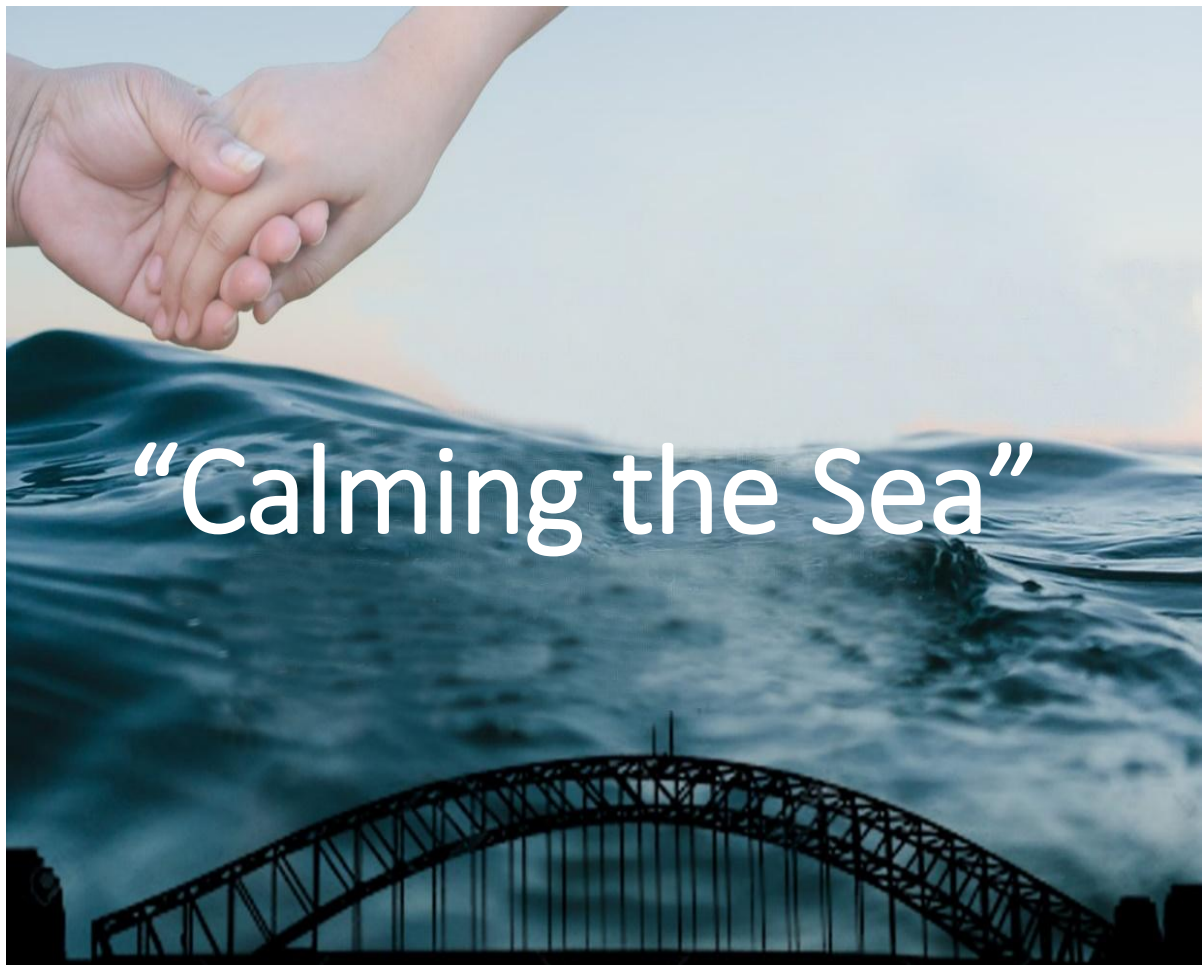


MSNA ANNUAL CONFERENCE PROGRAM
SYDNEY, 29th – 31st August 2019



“Calming the Sea”

MS Nurses steer patients through turbulent times and rocky waters to help create a smooth journey in the face of uncertainty – exploring the themes of patient centred care, wellness and hope

WELCOME ADDRESS FROM OUR PRESIDENT

I would like to warmly welcome you to Sydney for our 2019 conference. This annual event is keenly awaited by many as our opportunity to get together to hear about current research, treatment and management trends in Multiple Sclerosis, to hear about our colleagues' endeavours and achievements, and to collaborate, communicate and enjoy each other's company.

The effort that goes into preparing for our annual conference is immense, and I would like to recognise Meena Sharma and her hard-working team in NSW who hit the ground running almost before our last conference was even over, creating an agenda which will educate, excite and inspire us over the next three days. Thank you so much for your attention to detail, your organisational skills and your passion and determination to make this conference a success. We are the lucky recipients of all your hard work! I just hope your families are still speaking to you.

The conference theme "calming the sea" reflects the efforts that MS Nurses make on a daily basis to help patients adjust to their diagnosis, to assist them in challenging and troubling times throughout the course of their disease, to streamline the complex pathways of clinical care, and to provide them always with reassurance and hope in the face of an unpredictable chronic disease.

Our pharmaceutical industry partners have been incredibly supportive of this year's conference and I would like to make particular mention of Novartis as our very first Platinum sponsors of this conference, providing us with not only funding support but the opportunity to have an international key opinion leader speak to us on Friday, Prof Hans-Peter Hartung. We are also incredibly grateful to Bayer, Biogen, Sanofi-Genzyme, Merck, Roche and to Teva and our growing number of industry partners and collaborators for enabling us to keep our annual conference costs reasonable for our members. It would be lovely if you could visit their stands during the breaks to say hello.

The Executive Committee has worked tirelessly behind the scenes over the past few months to support the NSW crew in getting this conference off the ground. I would like to thank Melanie McMurtrie, Emma Christian and Imogen Milner for being so collaborative, cohesive, supportive and hard-working. Thank you all for your amazing efforts.

Susan Agland has hit the ground running since taking on the role of Web and Communications officer, resulting in the launch during this conference of our NEW website! Huge thanks to Susan for all the time and effort she has put into this major project on behalf of our organisation. With our new IT Subcommittee (thanks to Jess Morris and Louise Rath), we can expect to see great things coming along.

And finally, it takes time and courage to prepare a poster or a podium presentation, so thanks to those who have made the effort. This is always a major highlight for me as I love to hear what my colleagues have been doing. Thank you so much for sharing. Likewise, for anyone sitting the MSNICB exam, good on you for testing your knowledge and I wish you all the best.

That's more than enough from me. Let's get this conference started!


Belinda Bardsley, on behalf of the MSNA committee

SPEAKERS

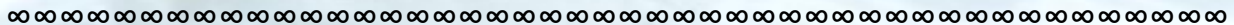


Karen Walshe

NUTRITIONIST




Karen Walsh is a qualified Nutritionist and community leader who has been in clinical practice since 2013. Karen was formally diagnosed with Multiple Sclerosis in 2004 and started investigating the role nutrition has in managing chronic illness. This curiosity quickly turned into a passion that led her to retrain with the purpose to help educate others on how making the right food choices can dramatically impact health. Karen works alongside evidence-based medicine to achieve better patient outcomes. In an attempt to inspire change within her community, Karen has developed the “Eat Better Feel Better Workshops” delivering 12 workshops to her local community in 2019 with the support of the Local Council and Clubs Australia. Karen also serves as a volunteer leader for the Better Health Workshops delivered through NSW Local Area Health. Karen with her no-nonsense approach to diet and lifestyle, will breakdown the latest research on how nutrition has a direct impact on health and wellbeing, with particular reference to Multiple Sclerosis and the gut-brain connection. You will walk away confident in the knowledge on how to make better food choices to achieve better health outcomes for you and your patients. Karen will inspire you to Eat Better, Feel Better Today!

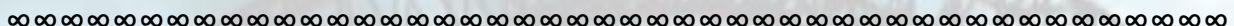


Polly Cartlidge

SENIOR NEUROLOGICAL OCCUPATIONAL THERAPIST AND OCCUPATIONAL THERAPY
TEAM LEADER




Polly graduated as an Occupational Therapist in 2010 from Coventry University and worked in the NHS in the UK across a variety of specialities before settling into her area of passion of neurological therapy. Polly has extensive experience in working with neurological patients with regards to promoting function and life participation through addressing cognition, upper limb function and home environments. She has extensive experience with implementing home modifications and assistive technology and in aiding people to achieve optimal independence and quality of life. She is passionate about empowering individuals and has been leading the upper limb bootcamp program here at ARC using evidence-based practice to promote recovery and neuroplasticity. Polly also works as the Occupational Therapy team leader supporting the development of a growing OT team.



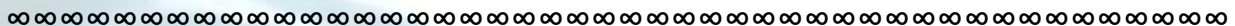


Anna Jones

ARC MANAGER AND SENIOR NEUROLOGICAL PHYSIOTHERAPIST




Before moving to Australia in 2007 Anna graduated in the UK with a BSc (hons) in Physiotherapy and worked across a broad range of neurological areas including stroke and spinal cord injury. Prior to joining the ARC team in 2014 as a senior neurological therapist, Anna was working as the Neuro Clinical Educator at Concord Hospital leading the neuro physiotherapy services and teaching students on clinical placements. Anna continues to lead our student education program here at ARC and also trains other health professionals in our PD Warrior program. Since identifying a lack of services in the Sydney area Anna has developed ARC's Functional Neurological Disorders service and continues to grow and develop this along with the team. She also leads the MS service and MS programs at the clinic including group programs in the gym and in the pool. As the ARC Clinic Manager Anna enjoys working alongside the management team and supporting staff to ensure we continue to provide an exceptional service. Outside of work Anna enjoys spending time outdoors with her family of 5 and finding new spots to explore in and around Sydney. Having grown up in the UK the beauty of Sydney's coastline continues to inspire and never gets old!

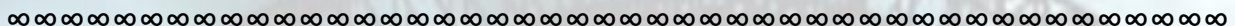


Dr Patrick Aouad

NEUROLOGIST




Dr Patrick Aouad obtained a Bachelor of Medical Science, majoring in neuroscience at the University of Sydney with a particular interest in neuroimaging whilst serving as the President of the Medical Science Society. He went on to complete his medical degree in his home town of Canberra at the Australian National University and then completed a Master of Philosophy (MPhil) by thesis under the mentorship of Professor Christian Lueck examining early CT signs and prognostic markers in acute ischaemic stroke. Concurrently Dr Aouad completed his intern and resident years and was awarded the intern of the year award before completing basic physician training at Royal North Shore Hospital. He went onto advanced training in neurology with a special interest in neuro-immunology. Dr Aouad was awarded the registrar of the year award and undertook a further fellowship with a primary focus in Multiple Sclerosis and obtained his FRACP as a consultant neurologist in 2016. He is an internationally published author and collaborator and has received several awards in recognition of clinical and academic leadership. He is a staff specialist at Liverpool Hospital in Sydney and works privately on the North Shore. He runs a busy neuro-immunology clinic and continues to pursue research in the field both through independent investigation and clinical trials. He holds a position as honorary fellow and research supervisor at the University of Sydney overseeing post-graduate degree candidates in the field of MS. Dr Aouad is also the founder of medical education organisation Physician Central and is the co-founder of Loxley Health.





A/Prof Fabienne Brilot - Turville

PRINCIPAL RESEARCH FELLOW AT THE UNIVERSITY OF SYDNEY




Obtained her PhD in Belgium and at the JD Gladstone Institutes, UCSF, USA. She then became postdoctoral fellow under the mentorship of Professor Christian Munz (currently located at the University of Zurich, Switzerland) at the Browne Centre for Immunology and Immune Diseases headed by late Professor Ralph Steinman (Nobel Prize for Medicine 2011) at the Rockefeller University, USA. She was recruited at the Children's Hospital at Westmead in Sydney in 2007 where she started the Brain Autoimmunity group. Fabienne is currently Principal Research Fellow at the University of Sydney, and her research focuses on immune-mediated brain disorders such demyelinating disorders and movement and psychiatric disorders. Her group aims to discover biomarkers and explores the autoimmune response in patients to improve their diagnosis and treatment. Fabienne holds research funding from the National Health and Medical Research Council, Australia. She is the President of Neuroimmunology Australia, is a member of the International Advisory Board of the International Society of Neuroimmunology (ISNI) and was the scientific chair of ISNI conference in 2018. She reviews for many journals and is Associate Editor of Frontiers in Immunology and Frontiers in Neurology, Section Multiple sclerosis and Neuro-immunology.



Professor Hans-Peter Hartung
MD FRCP FAAN FANA FEAN

Professor & Chairman, Dept of Neurology, Heinrich-Heine-University Düsseldorf



Professor Hartung received his undergraduate training at the Universities of Düsseldorf, Glasgow, Oxford and London. After graduation magna cum laude as MD in 1980 he served an immunology fellowship at Johannes Gutenberg-University of Mainz. He started his career in neurology at the University of Düsseldorf, where he became assistant professor in 1987. He is currently chair of the Department of Neurology at Heinrich Heine University Düsseldorf, a position he has held since 2001, and was also appointed Director of the Centre for Neurology and Neuropsychiatry in 2012. He is in charge of two busy inpatient departments with a total of 110 beds including a 24 bed stroke unit and a range of outpatient clinics, including Multiple Sclerosis and GBS CIDP Foundation International Centre of Excellence for immune neuropathies. He is also Medical Director of the Department of Conservative Medicine at Düsseldorf University Hospital. Professor Hartung's clinical and translational research interests are in the field of basic and clinical neuroimmunology and in particular multiple sclerosis and immune neuropathies, development of new immunological, neuroprotective and neural repair promoting strategies.

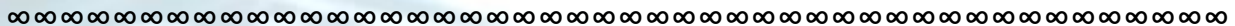


Professor Roy Beran

NEUROLOGIST


MBBS, MD, FRACP, FRACGP, Grad. Dip. Tertiary Ed., Grad. Dip. Further Ed., FAFPHM, FACLM, FRCP, FACBS, B Leg. S, MHL and FFFLM (Hon).

He is trained as a consultant neurologist and practices as such, as well as being accredited as a sleep physician. He is a Professor in the School of Medicine at Griffith University, Queensland; a Conjoint Professor of Medicine at the University of New South Wales; He is on the Council of the Australasian College of Legal Medicine, having been its Past President; he is the Australian Governor and Secretary General of the Board of Governors of the World Association for Medical Law; and past Board Member of the Australian & New Zealand Institute of Health Law and Ethics. He is a member of the Australian Academy of Forensic Sciences and an Honorary Fellow of the Faculty of Forensic & Legal Medicine of the Royal College of Physicians (London). He is a Member of the Australian & New Zealand Association of Neurologists and a Corresponding Fellow of the American Academy of Neurology. He has contributed approximately 300 papers, letters or book chapters within the scientific literature; he has presented approximately 335 papers at national and international scientific meetings; and has written or edited 15 books, dealing with issues relating to neurological and legal matters.



Dr Therese Burke

PhD RN MSCN



Therese is currently a post-doctoral researcher in the School of Nursing at The University of Notre Dame in Sydney, Australia, with a focus on MS nursing. Therese completed her PhD in February of this year, using qualitative inquiry to explore the life trajectory of people living with Relapsing Remitting Multiple Sclerosis. Several international publications have resulted from this research, including the *British Journal of Neuroscience Nursing, Research Theory and Practice* and the *Australian Journal of Advanced Nursing*. Therese is a Past President of MSNA Inc. and has also been a member of the MS Nurses International Certification Board since 2011, and is currently the immediate Past President and Recertification Chair. Therese was presented the John Study award from MS Australia in 2016 for her contribution to MS research and clinical care in Australia, and also the June Halper award from IOMSN for contributions to international MS care in the same year. Therese managed the MS clinic and research centre at Westmead Hospital, a teaching hospital of the University of Sydney, from inception in 2007 until 2017, before moving into academia. Current research interests include the transition from RRMS to SPMS from the patient perspective, the effects of a diagnosis of CIS on patients and nurses, and the role and education of MS Nurses.



THURSDAY 29th AUGUST

TIME	SESSION (The Terrace, Level 12)	SPEAKER/VENUE
10.00 – 13.00	MSNICB Exam	Exam Proctor Level 11, Room Hordern 2
11:00 – 12:00	MS Education for Beginners: Strategies for speaking with newly diagnosed patients	Edith Cinc – Immunotherapy Nurse – Austin Health
12.30	REGISTRATION OPEN – LUNCH PROVIDED	Level 11 - Tiled Area between the Cidery Bar & Sphere Restaurant
13.30 – 13.40	Welcome Address	President - Belinda Bardsley
13:40 – 14:10	Website Update	Christoph Gremm - Web Designer
14:10 – 15:00	Microbiomes	Karen Walshe - Nutritionist
15:00 – 16:00	"Optimising life with MS - understanding the impact of cognition and exercise in improving quality of life"	Polly Cartlidge and Anna Jones
18.00 – 21.00	Welcome Reception	The Terrace, Level 12

FRIDAY 30th AUGUST

TIME	SESSION (BALL ROOM 2 & 3)	SPEAKER/VENUE
08:00 – 08:30	Registration Open	Level 11, Lobby in front of ball room 2&3
08:30 – 08:40	Welcome	President - Belinda Bardsley
08:40-09:20	Progressive MS	Dr Patrick Aouad - Neurologist
09:20 – 09:45	NDIS and Access Request Forms made incredibly easy...Hopefully!	Rochelle Brown (MSWA)
09:45 – 10:10	Live attenuated vaccines and DMT	Jessica Deacon (NZ)
10:10 – 10:40	Morning Tea	Trade Area Visit
10:40 – 11:05	Changing language to acknowledging patients perceptions of “Treatment” in MS Care	Tim O’Maley (NP – QLD)
11:05 – 11:30	Anxiety, depression and suicidal ideation - Tips for nursing practice	Sharon Edwards, MSCN (Townsville Clinic)
11:30 – 11:55	‘A Place to Call Home’ (Vignettes of MSers’ living in supported accommodation describing what it has and does mean to them)	Sue Shapland (MSWA)
11:55 – 12:20	The effect of a Multiple Sclerosis massive open online course (MOOC)	Dr Suzi Claflin (Menzies Institute)
12:20 – 13:30	Lunch & Poster Session	Trade Area Visit
13:30 – 13:55	Update from the President	Belinda Bardsley
13:55 – 14:35	MOG antibody-associated disorders: diagnosis and treatment	Associate Professor Fabienne Brilot-Turville
14:35 – 15:15	The evolution of DMDs for MS – from injectables to tablets to infusions and beyond	Prof Hans-Peter Hartung
15:15 – 15:35	Afternoon Tea	Trade Area Visit
15:35 – 16:15	Drug safety monitoring and the legal implication for nurses	Professor Roy Beran
16:15 – 17:15	AGM	Level 11 – Room Hordern 2
18:30	Pre-Dinner Drinks	Level 11, Lobby in front of ball room 2&3
19:00	Annual MSNA Dinner Celebration	Theme: “Las Vegas-Elvis Presley”

SATURDAY 31st AUGUST

TIME	SESSION (BALL ROOM 2 & 3)	SPEAKER
	CONCURRENT SESSION	
	BALL ROOM 2	
08:30 – 08:40	Welcome	Meena Sharma
08:40 -10:40	Neurological assessment for the MS Nurses – For beginner	Susan Agland & Michelle Allan
	BALL ROOM 3	
08:30 – 08:40	Welcome	Imogen Milner
08:40 -10:40	Neurological assessment for the MS Nurses – For advanced	Tim O'Maley & Meaghan Osborne
10:40 – 11:00	Morning Tea	Trade Area Visit
11:00 – 11:40	Surplus Suffering: A sign of the times or a sign that it's our time?	Dr Therese Burke - PhD RN MSCN
11:40 -12:20	High efficacy drug masterclass: Role of nurses in treatment related risk management (Case interactive workshop - Pharma representatives excluded please)	Panel discussion - Chaired & Presented by Sharon Barlow
12:20 – 12:30	Report from award/grant recipients	Stephanie Rout Fiona D'Young
12:30 – 13:00	Awards & Presentations	MSNA Executive Team
13:00 -13:10	Close	President – Belinda Bardsley
13:10	Lunch and Departure	

Abstracts for Podium Presentations

Name: Rochelle Brown

Area of MS Nursing Practice: Community

Title: NDIS and Access Request Forms made incredibly easy...Hopefully!

Abstract: Here in Western Australia we are relative newcomers to the NDIS in comparison with other states, with the State Government not formally opting to join the scheme until 1st July 2018.

It is a challenge to evolve and adapt to the roll-out of a new scheme, whilst still supporting the MSWA's members access the NDIS. Like our sister states, our success to date has been mixed.

This led me to question, how can we improve this?

This question was the catalyst to my undertaking a project to develop an assessment tool demonstrating the biopsychosocial impact of MS in relation to an individual's functional capacity and psychosocial functioning.

Often in practice, nurses are requested to complete legal documents for patients of whom they have little or limited prior knowledge. Like our patients, nurses come from a wide and varied background. This presents a challenge in developing a universal assessment tool, encompassing a nurse's individual scope of practice.

In my presentation I will take you on my journey that led to the current NDIS Supporting Evidence Assessment used by the Community Access Nurses at MSWA.

Name: Jessica Deacon

Area of MS Nursing Practice: Neurology Outpatient Department

Title: Live attenuated vaccines and DMT

Abstract: What would you do if your patient had a live attenuated vaccination while on one of the multiple sclerosis (MS) disease modifying treatments which results in the patient's immunosuppression?

It is well known that live attenuated vaccinations are contraindicated for patients whilst on the majority of the MS disease modifying treatments. Consequently MS nurses include pre-treatment patient education on the importance of not having live attenuated vaccines. However, due to a recent increase in measles cases globally, inclusive of Australia and New Zealand, the importance of ensuring immunity against measles is being encouraged. MS patients currently being treated with disease modifying therapy could potentially seek the measles, mumps and rubella (MMR) vaccine, which is a live attenuated vaccine, without consulting their MS clinicians or MS nurse. This presentation will discuss the following;

- A patient diagnosed with relapsing remitting MS, being treated with natalizumab, receiving the MMR vaccine.
- The concerns associated with administering live vaccines to immunocompromised people.
- A brief overview of the mechanism of action of live vaccines.
- The treatment plan our service developed.

To conclude, information will be shared on the strategies we have developed to mitigate further risks to patients and clinicians.

Name: Tim O'Maley **Area of MS Nursing Practice:** Patient Care / Education – Shared Decision Making

Title: Changing Language to acknowledging patients perceptions of “Treatment” in MS Care

Abstract: The language we use in supporting our patients is crucial in fostering a long term relationship based on trust and understanding. However, it is important to remember that information does not equal education, and the ability to make the complexities of medicine comprehensible for patients is an important skill. Two recently published papers of almost opposing direction have highlighted the message that “I” can do better. Yeandle et al strongly emphasised the increased role patients and their families have in shared decisions making, noting “its success is reliant on effective patient-physician communication”. Burke et al in their paper on management of surplus suffering discuss HCPs can negatively impact the perception of the disease and recognising our control of information sharing may “go a long way to improving clinical encounters with patients and ultimately lead to greater satisfaction in care and shared decision making”. This presentation will briefly explore the core concepts of recent literature that have resulted in a shift in language used by the author in delivery of both clinical patient care and group educational opportunities, and the qualitative patient responses that emphasise the value of patient centricity in MS care.

Name: Sharon Edwards

Area of MS Nursing Practice: Townsville - clinic, MSCN

Title: Anxiety, depression and suicidal ideation - Tips for nursing practice.

Abstract: Anxiety and depression occur at greater rates in people with MS than in the general adult population. MS is a chronic condition associated with variable disability and often invisible symptoms. Average age of disease onset is between 20-40 years old, the prime of people's lives where they are navigating career, family planning, and sense of self. Diagnosis of MS challenges their identity and creates added stressors to their life. This can lead to varying depression severity, anxiety, social isolation, changes to cognition, career implication and financial burden. The psychological impact of having MS must not be underestimated or overlooked. Over a quarter of MS patients experience suicidal ideation, and suicide rates in people with MS are doubled compared to the general population. This presentation will focus on what to do when a patient presents to clinic (or phone consultation) with suicidal ideation; myths, facts and figures about suicide; questions to ask the patient; policy and protocols; legislation; crisis lines; who can help; and documentation.

Name: Sue SHAPLAND**Area of MS Nursing Practice: MSWA; GM Residential Options****Title: “A Place to Call Home”**

Abstract: The face of MS has certainly changed for the better; especially over the past ten – fifteen years. With 12 approved treatments, and more in the pipeline, we know the real difference that’s made to patients QOL and longer-term outcomes. There is reduced tolerance for treatment ineffectiveness and therapies are often switched to maximise benefit and reduce brain volume loss and reduce the risk of progression of disability previously accepted as part of the disease outcome. However, let us not forget the cohort of clients who were diagnosed before therapies came online, or who started therapy after the inflammatory damage was done or who have failed or even declined therapy; and of course, those with progressive MS. Many of us still support these clients and our treatment aims are to maximise their independence whilst we support them through disability progression and the deterioration that equates to ongoing losses and obviously impacts their QOL. Whilst our goal is to support individuals to remain living in their homes in their community this isn’t always safe or practical. In days not long past this cohort risked premature placement into Aged Care residential facilities. Thank goodness this is now changing thanks to access to the NDIS; funding is now available to support individuals to access in home supports and if required a range of age appropriate supported accommodation options, of their choice, in a timelier fashion. These supported living options are really changing lives. As a provider this is hugely satisfying; we get to see the real difference we can make. This presentation will include some vignettes of MSers’ living in supported accommodation describing what it has and does mean to them.

Name: Dr Suzi Claflin**Area of MS Nursing Practice: Research - Education****Title: The effect of a Multiple Sclerosis massive open online course (MOOC)**

Abstract: Massive open online courses (MOOCs) are highly accessible and flexible educational tools. MOOCs can be accessed anywhere using any internet-connected device. Working together over the past year, the Menzies Institute and MS Ltd. have developed a free six-week MOOC about MS for a general audience (the Understanding Multiple Sclerosis online course (UMS)) to improve participant knowledge about MS, health literacy and resilience. Here, we describe the MS community-focused approach taken in the development of the course and evaluate its effect on participant MS knowledge and satisfaction with the course. The course was developed in consultation with the MS community. Participants who completed the course were given the opportunity to provide feedback via a survey assessing participant satisfaction. We evaluated participant MS knowledge before and after completing the course in a cohort study. Of participants who completed the feedback survey, 97% were satisfied or very satisfied with the course overall. Participants stated that they learned the most from modules on biology and pathology (36%), symptoms and diagnosis (21%) and disease management (19%), and that these modules were also the most useful. Analysis of the effect of the course on MS knowledge is ongoing. We recommend the UMS as an educational tool for members of the MS community, including people living with MS, family members and carers. We believe that it is best used to supplement information provided by health care providers and will be particularly helpful for people who cannot access other educational resources due to time or logistical constraints.

Suzi B. Claflin¹, Rachael Gates^{1,2}, Maree Maher³, Barnabas Bessing¹, Bruce V. Taylor¹

¹Menzies Institute for Medical Research, University of Tasmania, 17 Liverpool Street, Hobart, TAS 7000

²Wicking Dementia Research & Education Centre, University of Tasmania, 17 Liverpool Street, Hobart, TAS 7000 ³MS Ltd., The Nerve Centre, 54 Railway Road, Blackburn, VIC 3130

Abstracts for Poster Presentation

Name: Jane Kabanoff**Area of MS Nursing Practice:** MS Clinic at Royal North Shore Hospital**Title:** BURNOUT

Abstract: Job burnout and compassion fatigue, it's one of those dangers we should look out for. Sadly often our "can do everything" personalities rarely see it coming. We are passionate about what we do, we thrive on the challenges, we love our job, and we're committed! BUT...we miss the signs, we are not indispensable. What is burnout, what are the signs and how can we refuel?

Name: Kathleen Styles**Employer:** MSWA (Community Access Nurse)**Title:** E-Resources for living well with MS

Being diagnosed with Multiple Sclerosis means learning to live with a lifelong and unpredictable illness. The experience of living with MS is different for everyone but concerns around how MS will impact on a person's health, family and employment are universal. My poster presentation will look at ways of coping with a chronic illness and continuing to live a meaningful and happy life with MS. My focus is on what resources are available as wellness apps and on websites. The resources presented can be used by the person with MS and the people who support them, including members of the health care team.

Name: Amanda Mouvet**Area of MS Nursing Practice:** Continence, Community**Title:** Delivering a training package results in catheter confidence

Abstract: Approximately 75% of people with MS experience bladder and bowel dysfunction at some point during the course of their MS. In response to the community gap in services for assisting clients to manage this symptom, the MS Society of SA & NT created a new Specialist Continence Nurse position in 2018. Referrals into this service include assessment and management of all aspects of bladder and bowel dysfunction in the home or clinic setting. The MS Continence Nurse received a request to provide catheter training for carers who are assisting one of our community based clients. The client requires intermittent catheterisation 6-7 times per day for neurogenic bladder dysfunction. An assessment was conducted in the home to determine current product use and catheterisation technique. In order to credential her carers, a training package was developed and delivered via small group education. Carers were provided with a variety of learning formats to gain competency with intermittent catheterisation. The package evaluation revealed very positive results and exceeded expectations from both the client and carers involved.

Name: **Nicola McGuinn** (MSNI Research Nurse) **Area of MS Nursing Practice:** Clinical and Research

Title: The role of the MS (Multiple Sclerosis) nurse in guiding implementation of preventative women's health guidelines

Authors: N McGuinn, J Richards, L Rath, V Jokubaitis, A Van Der Walt

Background: The Cervical Screening test¹ replaced the Pap test in Australia in 2018. Despite a public information campaign, little information was provided around screening guidelines for women with auto-immune disease who may be immunocompromised due to disease-modifying medications. This has resulted in inconsistent implementation of adjusted regular screening intervals and in the provision of cervical screening for people with a disability. Managing those who have declined previous testing, for personal reasons, remain suboptimal.

Description: We looked at two case studies that demonstrate the misconceptions around current cervical screening guidelines among both health care providers (HCPs) and people with MS. By identifying myths and clarifying processes with factual information we were able to support our clients to ensure the required screening was carried out. **Practice Points:** MS nurses are in a key position to ensure our patient population are up to date on current cervical screening guidelines. Providing accurate information to our patients will ensure greater compliance, leading to safer, holistic care.

References: <http://www.cancerscreening.gov.au/internet/screening/publishing.nsf/Content/www.cancerscreening.gov.au/cervical>

Name: **Louise Rath (MS Nurse)** **Area of MS Nursing Practice:** Clinical and research nursing

Title: Natalizumab risk surveillance strategies are dependent on nurse-led engagement

Authors: L. Rath, A. Van Der Walt, A. Hickmott.

Background: Natalizumab is a monotherapy for the treatment of relapsing remitting multiple sclerosis (MS). Natalizumab is associated with an increased risk of progressive multifocal leucoencephalopathy (PML), an opportunistic brain infection caused by reactivation of the JC (John Cunningham) virus that can lead to death or severe disability. Serum Anti-JCV antibody status identifies different levels of risk for PML in Natalizumab treated patients and has reduced the incidence of Natalizumab-associated PML. People with MS (pwMS) who are anti-JCV antibody positive, especially at an index >1.5, are at an increased risk of developing PML whilst those who are anti-JCV antibody negative are considered low risk. Recommended testing is pre initiation of treatment and then every 6 months. Anti-JCV antibody testing is complimented by MRI surveillance, particularly in those who are JCV antibody positive. Current recommendations require a yearly MRI for anti-JCV antibody negative patients and 6 monthly MRI for pwMS who are anti-body positive. PwMS who are anti-JCV antibody positive and continue Natalizumab beyond 24 months are at an even higher risk and 3-monthly surveillance MRIs are recommended by many institutions.

Description: We undertook an audit in March 2019 to evaluate compliance with Natalizumab safety surveillance guidelines in people receiving Natalizumab under our care. We examined both serum anti JCV antibody testing and MRI surveillance. **Results:** At the time of the audit, the MSNI Service at Alfred Health cared for 81 patients receiving 4-weekly Natalizumab infusions. The compliance rate with 6-monthly required testing of serum anti JCV antibody was 97.5% (2 initially missed). Our audit revealed 4 pwMS who converted from negative to positive anti-JCV antibody (4.9% conversion rate). All of these clients were informed of the seroconversion before their next infusion and individual risk stratification discussed. MRI surveillance with the required 6-monthly scans for pwMS who were positive for the anti-JCV antibody was 85%. Two patients were outside of the recommended time window and scanned at 9 months. MRI surveillance for negative anti JCV antibody patients was 99% with 1 patient scanned at month 13, outside of the recommended 12-month time window. Our audit confirmed that no pwMS with anti-JCV positive status remained on Natalizumab beyond 24 months. **Conclusion:** The MSNI nursing team is pivotal in contributing to compliance with anti JCV antibody testing and ensuring that MRI surveillance take place. Partnering with our Medical Day Unit staff to promote knowledge, and establishing batched testing, twice a year, have greatly enhanced compliance with risk management guidelines. Engagement with pwMS on Natalizumab, timely access and communication of results, is a key role of the MSNI nursing team.

Name: Louise Rath

Area of MS Nursing Practice: Patient engagement and infusions

Title: Multiple sclerosis and neuro-immunology patient preferences on outpatient's infusion therapy services

Authors: L.Rath, J Ellis, A Van der Walt MSNI Service, Alfred Brain, Alfred Health, Melbourne

Background: People with multiple sclerosis (pwMS) and neuro-immunological disorders are increasingly treated with infusible monoclonal antibodies. This rise in uptake has placed increased demands on current services and mandates careful strategic planning. Evidence suggests that effective strategic planning for health services, particularly when meeting demands for people affected by chronic diseases, requires an inclusive client engagement strategy. Including the disease-affected person's voice in the redesign and direction of the service leads to empowerment, increased client satisfaction and resource utilization. In turn, this could affect compliance with treatment and long-term outcomes. The MS nurse is in a key position to seek this information and advocate for client preferences and experience. This study examined patient preferences on timing and location of their infusions and their association with demographic and disease variables in order to contribute to ongoing patient focused strategic planning. **Methods:** Eighty-three patients with multiple sclerosis and neuro-immunology conditions receiving an infusion at our Medical Day Unit in the month of March 2019 were asked to complete a questionnaire looking at demographics, mobility, transport, employment/study commitments, child care needs, preference for time of infusions and location of infusion centers including access to home based treatment. Free text feedback on current service was also obtained. **Results:** Eighty-three patients completed the survey out of a possible ninety-one patients booked for infusions. (Mean age 42 years, 75% female). Infusions were predominately Natalizumab and Ocrelizumab (66% and 25%). 71% of our patients were engaged in some form of work or study and 83% of this group had to have time of work or study to attend their treatment. 70% of patients would prefer their infusion before 12-midday. 60% would consider the option of home-based infusions. The majority still used a car as their transport to the infusion. **Conclusion:** This combined qualitative and quantitative study demonstrates the diversity of needs of people requiring a chronic infusible therapy. This group of patients is more likely to prefer treatment in the morning and is open to the idea of home-based infusions. Our study provides information for health care services to target service delivery at peak times and consider alternate ways of delivering infusible treatments to people with multiple sclerosis and neuro-immunology conditions.

Name: K-J Lazarus

Area of MS Nursing Practice: Education

Title: An Australian Pilot Preceptorship Program for Multiple Sclerosis Nurses and Study Coordinators

Background: The care and management of Multiple Sclerosis (MS) varies widely across Australia. Consequently, the scope and delivery of clinical care, capacity for involvement in clinical research, level of support and opportunities for education and mentoring are dramatically different across Australia. The array of treatments now available creates challenges for sites in managing complex treatment decisions, drug administration and long-term safety monitoring. Similarly, clinical trials are becoming increasingly complex and challenging, making it important for Australian sites to have the tools and expertise to contribute quality data. N-CRESS recognises the reciprocal value of peer-assisted learning, and as a larger centre of excellence in MS clinical and research care, we commenced a pilot Preceptorship Program (PPP). With support from Novartis Pharmaceuticals we invited external nurses and study coordinators to observe our centre at work, share information and establish linkages for ongoing mentorship, collaboration and communication. **Objectives** To assess the PPP via participant feedback. **Method:** The PPP offered participants a Clinical MS Nursing focus and/or a Clinical Research educational focus. Before commencing, a *Needs Assessment Questionnaire* was completed, with an *Appraisal Form* completed after participation. **Results:** Eleven participants completed the program. Four focused on Clinical, Four on Research and three on both. All participants completed the appraisal form, which included eight questions about content, value and utility. Feedback was very positive. **Conclusions:** The PPP was judged worthwhile and will be continued. We recommend the implementation of this program in other regions to enhance MS Nurse professional development.

Name: Imogen Milner

Area of MS Nursing Practice: Sexual Health

Title: Persistent Genital Arousal Disorder – A case study

Introduction: Thelma, a 64 year old woman with MS (multiple sclerosis), called to report a feeling of constant arousal. On researching I discovered Persistent genital arousal disorder (PGAD), a disorder that was first described in scientific literature in 2001. It primarily affects woman and its prevalence is unknown possibly related to lack of disclosure. There are various causes postulated such as vascular changes, psychological and central dysregulation, and generally requires assessment on a case by case basis. **Case description:** Back to Thelma. Her symptoms started 5-6 years ago, intermittently at first then became constant, located from the clitoris to the vagina and described as a pre-orgasmic feeling. PGAD may or may not be related to MS and a full assessment is advised. It is often associated with feelings of shame, anxiety and isolation. Treatments have been anecdotal and include CBT, hypnotherapy and clitorrectomy. **Conclusion:** On ruling out all other possible causes we came to the conclusion that it was caused by a spinal MS lesion. We have tried medications to decrease vascular flow without significant effect; she has previously reacted to medications used for dysesthesias. We have discussed her case with colleagues and have recently had input from women's health. PGAD is a potential symptom of MS which is undoubtedly under recognised and disclosed

Name: Stephanie Rout

Area of MS Nursing Practice: Neurology Department, Nelson Marlborough District Health Board, Nelson, New Zealand.

Title: Myelin Oligodendrocyte Glycoprotein antibody (MOG-IgG) neuromyelitis optica Unicorns – An 'unfair' tale

Background:

Nelson Marlborough District Health Board (NMDHB) serves a population of 147,000 people in a wide catchment area at the top of the South Island in New Zealand, with limited medical and nursing support. This case study poster discusses 3 patients who, over a 6-month period were admitted to hospital with myelin oligodendrocyte glycoprotein antibody-positive neuromyelitis optica (MOG-IgG NMOSD). Due to the rare nature of their condition, 1 patient named himself a 'unicorn' and this name has stuck, hence the title.

Objectives:

MOG-IgG NMOSD is characterised by severe immune-mediated demyelination and axonal damage that specifically targets optic nerves and the spinal cord. The estimated prevalence is 0.5-1/100,000 and is a fairly recent discovery. Initially, MOG-IgG was thought to be a variant of multiple sclerosis, however it is now recognised as a distinct clinical entity due to independent immunologic features. There is a risk of developing disability with repeated relapse; therefore, due to the unknown disease course and disability outcomes, it is advised to immunosuppress for a medium term by the Oxford Study.

Methods:

Case study presentation poster, pathophysiology of MOG-IgG and nursing considerations.

Results:

All 3 patients presented very differently in their demographics; unicorn 1, 53-year-old Filipino non-smoking female, with no previous medical history of note. Unicorn 2, 23-year-old New Zealand European male, normally fit and well.

Unicorn 3, 17-year-old New Zealand European female, no personal medical history of note, however a strong family history of autoimmune conditions.

Conclusion:

This case study poster will highlight the importance of checking antibodies for MOG-IgG if a patient presents with symptoms

Name: Susan Agland

Area of MS Nursing Practice: Neurology Clinic

Title: Fulminant Multiple Sclerosis After Fingolimod Cessation

Abstract: Multiple Sclerosis (MS) is a complex neurological disorder, frequently diagnosed in young adults. Immune modulating therapy is often recommended shortly after diagnosis to prevent long term disability accumulation. As therapy will be ongoing for decades, interruptions to therapy due to family planning, adverse events or other reasons can occur. The outcome of therapy interruption is not well understood. We report a case of fulminant and aggressive MS three months after ceasing fingolimod, resulting in fatality. We review the available literature to assess the risk of treatment cessation to help guide clinicians to prevent such an outcome.

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