

# RESEARCH INFORMATION DAY AND RESEARCH STRATEGY LAUNCH

A woman with long brown hair and glasses is pointing at a computer monitor. The monitor displays a medical scan, possibly an X-ray or MRI. A man with a beard and glasses is looking at the monitor. The background shows a research or clinical setting with multiple computer monitors and equipment. The image has a purple overlay on the left side.

**PSP/**

SATURDAY 23 JANUARY 2021  
VIRTUAL EVENT USING ZOOM





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**PSP/**

# WE ARE DELIGHTED TO LAUNCH OUR 2021 RESEARCH INFORMATION DAY AND OUR NEW RESEARCH STRATEGY

The day brings together patients, carers and health professionals, in an informal way, to share knowledge, answer questions and learn. Patient engagement is now at the forefront of care in the NHS. In bringing the PSPA community together in this way, we hope, as the only UK charity dedicated to improving the lives of people living with PSP & CBD, we can enhance the care for, and awareness of, these conditions.

We have a range of speakers from leading researchers in the field of PSP & CBD, to a patient who will share their experience of taking part in research trials.

The day will run from 10.30am until 3.45pm and there will be three sessions of presentations with virtual breaks for coffee, lunch and tea.

Attendees will be able to ask questions using a private Zoom messenger chat (note: only the event staff will be able to see the questions and will present the questions to the speakers anonymously). 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.

We will also be launching our new PSPA Research Strategy as well as our PSPA Patient and Carer Voices in Research Network. This is an exciting time for PSPA – the new strategy is the product of a consultation last year with a wide range of stakeholders from patients to carers to neurologists and researchers. The day will end with an opportunity for patients and carers to have a shared voice by taking part in an interactive session discussing research engagement for PSP & CBD led by our Research Manager and our Director of Engagement.

The logo for PSPA, with the letters 'PSPA' in a bold, orange, sans-serif font, followed by a white stylized symbol resembling a forward slash or a partial 'A'.



# PROGRAMME

## **10.30am Introduction**

Dr Wendy Edwards  
PSPA Research Manager

## **10.40am Welcome**

Professor Nigel Leigh  
Brighton and Sussex Medical School/  
Kings College, London

## **10.50-11.50am Session One**

Chaired by Professor Huw Morris

Principal Investigator of PROSPECT study  
funded by PSPA, University College London

### **Dr Ed Jabbari**

University College London

**Genetic studies in PSP: discovering  
potential avenues for treatment**

### **Patient Speaker**

**A perspective of taking part in research**

Questions

## **11.50-12pm Short Break**

## **12pm Session Two**

Chaired by Professor James Rowe  
Trustee of PSPA, University of  
Cambridge/Addenbrooke's Hospital

### **Dr Negin Holland and**

### **Dr Maura Malpetti**

University of Cambridge/Addenbrooke's  
Hospital

**Causes and consequences of PSP & CBD  
– how brain imaging is helping the fight**

**What happens to brain communication  
in PSP & CBD?**

**Brain inflammation and tau build-up in  
PSP: predicting change**

### **Professor Chrystalina Antoniades**

University of Oxford/  
John Radcliffe Hospital

**Oxford Quantification in Parkinsonism  
study - OxQUIP - Updates and new data  
in PSP**

Questions

## **1-1.45pm Lunch**

# AFTERNOON

## **1.45pm Session Three**

Chaired by Dr Alistair Church

Member of the PSPA Research  
Committee

**Dr Diane Swallow**

University of Aberdeen

### **Diagnosis in PSP & CBD**

**Dr Edoardo de Natale**

University of Exeter

### **What can we learn about PSP using neuroimaging?**

Questions

## **2.45-3pm – Short Break**

## **3-3.30pm Session Four**

Chaired by Professor Nigel Leigh

Chair of the Research Committee

**Dr Wendy Edwards**

**Research Strategy 2020-2025**

**Patient and Carer Voices Interactive  
Session – led by Dr Wendy Edwards,**

PSPA Research Manager and

**Carol Amirghiasvand,**

PSPA Director of Engagement

## **3.30-3.45pm**

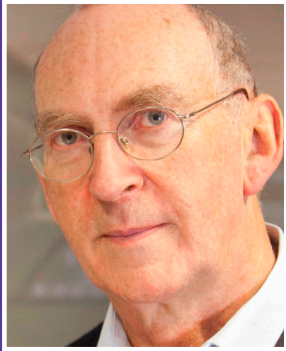
**Thank you and end of day**

The logo for the Parkinson's Society of Australia (PSPA) is located in the bottom right corner. It features the letters 'PSPA' in a bold, orange, sans-serif font, followed by a white stylized 'A' that is partially enclosed by a white curved line.



# SESSION CHAIR

# BIOGRAPHIES



**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.



**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, Queen Square. He was Senior Lecturer and then Professor in Neurology and Neurogenetics at Cardiff University, the Royal Gwent Hospital and the University Hospital of Wales from 2003-2013. His clinical and research training took place at the National Hospital Queen Square, the Mayo Clinic and the Western Pacific island of Guam. His main interests are Neurogenetics, Movement Disorders and Dementia. He is leading a UK-wide research network in PSP & CBD (PROSPECT) and a UK-wide research project in genetic Parkinson's (Parkinson's families project). He also studies genetic determinants of progression and variation in Parkinsonian disorders to define new treatments.



**James Rowe** is Professor of Cognitive Neurology and studies the mechanisms and potential treatments for PSP, Parkinson's disease and frontotemporal dementia. He trained in medical sciences and experimental psychology at Cambridge, before clinical studies in Oxford and his PhD at the Institute of Neurology, London. After further specialist training in Copenhagen, he returned to Cambridge in 2005. He is Associate Director of DPUK, leading the academic-industrial partnership for experimental medicine. He leads the Centre for Frontotemporal Dementia and the Clinical program within the Centre for Parkinson-plus, together with regional NHS clinics for these disorders. The integration of multimodal brain imaging, genetics, pharmacology and computational modelling provides a powerful platform to understand neurological disease, and to assess the efficacy of novel treatments.



**Alistair Church** has two working roles, as a GP principal in a semi rural practice in Gwent, South Wales, and as an Associate Specialist in Neurology at the Royal Gwent Hospital. His special interest is movement disorder, particularly atypical Parkinsonism. He is principal investigator in several pharma sponsored trials in PSP and Multisystem Atrophy. He was part of the guideline development group tasked with updating the NICE Parkinson's guidelines in 2017. He is the present editor of Neurodigest.



# SPEAKER PROFILES AND PRESENTATION SUMMARIES

# Ed Jabbari



Ed Jabbari currently works as a Neurology Registrar at the Royal Free Hospital London. From 2016 to 2020 he completed his PhD in Professor Huw Morris' group at the UCL Queen Square Institute of Neurology, focusing his research on discovering the genetic determinants of disease progression in PSP. Ed held the PSPA Sara Koe Research Fellowship and is now an MRC Clinical Research Training Fellow.

## **Genetic studies in PSP: discovering potential avenues for treatment**

Although there are treatment options to help alleviate the symptoms of PSP, frustratingly, there are no effective treatments to stop or even slow down the disease in its tracks. The classic form of PSP is characterised by problems with balance, eye movements and speech/swallowing. However, in the last decade, a number of different forms of PSP have been described, including those that look much more like Parkinson's disease.

Through our work on the UK-wide PROSPECT study, we have found that the different forms of PSP progress at different rates and are associated with specific patterns on imaging of the brain.

A lot of our understanding of the biological systems that are involved in increasing our risk of developing PSP have been shaped by genetic studies. Therefore, we have taken

a unique approach by aiming to discover the genes that are involved in determining: 1) the form of PSP that patients will develop; 2) the rate of disease progression. This approach has revealed two genes of interest – TRIM11 and LRRK2. There is now ongoing work looking at the potential to develop treatments that target these two genes to slow down PSP (and related conditions such as CBD) in its tracks.

## **PATIENT PERSPECTIVE**

### **A perspective of taking part in research**

What is it like to get involved in research? A talk about what to expect if you are eligible to take part in a research study such as PROSPECT from the perspective of a participant. The voice of the patient and carer is crucial to all research and can range from reviewing patient information leaflets to being part of a clinical trial.



Causes and consequences of PSP & CBD –  
how brain imaging is helping the fight

## Negin Holland



Negin Holland is a Neurology Clinician in Professor James Rowe's group at the Cambridge Centre for Parkinson-plus. Her current research focuses on the effect of tau protein build-up on brain communication in PSP & CBD using PET and MRI brain imaging. Alongside this, she sees patients in the Cambridge PSP/CBD/FTD clinics, working with patients and their families to manage these conditions.

### **What happens to brain communication in PSP & CBD?**

Brain cells communicate with each other through connections called synapses. They are essential to the function of the brain, for movement, memory and behaviour. Healthy brain cells have thousands of synapses, but the number falls early as people start to develop dementia and other brain illnesses later in life.

A lot of what scientists know about synapses has come from animal studies, or from post mortem patient brain donation. We are using a new method to measure the loss of synapses in living patients, using a special type of brain scan (called PET) and a new injectable 'dye' that lights up the synapses for

the scanner allowing us to visualise synapses for the first-time during life.

We have so far shown a significant loss of synapses in patients with PSP & CBD compared to healthy volunteers. The severity of synapse loss directly correlates with the severity of the patients' symptoms. Using another type of PET imaging ('Tau PET') we are investigating the effect of tau build on brain communications.

Our results help understand human brain diseases like dementia, and guide new experimental therapies targeting synaptic health, especially with growing interest in treatment before permanent brain damage.

Causes and consequences of PSP & CBD –  
how brain imaging is helping the fight

## Maura Malpetti



Maura Malpetti is a post-doctoral researcher at the Cambridge Centre for Parkinson-plus of the University of Cambridge. With an academic background in Psychology and Clinical Neurosciences, she just finished her PhD with Professor James Rowe. Her research focusses on brain scanning techniques (MRI and PET) and clinical progression in PSP and other tauopathies including CBD.

### **Brain inflammation and tau build-up in PSP: predicting change**

Considerable progress has been made in understanding brain changes associated with brain degeneration and the related symptoms. We now know that harmful junk proteins like tau protein that accumulate in the brain cells can lead to problems with, or changes in, memory, thinking, behaviour and movement. However, a lot is still unknown. For example, it is not clear why some people get worse faster than others. Growing evidence suggests that PSP is associated with tau protein build-up but also with brain inflammation. A brain scanning technique called Positron Emission Tomography (PET) imaging can be used to map junk protein, like tau, and the presence of inflammation in the brain

of living volunteers. Using this tool, we found tau pathology and inflammation occur in the same parts of the brain of people with PSP, and they are both linked to the severity of symptoms. Brain inflammation in these regions, as well as tau build-up too, is predictive of how fast the participants of the study declined over the years following the PET scan. This means that to visualise brain inflammation and tau build-up with this scan may be a good strategy to forecast the clinical progression of people with PSP & CBD. In addition, evidence for the role of inflammation in PSP may suggest that a combination of tau and immune-oriented strategies may be useful for effective disease-modifying treatments for this condition.

# Chrystalina Antoniades



Chrystalina Antoniades is an Associate Professor of Neuroscience in the Nuffield Department of Clinical Neurosciences at the University of Oxford, and an Official Fellow of the newly established Reuben College in Oxford. After finishing her PhD at the University of Cambridge, she moved to Oxford to take up a position at Clinical Neurology. She has set up her own research group, the NeuroMetrology Lab.

Professor Antoniades research studies Parkinsonism (Parkinson's and PSP) and, in her research clinics, uses a variety of quantitative experimental methods, based on precise measurement of subtle abnormalities of the speed and coordinate of various movements such as saccades (fast eye movements), motor control (such as finger movements) along with various aspects of gait control and cognitive dysfunction.

## **Oxford Quantification in Parkinsonism study - OxQUIP. Updates and new data in PSP**

It is estimated that there are seven to ten million people with Parkinson's and PSP disease worldwide. Currently available treatments are symptomatic only, and while they may be very effective for a number of years, they do not have any preventive or disease-slowing effect. Potential new treatments are in the early stages of development and we wish to develop new ways of

measuring Parkinson's symptoms as precisely as possible so that when new drugs are ready to test, we are able to very accurately measure their effectiveness in clinical trials. The OxQuip study asks people to perform simple tasks while researchers measure the eye, hand and body movements. We also ask people to undertake some tasks on a tablet computer that measure cognitive performance.

In this talk, Chrystalina will give a brief overview of what the study is looking into, what the aims are and what we have achieved to date. She will then share some of her recent results on gait and cognition using portable technology and smart analysis.



# Diane Swallow



Diane Swallow is a Neurology Registrar in NHS Grampian and a Clinical Lecturer in Neurology at the University of Aberdeen. Her clinical and research interests are in movement disorders, including PSP & CBD, and epidemiology. She recently undertook a clinical academic fellowship jointly funded by the Chief Scientist Office of the Scottish Government and PSPA focusing on diagnosis and care in PSP & CBD.

## Diagnosis in PSP & CBD

An improved understanding of the diagnostic process and sources of misdiagnosis or delayed diagnosis has the potential to inform and improve many areas of care and research in PSP & CBD. At an individual level, an accurate and timely diagnosis of PSP or CBD affords each person with these conditions the best opportunity for a positive health outcome, in that all decision making, communication and care is based on our best understanding of these particular diseases.

At a population level, health service planning, resource allocation and research priorities are influenced by the prevalence or number of people living with PSP & CBD, the accuracy of which is dependent on the accuracy of diagnosis. Diane will discuss some of her most recent research which has explored the diagnostic pathways of people with PSP & CBD from their first symptom to final diagnosis.



## Edoardo de Natale

Edoardo de Natale is a Senior Clinical Research Fellow at the Neurodegeneration Imaging Group, University of Exeter. He trained in Neurology at the University of Sassari, Italy, and has MSc in Clinical Neurology at UCL and a PhD in Neurophysiology at the University of Sassari.

### **What can we learn about PSP using neuroimaging?**

PSP is a neurodegenerative disease for which the exact causes and mechanisms are still unknown. Studies from brains of patients that have suffered from this disease and have donated their brain for research have shown that, in PSP, there is an increase of proteins in certain areas of the brain, all clumped together; and it is thought that this may play a major role in causing the symptoms. Since these studies come from autopsies, we do not know exactly when and how much these proteins accumulate during life. Do they accumulate before the disease starts? Do they accumulate only when the symptoms become severe? Why are they more in some places and less in others? Are they the real cause of PSP or just one of the consequences?

Neuroimaging is a field of medicine that uses technology to study the state of the brain in living people. One specific technique is called Positron Emission Tomography or PET, and uses small quantities of compounds that are injected in a vein, travel to the brain and bind to some molecules. We can then visualise with a machine, how much of the compound is bound to the molecules, as a measure of the activity, and quantity of these. PET imaging is now able to study the clumps of a protein called tau in the brain and it is hoped that current and future research could shed light on the questions above. In this talk Edoardo will summarise how much neuroimaging can help in improving what we know about PSP and in identifying new targets for therapies.

# Wendy Edwards



Wendy Edwards is the Research Manager at PSPA. She obtained her PhD in Biological Sciences at Queen Mary College, London. She has worked in research management for medical research charities for the last 20 years. She manages the research portfolio at PSPA. Her work involves the development and implementation of the new Research Strategy, and to engage patients and carers in research through the Research and Carer Voices in Research Network. She is also responsible for communicating research to members, liaising with researchers and clinicians, and supporting education of PSP & CBD to members and volunteers of PSPA.

## Research Strategy

The PSPA Research Strategy comprises of four strategic elements identified from a three-month consultation with patients, carers, clinicians, researchers and organisations with a link to PSP & CBD. The implementation of the strategy is supported by our Research Committee.

The strategy aims to:

1. Prioritise PSPA research
  - Prevention and causes
  - Awareness and education
  - Improved diagnosis, reduced misdiagnosis

- Drug discovery and targeted treatments for underlying causes
  - Improved interventions for the treatment of all the symptoms of the conditions
2. Support the research stars of the future
  3. Engage patients and carers in research
  4. Enhance communication, collaboration and change.

The full strategy can be viewed online at: <https://pspassociation.org.uk/research/research-strategy/>



## Carol Amirghiasvand



Carol 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.

She is also responsible for the development and systems coordination for all care information provided by PSPA for people living with PSP & CBD, their carers and healthcare professionals and has responsibility for ensuring that quality support services are provided to all those affected by PSP & CBD and healthcare professionals.

She has 20 years of experience of information and support within the voluntary sector working with Age UK, Parkinson's UK and MND Association. She has a special interest in neuro-degenerative conditions.

## Wendy Edwards and Carol Amirghiasvand

### Patient and Carer Voices in Research Network – Interactive Session

This network brings patients and carers together to support research which reflects patient views and priorities, and encourages anyone who wants to take part in research to have a shared voice.

Through participation in research studies and clinical trials the hope is that future generations of patients will benefit from better diagnosis and treatments for PSP & CBD.

During this session of the day, we will be asking people to answer questions on research engagement using online interactive questioning – it should be a fun and informative session for all.

# 10,000 VOICES

**During Rare Diseases Day, 28 February 2021, PSPA will be launching a new campaign called 10,000 Voices.**

The campaign has been developed after recent research indicated there could be up to 10,000 people living with PSP & CBD in the UK at one time. This is more than the number of people living with Motor Neurone Disease, yet PSP & CBD are still relatively unknown.

The 10,000 Voices campaign therefore aims to raise awareness of PSP & CBD, with healthcare professionals and the general public, so more people can spot the signs and symptoms, diagnosis can be made earlier and those diagnosed are referred to the appropriate services ensuring better care and support.

During Rare Diseases Day, PSPA will be calling on supporters to get involved in the campaign by lobbying their local MP,

sharing Red Flag posters with their local GP Practice and, sharing their experience of PSP & CBD with us.

More information about the campaign, including useful resources such as template letters, social media images and Red Flag posters, will be available on our website in February, please visit **[www.pspassociation.org.uk](http://www.pspassociation.org.uk)** or email **[communications@pspassociation.org.uk](mailto:communications@pspassociation.org.uk)** to share your experience.

# THANK YOU

**The presentations are being recorded and will be made available in February 2021 on the research pages of the PSPA website:**

<https://pspassociation.org.uk/>

**If you would like to find out more about our new Research Strategy please visit:**

<https://pspassociation.org.uk/research/research-strategy/>

**If you would like to sign up to our Patient and Carers Voices in Research Network please visit:**

<https://pspassociation.org.uk/research/patient-carer-voices-in-research/>

## HELPLINE

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**[helpline@pspassociation.org.uk](mailto:helpline@pspassociation.org.uk)**

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