



**2021  
AGM ANNUAL REPORTS**

**MS Nurses  
Australasia Inc**

## **Our mission**

MSNA Inc as the peak body for multiple sclerosis nursing in Australasia endeavours to support the advancement of the specialty of MS Nursing.

MSNA strive to provide professional development opportunities for nurses with continuing education opportunities, support of nurse led research and peer networking.

## **Key strategies**

1. Support strong formal and informal networking, peer support and mentorship opportunities for nurses working in this Neuroscience specialty.
2. Present an annual conference in different states/territories of Australia and New Zealand to showcase Australasian MS nurse research and practice developments inclusive and representative of our membership base.
3. Provide financial scholarship opportunities for MSNA Inc members to support and encourage further development of the MS nurse skill set, nurse led research, support career development and to advance MS nursing practice in Australasia.
4. Keep MS nurses updated on contemporary issues impacting people with MS to enhance their capacity to advocate and support people with MS and work effectively within that person's health care team.

## **Our Objectives**

- (a) To facilitate and promote the sub-specialisation of multiple sclerosis nursing;
- (b) Establish standards of evidenced based nursing care in multiple sclerosis;
- (c) Support, promote and or participate in multiple sclerosis research;
- (d) Educate the health care community about multiple sclerosis.

## **Our Purpose and History**

Multiple Sclerosis (MS) nurses are a subspecialty in neuroscience nursing and have become a dynamic group who have worked hard to ensure that high quality, evidence-based nursing care is promoted and delivered for all people diagnosed with MS (PwMS).

With the pace of ongoing change, and the need for high quality specialised services for PwMS, it is essential that nurses working in this area have the knowledge, skills and competence to provide accurate information and deliver effective and evidence based care for and with PwMS. MSNA is the peak body for MS Nurses in the Southern Hemisphere, providing education and support for MS nurses and other health care professionals in Australia and New Zealand.

Membership with MSNA Inc. is open to any Registered Nurse or Qualified Health Professional with an interest in Multiple Sclerosis. There are four membership categories to allow any Health Professional working with or having a special interest in Multiple Sclerosis to become involved.

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## **PRESIDENT'S REPORT**

### **Belinda Bardsley**

I'm sad to be delivering my final President's report to you via yet another virtual AGM. I would much rather be celebrating this milestone moment with my friends and colleagues in the warm and collegiate atmosphere that I remember when we were last together in Sydney in 2019 when we danced along with "Elvis" and we had no concept of the pandemic that was about to confront us in 2020.

The past two years have been a tough time for many of us, requiring us to show patience, resilience, flexibility, kindness and compassion; often at our own expense or at a time when we have been facing our own stress, anxiety and fear. In NSW and Victoria in particular, soaring COVID-19 numbers have placed significant and unique pressures on our healthcare sector, and many of us will have been impacted by these challenges.

Meanwhile, our own patients have needed us more than ever. The volume of anxious calls and emails has at times been overwhelming. Anxiety about the COVID-19 virus itself; questions about implications for MS treatments; complex queries in relation to vaccination and now a flurry of questions about the booster.

And who fields all these questions and provides the "balm of calm" in the face of anxiety (thanks Therese)? MS Nurses of course.

Which leads me to the reason I took on the role of President of MSNA in the first place.

I am acutely aware of the importance of the role of MS Nurses, and passionately keen to promote and empower MS Nurses, safeguard our role and expand our numbers to ensure equity of access for the benefit of all people with MS.

I have been frustrated by the lack of hard evidence to demonstrate all the good stuff that we do, every single day; the things that make a palpable difference to people's lives; and importantly, the things that people with MS value and, more cynically (but important for our viability) the things that the number crunchers can put a dollar value on.

I mentioned in last year's AGM that as President of MSNA, I sit on the AMSLS Steering Committee and that during one of these meetings I suggested that we ask the participants of this longitudinal study for feedback on their experience of MS Nurses. Last year we were still waiting on the findings, but it was worth the wait. This survey yielded some truly remarkable results.

This survey has resulted in the MS Nurse Report, and it has finally given us some incredibly important data! And I strongly suggest that we OWN it!! It's so important that we claim this evidence as our own in order to demonstrate our value to our employers, our health services, our clinics, our hospitals, our neurologists, to politicians, to state and federal governments. It's starkly obvious now that we make a massive difference to people's lives. We keep people out of hospital, out of Emergency Departments, we keep people at work and living happy, healthy and productive lives. And the economic benefits that arise from this are clear and striking and now, finally, quantifiable.

With my contribution towards this report, I feel my job is somewhat done and I am more than happy to step into the role of Vice President and support our incoming President.

In doing so, I would like to thank the dream Executive team who have made the past few years such a joy. Emma is a clear-thinking, patient, calm and wonderful Secretary who never finds anything too much trouble. Imogen has been such a supportive Vice President with the razor sharp clarity to cut through to the heart of an issue. She has also been the most incredible asset to the Education Sub-Committee. Thank goodness she is staying on in that capacity!! And my personal rock at work and on this committee is Mel who has made it her mission to keep me sane (or some version thereof) as well as handling all the financial stuff for MSNA.

Thanks too to our fantastic State Delegates for all they do to enhance communication and keep our network alive and thriving, despite the absence of face to face meetings in many states and regions.

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With the arrival of the MS Nurse Report, it is more important than ever to celebrate the power of the common voice, and recognise that MSNA's strength comes from collaborating, networking and communicating. It will be so important for us to find ways of ensuring the findings of this report are broadcast. It's essential that the findings are uppermost in the hearts and minds of people with MS and people who can make change happen.

The primary recommendation of the report was that every Australian with MS (and I'm going to extrapolate that to include every New Zealander with MS) deserves to have access to an MS Nurse. We need to ensure that they do. It's in our hands.

Let's make it happen.

A handwritten signature in black ink, appearing to read 'Belinda Bardsley', with a large, stylized flourish at the end.

Belinda Bardsley, President

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## VICE PRESIDENT REPORT

### Imogen Milner

Over this last year it feels a bit like the saga continues. Despite our best efforts to look at options for providing the MSNA members with a conference, COVID 19 thwarted our plans at every turn (we looked at many a turn) and in the end we needed to be realistic. I feel very sad that for the second year running we have not had the opportunity to see each other in the flesh and do what we do best.....network! I am hopeful that 2022 will bring us back together.

Outside exec decisions, one of my main roles as vice president has been chairing the education subcommittee - please see my separate report.

As I step down from the position of vice president I reflect on my time in this role. It has been such an amazing opportunity to learn the intricacies that occur behind the scenes of MSNA and my my there is a lot! As always there's ups and downs however no matter what, the coordination, support and collaboration of the team has been remarkable. It has been my absolute pleasure to work with the MSNA team and I take my hat off to the exec and delegates. Belinda, Emma and Melanie you are such special people. Your passion and dedication is palpable, thank you for making my time in the exec an absolute treat.

It is with great privilege that I pass the role onto Belinda. But you haven't gotten rid of me yet! Due to the number of various projects Belinda is involved in, I have been asked to continue chairing the Education (now Education and IT) subcommittee. With the subcommittee members consent I have accepted.

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## SECRETARY'S REPORT

### Emma Christian

Mail correspondence in relation to cancellation of MSNA 2021 virtual hub conference and withdrawal of Prospectus due to pandemic:

- Pharmaceutical sponsorship requests for proposed virtual conference
- Cancellation of event to sponsors
- MCI + Seed – Event management quotes & subsequent cancellation
- Novartis correspondence re initial offer of support
- Correspondence from the hotel re refund of deposit
- Accountant re financial review

Yvonne Learmonth - Murdoch University: C-RIMS - Optimising uptake of Crisis/Emergency plan  
MS Australia – Nurse Report correspondence

Contract correspondence:

- CEMCAT for MA webinar
- TEVA, Roche and Novartis for webinar sponsorship.

A big thank you to the wonderful work the Exec and delegates have done over the past year – you have all been amazing. I'm so fortunate to work especially closely with an Exec who go above and beyond, always making themselves available at any time of day to ensure we do our best to support MSNA nurses, through this pandemic and beyond. There has been a lot of work done behind the scenes to promote the work of MS Nurses & strategically look at how we can direct and best navigate future collaborations for our network both locally and abroad. Thanks for being a dream team to work with Belinda, Imogen & Mel!

I look forward to working again with the MSNA Exec and delegates in 2022. I'm always happy to hear from you so please feel free to email me anytime: [secretary@msnainc.org.au](mailto:secretary@msnainc.org.au)

## TREASURER'S REPORT

### Melanie McMurtrie

#### Financial members

As of 30 July 2021, financial members – 75. This is slightly higher than last year. Usually conference attendance encourages membership.

If you are not a current financial member, please join. If your not sure of you are, drop me an email at [treasurer@msnainc.org.au](mailto:treasurer@msnainc.org.au). [A reminder that you will only receive MSNA correspondence and access to webinars etc. if you are a financial member](#)

State reps have a current list of financial members

Memberships due at beginning of financial year.

#### Bank Balance

As of close of business on June 30<sup>th</sup> 2021, our bank balance was \$ 183,096.85 in the Business Transaction account and \$36,605.34 in Business Saver.

This gives us a total of \$219,702.19 across both accounts.

The NZ account had \$6404.00, with no transactions

#### Income for 2020-2021

Total income was \$40,969.64

- Our greatest income was again from generous support of Pharma companies for our ongoing efforts to provide education/ webinars despite no conference. - \$18,500 (\$15,000 from Novartis and \$3,000 from Roche and \$500 from Teva)
- Refunds for fights to CMSC (Agland, Burke and O'Maley) - \$16,487.64
- Membership- \$4,470.00
- Refund for venue deposit- Fremantle- \$1,500

#### Expenses for 2020-2021

Total expenses were \$8,884.80

- Greatest expenditure was webinar associated costs- payment of honoraria for speakers/ gifts for hosting- \$2248.95
- Website fees- paid to Grimmel- \$1856.80
- Other- (accountant auditing, office of fair-trading fees)-\$1531.60
- Insurances- \$1095.24
- Teleconferencing- \$379.35
- Eway-\$142.86
- Bank fees- \$120.00
- Grants – we paid a grant to Therese through the University of Notre Dame, for her ongoing project of \$1500.00

Total profit- \$32,084.84.

*Although it appears our income for the year greatly outweighs our expenditure, much of the income (\$17,987.00, is actually reimbursements for conference related expenses in late 2019)*

Of note, the substantial grant received from Novartis in 2019 for the redevelopment of the website is still in progress, as in the current climate, it has been hard to investigate the correct system/ team. We are currently in discussion with Grimmel about whether they can provide the assistance we are hoping to provide the correct workability for the website.

Thank you to Carly at RJ Sanderson and Associates PTY LTD for reviewing our financial records again and being so easy to deal with.

Thank you to the exec team for being delightful to work with. Many thanks to our outgoing exec members, to Belinda for your guidance and leadership throughout your presidency, and to Imogen for her drive in continuing the education of members through the pandemic in the absence of a conference.

Melanie McMurtrie,

Treasurer

Therefore, I move that the financial records are true and correct and specifically that as noted by Carly at R J Sanderson, that the financial report of MSNA Inc. satisfies the requirement of division 60 of the Australian Charities and Not-for-profits commission Act 2012 and gives a true and fair view of our financial position as at year ending 30<sup>th</sup> June 2021.

Seconded by\_\_\_\_\_



## **IOMSN/MSNICB REPORT**

### **Therese Burke**

Sadly, as with many international endeavours, we have not been able to progress these committees as we would have liked, and as was deserved, due to COVID-19. All of our in-person meetings and examination preparation have been suspended until 2022. After no meeting at all in 2020, a virtual meeting was attempted this year in March to create the new MSNICB examination for 2021- quite a feat across multiple time zones and with English as a second language for many European participants. However, it was successful and so a new examination was developed for 2021.

COVID-19 has forced an important change to the MSNICB examination this year in Australia, the possibility of being assigned a remote proctor (supervisor) and being able to take the test at home instead of a conference setting or examination centre. There is an opportunity in November to participate at nominated centres in Perth, Melbourne and Sydney in Australia and in Auckland, New Zealand or to take the test remotely at home, once certain conditions are met (flyer attached with all the detail which was sent to members in August 2021).

Our most significant achievement has been the announcement of two of the ten international Nightingale nursing research awards (grants for MS nursing research) being awarded to researchers in Australia (Therese Burke and Susan Agland). This has been a long road, but the international recognition and invitation to apply for the awards for our members has been a major step forward and an incredible opportunity.

Last year we launched a revision of the MSNICB learning guide, version 2 for interested candidates for the MSNICB examination to provide guidance and references to help in their learning. This document would also be an excellent resource for those new to MS nursing to provide an overview of areas to be covered in MS Nurse education and helpful pointers on where and how to access information. The learning guide sits on the MSNA Inc website under Education and can be accessed by MSNA members.

The IOMSN website continues to promote webinars for nurses to continue learning and professional development. As reciprocal members of IOMSN through your MSNA registration, this is a wonderful resource to access. See [www.iomsn.org](http://www.iomsn.org)

After ten years on the MSNICB and 4 years as President, Susan Agland will become the new AUS/NZ representative on the MSNIC Board and the Member-at-Large for the IOMSN. I am certain Susan will be inspiring and engaged in her new role and that she will enjoy it as much as I have done. It has been a treasured career highlight and provided the opportunity to meet some inspiring and amazing people, who have become dear friends, no matter the distance. I can sincerely and whole-heartedly recommend putting yourself out there and stepping up- it is well worth it!

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## **WEB AND COMMUNICATIONS REPORT**

### **Susan Agland - Chair**

- Website committee is Louise Rath (focus on content) and Jess Morris (focus on website back end), and myself (chair), meeting via Zoom every 1-2 months depending on workload;
- I attended the face to face meeting in Melbourne in Nov to assist with conference planning and website development;
- Bulk of work this year has been rolling updates to the website, including content and software (including COVID19 resources);
- Developed social media policy, ToR;
- Developed a calendar for specific social media posts.
- 2021 PLAN: conference prep, building website capacity with Exec and Ed subcommittee and planning for IT analytics.

A huge thanks to Louise and Jess for the mountain of work they have achieved this year. IT is bit like a duck on the pond – looks mostly smooth on the surface but the duck is paddling like mad under the surface. Thanks to the exec and educ subcommittee for the input for the website development.

### **MSNA and Social Media Engagement Plan for 2019 and Beyond - draft**

Aim: Regular engagement with current financial members, opportunity to engage with non-financial members, opportunity to promote the MS nursing role, to advertise conferences and meetings, promote issues relevant to MS, engage with other NFP MS agencies.

What it is Not: it is not a platform for political agendas or non-evidenced based health recommendations. It is not a forum for one on one engagement for people with MS to discuss personal health recommendations.

Platforms: Twitter, Instagram, Facebook

Plan:

1. W&C subcommittee will develop a series of tweets and social media posts to coincide with the MSNA conference;
2. Subsequent posts will be somewhat planned and somewhat in response to general media, research publications and other NFP organisation's posts;
3. W&C subcommittee will be responsible for delivering the content in a routine and planned way, planning at SC meetings, so that engagement with MSNA target population is persistent and consistent. Retweets and Reposts of other NFP organisations will occur with their permission.
4. W&C subcommittee will be responsible for monitoring feedback and use of the social media platforms and report any issues to the general MSNA committee.

### **2019 IT plan**

New website – increase functionality and productivity of the website and increase traffic, build skill base to implement expected changes on website, i.e. reduce dependence on fee for service IT support

Member support growth - investigate avenues to respond to member and committee communication needs, e.g. Google Group. This function will be co-designed and led by the Education subcommittee.

Boost MSNA and member engagement - establish social media engagement e.g. Facebook, Twitter, Instagram

Work with education SC to grow educational and resource content

Work with exec committee to grow governance and resource content

Develop IT subcommittee to expand role and expand workload capacity

### **2020+ plan**

Build research capacity; i.e. support for people applying for grants, IT support for projects and promotion of same, participate in MSNA research and professional scoping data collection

Build online capacity for feedback and take responsibility for collecting, interpreting and disseminating data from conference and other MSNA activities.

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## **RESEARCH SUB-COMMITTEE REPORT**

### **Therese Burke, Chair**

Despite a blazing start to the inaugural research subcommittee, but as with all other endeavours, COVID-19 and the subsequent demands heavily curtailed our activities this year. Our subcommittee started with 4 members - Jane Eagle (NZ), Susan Agland (NSW), Michelle Allan (Vic) and Therese Burke (NSW), and was convened to raise the profile of nursing research within the organisation. To this end, we have participated in teleconferences and emails to form some objectives and goals for the coming year in the research domain. Jane sadly left her MS nursing role at the beginning of the year and then resigned from this committee, and we have been unable to attract new members.

*Firstly*, we started a **mentoring group for new researchers** with the goal of matching mentors to be a support person for new researchers and help provide guidance along the research process. We have a bank of mentors and hopefully when MS nursing research starts again after the COVID crisis, we will be able to match people together.

*Secondly*, we worked on some short webinars exploring the research world with world class presenters (MS Nurses Dr Aliza Ben-Zacharia and Prof Marijean Buhse) encouraging and developing our nurse researchers – both new and experienced. These webinars will hopefully be available to access on our website in coming months in case you missed them.

And *thirdly*, but very importantly, we wish to set up a forum to enable MS Nurses from all over Australia and New Zealand to collaborate with each other on research projects and provide a centralised support group to increase our research output. It is also hoped that this can commence in the next year when COVID activities start to settle.

Longer range goals include sessions at the next conference on research skills and developing webinars to be available for all members. These need to be developed in the coming year.

We are also seeking new members to the research subcommittee, so please contact Susan Agland if you are interested in being a part of this exciting new group.

## **EDUCATION SUB-COMMITTEE REPORT**

### **Imogen Milner, Chair**

**Members:** Tim O'Maley, Sharon Stevenson-Hall, Therese Burke, Sharon Barlow, Imogen Milner

Firstly I'd like to acknowledge the amazing members of this team. I feel extremely lucky to be part of this group, you are continually so inspirational and a dream to work with! Thank you so much for all your work.

The education subcommittee meet via zoom monthly and have been looking into numerous avenues in an effort to meet the educational needs of our members. I'd like to thank all of you who participated in the survey monkey earlier this year, your comments were invaluable. We have used the information gathered from this and themes raised from Therese's MS nurse study to create a list of educational topics which we separated into 1. suitable for a webinar, 2. add information on the website and 3. more appropriate for conference presentation. Completion of this list will take time but we are getting through it and a number of the webinars have eventuated including resourcing international colleagues to present. Of note one of the recurring comments from members was to hear from our members....we will be following this up and have some ideas up our sleeves for increased member involvement ☺.

### **Webinars so far:**

<i>Date</i>	<i>MSNA Webinars</i>	<i>Presenter</i>	<i>Registered</i>
24/06/2020	Med Cannabis in MS	Tim O'Maley	23
30/07/2020	Compassion Fatigue	Dr Sally Shaw	34
1/09/2020	Compassionate Control	Jillian Kingsford Smith	29
20/10/2020	Conductors of Care	Dr Therese Burke	27
10/11/2020	The International MS Nurse Experience of the COVID-19 Pandemic	Miguel Angel Robles and Belinda Bardsley	?
27/01/2021	A Place to Call Home	Sue Shapland	12
24/03/2021	Getting Started in (Nursing) Research	Dr Aliza Ben-Zacharia	18
11/05/2021	Presenting Research Proposals	Dr Marijean Bushe	15
30/06/2021	Research Problems and Purpose	Dr Aliza Ben-Zacharia	7
24/08/2021	What Physios Hope MS Nurses Know	Gilly Davy	24
21/9/21	MS and Work Productivity	Barnabas Bessing	21

October 2021	No webinar as we are having our AGM		
Upcoming webinars already booked in Nov, Dec and Feb (break over Jan) dates to be confirmed, all speakers are MSNA members 😊.			

**A massive thank you to Tim who has been pivotal in making these webinars happen and giving up his precious time! We salute you!**

Other projects:

- List of helpful Journals for MSNA members compiled by Therese
- Mental health resources Au and NZ – available on the website
- Therese's employers have kindly allowed Therese to share a quarterly research update with MSNA members which will hopefully be added to the website
- Website:
  - Review of website and meeting with Jess Morris from IT committee in August suggestions made
  - On discussion with Exec and Ed SC (emailed to Jess who is on leave), as the IT and Ed SC overlap the plan is to encompass IT with the ED SC hopefully provided support for both. So we will now be the education and IT subcommittee
  - MSNA has been given some money to help upgrade the website and the Ed SC are meeting with a web designer on 6 October – Imogen to update

**We are very keen to add more members to our team please contact me via [imogen.milner@ccdhb.org.nz](mailto:imogen.milner@ccdhb.org.nz) if interested (we'd love to have you!)**

## **NSW DELEGATE'S REPORT - Meena Sharma**

### **Collective reports from**

- Concord Hospital,
  - Gosford hospital,
  - John Hunter Hospital
  - Liverpool Hospital,
  - Royal North Shore Hospital,
  - The Royal Prince Alfred / Brain and Mind Centre,
  - Westmead Hospital.
- ✓ Telehealth and virtual care has been the main mode of care provision.
  - ✓ Clinical trials continue.
  - ✓ Medical and Nursing Staff shortage across the board, recruitment process underway.
  - ✓ X 2 MS nurses moved to a new therapeutic area.
  - ✓ X1 MS Nurse practitioner appointed in Liverpool Hospital.
  - ✓ Karen Thomas has commenced MS Nursing Role at RNSH in June 2021 – Congratulations.
  - ✓ Westmead Hospital Prof Steve Vucic and team relocated and merged with Concord Hospital Neuro-immunology team.
  - ✓ Concord Hospital -Neuroimmunology Clinic already set up and a dedicated MS Clinic on Tuesdays.
  - ✓ Dr Justin Garber has taken over from Prof Steve Vucic at Westmead Hospital. At the moment there is no MS Nurse or dedicated staff looking after the clinic.
  - ✓ Two patients have commenced HSCT this year at GOSFORD hospital.

### **Positives**

- ✓ Home infusion services has helped to ease off the pressure on infusion services, as well as option for patient who doesn't want to visit hospital situated in red zone.
- ✓ Have unearthed many new contacts in rural hospitals who have helped facilitate infusions for our patients who live rurally.

### **Challenges/issues**

- ✓ COVID! Too few staff, both medicine and nursing. Wait list is longer than 6 months.
- ✓ Less clinic appointments available, relapse triage appointments are being added out of clinic sessions.
- ✓ Time constrain - Covid 19 vaccination discussions with every patient.
- ✓ Difficulties for some patients to get access to Covid-19 vaccinations.
- ✓ Delays in patients getting appointments in the infusion units.
- ✓ Challenging keeping infusions going with so much staff redeployment.
- ✓ COVID presents challenges for trials too, with the need to reschedule visits due to exposure etc, interstate patients unable to return for visits and monitoring visits not permitted so there is a backlog developing.
- ✓ MS patient pool getting bigger with the same staffing level, if not reduced.

**New MSNA State Delegate** – please join me in to congratulate and welcome **“Annmaree**

**O’Connell”**  
THANK YOU

## VICTORIA DELEGATE'S REPORT – John Mathews

What to say? Here we are still in Groundhog Day.

Like many of you I'm sure, I'm struggling with trying to work out what day of the week it is. I only work 2 days a week in my role as MS Nurse at Ballarat Health Service so keeping up with the day of the week is even harder! Here in Victoria we've lost count of what number lockdown we're currently in. It's been much harder for our metro colleagues without doubt. We in regional Victoria have not had to endure the hard rules set in Melbourne. Having said that, Ballarat is currently in a snap 7 day lockdown and in my sleepy little town we've had 3 recent tier 1 location alerts. The cat is well and truly out of the bag!

Thank goodness for our MSNA webinars that are the only means of bringing us together currently. Thank you to Tim, Imogen and teams for pulling it all together.

I guess most organisations are concentrating on how best services can be maintained during an outbreak of Covid and what needs priority. We're currently looking at adopting the 30 minute Natalizumab infusions that the Alfred Team have trialled and written up. I enclose the paper that Louise Rath has kindly sent and is happy for me to attach. This will enable us to free up beds sooner and because patients will only be in the hospital a much shorter time, less risk for them. I know, many people remain reticent about visiting hospitals and even leaving home.

I'm planning on retiring in the coming 12 months so we will be looking for a representative to carry the banner in Victoria. Please give it some consideration and if you feel so inclined please let me or Belinda know.

With very best wishes  
John.

## WA DELEGATE'S REPORT – Petrina Keating

- As of 2021 all the nurses at MSWA are now Neurological Liaison Nurses (NLN). Currently we have no MS specific nurses. Our NLN's at MSWA will still support all MS clinic's.
  - A new MS Clinic at Joondalup has been set up by Dr Kevin O Connor. This clinic runs monthly and is also supported by a NLN from MSWA.
  - Ongoing MS education to all hospitals.
  - Upcoming Understanding MS Children's workshop organised by MSWA
  - New nurses at MSWA. Now a team of 21 NLN's.
  - Stake holder involvement with C-RIMS study
- 

## QLD DELEGATE'S REPORT – Sharon Edwards

There are 11 active nurses in QLD registered with MSNA for this financial year.

### MS Clinics:

- Townsville University Hospital (and private practice) (including surrounding North QLD region) = 1x MS nurse, 0.4 FTE, ~350 MS patients.

- Gold Coast University Hospital = 1x MS nurse, 1.0 FTE, ~600 MS patients.

- Sunshine Coast University Hospital = 1x general neurology CN, 1.0 FTE, ??number of MS patients.

- Royal Brisbane and Women's Hospital = 1x MS (50%) & Stroke (50%) NP, 1.0 FTE - 2x MS clinics/week; 1x MS CNC, 0.8 FTE (was previously 1.0 FTE however this was decreased due to withdrawal of funding). ~1200 MS patients. Upcoming discussion of scope expansion for the NP role in MS: Lumbar punctures. Probably the largest change is takeover of care for a substantial cohort of patients that belonged to one of the Neurologists that has recently left the RBWH. This involves collaborative practice with one Neurologist on an 'as needed' basis as opposed to a share care arrangement. Essentially it means the NP has been given the ability to independently provide a service to MS patients without having to co-share DMT decisions with another consultant. The collaborative agreement still stands but the NP will be the primary provider.

- Princess Alexandra Hospital = 1x MS NP, 0.4 FTE – 2x NP MS clinics per week; 1x MS nurse (including MS research role), 0.8 FTE (plus she does 0.2 FTE in neuroimmunology). ~650 MS patients.

### Community Services Available:

- MS Qld = 1x MS nurse, 1.0 FTE; 1x MS NP, ?0.5 FTE. Phone support, home visits (mainly for NDIS applications and injectable training at present), assessment, training/education sessions etc. NeuroAssist phone line (including physiotherapists and coordinators). MS Qld Nursing contacts: over 2188 client phone contacts last financial year. The NP had 211 after hours contacts (after 5.30pm/weekends/PHs).

- Pharmaceutical company support programs: MS Alliance – 1x MS nurse, 0.8 FTE. Phone support, home visits, zoom meetings to patients, training/education sessions, referrals to allied health professionals etc.

### Research Nurses

- 2x research nurses in MS at Princess Alexandra Hospital (1x 1.0FTE, 1x 0.8FTE (as listed above doing MS nurse role and MS research, then 0.2FTE in neuroimmunology)).

### Ongoing Professional Development in Qld MS Networks

- Sporadic face-to-face meetings due to COVID-19 restrictions, but more so Teams online meetings in SE QLD since April/May.

- Pharmaceutical company webinars.

- MSNA webinars.

- MS Qld Nurses delivered 8 Health Professional Education sessions to 252 participants.

- Independently sourced training.

### COVID-19 response to work practices

- There has been a shift towards phone appointments, some telehealth, particularly in SE Qld. Increase in patients FTA due to fear of attending hospital. This has not really been the case in Townsville, however.

- As Townsville has had very few COVID-19 cases, the MS service is essentially 'business as usual', although face-to-face consults and phone/email queries always have concerns regarding COVID-19 discussed.

- MS QLD nurses are working from home primarily and doing appointments over phone or via Zoom/Teams. Virtual meetings have been great for reaching regional patients. Still permitted to do home visits when required with safety checks, NDIS applications or injectable training – need to wear face masks and do social distancing during home visits.

- MS nurses report and increase in number of calls from patients regarding questions on COVID-19 – including vaccines, prevention, risk management, DMTs etc. Needing to provide a lot of education and allaying fears regarding this.

- Massive change to Zoom education training visits; huge influx of calls specifically on COVID-19 and thus a big increase in daily hours for MS Alliance nurse.

- MS nurse reports talking to more patients who have deteriorated over the past 18 months and are now looking to increase their functional capacity.

- MS nurses reports noticing some patients are mindful/reluctant of being on an immunosuppressant DMT due to COVID-19 risk, and therefore HCP concerns of disability progression. Discussions with patients about risks of getting COVID-19 vs risks of uncontrolled MS disease activity.

- Some education events have had to be cancelled by MS Qld due to COVID-19 restrictions.



- MS research was temporarily relocated, and recruitment paused in some studies in 2020, but back to normal now in 2021.

- 'Core' roles for MS nurses haven't really changed, just in the way in which some aspects are delivered.

We are hoping to have a QLD crew face-to-face meeting by the end of 2021 in Brisbane. Unable to do this for the AGM as it is a public holiday in QLD that day.

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## **TASMANIA DELEGATE'S REPORT – Michael Mortensen**

No great changes in the MS Nursing landscape down here in Tassie. Two nurses employed by Multiple Sclerosis Limited – one in Hobart and one in Launceston, assisting with queries relating to symptom management and medications, and also assisting with NDIS applications. Two support nurses employed at the two main hospitals which operate MS clinics – one at Royal Hobart Hospital and one at Launceston General Hospital. Two clinical trial nurses employed by Menzies Institute for Medical Research in Hobart. One nurse employed at Day Procedure Unit at Launceston General Hospital.

TAURUS study continues at Menzies. This phase 1 study is looking into the benefits received from magnetic brain stimulation for people living with MS – hoping to expand to other centres in the future.

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## **SA & NT DELEGATE'S REPORT – Sharon Barlow**

### **Collective reports from**

- Flinders Medical Centre,
  - Lyell McEwen Hospital,
  - Multiple Sclerosis Society,
  - Royal Adelaide Hospital,
  - Royal Darwin Hospital
  - Specialists on College,
- ✓ Telehealth and virtual care has been utilised as required through the pandemic
  - ✓ Clinical trials continue
  - ✓ FMC have had the introduction of a MS/MND fellow which has allowed for 2 additional MS weekly clinics and improved access for relapse assessments
  - ✓ New member from NT Michelle Bijasa
  - ✓ MS Society has had a change at the guard: CEO- Tim Ryan, Client Services Manager- Danielle Hanisch implementing new model of service delivery
  - ✓ MS Society Continence Clinic model has changed. Amanda Mouvet has reduced her hours and works 1 day a week in the MS nurse led continence clinic

## **Positives**

- ✓ Some public hospitals have been able to access home infusion services which has helped to ease off the pressure public infusion services. This provides an option for patients with private insurance.
- ✓ Moving towards faster infusion protocols for Tysabri and Ocrevus as per data published by our Australian eastern state colleagues
- ✓ MS Society regional and NT members increasing access to virtual allied health services
- ✓ MS Society Allied Health Outreach trip to Darwin and Alice Springs for individual assessments and symptom management advice. HCP and client group education programs provided

## **Challenges/issues**

- ✓ COVID! vaccination discussions with every patient in this evolving space
- ✓ Increased administration demands to support COVID related delays in appointments infusions/imaging/reviews.
- ✓ COVID travel restrictions for interstate and regional patients impacting on accessing services
- ✓ The impact of not having face to face reviews – things get missed, the loss of connection between patient/client and MS nurse and service
- ✓ MS patient numbers increasing without increasing MS Nursing FTE

## **MSNA SA State Delegate**

- ✓ Sharon Barlow

## **SOUTH ISLAND DELEGATE'S REPORT – Jess Deacon**

### **Overview of Te Waipounamu (South Island)**

Te Waipounamu covers 150,437 square kilometers with a population of 1,155,400. There are Neurology Services in 3 of 6 district Health board in the cities of Nelson, Christchurch and Dunedin

We currently have 7 financial members in Te Waipounamu.

### **Whakatū (Nelson)**

Nelson Hospital covers the Nelson and Marlborough Region

- Neurology CNS 1.1 FTE
- MS Society field workers in Nelson and Blenheim
- 1-2 nurse led clinics per week plus available in neurologist clinic
- Considering joining MS Base
- Clinical trials: nil

### **Ōtautahi (Christchurch)**

Christchurch Hospital cover Canterbury, South Canterbury, West Coast, Chatham islands and Antarctica

- 1 MS Clinic weekly and 2-3 MS Nurse Clinics per week
- CNS – Multiple Sclerosis 0.5 FTE, MS Nurse 1.0 FTE and Research Nurse 0.25 FTE

- MS Society – x2 MS Resource Nurses in Canterbury and x1 in West Coast. A field worker in South Canterbury
- Service Delivery:
  - Continuing to move low risk natalizumab infusions to the Community Infusion Service
  - Contribute to Allied HealthPathways (pathways relating to MS for the allied health team)
  - Working group established for Haematopoietic stem cell transplantation (HSCT).
  - Maintaining iMed database and manage NZ ethics for the MSBase registry
- Clinical trials: ESTEEM observational study, DAYBREAK study and O-HAND
- COVID- 19 Response:
  - COVID-19 Alert levels 3 and 4 telephone consults for routine follow-up appointments. MS relapses which required intervention seen face to face in the Neurology Acute Clinic.
  - No delays on initiating most DMTs. Delayed starting people on ocrelizumab until vaccination complete
  - MS Society worked from home providing telephone or video contact with clients
  - Continue to offer telephone consultations for those who live out of town and or with high EDSS

### **Ōtepoti (Dunedin)**

Dunedin Hospital covers Otago, Southland and Stewart Island

- Neurology CNS - Neurology 1.0 FTE and MS Research Nurse 0.2 FTE
- No dedicated MS Clinics at Dunedin or Invercargill Hospitals
- Nurses fly to Invercargill where see 2 new MS patients and 5-7 follow-up per month
- MS Society field workers in Both Southland and Otago region
- Nurses Maintain iMed database
- Clinical trials: PrevANZ, ESTEEM observational study and O-HAND
- Education and professional development:
  - Organised and hosted the 6<sup>th</sup> NZ MS Nurses Meeting held in March 2021
- Service Delivery:
  - Clinical lead is trying to increase Neurology Nurse FTE
- COVID- 19 Response:
  - COVID-19 Alert levels 2,3 and 4 telephone consultation
  - Now offering telephone reviews as an option for people with travel concerns. Had been considering a telehealth option for MS review service for outreach areas.

### **Aotearoa (NZ) Wide**

- Ongoing bi-monthly MS Nurse teleconferences facilitated by Imogen Milner
- NZ MS Winter Meeting August 2021 attended by Neurologists, Neurology Trainees and MS/Neurology Nurses.
- 6<sup>th</sup> Annual NZMSN meeting held in Christchurch – 13 March 2020
- MS Society plans and projects for 2021
- Ongoing work with national and regional MS Societies
- Ongoing challenges with both clinic appointment availability and MRI capacity.
- Applying for and access to treatment changes effective March 2021:
  - Applications to the Multiple Sclerosis Treatment Assessment Committee (MSTAC) would no longer be required and funded multiple sclerosis

- treatments would be accessed by a standard Special Authority application in the same way as many other funded medicines.
- Access to funded multiple sclerosis treatments would be widened for people with an Expanded Disability Status Scale (EDSS) score of 0 to 6.0 (inclusive) meaning treatment would continue to be funded for patients while their EDSS is 6.0 or below.

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## NEW ZEALAND – NORTH ISLAND DELEGATE’S REPORT – Fiona d’Young

It’s been a challenging year across Australasia and the North Island of NZ reflects this. Interestingly with the ructions a pandemic has caused if I had to pick 2 words to sum up the last 12 months they would be: **increased equity**

Adapting to increased use of tele-health has provided a silver lining for many of our patients by creating better equity for those who found the cost: fiscal (petrol/parking) and physical cost of accessing in person of neurology care prohibitive, and this can only be a good thing.

In other positives we have had a major change in our PHARMAC process that has removed red tape and now allows for greater accessibility to DMDs with the EDSS entry criteria moving from 0-4 to 0-6. It’s been a game-changer.

MS Infusions numbers continue to grow with those starting an IV tx far outweighing numbers of people stopping tx and this in some areas eg. Auckland is leading to a capacity and demand mismatch. Shorter infusions protocols have been embraced in many areas and thanks to those of you who have shared your protocols and experience.

COVID Vaccination queries from those on DMDs are plentiful and time consuming **but important**.

Waikato has had a tough time suffered a major malware cyber-attack that crippled their DHB and its capacity to operate for a number of weeks which should be a red flag to us all to consider how we can continue service provision should electronic records be unavailable.

We have been exceedingly lucky to have had 2x opportunities to meet in person this year and do some well needed and ‘bucket filling’ and networking at our annual nurses day in Dunedin in March and at the MS national meeting in Queenstown in August.

So to my surprise this report is more positive than I expected when I started it! Roll on a fresh new start 2022. We hope to see you all in person then. We miss you 😊