

2025 RESEARCH INFORMATION SESSION 3: PROGRAMME

THURSDAY 13th NOVEMBER 2025 – 10am to 1pm

Website zoom.us/join - Meeting ID: 819 9293 2515 Direct link - https://us06web.zoom.us/j/81992932515



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WELCOME

We are delighted to welcome you to the 3rd Research Information Session of 2025.

The event will update patients, carers, and families on ongoing research that looks to improve the lives of people living Progressive Supranuclear Palsy and Corticobasal Degeneration (PSP & CBD). It will feature a mix of both lab-based and clinical research projects.

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 8

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	Presentation	Speaker
10:00am	Zoom Housekeeping	Megan Hodgson
10:05am	Welcome	Prof James Rowe
Part 1: Chaired by Rowena Ironside, Chair of Trustees		
10:15am	Targeting symptoms with noradrenaline in PSP	Dr Rob Durcan
10:45am	High-Throughput Screening & Drug Repurposing for PSP	Dr Paul Baxter
11:15am	User perspectives on the usefulness of Prism glasses as a visual aid for people with PSP	Prof Dan Smith
11:45am	Break	
Part 2: Chaired by Professor Karen Morrison		
12:00pm	Corticobasal Syndrome: Clinical, biomarker and pathalogical features	Dr David Vaughan
12:30pm	Using brain scans to study inflammation in people with PSP	Dr Maura Malpetti

SPEAKER PROFILES



Dr Rob Durcan is a Neurologist and previous PSPA funded Research Fellow working out of Professor James Rowe's lab in Cambridge. Dr Durcan has been key to the NORAPS clinical trial of an ADHD medication and it's affect on symptoms of PSP such as apathy and impulsivity.

Dr Paul Baxter is a Postdoctoral Research at the UK Dementia Research Institute at the University of Edinburgh. Dr Baxter is part of the Jeffery Young Research Programme, working on combining stem cell technology and high throughput screening methods to aid drug discovery.





Professor Dan Smith is a spart of Durham University's Department of Psychology. His research examines the interaction between the motor system, specifically the oculomotor system, and cognitive processes such as attention and working memory, with the goal to understand how activity in the motor system helps resolve competition between different representations in the visual system.

Dr David Vaughan is a Neurologist and Research Fellow who is completing his PhD under the supervision of Professor Huw Morris at the UCL Queen Square Institute of Neurology in London. His research focuses on genetic variation associated with an increased risk of developing PSP and CBS.



Dr Maura Malpetti is an Assistant Professor and Research Fellow at the Cambridge Centre for Frontotemporal Dementia and Related disorders. She is interested in the study of neuropathology, biomarkers and clinical features of neurodegenerative diseases. Her work focuses on the application of neuroimaging techniques to identify early diagnostic and prognostic markers.

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?"

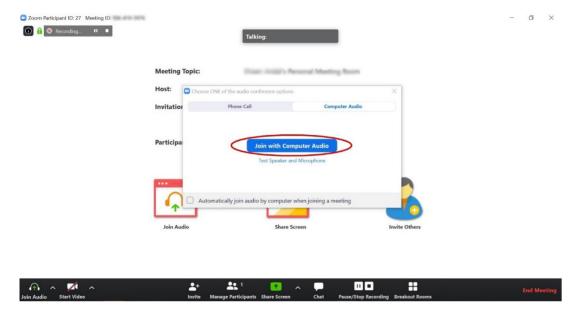
- You will need a device that is connected to the internet
- The device can be a smartphone, tablet or computer

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/81992932515

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: 819 9293 2515

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.







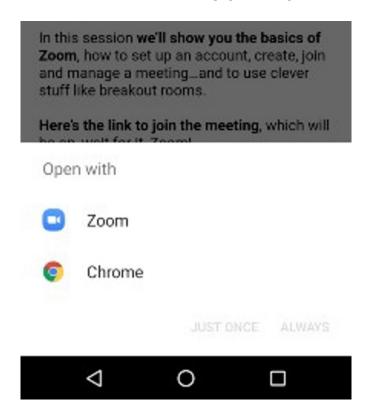
For Apple devices, i.e., iPhone or iPad, this is the App Store



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.

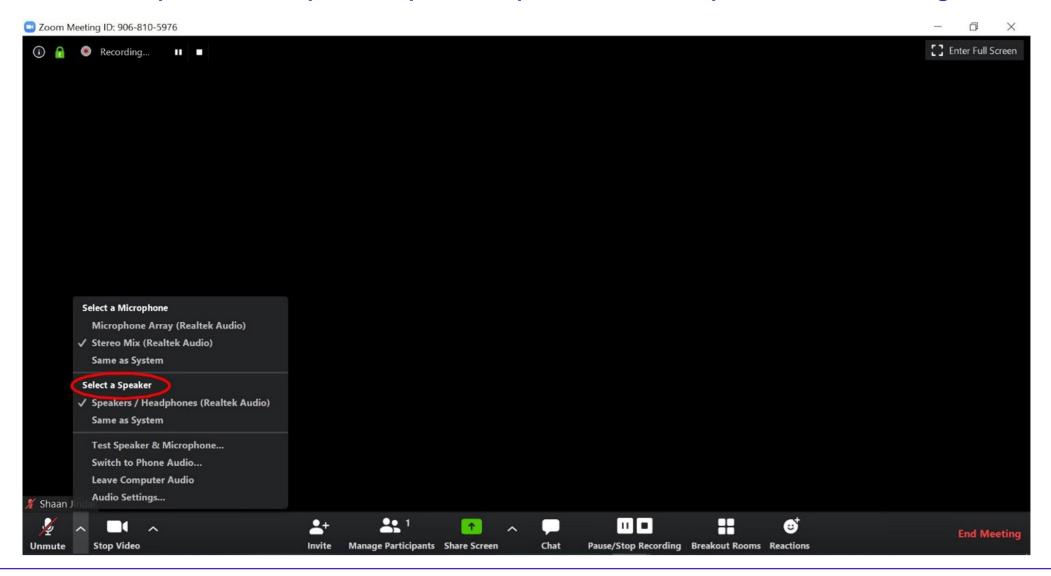
When asked what you'd like to open the link with select "Zoom".

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: 819 9293 2515 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