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From the President and Executive Officer

We are pleased to present the Annual Report for Palliative Care NSW for the year 2018/19.

Palliative Care New South Wales (PCNSW) continues to position itself as the leading voice for palliative care in NSW by providing support for our members and advice to government that reflects the broad range of service provision models.

PCNSW spent much of the last half of 2018 working on our biennial state conference 'Riding the Waves of Change held in Kiama in November. The we hit the ground running in 2019 with both State and Federal elections presenting us with opportunities to develop an election strategy and the chance to meet members of parliament in the lead up to the NSW election. The President's focus

for the first half of 2019 was to support the great work of the organisation including:

- A Review of the progress of the NSW Health previous commitment to palliative care workforce and education;
- Supporting aged care members or those who are engaged with this sector during the Royal Commission into Aged Care;
- Working with the Ministry on the 2018 National Budget announcement of matched State/Commonwealth funding to support palliative care in residential aged care facilities;
- Launching of the Art Gallery of NSW Palliative Care Program.







Julie Gissing and Robyn Swanson.



Biennial State Conference

In November 2018 we were fortunate to partner with our Kiama and NSW South Coast colleagues to host the PCNSW Biennial State Conference in November 2018.

We were successful in luring leading international Palliative Care expert Dr Robert Twycross, who made his first journey to Australia to present his keynote presentation in Kiama. It was an enormous honour for those who have dedicated their careers to the field of palliative care to have the opportunity to meet such a respected elder and intellect of the profession, and we were extremely fortunate he could join us. We are certain the attendance of Robert Twycross

contributed to us holding the largest ever conference at the Pavilion in Kiama, as well as the largest in the history of PCNSW.

Due to the ever-growing interest in our conferences we have endeavoured to secure conference venues that can accommodate over 300 attendees in the future. In early 2019 we announced that the next PCNSW Biennial Conference will be held on the Central Coast of NSW. Under the title of 2020 – A Clear Vision for Palliative Care. Thank you to the local conference organising committee for their support in bringing the upcoming 2020 conference to life in Terrigal.

Volunteer Support Services Programme

Throughout the financial year the Volunteer Support Services Programme has contributed significantly to our involvement and relationships with palliative care services around the state. The Programme aims to support and champion the work of the Palliative Care Volunteer Services throughout NSW.

Significant training and workshops have been provided all over NSW.

There has been a particular focus on Biography training and learning about the intersection of volunteering, palliative care and spirituality and self-care. All of these workshops have been enthusiastically attended, and we would like to thank all of the presenters and contributors at these events throughout the year.

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Danielle Galotta from the Art Gallery of NSW at the Professional Education Day.

National Palliative Care Week

During National Palliative Care Week the annual Palliative Care NSW Professional Education Day was held at the Art Gallery of NSW. Following the establishment of a relationship between AGNSW, UTS, City of Sydney and PCNSW we were able to provide an education day that was based on the existential aspects of palliative care. With a focus on the "whole" person.

Attendees were the first to experience a trial of the Art Access Program for carers and those working in palliative care. The day was a huge success and very much reflected the National theme for the week of "what matters most?".

The success of this day has led to the development of further art access programs for those working and caring in the palliative care field.

Membership

As a member-based organisation, our support base of palliative care professionals and others with an interest in palliative care is fundamental to us.

We welcome new members and thank all members for your ongoing support and we continue our commitment to making your membership fruitful and professionally supportive.

We offered complimentary memberships for the remainder of the financial year for non-members who attended the Kiama Conference, with a view to introducing them to the benefits of a paid membership into the future. We have received positive feedback from this initiative from people who were unaware of member benefits prior.

Donors

We receive regular donations from workplace giving arrangements and we thank all donors most sincerely for your support.

Grants

We gratefully acknowledge special funding granted from the Ministry of Health that allowed us to provide scholarship grants to Palliative Care Nurses from across NSW to attend the Kiama Conference. This was a significant factor in the overwhelming registrations we received and was an extremely well received initiative from our invaluable nursing community.

We also gratefully acknowledge the grant we received from the City of Sydney to progress the Art Access Program for carers, as well as the Art Gallery of NSW and UTS who have provided support in kind for this wonderful program.

We would like to gratefully acknowledge the ongoing funding for the Volunteer Support Services Programme through the Ministry of Health.

Acknowledgements

We acknowledge with thanks all our supporters of the last year.

We also thank our Management Committee for their unflinching commitment to this organisation and acknowledge their significant role in enabling us to achieve beyond our Strategic Objectives. We would also like to thank the staff at PCNSW who always go above and beyond what is expected in their respective roles. Alex Huntir has taken the fledgling Volunteer Services Support Program (VSSP) and turned it into a world-leading program of support for palliative care volunteers. Alex left in April 2019 and we can't thank him enough for the almost five years of leadership and innovation he brought to this project. Kate Bowman has been a key member of the VSSP team and we thank her for her wonderful commitment, professionalism and creativity in approaching this challenging work.

Colin Dent took over from Alex in May 2019 and has already made an impact on the Project. We look forward to working with Colin as the VSSP continues into 2019/20.

Megan Burke has been tireless in her efforts to get events happening, social media updated, member emails collated, Pallium - so much more. Thank you to all.

Linda Hansen

Executive Officer, Palliative Care NSW

Deb Parker

President, Palliative Care NSW

Our People

Management Committee

Deborah Parker

President

Therese Smeal

Vice President and Secretary

Peter Cleasby

Secretary until November 2018

Michael Edgar

Treasurer

Melissa Cumming

Peta McVey

Gerry Dixon

Joan Ryan

Colleen Carter

Liz Lobb

Felicity Burns

PCNSW Staff



Linda Hansen Executive Officer



Colin Dent Manager Volunteer Support Services Programme



Megan Burke Policy Officer



Kate BowmanPolicy Officer



Highlights

Media & Communications

2604

Facebook followers

500

new Facebook followers since last financial year

2500+

.....

Facebook post likes

1906

Twitter followers 50%

member email opening average

••••••

50%

Pallium online opening average

Research

2456 downloads of research and documents from PCNSW website 645

downloads of research reports from Volunteer Support Services Program website

••••••

1279

downloads of resources and publications from Volunteer Support Services Program website



Highlights

Attendance 2018

Volunteer Biography Training for Managers at Eastern Palliative Care, Vic

31 July - 1 August

VSSP hosted Broken Hill spirituality forum with Kate Englebrecht

23 August

NSW Network of Managers of Palliative Care Volunteer Services quarterly meeting

3 September

WNSWLHD volunteer project; Vision statement workshop with Mudgee stakeholders

20 September

VSSP hosted Orange spirituality forum with Kate Englebrecht

10 October

VSSP hosted Tamworth forum with Dr Michael Barbato

25 October

PCNSW Biennial state-wide conference, Kiama

8-11 November







The Patient Experience Symposium, April 2019 – Alex Huntir presenting.

Attendance 2019

NSW Network of Managers of Palliative Care Volunteer Services quarterly meeting

4 March

Commenced the Consumer and Carer Relief at End of Life (CCREOL) Project with funding from Coordinaire 14 March

VSSP presented at the launch of the new Palliative Care Volunteer Service in Coonabarabran

11 April

Hosted palliative care volunteer biography training, Surry Hills 18 April Presented on the WNSWLHD Volunteer Project at the Patient Experience Symposium

29 & 30 April

VSSP hosted Accidental Counsellor training in Mt Pritchard

15 May

VSSP hosted Accidental Counsellor training in Mittagong

20 May

PCNSW Professional Education Day at the AGNSW

24 May

PCNSW Volunteer Conference, Blacktown 3 & 4 June

VSSP hosted 'Life the universe and everything' forum with Kate Munro, Erina 19 June



Our areas of focus

Five areas of focus were identified by the Management Committee during strategic planning activities in 2017/18. Our strategic planning day in 2018 saw them subsumed into three:

AWARENESS & EDUCATION

Raise awareness about palliative care through the ongoing provision of relevant and up to date information and education.

PARTNERSHIP & COMMUNICATION

Increase the membership base to strengthen the core group of those engaged with palliative care. Build partnerships with related sectors, strengthen relationships with other relevant organisations.

LEADERSHIP

Increasingly position PCNSW as a thought leader in the area of palliative care.



Our areas of focus

Awareness and Education

We spent much of 2018 preparing for the November conference in Kiama, Riding the Waves of Change. The Conference Organising Committee did an amazing job throughout last year to ensure yet another very popular conference to our members. In addition to their already demanding roles and responsibilities, the additional work of organising a conference can be quite overwhelming at times. It was a pleasure to get to know the team from the Illawarra and South Coast regions, we thoroughly enjoyed your hospitality and benefited from your expertise over the past year.

The annual Professional Education Forum was held at the Art Gallery of NSW this year. Attendance at this forum was free for PCNSW members and is targeted to palliative care professionals. The goal of this forum was to increase the level of specialist palliative care knowledge for attendees. Communication with members and the public has increased steadily over the year. Facebook continues to be the most effective platform on which to link to our own original content as well as current news events in the palliative care world. With over 500 new followers on Facebook it is an increasingly popular medium.

Regular newsletters throughout the year have provided our members with palliative care news, stories, job opportunities and research. Complemented by the now online Pallium, released quarterly.

We continue to respond to the frequent telephone enquiries from members of the public, GPs and RACFs, in search of information and guidance about access and referral to palliative care services across NSW. There has been a small increase in calls this year. We continue to improve our website so that members of the public can find the answers they are looking for there without having to call us.

All existing resources about palliative care, end of life care, aged care, planning ahead as well as dementia specific and other disease specific resources are available for download via the website. Printed resources are also available free of charge to members and at a cost recovery basis to non-members.



Linda Hansen with NSW Premier Gladys Berejiklian, Health Minister Brad Hazard and Yvonne McMaster.

Partnerships and Communication

Membership

Representing and serving our members is an important goal for Palliative Care NSW. Our limited resources make this challenging, however with some generous sponsors we were able to offer incentives for people to join and renew their membership for 2018. Combined with the discounted registration fees offered to members for the November conference we have seen our membership increase by 40% for the year. The development of a new database will hopefully support further increases in our membership base, as well as opportunities for better engagement.

Leadership

Budget Submission Election Platform

PCNSW is represented on a range of government and non-government committees and groups including the Agency for Clinical Innovation, NSW Ministry of Health End of Life Advisory Committee and Palliative Care Australia National Policy Advisory Committee. As well, our President represents PCNSW at PCA President's meetings and other ad-hoc committees. We also support and attend the Palliative Aged Care Nurses group.

PCNSW develops an election strategy 'call to action' for every state election and a budget statement every year. The Executive Officer also meets regularly with representatives from the Ministry of Health and the Minister for Health and advisors.

We are very pleased to acknowledge the ongoing support and commitment of the Minister for Health, the Hon Brad Hazzard and the Ministry to improving palliative care in NSW with the announcement of \$45 million to increase the number of palliative care nurses in NSW.



Volunteer Support Services Program update

A significant event for the Volunteer Support Service Program for the year was the departure of Alex Huntir in April this year to commence work with Latrobe University. Alex's work over the years saw the program grow as a highly regarded program and holding significant achievements in understanding and recording the work of palliative care volunteers and volunteer programs across NSW as well as implementing projects that benefited palliative care.

In October 2018 **KPMG** were appointed by the Ministry to perform an external evaluation of the Volunteer Support Services Program. They conducted face to face, phone and email contacts. The report was received in January 2019 and it reflected the impressive work of the program and the possibilities that had been created for the future.

There were many events, forums, workshops and site visits with volunteers and volunteer managers throughout the year. Some of these appear in the Highlights section.

Planned forums were held in Broken Hill (August, Spirituality band Reflective Practice), Orange (October, Spirituality and Reflective Practice) and Tamworth (October, Experiences around Dying with Michael Barbato). May 15 saw the Accidental Counsellor training for SWSLHD palliative care volunteers at Mounties Club and Mt Pritchard forum was on May 20 also delivering 'The Accidental counsellor'. The Erina Forum in June was held with a presentation by Kate Munro titled 'Life the Universe and Everything'. Feedback was provided from all the forums. The forums brought together palliative care volunteers but are open to any interested health workers.

Alex, Kate and Linda attended the **PCQLD National Hospice Symposium** on the Gold Coast during March while Kate also coordinated a **focus group** with palliative care volunteers in Moruya, in understanding the challenges and barriers to this service in SNSWLHD.

April was a busy month with a biography training in Surry Hills in conjunction with the Sacred Heart Hospice St Vincent's, for volunteers and managers wishing to start a service. Alex presented on rural and regional volunteering research and other volunteering at the Victorian DHHS Ancillary Support Organisations Forum in Melbourne.

Kate spoke at the launch of the Warrumbungle Community Care palliative care volunteer service in Coonabarabran (WNSWLHD palliative care volunteer project).

Site visits to WNSWLHD, ISLHD, SNSWLHD took place – in Western NSW, the **WNSWLHD** Palliative Care Volunteer Support Program was reviewed and a progress report was written. The associated workshop in Mudgee was attended (part of ongoing involvement). VSSP also visited aged care facilities to explore issues around palliative and **aged care** and volunteers with a view to a project in this area in 2019.

April also had a presentation by Alex Huntir and Jane Beach from WNSWLHD on the palliative care volunteer project at the **Patient experience symposium, Darling Harbour.** The revised Palliare: A Handbook for Palliative Care Volunteers (Second Edition 2018) was released and printed and continues with distribution on a cost-recovery basis.

Feedback from stakeholders was sought on a proposal to develop a community visiting volunteer phone/ device application, a proposal to improve and standardise data reporting for volunteer services and on the Statewide Framework for Palliative Care Volunteering 2017 document.

Kate completed the **Snapshot 2018:** A review of Palliative Care Volunteering in **NSW**. This was, essentially, an update of the A Snapshot of Palliative Care Volunteering in NSW 2014.

Kate began an evaluation into the sustainability of the existing LHD-led palliative care volunteer services in Southern NSW. After receiving funding from the local PHN, Coordinare, this work fed into a new project - the Consumer and Carer Relief at End of Life (CCREOL) Project. The project focus is to create up to five new community-led palliative care volunteer services throughout Southern NSW LHD.

Support of the quarterly **NSW Network of Managers** of Palliative Care Volunteer Services meetings continued, and a survey of the managers group was conducted into their arrangements for travel by volunteers, their use of databases and their experience of accessing money from their 'finance department'.

In November 2018 a **volunteer biographer** initiative in NSW to engage volunteers and potential volunteers around biography, met with Sacred Heart Saint Vincent's biography service and since then at planning associated events in 2019 and at developing a state-wide interest group.

Colin Dent joined the PCNSW in early June 2019. Colin has spent more than seventeen years supporting, promoting, training and retaining volunteers in health, fundraising, emergency and international non-government organisations; managed relationships in volunteer networks and membership bases and contributed to organisational growth and volunteer policy development.

The biennial NSW Palliative Care Volunteer Conference was held in Western Sydney on 3-4 June. The organising committee included members from the NSW Network of Palliative Care Volunteer Managers and staff from the VSSP. It was a huge success with over 130 people in attendance. Website: www.pcvolunteers2019.com.au.

The VSSP volunteer hub website continued to engage with volunteers, managers and health professionals. The volunteerhub.com.au published 97 stories on its blog page and shared these and further engagements across to Facebook and Twitter. Our monthly e-news now has 873 subscribers.

Audited profit & loss report 2018/19

Income Statement for the year ended 30 June 2019	2019 \$	2018 \$
Income		
Grants	731,159	453,844
Interest Received	8,245	7,678
Donations	515	735
	739,919	462,257
Expenses		
Accountancy	10,473	4,083
Administration Charges	0	84,636
Advertising & Promotion	477	18
Auditors Remuneration - Fees	2,800	300
Bank Charges	1,620	643
Computing Expenses	11,797	10,368
Consulting Fees	-	-
Conference Expenses	110,976	10,903
Courier	0	-
Depreciation	3,534	3,759
Education Expenses	3,368	6,778
General Expenses	3,490	824
Insurance	6,056	4,397
Postage	1,754	1,661
Printing & Stationery	35,951	9,174
Employee Provisions	-21,838	(18,687)
Rent	13,090	2,961
Subscriptions	1,476	1,200
Superannuation	32,035	27,699
Telephone	3,785	1,061
Travelling	56,205	39,720
Wages	351,485	294,316
	628,536	485,814
(Loss) profit before income tax	111,383	(23,557)



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