MND NEWS

September/October

2020

The newsletter of the
Motor Neurone Disease
Association of Victoria

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

WALK TO D'FEET MND

TOUR OF VICTORIA

mnd Victoria

STATE COUNCIL

David Lamperd
—President

Katharine Barnett
—Vice President

Jeremy Urbach
—Hon. Treasurer

David Ali

Duncan Bayly

Christopher Beeny

Barry Gunning

Jodie Harrison-Fitzgerald

Angeline Kuek

Wayne Pfeiffer

Napier Thomson

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

MND Victoria Support Groups provide opportunities for people living with MND, their carers, and interested members of the public, to come together on a regular basis. For information about Support Groups, contact MND Victoria, phone: 1800 806 632 or **info@mnd.asn.au.**

Support Group Meetings:

Western Metro: Last Monday of each month at 12.30 in Footscray.
Coordinator – Christine Robson

Barwon Region: First Monday every second month at 12 noon
Coordinator – Ian Parton

Ballarat Region: Last Friday of each month at 1pm
Coordinator – Bev Phillips

Hoppers Crossing Area: Meet every 4 weeks on Thursday at 1pm
Coordinator – Leanne Dewhurst

Bendigo Area: Meet once a month on a Thursday from 11.30am to 3pm. Coordinator – Carolyn Hutchinson-Kane

STAFF

Chief Executive Officer: Kate Johnson

Manager Finance & Administration: Megan Crellin

Administration Assistants: Isabelle Lloyd, Rebecca Moussa

Manager Special Projects: Kathy Nightingale

Manager Supporter Development & Communications:
Daniel Woodrow

Communications & Fundraising Officer: Steph Cross

Manager Support Services: Jo Whitehouse

Team Leader MND Advisor/Support Coordinators:

Elizabeth Crask, Eric Kelly

MND Advisors/Support Coordinators:

Ruth McEvoy
Trish Duffy
Fran Hurst
Lesley Burcher
Alex Talvy
Jenny Waites
Sam Mitchell
Julie Wilson
David Cox
Sarah Barratt
Lauryn Matheson
Michelle Sharples
Jenny Fuller (Hobart)
Emma Forsyth (Launceston)

Coordinator Operations: Eric Kuncoro

Coordinator Equipment Service: David Harkin

Equipment Officers: Kathy Walker, Sandra Nicholls

Coordinator Volunteer Programs: Deb Olive

Education and Client Support Coordinator: Janette McDonald

Education and Client Support Team Leader: Olivia Verschuur

Education and Client Support Administration Officer:
Ruby Nunan-Jackson

FROM THE CEO

It's difficult to believe that it has been over seven months since COVID-19 hit our shores and launched us into a time we could never have anticipated.

Being physically isolated from family and friends, having to wear masks when in public, and having our time outside the home for essential shopping and exercise limited has taken its toll on all of us. These necessary measures have gone someway towards protecting all of us, and the broader community, from this dreadful virus.

We know that the impacts of these restrictions have been greater on some of the people with MND who we support. This is why MND Victoria has made every effort to ensure that people living with MND in both Victoria and Tasmania continue to receive the high quality care and support they need to ensure they can live as well as possible, for as long as possible.

Coming into Spring is usually the time when we are excitedly planning our Walks to D'Feet and supporting a range of community events that raise the much-needed funds for care and support.

This year's events will look a little different – our Supporter Development and Communications team have pulled out all the stops and have developed creative and innovative new approaches to Walks and fund-raising during a time when public gatherings are severely limited. You will read more about these inside our MND News and we ask that you support these events by sharing the information with family, friends and networks and encouraging them to participate – every bit helps.

I would like to take this opportunity to welcome Daniel Woodrow as our new Manager – Supporter Development and Communications. Daniel has been a member of the Supporter Development team at MND Victoria for over three and a half years and has brought added innovation and a passion for challenge events, among many other things, to the team. Daniel is a valuable addition to our Management Team and we look forward to working with him in this capacity.

I would also like to acknowledge the significant contribution over the past ten years of Kathy Nightingale as Manager – Supporter Development. Kathy has been instrumental in engaging with partners and donors and in raising the much-needed funds required for MND Victoria to provide the care and support needed by the people who we support.

We are very fortunate that Kathy will stay on with MND Victoria as Manager – Special Projects for a few months, and has also taken on the role of National Fundraising Coordinator, supporting the network of State MND Associations and MND Australia in National fundraising activities.

We will properly acknowledge and celebrate Kathy's contribution to the MND Community in the coming months.

From all of us at MND Victoria – to all our valued members, families and supporters – stay home, stay safe and do let us know if there is anything more that we could be doing to support you.

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

Kate

SUPPORT SERVICES

Jo Whitehouse

Collaboration is the key word for the focus of much of our recent work in the Support Services team.

MND is a complex condition and, in order for us to support people with MND to the best of our abilities, collaboration with the wider MND community of health professionals, support services and clinics is vital. We are keen to work together with all AHPs that support people with MND – what does this look like?

Virtual National Support Services Conference

Our staff are very adaptable and have taken to using remote technology for all aspects of their work! When we had to cancel our face to face National Meeting (all Support Service staff across Australia try to meet up every 2 years) that was scheduled to take place in Sydney, the team were keen to try out meeting virtually and so a virtual conference was born! It was a great success. Sam and David have written about this in more detail. This type of meeting is all about sharing resources and skills across the staff Australia wide and trying to avoid duplication!

iPad project collaboration

Ruth, one of our MND Advisors, together with Deb our Coordinator Volunteer Programs and Sandra from our Equipment Service have been working collaboratively with Kaela, Senior Speech Therapist from CHCB to review our iPad program.

We wanted to find out if the people we had loaned an iPad to were finding it helpful to aid with communication and to remain connected with family, friends and their medical and support teams. 7 out of 23 who responded to our survey said they are comfortable in using it! This means 16 were not!

We will be looking at ways in which we can work together to develop training and tools that we can use to make sure the best piece of equipment is prescribed.

Equipment Reference Group

Seeking people impacted by MND to join the group

The MND Victoria Equipment Service (ES) fills a vital need for people with MND in Victoria. Successful provision of appropriate equipment relies on a collaborative approach between:

- MND Victoria, who procure and provide the equipment and
- Allied Health Professionals (AHPs) from the MND Clinics/private therapists, who prescribe the equipment and train the person with MND in its use.

The relationship between the ES and AHPs at the 3 MND clinics is good and the MND Victoria ES can (and does) seek advice on an adhoc basis on a range of equipment issues, however, in the interests of improving it further, we have set up a reference group to consider the type of equipment we have in our equipment that library and to make sure we keep as up-to-date as possible.

The service is very good, but how can we make it better!?

The inaugural meeting took place on 1st September. At the first meeting, we had representation from the MND Vic ES, and AHPs from Calvary, Barwon and Bundoora MND Clinics. We would like to include in the reference group 2 people with MND (or their carers) and also private therapists with experience working with people who have MND.

Expression of Interest: If you are interested in joining the reference group, please email or call me for further information and tell me why you are interested in joining the group. Meetings will be held over Zoom, (so you can live anywhere in the state as long as you have internet connection!), and will be 6 weekly initially.

Our Information Team has had a name change!

Our Information and Resourcing Team has become our **Education and Client Support Team…** to reflect the more outward facing activities we hope to do in the coming year. Olivia Verschuur joined the team at the beginning of September – I will introduce her properly in the next edition when our team will be fully staffed and we can introduce the whole team.

As always, please do not hesitate to contact me if you have any feedback about any of our Support Services.

Jo Whitehouse,
Manager Support Services

jwhitehouse@mnd.asn.au
0402 183 140

YOUR STORY

Bob Kelly

A Boatiful Act of Kindness

Ever since he was a kid, Bob Kelly was fascinated by motors and how things work.

And as a history buff, he had a keen interest in wars and, in particular, war-time memorabilia. Over the years, he collected all sorts of items, but his most prized possession was a World War II Rescue Boat. Recently, Bob made the decision to part ways with his vessel and donate the $25,000 he received from the sale to MND Victoria, as a way of giving back and thanking them for the help and support he and his family have received.

Bob always loved anything large and motorised; and as far as he was concerned, the bigger and louder, the better. He always dreamed of owning a WWII Rescue Boat, and, in 1996, that dream became a reality. He found one of the original timber boats that had been stationed at the Rathmines RAAF Base up for auction in Goolwa, South Australia, and ended up purchasing it. As Bob lived in Irymple, Victoria (right near Mildura), the 38-foot long boat underwent a 10-day journey across Lake Alexandrina and up the Murray River, before it found its new home.

Although it never saw any action, the boat needed a bit of work, so Bob spent 10 years refurbishing the whole vessel and turning it into the family holiday houseboat. Every weekend it cruised up and down the Murray River as his family and friends fished, relaxed and made memories together.

At the age of 81, Bob recently lost his two-year battle with motor neurone disease. His loving wife, Marie, was his primary carer, and his three daughters visited a few times each week to help.

It took a fairly long time for Bob to receive his MND diagnosis, despite having had symptoms for a while. Bob had been very unwell and had ended up on life support as his carbon dioxide levels were essentially poisoning him, but no one could tell him why. Eventually, he was brought to St Vincents Hospital in Melbourne where a neurologist finally diagnosed him with MND. Whilst they felt relief at having an answer, this was quite a shock to Bob and his family as they had never heard of MND before. MND Victoria was quick to get in touch with the Kellys and provided support throughout Bob's disease progression, and will continue to support the family through their bereavement.

When Bob could no longer use his WWII Rescue Boat and, not wanting to burden Marie with all his 'extra stuff', he decided to part ways with the crown jewel in his collection. He wanted the boat to go to someone local (which it did) so they could use it for the same reasons he had – to create memories with loved ones.

Bob also decided to donate the proceeds from the sale of the boat to MND Victoria, as he said he could not have gone on this journey without them. When diagnosed, he had no idea what MND was or how to deal with anything it threw his way, but MND Victoria could always help or link him in with someone who could. He and his family are forever grateful to his advisor, Lauryn, and all the staff at MND Victoria.

MND Clinic Communication Snippet

The Barwon Health Motor Neurone Disease Clinic is based in Geelong and provides a service to a huge area, from the suburbs of Geelong, the Surf Coast and Bellarine, all the way to the Western District of Victoria.

We are a small part-time service with a very skilled team of medical and allied health clinicians who are committed to providing quality care for our MND patients.

Barwon Health's MND Clinic follows a multidisciplinary team model, which has been shown to be the most effective approach in supporting those with MND, as well as their carers and family members. We also offer specialised respiratory consultations that are supported by medical professionals who travel from Melbourne.

In normal circumstances, the whole clinic runs one day a week and clients can be seen by many of the clinicians on the same visit. Assessments are undertaken in the morning and a thorough multidisciplinary team meeting is held to discuss all the clients' needs and concerns, followed by a detailed care plan that is provided to the clients and their involved treating teams. At these meetings, we also regularly have someone from MND Victoria and the local Palliative Care team attend, which aids the holistic approach for those attending our service. This model of care has been shown to improve outcomes by enhancing communication, reducing frequency of appointments, reducing anxiety and concerns, and improving responsiveness to changes in function and care requirements.

Under the current COVID climate and related restrictions, it has been essential that we continue to offer our clients this specialised service, so we have adapted to predominantly offer telehealth appointments. These have been well received, especially by those who would normally travel quite a distance to access the service. We are also keeping in close contact via phone with all of our patients at this time to ensure people continue feeling connected and supported.

The statistics over the past four months have shown that the clinic continues to reach well above targets, even with the restrictions of COVID-19 in place. Our team, which has adapted to these restrictions while understanding that our clients are one of the more vulnerable groups, and is now working from home, providing home visits to those more susceptible clients, physically distancing while at work and assisting other services, all while continuing to provide a quality service for our MND clients with the philosophy "until there's a cure, there's care".

Image Below - From Left to Right: Cheryl Vanderkaay (Social Worker); Ingrid Swain (Dietitian); Renee Heard (Speech Pathologist); Jeanette Wallish (Coordinator); Jennifer Buchanan (Social Worker); Diana Ormeno (Occupational Therapist); Katie Hurst (Physiotherapist).

Missing: Kim Clatworthy (Physiotherapist); Lee Fatone (Administration Assistant); A/Prof Paul Talman; Dr Caron Chapman; Dr Chris McAulay-Powell; Dr Michael Bennett; Dr Siew Kar Chen (Medical Team)

VOLUNTEERS NEWS!

Deb Olive

MND Victoria is fortunate in that the strength of our volunteer services has meant that while our volunteer programs have changed significantly over recent months, many have been able to continue in modified ways.

MND Victoria volunteers have continued to provide services remotely to clients wherever possible over the period of COVID-19 restrictions. We have also been grateful to volunteers who have been able to undertake project work to improve services we deliver and resources to which we have access.

While returning to the office remains a future goal, a number of Reception Volunteers are currently working from their homes to manage calls and ensure that those who need to connect with the organisation are directed to the right person.

The benefits of volunteering

It has long been recognised that, not only does volunteering benefit the receiver and the broad community, but also those who volunteer themselves.

It is said that, for many volunteer programs, people "join for the cause and stay for the community". We know many of our volunteers have joined the organisation based on their own experiences with MND or through supporting family and friends with MND. The depth of understanding and empathy these volunteers bring to the organisation is invaluable.

Volunteering connects people

Through volunteering, people meet others they might not usually connect with – people from different places, age groups, ethnic and social backgrounds. Friendships are formed and maintained through these connections.

The MND Victoria community of volunteers has stayed strong and connected over recent months with regular team meetings, education updates and catch-ups attended by large numbers of our volunteers.

Volunteering builds self-confidence and self-esteem

Volunteering in meaningful roles can provide a sense of accomplishment. Assisting others, being part of a team, and completing activities which may even be outside your comfort zone, can lead to positive feelings and impacts in everyday life.

Volunteering is good for people's health

There is a growing body of research showing people who volunteer have lower blood pressure and a longer life. For some, this can be related to an increase in activity through volunteering. Volunteering has also been shown to be associated with reduced stress, anxiety, and depression. It has been stated that volunteering results in a "helper's high".

Volunteering provides a sense of purpose

Through volunteering, people can choose to make a difference to causes and issues that are important to them. Volunteering can help people develop a sense of balance and perspective in their life.

Volunteering provides opportunities to utilise and develop skills

MND Victoria volunteers bring a wide range of skills, abilities and expertise to the organisation. Whether people are entering the workforce, currently employed, seeking employment, or have left the paid workforce, volunteering can provide a way to utilise skills, develop new skills and explore new directions.

MND Victoria is committed to exploring individual motivations with each volunteer. As well as addressing the needs of the organisation, our volunteer recruitment processes endeavour to identify with each volunteer what they are seeking to gain through their volunteering.

Through this process we endeavour to ensure volunteering with MND Victoria is mutually beneficial and sustainable.

GROUP PROGRAMS

MND Victoria runs a 6 week **Living Well program** for people with MND and their carers. Participants have the opportunity to share knowledge and discuss topics relevant to living with MND as well as provide ideas and support for each other.

The next program is scheduled to commence **October 2nd.** Please contact MND Victoria either by phone or email to register your interest and you will be notified when the starting date has been confirmed. Phone: **(03) 9830 2122** 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 via phone, email, and video conference.

Facebook support groups

MND Carers Australia: An online support group, independent of MND Victoria, for Australian MND carers to discuss issues they face. To join, go to Facebook and search for: "MND Carers Australia" or visit: 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. To join, go to Facebook and search for: "MND Angels Australia" or visit: www.facebook.com/groups/1512117609036086

Are you an MND Genie? About 10% of people diagnosed with MND have a familial form of the disease. MND Genies is a closed and unlisted Facebook group; to join or for more information, please contact Kate Maguire, MND NSW at: **mndgenies@mndnsw.asn.au** or phone (02) 8877 0902

Support services for carers of people with MND

Carers Victoria— 1800 514 845
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

THE 31ST INTERNATIONAL SYMPOSIUM ON ALS/MND

The 31st International Symposium on ALS/MND will be a Virtual Symposium which will open it up to participants across the globe. For more information about the symposium, including the Programme and how to Register, please visit the website https://symposium.mndassociation.org/

YOUR STORY

Robert Wilson

Sixty and Sensational

Like most people who reach a milestone birthday, Robert Wilson decided to have a celebration to mark the occasion.

He and his gorgeous wife Tina opened their home where, over the course of the day, 60 of Robert's family, friends and work colleagues came to celebrate his 60th birthday. But this celebration had a point of difference. Instead of gifts, Robert was asking for donations to MND Victoria.

Robert has been living with motor neurone disease for nearly two years. He first started noticing something was not right back in February 2018. His left foot had started to drag, causing him to stumble and have a few falls at work. Many tests were done and almost six months later he was referred to Calvary Health Care Bethlehem where he received his diagnosis. After nearly 30 years working at Coles Warragul, Robert decided to leave so that he could enjoy the time he had left. Not long after, Tina, who worked as a personal carer, also decided to retire so that she could care for Robert. The two managed to do some travel, going on a cruise to New Zealand and enjoying some time together in Tasmania.

Robert's birthday celebration was a very special day for him. As well as his family and friends, colleagues he had not seen for years came over and spent some quality time with him. He was exhausted by the end of the day, but it was worth it.

After deciding he did not need anything for his birthday, Tina suggested he turn it into a fundraiser so that people could donate to MND Victoria. "We've been really blessed by the support MND Victoria have given us," he says. "The willingness of Jenny Waites *[his MND Advisor and Support Coordinator]* has been brilliant. The equipment we get has made our lives so much easier."

"I honestly didn't think that, at this stage in Robert's life, I would still have him at home," says Tina. "We're very well supported".

Robert and Tina both have a very positive outlook on life and show such strength. They try and make the most of every day and enjoy their lives as much as possible. "All things considered, I have a very good life. I have a beautiful wife, wonderful children both of whom have found wonderful partners, two lovely grandsons and some great carers. I'm very blessed," says Robert.

"My hope is that somebody else down the track can have the same support. Or a cure might be better."

And **until there's a cure, there's care.**

NATIONAL SUPPORT SERVICES MEETINGS – GO VIRTUAL!

The Support Services team recently participated in a series of virtual meetings with their relevant counterparts around Australia.

Every 2 years, the Support Services from each of the MND State Associations meet as a group as part of the National MND Conference. In 2020, this was not possible due to the global pandemic, so the need to adapt to the circumstances was evident. Technology made this possible, as with so many aspects of the services currently provided by MND Victoria.

Four sessions were arranged, led by an organising committee from MND Victoria and MND NSW. The underlying focus of these sessions was building connections with others, learning more about how services are provided between the state associations, and working together to improve the services provided to people living with MND.

In session one, Carol Birks, CEO of MND Australia, provided an update on MND Australia. Participants also had the opportunity to meet each other in small groups and to share resources that are helpful in their role. This session highlighted how knowledgeable members of our own team are and how useful it can be to tap into these resources.

MND NSW then hosted an "Ask the Experts" session focused on several areas, including the genetics of MND, an update on Australian MND research, and the feasibility and effect of swallowing exercises and diet modifications for people living with MND. This recording is available on the MND NSW YouTube channel for anyone who may be interested in watching it.

The third session focused on mindfulness, self-care and positive psychology, presented by Jodie Cooper. It is important that, even in these difficult times, staff look after themselves and reflect on the positives we have in our professional and personal lives.

The fourth and final session focused on two case studies and providing staff with the opportunity to work in small groups. The first case study focused on holistic aspects of care relevant to people living with MND, including care for those newly diagnosed. The second case study looked at what needs to be considered for someone travelling who has MND. It was very useful to take things back to basics, thinking about the person as a whole and providing support and information at their own pace. The sessions also highlighted some slight differences in the way services operate in each state, but the overriding consensus was that we have more similarities than differences and there is scope to work more seamlessly together to help people with MND achieve their goals.

Technology provides the opportunity to meet more frequently as a National Support Services group. It is anticipated that virtual meetings will occur every 6-12 months in the future, in addition to ongoing face-to-face meetings. The sessions provided a wonderful opportunity to further build connections between MND association staff across Australia, and ultimately focus on strengthening the services provided to people living with MND. Afterall, until there's a cure, there's care!

LIVING BETTER FOR LONGER:

MND AUSTRALIA FACT SHEET - RILUZOLE

What you should know

Riluzole:

- is an anti-glutamate medication
- does not cure MND but may slow disease progression
- probably prolongs average survival by 6 to 19 months
- is best taken soon after diagnosis to have the greatest benefits
- has only been studied for its safety and efficacy in ALS, including progressive bulbar palsy (PBP).

About riluzole

Some neurones in the brain and spinal cord release an amino acid, called glutamate, to carry signals to other neurones. Glutamate is released at the synaptic junction where two neurones meet. If too much glutamate is released by the neurone sending a signal, it can over-stimulate the neurone receiving the signal. This is called glutamate excitotoxicity. Riluzole is an anti-glutamate medication that appears to block the release of glutamate from neurones. Riluzole may also exert some effects on MND through other mechanisms but this is yet to be firmly established.

Riluzole and MND

Motor neurone disease is a general term applying to progressive, degenerative disorders affecting the motor neurones. Motor neurones carry signals from the brain to the muscles. In people with motor neurone disease, the motor neurones deteriorate and can no longer carry these signals.

Researchers have found that glutamate excitotoxicity may accumulate to harmful levels and contribute to motor neurone deterioration (Miller et al. 2012). The effect of riluzole, an anti-glutamate medication, has been investigated on people with the following forms of motor neurone disease:

- amyotrophic lateral sclerosis (ALS) – that first affects muscles controlling the limbs
- progressive bulbar palsy (PBP) – that first affects bulbar muscles (speech and swallowing muscles) but often progresses to ALS.

Medical literature about riluzole generally uses the term amyotrophic lateral sclerosis (ALS) as an umbrella term to include progressive bulbar palsy (PBP). This is because there is:

- uncertainty about the cause and mechanism of motor neurone deterioration
- debate about the extent to which different forms are simply variations in the same disease process or whether there are several different disease mechanisms
- international difference in terms used to describe motor neurone disease.

Getting riluzole

Riluzole is manufactured under the names Rilutek™ and APO-Riluzole. In Australia riluzole is available for eligible people at a subsidised price on the Pharmaceutical Benefits Scheme (PBS) under an authority prescription. To get your first authority prescription for riluzole, you must be diagnosed with the ALS form (including PBP) of MND by a neurologist, have had the disease for five years or less, and meet several other criteria. Your doctor needs to provide your date of diagnosis and information about your forced vital capacity* with the first application. Subsequent prescriptions may be issued by your general practitioner.

Teglutik® (riluzole), a liquid formulation (for ease of swallowing or use via PEG tube) of riluzole, distributed by Seqirus (Australia) Pty Ltd, was listed on the PBS in April 2019 under the same prescribing conditions as Rilutek™ and APO-Riluzole.

* Forced Vital Capacity (FVC) is a respiratory function test. For more information about FVC see Living Better for Longer fact-sheet and motor neurone disease: an introduction, on the MND Australia website.

Evidence about riluzole

For people with MND who have ALS (including PBP)

In their analysis of the results of four double-blind randomised controlled trials, involving 1477 people with the ALS form (including PBP) of motor neurone disease, Miller et al. (2012) found that taking 100 mg of riluzole daily:

- probably prolongs median survival by two to three months - (median is the mid-point – half those taking riluzole have survival prolonged by more than two to three months).

One of the trials included in the analysis only enrolled people older than 75 years or who had the disease for more than five years. The inclusion of this trial decreased median survival time.

Several riluzole studies were not included in the analysis because they were not double-blind randomised controlled trials (the best evidence). These excluded studies reported a median survival prolongation ranging from 6 to 21 months. It is not known what other factors, such as other interventions and stage of the disease, might have influenced the results of these excluded studies (Miller et al. 2012).

More recently, a review undertaken by Andrews et al. (2020) suggests that taking riluzole may be more effective than first thought. A review of 15 population studies undertaken by clinicians treating people with ALS/MND found that people who took riluzole, when compared with those who didn't, generally lived longer, anywhere between 6 to 19 months longer (Andrews et al. 2020). The review, which was of real world evidence studies, provides additional insights on the effectiveness of riluzole as an important treatment option for people living with ALS. Additionally, the review found that, in several population studies, the greatest benefit of riluzole occurs early in the course of the disease thereby providing evidence both for early and prolonged riluzole therapy (Andrews et al. 2020).

For people with other forms of MND

All trials of riluzole published in the medical literature have only allowed people diagnosed with the ALS form (including PBP) of motor neurone disease to participate. There is strong clinical support for the use of riluzole in other forms of motor neurone disease (National Institute for Clinical Excellence 2001). However, in Australia, subsidised PBS prescriptions for riluzole are limited as a treatment for the ALS (including PBP) forms of motor neurone disease alone (Australian Government Department of Health and Ageing 2009).

Adverse effects

Adverse effects from riluzole are relatively minor and, for the most part, reversible after stopping the drug (Miller et al. 2012). The most common adverse effects are fatigue and nausea. Riluzole affects liver function and should be prescribed with care in people who have pre-existing problems with liver function.

Ongoing liver function testing

Regular blood testing to monitor liver function (every month for three months, then every three months for a further nine months and annually thereafter) is recommended for people taking riluzole (National Institute for Clinical Excellence 2001).

Getting advice about riluzole

Your neurologist can offer advice about riluzole. If you have been refused access to riluzole under the PBS and think you are eligible, talk with another neurologist or contact your MND clinic. Contact your local MND Association for more information.

References:

Andrews JA, Jackson CE, Heiman-Patterson TD, Bettica P, Brooks BR, and Pioro EP 2020, Real-world evidence of riluzole effectiveness in treating amyotrophic lateral sclerosis, Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration, Ahead of Print 1-10, https://doi.org/10.1080/21678421.2020.1771734

HealthDirect, Brand name: Teglutik™ https://www.healthdirect.gov.au/medicines/brand/amt,1190711000168104/teglutik

Miller RG, Mitchell JD, Moore DH 2012, Riluzole for amyotrophic lateral sclerosis (ALS)/motor neuron disease (MND), Cochrane Database of Systematic Reviews 2012(3). Art. No CD001447

National Institute of Clinical Excellence 2001, NICE: Guidance on the use of riluzole (Rilutek) for the treatment of motor neurone disease, http://guidance.nice.org.uk/TA20

NIH U.S. National Library of Medicine National Center for Biotechnology Information Modify Date: 2018-10-20, Riluzole https://pubchem.ncbi.nlm.nih.gov/compound/riluzole#section=Drug-Indication

Pharmaceutical Benefits Scheme, Department of Health, accessed 3 April 2020, Riluzole, http://www.pbs.gov.au/medicine/item/11662T-8664B

For more information contact

To find out about motor neurone disease and other fact sheets in this series, contact the MND Association in your state or territory, phone 1800 777 175 or visit www.mndaustralia.org.au

REGIONAL FOCUS

13 members access the NDIS

7 members are in the Commonwealth Home Support Programme (CHSP)

19 members are supported under 'the Aged Care' System

'My Aged Care' system fails to meet the needs of people with MND. Please join the campaign to make Aged Care fair: www.mndaction.org.au

Alex – MND Advisor & Support Coordinator

Alex has been an MND Advisor & Support Coordinator with MND Victoria since January 2020

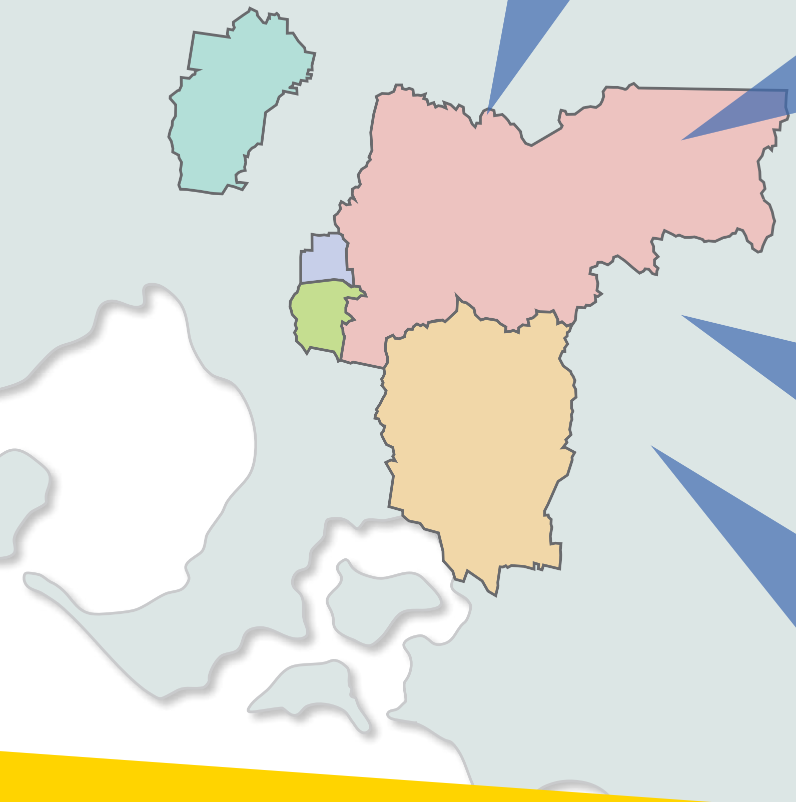
Most people with motor neurone disease in this region attend the Statewide Progressive Neurological Disease Service at Calvary Health Care Bethlehem. Clients also attend the Victorian Respiratory Support Service at Austin Health as well as using many local Allied Health Services.

MND Victoria volunteers are active in Alex's area and they are available to support people living with MND with services including **Life Stories and Hand and Foot Massage.**

Volunteers also travel from this area to participate in fundraising and other events, to assist with **Reception** and roles at head office including sending out **MND News**.

We look forward to getting together with our volunteers when we are able.

Currently, Alex is personally working with 39 people with MND.



In the last 8 months, Alex provided
723
hours of support
to people with MND

Like all our Victorian MND Advisors/Support Coordinators, Alex has been using Zoom, phone calls and emails to deliver support services.

Alex mainly works with members in the Yarra Ranges, Maroondah, Knox and Cardinia (north of the reservoir) regions.

FUNDRAISING EVENTS
IN ALEX'S REGIONS

Sadly, due to COVID-19, there have been no fundraising events in Alex's area since he commenced with MND Victoria. However, we have been well supported in previous years by numerous groups and services clubs such as Maroondah Rotary. For six years, our Volunteers have attended the annual Wandin Park Equestrian event and helped raise awareness and funds for the Association. Unfortunately, the 2020 event was cancelled but we are hopeful that we will again participate in 2021.

For two years the Lilydale Cricket Club hosted the 'Lilydale Little Chill Ladies Day' for MND in honour of a club legend who died from MND in 2018.

MND Victoria appreciates the on-going commitment from the community to raise awareness and funds that enable people with MND to live better for longer. We hope that once the COVID-19 restrictions are lifted, communities will once more be able to run events to financially support the vital services delivered by MND Victoria.

FUNDRAISING

Daniel Woodrow

Kathy Nightingale has been an absolute pillar of strength and consistency over the past 10 years at MND Victoria.

Through her passion, professionalism, dedication and incredible work ethic, MND Victoria and thousands of people with MND during that time have benefited greatly from the significant fundraising work Kathy has developed and led.

As they say, all good things must come to an end and that is why you see me writing my first column in this newsletter. At the beginning of August, I was handed the reins of the position of Manager – Supporter Development and Communications. After more than three and a half years of working in the Supporter Development team, it's an honour to be tasked with the responsibility of driving the team which is responsible for funding a major portion of the overall funds required to provide the best possible care, support and vital assistive equipment to all Victorians and Tasmanians living with MND. One of the best parts of this news is that we have not lost Kathy just yet! Although a well-deserved retirement is on the horizon, Kathy and her wealth of knowledge will stay part of the team and provide extra assistance and guidance over the next few months.

Speaking of the next few months, they are going to be tough for so many people, none more so than those living with MND and their families. MND Victoria and all 34 current staff are incredibly proud of the services we have been delivering for 39 years. Since the COVID-19 pandemic began, however, there is an extra sense of accomplishment due to the lengths the staff and Association in general have gone to, so that there is little to no effect on those who are in need of our MND Advisors, information and equipment to help them navigate through their already difficult journey.

MND Victoria's services have always been, and will continue to be, built on our very generous fundraisers and donors. Simply put, we cannot do what we do without our various fundraising activities. Now, more than ever, we need you and all of our amazing supporters. With the worldwide economic crisis and the inability for anyone to host any in-person fundraising events for the time being, it is only natural for our donations to take a hit. Kathy, Steph and I are committed to working as hard as possible to adjust, plan and communicate through these incredibly difficult times. That will not be enough though. We need all of our supporters and the greater MND community to help us out by being advocates for the services MND Victoria provides to so many people with MND and their families. Financial support is the ultimate goal from those who can spare something, but awareness raising throughout the public doesn't cost a cent and can lead to financial support from others. As we say regularly, until there's a cure, there's care. We cannot wait until the day, we have no job because a cure has been found. Until that day however, MND Victoria's work is absolutely vital in the lives of all those impacted by MND, now and in the future.

WALK TO D'FEET MND

In the 16 years it has been running, Walk to D'Feet MND has become synonymous with MND Victoria and so many families that have been impacted by the disease. The event has grown from a standalone Melbourne based event. Now, Walk to D'Feet MND events take place throughout the state because of so many incredible volunteers who put their time and effort in to organise regional based Walk to D'Feet MND events. This year, because of COVID-19, we have had to significantly adjust what this event looks like. A virtual tour of Victoria is how it is framed, and it will incorporate all 14 MND Advisor specific regions over a two week campaign period. We will be highlighting all of our dedicated and hardworking Advisors whilst showcasing relevant information in each area. Registration is the same as previous years and T-shirts will still be provided. We are encouraging as many people as possible to register and take part in a fundraising campaign. Accessibility to our flagship event has never been easier as all you need to do is walk 1km per day around your own neighborhood and share the love whilst doing it! You don't have to walk every day, you may choose to only walk on Sunday 15th November. Your registration, and hopefully your fundraising efforts, show your support to MND Victoria and all those people impacted by MND.

For all event information, please refer to the huge advertisement within this newsletter. You can also keep an eye out on our Social Media pages. This is our time to really support one another and finish off what has been a very ordinary year, strongly! Let's get together and help raise the funds that are needed to continue providing the **best possible care and support for all Victorians and Tasmanians living with MND.**

Daniel Woodrow
Manager – Supporter Development and Communications

HAVE YOU HEARD ABOUT THE WORLD'S FIRST DONATION DOLLAR?

It's a one-dollar coin designed to be donated, and which some believe has the potential to deliver millions of dollars in additional funding to the charity sector each year.

The coin was released on September 2 ahead of International Day of Charity which is celebrated on September 5 each year. The Royal Australian Mint will distribute 25 million of these $1 coins over the coming years – one for every Australian.

While the Donation Dollar can be spent just like any other Australian $1 coin, it is hoped that, when people get one in their change, it will serve as a "reminder to give" and they will donate it to a charity.

According to Royal Australian Mint CEO, Ross MacDiarmid, "If every Australian donated a Donation Dollar just once a month, it has the potential to raise an additional $300 million annually for those who need it most. So, with Australia's support, we believe Donation Dollar has the power to make a real difference."

If and when you find a Donation Dollar in your change, please consider passing it onto MND Victoria so that we can positively impact the lives of people with MND.

KENNEDY'S DISEASE

MND AUSTRALIA FACT SHEET

What you should know

- Kennedy's Disease refers to Spinal and Bulbar Muscular Atrophy (SBMA) and is a rare kind of inherited disease that affects the nerve cells in the human brain
- The disease causes the muscles of the face and limbs to become weaker and waste away
- Other major symptoms include enlargement of breasts, muscle cramps and spasms, hand tremors, impotence and speech and swallowing difficulties
- The symptoms can be managed and the disease is not usually life limiting, but there is no cure
- Age of onset is usually between 35 and 40 years and men are more commonly affected.

What is Kennedy's Disease?

Kennedy's Disease refers to Spinal and Bulbar Muscular Atrophy (SBMA) and is a rare type of inherited disease that affects the neurons (more commonly known as nerve cells) in the brain[1]. Kennedy's Disease is named after William R. Kennedy who reported seeing this disease in patients in 1968[1].

It is estimated that around 1 to 2 per 100,000 people worldwide have Kennedy's Disease, although the number may be higher due to difficulties with making a definitive diagnosis[1].

The disease is characterised by the degeneration of lower motor neurons of the brainstem and spinal cord[2]. This results in the muscles of the face and limbs becoming weaker and wasting away[3]. The loss of muscle strength eventually leads to weakness in muscles throughout the body which makes movement difficult, particularly in the legs and arms, and with speech and swallowing.

Kennedy's Disease more commonly affects men

Other major symptoms of the disease include enlargement of breasts, muscle cramps and spasms, hand tremors, impotence and speech and swallowing difficulties[4]. The symptoms can be managed, but there is no cure[5].

Age of onset is usually between 35 and 40 years[1]. The disease generally progresses slowly[6] and does not usually impact life expectancy[7].

Genetic mutation and Kennedy's Disease

A mutation in the androgen receptor gene (AR) is responsible for the disease[8]. The androgen receptor gene is located on the X chromosome[9] and helps to control the activity of male sex hormones (androgens).

Why are men mostly affected?

Men who inherit the mutated androgen receptor gene develop the disease. The mutated gene is present on the X chromosome, which is one of two chromosomes that decide the sex of a human. Men have X and Y chromosomes[10].

Women have two X chromosomes[10]. Women who inherit the mutated gene also carry it on their X chromosome. The impact of the normal gene on the other X chromosome usually overrides the mutated gene so this makes it rare for a woman to develop the disease. Women who have inherited the mutated gene are carriers of the disease[1]. Each son of a woman who is a carrier has a 50% chance of inheriting the gene and developing the disease[1].

Diagnosis

Kennedy's Disease is rare and can be misdiagnosed, often being mistaken for motor neurone disease (MND) as it shares a lot of similar symptoms. A thorough medical review is required to make an accurate diagnosis and includes assessment of the patient's family history, symptoms and rate of progression. Tests[11] used to confirm a diagnosis of Kennedy's Disease include:

- Genetic tests using a blood sample that looks for the faulty gene
- A blood test to check for elevated serum creatine kinase (CPK) as almost all patients with SBMA are found to have very high levels, and
- Neurologist assessments for elevated CAG repeats (a segment of DNA).

Similarity and differences with MND

The main similarity between Kennedy's Disease and MND is the symptoms they display. Both diseases cause the weakening and wasting of muscles. While the wasting of muscles can make Kennedy's Disease easy to mistake for MND, there are a number of significant differences between the diseases.

Differences

	Kennedy's Disease	MND
Onset	Onset is usually between 35 and 40 years	Can affect adults at any age, but most people who develop MND are in their 50s or 60s
Cause	Inherit the faulty gene from mother	The causes for the majority of cases of MND remain unknown. However, about 5 to 10% of cases are caused by inheriting a mutated gene from a parent.
Incidence	Approximately 1-2 per 100,000	Approximately 8.7 per 100,000
Progress	Slow	Rapid
Life expectancy	Usually normal	Average survival time after diagnosis is 2.5 years
Gender	Men more commonly develop the disease	MND affects both men and women

How is Kennedy's Disease managed?

Currently, there is no cure for Kennedy's Disease. Treatment aims to reduce and manage the symptoms. A healthy lifestyle that includes a balanced diet, gentle and regular aerobic exercise, getting plenty of rest, and avoidance of exhaustion play a big part in daily management of the condition. Regular stretching to help reduce muscle cramping is also useful. Other interventions[11] include:

- medications to reduce muscle cramps and tremors
- pain management
- speech therapy
- occupational therapy
- physiotherapy
- dietary advice
- fall prevention

Where to get support

Talking with your General Practitioner (GP) is the best place to start if you have any suspicions that you may have Kennedy's Disease. You will usually be referred to a Neurologist for further review and testing. If you do have Kennedy's Disease, your GP can help you access the health professionals you need as time goes on.

Female carriers of Kennedys Disease can receive genetic and fertility specialist advice to help reduce the chance of passing on the disease. MND state-based associations provide ongoing support through their Advisors.

A place to find support from others affected by Kennedy's Disease is via the private Facebook group Kennedys Disease Downunder.

References

1. Breza and Koutsis, 2019, 'Kennedy's Disease (spinal and bulbar muscular atrophy): a clinically oriented review of a rare disease', Journal of Neurology 266 (3): 565-573.
2. Hoo et al, 2015, 'Androgen-modulating agents for spinal bulbar muscularatrophy/Kennedy's Disease (Protocol)', Cochrane Database of Systematic Reviews, Issue 12.
3. Liu et al, 2019, 'Clinical manifestations and AR gene mutations in Kennedy's Disease', Functional & Integrative Genomics, 19(3): 533-539.
4. Motor Neurone Disease Association, 2019, 'Kennedy's Disease: Information for people with or affected by Kennedy's Disease', Northampton, United Kingdom.
5. Orrell and Figlewicz, 2001, 'Clinical Implications of the Genetics of ALS and Other Motor Neuron Diseases', Neurology, 57(1):9-17.
6. Lu et al, 2017, 'Kennedy's Disease 1234 scale: Preliminary design and test', Journal of Clinical Neuroscience, 40:185-189.
7. Querin et al, 2018, 'Biomarkers of Spinal and Bulbar Muscle Atrophy (SBMA): A Comprehensive Review', Frontiers in Neurology, 9: 844.
8. Rosenbohm et al, 2018, 'The metabolic and endocrine characteristics in spinal and bulbar muscular atrophy', Journal of Neurology, 265(5): 1026-1036.
9. Finsterer et al, 2016, 'Onset Manifestations of Spinal and Bulbar Muscular Atrophy (Kennedy's Disease)', Journal of Molecular Neuroscience, 58(3):321-9.
10. Bakker, 2019, 'The Sexual Differentiation of the Human Brain: Role of Sex Hormones Versus Sex Chromosomes', Current Topics in Behavioral Neuroscience, 43:45-67.
11. Better Health Channel, 'Kennedy's Disease', Accessed: 12 May 2020, https://www.betterhealth.vic.gov.au/health/ConditionsAndTreatments/kennedys-disease

For more information contact

To find out about motor neurone disease and other fact sheets in this series, contact the MND Association in your state or territory, phone 1800 777 175 or visit www.mndaustralia.org.au

Kennedy's Disease Association:
https://www.kennedysdisease.org/

How Can I Help MND research

Familial MND research

Prof. Garth Nicholson and team based at the ANZAC Research Institute, Concord Hospital Sydney, are studying gene variations in familial MND. They are keen to obtain DNA samples from patients with familial MND. 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. Please phone (02) 9767 6796 or email **molmed@med.usyd.edu.au** for further details.

ALS Quest Survey

ALS Quest, a University of Sydney project, is an online anonymous questionnaire looking at environmental risk factors for MND: **www.alsquest.org**

Both people with and without MND can fill in the survey—it takes approx 90 minutes to complete.

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: fairlie.hinton@florey.edu.au Phone: (03) 8344 1900 Mobile: 0438 530 372 or visit: **www.florey.edu.au/vic-brain-bank**

Join the Australian MND Registry

The Motor Neurone Disease Registry is an ambitious project to register and collect data from every person in Australia diagnosed with MND. It contains de-identified data from people with MND including information about the diagnosis, symptoms, treatment and management. This information is made available to MND researchers. 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 can decline or withdraw from the study at any time.

Please contact Anna Smith: (03) 9595 3355 email: anna.smith@calvarycare.org.au or visit the website: www.mndregistry.org.au

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

WALK TO D'FEET MND

TOUR OF VICTORIA

2 November to 15 November 2020

In your local area / within COVID-19 restrictions

Each day from Monday 2nd November - Sunday 15th November we will be virtually walking through one of the 14 Victorian regions and will share via Social Media how MND Victoria provides care, support and vital assistive equipment for people living with MND. Once you've registered, you can choose to walk 1km per day for 14 days around your neighbourhood to represent the 14 different Victorian regions, or you might just want to walk on Sunday November 15.

Adults $40, Children $10 (5-18yrs), **Families $80** (2 adults + 1 child), **$90** (2 adults + 2 children)
Special Registration Fee for person with MND and 1 companion $20 each.
Free Walk to D'Feet MND T-Shirt included with each registration

Register online at: www.mndwalk.org.au
OR complete and return this form

Show your support of people impacted by MND.
Your fundraising is VITALLY important to ensure people living with MND can access care and support regardless of where in Victoria they live. Get your family and friends together and see who can raise the most funds.
Thank you for your support.

mnd Victoria

Registration Form

Please complete details for each participant and mail form with entry fee to:

Walk to D'Feet MND
PO Box 23 Canterbury Vic 3126

Save time - register and order Walk T-Shirts online:
https://www.mndwalk.org.au

https://www.facebook.com/MNDVic
https://twitter.com/MNDVic
https://www.instagram.com/mnd_vic

www.mnd.asn.au

ENTRY FORM (PLEASE PRINT DETAILS IN CAPITAL LETTERS)

Name(s):

Address:

Suburb: Postcode:

Telephone: Email:

ENTRY FEES (INCLUDES FREE T SHIRT)

ENTRY FEE	NUMBER	COST
Adult $40		
Person with MND and 1 companion $20 each		
Family (2 adults + 2 children *NB Child is aged 5 – 18 years)* $90		
Family (2 adults + 1 child *NB Child is aged 5 – 18 years)* $80		
Additional child $10		
Merchandise: ☐ Bandanas $8		
☐ Dog Leads [☐ Large ☐ Medium or ☐ Small] $12		
My Donation (over $2 tax deductable)		
	TOTAL PAYABLE	

METHOD OF PAYMENT:

☐ Cheque/money order ☐ Cash ☐ Visa ☐ Mastercard

(please make payable to MND Victoria)

Card Numbers:

☐☐☐☐ ☐☐☐☐ ☐☐☐☐ ☐☐☐☐

Name on card:

CCV: Expiry Date: /

Signature:

IMPORTANT

By registering for the Walk to D'Feet MND, you:

- agree that MND Victoria shall not be held responsible for any loss, damage or injury arising from the Walk to D'Feet MND
- have physical fitness to safely complete the Walk to D'Feet MND
- consent to receive medical treatment if deemed advisable
- follow instructions given by the event organisers
- have sole responsibility for your personal possessions and equipment
- agree that the entry fee is non refundable
- permit free use of your photograph in print and electronic media

T-SHIRT REQUIRED:

T-shirts will be mailed for all orders. *Please indicate the number of t-shirts required in the box next to the sizes required:*

☐ 4XL ☐ 3XL ☐ 2XL ☐ XL ☐ L ☐ M ☐ S
Adult Sizes

☐ 14 ☐ 12 ☐ 10 ☐ 8 ☐ 6 ☐ 4
Children Sizes

DONATIONS RECEIVED … THANK YOU!

In Memory

Christine Stafford
Philip Jago
Peter Lowe
Jim Mantovani
Robert Howden
Robert Eastgate
Martin Williams
Shantha Abeysundara
Keith Majoos
Doris Little
John Heriot
Jenny Steinicke
Robert Kelly
Les Hazel
Geoffrey Stone
Glen Roach

Corporations

Express Insurance Brokers
Specsavers Pty Ltd.
Ritchies Supermarkets and Liquor Stores

Organisations

Eyecare Plus Cranbourne
Terry White Chemart Narrandera
Vitality Brands Worldwide

Clubs

Portsea Golf Club

Trusts

Australia Post Workforce Grant

Bequests

The Estate of Shirley McCosh

Thank you so much for your support of our work and people with motor neurone disease!

MND Victoria Membership

Have you renewed your membership for 2020?

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 story or article with a photo to: info@mnd.asn.au by 26 October for the November/December issue.

Get Involved in an Event via internet!

Date:	Event:	Find out more:
Tuesday 22 September 2020	**Remote MND Information Session - Remote Conference**	Email: info@mnd.asn.au
Monday 26 October 2020 : 11am	**39th Annual General Meeting**	Ph: (03) 9830 2122 E: info@mnd.asn.au
2-15 November 2020	**Virtual Walk to D'Feet MND in your local region**	Email: fundraising@mnd.asn.au
6-14 May 2021	**National Kokoda Challenge 2021**	Email: fundraising@mnd.asn.au

We are still providing vital support and care for all Victorians and Tasmanians living with motor neurone disease (MND). Our MND Information Sessions are presented live via Zoom, allowing access to everyone throughout Victoria and Tasmania.

For more information and the latest events updates, please visit our website www.mnd.asn.au/events

From all of us here at MND Victoria, we want to say a very BIG thank you to all of our donors, supporters, fundraisers and event organisers. We look forward to working with you all again in the near future, once all COVID-19 gathering restrictions have been lifted.

39th Annual General Meeting

Monday 26 October 2020 : 11am

Due to COVID-19 restrictions, the 39th Annual General Meeting will be held via Zoom. All members are encouraged to attend to hear from our guest speaker, Creighton Parker, sharing how he lives with MND.
The AGM will also:

- Confirm the 38th AGM Minutes
- Adopt the Treasurer's Report & Financial Statement for 2019/2020
- Appoint the auditor
- Elect State Council Members

RSVP By 22 October to receive a Zoom video link. Ph: (03) 9830 2122 E: info@mnd.asn.au

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 | www.linkedin.com/company/mndvic