

MND NEWS



The newsletter of the
Motor Neurone Disease
Association of Victoria

**Until there's a cure,
there's care.**



www.mnd.asn.au

march/april
2018

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SUPPORT GROUPS

Western Metro

Last Monday each month at 12.30 pm in Footscray
Mrs Christine Robson, (03) 9379 7715

Barwon Region

St David's Hall, Aphrasia St, Newtown
First Monday every second month at 12 noon
Rev. Ian Parton, (03) 5241 9344

Ballarat Region

Meets at various locations around Ballarat
Contact: MND Victoria on Tel: (03) 9830 2122 or 1800 806 632

STAFF

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Coordinator Equipment Service: David Harkin

Equipment Officer: Kathy Walker

Coordinator Volunteer Programs: Deb Olive

Coordinator Information & Resourcing: Alison Jones

Information & Resourcing Officer: Sarah Wilkie

FROM THE CEO ...



On 24 and 25 February I was in Benalla for the Act to D'feet MND. On the Saturday evening, a Twenty20 cricket match was played, with lusty blows struck around the ground and fearsome pace generated by the bowlers. It was clear from the oohs and ahhs from the sideline that a great night was had by all.

On the Sunday, a combination of bike rides, races and relays around the lake, and the Act to D'feet walk around the lake brought home the passion and commitment the organisers, all participants and attendees have for the fight against MND. The day, as usual, ran like clockwork – under sunny skies and moderate temperatures. The financial outcome is still to be calculated, but the emotional and cause driven outcomes were very clear – we are all part of the fight against MND, and we do that in many ways. We raise money; we deliver services; we invest in research; we advocate with passion and conviction; we support each other; we talk MND to those who don't know about it; we enthuse and recruit others to the fight, and we do more.

And I am asking all of you to do more, and do something specific.

You will be aware of the benefits of the National Disability Insurance Scheme (NDIS) that have come to people with MND under the age of 65. More people than ever before have packages of support to help them live better, safer, for longer while fighting MND.

But people diagnosed when they are over the age of 65 do not have the NDIS – they have Aged Care – a system designed for the frail aged and those with dementia. Aged Care knows nothing about progressive neurological conditions or disability they create; Aged Care doesn't understand the need for aids and equipment to help people regain, retain and extend their independence, safety and participation in the community, and Aged Care doesn't understand the urgency that progression drives for support to remain at home for as long as they wish.

While Aged Care does provide packages of support, they are too slow – recent newspaper reported a waiting list of 100,000 people for an Aged Care package. And people with MND require the larger packages, Levels 3 and 4, which are like hen's teeth.

So, what do I want you to do?

MND Week is the first full week in May. MND Australia is developing a campaign to wake up Aged Care, wake up Government and the public servant bureaucracies and clearly state what is needed for people over 65 living with MND. We need you to write to your local State and Federal politician. Tell them about MND. Tell them what is needed NOW! We have told them, and they have recognised the issues that we raised, but they need the jolt of letters from you – people with MND, families that have lost someone from MND, health care professionals, relatives and friends who want to see all people with MND having the support they need to help them live better, safer, for longer while fighting MND – not just if you have the misfortune of being diagnosed with MND before 65.

We will provide you with the tools you need. All you need is to convey our message and include your personal MND story.

We want and need all Australians diagnosed with MND to be supported with appropriate services and disability aids and equipment to remain at home – safe, supported, and engaged with their community.

Will you take up the challenge?

Rodney Harris, CEO

SUPPORT SERVICES



Since last writing this column we have had further changes and additions to our support services team. David Kerley, Coordinator Information and Resourcing resigned and Alison Jones, previously Information and Resourcing Officer, has been promoted to this position. Sarah Wilkie has commenced as the Information and Resourcing Officer and Ailish Ivers is working with us in a student placement role as part of her Social Work Degree.

The Support Services team now has 18 staff based across Victoria and Tasmania working with about 450 people living with MND and their families. The constant changes in the aged and disability sectors make it even more important than ever before, for you and your family to link in with your MND Advisor who can assist you to navigate the system to ensure that you get the most appropriate and best possible support from My Aged Care or the National Disability Insurance Scheme.

I have once again included in this column the roll out information of the NDIS as it is vitally important that you have the information to assist you to commence your planning, if you are under 65 and therefore eligible for the scheme. A person may meet the access requirements to become a participant of the NDIS up to 6 months prior to this date. The following roll out information refers to Victoria.

The NDIS commenced in Hume Moreland on the 1 March 2018. This area (surprisingly) covers the local government areas of Hume and Moreland.

The NDIS will commence in the Bayside Peninsula area from 1 April 2018. The Bayside Peninsula area covers the local government areas of Bayside, Frankston, Glen Eira, Kingston, Mornington Peninsula, Port Phillip and Stonnington.

From 1 September 2018 the local government areas of Cardinia, Casey and Greater Dandenong will be included in the Scheme. The last area to come on board will be Western Melbourne from 1 October 2018. The Western Melbourne area covers the local government areas of Hobsons Bay, Maribyrnong, Melbourne, Moonee Valley and Wyndham.

In Tasmania, the NDIS is being introduced by age group. Currently it is available to eligible people aged between 4 and 34 years. From 1 January 2018, it became available for adults, aged 29 to 34. From 1 July 2018, the NDIS will be available for children, aged 0 to 3, and adults aged 35 to 49. By 1 July 2019, the NDIS will be available to all eligible Tasmanians. Eligibility does not of course include people 65 plus years of age.

Developing, achieving and implementing the correct plan can at times be confusing and seem tricky. Please contact your MND Advisor or Janette McDonald at Canterbury for more information and all pre-planning advice regarding accessing the NDIS and developing and implementing a plan. Aspects of accessing the NDIS and the planning process can be confusing for us all. Our experience is that when our clients have a well thought out and appropriate NDIS plan their support needs are generally well met.

In June we will once again be open for audit against the Department of Health and Human Services and ISO 9001-2015 Standards. As with previous audits the auditors will be seeking input from our clients and families to ascertain if we are delivering our support and services according to the standards and your expectations. If you or a family member would like to speak with one of the auditors either in person, via the telephone or email please contact Georgina on 9830 2122 and she will make a note for the auditors.

Over the past month I have attended two notable meetings with government bodies. Georgina Diacos, Coordinator Operations and I attended the NDIS National Forum where we were advised about the implementation of the NDIS Quality and Safeguards

MND WEEK ... 6-12 MAY 2018

MND Week is a national event from 6-12 May 2018. It is an excellent opportunity to raise awareness of MND and for the MND community to come together. It is also a great time to fundraise to support services for people with MND. To find out about other fundraisers and events during MND Week, please visit our Events Calendar:

www.mnd.asn.au/events

Blue Cornflower Day

Would you like to sell cornflowers in a venue near you on **Friday 11 May**? Please fill in the enclosed order form and return it to MND Victoria.

Commission. Compliance with these safeguards will become mandatory for all people provided support and services within the NDIS across the country commencing in July in NSW and South Australia and Victoria in 2019.

Until these are implemented nationally organisations are required to comply with the standards and safeguards of their respective state bodies. It is hoped that the method of auditing against NDIS safeguards will eventually be incorporated into that of other government standards. We are required to comply with in the delivery of our work in the interests of effectiveness and efficiency. During this forum the outcomes of the Participant and Provider Pathway Review were also presented. If you would like to read more about this review, this is the link on the NDIS website www.ndis.gov.au/pathways-experience. There are a couple of standout points, the first being that there will always be a face-to-face planning meeting and secondly at the time of this planning meeting the participant will be able to see a copy of the working plan at the time it is being written.

Rod and I recently attended a meeting with the review panel appointed to consider alternate funding models for palliative care in Victoria.

Day of Hope and Remembrance

The **Melbourne Day of Hope and Remembrance Service** will be held from 10.30am-12.00pm on **Sunday 6 May 2018** in the Bourke Room 1, Level 2, at the RACV Club, 501 Bourke Street, Melbourne. Please RSVP to: info@mnd.asn.au or (03) 9830 2122 by Tuesday, 1 May 2018.

The Geelong **Day of Hope and Remembrance Service** will be held at 2pm on Sunday, 6 May at St Lukes Uniting Church, Highton. RSVP: Ian Parton 03 5241 9344

Ask the Experts

This year's Ask the Experts research seminar and lab tours is from 10am - 3pm on **Tuesday 8 May 2018** at Level 5 Seminar Room in the Kenneth Myer Building, 30 Royal Parade, Parkville. RSVP to: (03) 9830 2122 or info@mnd.asn.au or by Tuesday, 1 May 2018.

It was an opportunity for us to talk about the inconsistencies around access to both community and inpatient palliative care we experience around the State and discuss the support and care needs particular to people living with MND.

Rod emphasised the importance of palliative care being about quality of living and programs within palliative care developed that are accessible and supportive to all who choose to use it not just certain sections of the community.

Last Sunday I joined the Benalla community to walk around the lake in support of people living with MND. It is a lovely setting; the weather was perfect for walking and the participants full of hope and purpose. Congratulations to all involved for their commitment and contributions.

As always we welcome your feedback.

Julie McConnell, Manager Support Services

YOUR STORIES



Dealing with Motor Neurone Disease

By Laura Morrison, Speech Pathologist

JOURNAL of a Speech Pathologist living in London, working as a Speech and Language Therapist (SALT), written on 10th June 2017 by Laura Morrison

Please be aware that this a true story of the challenges someone may face if diagnosed with Motor Neurone Disease. It is a confronting and sad recount, however I hope that with this story awareness is raised as to the importance of the Speech Pathology profession and the need for further funding to support finding a cure for MND.

I can talk, I can walk, I can swallow, I can read, I can write, I can itch my head if I need to, I can laugh when I want to. I can wipe my own tears. You're thinking, what's the big deal? So can I.

Not all of us are so fortunate. Today I met a lady who struggles to do all of these things.

Ms. S is an ancient history and Greek language secondary college teacher. At the age of 43 she has been told that it is an Occupational Health and Safety risk for the other staff and students for her to work. Sure the other teachers have to push her in a wheelchair between classes, because she can no longer walk, and her students now sit close to hear her now weak voice. But, Ms. S has full cognitive ability and I can guarantee, her students listen to her with more attention than they do any other teacher. This is because while Ms. S's

speech is slurred and quiet, at this point, each word is highly valued and precious.

Today I had to be the person to explain to Ms. S that it may not be long until she can no longer speak...at all. That is, her lung capacity may reduce to a point where she does not have enough expiration force to drive her vocal folds and produce voice and loudness on top of the diminishing nerve function required for voicing and speech. While there are amazing technologies which can record and save your voice to create synthetic speech to allow a computer to speak on your behalf (like Stephen Hawking), Ms. S is now faced with the grief of losing yet another function; the ability to speak.

A voice amplifier is currently helping her to increase the loudness of her voice. While I sit and talk with Ms. S the microphone headset begins to slide down her head and on to her forehead. I watch and wait for an indication as to if she would like my help because I know that her independence is slipping through her now very weak hands and my priority is to empower her. She looks at me and asks that I help because she can no longer lift her hand to move the headset back on her head. As it turns out, I managed to help her realise that she can still do this using her hand in an atypical way.

We are interrupted by a phone call from the Occupational Therapist (OT) who arranges her care. Concerns were raised by the Physiotherapist who visited yesterday as there has been further deterioration in Ms. S's mobility and she can no longer transfer into bed with 1 carer, she requires 2. The service is strapped and they can't send 2 carers at her already early bedtime of 7, and today Ms. S will be helped to bed at 4 o'clock. She says 'My students won't even be home from school yet, and I'll be put to bed'. The OT adds that she'll bring a pad because she'll be in bed so long without a way to reach the toilet that a pad may be required.

Ms. S finishes the phone call, looks at me and bursts in to tears.

Her diagnosis of Motor Neurone Disease (MND) was confirmed last month with a life expectancy of 1 year given.

All she wants is to be able to sit in her recliner chair by the window to watch her cat and the birds who feed

in the bird house she once made. She can't do this today because when the carers come they'll close the curtains and put her to bed with the light off to prevent her from sleeping the night with the light on and waking at sunrise. With nothing to do but stare at the ceiling she tells me she spends most of her nights thinking...about MND.

I console her as much as I can. She eventually stops crying, looks at me, and asks that I wipe away her tears because she no longer can.

Ms. S goes on to say that she is really hungry. Her carer hadn't been since lunch and it was now 4pm. She has no way of getting any food for herself so she has resigned to having a box of chocolates next to her chair not because she is being over indulgent, but because they don't have a packet (so she can easily place in her mouth even with her limited hand function) and because she can manage to swallow chocolate.

Her swallow has started to deteriorate. Ms. S says she is coughing more often. Just yesterday she was drinking a glass of water and her sister made her laugh (she smiled as she told me), but then she started coughing and lost her breath taking a few minutes to recover. Ms. S looked at me and asked, 'Is my swallow going because of MND?'

As a Speech and Language Therapist you get asked difficult questions all the time, and there is never really a right way of answering. With no way around it, I said 'Yes, your swallow is deteriorating because of MND'. I explained that it's typical of MND that your swallow will start to deteriorate around a similar time that your speech does due to the nerves and muscles that are involved; otherwise known as 'Bulbar' symptoms.

Ms. S has been grappling with the loss of her mobility (walking with a frame inside and using a wheelchair outside), reduction in hand function, and change in speech and voice for some time, but today, she realised that the symptoms of MND were in fact worse than she had thought. She is now having difficulty swallowing.

Ms. S was aware that this was going to happen at some point because she had received a letter

from her neurologist suggesting that she has a PEG (percutaneous endoscopic gastrostomy) tube inserted. That is, a tube in to the stomach which allows nutrition to be provided whilst completely bypassing the swallow mechanism. It is important for this to be placed now as if too long Ms. S may not withstand surgery due to decreasing lung function. Again, a tricky subject because PEG tubes are life prolonging and as I'm sure you've realised, living with MND is not easy and not everyone chooses to prolong their life.

In fact in my opinion Motor Neurone Disease is one of the most crippling and devastating diseases that I know of.

People talk about the glass half full or half empty phenomena. I'd like you to think about this in another way.

Before people are diagnosed with MND their glass is full...of friends, family, work, sport, reading, eating, breathing; everything that we all do. Over time, their glass evaporates drop by drop. Very small changes in function occur each day, some more noticeable than others. It is at that time, when people with MND feel 'impaired', that we must highlight to them what they can do. While there is time to grieve for the function that is lost to MND, do not let MND define who a person is. It is a disease, not a person.

The next time you meet someone with MND help them to make every last drop count!

MND INFORMATION SESSIONS

We warmly invite people with MND, their families and friends to an Information Session about MND.

At 7pm on Wednesday, 2 May at MND Victoria, 265 Canterbury Road, Canterbury.

Please RSVP by 5pm, Monday, 30 April.
Phone: (03) 9830 2122, 1800 806 632 or
Email: info@mnd.asn.au

The following session will be held on Thursday, 14 June at 7pm in Canterbury.

YOUR STORIES



Diagnosed with MND - 1 June 2016

By Carolyn Hutchison, Bendigo

I was a stay at home single mum with 3 children aged 5, 7 and 9 in 2003 and my youngest was recovering from cancer treatment. I had left my husband in 2002 while my son was having his treatment. During the time from 2003 to 2012 I went back to TAFE to study Information Technology, Business, Business admin, Project Management and Education Support completing all courses with Qualifications. I was accepted into Diploma of Children's services for 2013 however could not afford the fees to study and was attending compulsory Job Network Training as well as working 3 days a week in a Pizza shop washing dishes, taking orders and doing some kitchen work.

I first noticed symptoms while working in the pizza shop, I was having difficulty holding things like the pen to write orders. My fingers would cramp while stirring food on the stove and it was becoming difficult holding dishes to wash and dry them. My legs would cramp numerous times of a night when I was trying to sleep and I would get tingling and numbness in my fingers, especially in my dominant right hand. Visits to my GP proved fruitless as every test came back fine.

In August 2013 I secured a permanent part time job at Brumby's bakery and my hand deteriorated more. The muscles were wasting away and I lost the use of my thumb. My GP sent me to the local Neurologist

(who I had seen for Ulnar Nerve issues previously) and the more invasive tests began. I had EMG's which showed no blockages, I went to Cabrini for a second opinion which determined I did have muscle atrophy which was clearly visible and it was slowly spreading into my forearm. Both neurologists agreed to try IVIG (intravenous Immunoglobulin) treatment for 3 months looking for Multifocal Motor Neuropathy (MMN) This treatment did not help and I was sent for an MRI and a Lumbar Puncture which also provided no insight. I visited my local Neurologist again on June 1st 2016 and was diagnosed with Progressive Muscular Atrophy (PMA) which is a slow progressing form of MND. I left the specialists confused and not knowing what I was meant to do next.

I got home, started searching the internet for some answers and was coming up with very little, when I found MND Victoria's site and decided to message them. If it were not for you I would have had no idea where to go or who to speak to. I gave up working on August 22nd 2016, 3 years to the day from when I started as it was the repetitive twist tying bread bags that had affected my hand.

My PMA still remains slow but it is spreading to my other limbs. I am still able to do most things, it is just more awkward now and very frustrating. I can't express how grateful I am to MND Victoria and especially Eric my Regional Advisor for all the support, care and invaluable information you have provided me since my diagnosis.

WRITE YOUR MND STORY

We'd love you to share your MND story. Please email your text and a photo to: info@mnd.asn.au by 9 May for our next edition.

YOUR STORIES



Andy's MND Journey

By Ron Camier

On Friday 1st December 2017, despite extreme weather warnings, about 400~450 people gathered at Eternity Church in Morwell to celebrate the life of Andrea Camier. Her extraordinarily loving and caring nature, beaming smile and sparkling personality had impacted many people.

As well as adoring her husband, three married children and seven grandchildren, she had been like a mother to many. This was through her work supporting families as a speech pathologist, through her fun engagement with people in our 4WD tour business, through her enthusiastic organisation of community festivals and church outreach events, through caring for young people living in our home, and through simply meeting and greeting people in the streets, schools and shops around our town. It didn't matter to her whether people were rich and famous, or poor and needy, everyone was of value. Andy lived out her Christian faith through everyday practicalities.

Her MND journey began after noticing difficulties with slurring speech. Medical investigations led to a local neurologist in May 2015, who suggested motor neurone disease as a possible cause. A quick search on the internet led me to the realisation that her symptoms 'ticked all the boxes', and I probably alarmed all the family with the information that the likely

survival time would be 2~5 years. (In fact she had 2½ years from this date.) The diagnosis, by elimination of other possible ailments, was confirmed at Bethlehem Hospital, the state centre for neurological diseases in Melbourne, in November 2015. We learned that there was no known cure or cause, although there was suspicion of anti-cholesterol medication prescribed a few months earlier. We were linked with MND Victoria, LRH allied health, LCHS palliative care and DHHS funding support. So with additional help from family, friends and her employer we were well looked after through this terrible journey. I was given information on what to expect in stages: 1. Diagnosis – loss of our future, 2. Physical decline – loss of function, 3. Death – loss of life partner, and 4. Emptiness – loss of activity.

We were advised to have a good holiday because it would be our last, so a campervan tour of New Zealand was undertaken. This was like a second honeymoon and a great adventure with many amusing episodes brought about by Andy's communication difficulties and my interest in 'getting off the beaten track'.

Immediately upon our return in April 2016, Andy was admitted to the Austin Hospital to be fitted with a ventilator to assist breathing, and a PEG tube into her stomach to assist nutrition. Although confronting, she happily accepted that this was necessary to 'see her grandchildren growing up'. As her speech disappeared she began using an iPad with voice synthesiser to communicate.

Over the next 18 months her arms, hands and neck muscles stopped working, and care requirements increased to 24/7 with professional carers coming 5 days/week, and tremendous help from family and friends. So she was still the centrepiece of our home, with numerous visitors, in sickness as she had been in health. Australia Post, local florists and our internet service had a pretty heavy workout. The night before she passed away she had breathing difficulties and was taken by ambulance to LRH. The following morning, 25th November, she had a far-away look in her eyes, then peacefully closed them.

Judging by the avalanche of tributes received, Andy's selflessness inspired many, and she will be greatly missed by family, friends and the communities she touched.

VOLUNTEER NEWS!



By Deb Olive, Coordinator Volunteer Programs

MND volunteers have had a busy beginning to the year. We have been fortunate to have a number of people join us as new volunteers already this year. We welcome our new volunteers to the team and look forward to working with them to ensure their volunteer experience is rewarding.

Our volunteers held a successful Sausage Sizzle at Bunnings Box Hill on Australia Day. Despite the heat our team cooked on. It was a great effort and much appreciated by all who braved the heat of the day. In March MND volunteers were at the gates during the two day Wandin Park Equestrian Event. Patrons were happy to donate to support the work of MND Victoria and to become a little more aware of MND. In regional areas MND Walk events have been possible because of the work of dedicated teams of local volunteers bringing the community together.

Across the state volunteers are involved in many different ways. Over the coming issues of MND News we will feature some of our volunteers and the work they do.

MND News Mailouts

Have you ever considered how your copy of MND News gets to you? There is no doubt MND News is a team effort with contributions and contents sourced from across the organisation, the state, nationally and internationally. The communications team of staff and volunteers then does an amazing job designing

and bringing the newsletter together into such an informative print and online publication.

But how does it get to you? Well - every two months a team of committed volunteers come together for the day at the MND offices in Canterbury. The morning starts early with staff ensuring everything needed is in place when the volunteers arrive - often well before 9am. Staff then get out of the way and allow the volunteers to manage the collating, labelling and filling of envelopes. While it's a busy day there is always time for a shared morning tea and the radio provides a range of music as a background to the conversation and camaraderie as more than 1500 copies of MND News are made ready to catch the afternoon post.

Thank you to our MND News team of volunteers. We couldn't do it without you and we look forward to the mailout days and having you with us in the office.

National Volunteer Week



National Volunteer Week (NVW) is an annual celebration of the generous contributions volunteers make to our Australian community. The theme for 2018 is: Give a little. Change a lot. This theme reflects the impact millions of volunteers across Australia make in their communities and for our society, by giving a little of their time.

National Volunteer Week 2018 is occurring from 21-27 May 2018. MND Victoria is able to provide the care and support it does because of our volunteers. More than 130 regular volunteers across the state providing support, expertise and care enable MND Victoria to reach out into the community. During National Volunteer Week MND Victoria will take time to acknowledge and thank our incredible volunteers.

We invite you to say thanks to volunteers whose input has meant a lot to you. During National Volunteer Week (21-27 May) we encourage you to add a post to MND Victoria's Facebook page to say thanks to the volunteers who have given a little and changed a lot for you.

VOLUNTEER OPPORTUNITIES ...

MND Friendship Group Coordinator Werribee area - we have a number of people living with MND in the Werribee area who would like to organise to meet for regular social time together in the Werribee area. To help make this happen we are looking for someone who could act as a point of contact and coordinator for the group. The role would involve contacting group members to coordinate times and dates of get togethers and welcoming new members to the group.

Time required: The role will involve 1-3 hours per month liaising with group members as well as attending friendship group get togethers (1-2 hours) at a local venue.

Skills required: Access to email or phone to contact and connect with group members. Interest in assisting people to stay connected with others in their local community.

Hairdresser - we are seeking an experienced hairdresser who is able to visit clients living in the North West suburbs of Melbourne to provide a trim in the comfort of their own home. This role requires volunteers to provide their own equipment and will involve travel within the area.

Time required: appointments will be organised to suit the needs of clients and the availability of the volunteer.

Massage Volunteers Geelong - our massage volunteers provide hand and foot massage for people living with MND. The aim of the massage is to assist with relaxation and comfort. We currently have clients in the Geelong area who are hoping to be matched with a massage volunteer who may be able to provide them with a weekly, fortnightly or monthly hand and /or foot massage in their home or place of residence.

Time required: Our experience has been that each massage visit takes approximately one hour plus travel time. Massage volunteers let us know how much time they have available - some massage volunteers visit one client each month others support a number of clients on a regular basis.

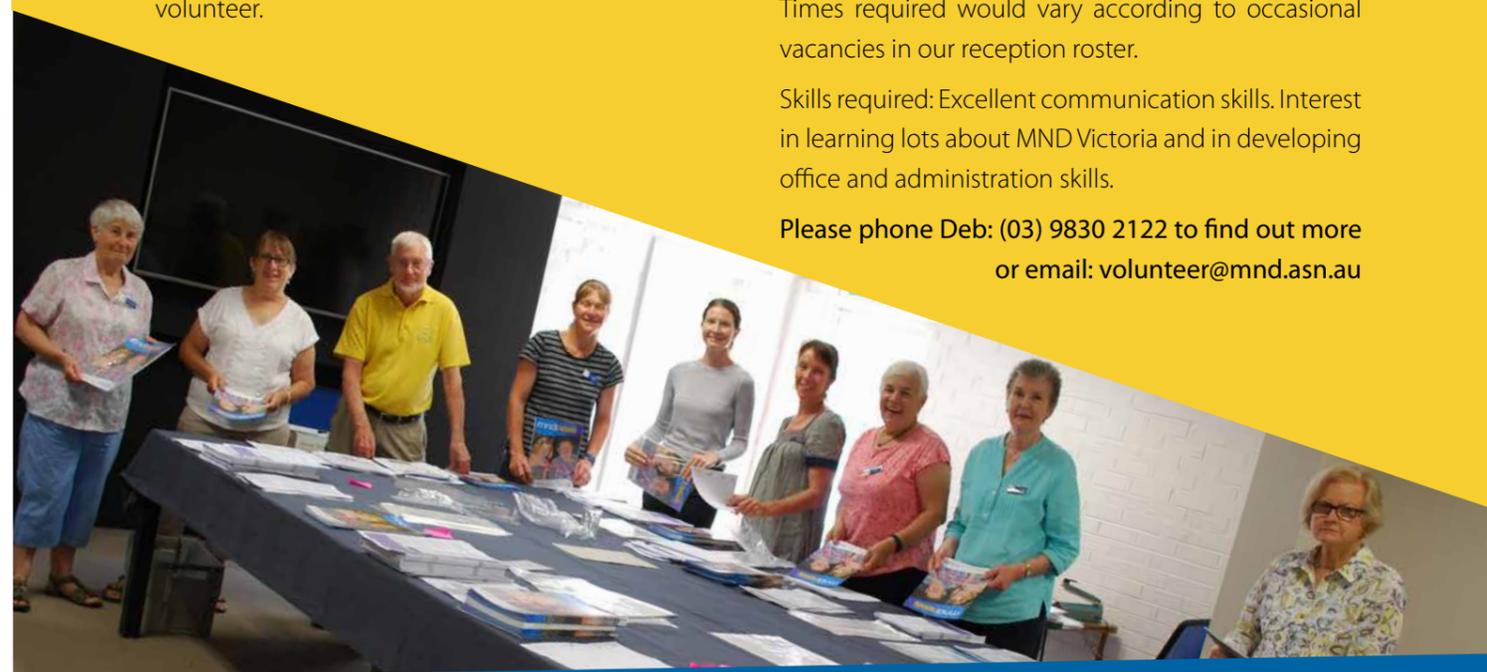
Skills required: Massage volunteers are not required or expected to come with skills in massage. MND Victoria provides training and resources to prepare volunteers for their role in hand and foot massage.

Relief Reception Volunteer - we still have a need for one or two relief reception volunteers. Our volunteer receptionists are our frontline at the MND Canterbury office. We are seeking to develop our small pool of relief reception volunteers, able to provide backup support to our reception team.

Time required: Reception shifts are Monday to Friday for 3.5 hours in the morning or afternoon. Times required would vary according to occasional vacancies in our reception roster.

Skills required: Excellent communication skills. Interest in learning lots about MND Victoria and in developing office and administration skills.

Please phone Deb: (03) 9830 2122 to find out more or email: volunteer@mnd.asn.au



GROUP PROGRAMS

Living Well

Living Well is a group program for people with MND and their carers. Participants have the opportunity to share knowledge and discuss topics relevant to living with MND.

The format of the program varies to suit the needs of participants and may include readings, group discussion, video presentations and guest speakers. Additionally, participants provide each other with support and are able to share ideas and solutions of their own.

Living Through

Living Through provides an opportunity for newly bereaved carers and family members to meet with others who share similar experiences in an informal and friendly environment.

Participants hear from a guest speaker who presents on typical grief experiences. They also have the opportunity to share advice with one another and have access to bereavement support resources.

Living On

Living On is a four week program designed for former carers. It provides the opportunity for people who have been bereaved for 12 months or more to meet in a facilitated group to explore positive ways of moving forward whilst finding ways of retaining treasured memories.

How do you get involved with the groups?

MND Victoria will contact potential participants for the Living On, Living Through and Living Well programs shortly before the groups are run. However, you are more than welcome to contact MND Victoria to register

your interest: Phone: (03) 9830 2122 or 1800 806 632 or email: info@mnd.asn.au

Meeting others

Are you interested in having contact with others living with MND?

MND Victoria can assist people with MND, carers, family members and friends to get in contact with others in similar circumstances.

This can be done through:

- MND Victoria group programs
- Ongoing support groups
- Facilitating contact either in person, by phone or by email
- Referring to external online support groups.

If you would like to be in contact with others, but are uncertain of how to go about it, then contact us and we can talk you through your options.

Phone: (03) 9830 2122 or 1800 806 632 or email: info@mnd.asn.au

Facebook support groups

MND Carers Australia

An online support group for Australian MND carers to discuss issues they face. MND Carers Australia is independent from MND Victoria, but has asked us to promote their group. To access the group you will need a Facebook account.

A message from MND Carers Australia's administrators: MND Carers Australia's focus is to support the primary carer of someone with MND. The primary carer faces many challenges. They often feel isolated, feeling like no-one understands what they are going through. Only one family member is allowed in the group as the primary carer needs a safe place to discuss any and all issues they may face. This is a private group where you can feel supported, ask questions and vent about the difficulties you face as the primary carer of someone with MND. We hope you will be proactive in the group and gain knowledge from others, but we understand everyone will be at a different point on the MND road. If you would like to join, go to Facebook and search for: "MND Carers Australia"

MND Angels Australia

An online support group for people in Australia whose partners have died from MND. MND Angels is independent from MND Victoria, but has asked us to promote their group. MND Angels offers participants an opportunity to share experiences and support one another. To access the group you will need a Facebook account.

If you would like to join, go to Facebook and search for: "MND Angels Australia".

Kennedy's Disease Facebook Group

Did you know that MND Victoria also provides support to people living in Victoria with Kennedy's Disease? Kennedy's Disease (also known as Spinal and Bulbar Muscular Atrophy) is a condition that has similar symptoms to MND. One of our members has shared a Facebook group for Australians with, or affected by, Kennedy's Disease. The group aims to help raise awareness within our communities and to help out each other: <https://www.facebook.com/groups/340781642962036/>

Support services for carers of people with MND

Carers Victoria—(03) 9396 9500
www.carersvictoria.org.au

Carer Gateway—1800 422 737
www.carergateway.gov.au

CareSearch—www.caresearch.com.au

BrainLink—1800 677 579 www.brainlink.org.au

MND Victoria—(03) 9830 2122 www.mnd.asn.au

Experiences of Family Carers in Australia - research project

QUT (Queensland University of Technology) are inviting carers to participate in their research project 'Experiences of Family Carers in Australia' via an anonymous online survey.

Find out more and participate at: www.survey.qut.edu.au/f/190710/67f7

BENT THUMB THINKING - THE BOOK ...

Graham Crossan, Author of Bent Thumb Thinking writes, "It was a thrill during the week to hand over a bank cheque for \$1,200 to MND Victoria. This was from funds raised with the crowdfunding and sales of Bent Thumb Thinking – the book.

MND Victoria does an amazing job of supporting people living with motor neurone disease and their carers. Thanks from the bottom of my heart.

At the presentation we had Rod Harris, CEO, and Kathy Nightingale, Manager Fundraising of the organisation that does such wonderful work in an extremely difficult environment. In the photograph are Rod, my wife Gaynor and I.

A copy of the book was also given so that staff members have access to the two stories that relate to my journey with a disease that is still something of a mystery in terms of how it starts, how to treat it and what it means to those living with it ..."



RESEARCH UPDATE

It's not just about the neurones

By Dr Brian Dickie, UK MND Association

Long before the latest wave of cellular and molecular biology advances started to give us new information on what was going on at the cellular level in MND, some doctors had observed that if the disease started in one particular part of the body, it would be neighbouring parts that became affected next. This suggested that the disease usually starts in a single part of the brain or spinal cord before spreading further, like ripples in a pond.

How this happens is not well understood. It is likely that there are a number of processes going on, but they can broadly be divided into two theories. One of these is that damaged proteins can leak out of sick neurons and 'infect' their neighbours – a subject we have discussed at previous international Symposia.

The other theory is that the spread of the disease could be dictated by chemicals released by other cells in the central nervous system, in particular the glial cells, which may outnumber the nerve cells in the human CNS. The word 'glia' comes from the Greek word for 'glue' and was so named by neuroscientists in the 19th century as it was believed that they basically acted as the 'filling' of the brain to hold the 'wiring' of the nerve cells in place.

However, it has since become clear that they play a much more important role in helping to support and protect the neurons..... at least most of the time. Research over the past decade has shown that they have a darker side – a so-called 'activated state' – which can have the opposite effect and cause damage to neurons in the cellular neighbourhood.

Although both theories are still very valid, with ongoing research presented at the recent 28th Symposium, the role of glial cells formed the theme for Session 9A on

the last day of the meeting. There are several types of glial cells found in the CNS, but researchers have largely focused their attention on two particular members of the glial cell family: astrocytes and microglia.

Advances in neuroimaging

Dr Nazem Atassi (Harvard) kicked off the session by showing the latest neuroimaging techniques that are being applied to measure the amount of glial activation that is occurring in people with MND. Using a combination of cutting-edge positron emission tomography (PET) and magnetic resonance imaging (MRI) techniques, he was able to show that in ALS and PLS (a rarer form of MND) patients, the activity of glial cells in the brain was significantly increased in areas where nerve damage was occurring and that this also correlated with the clinical measures of the disease. He also showed some preliminary results of an ongoing study showing increased glial activity in the spinal cord – an incredibly technically challenging piece of work. To show that PET imaging of the spine is feasible is an exciting advance.

So – in a nutshell, these imaging studies show that what is happening 'on the inside' is reflecting the physical changes 'on the outside'. Dr Atassi intends to further refine these techniques so that they can be incorporated into future clinical trials, in particular for drugs aimed at targeting the glial cells.

The importance of astrocytes

The potential role of astrocytes in causing motor neuron death was explored by Dr Laura Ferraiuolo (Sheffield) who has developed an elegant laboratory technique that allows mouse motor neurons and human astrocytes (created from human skin cells) to be grown together in a dish, but separated by a porous membrane that allows chemicals released from the astrocytes to travel across to the motor neurons.

Using this technique, the Sheffield team developed a theory that astrocytes from ALS patients might release chemical factors that are toxic to motor neurons. These factors may be contained within structures called extracellular vesicles (EV) that cells appear to use to 'eject' unwanted substances. In trying to work out what these factors are, they focused on a series of molecules known as 'microRNAs', measuring the types

PROJECT MINE - 10,000+ DNA PROFILES!

Project MinE plans to map the full DNA profiles of at least 15,000 people with MND/ALS and 7,500 control subjects, and to perform comparative analyses on the resulting data.

Eighteen countries collaborating in Project MinE have collected more than 10,000 DNA samples for sequencing (whole genome sequencing, WGS).

This will be the most detailed genetic dataset that has ever been available for MND/ALS research and will help to find more MND/ALS genes and to develop tailored treatments for MND/ALS.

New collaborations allow for even more sharing of data, especially from healthy controls. In collaboration with the USA FALS consortium an exciting large analysis will be performed to help explain disease onset. Also, several upcoming batches of DNA samples for WGS will come in early 2018. More DNA samples will help to find more (rare) ALS genes.

To find more MND/ALS genes Project MinE need 15,000 DNA profiles from MND/ALS patients and many DNA profiles of healthy control persons.

Find out more about the project at:

www.projectmine.com

that were released by C9orf72 patient's astrocytes compared with control (non-ALS) astrocytes.

They found that the C9orf72 astrocytes released fewer EVs, which was associated with a significant reduction in the release of two particular microRNAs from the cells. Moreover, by supplementing these microRNAs directly into the dish, they could improve the health of the motor neurons.

In the light of these results, their initial theory that a toxic factor may be involved has been somewhat 'turned on its head' to a new theory that the damage to motor neurons may be due to the loss of essential survival factors, such as microRNAs, which are released by astrocytes. If this is the case, then it might be possible to use gene therapy approaches to increase the levels of these microRNAs and keep the motor neurons in a healthy state. Their next step is to find out whether this effect only happens in C9orf72 ALS or in all forms of the disease.

Moving on to microglia

The final two speakers in the session focused on the other likely glial culprit, the microglial cell. The brain does not have the sophisticated immune system that is found in the bloodstream and other parts of the body, but it does have its own version in the form of these cells, which form the

DONATE TO THE TISSUE BANK

People with a diagnosis of MND confirmed by a neurologist are needed to donate tissue to MND research.

If you are interested in donating, or if you are just interested in finding out what tissue donation involves, please contact Ms Fairlie Hinton, Coordinator, Victorian Brain Bank or find out more on The Florey's website:

www.florey.edu.au/vic-brain-bank

Email: fairlie.hinton@florey.edu.au

Phone: (03) 8344 1900

Mobile: 0438 530 372

first line of defence against invaders. Unfortunately, they do have a tendency to become overactive, giving rise to a lot of collateral damage to neurons.

Dr Fei Song (Chicago) outlined how motor neurons communicate with microglia. She has previously shown that in the SOD1 mouse model of ALS as well as in human post mortem ALS tissue, this overactivity may be mediated through proteins (called neuregulin receptors) on the surface of microglial cells. In her presentation in Boston, Dr Song outlined how she and colleagues have developed a large protein-based molecule that blocks the neuregulin receptors. Administering this molecule directly into the spinal fluid of SOD1 mice reduced the activity of the microglia, delayed the onset of disease and increased survival. This may open up a new therapeutic approach, though as we know from hard experience, approaches that appear to work in the SOD1 mouse have invariably failed in human trials, so there is still a lot of work to do be done if this is to be taken into clinical trials.

In addition to their immune-like role when they become activated, microglia also appear to have a day-to-day role in clearing up unwanted debris in between cells. Dr Marco Morsch (Sydney) showed that microglia can help to mop up proteins such as TDP-43 when they leach out of sick or injured cells.

Dr Morsch showed a series of studies using an embryonic zebrafish model, which allows individual neurons to be studied in the living animal. The fish were genetically modified to produce human TDP-43 (a protein linked to over 95% of ALS cases) and in these animals he was able to show how microglia are attracted to sick or damaged neurons and help to clear up any TDP-43 that is leaking out of these weakened neurons. If the microglia were absent, the damage was much more severe. These findings indicate that microglia may also play a role in the first theory of disease spread (mentioned at the beginning of this article) by helping to stop damaged proteins from sick neurons 'infecting' their neighbours.

In turn, this suggests that any drug therapy that targets microglia might work best if it can effectively stop the microglia from becoming activated and aggressive, but not to the extent that it stops these essential cells from doing their day job of Hoovering up cellular debris.

This article was originally published at: www.mndresearch.wordpress.com/2018/01/05/its-not-just-about-the-neurones

INTERNATIONAL SYMPOSIUM ON ALS/MND

The 28th International Symposium on ALS/MND was held in December 2017 in Boston USA. We will keep you updated on the research presented at the Symposium over the next few editions of MND News.

Biomedical research stream

Motor neurones are very long, complex cells, and it is likely that their death in MND is caused by attacks from multiple sources. Researchers are working hard to defend motor neurones 'from all sides' and, to do this, they need to know the neurones' weaknesses.

They believe there are two ways in which motor neurones are attacked. Firstly, proteins are moving out of the control centre of the cell (the nucleus) and into the area around the nucleus (the cytoplasm) and clumping together there. Secondly, they believe that the support cells that should protect the neurones 'go wrong' and instead of protecting, they start attacking the neurones.

ALS Quest Survey

The ALS Quest survey is an online questionnaire looking at environmental risk factors for MND.

You can take the survey online at: www.alsquest.org

Both people with and without MND can fill in the survey - it will take around 90 minutes to complete.

This is a University of Sydney project.

Cellular structure and transport

If you look at a motor neurone affected by MND down the microscope, you'll see clumps of proteins. But how did those proteins get there? These proteins are the wrong shape, as they have clumped together, and are in the wrong part of the cell, the cytoplasm, instead of the central nucleus. Clues on how they are getting there are found by studying an inherited form of MND, for example the one caused by mutations in the C9orf72 gene.

To get through to the cytoplasm from the nucleus, the proteins need to cross the equivalent of a city wall. They do this by passing through controlled 'gateways'. Some researchers are looking at these gateways and how they are controlled and also the structure of the gateways themselves. The proteins have important jobs to do in the cell nucleus to keep motor neurones healthy and functioning well.

Their movement into other parts of the cell, and staying there in clumps, could be one of the reasons why motor neurones die. If the gateways can be kept secure, structurally sound and work properly, that may slow down MND.

Support cells

Researchers are also looking at what happens when the cells that support motor neurones 'go wrong'. Motor neurones are surrounded by support cells called glial cells. In MND, something happens to change them and they appear to attack the motor neurones instead of protecting them.

Two particular support cells have been studied the most in MND. These are called microglia and astrocytes. Microglia help protect motor neurones from damage and injury. Astrocytes have more of a role in supporting the health of neurones. How they do this, however, is less well understood.

Researchers have developed different ways to learn about microglia. This includes (a) learning about microglia activity using a brain scan 'live tracker', (b) how blocking attack by microglia can increase the lifespan of mice with MND, and (c) how microglia can help reduce the effects of MND by clearing away dead motor neurones.

Motor neurones will grow quite happily on their own in a dish in the lab. However, if astrocytes are grown in the same dish, or motor neurones are grown in liquid that has previously contained astrocytes, the motor neurones die. This suggests that astrocytes are passing something toxic onto the motor neurones.

A team of researchers has been looking at what causes this in more detail. They took skin cells from healthy people and from people with the C9orf72 inherited form of MND. They used these to create astrocytes in the lab using stem cell technology. Stem cells are cells that have not yet been given a function and can turn into any type of cell. They particularly looked at what healthy astrocytes are passing on compared to the astrocytes in people with MND. They have found two factors that may be causing the toxicity which may become a target for future therapies.

This article was originally published at:

www.mndassociation.org/symposium/symposium-live/biomedical-research

You can catch up on all the abstracts from the Symposium online at: www.mndassociation.org/symposium/abstracts-online

The future of MND research - high throughput drug discovery

Join The Florey Institute of Neuroscience and Mental Health's Dr Brad Turner speaking on 'The future of #MND research - high throughput drug discovery'.

The MND Laboratory at The Florey employs a combination of cell and molecular biology to study the molecular basis of MND using patient stem cell-based models, cell culture and animal models. The team seek to identify and understand the primary mechanisms causing motor neurone disease, while translating their discoveries into relevant therapeutic targets for effective intervention. The team has recently embarked on a world first drug screening program for MND patients which is the main topic of this lecture which will be held from 11:00 am-12:00pm, Tuesday, 5 June 2018 in Parkville.

Tickets available at: www.eventbrite.com.au/e/the-future-of-mnd-research-high-throughput-drug-discovery-tickets-42187198045

FUNDRAISING



“If you are working on something that you really care about, you don’t have to be pushed. The vision pulls you.”- Steve Jobs

MND Victoria’s vision is 'a world without MND 'but until that happens our mission is to provide and promote the best possible care and support for people living with MND.

Last year MND Victoria supported 575 people in Victoria living with MND, a 10% increase over the previous year. Partly as a result of this increase we also saw an increase in the number of disability aids and equipment provided to address mobility, care and communication issues. These two services, plus the provision of current information on care, support and research, form the core of our activities. Activities which enable people with MND to remain connected with their family and community and reducing the risk of social isolation.

As I mentioned in the last newsletter, the Association receives only 25-30% of our funding from Government sources, including the NDIS. If you’re like me, you’ll have a better understanding of this gap by looking at the graph (see right) which clearly highlights how important fundraising activities are.

While NDIS funding is becoming available to more people throughout Victoria there is a large number of people who do not have access to NDIS funding now and will not have access in the immediate future. These are the people who are aged 65 years or older when

first diagnosed, so there is always a need for us to raise funds to ensure that people in this age group are not denied access to the services they require and deserve.

Monies received from our donors, fundraising groups, challenge event participants, Trusts and Bequests underwrite our services, particularly for everyone 65 years and older.

It is imperative that we continue to receive this support so that everyone with MND has equal access to care and support regardless of their age or where they live. Last year these funds enabled us to purchase new assistive technology devices, as well as continue to enhance our service delivery.

There are numerous ways you can support people living with MND and I encourage you to check out our new website www.mnd.asn.au as well as our Facebook page www.facebook.com/MNDVic so you can stay informed of the many and various fundraising activities taking place throughout the year.

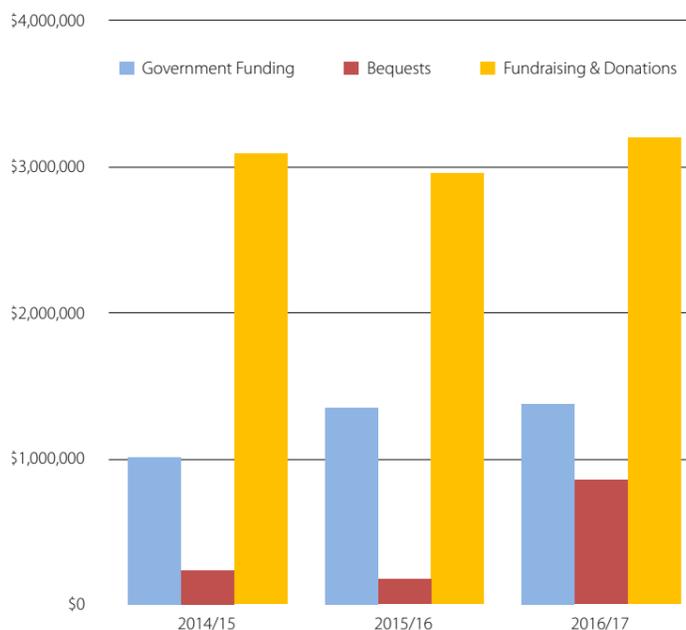
If you have an idea for fundraising, we’d love to support your efforts. Contact us by phone: 03 9830 2122 or email: fundraising@mnd.asn.au

Until there’s a cure there’s care.

Kathy Nightingale

Manager Fundraising

MND Victoria Income Sources



11TH BENALLA ACT TO D' FEET MND!

Now in its 11th year, the Benalla event that started following Benalla’s Mick Rodger’s diagnosis with MND has grown into an event that continues to raise funds for research to find a cure and raise awareness, but also to support so many in the Benalla and surrounding communities affected by this disease.

“Each year we hear of more and more families affected by this insidious disease; uncles, aunts, fathers, mothers, brothers and sisters,” Robyn Smith said.

Every day in Australia two people die from MND and two people are newly diagnosed with the disease. Therefore it’s not surprising that Benalla continues to be affected as members of the community are diagnosed or die from MND. This year was another difficult year for committee members as they faced the death of Peter Bennett whose wife Leonie is on the committee.

The Benalla event is always a great day but this year saw a new addition - the well-known trotter Smudge Bromac, whose owner recently died from MND, took part much to the enjoyment of the many children participating.

Despite the growing number of losses, the Benalla Act 2 D'feet MND day was a wonderful day in perfect weather enjoyed by all.

What started as a Benalla event is now an event that reaches out to much wider communities, including Nagambie, Violet Town and Kyabram.

King of the Lake winner Kyle Pearce kicked strongly to surge past Myrtleford’s Brenden Norden in the finish straight. Norden had taken part in a run in Wangaratta earlier in the morning, but with a connection to the Bennett family he wanted to compete in the race. Queen of the Lake went to Jenna McHugh. Princess of the Lake was a tie between Maya Rhodes and Olivia Ham.



HEATHCOTE BOWLS CLUB MND SUPER CHALLENGE!

It was a sensational day up at Heathcote Bowls Club on 26 January for their annual MND Super Challenge! Two full greens of new and experienced players alike, combined for some lighthearted competition and fun to raise funds for MND Victoria.

This is the second year the club has run an event for MND Victoria. A huge shout out to the club officials and local Heathcote community who have really supported the cause and made the day a huge success!



MND HOODIES!

Our MND hoodies are super warm and comfy and best of all ... your purchase helps support people living with MND and funds research.

WOW! What a hoodie!

Yours for only \$69 at:

www.mnd.asn.au/gear

Order your hoodie by 1 April to ensure they are delivered by MND Week on 6 May!



ROCK OFF MND 2018 - A NIGHT TO REMEMBER!

Thank you to everyone who attended and supported Rock Off MND on 20 January 2018! It was an incredible evening which raised \$141,970 for MND Research!

A HUGE congratulations to the Simko family and their organising team for putting on another stellar event with Kate Ceberano as lead act, performing alongside Madhouse and Woodlock. A great night was had by all!

David Lamperd, President of MND Victoria also accepted a cheque from Chris Hall (Wheel 4 MND) for \$11,000 he has raised over the past 12 months.

In 2018, the Jenny Simko MND Research Grant is funding two research projects at the Florey Institute. One project is understanding how essential elements like copper, iron and zinc are involved in MND looking to provide an earlier detection test. The second project is looking to improve understanding of MND biology and lead to the identification of new drug targets.



COMMUNITY FUNDRAISING EVENTS

Ocean Grove Rotary

Ocean Grove Rotary Club contacted us nearly 12 months ago wanting to host a fundraiser in honour of a long time member, Maurie Fowler who was living with MND. Unfortunately, Maurie died prior to the event. As a result the organising committee was even more determined to create an unforgettable event.

On a Tuesday night, at the usual meeting time, and usual venue, Ocean Grove Bowling Club, the Rotary members met. Only this time they had seating for 235 people. Ian Cover from ABC Radio and The Coodabeen Champions donated his time to be the MC for the night. He had the crowd in stitches each time he spoke. Maurie's step-daughter, Kristen Hilton was the guest speaker. She delivered a very powerful speech about MND and how it affected Maurie and those around him.

Later in the night there was an auction of many items that had been generously donated. Everything from sporting memorabilia, accommodation at local hotels, and a home cooked meal on a Rotary member's deck. There was something for everyone! There were also silent auctions going on through the night as well as various raffles.

Soon after the event John Calnin, President of the Ocean Grove Rotary Club, presented us with a cheque for \$13,900. We are very thankful to all those involved with Ocean Grove Rotary Club for putting on a fantastic night and raising a significant amount of money.



Lilydale Cricket Club

Ladies day is a regular annual fixture at many cricket clubs. On Saturday afternoon in February, Lilydale

C.C. hosted their very own and it doubled as an MND fundraiser. The organising team did an incredible job putting together a fantastic event. A lifelong member was diagnosed with MND last year, so this was something they wanted to do well. MND and ice buckets are synonymous with each other so the highlight of the day was clearly the dunk tank where numerous people were dunked into the cold water!

We are very thankful to those involved who helped raise in excess of \$3,000 for MND Victoria and all those Victorians currently living with motor neurone disease.



Northern Motor Group Golf Day

We were delighted when we were approached by the Northern Motor Group to be the recipient of funds raised at their annual charity day at Heidelberg Golf Club. On a perfect summer's day, approximately 80 players teed off knowing the day was all about raising funds for all Victorians living with motor neurone disease. A number of celebrities were in attendance including Melbourne Vixens captain, Kate Moloney, Football stars, Tony Shaw and Robert DiPierdomenico and award winning actor, Gyton Grantley.

Once the golf was over it was time for some food, refreshments and a very competitive auction that had a number of fantastic items to be won. Tony Shaw was a very energetic auctioneer! At the end of a big day, the overall amount that Northern Motor Group donated to MND Victoria was \$5,945. A great result!

KOKODA!

In August this year we are embarking on the challenge of a lifetime: to conquer one of the most iconic treks for Australians and one of the toughest sea level hikes in the world. Do this for yourself and also for all those Victorians living with motor neurone disease.

This trip follows on from our incredibly successful Great Wall of China adventure last year where 11 participants managed to raise \$111,000 and spend 10 days in Beijing, walking on some amazing parts of The Great Wall.



All participants taking on Kokoda will have their own fundraising campaign, fully supported by our fundraising team.

Are you up for the challenge? Do it for yourself and the 400+ people living with MND.

Email Daniel: dwoodrow@mnd.asn.au to find out more or phone: 03 9830 2122 - don't miss out on your place on this trip of a lifetime!

VIRTUAL WALK - MND WEEK TO GLOBAL DAY!

Have you always wanted to raise awareness and funds by taking part in a Walk to D'Feet MND event but the place and/or time didn't suit you? Well 2018 is your year to succeed! We are challenging you to complete your Virtual Walk to D'Feet MND beginning at the start of MND Awareness Week on 6 May and finishing on Global MND Day 21 June.

We've made it easy for you to take part! Just start your Virtual Walk to D'Feet MND MyCause fundraising page at www.mnd.asn.au/virtualwalk

Set your own goals – always wanted to complete a marathon? Easy just walk 1.61 kms/day for 46 days and your marathon will be complete. Of course if you're very fit and competitive, you might want to complete a marathon each week! Remember to get sponsored for every kilometre you walk and see how much you can raise - \$130 could purchase a walking frame; \$1,000 could purchase a manual wheelchair, \$2,200 could purchase an electric riser chair.

Grab your MND Hoodie, put on your walking shoes and Walk to D'feet MND T-shirt and get started!



DONATIONS WERE RECEIVED ...

In memory of

Giacomo Andronaco
Mary Anthony
Allison Baldwin
Terry Beat
Joy Beck
Robert Biscoe
Fred Blencowe
Jack Blyth
Richard Bottomley
Kaye Boyle
Antonia Bugeja
John Cannington
Crocket Cook
Sue Davidson
Frank DeRango
Ray Draper
Max Flavell
Stephen Fullarton
Anne Garner
Carole Gowty
Christine Handson
Leona Harmor
Dorothy Holding
Dr Robert Hudson
Rhondda Jephson
Stefan Krix
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Geelong Connected Communities
Kyneton Uniting Church Op Shop
Sorooptimists of Cobram Barooga
Mercedes-Benz Club (Victoria) Inc.

Bequests

Estate of the late Dudley Barton Adams
Estate of the late David William Bloom
Estate of the late Dorothy Mary Cooke

Research donation

Serena & Patrina Patti

Trusts & foundations

Reece Australia Ltd

MND Victoria Membership

Have you renewed your membership for 2018?

You will have received a reminder if your membership is due for renewal. Please keep up your membership—we need you.

Please phone the office on: 03 9830 2122 or email: info@mnd.asn.au for more information on MND Victoria membership.

Contributions are invited!

MND Victoria members are invited to write stories, anecdotes, letters, or 'Handy Hints' for the newsletter. We cannot guarantee that all contributions will be published as this is dependent on available space, but every effort will be made to do so.

Please email your text & photo to: info@mnd.asn.au by 9 May for the next edition, mailed on 5 June.

GET INVOLVED IN AN EVENT NEAR YOU!

Date	Event	Contact
Wednesday, 2 May 2018	MND Information Session	Email: info@mnd.asn.au
MND Week 6-12 May 2018		
Sunday, 6 May 2018	Day of Hope and Remembrance	Email: info@mnd.asn.au
Tuesday, 8 May 2018	Ask the Experts Research Seminar	Email: info@mnd.asn.au
Friday, 11 May 2018	Blue Cornflower Day	Email: fundraising@mnd.asn.au
Monday, 21 May 2018	National Volunteer Week begins	Email: volunteer@mnd.asn.au
Thursday, 14 June 2018	MND Information Session	Email: info@mnd.asn.au
Thursday, 21 June 2018	Global Awareness Day	Email: fundraising@mnd.asn.au
Sunday, 21 June 2018	Stadium Stomp (MCG)	Email: dwoodrow@mnd.asn.au
Sunday, 29 July 2018	Run Melbourne	Email: dwoodrow@mnd.asn.au
26 August - September 2018	Kokoda Trail - Challenge Event	Email: dwoodrow@mnd.asn.au
Sunday, 14 October 2018	Melbourne Marathon Festival	Email: dwoodrow@mnd.asn.au
Saturday, 20 October 2018	Cox's Bridge to Cox's Place Cycle	Email: dwoodrow@mnd.asn.au
Sunday, 18 November 2018	Melbourne Walk to D'feet MND	Email: fundraising@mnd.asn.au
Sunday, 25 November 2018	Bendigo Walk to D'feet MND	Email: fundraising@mnd.asn.au

For further information and the latest events list, please visit our website: www.mnd.asn.au/events

Please email details of events you would like listed on our events calendar to Kathy Nightingale: fundraising@mnd.asn.au We can also provide you with our Event Flyer template to use for your event.



Visit our website at: www.mnd.asn.au or follow us on:

www.instagram.com/MND_Vic | www.facebook.com/MNDVic | www.twitter.com/MNDVic