

MND NEWS



july/august
2018

The newsletter of the
Motor Neurone Disease
Association of Victoria

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



www.mnd.asn.au

INSIDE THIS EDITION:

- From the CEO
- Support services
- More on Riluzole side effects
- My Mission ... To Care
- Your stories
- Group programs
- Spotlight on women and unpaid care
- Volunteer news
- Our hoodie travels!
- Research: Appetite and MND
- My Health Record
- Awareness and fundraising
- Donations
- Events



STATE COUNCIL

David Lamperd
—President

Katherine Barnett
—Vice President

Jeremy Urbach
—Hon. Treasurer

David Ali

Duncan Bayly

Christopher Beeny

Barry Gunning

Jodie Harrison-Fitzgerald

Angeline Kuek

Wayne Pfeiffer

Chloe Williams



MND Victoria

265 Canterbury Road (PO Box 23)
Canterbury VIC 3126

Phone: (03) 9830 2122
Freecall: 1800 806 632
Fax: (03) 9830 2228

Email: info@mnd.asn.au
Website: www.mnd.asn.au

Facebook: www.facebook.com/MNDVic
Twitter: www.twitter.com/MNDVic
Instagram: www.instagram.com/mnd_vic

ABN 44-113-484-160
Reg. Assoc. No. A7518

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

Chief Executive Officer: Rodney Harris

Manager Finance & Administration: Megan Crellin

Administration Assistants: Isabelle Lloyd, Rebecca Moussa

Manager Fundraising: Kathy Nightingale

Fundraising Officer: Daniel Woodrow

Digital Communications Officer: Heidi Bryce

Manager Support Services: Julie McConnell

Coordinator MND Advisor Service: Janette McDonald

Team Leader MND Advisor/Support Coordinators:

Elizabeth Crask, Eric Kelly

MND Advisors:

Ruth McEvoy	Lauryn Matheson
Jenny Waites	Trish Duffy
Leanne Conway	Melissa Kettle
Fran Hurst	Rachel Ritchie

Coordinator Operations: Georgina Diacos

Coordinator Equipment Service: David Harkin

Equipment Officers: Kathy Walker, Sandra Nicholls

Coordinator Volunteer Programs: Deb Olive

Coordinator Information & Resourcing: Alison Jones

Information & Resourcing Officer: Sarah Wilkie

FROM THE CEO



Our financial year is over and our administrative team is in full throes of preparing for audit and our necessary financial reporting activities.

However, our services just continue on, ensuring that people living with MND, their families, friends and colleagues continue to be supported and assisted to live as well as they can.

And our campaigning about Aged Care and making it fair continues. With over 106,000 people on the waiting list for an aged care package, waiting lists of up to a year and with no provision for necessary assistive technology, Aged Care is not fair! If you are under 65 when diagnosed, the NDIS provides the best ever response for people living with MND. It is an entitlement, and is at no cost to you. But not if you are over 65! People over 65 are thrust into an eligibility program that delivers services if there is enough money and packages available. It is means tested and requires contributions from participants if they can pay. It doesn't provide separate funding for assistive technology to help people retain their independence, maintain their engagement with family and community, and be safe in providing personal care and support.

If you have access to the internet, please go to: **www.mndaction.org.au** and sign on to be a part of our campaign to make aged care fair. MND Australia, supported by MND Associations across Australia, is working to ensure that people with MND receive the

support they need when they need it no matter their age.

Please, sign on to join the campaign and ask your family and friends to do the same. We need to represent all those who want people with MND over the age of 65 to live better for longer while fighting MND with appropriate and timely support.

The last rollouts of the NDIS in Victoria have commenced and by 30 June 2019, all people under the age of 65 will be entitled to the support provided through the NDIS. Already we are seeing that more people are receiving packages of support than were previously provided through the state government. They can access personal care, therapy, assistive technology and more to address the reasonable and necessary needs created by MND.

Our MND Advisors are working hard to prepare people for the NDIS, and to make sure that their support plans address their needs appropriately.

It is sad to report that Julie McConnell, Manager Support Services, is retiring in mid-August. Julie has made a huge contribution to the development and management of our support services. Her vision and leadership has been a driving force in improving our support for people with MND. She will be missed. Lesley Burcher has also retired after more than 20 years as a MND Advisor, and we farewelled her in the last week of June.

We welcome Jo Whitehouse as Manager Support Services, and Fran Hurst, Rachel Ritchie and Melissa Kettle as MND Advisors. We have expanded our MND Advisor numbers in the face of significant growth of people with MND registering over the last two years.

A great start to the new financial year was the receipt of \$250,000 in a bequest. The donor was not known to us, but clearly recognised the value of our work and the needs of people with MND. These funds will be added to the MND Care Foundation and invested to provide income for the provision of care and support until a cure is found and we are no longer needed.

And our annual general meeting is not far away!

So, until next time!

Rod

SUPPORT SERVICES



This is my final newsletter contribution before I commence long service leave and then retirement. Thinking about the future has led me to reflect on the past and my time with MND Victoria.

In June 2008, when I commenced, the MND Victoria team comprised of seventeen staff; the CEO, Manager Fundraising, six MND Advisors, two staff each in the Equipment and Information Services, one in administration, coordination of volunteer programs and support services and me. During the financial year 2007-08, there were 131 new clients and the Support Services team provided care and support to approximately 400 people living with MND plus their families and friends.

Now, if you are interested, read on to learn about the 2018 story. MND Victoria today has 27 staff.

Twenty of those are in the Support Services Team and seven in Administration including the CEO, Manager Finance and Administration, two part time Administration Assistants, Manager Fundraising, Fundraising Officer and Digital Communications Officer.

Our Association has actively created a culture of care for all who are part of our community; clients, families, staff, volunteers, members, donors and health professionals. We continue to:

- be governed by a committed, knowledgeable and

supportive Board who take an active interest in the ongoing work of the Association

- have an experienced and skilled CEO with a passion to improve the well-being of people living with MND
- comprise a team of dedicated, accomplished, enthusiastic and passionate staff
- work in a bright and spacious building and within a culture of care
- benefit by the support of an extensive network of volunteers which underpins all of the Association's activities. There are approximately 130 registered volunteers working in support services, administration and fundraising.

During the past financial year, we worked with approximately 680 people living with MND, including 64 in Tasmania, plus their families, friends and health professionals. Approximately 260 of these people registered with us for support during 2017-18.

The Support Services team now has eleven MND Advisors, six working in the metro area, four working in regional Victoria and one in Tasmania. MND Advisors assist clients with pre-planning for participation in the NDIS and provide Coordination of Support when our clients obtain their NDIS plan. They make referrals to My Aged Care and provide information and training to health professionals.

MND Advisors work across the 79 local government areas in Victoria, 29 in Tasmania, which means they need to have local knowledge of each area to ensure they provide the best possible advice and information regarding the available services, and make the most appropriate referrals.

The three staff in the Equipment Team have organised the despatch of more than 2500 items this year whilst in 2007-08, 548 items were issued to clients. The stock held in our equipment service has significantly increased over these past 10 years with more than \$2 million invested into new equipment purchases.

Information provision is a highly valued component of our suite of services. However, with a much stronger emphasis on electronic mediums such as email, internet and social media, the method of access and dissemination has changed greatly over recent years. There are now less individual requests for information

via the telephone but many more hits on our website and followers of our social media platforms such as Facebook, Instagram and Twitter.

Volunteers continue to play a vital role within the organisation. In June 2008 there were 52 active volunteers with 8 new volunteers appointed during the year. In 2017-18 there are 130 active volunteers, 19 of these were recruited during the financial year. These volunteers provided 5,313 hours of service. If each hour of work is estimated @ \$25.00 the volunteer contribution to the Association, and hence to the well-being of people living with MND, is approximately \$133,000. Fabulous and fantastic!

To ensure that we keep up to date with community trends and the requirements of the Department of Health and Human Services, our investment in Quality continues to play a vital role in the provision of supports and services. It assists us to meet the expectations of our clients and provides a means of measuring the success of the programs. In 2009 we received our initial accreditation with the Department of Health and Human Services (DHHS) Standards and in June this year we successfully completed our fifth audit and now have accreditation with both DHHS and ISO 9001-2015 Standards.

Given the increase in the number of MND Advisors and to ensure they receive appropriate support in their roles, Eric Kelly and Elizabeth Crask, both MND Advisors, have been appointed to the new role of Team Leader MND Advisor/Support Coordinator. Both have a team of four Advisors and, whilst leading them, will continue to work with a number of clients.

Fran Hurst and Rachel Ritchie have recently joined the MND Advisor team. This has resulted in a reallocation of Regions to better serve our clients and staff. Clients affected by this have been notified. If you have any concerns please let me know.

(Photo: New MND Advisor Fran Hurst)



Photo: New MND Advisor Rachel Ritchie

We welcome Fran and Rachel to our team. Fran previously worked at the Austin Hospital in both palliative care and the Victorian Respiratory Support Service and Rachel in disability services at Yooralla. Both bring considerable experience and skills and I am confident will make a valuable contribution to our mission and outcomes for people living with MND.

Also Isabelle Lloyd, who has been working in a part time role with the admin team for about 12 months, has agreed to take on some extra hours in the Support Services Team. Isabelle has a psychology degree and will take over the duties that Ailish was undertaking during her social work placement and you may be speaking with her sometime soon regarding service provision.

In June we sadly farewelled Lesley Burcher after more than 20 years working as an MND Advisor. Lesley has

MND INFORMATION SESSIONS

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

At 7pm on Tuesday, 11 September at MND Victoria, 265 Canterbury Road, Canterbury.

Please RSVP by 5pm, Friday, 7 September.
Phone: (03) 9830 2122, 1800 806 632 or
Email: info@mnd.asn.au

The following session will be held on Wednesday, 24 October at 7pm in Canterbury.

made a significant and highly valued contribution to our work. Her skills, experience, care, warmth and sense of fun will be greatly missed by staff, colleagues and clients alike. We wish her much happiness in her future endeavours. *(Photo: Lesley Burcher)*



Last but by no means least, I am delighted to advise that Jo Whitehouse has been appointed the new Manager Support Services. Jo has considerable experience in the disability sector both here and in the UK working in senior roles within NDIA and MS and most recently with Younger People in Nursing Homes Alliance. Jo commences on 16 July so you will be hearing from her in the next newsletter.

Whilst it is reassuring and heartening that the Association has the resources to enable us to engage more staff and

acquire additional equipment to better support people living with MND, it is extremely disappointing that this remains necessary. Our vision is 'working towards a world without MND'. Once achieved, this will make organisations such as ours redundant. Unfortunately we are not there yet. However until there is a cure MND Victoria will continue to provide care.

In closing, I thank you all for your support and contributions to the work of the Support Services team. I am, and will remain, in awe and admiration of the resilience, spirit and strength of those living with MND. You and your families are amazing people, role models for others, who never give in, as MND Victoria won't give in until MND is no more. It is warming to know that since its creation by a small group of volunteers the Association has never lost sight of its roots and reason for being. The well being and quality of life of people with MND and their families and carers is central to all of our planning and programs and volunteers remain a vital part of the Association.

As always we welcome your feedback. Best wishes to you all, **Julie McConnell, Manager Support Services**

MORE ON RILUZOLE SIDE EFFECTS ...

I have just read the May/June Tasmanian and Victoria MND newsletters. A gentleman from Warrnambool wrote the story of his experience with the drug Riluzole. I would like to share my similar story.

I was diagnosed with Bulbar onset MND in June 2016. A few months later I started taking Riluzole. At the beginning of April this year I had surgery, and was in hospital for 4 days. During the routine observations my blood pressure was always normal, but my pulse rate was fast 120 - 130 per minute. I knew this was not normal for me but because no one said anything I just ignored it. I recovered quickly and well from the surgery.

In May I started to feel dizzy whenever I bent over, which is often, as I drop everything I touch, and have to bend over to pick it up. I also, out of the blue, became quite short of breath, and had to sit down after doing the smallest of chores. After the hospital episode I checked my pulse every now and again and it remained fast. After having had the symptoms for about a fortnight and thinking it was the progression of the MND, I got a

new box of Riluzole and for the first time there was an information leaflet included. I read the whole leaflet, when I got to the side-effects I found my symptoms among the long list named. As I know Riluzole is not a cure, but it MIGHT slow the progression of the disease by up to 3 months, I decided 3 months, does not mean that much in the great scheme of things, so I stopped the Riluzole.

After a few days the dizziness vanished, after a couple more days the shortness of breath was gone and a week later my pulse was back to its normal 78. I don't fall asleep through the day anymore, and am able to do all that I could before, and have energy left to go for walks.

PS.. I am not advocating that anyone should make decisions about changing their medication without consulting a doctor, but after being a Registered Nurse for 40 years, I have some idea, and did not think it would harm me!!!!

Karine Radcliffe, Burnie, Tasmania

MY MISSION ... TO CARE - MND WEEK 2018!

A HUGE thank you to everyone who took part in our MND Week challenge My Mission ... To Care. Together we raised \$7,540 to fund vital care and support for people living with motor neurone disease.

One STAR, seven year old Emily raised \$2,655 with the help of her friends, family and community ... here is the story her parents wrote to update her supporters along the way:

7 May (AM) ... So Em commenced her walking today and has walked 2kms to school. She was very excited to commence her walking for a great cause. Em was also very excited when her school friend joined her for support. Em will be wearing her blue cornflower all week to show a symbol of hope for people living with MND and will be accessorising in blue - as that is very important apparently!!!



7 May (PM) ... I have a very exhausted little girl after day one of her walking. She has set a very fast pace and has already covered over 5kms. 2kms to school, 5 laps of the school oval, and 2kms home from school.

Tomorrow Em will walk to school and she will also be competing in her school cross country and in the afternoon I might just have to drive her home!! She is very excited to be able to wear her MND shirt to school tomorrow.

8 May (AM) ... A very cheeky and energetic little girl on her walk to school today!! Good luck White House in the school cross country today and best of luck Em. Em is very proud to be wearing her MND shirt and Cornflower.



8 May (PM) ... Day two and Em has covered 9kms. Even though Em walked to school today she still managed to run her little legs off in the school cross country. Em came home with a first place in the girls grade 2 cross country and she finished 3rd if you include the boys. Top effort Em.



10 May ... After day 4 Em is still covering the kms very well. She has walked a total of 15kms so far. A big thank you to Em's school friend Rose for keeping Em company on her walks. It is also fantastic to see Em's school encouraging her and teachers offering to walk laps of the oval with her during lunch times.

Thank you again to each and every one of you for donating and supporting Em on her walk.

12 May (AM) ... So yesterday I didn't count the miles Em walked whilst at her horse competition although today was extremely special. Em's uncle was visiting and offered to go for a walk with Em to get some more kms on the board. Em's Uncle was so proud of her and it was such a special moment to witness.

Another 2kms down bringing the total to 17kms!



17 May ... A massive thanks to this amazing lady for helping Em to reach her goal of walking 36kms. Not only are you encouraging Em, you are also walking laps of the school oval during your lunch break with her.

With your help Em has walked over 25km so thank you



21 May ... Em would like to say a big Thank you to Briagolong and District Pony Club who have supported her in raising money for her walk. The Pony Club held a blue dress up rally to raise awareness and funds for MND. Members could give a gold coin for dressing up in blue and could also buy MND merchandise. Once again thank you to Briagolong and District Pony Club members for your support.

22 May ... I am very happy to report Em is smashing both her targets with kms and funds!!! Em has now walked over 30kms and on Monday the 28th May I would like to invite anyone wishing to show additional support to Em please come and join her walk her remaining kms. Please meet at our house at 3.45pm, Em will be doing half a lap around the redgum reserve, so it will be an easy walk, roughly 2kms. Come dressed in blue for a gold coin donation! Em started with a target of raising \$500 and after an overwhelming response and support we increased our target to \$1000. As Em's campaign is drawing to an end I am hoping she might be able to raise a few extra dollars and reach \$1500. Best of luck in your final days Em, you have been an amazing young girl during this campaign and I will be forever grateful.



25 May ... Emily was super excited to have her Aunty and Cousin come out for a walk around the redgums on Wednesday after school.

Emily and Gracie had so much fun walking together and chatting the entire 3.2kms...

Thanks again so much Aunty Kel and Gracie.

28 May ... So Emily has finally finished her campaign 'my mission to care' and has walked 36kms. This campaign is raising awareness and funds for Motor Neurone Disease (MND) which is a disease that is hereditary to my family. The 36kms represents the number of people in our area who have MND. Words can't explain how grateful I am to my daughter Emily who has taken part in this campaign at such a young age, as I am currently injured.

A massive thanks to all those wonderful people who helped Em walk her final kms after school today. Also to the many sponsors who have helped Em reach over and above all the donation expectations we had! We were happy just to reach \$500 but to have raised over \$1600 is just humbling - we are so extremely grateful to everyone who donated.

Another thank you to Briagolong Primary School for the continued support they have shown Emily. Today the entire school walked around the oval with Em for her last day. Also on a Tuesday and Thursday lunch time the school would encourage kids to walk laps with Em. This support is very much appreciated so thank you. Em was also very excited when the principal agreed to let her wear her MND shirt again to school today for her last walking day.

Thank you also to Emily's best friend Rose. Rose rode her bike to and from school with Em and would quite often have to pedal very slow as Em's legs couldn't go as quick as the bike. Thank you again xoxoxoxo



AN ODE TO MND

By Joy Blakeley

I cannot walk, talk, write

Or feed myself

I can't do many things

And excess saliva is a pain!

After over 75 years of being able

I'd love to scratch

An itchy spot if able!

When I go to bed at night

I'm grateful that I haven't fallen

Bed is great, the only challenge is

I can't turn over when I want!

I have a lovely lady

To clean and dress me

And do my makeup

And hubby/carer attends

To my other personal needs!

I felt very self conscious

When having to use

A walking stick, then a walker

But now I wouldn't survive

Without my loaned wheelchair!

Family, friends, MND,

Calvary Care and local

Community health services

Offer great support

So life goes on

But one doesn't know

For how long!



WRITE YOUR MND STORY

We'd love you to share your MND story, poetry, or tips and tricks for making life with MND a little easier.

Please email your text and a photo to: info@mnd.asn.au by 5 September for our next edition.

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.

Our next six week Living Well program is starting on Friday 10 August and will be held every Friday until 21 September (except Friday, 31 August).

Please contact our Information team: 03 9830 2122 or info@mnd.asn.au to find out more or register.

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 on 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" or visit: <https://www.facebook.com/groups/1408400102747388>

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" or visit: <https://www.facebook.com/groups/1512117609036086>

Kennedy's Disease Facebook Group

Did you know that MND Victoria also provides support for 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 each other out: <https://www.facebook.com/groups/340781642962036/>

Support services for carers of people with MND

Carers Victoria— 1800 242 636
www.carersvictoria.org.au

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

CareSearch— (08) 7221 8233
www.caresearch.com.au

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

MND Victoria—1800 806 632
www.mnd.asn.au

SPOTLIGHT ON WOMEN AND UNPAID CARE

By Women's Health Victoria

Women's unpaid care work makes a huge contribution to the economy and the wellbeing of families and communities. Despite our society's reliance on it, women's unpaid care work is often taken for granted because of the expectation that unpaid care is naturally or traditionally women's responsibility, and not really 'work'.

In Australia, it is more common for women to provide care in all age groups between the ages of 18-74. Women are also more likely than men to have care responsibilities involving greater time and intensity. In Victoria, 71% of all primary carers (defined as carers who provide the majority of the ongoing informal assistance to a person with a disability) are women. Half of all Victorian carers take on a caring role because they believe they can provide better care than available services, and 35% of primary carers spend on average 40 hours or more per week providing care.

The undervaluing of women's unpaid care work is linked to poorer health and wellbeing outcomes for carers and limits women's participation in the paid workforce. It is also related to the undervaluing of paid work in care-related or 'feminised' industries, such as child care and community services. Carers are likely to accrue little or no superannuation because of lowered participation in paid work and reliance on income support. This impacts the ability of carers to fund their own retirement or future care needs.

Improving the suitability of, and confidence in, social supports and services for people who require care would improve the circumstances, health and wellbeing of women in unpaid care roles. Also important is the need to transform gendered norms so that unpaid care work is shared more equitably between women and men.

Read the full report at: http://whv.org.au/static/files/assets/ba8dd6fd/Spotlight-on-Women-and-unpaid-care_June-2018.pdf

VOLUNTEER NEWS!



By Deb Olive, Coordinator Volunteer Programs

MND volunteers provide incredible support for people living with MND and their families, to the day to day work of the organisation and to promote MND awareness, community engagement and support.

Why do people go out of their way to volunteer with organisations such as MND? Often there is a personal connection and a commitment by those who have been impacted by MND to make a difference or to 'give back' to the community.

When working with our volunteers or talking with people who are interested in becoming volunteers I regularly mention that volunteering is a two-way process. Volunteering is about giving, and it is also about volunteers gaining something from the experience in return.

Studies have shown that, in addition to significant benefits to the Australian community and economy, volunteering can provide benefits to the individuals who volunteer including giving a sense of self-worth, improved mood and outlook, regular social connection with others, health benefits, opportunities to share and develop skills and creating work-life balance.

As you engage with your community through volunteering I encourage you to consider what you have to offer as a volunteer and also what volunteering offers you.

During National Volunteer Week we asked a number of our volunteers what volunteering means to them.

Here are some of their responses:

1. **Vital**
Organised
Lovely
Unique
Nurturing
Talented
Enthusiastic
Enduring
Reliable



That's what a volunteer is!

2. My volunteering has given me a great deal of satisfaction. I have learnt new skills and best of all, have met so many beautiful people – volunteers are special people and I am proud to contribute to MND Victoria.

3. My volunteering has Enriched my life.

4. It has given me friends, fun and the pleasure of playing a small part in supporting people living with MND.

5. My volunteering has opened my world to meeting amazing people.

6. Given me the opportunity to do things I never would have experienced.

7. My volunteering has given my life another sphere. It has shown me the strength of those who suffer, the love and strength of families who support them.

8. My volunteering has been more rewarding than I could have imagined.

Vale

We are sad to receive the news that Irene McInerney, one of our long-term volunteers, died early in July. Known for her quiet commitment and determination to promoting the needs of people with MND, Irene gave her time to MND Victoria for more than fourteen years.



Irene lived in Bendigo and was actively involved with the MND Bendigo Support Group and as Treasurer of this group until it finished up three years ago.

Over many years, Irene was committed to the cork collection and recycling fundraiser which was an iconic part of MND Victoria. Irene was well known by the owners of Bendigo cafes and bars as she regularly encouraged them to save corks. Irene then collected, sorted and prepared the corks for transport to Melbourne. Eric Kelly, our local MND Advisor recalls he transported carloads of corks - corks by the millions - collected by Irene, to Melbourne.

Always involved, Irene assisted at many MND Bendigo walks and local fundraisers. Irene is remembered fondly by all who had the opportunity to know and work alongside her. MND Victoria is grateful for her service. Our thoughts are with Irene's family and friends.

VOLUNTEER OPPORTUNITIES

Massage Volunteers – Watsonia, Bundoora, Lalor, South Morang

Massage volunteers provide hand and foot massage to assist with relaxation and comfort for people living with MND. We currently need volunteers around the areas above.

Time required: 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 or visit on a more 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.

Hairdresser – Northern Suburbs

We are seeking an experienced hairdresser to visit clients living in the northern suburbs of Melbourne. Volunteer hairdressers provide a client with MND with a trim in the comfort of their own home. This role is suitable for a qualified hairdresser with their own equipment and will involve travel within the area.

Time required: appointments will be coordinated with the client and volunteer to suit their needs and availability.

For more information about either of these roles or other opportunities to volunteer with MND Victoria, please contact Deb, phone: (03) 9830 2122 or email: dolive@mnd.asn.au

OUR HOODIE TRAVELS!

Our #NeverGiveUp hoodies are popping up all over the globe, raising awareness wherever they go! Most recently they were spotted in London and previously at the World Cup Soccer in Russia ...



RESEARCH UPDATE



Appetite and MND

By Dr Frederik Steyn, Postdoctoral Research Fellow, University of Queensland Centre for Clinical Research, Faculty of Medicine

Appetite is a complex behaviour that is defined by our desire and our capacity to consume energy. While we tend to only think of appetite as our desire for food, it is important to know that internal and external factors can greatly impact appetite – these factors include our biology and our physical capacity to access food. Changes in appetite are documented in people with neurodegenerative diseases such as Alzheimer's, Huntington's, and Parkinson's disease, and in people with frontotemporal dementia.

Loss of appetite is often reported in MND¹ and can be part of the many complex and sometimes distressing changes that people experience. At the University of Queensland Centre for Clinical Research, the focus of my studies is to increase our understanding of why people with MND might lose their appetite. We hope to improve our understanding of how and why loss of appetite impacts quality of life, disease progression and survival.

When approaching studies on appetite, it is important to recognise that many factors might influence how people with MND might feel about food, and why their capacity to consume calories is limited². For 25 to 35% of people, bulbar symptoms are the first signs of MND and can potentially be the first cause for

loss of appetite. As muscles in the throat and mouth weaken, people start to experience difficulties in swallowing (dysphagia). It is thought that up to 75% of people with MND experience changes in swallowing. Because of this, impairment of the muscles needed for swallowing is thought to be a major cause for loss of appetite in MND. In fact, those with bulbar symptoms report delayed meal times, loss of pleasure associated with eating, loss of the social aspects of eating, and fear of choking.

Many of the people we see during our research report loss of appetite in the absence of bulbar symptoms. To me, these reports highlighted the complexities of loss of appetite for those living with MND. In some cases, loss of appetite is associated with a change in taste. Indeed, reduced taste (hypogeusia) is not uncommon in people with MND, and it is thought to occur due to altered function of the taste buds on the tongue³. There is also evidence that taste preferences can change in MND, a phenomenon that is thought to involve higher brain areas that regulate behaviour and thinking. Some people find that fatigue (a very common feature of MND) can make meal times exhausting. This can be compounded by weakening of muscles that are needed to prepare food, or muscles needed to bring food to the mouth. At the same time, prolonged periods of sitting might contribute to gastric discomfort, and many patients report constipation. Altogether, these factors can greatly impact desire to eat.

More recently our attention has turned to the biology of eating, and in particular the physiological processes that promote energy use and energy intake. Working with Dr Shyuan Ngo at the Australian Institute for Bioengineering and Nanotechnology at the University of Queensland, we are conducting studies on energy use in MND. In these studies, we expected to see greater weight loss in MND patients who undergo an increase in their resting energy use, which accounts for roughly 70% of the energy that our bodies consume over the day. While we found that MND patients were five times more likely to have an increase in resting energy use when compared to people who do not have MND, this increase in energy use did not universally contribute to weight loss. Rather, we found that weight loss occurred in individuals who were unable to adjust their food intake to meet their energy needs. From a

physiological perspective, our results point to potential changes in the homeostatic processes in the body that control our energy intake relative to our energy needs. These processes are hardwired in a part of the brain called the hypothalamus. Cells in the hypothalamus receive signals from the body (including hormones from the gut and our fat cells) to inform the brain of our overall energy status. In turn, the hypothalamus directs signals to the rest of the brain to promote or diminish our desire to eat. Thus, weight loss in MND might be due to an inability for the brain to recognise or respond to changes in energy needs.

Researchers abroad found that atrophy of the hypothalamus occurs in MND, and that the degree of atrophy is associated with lower body mass index (a rough measure of fatness). Hypothalamic atrophy was also seen in asymptomatic patients who carried a gene known to cause MND⁴. Collectively, these observations would suggest that, for some patients, changes in appetite (even prior to the development of MND) might originate from the hypothalamus. With support from Wesley Medical Research, and the Faculty of Medicine at the University of Queensland, we are now conducting the first set of a series of studies to test this hypothesis. Imaging studies at the Herston Imaging Research Facility in Brisbane will allow us to look at the structure and the function of the hypothalamus in controlling energy use and appetite. Working with Dr Christine Guo at the Queensland Institute for Medical Research, we are looking at the brain as a whole, and in particular the complex wiring that guides perception and pleasure derived from food.

With support from the MNDRIA, we are also testing if there is a change in the release of factors from the body that control how the brain responds to food. This ties in closely with some of our earlier work, as we were one of the first groups to report a reduction in the release of a key hormone involved in promoting hunger in MND⁵.

By conducting these studies, we hope to uncover how MND might affect areas of the brain that are involved in regulating behaviours

around food, and how these brain areas can be targeted to improve quality and duration of life for those living with MND. To help understand the complexities of appetite control, we are working with colleagues across the University of Queensland, including a neuropsychology team led by A/Prof Gail Robinson (UQ School of Psychology) and research dietitians directed by Dr Veronique Chachay (UQ School of Human Movement and Nutrition Sciences). It is through this multidisciplinary approach that we hope to make sense of the variability of MND. In many ways, our approach to research is inspired by what we see in the clinic. Working in close collaboration with neurologists at the Royal Brisbane and Women's Hospital, I have come to recognise the importance of multidisciplinary care as a model for improved outcomes for those living with MND. In the context of appetite, this includes engagement with dietitians. In time, I am hopeful that our research will inform care specialists of the causes for loss of appetite in MND, while leading to the development of strategies to overcome this.

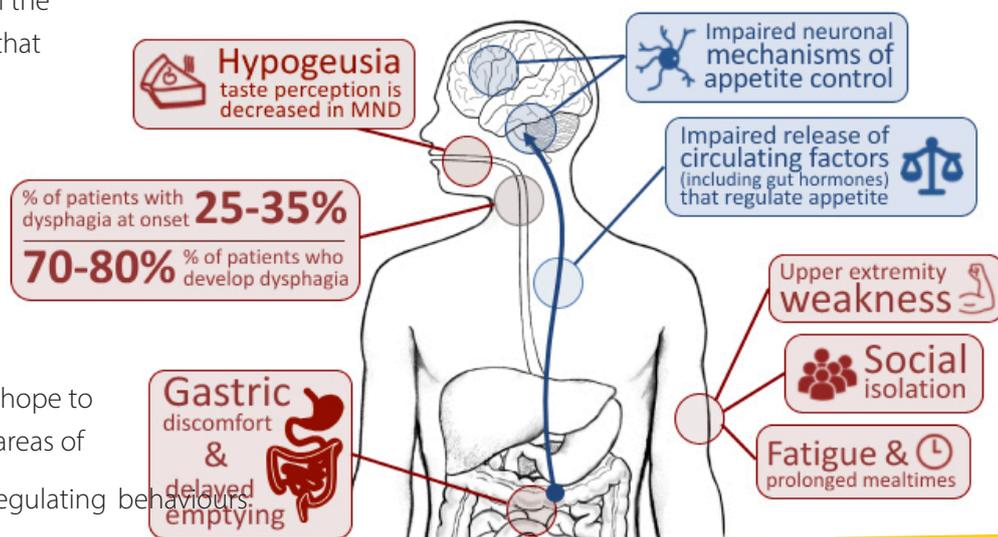
¹ Holm, T. et al. Severe loss of appetite in amyotrophic lateral sclerosis patients: online self-assessment study. *Interact J Med Res* 2, e8 (2013).

² Ngo, S.T. et al. Exploring targets and therapies for amyotrophic lateral sclerosis: current insights into dietary interventions. *Degenerative Neurological and Neuromuscular Disease* 7, 95-108 (2017).

³ Pelletier, C.A. et al. Is Taste Altered in Patients with ALS? *Chemosensory Perception* 6, 101- 107 (2013).

⁴ Gorges, M. et al. Hypothalamic atrophy is related to body mass index and age at onset in amyotrophic lateral sclerosis. *J Neurol Neurosurg Psychiatry* 88, 1033-1041 (2017).

⁵ Ngo, S.T. et al. Altered expression of metabolic proteins and adipokines in patients with amyotrophic lateral sclerosis. *J Neurol Sci* 357, 22-7 (2015).



\$426,700 INVESTED INTO MND RESEARCH!

Thanks to our incredible supporters, we've invested \$426,700 into MND research in the past financial year!

YOU have made this possible... whether you've attended a Walk to D'feet MND, the Benalla Act to D'feet MND, Rock Off MND or the Superball, if you've fundraised for us or made a direct donation to MND Victoria - thank you so much.

These research grants will be awarded in November 2018 by MND Australia for research to be undertaken in 2019.

Until MND researchers find cause, treatment and cure for MND, we will continue to provide the best possible care and support for people with motor neurone disease.

HOW CAN I HELP MND RESEARCH?

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.

Participate in Familial MND research

Professor Garth Nicholson and his research team based at the ANZAC Research Institute, Concord Hospital Sydney, are studying gene variations in familial motor neurone disease. Professor Nicholson and his collaborators are keen to obtain DNA samples from patients with familial motor neurone disease.

To assist this research, a single blood sample is required together with your consent to take part in the research and, where necessary, your permission to obtain a copy of clinical information from your treating physician. The blood sample can be taken locally and then sent to Sydney for analysis. If you are interested in donating, then phone (02) 9767 6796 or email molmed@med.usyd.edu.au for further details.

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 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

Join the Australian Motor Neurone Disease Registry

The MND Registry is an ambitious project to register and collect data from every person diagnosed with MND in Australia. It contains de-identified data from people diagnosed with MND including information about the diagnosis, symptoms, treatment and management. This information is made available to researchers studying MND. The MND Registry provides people living with MND with an opportunity to actively contribute to research and learn more about the disease. The participant's neurologist will fill out a case report form detailing the treatment and health situation at the time of the visit. There are no extra tests, procedures or treatments involved. People are free to decline or to withdraw from the study at any time.

If you would like any further information concerning this project please visit: www.mndregistry.org.au or contact Anna Smith by phone: 03 9595 3355 or by email: anna.smith@calvarycare.org.au



My Health Record

"My Health Record" is an online summary of a person's healthcare information. It can contain:

- A list of dispensed medicines
- A shared health summary from GPs
- Uploaded letters from specialists
- Hospital discharge summaries
- Reports from tests and scans
- Referral letters from doctors.

When will this occur?

By the end of 2018, every Australian will be given a My Health Record unless they choose not to have one. People who do not want a My Health Record need to tell the government between 16 July and 15 October that they don't want one.

They can do this by phone or via the MHR website. More information can be found at www.myhealthrecord.gov.au In some situations, a form can be completed to opt out of My Health Record.

Benefits for people with MND

For people living with MND, having a My Health Record means they can keep all their information in one online

location and, depending on their health, can access it on their smart phone or a computer wherever they are and at any time. They don't have to remember everything, nor do they have to repeat their health history each time they see a healthcare provider. They can access their organ donor decision, immunisation register, and allergy information with ease and simplicity.

Benefits for people caring for someone with MND

For carers of someone with MND, My Health Record is ideal because carers, for example family members, can become authorised representatives or nominated representatives and access the My Health Record of the person they are caring for. This is convenient and easy and means that different family members can share the care of the person with MND. Contact numbers and emergency details can be added to a person's My Health Record.

Privacy safeguards

My Health Record has strong safeguards to protect privacy and misuse. These safeguards include encryption, firewalls, secure logins, authentication mechanisms and audit logging. There are strict rules about who can access a person's My Health Record.

More information

Please access www.myhealthrecord.gov.au for more information.

LINDSAY'S BIG CHOP!

Lindsay Grey is from Yendon, a tiny town south east of Ballarat with a population of around 300. Lindsay lost his wife, Rosie, to motor neurone disease and he wanted to do something to honour her. He doesn't use a mobile phone or computer so we had the pleasure of receiving a couple of hand written notes from Lindsay outlining what he plans to do to fundraise for MND Victoria.

Lindsay is well known for his long and rugged beard and hair which hadn't been cut for many years... He decided this was a perfect opportunity to get a few donations

from friends and family. On a Saturday afternoon in the carpark at the local park, a small crowd gathered to watch Lindsay's beard and hair disappear. A few donations turned into over 100 with a total close to \$9000 being raised. It is fair to say that this will go down as the most famous haircut Yendon has ever seen!



FUNDRAISING



- *At last an organisation which understands my condition and needs*
- *It's the understanding, knowing that when I phone you, MND Victoria always understands what it is that we are feeling, or what it is that we are needing, you just understand.*

(Clients commenting on MND Victoria's services).

It has been another busy year and I'm happy to report that we have once more raised \$3,072,550 of the \$4,555,555 required to underwrite the cost of service delivery including equipment purchase and maintenance. And while this is a good result, it is due in large part to the increased income from Trusts and Foundations and our Walk to D'feet events.

We are concerned that fewer people are nominating MND Victoria as the recipient of their fundraising activities resulting in a loss of income from these events.

As I have highlighted in previous newsletters the Association receives only between 25-30% government funding and the remaining 70-75% must come from our fundraising activities.

If you are currently living with MND or have been impacted by the disease in past years you know just how quality of life is improved because of access to the right equipment, at the right time, and at no cost to the person with MND.

Ten frequently asked questions about fundraising/donations

1. I've never done any fundraising and don't know how to get started. What can I do? There are many ways you can raise funds, from something as simple as holding a Drink Tea for MND at your work/school to organising a ball – and everything in between. The Fundraising Team at MND Victoria is ready to help! We love to support people who care enough to help people living with MND. We can provide advice on setting up a MyCause Fundraising page; how to set up a Facebook Events page; how to promote your event to your local community. We can also help find volunteers if you need them and provide Public Liability Insurance coverage for those volunteering at the event. This is just a taste of how we can support your efforts.

2. I like taking part in challenge events, can I raise funds for MND Victoria this way? Absolutely! Most Challenge Events encourage fundraising as part of the activity. Once you register for a challenge event such as Stadium Stomp, Run Melbourne, Melbourne Marathon or any other event, just contact us and we can help you set up your MyCause fundraising page. We are also happy to provide you with an MND Victoria Singlet to wear while training and on the day of the event. PLUS MND Victoria has an annual Challenge Event such as Trek Kokoda 2018 where you can participate and raise funds, or support those already taking part. Check out our fundraising page at <https://www.mycase.com.au/events/kokodamndvic>

3. I've taken part in MND Walk to D'Feet events in the past. Is paying the registration fee enough or should I fundraise too? Am I able to start a Walk where I live and if so how do I do this? Registration fees do help with our fundraising, but a portion of the fees are used to underwrite the cost of running the event. The Walks are the biggest single fundraising activity sponsored by the Association and it is vital we continue to increase the dollars raised if we are to fund new equipment purchases, underwrite MND Advisor services and help fund research into cause, treatment and cure. So we encourage everyone to put together as big a team as possible and set a challenging fund raising goal. In 2017/18 Walk events took place in Lakes Entrance, Rosebud, Melbourne, Benalla, Bendigo, Geelong, and Violet Town. We're pleased to welcome Echuca to the

Walk to D'Feet MND program and encourage anyone who wants to run a Walk in their area to contact the Fundraising Team at fundraising@mnd.asn.au We will provide you with a "How To Run a Walk" pack and as much guidance, mentoring and support as you need to run a successful event.

4. Can people donate monies to MND Victoria instead of giving me a birthday / wedding / Christmas gift, and if so what's the best way to do this? This is a great way to acknowledge and honour someone you love who is living with or has died from MND. The easiest way to do this is via a MyCause page which you can use to explain why you are raising funds, invite your family and friends to support your efforts and, best of all, everyone who donates gets an automatically generated tax receipt thus taking the hard work away from you.

5. How do I know the monies I raise will go to help someone living with MND rather than just administration / salaries? In the past there has been negative publicity regarding some not for profit organisations who spend most of their fundraising dollars on administration, salaries, cars etc. At MND Victoria we are proud of how we manage our expenses and can confirm that \$0.75 of every \$1 is used to deliver care and support services. This is well within the industry guidelines.

6. I'd like to give a donation regularly and wonder if you can accommodate this? The Association does have a regular giving program and we also participate in Workplace Giving programs through such platforms as Good2Give. Regular Giving is very beneficial to the Association as we incorporate these donations into the budget enabling better decision making on equipment purchases and other expense items. Regular Giving via Workplace Giving has the advantage that the donor gets some tax relief through their donation coming out of gross wages and in some instances employers match employee giving. For more information on Regular Giving / Workplace Giving please contact the Fundraising Team: fundraising@mnd.asn.au

7. I'm about to organise my Will. If I leave a Bequest to MND Victoria how will this be used? The Association implemented the Care Foundation in 2000 and all Bequests are deposited into this account. Investment income from the Care Foundation is used to purchase

equipment and underwrite programs that enhance our delivery of care and support. The Care Foundation ensures that, in the event of a downturn in giving, there are sufficient funds to continue delivering services and people with MND will not be impacted.

8. MND has impacted several generations of my family. If I participate in fundraising or give a donation, can I nominate the funds be used specifically for research?

Although the main mission of MND Victoria is to provide and promote the best possible care and support to people living with MND we also fund research. In fact the Association has been funding research since 1985. It is because of this ongoing funding that such great strides have been made in identifying potential causes and treatment. The Association funds the best of the best Australian researchers through the MND Research Institute of Australia.

9. Mysporting club/school/service club has nominated MND to be the recipient of their fundraising. Why does it matter if these funds go to FightMND or MND Australia rather than MND Victoria, isn't it all the same cause?

a. Yes it's the same disease, but No it's not the same cause! MND Victoria's main mission and goal is to provide and promote care and support to people living with MND today, tomorrow and until a cure is found. Last year alone, the funds raised for MND Victoria enabled us to deliver services to 575 people living with MND, deliver 1,644 pieces of assistive technology devices to 340 new clients – all at NO COST to the person with MND. Without access to these services many people with MND, particularly those aged over 65 when diagnosed, would have the added stress of how to manage their disease, how to continue living in their own home, how to cover the huge financial burden associated with their high care needs or, even worse, be forced to live in a nursing home. Ask anyone living with MND how important it is to access these services and you're likely to be told:

i. "(MND Advisor) has been brilliant from the start. I would have been lost without them."

ii. "The accessibility of equipment has helped to alleviate a lot of stress for myself and my family."

iii. "Her understanding of MND is vital in assisting us to make the correct decisions both for now and the future"

b. MND Australia and FightMND mostly raise funds for **research** into cause, treatment and cure. We recognise this is very important and their efforts are to be commended.

c. It is vital that potential fundraisers and people currently living with MND and receiving services from the Association realise the difference between the “causes” and the need to raise funds for MND Victoria if we are to continue to deliver the care and support services so vitally needed by someone living with MND.

10. Are there any other ways to raise funds for MND Victoria?

MND Victoria has some great merchandise that you can purchase from our website www.mnd.asn.au/gear or by calling the office and placing your order. By purchasing

our merchandise you can show your support for people living with MND knowing that all profits are used for service delivery.

All of us at MND Victoria would love to see the day when there is a cure for MND, and we can close up shop and go home. But until that day we will do everything we possibly can to support those living with the disease today.

So thank you very much if you supported one or more of our Fundraising activities last year. Can I please encourage you to continue supporting MND Victoria this year because Until there's a Cure ... there's Care.

Kathy Nightingale, Manager Fundraising

COMMUNITY FUNDRAISING EVENTS

Harry's fundraising in Lang Lang

By Amanda Brian

My two boys Marcus (10 years old) and Harry (8 years old) unfortunately lost their nana to MND in April 2018. Nana was only diagnosed 8 months earlier.

The boys didn't really understand what was going on. It wasn't until Nana's passing that Harry suggested doing a fundraiser for MND. Harry approached his school Principal who agreed to do a gold coin donation free dress day at school. Harry asked if the students could come to school dressed in blue from head to toe as MND affects people from head to toe. The blue MND Day was Wednesday 20th June. Harry did a speech at school assembly telling everyone what MND was and how they can help. He told the teachers and students how fundraising can help find a cure.

In the meantime I contacted MND Victoria about Harry selling merchandise to raise money. Harry sat at the local bakery from 9am-3pm on Saturday the 16th and sold over \$700 worth and with back orders. Harry

was then asked to go back the following Saturday. Harry's fundraising was mentioned on the Lang Lang notice board where he received over 180 likes. Harry also had some people asking where to donate online. Harry's grandad matched Harry's sales from Saturday and donated \$900! When Harry's fundraiser reaches his target we will tip a bucket of ice on him as that's what he would love to do for his nana!

Harry at the Lang Lang bakery (left) Marcus + Harry (right):



NEW! BLUE CORNFLOWER JEWELLERY

We are super excited to launch our new Blue Cornflower Jewellery range!

The silver earrings and pendants are \$29 each and the keyrings (not pictured), available in silver or black are \$19 each.

Check them out in our MyCause store:

www.mnd.asn.au/gear

Or phone: 03 9830 2122 to order!



>> NEW STUBBY HOLDER DESIGN >>

Our all new design #NeverGiveUp MND Victoria stubby holders are perfect for your spring BBQ ...

At only \$10 each, why not grab one for each of your mates?

Check out our new stubby holders and all of our other MND gear at:

www.mnd.asn.au/gear

Or phone: 03 9830 2122

Can you convince your local pub to stock our stubby holders? Give Daniel a call on: 03 9830 2122 to organise a bulk order!

EVERY purchase supports people living with motor neurone disease and funds MND research.

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



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

WARRAGUL'S BIG MILK FREEZE!

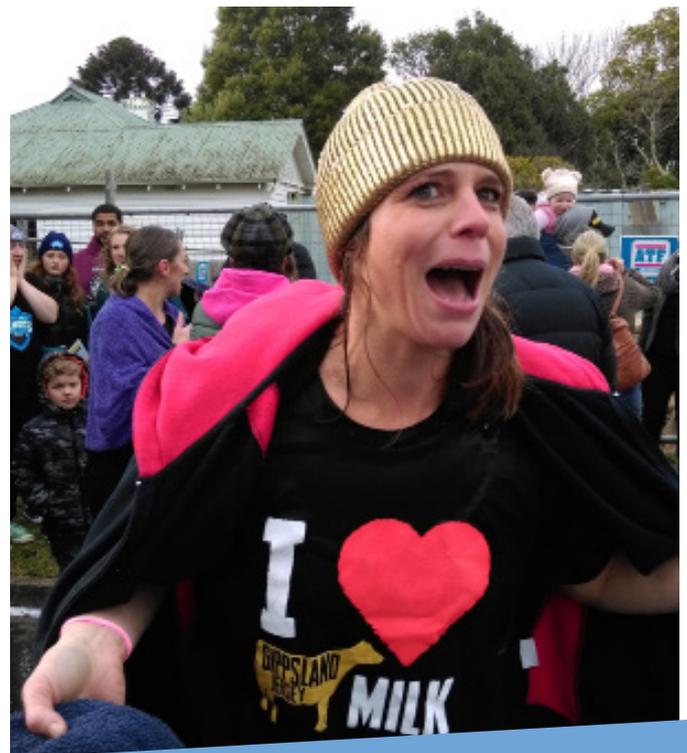
For the second year in a row, Sallie Jones, who owns Gippsland Jersey, created a Big Milk Freeze to raise funds in honour of long-time friend Wendy Gillham who had motor neurone disease. Wendy was the centrepiece of the event last year, having buckets of icy milk poured over her from the back of a truck. This year, she wasn't well enough to participate but she was delighted it was happening again. We were very saddened to hear that Wendy died in early July, shortly after this event took place. Our thoughts are with Wendy's family and community at this time.

This year's event was hosted by Warragul Farmers Market on a very cold and grey Saturday morning in

June. The weather certainly didn't deter the locals with an incredible amount of support from the surrounding community.

Last year there was icy milk in buckets, this year there was snow that had been brought down from Mount Baw Baw and a small amount of milk placed in a tractor loader. This was tipped over a number of very brave participants. Donations came from everywhere for those willing to be saturated in freezing milky snow.

Through the generosity of so many, close to \$7500 was raised. We thank everyone who helped make this a huge success!



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 and photo to: info@mnd.asn.au by 9 September for the next edition, to be mailed on 2 October 2018.

DONATIONS WERE RECEIVED ... THANK YOU!

In memory of

Dot Dickson
Brian Kane
Bruce Peucker
Christine Handson
Ian Aitken
Patricia Balsillie
Serge Liberman
Margaret Lyons
Margaret Seller
Johanne Yianni
Peter Patti
Anne Jennifer Cowie
John McIntosh
Christopher de Kretser
Ron Godfrey
Joy Iggulden
Tony Page
John Naarden
Kathleen McDonnell
John Ryan
John Winstanley
Anne Di Nardo
Leslie Lord
Flo Troeth
Nicole Hall
Ciro Gualano
Pamela Davidson
Ken Davis
Michael Sibly
Nola Kirwood
Ron Boyd
Kumara Tennakoon
Peter Miller
Jeff Renkin
Heather Thompson
Ronald McCann
Donald George Bausch
Panagiotious Papoutsis

Dennis
Daryl Lacey
John Brick
Kumara Tennakoon

Research in Memory

Bob Martin
Rod Crook
Philip Gulle

Trusts

Dimmick Charitable Trust
GW Vowell Foundation Ltd
The Mulgrew Family Endowment
The Dawn Wade Foundation

Bequests

Estate of Daniel John O'Callaghan
Estate of Cliff Prowse
Estate of Bruce Angus Marston
Estate of Peter Ryall
Estate of James Holt
Estate of Kevin Leslie Howard

Clubs

Ivanhoe Bowling Club
Lions Club of Blackburn North
Midlands Golf Bowls Club Inc.
Lions Club of Leopold Inc.
Mornington Lions Club Inc.
Broadford Lions Club Inc.
The Heidelberg Over 50s Dance Group

Lioness Club of Berwick
Vermont Lions
Sportsmens Association of Australia- Ballarat Branch

Blue Hills Rise Singles Group
Ballarat Woodworkers Guild

Gisborne and District Bowling Club Inc

Numurkah Lions Club
Inner Wheel Club of Bendigo

South Barwon Football & Netball Club

Nambrok Cricket Club
Vietnam Veterans Association Victoria- Wimmera Branch

Westvale Men's Shed
Wodonga Raiders

Orbost Croquet Club
Golden Girls Golfing Group

The Dendy Icebergers

Schools

Wonthaggi Secondary College

Ferny Creek Primary School

Springside P-9 College

Lang Lang Primary School

Drouin West Primary School

Kent Park Primary School

Organisations

All Souls Opportunity Shop
Lodge of Euclid

Torquay Pharmacy

Botanic Gardens Retirement Village

Chapter 3 Espresso & Bar

The Phoenix Hotel

Doposcuola Teachers

Victorian Association of Teachers of Italian

Churches

Swan Hill Parish Centre

Corporate

Magistrates Court of Victoria

Associated Concepts Pty Ltd.

Trevor Weichmann & Associates Pty Ltd

Central University of Queensland

Coles Bay Holidays Pty Ltd.

Bellarine Community Health Limited

InterRisk Australia Pty Ltd.

Bank of Melbourne

U3A Moonee Valley

Qenos Pty Ltd

Edgewise Insurance Pty Ltd.



Thank you all so much for your support of the 440 Victorians with motor neurone disease!

GET INVOLVED IN AN EVENT NEAR YOU!

Date	Event	Contact
Friday, 10 August 2018	Living Well Group begins, Canterbury	Email: info@mnd.asn.au
Friday, 17 August 2018	Heathcote Golf Club Awareness Dinner	Email: dwoodrow@mnd.asn.au
27 August - 5 September 2018	Kokoda Trail - Challenge Event	Email: dwoodrow@mnd.asn.au
30-31 August 2018	9th National MND Conference	Email: info@mnd.asn.au
Tuesday, 11 September 2018	MND Information Session	Email: info@mnd.asn.au
12-16 September 2018	Wangaratta to Melbourne Run	Email: dwoodrow@mnd.asn.au
Saturday, 6 October 2018	Daylesford Dunking Derby	Email: dwoodrow@mnd.asn.au
Monday, 15 October 2018	MND Victoria AGM	Email: info@mnd.asn.au
Saturday, 20 October 2018	Cox's Bridge to Cox's Place Cycle	Email: dwoodrow@mnd.asn.au
Sat/Sun, 20-21 October 2018	Tough Mudder	Email: dwoodrow@mnd.asn.au
Wednesday, 24 October 2018	MND Information Session	Email: info@mnd.asn.au
Sunday, 4 November 2018	Village Glen Walk to D'feet MND	Email: fundraising@mnd.asn.au
Saturday, 10 November 2018	Show 'n' Shine Movie Night	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
Sunday, 2 December 2018	Echuca Walk to D'feet MND	Email: fundraising@mnd.asn.au
Thursday, 6 December 2018	MND Information Session	Email: info@mnd.asn.au

For further information and the latest events list, please visit our website at: 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