

InTouch
Support Group Newsletter
February 2022

Maitland fundraises with successful art exhibition

A successful art exhibition by Maitland Support Group attracted both publicity and financial support in December.

Titled *Looking through windows in the time of COVID-19*, the exhibition featured fibre art by Helen Tolhurst – the Leader of Maitland Support Group. The exhibition was formally opened by Cassie Morgan, Support Group Coordinator of Parkinson's NSW.

Helen Tolhurst is a retired GP who is living with Parkinson's. She has been working with embroidery, fabric dyeing, felting, and beading for more than 40 years.

Her works in the exhibition were mixed media – some made with hand-made felt which is created from wool and silk fibres, and others with a base of synthetic fabric which was hand dyed.

The works were hand embroidered with wool, silk, cotton, and synthetic threads. Some of them also included pieces made from polymer clay.

In addition benefiting from funds raised on the day from sales of the artworks, the craft group from the Walker Grange Lifestyle Village made a generous donation of \$1,000 to the Maitland Support Group.

The Group plans to use the donation remote car racing, African drumming, and the formation of a choir.

The Maitland Support Group was established in 2019 and grew quickly from 12 participants to more than 70.

Australia Day Honors

Di Lymbury, long-time leader of the Lismore Parkinson's Support Group, was honoured in the Australia Day Awards as Citizen of the Year.

The Award recognises her role since 2015 in creating, nurturing, and maintaining a safe place for citizens of Lismore and its Local Government Area who are living with Parkinson's, or caring for someone who is.

A tribute from her Support Group states:

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She has humbly served the community without fanfare or applause yet has made, both directly and indirectly, degrees of difference in people's lives that can only be measured in magnitudes.

Asked to comment on her honour, Di said:

“Those who experience the diagnosis of Parkinson’s and their carers belong to a very special group. As a result of their daily battles, I believe they have learned a great deal of tolerance and understanding and have also developed great empathy for others.

“They have learned the value of support and friendship. They have learned to value what is truly important and to take the time and, in some cases, make huge adjustments in their lives in order to do those things that are of most import.

“In the role of a Convenor of Lismore Parkinson’s Support Group, I’m inspired by the participants – those with Parkinson’s as well as their wonderful carers – and I already feel richly rewarded.

“To then be honoured by the broader community is a very high honour indeed. I am extremely humbled that some have taken the time to nominate me for these awards. I am aware that there are many community members deserving of such an honour themselves.

“I consider myself most fortunate to be chosen as the Lismore Citizen of the Year, 2022, and am most grateful to Lismore City Council. The response has been overwhelming.

“I see this as very good news for our local Parkinson’s community as well as the wider Parkinson’s community. It will enable us to increase awareness of this disease in the community and the many ways it can affect our lives. It will also mean we can continue to advocate, with the assistance of Parkinson’s NSW, as well as our patrons, Member for Lismore, Janelle Saffin, and Jenny Dowell, OAM, for a much-needed community based dedicated Parkinson’s Specialist Nurse in our Local Government Area.

“With its two major hospitals, Lismore Base Hospital and St Vincent’s Hospital as well the University Centre for Rural Health, Lismore has for many years served as a base for many of the health services that meet the needs of rural communities right across the North Coast Region. Our group’s aim for a Parkinson’s Nurse appointment is to help service not only those in our immediate community, but to reach out to the more isolated rural areas from Urbenville to Yamba and everywhere in between.

“Our entire Parkinson’s community would benefit greatly from such an appointment. I am very much looking forward to reaching out to many more who are living with Parkinsons, to continuing my role with an extra special group of people and to work to improve the lives of many in our community. I shall also continue to value the role that Parkinson’s NSW plays.”

New Directors appointed to Parkinson's NSW Board

Two newly appointed Directors joined the Board of Parkinson's NSW in November 2021. They are Rachel Tanny and Roy Wakelin-King.

With more than a decade of community leadership and advocacy work for vulnerable people, Rachel Tanny brings a deep understanding of both the aged care industry in Australia as it currently stands and insight into forthcoming changes.

She also has experience in innovation incubation with a focus on big picture strategy within a risk assessment framework leading to financial growth and sustainability.

Rachel holds a Diploma of Business Governance from the Institute of Community Directors Australia as well as a Juris Doctor from the University of Richmond. She currently sits on the Multicultural Advisory Committee for Waverley Council and on the Jewish Board of Deputies.

She is currently the Chief Executive Officer of COA Sydney, Inc.

Roy Wakelin-King has held very senior positions across a range of government, private sector, and not-for-profit organisations.

Roy has extensive experience in executive leadership, with a successful career in transport and logistics, delivering multi-billion-dollar services and infrastructure programs, particularly for communities in regional NSW.

He was the Chief Executive at the NSW Taxi Council where he led the NSW taxi industry through a period of unprecedented disruption and transformation arising from the arrival of the ridesharing platform Uber, as well as the NSW Government's point-to-point transport reforms.

As Chief Executive of the World Youth Day Coordination Authority, Roy led the NSW Government's support to the highly-successful World Youth Day 2008 – a major international event that won great acclaim for Sydney and NSW.

Roy has held a number of Board appointments including with the Redfern Waterloo Authority and Australian Technology Park Sydney Ltd Boards, as well as the Board of the NSW Tow Truck Authority. Roy has also held the position of Company Secretary.

Roy served as a commissioned officer in the Australian Army, which included active service as part of the multi-national force that delivered humanitarian and security aid to war-torn Somalia.

Roy was awarded the Member of the Order of Australia for his service to public transport and his role in leading Government support to World Youth Day 2008. He has a Master of Business Administration and is a Graduate of the Australian Institute of Company Directors Course.

Tamworth Support Group celebrates 30 years

Tamworth MP Kevin Anderson summed up the three decades of community service provided by Tamworth Support Group at its anniversary celebrations in December, saying that the care and support of those most in need was "...driven by passionate community members who have given up endless hours of their time."

"It is a group that has worked tirelessly for three decades under the leadership of many community stalwarts," said Mr Anderson. "Today is about thanking those who care for people with Parkinson's. Family members, relatives, friends and specialists are all crucial in caring for those with Parkinson's and I can't thank them enough for the sacrifices they make."

"The group's current leader, Kevin Robinson, whose mantra is 'Sharing the load' – a mantra that recognises that a group is stronger and more united. I want to thank Kevin and the group for inviting me...they truly deserve the commendation of our community and I look forward to supporting them in any way that I can in the future."

Deputy Prime Minister Barnaby Joyce also sent his apologies along with a letter of congratulations to the group.

The luncheon was held at the North Tamworth Bowling Club, with tables carefully decorated, including special souvenir placemats featuring photos of the seven group leaders over the years.

The group was formed on 2 December 1991, at a meeting convened by Dr John Dearin from the Tamworth Base Hospital Rehabilitation Unit. Mrs Daisy Ivin became the group's first president. After 14 years in the position, Mrs Ivin was followed by Mrs Pat Johnson, then Denise Sullivan, Trish Betts, Len Mutton, Brian Harrison and current group leader Kevin Robinson.

In his address to the luncheon, Brian Harrison noted that Mrs Ivin was now living at Moonbi House, (a residential care home), while Mrs Pat Johnson and Denise Sullivan were at the luncheon, and Len Mutton was the MC.

Brian went on to highlight some of the achievements of the group over the years, which have greatly benefited people living with Parkinson's in the region.

"Trish, along with John and Ann Crosby, lobbied to have a Parkinson's nurse funded by the Department of Health appointed," Brian recalled. "Trish was also instrumental in having the Parkinson's exercise program established as Rural Fit."

"In March 2015 under Trish's leadership we hosted a seminar on Parkinson's at West's Leagues Club. Over three hundred people attended – people with Parkinson's, their carers, and medical professionals."

Carers were also specially thanked for their efforts.

"Our carers encourage us, they help us through the day, they are aware of our every movement during the long Parkinson's night," said Brian. "They remind us to take our

medications because we are becoming more and more forgetful. Sometimes they even have to help us dress and shower, and they prepare our meals.

“They drive us around, some even boss us around, and no doubt we nearly drive them around the twist, but they care. In caring, they share the burden, they lighten the burden.”

In closing, Brian thanked Kevin for his leadership and his enthusiasm for organising the anniversary celebrations, as well as thanking all who attend meetings, provide morning teas and take on various roles within the group.

Support Group Consultative Committee established

Parkinson’s NSW has established a Support Group Consultative Committee to act as a sounding board for ongoing decision-making about Parkinson’s NSW Support Group communications, education, Leadership Team training, operations, and activities.

In order to establish the Committee, an invitation was sent out to all Support Groups for people who wanted to nominate themselves for the role based on the following **core competencies**:

- Commitment to the purpose and values of Parkinson’s NSW.
- Belief in the value of Support Groups for enhancing the lives of people living with Parkinson’s and their caregivers.
- Must be – or have recently been – part of the Leadership Team (Committee) of a Parkinson’s NSW Support Group. (This includes people living with Parkinson’s, caregivers and Allied Health professionals who may be in leadership roles).
- Interest and/or experience in education and training.
- Belief in the role of Support Groups in advocating for the Parkinson’s community and raising community awareness of the disease.
- Prior involvement in fundraising activities.
- Ability to engage in respectful and thoughtful discussion of Support Group needs and issues.
- Willingness to abide by the legislative and legal requirements pertaining to Support Groups under:
 - The Australian Charities and Not-for-profits Commission (ACNC)
 - The Australian Tax Office (ATO)
 - The Fair Trading, Corporations Act
 - The Privacy Act

In addition we sought people with specific **functional competencies**:

- Ability to communicate via email, telephone and Zoom videoconferencing
- Knowledge of the structure, leadership requirements and operations of Parkinson’s NSW Support Groups.
- Some prior business, finance, management, planning, strategy, communications, education, sales, education, training, or other leadership experience.
- Experience in a caring role.

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- Ability to commit to three formal meetings per year, plus fulfilling requests for comment and feedback via email between meetings.
- Regional- or Sydney-based (a balanced representation was sought)

Eleven Support Group Leaders nominated themselves. The quality of their applications was such that all have been accepted for the Support Group Consultative Committee.

The successful nominees and their Support Groups were:

- Chris McCombie of Central Coast Support Group
- Claire Rich of Blacktown Support Group
- Jenny Zirkler of Nambucca Valley Support Group
- Joy Overs of Eurobodalla Support Group
- Karen Doyle of Tumbarumba Support Group
- Kim Dahler of Port Macquarie Support Group
- Lesley Errington of Kiama Support Group
- Sandra Elms of Newcastle Support Group
- Sue Sarlos of Illawarra North Support Group
- Terry Wiesner of Inner West Support Group
- Warwick Bisset of Goulburn Support Group