

RESEARCH INFORMATION DAY 2023 PROGRAMME

FRIDAY 3 FEBRUARY 2023 – 10am to 3.30pm

VIRTUAL EVENT ON THE ZOOM PLATFORM

Website zoom.us/join - Meeting ID: 878 0886 7254

Direct link us06web.zoom.us/j/87808867254

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WELCOME

We are delighted to invite you to our Research Information Day 2023.

The event will update patients, carers, families and health professionals on ongoing research and the use of several research methods and techniques to explore causes, improve care, find a cure, as well as raising awareness regarding Progressive Supranuclear Palsy and Corticobasal Degeneration (PSP & CBD).

We have a range of speakers from leading researchers in the field, to our 2022 patients and families survey leads.

The day will run from 10.30am until 3.30pm and there will be five sessions of presentations with virtual breaks for coffee, lunch and tea.

We will use the Zoom platform – see page 19

Attendees will be able to ask questions writing them into a Zoom chat 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.

Questions that are not answered will be sent to speakers after the event and responses shared.

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		
10am	Introduction - PSPA Chief Executive Officer	Ms Rebecca Packwood
10.05am	Welcome - Chair of the PSPA Research Committee	Prof. Nigel Leigh
10.10 - 10.55am	SESSION ONE Observational studies: What are they for and what have we learned?	Chair: Dr Alistair Church
	PROSPECT-M-UK, PROgressive Supranuclear Palsy CorTico-Basal Syndrome Multiple system atrophy longitudinal study UK	Prof. Huw Morris
	OxQUIP, Oxford QUantification In Parkinsonism	Prof. Chrystalina Antoniades
	Pick's disease and Progressive supranuclear palsy Prevalence and INCidence study (PIPPIN)	Dr Katherine Stockton
10.40 - 10.55am	Question time	
10.55 - 11.05am	Break	
11.05am - 12.20pm	SESSION TWO Causes and cures: How technologies can help	Chair: Prof. Johannes Attems
	Neuroimaging: PET, Positron Emission Tomography	Dr Maura Malpetti

	Neuropathology	Dr Annelies Quaegebeur
	Genetics: is PSP genetic?	Dr Ed Jabbari
	Stem cells	Prof. Siddharthan Chandran
	Artificial Intelligence	Dr Tim Rittman
	Brain-banks	Prof. Tammaryn Lashley
12.05 - 12.20pm	Question time	
12.20 – 1.15pm	Lunch	
1.15 – 2.00pm	SESSION THREE Cures: Clinical trials	Chair: Dr Catherine Mummery
	NORAPS, Noradrenaline treatment of Apathy and impulsivity in participants with Psp Syndromes	Prof. James Rowe
	Novartis: Safety, Tolerability and Pharmacokinetics of Multiple Ascending Doses of Intrathecally Administered NIO752 in Participants with PSP	Dr Boyd Ghosh
	International overview	Prof. Larry Golbe

1.45 - 2.00pm	Question time	
2.00 – 2.30pm	SESSION FOUR Navigating and improving the health and social care system	Chair: Prof. Adrian Williams
	Lessons learnt from the MND community to accelerate PSP & CBD care	Mrs Rachel Marsden
	NICE guidelines: Building up the argument	Dr Boyd Ghosh
2.20 - 2.30pm	Question time	
2.30 - 2.45pm	Tea Break	
2.45 – 3.25pm	SESSION FIVE Patients' voices via surveys and focus groups	Chair: Ms Rowena Ironside
	THIS Institute survey on end-of-life	Prof. Graham Martin
	PSPA patients' and carers' 2022 survey results	Mrs Carol Amirghiasvand
	PSPA public involvement group, PRIM (see page 24)	Dr Annalisa Casarin
3.15 - 3.25pm	Question time	
3.25 - 3.30pm	Thank you and close of day	Ms Rebecca Packwood

BIOGRAPHIES: SESSION CHAIRS



**PSPA Research
Committee Chair**

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. He has received The Forbes Norris Award of the International Alliance of MND/ALS Associations, the Erb-Duchenne Prize of the German Neuromuscular Society, and The Sheila Essey Prize of the American Academy of Neurology. His research focuses on neurodegeneration, especially MND/ALS and PSP.



Dr Alistair Church has two working roles, as a GP principal in a semi rural practice in Gwent, South Wales, and as a Consultant Neurologist at the Royal Gwent Hospital. His special interest is movement disorder, particularly atypical Parkinsonism. He is principal investigator in several pharm sponsored trials in Progressive Supranuclear Palsy and Multi System Atrophy. He was part of the guideline development group tasked with updating the NICE Parkinson's guidelines in 2017.



Prof. Johannes Attems is Professor of Neuropathology at Newcastle University, Honorary Consultant Pathologist at Royal Victoria Infirmary, Newcastle and Director of the Newcastle Brain Tissue Resource. He is Editor in Chief of *Acta Neuropathologica* and leads the Neurodegenerative Pathology Research Group. His research interests are in neurodegenerative diseases of the ageing brain with a focus on clinico-neuropathological correlative studies. He aims to evaluate the combined influence of multiple pathologies present in the aging brain on the clinical syndrome as this might lead to the identification of new disease subtypes, and thereby the development of novel therapeutic strategies against age associated neurodegeneration.



Dr Catherine Mummery is a Consultant Neurologist and Honorary Associate at the National Hospital for Neurology and Neurosurgery (NHNN). As Head of Clinical Trials at the Dementia Research Centre, University College London (UCL), she focusses on early phase disease modification trials including immunotherapies, genetic therapies and novel methodologies in sporadic AD and genetic forms of AD and FTD (Alzheimer's disease and frontotemporal dementia). She is Clinical Lead for the Neurogenetic Therapies Programme at UCL and Deputy Director for the Leonard Wolfson Experimental Neurology Centre, dedicated to early phase neurodegeneration trials. She is Head of the Cognitive Service at NHNN, and on the Alzheimer's Research UK Taskforce.



Prof. Adrian Williams is Consultant Neurologist and Professor of Clinical Neurology at the University Hospitals Birmingham NHS Foundation Trust. He was appointed to the NHS England Chair of the Neurosciences Clinical Reference Group, the National Neurosciences Advisory Group and the West Midlands Senate.

Prof. Adrian Williams is also a GIRFT (Getting It Right First Time) Advisor Neurology and Ambassador for London.

The Professor is also a member of the Acquired Brain Injury Steering Group and Programme Board and works very closely with policy officials in both NHS England and the Department of Health & Social Care.



**Chair of the Board
of PSPA Trustees**

Ms Rowena Ironside studied Information Processing in Australia before spending 25 years in the ICT industry. After completing the Sloan Masters at London Business School in 2002, she built a second career as an international advisor, non-executive board member and diversity champion. Her board experience includes roles in the end-of-life sector as non-executive director and Vice Chair of Dignity in Dying and Inaugural Chair of the sister charity, Compassion in Dying, as well as five years on the board of the entrepreneurial start-up, Cupcake Mum and three years as a City Fellow of Hughes Hall, Cambridge. Rowena is a founder and non-executive Director of Women on Boards UK, a company providing the information, connections and encouragement to ensure more women are appointed to boards and senior leadership positions across all sectors. She sits on the Steering Committee of The Healthcare Improvement Studies Institute, Cambridge.

SPEAKER PROFILES



Prof. Huw Morris is Professor of Clinical Neuroscience at UCL Institute of Neurology, and Honorary Consultant Neurologist at the Royal Free Hospital, and the National Hospital for Neurology, London. His clinical and research training took place at the National Hospital, the Mayo Clinic, and the Western Pacific Island of Guam. He began research in PSP and related disorders as a PSP Association and MRC Clinical Research Fellow in 1997. His main interests are neurogenetics, movement disorders, and dementia. He is leading a UK-wide research network in PSP and Cortico Basal Degeneration (PROSPECT-M-UK), a UK-wide research project in genetic Parkinson's (Parkinson's families project), and a study of biomarkers in sports concussion.



Prof. Chrystalina A. Antoniadou is Associate Professor of Neuroscience and Head of the NeuroMetrology Group at the University of Oxford. In her research clinics, she uses a variety of quantitative experimental methods, based on precise measurement of subtle abnormalities of the speed and coordination of various movements such as saccades (fast eye movements) and hand movements. She recently published the results of a study looking at measurement of gait and speed in Parkinson's and PSP patients using movement sensors. The signals predicted deterioration before standard clinical assessments, an important finding for diagnosis and further research.



Dr Katherine Stockton trained to be a Neurologist committed to improving the future for people with PSP, she has chosen to undertake a PhD with Prof James Rowe at Cambridge University. She is looking into new tests to diagnose and monitor Progressive Supranuclear Palsy, Corticobasal Syndrome and Frontotemporal Dementia. This is done within an epidemiological study called PIPPIN, so that the results can be related to everyone with the illness.

Her career began with Bachelor's and Master's degrees in Neuroscience from UCL, with Professor Jon O'Keefe and Professor Cathy Price. She then worked at the UCL Dementia Research Centre before completing her medical degree at Bart's and The London. Since 2008, she has trained at hospitals in Oxford, London and Cambridge, alongside raising her family and her love of good food, music and Polish dancing. Currently, she works with Dr Timothy Rittman and Prof James Rowe at Addenbrookes Hospital, gaining both clinical and research expertise in PSP and CBD. She is very grateful for the PSPA's support for her research and to her patients and families affected by PSP and CBD.



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.



Dr Annelies Quaegebeur is a Senior Clinical Research Associate at the University of Cambridge. Her research group studies the molecular and cellular processes underlying primary tauopathies, with a particular interest in microglial responses and neuropathological validation of PET biomarkers. After completing a clinical training in Neurology and a PhD in neuroscience, she trained as a neuropathologist in the National Hospital of Neurology and Neurosurgery in Queen Square, London and researched frontotemporal lobar degeneration at the Dementia Research Institute of University College of London. She is now working as a Consultant Neuropathologist in Cambridge University Hospitals and is the Research Director of the Cambridge Brain Bank.



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.



Prof. Siddharthan Chandran is Dean of Clinical Medicine, Head of Edinburgh Medical School, Director of Edinburgh Neuroscience, Euan MacDonald Centre and Anne Rowling Regenerative Neurology Clinic in Edinburgh. He works in the emerging discipline of Regenerative Neurology. His research combines laboratory activity that includes human stem cells with specialist clinics (multiple sclerosis [MS] and motor neurone disease [MND]) to both study disease as well as undertake early-phase clinical trials.

The ultimate aim is to develop novel regenerative therapies for neurodegenerative disease.



Dr Timothy Rittman is a Senior Clinical Research Associate at the University of Cambridge where he studies rare types of dementia including PSP & CBD. He combines neuroimaging, cognitive assessments and neuropathology to understand how these diseases affect the whole brain. He also has an interest in translating methods from artificial intelligence and big data for use in memory clinics. He co-leads the DEMON dementia network's Imaging Working group and is an adviser to the World Young Leaders in Dementia. He is an Honorary Consultant Neurologist at Addenbrookes hospital, as a consultant in the Addenbrookes Memory Clinic, and leading a clinic for people with Progressive Supranuclear Palsy and Corticobasal Degeneration, and co-leading a dementia genetics clinic.



Prof. Tammaryn Lashley is Professor of Neuroscience and Director of Research at Queen Square Brain Bank for Neurological Disorders in London, at the UCL Queen Square Institute of Neurology. Her research encompasses the pathological characterisation of post-mortem human brains with neurodegenerative diseases supported with biochemical and molecular biological investigations. Her senior fellowship focuses on potential pathogenic mechanisms underlying frontotemporal dementia and whether multiple mechanisms are associated with the different pathological subtypes. Her research group also pursues other avenues of research encompassing neurodegenerative diseases including familial and sporadic Alzheimer's disease and Parkinson's disease.



Prof. James Rowe leads the Cambridge Centre for Frontotemporal Dementia and related disorders (including regional healthcare clinics for PSP & CBD), is a Principal Investigator in the Cambridge Centre for Parkinson Plus and is honoured to be a Trustee of the PSP Association. His research into the pathophysiology and cognitive syndromes of PSP & CBD promotes the development and validation of disease-specific biomarkers and new therapeutic strategies. This brings together advances in imaging and pharmacological interventions to understand and restore brain function.



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.



Lawrence I. Golbe, MD, is Emeritus Professor of Neurology at Rutgers Robert Wood Johnson Medical School in New Brunswick, New Jersey. His research is in the clinical genetics, clinimetrics and epidemiology of the parkinsonian disorders. In 1988 he co-led the first studies of the prevalence and risk factors in PSP. He led the clinical portion of a decade-long project that in 1997 identified the first known Mendelian mutation causing Parkinson's disease in the gene for alpha-synuclein. He devised and validated the PSP Rating Scale, which since its publication in 2007 has become the standard clinical measure for PSP world-wide. He is Chief Clinical Officer and Scientific Advisory Board Chair of CurePSP in New York.



Mrs Rachael Marsden is an Motor Neurone Diseases Nurse Consultant and the Care Centre Coordinator. She provides a point-of-contact service for patients between clinic visits and facilitates the communication of information between all those locally involved in an individual patient's care. She also provides emotional support for patients and their carers.

Mrs Marden and her travel partner Cat Dixon have been named in the top 100 women cyclists in the UK. Cat and Raz became the fastest people to circumnavigate the world on a tandem in 2020, raising thousands of pounds for charity in the process.



Prof. Graham Martin is Director of Research at THIS Institute, Cambridge, leading applied research programmes and contributing to the Institute's strategy and development. He has a degree in Geography from Oxford University, an MSc in Society and Space from the University of Bristol, and a PhD in social policy from the University of Nottingham. He was previously Professor of Health Organisation and Policy at the University of Leicester. Dr Martin's research interests are in the organisation and delivery of healthcare, and particularly the role of professionals, managers and patients and the public in efforts at organisational change.



Mrs Carol Amirghiasvand joined PSPA in March 2013 to set up the new PSPA helpline service. She is now Director of Engagement and is responsible for PSPA's volunteering service, information and support service and engagement across the organisation. Carol is responsible for training and supporting PSPA volunteers. She ensures PSPA offers high quality service provision, implementing policies and procedures, and maximising the quality experience for PSPA volunteers.

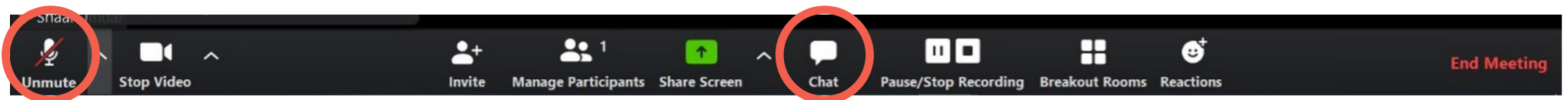


Dr Annalisa Casarin trained as a doctor in Italy, and went on to train and work in anaesthesia, intensive care and pain management. She cared for her mother who had PSP. Motivated by her personal experiences, Dr Casarin has worked extensively in research projects with a passion for meaningful involvement of patients and the public. This has led her to her current roles as Research Coordinator at the PSPA, Senior Research Fellow at the University of Hertfordshire's Health Research Methods Unit, and Adviser for the National Institute of Health Research.

ZOOM INSTRUCTIONS

Zoom is a website and an application on the phone 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 chat box.



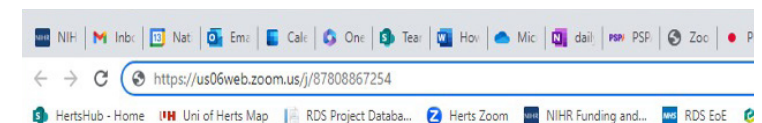
“WHAT DO I NEED?”

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

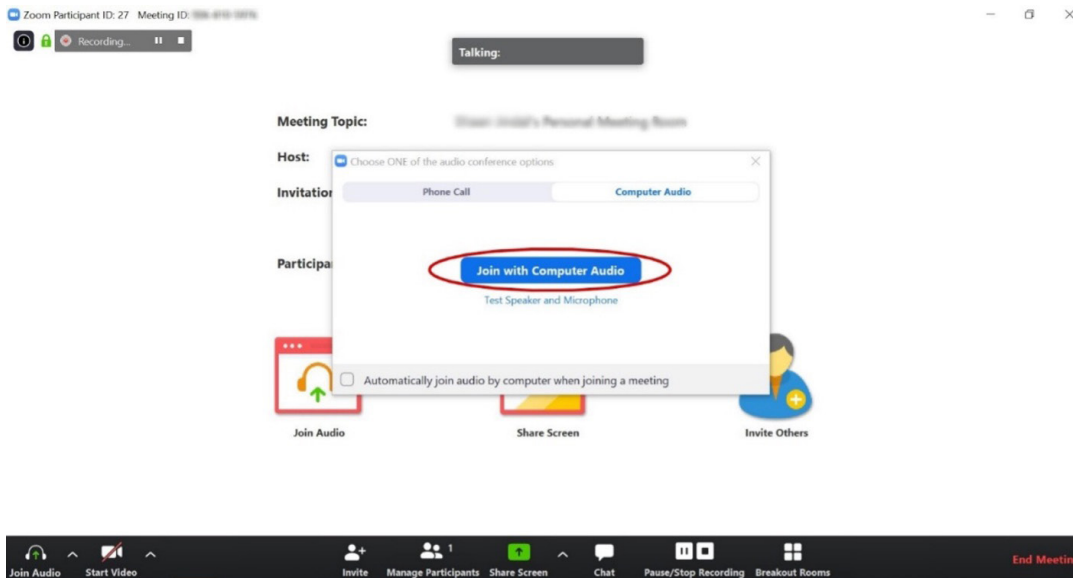
How to join a Zoom Meeting – few options:

- 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: us06web.zoom.us/j/87808867254



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: **878 0886 7254**

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.

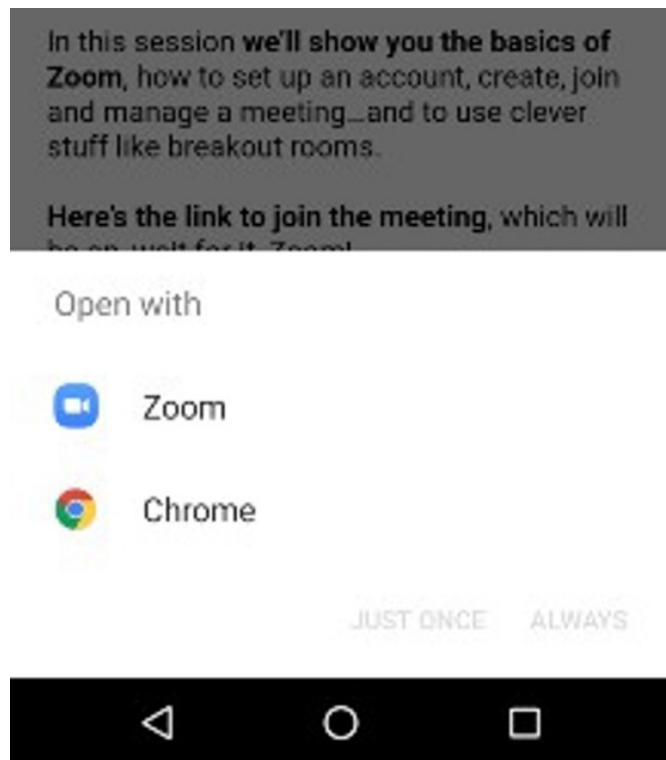


 For Apple devices, i.e., iPhone or iPad, this is the App Store

 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: **878 0886 7254** to join the event.

- Or dialling in when you use your phone (for an audio only version using a landline or mobile phone)

Just dial one of the numbers below and enter the Meeting ID **878 0886 7254** when prompted. Assuming you're joining a UK call with a UK phone number, you will be charged your normal call rate with no extra fees.

Dial-in numbers are:

United Kingdom +44 131 460 1196

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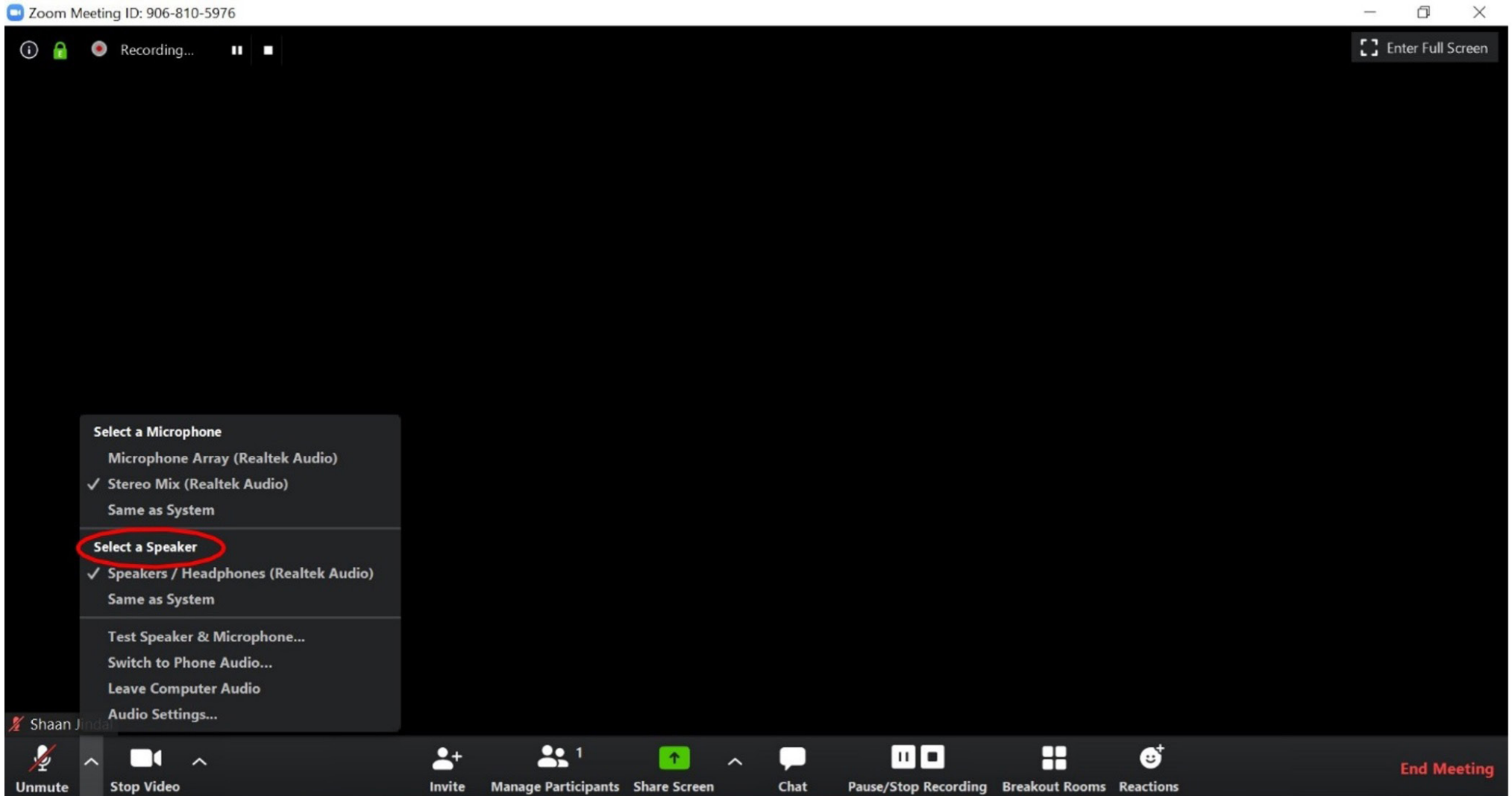
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TROUBLESHOOTING

- 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 July 2022 to ensure the engagement and involvement of people living with PSP & CBD, their carers and family members in research sponsored and supported by PSPA. The aims of the 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; and
- Assist, support and advise researchers, and act as a 'critical friend' on how to best improve research strategy and projects.

In return, PSPA provides training and support, keeps members updated on research activities and outputs, provides feedback from researchers and company 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 the PRIM, please express your interest sending an email to [**research@pspassociation.org.uk**](mailto:research@pspassociation.org.uk)

THANK YOU