EXTENDED MS CONNECT HOURS STARTING 1 JULY

Following feedback from the MS Community we are extending the hours of MS Connect as a 6 month trial and one of our team members will be available from 8am until 6pm, Monday to Friday to respond to your phone calls, emails, live chats.

If the line is busy please leave a message and one of the team will get back to you, and we have a commitment to respond to you within one working day.

The team are here to answer your questions, provide you with support and ensure that you get the right advice.

We have recently welcomed three new members to our team. Emily, Jessie and Amanda.

They join Jenni and Katie to complete our team. Jessie has a passion for empowering people living with a disability and has experience in providing self-advocacy, education and community access.

Emily has vast experience over varying roles including supporting people to access My Aged Care services as well as being a trainer in delivering certificates in disability services and transitions education to adults with disabilities. Amanda has come from the NDIA where she worked as a planner and has previous experience with DHS.

Multiple Sclerosis Advisory Council – Tasmania (MSAC-TAS) are recruiting!

The MS Advisory Council of Tasmania’s mission is to represent the needs and views of the MS community to the Board of MS Limited to help them provide the most relevant and effective services possible. The Council is completely independent from the MS organisation.

The Council members are made up of people affected by MS, both people living with the disease and carers. MSAC-Tas council seeks a representation which broadly reflects the MS population demographics across Tasmania.

As such we are seeking to recruitment 2 people from the MS Community in Tasmania who meet the following criteria:–

1. Live in the North or North/West of the state
2. Live with MS or are a carer of a person living with MS
3. Can commit to meetings by dial-in once every 6 weeks for 1.5 hours
4. Are willing to reach out to as many people in the MS community through their own personal networks
5. Willing to work alongside other members of MSAC-Tas in a respectful, cooperative manner on projects and topics of importance and relevance to the MS Community

If this is of interest to you or someone you know or you would like more information please contact Vivienne Jones, Chair MSAC Tasmania on 0407 486 425 or email jonesbnv@bigponnd.com or send in your expression of interest by email.
If you have an NDIS plan that has Support Coordination in it, did you know this is a service we can provide for you? Your Support Coordinator assists you to connect to supports and services relevant to you as per your NDIS plan. We understand that deciphering your NDIS plan can be difficult. If you have support coordination in your plan and need assistance, please call MS Connect on 1800 042 138 with your plan and your NDIS number.

**MYTH** – My application to the NDIS was not successful, which means I can never access the NDIS

**FACT** – You have the right to a review if you have been rejected. Alternatively, you can also reapply for access three months after your rejection

**MYTH** – I am 64 now which means I cannot access the NDIS

**FACT** – If you are under 65, you can apply for access to the NDIS. Call the NDIS on 1800 800 110 to ask for an access request form

**MYTH** – I don’t have many visible physical symptoms. The NDIS is not for me

**FACT** – Eligibility is not limited to people with mobility issues. The NDIS want to know about the functional impact of your condition. This can include things like fatigue, heat sensitivity, brain fog, cognition changes, incontinence, numbness and any other of your MS symptoms that impact on your day to day life

**MYTH** – The NDIS will leave me out of pocket

**FACT** – The NDIS is fully funded by the federal government, meaning anything they deem reasonable and necessary can be covered in your NDIS plan

**MYTH** – I will be worse off under the NDIS

**FACT** – It's part of the NDIS Act that a person must at the minimum receive the same level of supports they are getting through current disability services

**MYTH** – As soon as I get my plan, I can get everything I need immediately

**FACT** – Unfortunately, depending on what service you require through your plan, there could be a wait. This is especially relevant in Tasmania with a wait for Occupational Therapy assessments and interventions of up to five months in some cases

**MYTH** – There is so much planning and paperwork, I won’t be able to manage it on my own

**FACT** – We are here to help you. Call MS Connect on 1800 042 138 to ask for assistance

**MYTH** – I am stuck with the providers I already have

**FACT** – You get to choose your providers and how you use them

**MYTH** – I own my own home/earn too much money. I won’t be eligible for funded supports

**FACT** – The NDIS is not means tested, it is there to provide funded supports for people living with a significant level of functional impairment/disability no matter what their financial circumstances

**MYTH** – If I become a participant and then turn 65, I will no longer be eligible for the NDIS

**FACT** – The NDIS is a whole of life approach, you receive the supports you need to achieve your goals across your lifetime
Come along to the inaugural Tasmanian MS Walk + Fun Run!

The first-ever Tasmanian MS Walk + Fun Run will be held on 22 September 2019 at Inveresk Precinct in Launceston.

The MS Walk + Fun Run is a combination of the classic fun run model, a big spoonful of community spirit, and a sprinkle of health and wellness, all mixed together to create an opportunity to make a real difference to people’s lives.

It’s a fantastic day out and we’re so excited to be bringing this event to Tassie for the first time! So, come along with your friends and family and get involved in what will be a fantastic day out.

Register, donate or volunteer today at www.mswalk.org.au or contact us on 1300 733 690

Get involved in a BIG way in the Tasmanian MS Walk + Fun Run

Want to be an integral part of the Tasmanian MS Walk + Fun Run? Do you have contacts and links with the local community? We want to hear from YOU!

We’re currently seeking a volunteer Team Leader to engage with the local community in Launceston. If you know anyone who would be suitable, please encourage them to apply at https://www.sportspeople.com.au/jobs/59679-team-leader-launceston-ms-walk-fun-run-multiple-sclerosis-limited-ms

Community Fundraising – World MS day success!

Our community fundraisers kept us busy in May with a huge variety of amazing activities to raise funds for MS! Our first group of Red Centre Adventure trekkers rose to the challenge and tackled the spectacular Larapinta Trail – over a fun filled 7 days/120 km’s.

Closer to home, the Launceston Town Hall even celebrated with us – by lighting up red to raise awareness for the cause.

And hearty congratulations must also go to the organisers and supporters of another great Red Affair ‘A Night for MS’. Our CEO John Blewonski, was in attendance and reported a wonderful evening was had by all.

With the end of financial year fast approaching, funds from events across May are still coming in, and we’re excited about the amazing community fundraising outcomes we’re seeing so far!

Don’t forget you can get in touch with the friendly Community Fundraising Team at any stage. If you’re interested in putting together your own activity, big or small, get in contact with Erin via communityfundraising@ms.org.au or on 03 9845 2825 and she’ll help you make something magic happen.

2019 MS 24 Hour Mega Swim Event

The Hobart MS 24 Hour Mega Swim will be taking place at Hobart Aquatic Centre on 2-13 October.

Sign up for this awesome day out!

Register, donate or volunteer today at www.msmegaswim.org.au or contact us on 1300 733 690
Generic Drug for Teriflunomide (Aubagio)

A generic version of Aubagio (teriflunomide) has come onto the market from 1 June 2019 and is covered by the PBS. It is called “Teriflunomide Sandoz” and may be offered to you when you next attend the pharmacy to collect your prescription for teriflunomide (Aubagio). You should make an informed choice about whether or not to accept the generic brand if offered to you at the time of dispensing.

People taking the original brand Aubagio (teriflunomide) can access Sanofi Genzyme’s “MS one to One” patient support program and blood test service, those who choose the generic cannot.

In the case of Aubagio and Teriflunomide Sandoz, both the packaging and the tablets themselves will look different.

MS Australia has produced a fact sheet which can be found at www.msaustralia.org.au/about-ms/medications-treatments.

From World MS Day

New Norfolk Primary School students wearing red to create awareness around MS. Danny (student with the scarf in the front) is the reason his school is creating awareness and taking part in World MS Day.

His mum has MS and Danny took it upon himself to address the assembly last week. This was a very special day for the school community.

MS EDUCATION
Webinars, Wellness and other Education Events

Working with Multiple Sclerosis Webinar Tuesday 9 July 7.00pm - 8.00pm
Sleeping Well with Multiple Sclerosis Webinar Wednesday 17 July 11.00am -12.00
Managing Fatigue in Multiple Sclerosis Webinar Wednesday 7 August 3.00- 4.00pm
Mindfulness by Webinar with focus on pain (8 weeks) Monday 14 October - 2 December 1.00 - 2.00pm

NDIS Information Sessions - Various webinars and workshops

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

MS RESEARCH AUSTRALIA TEAM CHANGE

Head of Research Dr Lisa Melton who has been with MSRA since 2011 has left to take on a role as Institute Manager UNSW Ageing Futures Institute and has been replaced by the current Deputy Head of Research Dr Julia Morahan.
**Staff Update**

We have some staff updates we would like to share with you.

We are currently recruiting another full time staff member to work from our Launceston base as an NDIS Support Coordinator and they will join Kelly Bowen who is working in the Hobart office.

Anthea Stutter and Lucy Pratt are both moving to 2 days per week, Miriam Rainsford is remaining on 5 days a fortnight and Michael Mortenson and Annette Crawford will continue to work 4 days a week as will Jen Lowe. These arrangements will be in place until the end of September.

**MS CLINICAL TRIAL VOLUNTEERS BEING RECRUITED.**

*The Menzies Institute for Medical Research* are currently seeking volunteers with early progressive MS to participate in a clinical trial evaluating the safety of non-invasive magnetic brain stimulation, a painless and tolerable therapy, aimed at increasing myelin producing cells.

You may qualify for the trial if you:
- Have secondary progressive or primary progressive MS
- Are aged between 18 and 65 years old
- Can walk unaided or with the use of a walking aid
- Can attend daily appointments (Mon-Fri) of up to 45 minutes at the Menzies Institute over a 4 week period
- Meet the requirements of a medical assessment at the start of the trial

**Reimbursement of travel-related expenses are available and free on-site parking will be available at the Menzies Institute, 17 Liverpool Street, Hobart**

For further information please contact Menzies Reception on 03 62 267700 to leave your details and a member of the MS Flagship Research Team working on this trial will contact you.

*It is important to note that this study may in no way benefit you or alter your MS*

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**Pilates Classes designed for people living with MS**

We are running a Pilates class in Launceston that is being instructed by Pilates Tasmania.

**Class Day & Time:** Fridays 12pm

**Class Length:** 45 minutes

**Location:** Norwood

**Cost:** The classes are free due to funding MSL has received from City of Launceston Council.

If you are interested in attending please email tasenquiries@ms.org.au with your name and contact details.

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Have you connected to the Internet recently?

Do you have an email address?

If you wish you can contact MS Connect 1800 042 138 and notify us of your email address, you would receive your Newsletter quicker and we can save some trees.
PEER SUPPORT MEETING TIMES

CIRCULAR HEAD
Meets: First Monday of the Month from 7pm to 8:30
Venue: Circular Head Rural Health Centre, Smithton
Next Meetings: Mon 1 July
*We are combining face to face group & Telegroup.
RSVPs: msconnect@ms.org.au

DEVONPORT
Casual Coffee Group
Next meeting TBA

NORTHERN (Launceston) - Social Group
Meets: Second Thurs of the month, 11am to 1pm
Venue: Kings Meadows
Next Meeting: Thurs 11th July
Social Gathering

WYNYARD PEER SUPPORT GROUP
Meets: First Wednesday of the month, 2-4pm
Venue: Wynyard
Next Meeting: Wed 3rd July & Wed 7th August
Guest speaker: Coffee catch up
RSVP: msconnect@ms.org.au

ULVERSTONE
Meets: Fourth Wed of the month, 11am to 1pm
Venue: Ulverstone
Next Meeting: Wednesday 24 July
Guest Speaker: TBA
RSVP: msconnect@ms.org.au

NEW NORFOLK PEER SUPPORT GROUP
Meets: First Wed of the month, 10:30am to 12.00
Venue: Banjos Café New Norfolk
Next Meeting: Wednesday 3rd July
Social gathering, coffees and cake etc at own expense
RSVP: msconnect@ms.org.au

LAUNCESTON UNDER 50'S PEER SUPPORT GROUP
Meets: Last Monday of the month, 10am to 12 midday
Venue: Linc Library, Launceston
Next Meeting: Monday 29th July
Social Gathering
RSVP: msconnect@ms.org.au

KINGSTON, EASTERN SHORE, GLENORCHY & MENS PEER SUPPORT GROUP
Combined Christmas in July Lunch
RSVPS 5th July to Chris Gumley
cegm58@icloud.com OR Angela Land 6220 1121

MS CHRISTMAS IN JULY
SATURDAY 13 JULY
12 Midday onwards

THE BLACK BUFFALO
14 Federal Street
North Hobart

MAIN
Christmas Roast Turkey & Pork Loin, Baked Seasonal Root vegetables, Apricot & Hazelnut stuffing with Rosemary Jus
OR
Prosciutto Wrapped Chicken, Potato Gratin and buttered greens with Gorgonzola and Lemon Sauce
OR
Gremolata crusted grilled fish served with mash potato and steamed vegetables.

DESSERT
Warm Christmas Pudding, Honey Crème Anglaise & Vanilla Ice Cream
OR
Eggnog Panna Cotta, Macadamia Ice Cream & Ginger Sable

2 Courses - $30 OR 1 Course - $23

*Gathering interest in working persons/professional group & a facilitator to lead - watch this space for Sorell group