be an external speaker, headphones, your computer's internal speaker or something else.



EXPRESS YOUR INTEREST IN RESEARCH

You can let the PSPA know you're interested in the following aspects of research using the [Expression of Interest in Research Form](#)

- 1) Receiving information and knowledge about research provided and disseminated: you are consenting to receiving research information and updates. This is called '**Engagement**'.
- 2) Being a participant in a research study. You are consenting to your details being shared with study coordinators and being contacted for participating in studies. This is called '**Participation**'. For Carers and family members, being a participant as a healthy control may mean you receive a 'dummy pill' or take part in testing.
- 3) Being involved with PSPA research activities providing support to researchers and research organisations (identifying priorities, commenting on materials, etc.) This is called '**Involvement**'. You can learn more about this on the next page.

PRIM - PSPA RESEARCH INVOLVEMENT MEMBERS

The PRIM group was formed in 2022 to ensure that people living with PSP & CBD, their carers and family members were engaged and involved in research.

The aims of the PRIM group are to:

- Ensure that the charity maximises its research performance on behalf of people affected by PSP & CBD.
- Increase the use of involvement and co-production to support research activities.
- Provide people living with the conditions and their carers a voice regarding priorities into research on the conditions.
- Assist and support researchers, and act as a 'critical friend' on how to best improve research strategy and projects.
- Advise on research delivery and practicalities of how best to support people living with PSP & CBD to take part in research.

In return, PSPA provides training and support, keeps members updated on research activities and outputs, provides feedback from researchers and pharmaceutical companies on the group impact, and shares study results.

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Meetings run every month virtually, but members are actively involved during the period between the meeting by reviewing research materials and providing insights on research strategy, scientific days agendas, and the content of our website.

The aim of the partnership between researchers and PSPA is to identify unmet needs, novel research areas, and to communicate research in a way that is understandable by lay members, bringing research findings to the people affected by PSP and CBD, our supporters and funding partners.

If you would like to join PRIM, please express your interest sending an email to Megan, the PSPA's research coordinator at research@pspassociation.org.uk

You can express your interest in taking part in research here:
https://pspassociation.tfaforms.net/f/Expression_of_Interest_Form

THANK YOU