National Parkinson's Alliance











UNIVERSITY of TASMANIA





For more information please visit nationalparkinsonsalliance.org.au

National Parkinson's Alliance

The National Parkinson's Alliance is a new national collaboration of key stakeholders and leaders in the Parkinson's community in Australia who have come together to inform and shape policies, strategies, and initiatives that will enhance the lives of individuals affected by Parkinson's disease across Australia.

Through national collaboration and leadership, the Alliance is working across and within different regions and populations, with and for the Parkinson's community, to address earlier detection and diagnosis of Parkinson's disease, better access to healthcare, resources, supports and treatments and research to better understand causes, mechanisms, new and improved treatments and prevention.

The Alliance will drive action and change with and for the community by:

- 1. Holding an Australian Summit to End Parkinson's in Canberra, 2024
- 2. Develop and deliver a National Parkinson's Action Plan
- 3. Formation of the National Parkinson's Alliance to advocate with and for people living with Parkinson's and the Parkinson's community

Through our collaboration across organisations, sectors and professional disciplines, we have harnessed the collective power of our diverse national community. By pooling our knowledge, resources, and expertise, we will achieve greater impact, address complex challenges, and create transformative solutions to enhance the lives of people with Parkinson's in Australia.

About Our Beginnings

Through Wings 4 Parkinson's intelligence gathering across various sectors including government, research, healthcare, and the community, the development of a National Action Plan for Parkinson's disease in Australia was recommended - in-line from advice received from Tasmanian senators Wendy Askew and Catryna Bilyk, Co- chairs of the Parliamentary Friends of Parkinson's. This initiated the formation of our new entity to support national leadership and advocacy for the Parkinson's community.

Our Reach

The National Parkinson's Alliance will lead nationwide advocacy efforts on behalf of the Parkinson's community, leveraging its extensive community engagement, which surpasses 600,000 contacts through various channels such as web platforms, social media, direct mail, and health calls. Member organisations of the Alliance, including Parkinson's NSW, Fight Parkinson's, the Shake It Up Australia Foundation and Parkinson's Tasmania play pivotal roles in providing services and support to individuals and communities affected by Parkinson's disease.

The Alliance members from NeuRA, WEHI, Menzies Institute of Medical Research, the University of Tasmania and Queensland University of Technology are leaders in the Movement Disorder and Parkinson's research fields nationally and internationally. Leveraging their collective expertise, these institutions not only lead ground-breaking research initiatives but also play a pivotal role in fostering collaborative efforts and knowledge exchange within the scientific community and beyond.

National Parkinson's Alliance Members



Parkinson's

Together we can

🖉 Fight



Emma Collin joined Fight Parkinson's (formerly Parkinson's Victoria) in 2013 as CEO. Emma's leadership ensures Fight Parkinson's has the most comprehensive and advanced information, education, and support programs that empower people living with Parkinson's and Atypical Parkinson's, enabling them to thrive.

Emma's leadership has seen Fight Parkinson's adopt and invest in an Australian first NFP organisation's best practice multidisciplinary model of care, establishing prominent academic and clinical peer-to-peer networks, facilitating the translation of existing research and stimulating future research.

Since 2016, Emma has been a member of the World Parkinson's Coalition (WPC) Leadership Forum Executive Team, which led to her current appointment as co-chair in 2019. Emma is also a member of the WPC Executive Committee providing oversight of international meetings.



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MENZIES 🛑

Institute for Medical Research

A/Prof. Michele Callisaya

Principal Research Fellow - Menzies Institute of Medical Research, Parkinson's Tasmania and Wings 4 Parkinson's

Michele is a Principle Research Fellow at the University of Tasmania and Senior Research Fellow at Monash University (field of research: dementia, falls and frailty).

Michele is a registered physiotherapist working for over 20 years in general and neurological rehabilitation.

She is a member of Parkinson's Tasmania management committee and WINGS for Parkinson's, and living with Parkinson's Disease.

Michele is a part of the Fight Parkinson's physiotherapy and exercise physiology Community of Practice; a number of Parkinson's peer support groups including Fight Parkinson's YOP group, and Facebook Australian and NZ Parkinson's groups, and has links to university and allied health professional Parkinson's researchers.





Prof. Tracey Dickson

Director - Menzies Institute of Medical Research

Professor Dickson (BSc, PhD) is a neuroscientist with a national and international reputation in determining the pathological basis underlying Parkinson's disease, Motor Neuron Disease, and the neuronal response to trauma. She currently holds the role of Director of the Menzies Institute for Medical Research at the University of Tasmania.

In addition to her leadership roles in the College she leads an ambitious and productive research team consisting of three post-docs, four PhD students, one research assistant and one honours student.

Professor Dickson was previously an NHMRC Career Development Fellow (2008-2012), and CJ Martin Postdoctoral Fellow (2001-2004), spending two years at the Mount Sinai, New York. The goal of her Parkinson's research is to understand underlying mechanisms and develop new therapeutic targets with a particular focus on spread of disease and the role of non-neuronal cells.





Prof. Carolyn Sue AM

Kinghorn Chair, Neurodegeneration - Neuroscience Research Australia

Professor Carolyn Sue, MBBS, PhD, FRACP, is an internationally recognised clinician-scientist and leader in Parkinson's disease clinical care and research. She is the inaugural Professor and Kinghorn Chair, Neurodegeneration at Neuroscience Research Australia and University of New South Wales, Sydney. Professor Sue is the immediate past Executive Director of the Kolling Institute, where she positioned the institute as a centre of world-leading translational research excellence.

She is recognised for her research combining the use of genomics, molecular neuroscience and adult stem cell models to identify and develop targeted therapies for Parkinson's disease. Carolyn's experience, expertise and contribution have been widely recognised. She is a Fellow of the Australian Academy of Health and Medical Sciences and serves on the Council of the National Health and Medical Research Council.

She is the current President of the Movement Disorder Society of Australia and New Zealand, and holds multiple leadership roles at International Parkinson's disease and Movement Disorder Society. In 2019, Carolyn was awarded a member of the Order of Australia (AM) in recognition of her significant services to medicine, particularly mitochondrial disease.





Mary Kay Walker CEO - Parkinson's NSW

Mary Kay Walker joined Parkinson's NSW in 2018 as Chief Operating Officer. In that role, she was responsible for delivering on the organisation's servicesled strategy by driving sustainable financial and operational performance. Mary Kay brought this deep operational knowledge to the position of Chief Executive Officer when first appointed in an acting role in 2023.

Her priorities are contributing to the National Parkinson's Action Plan, and advocacy to NSW Government Ministries and NSW Health. She is also strengthening relationships with researchers, Movement Disorder Specialists, and Parkinson's nurses across the state.

Prior to joining Parkinson's NSW, Mary Kay built a 32-year career in key finance and administration roles in Australia and the United States. She holds a Bachelor of Science with a double major in Mathematics and Bachelor of Science (Honours) in Psychology from the University of Sydney and a Diploma in Securities and Financial Markets from the Financial Services Institute of Australasia.







Mike Whitehouse OAM

President - Parkinson's Tasmania and Wings 4 Parkinson's

Mike has been on the Board of Parkinson's Tasmania for the past 17 years and took on the role as President with the death in December 2022 of Helen Connor Kendray.

Improving the wellbeing of people living with Parkinson's, and their carers, will allow greater independence and quality of life. He has represented Parkinson's Tasmania on the board of Parkinson's Australia for a number of years.

He is a retired Chartered Accountant who worked in business as the Chief Financial Officer of corporations including Richardson's Meat Industries, Savings Bank of Tasmania, Tasmanian Government Insurance Office and Hobart Ports Corporation. He has been a member of Rotary International since 1974 and has held numerous honorary financial positions at Club, State, and National levels. In 2022, the Directors of Rotary International in Chicago USA awarded Mike Rotary's top recognition, "a Service Above Self Award", for his contribution to the organization and community.





A/Prof. Richard Gordon

Program Lead, Translational Neuroscience & Therapeutics Program -Queensland University of Technology

Associate Professor Richard Gordon is a Group Leader in Translational Neuroscience and Therapeutics Development at The Translational Research Institute (TRI) and Queensland University of Technology (QUT). He has a career track record of research in Parkinson's disease with a focus on developing new treatments.

Dr Gordon leads a large research program funded by the US Department of Defense, the Michael J Fox Foundation, Queensland Government and US Biotech companies. His research team uses clinical studies and experimental models to identify mechanisms and pathways involved in Parkinson's, with the ultimate goal of developing treatments and tools for early diagnosis. Dr Gordon is a Science Ambassador for the World Parkinson's Coalition (WPC) and a certified Toxicologist with the American Board of Toxicology and studies how environmental factors, such as chemical exposures, contribute to Parkinson's disease.

He is also a member of the Advisory Committee on Chemicals Scheduling (ACCS) for the Australian Therapeutics Goods Administration's (TGA), which makes recommendations to the Department of Health on the scheduling of chemicals and medicines in Australia.



Vicki Miller

CEO - Shake It Up Foundation

Vicki Miller joined Shake It Up in 2017 as Executive General Manager and took on the CEO role in 2022.

During her time with Shake It Up Vicki has worked to increase the profile of the foundation and raise significant funding to support Australian Parkinson's research. Shake It Up is the largest non-government funder of Parkinson's in Australia and in partnership with The Michael J. Fox Foundation for Parkinson's Research has granted more than \$32 million to 23 Australian research Institutes funding 79 research projects since 2011.



Vicki is a passionate advocate for people living with Parkinson's after watching her grandmother live with the disease and was attracted to the not for profit sector because of her desire to work for purpose and help others. Vicki has also served on several boards including the Children's Medical Research Institute and is currently on the Board of the Southern Highlands Community Hospice.

A/Prof. Jane Alty

Movement Disorders Neurologist - Menzies Centre and Co-Director of the Island Clinic - University of Tasmania

Jane is a UK-trained Neurologist who moved to Tasmania in 2019 and is currently working as a Staff Specialist at Royal Hobart Hospital and a researcher at UTAS.

Jane is passionate about improving medical care and research for people with PD. Key immediate objectives include 1.) Building a data base of people with Parkinsons (PwP) in Tasmania; and 2) Developing straightforward computer tests that can be used at home or in GP clinics; 3) Expanding the UTAS courses to include an UP MOOC (Understanding Parkinson's Massive Open Online Course).

Jane was formerly Consultant Neurologist at the Yorkshire Regional Neurosciences Centre and has received numerous awards for clinical excellence and is highly regarded by international colleagues for her research and work on Parkinson's.









Assoc. Prof Grant Dewson

Laboratory Head, Ubiquitin Signalling Division - WEHI and Head, WEHI Parkinson's Disease Research Centre

Cell biologist with a research focus on cell death mechanisms, mitochondrial function and ubiquitin signalling in disease. His lab's research aims to understand the coordinated control of these fundamental processes and to exploit this knowledge to develop new drugs that can improve neuronal survival. His teams Parkinson's research has been supported through funding from NHMRC, Parkinson's Foundation, and MJFF.

In 2021, established WEHI's Parkinson's Disease Research Centre that now comprises 9 WEHI research labs, together with the RMH Movement Disorders Clinic and a passionate Parkinson's advocacy team (12 consumers).

The goal of the Centre is to undertake multi-disciplinary research to understand the underlying causes of Parkinson's to enable a precision medicine approach to develop targeted disease modifying therapies.





Wings for Parkinson's

Dr Harley Stanton

Chair - Wings 4 Parkinson's

Harley retired to Launceston after some 30 years working with WHO, UICC and other international agencies especially in reducing tobacco use in Australia, the Pacific and Asia. In 1999 the Australian Government seconded Harley to support the development of the WHO Framework Convention on Tobacco Control (WHO FCTC).

As part of the ISLAND Wicking Dementia Project Harley asked Associate Professor Andrew Williams what was being done on Parkinson's who suggested he contact Dr. Jane Alty. The fledgeling meeting in 2021 led to the WINGS 4 PARKINSON'S Specific Interest Group. Harley was diagnosed with PD in late 2019 and has appreciated the input from Tasmanian Health Service.

Harley is keen to see more focus and awareness on PD particularly on non-motor aspects including possible research with PD Warriors groups, Parkinson's Tasmania and other community action. He is also keen to see the national and global inputs can give us the best directions for diagnosis and treatment into the future. His aim is to give focus to PD in Tasmania and ensure that we collaborate and develop the best of care, research and support to PwPD in Tasmania and nationally.

The National Parkinson's Alliance is committed to visionary and impactful leadership that will drive change to achieve greater impact for the Parkinson's community.

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