

2024 RESEARCH INFORMATION SESSION 1: PROGRAMME

THURSDAY 23RD MAY 2024 – 10am to 1pm

VIRTUAL EVENT ON THE ZOOM PLATFORM

Website zoom.us/join - Meeting ID: 824 3169 1472

Direct link <https://us06web.zoom.us/j/82431691472>



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WELCOME

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

The event will update patients, carers, and families on ongoing research that looks to improve the speed and accuracy of the diagnosis of Progressive Supranuclear Palsy and Corticobasal Degeneration (PSP & CBD).

We have a range of speakers from leading clinicians and researchers in the field of PSP and CBD research.

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. Nigel Leigh
	Part 1: Chaired by Dr Boyd Ghosh	
10:15am	Brain scans and blood tests to track inflammation	Dr Maura Malpetti
10:45am	Visual Attention: A Potential Cognitive Marker for PSP	Prof Dan Smith
11:15am	Break	
	Part 2: Chaired by Rowena Ironside	
11:30am	Diagnosing Parkinson Plus Syndromes Earlier: The ExPRESS Study	Riona Fumi
12:00pm	Molecular Imaging of Synaptic Loss in PSP	Dr Alana Terry & Holly Wright
12:30pm	Development of a tau seeding assay as an early diagnostic test	Dr Edwin Jabbari

BIOGRAPHIES



Prof. Nigel Leigh is Professor of Neurology at Brighton and Sussex Medical School, Emeritus Professor at King's College London, Honorary Consultant Neurologist at Brighton and Sussex University Hospitals Trust and Director of the Sussex MND Care and Research Network. After training in general medicine and neurology he completed his PhD with Professor David Marsden FRS at the Institute of Psychiatry, London and was appointed to the University Chair of Neurology at The Institute of Psychiatry in 1989. His research focuses on neurodegeneration, especially MND/ALS and PSP.

**Chair of the PSPA
Research Committee**



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 sees mostly general neurology patients in Salisbury and patients with cognitive disorders and atypical movement disorders in the Wessex Neurological Centre in 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.

**Trustee & Research
Committee member**



Ms Rowena Ironside's executive career was in the information technology industry, developing software and leading tech services teams in Europe the US and Asia-Pacific. Her non-executive career has spanned the public, private and not-for-profit sectors in the UK and includes five years as the inaugural Chair of Compassion in Dying, the UK charity helping individuals prepare for the end of life. She is currently a non-executive director and past chair of Women on Boards UK and as well as chairing the PSPA board, she sits on the Steering Committee of The Healthcare Improvement Studies (THIS) Institute, Cambridge.

**Chair of the Board
of PSPA Trustees**

SPEAKER PROFILES



Dr Maura Malpetti is a Race Against Dementia & ARUK 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, with special interest in frontotemporal lobar degeneration and Alzheimer's disease. Her work focuses on the application of neuroimaging techniques (multi-tracer PET and MRI) to investigate the pathophysiology of neurodegenerative diseases, in order to identify early diagnostic and prognostic markers. As a RAD fellow, she is studying novel clinically viable PET and other biomarkers for inflammation, tau and synaptic loss in FTLD.

Professor Dan Smith is part 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.



Riona Fumi is a Research Coordinator at the UCL Queen Square Institute of Neurology. She has an MSc in Clinical Neuroscience from University College London and became the coordinator for the PSPA funded PROSPECT study in 2022. This year she has begun as the coordinator of the ExPRESS study led by Prof Huw Morris which will follow on from the foundations set by the PROSPECT study with funding from the Medical Research Council and National Institute for Care and Health Research.



Dr Alana Terry is a clinical research fellow in the Neurodegenerative Imaging Group, part of The Medical School at the University of Exeter. Since graduating from the University of Liverpool in 2020 she has been involved in several ongoing studies investigating conditions including PSP, Parkinson's, Huntington's, ALS and MSA.



Holly Wright is a Fellow of the Chartered Management Institute with an extensive background in Operations, Leadership and Project Management within both the public and private sectors. She supports the study teams within the Neurodegeneration Imaging Group in the day-to-day running and delivery of research studies.

Dr Edwin Jabbari is a Post-Doctoral Clinical Researcher at the UCL Queen Square Institute of Neurology and a Neurology trainee at the Royal Free Hospital and National Hospital for Neurology and Neurosurgery. Since 2016 his research has focused on using genetics and fluid biomarkers to identify biological determinants of disease progression in PSP via funding from the Medical Research Council and the PSP Association. Most recently, he has obtained funding from CurePSP to explore LRRK2 as a new potential treatment target and from the PSPA to develop tau seed amplification assays.



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?”

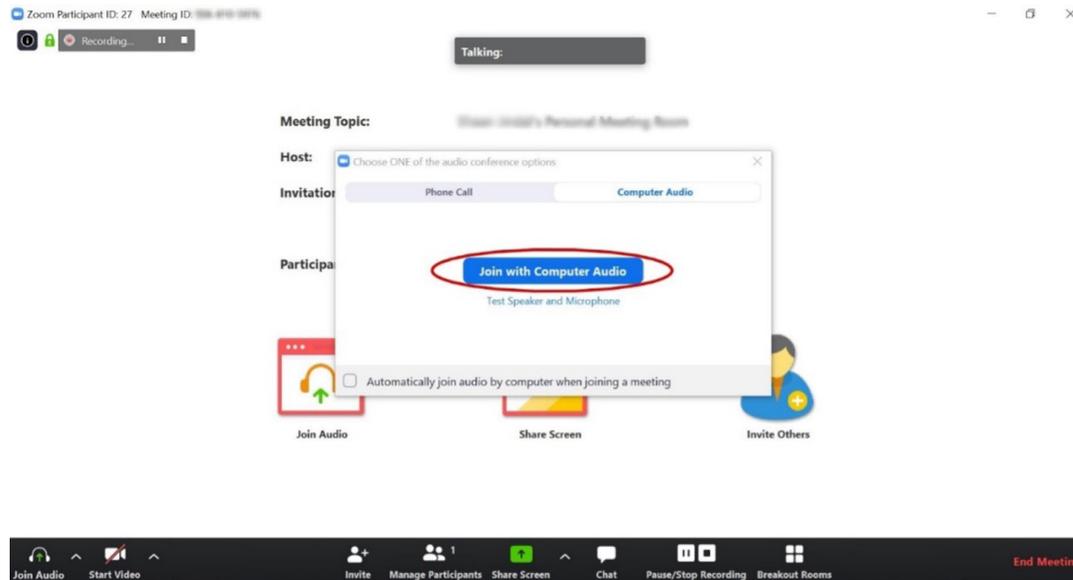
- You will need a device that is connected to the internet
- The device can be a smartphone, tablet or computer

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/82431691472>

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: **824 3169 1472**

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.

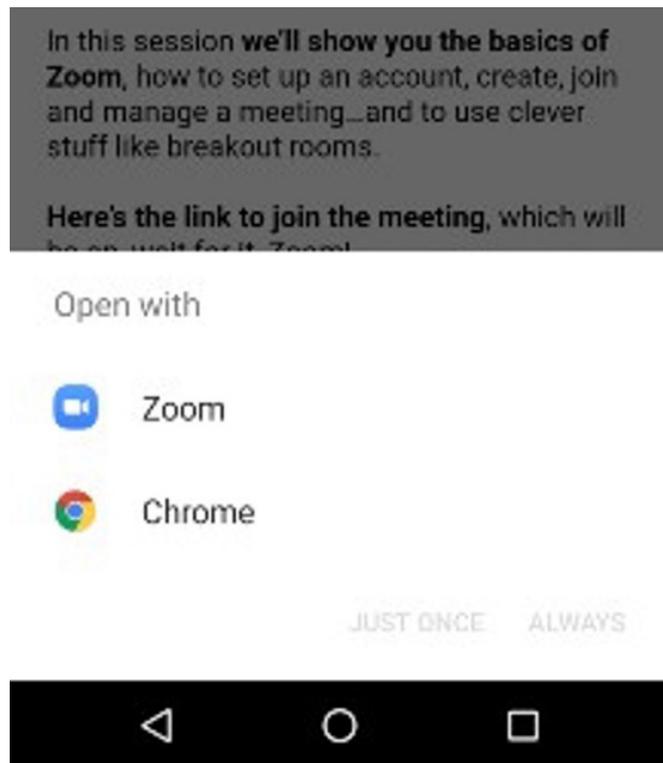


 For Apple devices, i.e., iPhone or iPad, this is the App Store

 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.

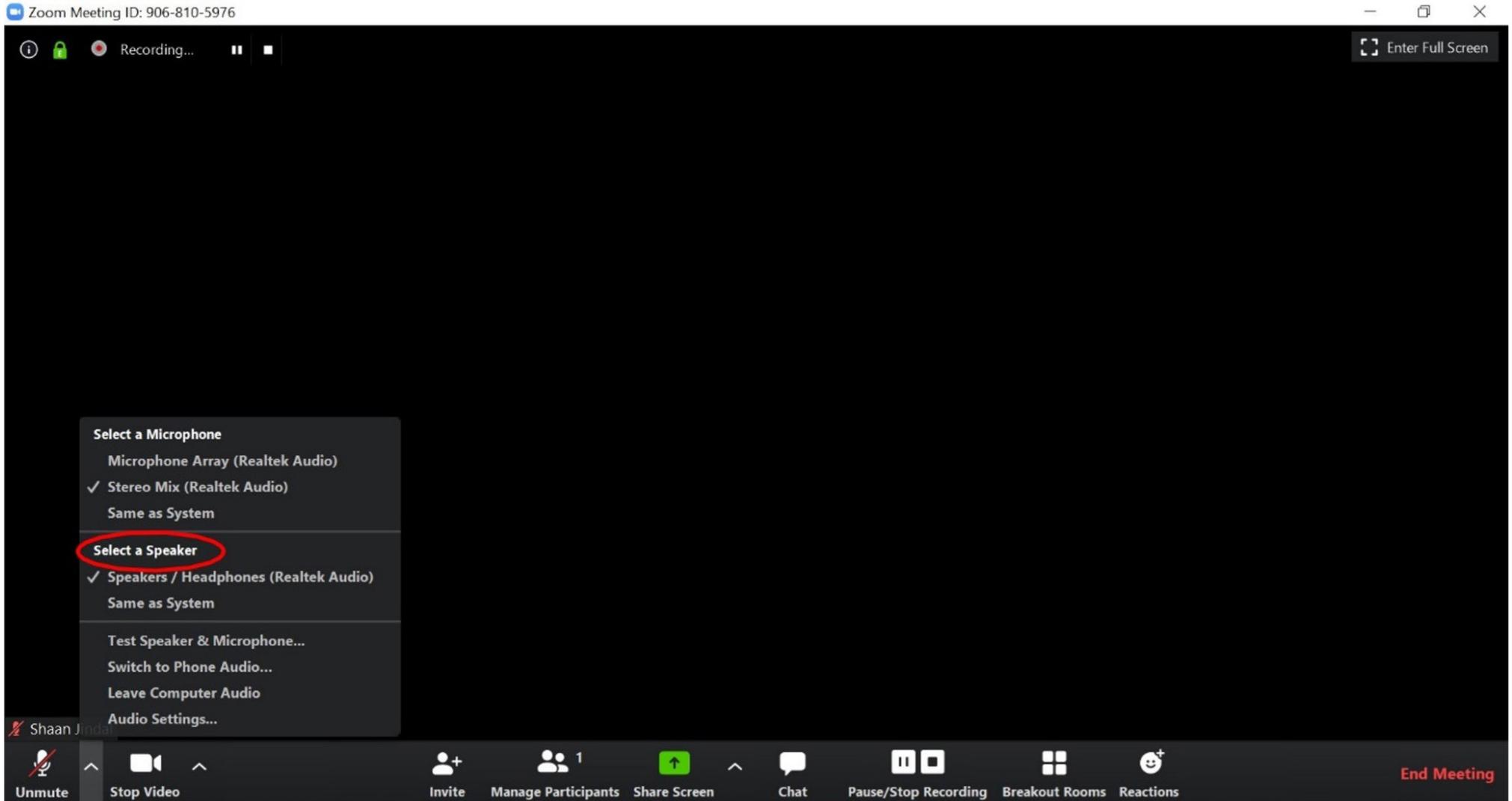
When asked what you'd like to open the link with select “Zoom”.

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: 824 3169 1472 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.



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.

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://www.tfaforms.com/5069193>

THANK YOU