

President's Report

It is now my privilege to present the President's Report to this Annual General Meeting.

As is our tradition, I would like to begin by asking for a minute of silence in memory of those in the Parkinson's community who have passed away since our last meeting.

<Minute of silence>

Thank you.

Fiscal 2019-20 was my second year as President of Parkinson's NSW. It was a year in which we refreshed our Board and strengthened the array of skills available for the governance and direction of the organisation.

I would like to formally welcome our new Directors: Janina Jancu, Nicole Schliecher, Margaret Scott, and Denise Thomas.

Margaret Scott was also voted into the position of Vice President of the Board in March of this year.

I would also thank our outgoing Directors: Rodney Chaplin, Ramy Soussou, and Jaimee Thompson.

The skills we now have on the Board include executive management across multiple sectors, fundraising, corporate governance, law, finance, quality management, service delivery, and risk management.

As the Constitution of Parkinson's NSW suggests, two Directors – including myself – are living with Parkinson's. I am also the regional NSW representative on the Board.

Parkinson's NSW now has a strong, accomplished, and united Board in place.

Together we are focused on strategy and governance that will enable us to better execute the Parkinson's NSW Mission of delivering life-enhancing services now, as the search for a cure continues.

One particularly troubling governance issue was resolved over the second and third quarters of fiscal 2019-20.

It related to the operations of the Parkinson's NSW Trust which were not in alignment with the Vision, Mission and Purpose of Parkinson's NSW.

Accordingly, the Board of Parkinson's NSW made the decision to remove the Trustee of the Parkinson's NSW Trust.

The Trust is separate from the charity Parkinson's NSW and has its own, separate Board.

However, the Trust is a 'related entity' of Parkinson's NSW and is included in our financial accounts.

During the year under review, Parkinson's NSW as a charity was able to post a significant net profit of \$264,663.

Due to the impact of COVID-19 on financial markets, investments by the Parkinson's NSW Trust delivered lower returns than in previous years.

Although the Parkinson's NSW charity delivered a profit, its consolidation with the Trust as a related entity resulted in a loss of \$309,249.

The new Trustee Board subsequently put the investment management of the Trust funds out to tender. A new fund management firm was appointed.

The Trust Board is now working with the new fund manager on the future investment strategy of the Trust, as well as its distribution policy – while exercising appropriate governance and compliance with the Trust's mission and purpose.

Our other major challenge during the year was the same one facing every enterprise and individual in Australia – the COVID-19 pandemic.

On a personal note, I must say it has been a disappointment that I have not been able to get out and visit more Support Groups in person since early this year.

However, I thank our staff for their Herculean efforts and ingenuity in adapting to this significant challenge – and continuing to deliver services and support at very high levels.

Despite these challenges, we have grown our Support Group network to 90 Groups with more than 1,850 participants across NSW.

This represents a growth of 30% over one year.

I must also applaud Support Group leaders and participants.

They acted quickly and went to extraordinary lengths to continue supporting to one another – despite living under great stress due to COVID-19.

While the ongoing rollout of our Parkinson's Specialist Nurse program is going slower than I would like, we are still making progress.

Parkinson's NSW signed an agreement with the Northern NSW Local Health District to co-fund and recruit a full-time nurse to support people living with Parkinson's in the Tweed Region. That new nurse starts work this month.

Our existing Parkinson's Specialist Nurses remain in place in the Shoalhaven region, Coffs Harbour and Port Macquarie.

I have also joined a committee to oversee and monitor the roll out of the Federal Government's Neurological Nurse Trial in Far Western NSW.

Our research in conjunction with Charles Sturt University shows that the Local Health District-based model delivers superior results and cost savings to Government.

However, we are certainly not going to discourage investment in any form of nursing that holds promise for people living with Parkinson's in under-served regions of NSW.

I should also note that Associate Professor Rachel Rossiter from Charles Sturt University sits with me on the Governance Committee for this Far Western NSW Neurological Nurse Trial.

We have a long association with the CSU School of Nursing, Midwifery, and Indigenous Health.

It was Dr Rossiter and her team who conducted our joint research into the viability of the community-based Parkinson's Specialist Nurse model.

This is just one example of the research and sector partnerships we have underway.

Another important project is being conducted by our most senior Parkinson's Specialist Nurse. He is undertaking PhD research at Charles Sturt University with a focus on identifying the best models for effective Parkinson's Support Groups.

We have also reached agreement with Parkinson's Victoria to work together on projects of mutual benefit – such as joint advocacy to the Federal Government.

I am also pleased to report that we have signed an MoU with Hornsby Hospital for a Nurse placement to support Parkinson's patients living on the northern fringes of the Sydney metropolitan area.

The population of the Northern Sydney Local Health District – where Hornsby Hospital is located – is more than 800,000 people. So, it is an area of significant unmet need for the Parkinson's community.

Before closing, I would like to thank the NSW Parkinson's community for its overwhelming support for the myself... the new Board... management and staff.

This is reflected in the significant majority of proxies I have received.

People living with Parkinson's just want to know about their services and support – and how related projects which will improve their lives now, as the search for a cure continues.

So, I challenge you all... if you really care about this organisation... then step up and make a real contribution.

There are many ways other than being a Board Member to make a contribution to Parkinson's NSW.

Volunteer your skills and services at the coalface where the real work is done.

We welcome questions, constructive suggestions, and practical offers to share skills and contacts.

Margaret Scott's appointment as Vice President has allowed me to share my workload and free up more time for outreach to Support Groups and advocacy for more community-based Parkinson's Specialist Nurses.

So, you can expect to see and hear even more from me over the coming year!

Thank you.