IN THIS TOGETHER
parkinson's
TASMANIA

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From the President

– Mike Whitehouse OAM

2025 is shaping up to be an exciting year for all aspects of improving the wellbeing of those living with PD in Tasmania, be it ongoing care and support, advocacy, research, awareness and education.

Professor Jane Alty, a UK trained Neurologist, has joined the Parkinson's Tasmania Committee. Jane is passionate about improving medical care and research for people with PD and has achieved much since moving to Tasmania in 2019. Her latest achievement is her involvement in the Parkinson's MOOC [Massive Open Online Course], to be launched-on 5th February 2025, where training in Parkinson's can be undertaken anywhere in the world. [See Jane's commentary later in this journal.] Welcome Jane!

The formation in 2024 of the National Parkinson's Alliance Ltd by so many of the Tasmanian Parkinson's cohort, to become the "go to" Parkinson's advocacy body in Canberra, let alone the $880,000 Federal Budget allocation to develop and implement a National Parkinson's Action plan deliverable in 2026, is testimony to the power and dedication of those involved in every aspect of Parkinson's in Tasmania. The Parkinson's MOOC is yet another illustration of this.

In April, Parkinson's Tasmania [PT] will be collaborating with MSPlus, Coloplast and Royal Hobart Hospital [Dr Foong Yi Chao] to deliver a neurological workshop evening training event for GP's. Dr Chao will be the keynote speaker. Professor Michele Callisaya [Researcher/academic with Menzies, UTas and Monash], who lives with PD, will also be a keynote speaker.

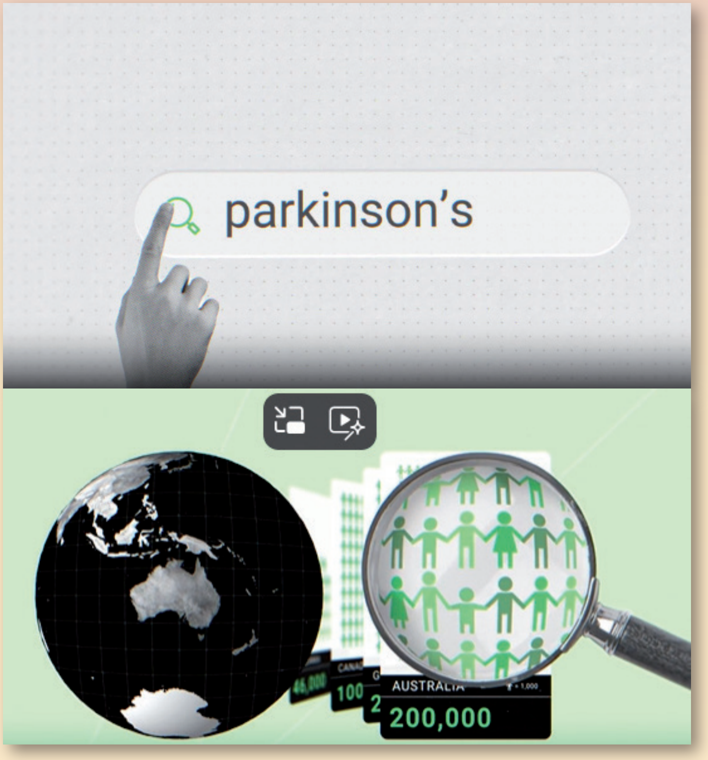
In May, PT will be having a day long education seminar lead by Professor Michele Callisaya and I look forward to welcoming PT members to attend. Dates and information will be published shortly, so lock in the date and register early.

In June, PT will be sponsoring "Subarus Crossing the Simpson Dessert – Pressing on for Parkinson's".

A group of eleven car enthusiasts are rallying together with one of their mates living with PD. Five 30+ year old restored Subaru Foresters plus a support vehicle plan to leave Hobart to Alice Springs, then cross the remote Simpson Desert to Birdsville, Queensland. A steady stream of social media updates will occur, the aim being to both increase awareness of PD and raise money to support research and costs associated with specialist Parkinson's nurses in Southern Tasmania. This journey is fully funded by the participants, so every cent donated via the PT website will reach the recipients.

Welcome to the new Tassie-made Parkinson's Massive Open Online Course (MOOC)!

By Jane Alty



On behalf of all the team, I am pleased to announce that the new Parkinson's Massive Open Online Course (MOOC) was launched on 5th February 2025! Tassie is certainly making its mark on the map as one of the world's leading producers of MOOCs and we have attracted more than 100 contributors from 6 different continents to help make the course, as well as several thousand participants already!

You may be wondering what a "MOOC" is though – well, it is a free course that can be completed by anyone anywhere in the world at their own pace and at their own preferred time. To do the course, you simply need a computer (laptop, desktop, ipad or other tablet are all fine) or a smartphone with access to the internet. The great thing about this MOOC is that it has been designed to give lots of information on Parkinson's in a very easy to follow style – it does not use long pages of complicated text but instead we use interesting video interviews, colourful animations (like the one above), fun quizzes and all written sections are kept quite short and understandable. All of the MOOC has been reviewed by people with Parkinson's and given the 'thumbs up' as easy to follow and useful!

So, want to know more about the MOOC? Here are a few commonly asked questions:

Who has developed the MOOC?

The Parkinson's MOOC has been developed by a team at the University of Tasmania led by two of our Parkinsons Tasmania board members - Jane Alty, who is a neurology doctor at the Royal Hobart Hospital and Professor at the university, and Michele Callisaya, who is living with early onset Parkinson's, a physiotherapist and Professor at the university. Together they were funded by the Parkinsons Research Foundation to develop a new Parkinson's MOOC and this has been more than 6 months in the making. They have worked closely with Harley Stanton from Launceston, who lives with Parkinson's, and many other people across Tasmania, as well as mainland Australia and the rest of the world.

Jane Alty and Harley Stanton attending an advocacy meeting to promote the Parkinsons MOOC.

Who is the Parkinson's MOOC for?

This course is for everyone. It is primarily for people living with Parkinson's, their friends and family, but also for health professionals, researchers, support staff and the wider community. The aim of this course is to increase understanding and awareness of Parkinsons, to reduce stigma and to encourage everyone to work together to improve the lives of people with Parkinson's.

Michele Callisaya, co-lead of the MOOC, being interviewed for the Parkinson's MOOC.

Have people with Parkinsons been involved in the course?

Absolutely! Michele, co-lead of the MOOC, and Harley are both living with Parkinson's and we have purposefully kept the focus of this course on people who live with Parkinson's. We recognise that people with Parkinson's are the true experts of what it means to live with this condition. They have generously shared their expertise through video-recorded interviews, stories and advice on how to live well with Parkinson's and we are very grateful for this input. We are also extremely grateful to have interviews with some of the world's leading medical and allied health professionals, scientists and researchers in Parkinson's.

Are the MOOCs any good?

Well of course, I would be biased when I say "they are superb" as I am co-lead but if you want some "hard facts" you only have to look up the Class Central independent ratings where you will see that the previous four University of Tasmania MOOCs (two on dementia, and one each on multiple sclerosis and traumatic brain injury) are in the top 10 highest ranked health-related MOOCs out of >2,000 worldwide! Since 2016, our MOOCs have had approximately 800,000 enrolments from more than 240 countries and we have an internationally renowned reputation for producing high quality online education that is interesting and engaging.

What will I actually have to do if I sign up for the Parkinson's MOOC?

Mostly it involves watching a series of videos lasting about 1-5 minutes each – which are both engaging and informative. These "bite size" pieces of information delivered though videos are a great way to learn at your own pace without feeling it is too much effort. The Parkinson's MOOC comprises 5 modules and each module will cover a different aspect such as 'understanding the symptoms' and 'learning about medications'. When you log into the course, you will be guided through a series of screens where you get to watch fascinating interviews of people with Parkinson's sharing their insights and advice, as well as doctors, nurses and others explaining key points. You can also watch animations that are like a cartoon summary of a topic and then can test out your knowledge by trying out some quizzes. There are also optional extras such as posting your own pieces of advice,

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tips and feedback online to interest with other MOOC uses on "discussion boards" and taking part in research surveys.

How long will it take?

This depends a bit on how much you interact with each of the five modules. Some people will choose to just watch the videos and not do the quizzes for example, and some people will jut skip over certain sections. The nice thing about the MOOC is that you can choose which parts you want to interact with. If you completed all elements in a module, it would take you about 2-3 hours to complete. You do not need to do this in one sitting though and you can choose whether to do, say 15 minutes of MOOC every day for a few weeks, or do 1 hour a day at the weekends. Each time you log back in to the MOOC, the website will take you to where you last left off too – so it is really easy to dip in and out of the course - and at the end you get a certificate of completion.

How do I sign up?

All you have to do is type this webpage address: "mooc.utas.edu.au" into your phone or computer to find the Parkinsons MOOC and then enter your name and email into the "Expression of Interest" section. You will then be emailed the details of how to access the course and you are ready to go! Don't forget to spread the word among your friends, family and community groups too – each person just needs to follow the steps above so they can get their own unique log in and password.

On behalf of all the Parkinsons MOOC team, I would like to thank everyone for their contributions and encourage you all to join up to do the course, spread the word and give us your feedback!

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Parkinson's Research (June 2024) "Major step" in Parkinson's Research as new staging framework announced

Leading scientists and patient organisations have worked together to release a research framework for defining and staging Parkinson's based on biology, rather than clinical symptoms. The impact of this framework could accelerate research, improve the development of new drugs and help diagnose Parkinson's before physical symptoms emerge.

25 January 2024 By Laura Vickers-Green
News MJ Fox Foundation, Parkinson's UK, Research

An international working group of Parkinson's experts and patient organisations has proposed a significant new research framework that – for the first time – stages Parkinson's and defines it based on its underlying biology.

This new framework has been published in a paper in the January issue of The Lancet, after being developed by the Critical Path for Parkinson's Consortium (CPP), which was founded by the Critical Path Institute and Parkinson's UK, with collaboration from organisations including The Michael J Fox Foundation and Parkinson's Europe.

What is the new Parkinson's framework?

The new proposal outlines how two medical tests could be used to accelerate research by more accurately identifying Parkinson's in clinical trials. The two tests are:

- a new test that can identify a protein called alpha-synuclein (which Parkinson's causes to clump together, damaging the brain) in spinal fluid taken via a lumbar puncture – making this test the earliest known indicator of Parkinson's

- a brain scan called a DaTSCAN that can tell if there is a lack of a chemical called dopamine in the brain, another crucial sign of Parkinson's

Importantly, both tests can help to identify Parkinson's in people even before symptoms emerge, which The Michael J Fox Foundation describes as a 'paradigm shift after nearly two centuries of relying on outward, primarily movement-based symptoms' to detect the condition.

This new biological framework for Parkinson's can then be used in a system for staging the disease that accounts for Parkinson's risk, diagnosis, and functional impairment ranging from slight to severe. A person's Parkinson's "stage" is based on a combination of their genetic risk factors and the results of the two tests above (i.e the presence of alpha-synuclein in the spinal fluid, and depleted levels of dopamine in the brain).

Accelerating research

While this new staging system isn't being used for Parkinson's treatment just yet, the framework will help with clinical trials. Claire Bale from Parkinson's UK explains how:

'A huge challenge for Parkinson's clinical trials is that the condition is currently diagnosed and monitored based on symptoms which can vary from person to person, and from hour to hour.

For trials to be successful, it is important that the right people are identified to take part, and that we can measure whether the treatment has the desired effects.

Having tests that can tell us what is happening inside the brain has the potential to revolutionise clinical trials. They will allow us to select the right people and better measure the potential of the treatment under investigation.'

Being able to begin clinical trials in people with Parkinson's who aren't even showing physical symptoms yet could ultimately lead to therapies that prevent the onset of those symptoms entirely.

Just the beginning

This new framework is an exciting milestone for Parkinson's, but members of the Critical Path for Parkinson's Consortium view it as the starting point in an ongoing effort to develop the scientific knowledge that will help to identify, treat and ultimately cure Parkinson's.

Peter DiBiaso, co-author of the paper and member of The Michael J Fox Foundation's Patient Council, says:

'It's still early, but this framework will have an immediate impact in terms of how we're designing clinical protocols and optimising research that can lead to better treatments that patients are waiting for. We know there's a lot of work to be done, but this is the most important first step the field can take together to rapidly advance breakthroughs for patients and families.'

Professor David Dexter, Director of Research at Parkinson's UK, says:

'This initial framework is just the beginning. These two tests are a great start but there are lots of exciting advances happening in this field at the moment… The ultimate goal is to accelerate the development of new treatments that can transform the lives of people with the condition.'

And finally, Tanya Simuni, MD – lead author of the research paper and director of the Parkinson's Disease Movement Disorders Center at Northwestern University, says:

'Our shared hope is that this new framework will foster innovation in clinical development, making trials more efficient and streamlining regulatory review… The success that the Alzheimer's field has had with its biological framework provides the inspiration and motivation to achieve similar accelerated timelines in Parkinson's. Ten years from now, we hope we will look back and say this framework was the key that finally opened the door to next-generation treatments in Parkinson's.'

What Parkinson’s Feels Like: artist with Parkinson’s publishes illustrated e-book

A new illustrated e-book What Parkinson’s Feels Like by Canadian artist with Parkinson’s Barbara Salsberg Mathews is now available to download (06 November 2024 By Verity Willcocks)

A new e-book, What Parkinson’s Feels Like: a collection of illustrations inspired by descriptions written by people with Parkinson’s around the globe, has been created by Canadian artist with Parkinson’s Barbara Salsberg Mathews to raise awareness and share with others what it’s like to live with the condition.

Free to download, the e-book is the result of a question Barbara posted to her social media followers with Parkinson’s earlier this year: what does Parkinson’s feel like for you? Barbara then created several artworks conveying the essence of the responses she received using mixed media including watercolour, ink, acrylic paint and Photoshop.

Describing what she wanted to achieve with the book, Barbara says: “As [cognitive psychologist, musician, and author] Daniel Levitin wrote, ‘The power of art is that it can connect us to one another and to the larger truths about what it means to be alive and what it means to be human.’ So, I used my skills as an illustrator, especially while I can still draw and paint, to capture what Parkinson’s really feels like.”

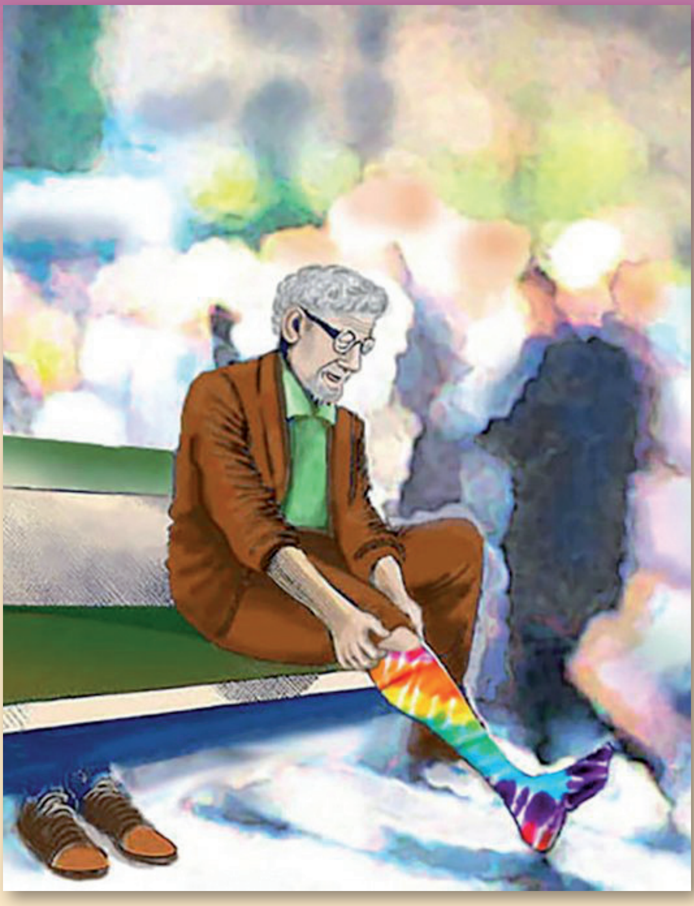
Barbara found the process of working on the illustrations profoundly meaningful.

“At first, I had thought we’d create a comic book with a few drawings per page. But the descriptions submitted were often quite complex and deeply moving. These required more time to capture the visuals that I saw in my imagination, all the while honouring the contributors’ voices.”

Barbara Salsberg Mathews

Sometimes Barbara’s Parkinson’s symptoms slowed her down, with fatigue forcing her to pace herself. “At times, I pushed my weak, formerly dominant hand and arm to convey what was in my head, as often my body ran ‘out of gas’ when my meds wore off. But I got used to telling myself, ‘I can still draw and paint, it just takes me longer.’”

Barbara also believes that working on the project improved her art. “Many of the submissions challenged me as an artist, which helped make my work stronger. For example, Dave Clark, one of the presenters of podcast 2 Parkies in a Pod, described living life in slow motion. I wanted to suggest a fast-moving world in contrast to the slow-moving person in my artwork. So, I blurred the people in the background.”



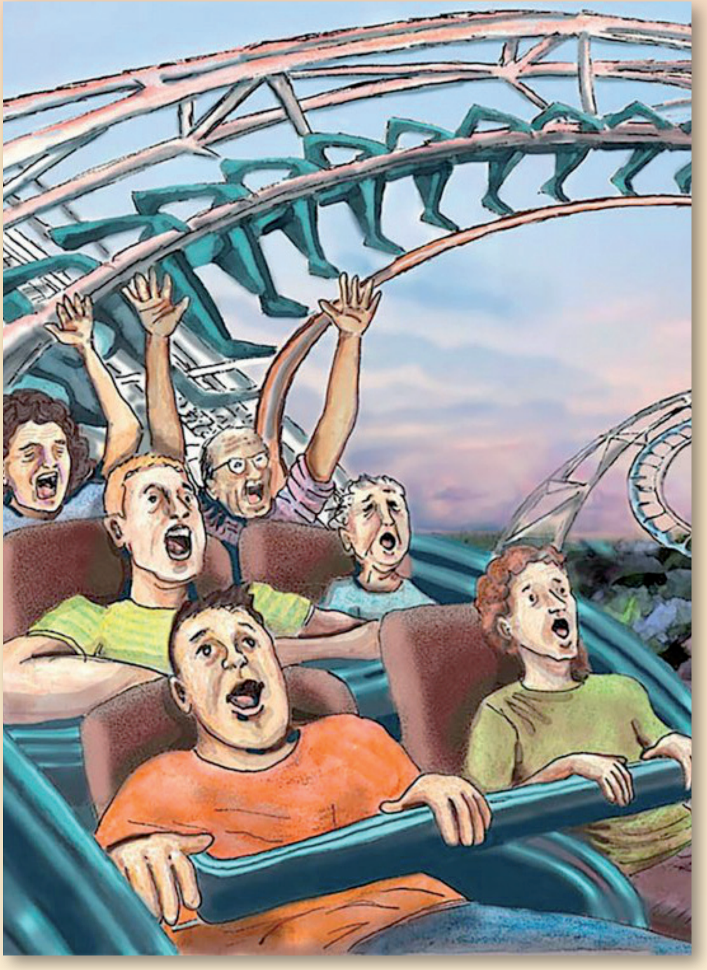
Seeing their thoughts converted into art struck a chord with those who sent their descriptions of Parkinson's to Barbara.

Those sent in by Richelle Flanagan, an Irish dietitian with Parkinson's and founder of the My Moves Matter app, and Dr Soania Mathur, a Canadian Parkinson's advocate with Parkinson's, were merged as follows: "Parkinson's feels like an unwelcome guest who is still in my house when I get home and I have to look after them. They try holding me back as I do my best to face the challenges that are inevitable."

Barbara's resulting painting, of a woman coming home to find a man sitting at her table expecting dinner, provoked this response from Richelle: "Mr Parkinson is feeding on my dopamine neurons. I look forward to the day that I can stop feeding him and boot him out!"

Paqui Ruiz, of the Spanish association of women with early onset Parkinson's Con P de Parkinson, likened having Parkinson's to being on a rollercoaster – a view shared by Ben Stecher and Judy Furman: "Parkinson's feels like a never-ending roller coaster ride of emotions, with ups and downs, never knowing what's around the next bend."

In response, Barbara drew a group of people on a never-ending rollercoaster.



Commenting on the picture, Paqui said: "This is how I think the disease develops. There is a twisted side and there are better sides; it's the duality of our body, how we feel, how we are seen. Our essence as a human being is something that neither this nor any other disease can take away from us."

Barbara says: "Reading these descriptions reminded me that I'm not alone with these symptoms. I could never have created this booklet without the descriptions of all those who shared their lived experiences with Parkinson's. I'm most grateful to my fellow Parkinson's sisters and brothers."

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Dates to Remember

SUPPORT GROUP MEETINGS

SOUTH
2.00pm Senior Citizens Club Rooms
Lambert Ave., Sandy Bay
26th February, 26th March, 30th April, 28th May 2025

NORTH
2.00pm Launceston Conference Centre, Door of Hope Church, 50 Glen Dhu St., Launceston
11th March, 8th April, 13th May, 10th June 2025

NORTH WEST
2.00pm Gnomon Pavilion, 3 Wharf Road, Ulverstone
12th March, 9th April, 14th May, 11th June 2025

CARERS GET-TOGETHER

SOUTH
10.00am 12 Adelie Place, Kingston
20th March, 22nd May 2025

NORTH
2.00pm Launceston Conference Centre,
Door of Hope Church, 50 Glen Dhu St.,
Launceston
14th March, 13th June 2025

NORTH WEST
2.00pm Willaway Apartments,
2 Tucker Street Ulverstone
13th March, 12th June 2025

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Nor is it to be construed that other material on any of the subject matter is unavailable.
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