

MS NURSES AUSTRALASIA INC 2018 AGM Minutes
14th September 2018, Brisbane, QLD

AGM meeting commenced at 4:30pm

Present: As per signing in sheet attached

Apologies: Lou Hatter, Pamela Klaer, Karalyn Ernst, Helen McCarl

Confirmation of minutes of previous meeting

Moved – Susan Agland

Seconded: Michael Mortenson

1. Results of nomination for executive positions

- President – Belinda Bardsley
- Vice President – Imogen Milner
- Secretary – Emma Christian
- Treasurer – Melanie McMurtrie

2. Business arising from the 2017 AGM minutes

Nil

3. Reports

3.1 President Report Belinda Bardsley

In my first year in this role, I have been fortunate to be given a number of opportunities to represent MSNA and to showcase the important role of the MS Nurse, in keeping with the MS Specialist Nursing in Australia (MSSN) Project. As you will recall, this project commenced in 2017 and seeks to establish an evidence-based business case to support a successful advocacy campaign for sustainable and increased funding for MS Specialist Nurses in Australia. Some important events have occurred in relation to this.

· In February I attended a face-to-face meeting with the project advisory group, which comprises representatives from MS Australia, MS Research Australia, MSNA, MSHPN, ANZAN and consumers. This meeting agreed on recommendations for focused effort in key areas, and further work continues in this regard. For example, a template is in development which aims to equip nurses and neurologists to develop business cases to support local roles.

· I was invited to represent MSNA at World MS Day at Parliament House on 30 May, where the Roadmap to MS was launched and endorsed by Greg Hunt, Federal Minister for Health. This outlined a 10-year plan to defeat MS in Australia, and MS Nurses were an important inclusion in this plan.

· Along with several other MS Nurses, I attended the Modifiable Lifestyle Factors in MS Workshop, where the important role that nurses contribute in counselling patients about diet, exercise and smoking cessation and maintenance of brain health was acknowledged.

· Very recently, I was invited to speak at a MS Australia Board meeting to highlight the diverse roles of the MS Nurse. In preparing for this talk, I thought about the interventionist role that we all play when caring for our patients, and the many occasions when this completely changes the outcome or the trajectory of their disease course. I will speak more about this at a workshop during our conference, but I wonder if we could consider some collaborative multicentre nursing research in this area, in an effort to gather further evidence of the benefits that we bring: those of broadened therapeutic options, improved health economics, but most importantly, enhanced patient wellbeing.

While it's fair to say that maintaining momentum in showcasing the important role of the MS Nurse has been a focus of my first year as President, it's important that we maintain our educational, collaborative and networking role. We will have further discussion about the relevance of the Australian MS Nursing Manual and opportunities for developing structures for web-based communication, as well as linkages for those interested in participating in nursing research, and those working in the field of clinical trials.

My final note in this report is to acknowledge the enormous role that Lou Hatter has played in the MSNA arena for 11 years, and to sadly farewell her as she stands down from the role of secretary after 4 years. Her breadth of knowledge, experience and wisdom will be sadly missed. I am so grateful to you Lou for all your support and assistance to me in this first year as President. Thanks so very, very much.

3.2 Vice President Susan Agland

I have done very little this year, when compared to the previous few years. My role has largely been transitioning from the president role, assisting the rest of the exec and general committee in their roles and conference preparation. In handover from the previous VP, Sharon Stevenson-Hall, I undertook to continue the education stewardship. However, progress in this respect this has largely been inert. I hope this will regain momentum with the inbound VP, as the nurse manual issues and website updates are resolved.

My representative committee roles have been transitioned to the new president. These include the MSSN committee and Longitudinal Study steering committee.

Separate from my role with MSNA I have taken up a request to re-join the IOMSN website and communication committee. I hope to both learn from a larger organisation's communications strategies and instil a strong presence representing the Australia and New Zealand. IOMSN web and communications would welcome other expressions of interest for this committee membership. If you are interested please let me know. It would be terrific to boost the 'international' presence in this international MS nurse group.

While I step down from MSNA exec I hope to remain involved with the organisation. We are a strong community of nursing specialists and I am driven to keep pushing for acknowledgment of the role of the MSSN, securing MS nurse position permanency, nurse research opportunities and improve patient care.

Thank you for this amazing opportunity to represent you. (Mic drop)

Susan (Agland)

3.3 Secretary – Lou Hatter

Thank you to the conference committee and EXEC for all their hard work in bringing together another successful conference. Sorry I am not there (again) to join in.

This is my last year as Secretary so I would like to thank all past and present EXEC and Delegates for making this volunteer role both fun, empowering and innovative over the last 11 years during my roles as either State Delegate or Secretary. Good Luck to Emma Christian as she steps up to now become the new Secretary.

Secretary Report -

- **Education Grant Applications:**
- Fiona D'Young

- **Mail In –**
- Pharma sponsorship from Bayer, Biogen Idec, Teva, Genzyme, Merck, Novartis and Roche.
- QLD Office of Fair trading re: incorporation
- Auditor financial Report (Treasurer)
- BRAIN HEALTH
- IOMSN
- Murdoch University – Physio research in rural Australia

- **Mail Out –**
- BRAIN HEALTH endorsement from MSNA
- Pharma Sponsorship request to Merck Serono, Bayer, Biogen Idec, Genzyme, Novartis, Roche and Teva

3.4 Treasurer – Melanie McMurtrie

Financial report as per attached

Audit 17-18

2017- 2018 Financial Report for AGM - Melanie McMurtrie

Financial members

2017- 96 members

2018- 100 members- Michael will be pleased to know we finally hit the magic number!

Bank Balance

AS of close of business on June 30th 2017, our bank balance was \$130,837.00 in the business transaction account and \$36,393.00 in business saver, giving us a total of \$167,230 across both accounts.

Total income for 2017-2018

\$140,070, up from \$117,813.83 previous year

Our greatest income from generous support of Pharma companies, particularly in support of conference, along with membership subscriptions and conference registrations.

Total expenses for 2017- 2018

\$90, 441.52, which was also slightly up from last year (\$83,808.82)

Main expenses were Hobart conference -\$51,427.69, which was up from previous year and will be less than this year, along with travel and accommodation expenses.

Grants

We provided \$1500 each to Michelle Allan, Amanda Lyndon and Fiona D'Young for study or research projects.

As well as the usual prizes for poster, novice presenter and overall presentation at last years conference, which saw Imogen jet off to CMSC in Nashville, with the other winners given cheques.

General

The beginning of the year saw us have some fraudulent activity through e-way, which, whilst we did not end up out of pocket, caused us to put fraud protection on the e-way website. That certainly made for an interesting start to the year.

This year has been a very steep learning curve for me, especially in the last couple of months in the lead up to conference and I would like to thank, my work colleagues, who have put up with me trying to wrap my head around conference registrations, tax invoices, receipts and auditors reports etc.

Thanks again to John Cook at Mitchell, Cook and associates for auditing our financial records again and being so easy to deal with.

Thank you lastly to members of the executive, who have welcomed me into the group, especially Michael for leaving the books in such good order, and to Belinda, Michael and Tim who have supported and helped and answered dumb questions throughout this year, I hope to have less questions next year....

Thank you

3.5 State delegates reports 2017-2018

ACT – vacant

NSW – Meena Sharma,

- **John Hunter**
 - o Multiple clinical trials including PI initiated.
 - o Nurse led study – recruiting
 - o Lots of local presentations
 - o Amanda Lydon- An abstract for a poster accepted for ECTRIMS, the Poster is in regards to the study on Diet and MS - received the grant from MSNA last year.
 - o Susan Agland - presented at the Immunology Crossroads meeting about managing expectations and lifestyle of those who are chronically immunosuppressed

- **Liverpool Hospital**
 - o Various national, international and PI initiated clinical trials in progress

- o Meena Sharma – Podium presentation in Maximising success nurses meeting, MerckSerono
- Royal North Shore Hospital
 - o multiple in-hospital education sessions, planning a family support/information evening conducted
- **Royal North Shore private Hospital**
 - o Karen Thomas 7 August - Biogen Infusion Nurse Dinner Meeting- the experience of nursing MS patients in the infusion centre setting.
- **MS Connect –**
 - o More nurses have been made redundant this year
 - o Sue Tamworth – untimely death
 - Common NSW MS Nurses Challenges –
 - o Managing increasing numbers of people with no staff growth.
 - o Large number of patients receiving potent treatment infusions which requires a lot of monitoring and organisation.
 - o Gap in care for private patients that do not have access to MS nursing services.
 - o Most of the nurses are pharma funded
 - o No replacement or taking time to replace the vacant position.
 - Maven clad patient Access Program (PAP) active in few hospitals
 - Many local educational events and opportunities provided such as – dinner meeting, weekend meeting, and full day education, especially Pharma Company initiated.
 - Nurses are being encouraged to become a MSNA member at regular interval

NZ South – Stephanie Rout

This is my first delegate report since taking over the position from Rachel in 2017. This first year has been motivating as I am getting to know and understand how the organisation works; I am thankful that we have the networks to communicate with so many passionate and inspiring nurses within MSNA.

As with last year's report, treatment has remained with: Fingolimod, Dimethyl Fumarate, Natalizumab, and Teriflunomide. Injectables are rarely given as first line treatment. There are talks currently with our NZ government medication funding agency Pharmac about the funding of Ocrelizumab for RRMS; unfortunately it has already been declined for PPMS. We are hopeful it will be funded by the end of this year to give our patients another choice of therapy.

Locally, within the South Island we continue to build on our numbers of nursing colleagues within the organisation. Our Canterbury nurses have finally had their roles made permanent and increased their combined hours. Dunedin and Nelson remain the same in terms of nursing hours.

MS has been in the national media lately, which has increased the visibility of how difficult it is for patients to receive and stay on treatment. Although improved from a few years ago, it is still a challenge for patients to stay on treatment if their EDSS increases past a 4. This campaign is highlighted with support from the MS Society of NZ, of which a few of their nurses are members of MSNA.

Education within NZ is ongoing with our nurses being able to attend many excellent educational opportunities throughout the year. We held our annual MS nurses meeting in May and welcomed new faces from across the country, many of us recently returned from the Queenstown winter meeting which is also a brilliant opportunity to meet up and learn. It helps that it is run in one of the world's most beautiful locations! There have been a few trips across the Tasman to attend many Pharma run meetings also. We are grateful to the support of our Pharma colleagues for providing these opportunities.

I look forward to the year ahead and see what it holds whilst continuing to be inspired by our colleagues and patients.

NZ North – Imogen Milner

MSNA membership:

- It's been a pleasure to welcome some new nurses to our team Marian O'Connor in Taranaki and Veronica Duque in Rotorua and I'd like to welcome back Rosemary Buglass in Hawkes Bay.
- I look forward to the website changes with access to MSNA members only as I think this will increase our recruitment.

Education:

- We have managed to continue our annual NZ MS nurses meeting which was again very successful both in education content and networking. This forum has now given 2 people the encouragement and confidence to present at the MSNA conference.
- By a number of us planting a seed Biogen has also organised an infusion nurses study day.
- Many of us have had the opportunity to attend pharma funded conferences in Australia and NZ.
- I also had the honour of attending CMSC which was a magnificent experience and I would urge anyone who has the resource to attend.
- Education with patients at local level continues on a daily basis and with patient centred study days.

Changes afoot:

- We are still awaiting the results from Roche's application for registration of Ocrelizumab, likely to be funded for RRMS but not PPMS. As yet no word on Lemtrada in NZ although Cladribine may be coming.
- MS society NZ has been putting in submissions for changes to the exit criteria for funding.
- This year I have passed on my delegate hat and I hope you will join me in warmly welcoming Fiona d'Young as the NZ NI delegate. She has a wealth of knowledge and is an incredibly inspiring MS specialist nurse. She will be an asset to the delegate team.

I'd like to thank the executive team for all their work over the last year and for the executive and delegates I have worked with over the last 7 years, it has been a privilege. To the local conference team, well done for all your hard work in what I know will be another fantastic MSNA conference.

QLD – Meaghan Osborne

Report unavailable

SA & NT– Sharon Barlow

Sharon Barlow will remain the MSNA SA state delegate for next year. As a group we have met a few times which has been great. The relationships between our members are strong and there is good communication between members to seek an opinion or discuss mutual patients which has been excellent. We had 3 members complete the International credentialing exam at the last MSNA Conference. We have 3 new financial members. We have 3 members unable to attend the conference this year Helen McCarl (Life Member), Pamela Klaer and Karalyn Ernst who send their apologies for the AGM. We still do not have a MS Nurse in the NT.

Flinders Medical Centre

Sharon Barlow, Anne Green, Marie Toubia, Karalyn Ernst, Susan Hopkins (new member)

- 550-600 patients in our outpatient MS Service
- 4x Consultant clinics weekly, 2x MS Nurse led clinics weekly, 1x Registrar clinic weekly
- We lost our specialised MS Relapse Ax clinic in the RGH closure when services were intended to move to FMC- can still refer to Rehabilitation
- Research:
 - TOP – Tysabri Observational Program. (14 participants recruited)
 - ESTEEM – Tecfidera Observational . (16 participants recruited)
 - MS Base – Sub studies
 - The Primary Progressive Multiple Sclerosis Study: Case Control Study in Primary Progressive MS
- Increase in workload due to new treatment and increase in monitoring requirements for new drugs
- Nursing FTE demand increasing however no funding available. Current positions have permanent funding

Multiple Sclerosis Society of SA & NT

Emma Christian, Pamela Klaer, Johanna Walters (new member), Amanda Mouvet (new member), Helen McCarl (Life Member)

- A lot of changes to the nursing team this year- Helen McCarl retired in April after many years of service
- Nursing team has expanded and we welcome Johanna Walters and Amanda Mouvet to the team!
- New Specialist Continence Nurse position was created in July and Amanda's wealth of experience in this area is exciting with an already large uptake of this service in just a couple of months
- Nursing team service over 2300 active clients and approximately 1500 on MS treatments
- Regular new small group 'Wellness Series' to start in November supporting people to adopt the 'Brain Health' lifestyle modification recommendations
- Physio/PT run gym and hydro classes continue along with a high client uptake of our OT/social welfare services
- Education seminar series on a wide range of topics continue to be popular, run by our Education Co-ordinator
- NDIS specific team assist with coordination and access to this system. MS specific documents have been produced for clients to assist with navigating this process. Huge demand!
- Pam on long service leave for 10 weeks until November

Royal Adelaide Hospital

Kevin Webb

Report unavailable

The Lyell McEwin Hospital

Vanessa Maxwell

- Approx. 200 Ms Pts. In our service. Treatment options include approx. patient numbers (Tysabri 40, Lemtrada 14, Ocrevus 15, oral and general pts 138)
- Business plan has been submitted for 1.0 FTE Neurology Nurse level 3, currently funded via clinical trial funds (MS and Stroke trials)
- Position supports nurse led clinics, symptom management, infusion set up support, education and reduction ED and Inpatient stays
- This position notes a reduction of ED visits from 21 to 9. A 2 bed day reduction with a saving of \$1,168,702 in 2016 to \$471,940 in 2017 and prediction for 2018 of a further \$60,000 saving
- IN last 18 months position has seen reduced inpatient stays due to relapse by approx. \$66,584 with implementation of the oral methylprednisolone protocol.
- New challenges for the position include increased time required for education due to complexities of treatment options now available and the blood monitoring regimes each DMT specific
- MS Base has been implemented at this site and benefits are already showing
- Increase in new patients every year further highlighting the necessity for this position and being hospital funded. We are feeling positive this will be approved in 2019

Specialists on College (Private)

Paul Stockle

- No change in Nursing FTE for the service despite more and more pts resulting in an increase in medication education sessions
- Ocrevus has had a big impact with the service with more and more people changing to it from injectables and orals and therefore increased workloads for all
- Passed my MSNICB exam (I do know something)
- Attendance at ECTRIMS 2017, it was amazing
- No funding issues for nursing staff

TAS – Michael Mortensen

A little bit of movement over the past 12 months in Tassie. Sue McGregor has been employed at .5 FTE as CNC Neurology at Royal Hobart Hospital. Kim McCarthy resigned her position at MSL in January, and has been replaced by another nurse, Annette Crawford (although she is not practising as a nurse - position is MS Consultant). Kim has been very sorely missed by many of her clients, as she did a most wonderful job managing the North of the State. Karen Lewis continues at the Launceston General Hospital as the spinal nurse/neurology nurse.

The main focus of the Tasmanian MS Consultant positions at MSL has been preparing clients to enter the NDIS, and assisting those over 65 to enter My Aged Care. Nursing inquiries continue to be directed to MS Connect at MSL Head Office. The Royal Hobart Hospital MS Clinic is supported by Sue McGregor, and as yet, there is no presence at the clinic from MSL staff.

VIC – Edith Cinc

During the past 12 months in Victoria, we have continued taking advantage of the ongoing educational opportunities offered by the different pharmaceutical companies. Many of our members have had the chance to attend these varied meetings throughout the course of the year.

Via the MSHPN, the Victorian MS Health Professionals Network, we meet several times over the year. This provides a great opportunity for support and networking and again other educational opportunities. Our membership has welcomed several Ambulatory Care/Infusion Nurses who have an increasingly vital role in the care of people with MS and we are thankful for their wonderful insight and contribution. We have heard from MS Australia, the MS Employment Support Service and we received a presentation from a patient who gave us an interesting perspective of living with MS. We have heard from Michelle Allan and KJ Lazarus who attended CMSC in Nashville, along with other attendees, Jenni Clarke, Jodi Haartsen and Louise Rath who were also fortunate to attend. Congratulations to KJ Lazarus who presented a poster at CMSC, titled "Australian Pilot Preceptorship Program for MS Nurses and Study Coordinators". Michelle Allan conducted a very successful patient seminar at Monash Health, titled "Staying up to Date with MS in 2018." There have also been regular updates pertaining to the numerous local clinical and investigator driven research projects which are happening across the Victorian sites.

MSHPN conducted a short Survey to ascertain the needs of our members and their motivation to join our group. Members gain benefit from both networking and the education sessions provided. The members expressed they would like more information on topics including diet trends, exercise, psychology, sleep, continence, symptom management, research updates as well as the new and emerging therapies.

It is also worth noting, that at Austin Health we continue to run a Nurse Preceptorship Program for MS Nurses and Study Coordinators, which gives nurses the opportunity to learn, network and build a reciprocal relationship with colleagues from anywhere in Australia.

WA – Dee Menzies

It has been another busy and productive year for MSWA with the ongoing changes that NDIS funding has brought about.

NDIS will continue its roll out in WA and switch to the new model by October/November.

This has increased MSWA staffing numbers and everyone is working together to ensure a smooth transition for our customers.

MSWA have rolled out a new innovative scheme called Flexicare for our customers that have other neurological conditions to try and bridge the gap in areas that have yet to receive NDIS funding.

MSWA continue to be active in contributing to Neurological research both in MS and other Neurological conditions with a record-breaking contribution of \$3 million which is the largest in Australia's history.

This has included:

- \$1 million to MS Research Australia;
- \$500,000 to the international research programme into progressive MS; and
- \$450,000 for research into other neurological conditions.

Contributions have increased over the last 11 years with an investment of \$13.9 million to fund research into finding a cure for MS and other neurological conditions.

MSWA facilities continue to expand with new premises already open in our Northern and Southern suburbs. There will be further premises open this year and a large facility is due to open at the beginning of 2019 which will include, outreach, respite and residential facilities to support our customers ongoing needs.

3.6 Communications Report – Tim O'Maley

- Tim is handing over the communications role to Susan Agland for 2018-2019
- Website undergoing review and requires a new platform
- It has been a slow work in progress and further development is required
- Tim is available to mentor as required

3.7 IOMSN Report –Therese Burke

IOMSN Member at Large role

I took over in caretaker capacity the Member at Large role until this year's AGM where the role will be discussed today.

There have been significant events this year in the IOMSN. Incoming President Aliza Ben-Zacharia has been replaced by the President Elect Patricia Pagnotta. The circumstances surrounding this change will be discussed in person at the AGM. Meanwhile, IOMSN has issued a statement to explain the change, which has been circulated by MSNA.

In coming months the plans and objectives for IOMSN will be released and I will keep you informed as things progress.

MSNICB role

As the Past President of the MSNICB, I still have another year in my tenure. It is an important role as it takes on the Chair of the recertification committee, a busy and demanding role at times. Major changes in recertification guidelines will be released next month to make it much easier for MSCN's to recertify, including an on line form to keep on your desktop to add learning activities as you do them.

Australia/New Zealand had 10 candidates take on the MSNICB exam to become certified last year. All ten candidates passed, an incredible and amazing result, which shows the calibre of talent in our organisation.

I am presenting information about the exam tomorrow and I encourage you to think about the exam in 2019 as a way of progressing your own professional development, as well as that of our region. There are many mentors that can help you formulate a study plan and give help. You have the education and the clinical knowledge. Now show it

4. New Business

- **MS Australasia Nursing Manual – Sharon Barlow**

Outlined the history of MSNA approaching Merck to update the Nursing Manual over the last few years. Merck is now in a position to fund a new edition. A meeting has been scheduled for tomorrow to discuss further details including intellectual property, what their support is inclusive of and future updates. A discussion ensued amongst AGM attendants and the overall consensus was that the manual still added great value in a variety of nursing settings and enthusiasm for investigating options to facilitate a new version. Sharon will continue to work with Belinda to develop a pathway forward and will work within the framework of the current educational subcommittee.

- **MSNICB - Therese Burke**

Therese is the past president for MSNICB and has one year left of her term. She recommends that the MSNICB delegate going forward has a dual role that includes Australian delegate for IOMSN member at large role. These two independent meetings are held back-to-back in the US. She suggests that the delegate be provided with upgraded premium economy flights to attend the annual meeting with the extra costs covered by MSNA due to the long travel time and intensity and importance of the meeting.

- **IOMSN – Therese Burke**

Discussion of recent leadership changes in IOMSN. Member at large role as above. Discussion of current MSNA/IOMSN reciprocal membership and proposal for Au/NZ nurses to independently join IOMSN to show strength of our organisation and respect for the IOMSN role.

5. Other business

Nil

6 Conference 2019

Conference to be held in NSW – date and venue to be confirmed.
Next AGM to coincide with next MSNA Inc conference in 2019

Meeting closed 5:40pm

