

MSL / MS TAS Integration Project Newsletter



MOVING FORWARD

Thank you to everyone who attended the MS SYMPOSIUM on World MS Day. We had a fantastic range of guest speakers and were pleased to be able to bring researchers from not only Menzies but also the Royal Melbourne Hospital to cover a range of topics. Our guest speakers included Dr Kaylene Young from Menzies, Ella Wong and Mary McArthur from Pilates Tasmania, Dr Thomas Kalincik, Nick Hakes from Pro Bono Financial Planning, Dr Litza Kiropoulos, nutritionist, Ngaire Hobbins and the CEO of TasCOSS, Kym Goodes. We had 115 people from across the State register and attend.

A big thank you to our volunteers and MS staff who helped out on the day to help make the event so successful. If you weren't able to make it, but would like to see all the presentations – we've got you covered! Simply jump on our website and you can watch them all from the comfort of your own home - www.ms.org.au/world-ms-day

In August the MSL Board will be meeting in Tasmania and as with last year, we are planning to have a period of time on the Board meeting day that you, the MS Community can meet the Board to discuss any topics you wish. This year the Board has decided to meet in Launceston and we will be sending out invitations to you all to meet with them.

The NDIS will continue to roll out in Tasmania and to assist in helping you decide if the NDIS is for you, we will be offering some workshops with team members in July and August.



Regards, Sandra



MS Connecting with people after hours.

Recently in MS Connect we received a web enquiry from Kate, Kate and her partner had recently been married and he had been diagnosed with MS very shortly after that. She was wanting to find out all she could about multiple sclerosis but he wasn't ready for that yet.

Both work as lawyers in a very busy corporate setting. While we can't talk specifically about someone's condition without their direct consent but we were happy to be in contact with Kate who had many general questions a bout MS and wanted to check with us about some of the things she had been reading. Due to her hectic work commitments Kate found it easier to email us her questions and then have time to read and consider the information we emailed back to her after work when she had time to concentrate.

Kate found that she was also able to introduce some of the things she was learning into her discussions with her husband. Kate contacted the team at MS Connect and thanked us for being available to her and her husband outside their hectic work hours.

Don't forget that you can also contact MS Connect through email msconnect@ms.org.au or via our web enquiry form https://www.ms.org.au/support-services/ms-connect/contact-us.aspx on the Contact Us page on the website.

COMPLIMENTS & FEEDBACK

I had a visit from the very lovely & efficient Olivia yesterday. It was so great to meet her and she is so very helpful and has already sent me several follow up emails.

Tasmanian Telelink/Telegroup Program:



May 2018 saw the launch of the Tasmanian Telelink programs and we have been delighted by the success so far. The first 4 programs have been run with a further 7 commencing from June onwards.

The telelinks have been an easy way of connecting people living with MS. They are six week programs with educational speakers, social interaction and so much more. After the conclusion of the 6 week program, the participants are going on to become Telegroups to stay in touch.

Please see below the amazing feedback from some of those that have participated so far:

"I heartily recommend this form of education, connection, information gathering and sharing, and self-help to everyone in the MS boat." Marg (Over 65's Telelink)

"The telelink program put me into contact with professionals who were able to answer a great many of my questions about MS. I found the program to be a great launching pad for future inquires that I have about this condition. Thank you so much for putting the telelink on. " Brett (Telelink for people recently diagnosed)

"The facilitator was professional, friendly and receptive to all requests by group participants for further information and support. I found the weekly sessions informative, supportive and very helpful.

The group worked very well together and was able to form a positive, productive and personal bond over the weeks of the link." Nichole (Telelink for Women)

"Thanks so much for your terrific facilitation and organisation of the Telelink Program. I found it particularly rewarding and supportive. Participants being age-related was valuable in that there were some similarities in life experiences and coping mechanisms, and minimal inhibitions discussing sensitive or personal issues which a more diverse age cohort may have faltered over. The group was small enough to get an idea of each person's experience across the differing forms of MS, and inclusive of all forms of MS which is a rarity. Having someone else in the group with PPMS made me feel less isolated."

Upcoming Education session in Hobart

<u>Presentation: The Benefits of Exercise for People with Multiple Sclerosis</u>



Dr Phu Hoang, MS Consultant Physiotherapist will present two education sessions on the benefits of exercise for people with MS.

Dr Phu Hoang has been working as a clinical physiotherapist with people with multiple sclerosis (MS) for over 15 years and works with MSL as an MS Consultant Physiotherapist and at Neuroscience Research Australia as a Senior Research Officer. He is working on projects that aim to improve mobility and reduce falls in people with MS.

What: The Benefits of Exercise for People with Multiple Sclerosis

When: <u>Tuesday 24 July 2018</u> 7.00pm - 8.00pm

Wednesday 25 July 2018 10.00am - 11.00am

Where: The Bellerive Yacht Club

64 Cambridge Road, Bellerive TAS

Bookings Click here to book online or call MS Connect on free call 1800 042 138

Registrations close Tuesday 17 July 2018

STAFF UPDATE IN TASMANIA:

From Jen Lowe, Practice Leader

We are pleased to announce that Lucy Pratt will be joining us, as an NDIS Engagement Officer, based in our Launceston office.

Lucy will work Monday, Tuesday and Wednesday weekly (.6), and commenced on 18 June.

Lucy is a registered Occupational Therapist who has worked in a variety of hospital inpatient, outpatient and community settings, most recently at Launceston General Hospital.

During this time she has worked with a wide range of clients with varied and often multiple conditions such as stroke, Multiple Sclerosis, Parkinson's Disease, Dementia, Amputees, Guillain-Barre Syndrome, Depression and Anxiety.



VOLUNTEER WEEK THANK YOU

On Tuesday 29 May we had a special thank you afternoon tea for our volunteers. This was to celebrate National Volunteer Week which ran from 21-27 May.

We have some exceptional volunteers at MS, from our peer support facilitators, MSAC members, two Tasmanian board members and volunteers who help with administration for us.

From all of us at MS thank you to our wonderful volunteers.

Workshop: Understanding and Preparing for the NDIS

Robyn Lang, MS NDIS Project Advisor will host a workshop to help you to:

- understand the NDIS and the opportunities it offers
- understand your current supports and consider if they're meeting your needs use the 'My support plan' tool to develop your goals



All of this is very important to help you achieve the best possible outcome at your NDIS planning conversation.

What: Understanding and Preparing for the NDIS

When: <u>Wednesday 1 August 2018</u> 10.00am – 12.00pm

Where: The Bellerive Yatch Club

64 Cambridge Road, Bellerive TAS

Bookings: Click here to book online or call MS Connect on free call 1800 042 138

Registrations close Wednesday 25 July 2018

Please note: For the north and north west of the state, our Tasmanian MS staff will be holding NDIS information sessions in the near future - details to follow in subsequent newsletters

MS EDUCATION - Webinars and other Education Events

Webinar - Multiple Sclerosis and Depression - It is seriously complicated Thursday 5 July 2018 11.00–12.00

Webinar - Fatigue Management in Multiple Sclerosis Wednesday 11 July, 10.30am – 11.30am

Webinar - "Let's think about your thinking - An interactive session with Dr Luke Smith" Friday 20 July 2018

11.00- 12.00

Webinar - Bladder and Bowel Changes in Multiple Sclerosis Tuesday 31 July 2018 11.00am - 12.00

Webinar - Eat Well, live Well Wednesday 8 August, 11.00am – 12.00pm

Webinar - Get Active with MS - Falls Prevention Tuesday 21 August 2018 10.30 - 11.30

Webinar - Brain Wellness in Multiple Sclerosis Thursday 30 August, 11.30am – 12.30pm

NDIS Information Sessions, Various webinars and face-to-face sessions in various locations

For more information please email <u>education@ms.org.au</u> or call <u>MS Connect™</u> (Freecall 1800 042 138) or check our Website.

PEER SUPPORT MEETING TIMES

CIRCULAR HEAD

Meets: First Monday of the Month 7:30pm to 9pm Venue: Circular Head Rural Health Service, Smithton

Next meeting Mon 2nd July

Guest Speaker: Simon West, Physio re Exercise to

keep you healthy

Please RSVP to Jenny: jennywallis@iprimus.com.au

Devonport Peer Support Casual Coffee Group

Meets: Third Saturday of the Month 10:30am to

11:30am

Venue: Drift, The Bluff Devonport Next Meeting: Saturday 21st July

Meals at own expense

Please RSVP dawn e murray@hotmail.com

ULVERSTONE

Social Gathering/Christmas in July

Please note temporary change in venue as follows:

Windows on Westella, Ulverstone

Next Meeting: Wed 25th July, 12 midday onwards

Special Guest/Visitor: Kim McCarthy

Meals own expense

Please RSVP to Robin: robbiet100@hotmail.com

NORTHERN (Launceston)

Please note temporary change in venue as follows:

The Riverside Tavern, Riverside Launceston

Next Meeting: Thurs 19th July, 12 midday onwards

Meals own expense

Please RSVP to Angela: angela@ms.org.au

EASTERN SHORE, KINGSTON GROUP GLENORCHY GROUP. MENS GROUP

Christmas in July, this gathering is in substitute of normal meetings.

Christmas in July

Saturday 21 July Date:

Time: 12 Midday

The Black Buffalo Venue:

14 Federal Street

North Hobart

RSVT: Monday 16 July

Email: Chris Gumley

cegm58@icloud.com

Or Thone: Angela Land

6220 1121

Please note meals and drinks at own expense



Tasmanian Community Fundraising Update

We've launched an exciting new program to help encourage fundraisers to pound the pavement for MS – Run For MS! Check out the Run For MS program via https://www.doitforms.org.au/run-for-ms

Point to Pinnacle

Mount Wellington 18 November 2018 21.4km half marathon http://www.pointtopinnacle.com.au/

MS 24 HOUR MEGA SWIM

<u>Launceston MS 24 Hour Mega Swim</u> Saturday 4 – Sunday 5 August 2018 Launceston Aquatic Centre



Hobart MS 24 Hour Mega Swim
Saturday 13 – Sunday 14 October 2018
Hobart Aquatic Centre

<u>Register</u> before 31 August (Hobart) and not only will you have a great time with your friends and family, but you will also save on your entry fee. Plus registration for people with MS is FREE!

A HUGE shout out to our amazing Tassie fundraisers who are all doing incredible work to raise both funds and awareness for MS! We'd love to give a special mention to three superstar fundraisers:

To **Bek Thorpe** who set herself the challenge of trekking Mt Amos and raised \$2100 in the process! You can check out more of Bek's story and why she chose to Do It For MS in honour of her very special mum Jude via her fundraising page <u>'Team Jude- Doing It For MS!'</u>

To **Dawn Murray** who has not only broken through the \$1000 mark for her online fundraising but also had an incredible article published in The Advocate this month and was a fantastic advocate for MS on Southern Cross news! Thanks Dawn for not only raising funds but also using your up-coming 330km Camino Walk to raise awareness about multiple sclerosis. You can <u>read the article here</u> and check out Dawn's fundraising page via her <u>Do It For MS webpage</u>.

To 15 year old **Siarne** who is using her role as a National Finalist in the Mini Miss Tasmania competition to raise awareness and funds for MS in support of her very special aunt. Siarne has set herself the goal of raising \$500 and we wish her all the very best! You can follow her story via her <u>Do It For MS fundraising page</u> or via her <u>Mini Miss Tasmania Facebook page</u>.

Don't forget you can get in touch with Erin any time to discuss/create fundraising plans and get advice, materials and moral support: erin.wicking@ms.org.au 03 9845-2825.

Come be part of the Event Management team for the MS 24 Hour Mega Swim! We are seeking fun, driven individuals or groups to come together and assist with the delivery of the annual 24-hour swimming event at Hobart Aquatic Centre on 13-14 October. Send us an email at megaswim@ms.org.au or call 1300 733 690 to find out more information about this great opportunity.



MS Employment Support Service in TASMANIA

The MS Employment Support Service is expanding and from July 1, 2018 will be available in Tasmania!



The MS Employment Support Service is the only MS specialist employment service for people living with multiple sclerosis in Australia that can help you succeed at work, whether that is staying in your current job or finding new

employment. This may be to find strategies to better manage your symptoms, it may be utilising technology or equipment to enable you to function more effectively in the workplace, assistance to write a resume and practice interviews or may include providing education to your employer.

If you would like to be one of the first to receive this support in Tasmania from July 1, contact MS Connect or visit www.ms.org.au/support-services/employment-support for more information

The i-FIMS study Hobart Neuroscience Research Australia



The i-FIMS research study (Interactive Step Training to Reduce Falls in People with MS) has now commenced in the Hobart region. 15 people have been recruited into the study. Thank you to all who have expressed interest and who have become involved in the study.

The ongoing i-FIMS study is researching whether using a home-based step-training program for six months can reduce the risk of falling and improve balance and cognitive abilities. At the start of the 6-month program, participants complete an assessment which involves thinking tests (to assess attention, logic and reasoning) as well as physical assessments (to evaluate balance, coordination and mobility).

As this is a randomised controlled trial, participants are subsequently placed at random into one of two groups – the 'step training group' or the 'exercise as usual group'. Participants in the step training group complete a six month program based in their home which involves interactive stepping exercises using a mat connected to a television or computer screen.

Who can participate in the study? People who have confirmed diagnosis of MS, aged 18 and over, living in the community.

To be included in the study, MS participants need to be:

- Able to walk without an aid, or more than 50 minutes with a walking stick or single crutch
- Able to stand unaided for about 1 minute
- Having stable MS (with or without disease modifying drugs) with no exacerbation in the past 3 months.

If you would like more information about this study or to volunteer, please contact the research assistant, Jessica Turner, at ifims.hobart@neura.edu.au or on 0447 937 071.



