

MND NEWS

September/October

2019

The newsletter of the
Motor Neurone Disease
Association of Victoria

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



SPOTLIGHT ON CARERS

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MND Victoria

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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 on Tel: 1800 806 632 or info@mnd.asn.au

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

Melton Area: Meets every 4 weeks on Fridays at 12pm
Coordinator – Leanne Dewhurst

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

Bendigo Area: Meets 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 Supporter Development: Kathy Nightingale

Supporter Development Officer: Daniel Woodrow

Lead Digital & Communications: Heidi Bryce

Manager Support Services: Jo Whitehouse

Coordinator MND Advisor Service: Janette McDonald

Team Leader MND Advisor/Support Coordinators:

Elizabeth Crask, Eric Kelly

MND Advisors/Support Coordinators:

Ruth McEvoy Lauryn Matheson

Jenny Waites Trish Duffy

Melissa Kettle Fran Hurst

Rachel Ritchie Sam Mitchell

Jenny Fuller (Hobart)

Coordinator Operations: Eric Kuncoro

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



With National Carers Week just around the corner, in this newsletter we focus on those family members and friends who provide care and support to a person with motor neurone disease.

At MND Victoria, when we talk about “people living with MND,” we include people who have been diagnosed, those yet to be diagnosed, carers, former carers, families, friends, workmates and any other person whose life is, or has been affected by, a diagnosis of MND. This is because we are keenly aware of the impact that MND has on those around the person with the diagnosis, in particular on those who become their carers.

The term ‘carer’ has never been one that sits well with those to whom it is applied. Carers often say - “I’m not a carer – I’m a wife, a husband, a mother, a son, a daughter – it’s just what you do” – but carer is a catch-all term – publicly and politically recognised for those who provide unpaid care and support to a family member or friend who, without their support, may not be able to remain living in the community.

There are joys in caring and many see their caring role as an honour in being able to support a loved one. Caring for loved ones comes with compassion, often a deeper relationship and the development of skills and knowledge that otherwise the carer wouldn’t have.

However, the life of a carer is hard. It is often relentless, often means giving up or reducing other roles, such as

employment, social networks, time with other family members and time for yourself. If someone wrote the carer job description, there would be very few who would voluntarily sign up for this unpaid role. But mostly people don’t choose to become carers – it is a role that comes, usually unexpectedly, often suddenly, and with very little preparation.

It is important that carers see the significance of caring for themselves as well as caring for the person with MND. Caring is demanding – physically, mentally and emotionally – and will take a more significant toll on the carer if they are not looking after their own well-being. This may be through ensuring a healthy diet and good sleep, making sure to take some time out from caring to relax and recharge and importantly – asking for and accepting help.

If you are a carer or know a carer of someone with MND who needs extra support, we at MND Victoria can help, or you can call the Australian Government Carer Gateway or Carers Victoria. Carers Victoria also have a number of videos on their website about self-care for carers.

- MND Victoria 1800 806 632
- Carer Gateway 1800 422 737
- Carers Victoria 1800 242 636

National Carers Week is a week to acknowledge, celebrate and say thank you to the 2.7 million carers in Australia – and for us at MND Vic to particularly acknowledge and thank those who are caring for a person with MND.

Kate

MND INFORMATION SESSION

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

7pm on Wednesday, 9 October at MND Victoria, 265 Canterbury Road, Canterbury.

Please RSVP by 5pm, Monday, 7 October 2019.

Phone: (03) 9830 2122, 1800 806 632 or

Email: info@mnd.asn.au The following session is on Thursday, 21 November at 7pm.

SUPPORT SERVICES



MND Victoria's Support Services continue to focus on delivering key services to people living with MND to support them to live better for longer, remain active in their community, and to be safe in their environment. We do this through the provision of four key services – Information and Resources, MND Advisor and Support Coordination, Assistive Technology and our Volunteer programs.

In 2018/19, **209 Victorians** and **16 Tasmanians** newly diagnosed with MND registered with the Association, and we delivered support and services to a total of **655 people** over the year.

Annual Quality Survey

Thank you to everyone who responded to our client survey which was sent out earlier this year. We had a 21% response rate, with a total of 102 surveys returned.

Key results were overwhelmingly positive and there were some good suggestions on things we could consider improving.

Snapshot of results:

- **98% thought our newsletter was good, very good or excellent, so that is positive feedback indeed!**
- **96% thought our equipment service was good or better than good!**

- **97% rated our MND Advisor service as good, very good or excellent**
- **8% did not know MND Victoria had a website!**

One great suggestion for improvement was to make sure that the MND Clinics have information about MND Victoria's services which can be given out to people when they are diagnosed. We will be making sure that this is available at Clinics in future.

Support Services Staff Update

I am sad to advise that Leanne Conway has resigned after working for the Association for nine years.

Leanne has been a wonderful member of the team at MND Victoria, both in her previous role of Coordinator of Volunteers, and more recently in her role as MND Advisor and Support Coordinator. We wish her well in her future endeavours. Recruitment to find a replacement is underway.



We have recruited a new MND Advisor and Support Coordinator to work in the north metro area. Julie Wilson will commence on 14 October. She has been working as a palliative care specialist nurse for many years and has immense experience and passion about working with people with MND.

Recruitment is also underway for the MND Advisor and Support Coordinator role to cover the north and north west of Tasmania.

We are very pleased to welcome back Lesley Burcher who, after retiring a year ago, has come back to assist with covering staff leave. It's like she never left! Lesley will be with us until Christmas.

The Walk to D'feet MND season is nearly upon us and I look forward to introducing my dog Nala to many of you at these events.

As always, if you have feedback, please don't hesitate to email or call me.

Jo Whitehouse, Manager Support Services
jwhitehouse@mnd.asn.au or 0402 183 140



SPOTLIGHT ON CARERS . . .

BEING A CARER

By John Caliste

This is one job I never thought I would sign up for. I'd like to think that I'm a caring person but the idea of being a carer for one of my children never existed. I was lucky, if you can call it lucky, that of both my parents passed quickly.

This all changed when the dreaded acronym MND entered my family's world.

My beautiful son Robert, Robbie to all who know him, was diagnosed in May 2017 and our world hasn't been the same.

At the start, life wasn't too bad as Robbie was fiercely independent and living his own life in the house he shared with his friends. The understanding was that when he felt the time was right, he would come home to us, to what we called the Caliste bubble made up of his brother Paul, his mum Michelle and myself. His only need was, at that time, his monthly visit to Calvary Health Care, Bethlehem.

However, as the disease progressed, and he started losing some functions and had many falls, Robbie came home and full time caring became a reality and a labour of love. Who wouldn't do the same for their children?

Before I proceed to the role of the carer of a person suffering MND, I must mention MND Victoria who provide the utmost amount of support with equipment and administrative needs. Their motto of "until there's cure, there's care" is so true.

When Robbie moved home he struggled with the whole situation. He couldn't come to terms with the amount of invasive care that he would receive from us. Be it wiping his backside or cleaning his private parts. Total loss of dignity for a person, regardless of age, but especially for a previously active and independent young person.

Our role now is to ensure that he receives his medications and painkillers at the right time and as required. And his emotional needs are met as dark depression is a reality with this disease. He has a ringer to summon us when needed, which could be for a toilet need or something

as simple as an itch that needs scratching because he has limited use of his limbs and fingers. Getting him out of bed is no easy task with an almost dead weight. I don't know how Michelle manages this if, for some reason, I'm not around. He also suffers from the most incredible cramps which reduces me to tears due to my inability to help him.

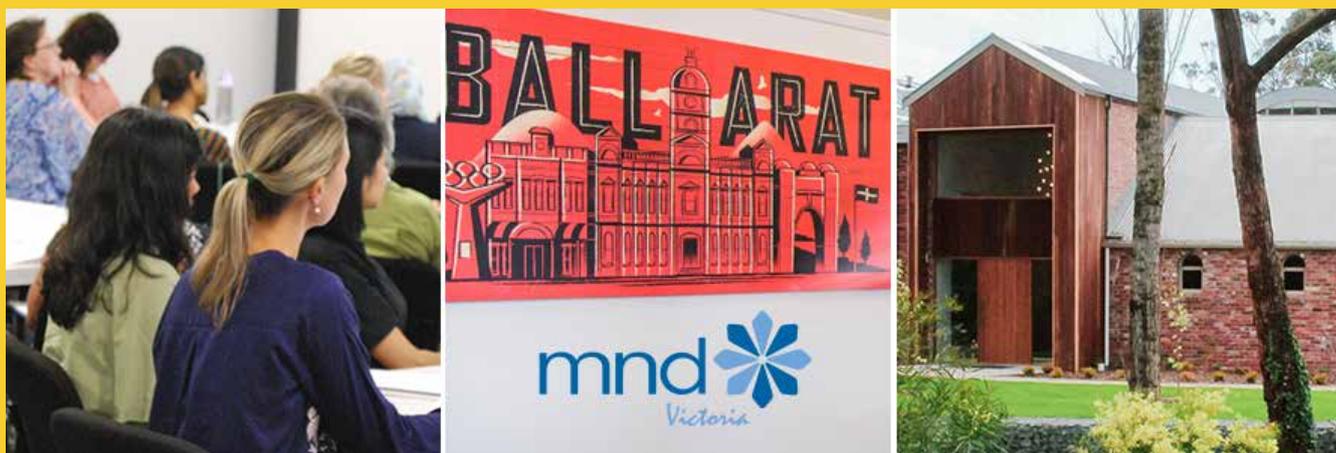
This is around the clock and we have a roster. His mum looks after meds and I feed him by hand. Continuous sleep is non-existent for us as that ringer will go off at any time. His brother Paul has been fantastic and, with his help, Michelle and I have been able to enjoy the odd night out. Not too many though as you are always on edge in case you get a phone call.

There are so many more aspects of this insidious disease that I could mention, but even putting them into words is hard as you are adjusting on the run. The emotional toll on all of us is indescribable.

Having said all this, in spite of all the frustrations and sadness, we would not pass up on the opportunity to see our son through the biggest fight of his life.



MND HEALTH & COMMUNITY PROFESSIONAL FORUM IN BALLARAT



'MND Update: A Regional Focus for Health Professionals'

Join us at **10am on Friday 11 October 2019** at the **Mercure Ballarat Hotel & Convention Centre** for an all day forum designed specifically for health and community professionals working with people who have motor neurone disease.

Presentations will be provided by MND Specialists from **Barwon Health**, speakers from the **Grampians Regional Palliative Care** team along with local health and community professionals.

For further information and to book, please visit: www.mnd.asn.au/health-professionals

CARING AND SHARING

By Maureen, past carer and MND Victoria volunteer

As I sit and reflect over the past few years
Some days full of hope, others full of fears
My mind wandered back to how things used to be
And a voice in my brain asked why did this happen to me?
But happen it did and I couldn't alter that fact
However one thing I could change was the way I react.

I wasn't the person with MND but I lived with it just the same
I went through all the emotions of the heart and I felt the pain
But we lovingly cared for each other and shared each brand new day
And together we tackled the obstacles that often came our way.

Now some days seemed like a journey of endless miles
When hours were full of tears instead of happy smiles
But I tried not to let that get me down feeling sad and blue
Cause there were lots of other things I knew that I could do.

I wanted to be a support when things didn't go right
And I wanted to be a beacon on the darkest night
I wanted to calm the waters when there was fear
I wanted to be able to wipe away each and every tear.

Now some things I could do and with others I needed a hand
But I wasn't afraid to ask when things didn't go right to plan
I was not on this journey alone, as help abounded you see
As somehow, somewhere we have all been touched by MND.

Yes, MND is a terrible disease of that there is no doubt
And at times we may question the way some things turned out
But we are only on this earth just once, there is no second chance
So let's make each day count in what can be termed life's dance
And "Caring and Sharing" made our journey a little easier to do
Now I hope and pray our philosophy will work for others too.



38TH MND VICTORIA ANNUAL GENERAL MEETING

You are invited to join us for the **38th Annual General Meeting of MND Victoria on Monday, 28 October at 11am** at MND Victoria, 265 Canterbury Road, Canterbury. Come along and hear about our last year and our work supporting people living with motor neurone disease.

Guest speaker A/Prof Peter Crouch will present on the Copper-ATSM trial.

The meeting will be followed by a light lunch. Please RSVP for catering purposes by 24 October, phone: (03) 9830 2122 or email: info@mnd.asn.au

SLEEP DISTURBANCE IN MND

Sleep disturbance is commonly experienced by people with MND which adds to the burden of the disease for both the person concerned and their carer.

Disrupted sleep can be caused by physical symptoms, such as muscle cramps, pain, reduced mobility, spasticity, mucus retention, and restless legs syndrome. Depression and anxiety may also lead to insomnia.

The timely introduction and use of mechanical ventilation is one of the most significant therapeutic measures available to prolong life span in people with MND. Non-invasive respiratory support can improve sleep quality and reduce day time exhaustion or sleepiness. It is recommended that a referral to a specialist respiratory physician be obtained soon after diagnosis so that baseline measurements of breathing function can be

performed and an assessment made regarding the suitability of using non-invasive ventilation. Anyone with MND who is experiencing sleep disturbance should discuss this with their treating doctor and have it investigated in order to identify the cause and any measures that can be taken to improve or stabilise quality of life.

Carers need good sleep too. The role of carer can be demanding and stressful which in turn can affect sleep. Disturbed sleep or insomnia is a common sign of stress which can impact on a carer's resilience and ability to look after the person they are caring for. Seeking respite care and other support such as counselling may be helpful in dealing with stress and getting the necessary rest to be able to function well.

The MND Australia website has further information on sleeping better: www.mndaust.asn.au/Get-informed/I-have-MND/Living-better

GROUP PROGRAMS

Please contact MND Victoria to register your interest in our group programs for people with MND and their carers: 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.

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: <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. To join, go to Facebook and search for: "MND Angels Australia" or visit: <https://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 ph. 02 8877 0902

Kennedy's Disease Facebook Group: Did you know that MND Victoria also provides support for people in Victoria living with Kennedy's Disease? One of our members has shared a Facebook group for Australians with, or affected by, Kennedy's Disease:

www.facebook.com/groups/3407816342962036/

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



THE LIGHTHOUSE PROJECT IS MOVING INTO LARGE PHASE 3 CLINICAL TRIAL

The Lighthouse Project will soon move into a large Phase 3 clinical trial. The project is investigating whether the HIV drug Triumeq is effective in treating people with MND. This project was partly funded through the MND Research Institute of Australia which includes research funding from MND Victoria.

Professor Julian Gold (*photo right*) and his team are investigating whether human endogenous retroviruses (HERVs) may play a role in motor neurone disease (MND) and whether targeting HERVs might provide a novel therapeutic avenue. This was the first Phase 2 clinical trial in the world to use modern combination anti-retroviral therapy in patients with MND.

The summary results show that Triumeq appears to be safe and well tolerated in patients with MND.

It has considerable administration advantages as a single once-daily tablet which can be taken either whole or crushed.

Moreover, it is already licensed for HIV treatment and is available in most countries.

Initial results indicate Triumeq may have a biological effect both clinically and on biomarkers in patients with ALS, and all effects appear to be positive.

However, this was only a small study and a much larger international multicentre phase 3 placebo-controlled

trial is now planned to determine if Triumeq improves both survival and clinical progression. This definitive trial will be conducted in Europe, the UK and at five sites in Australia. It is hoped this trial will begin early in 2020.

For further information about the Phase 3 trial and recruitment, please discuss with your neurologist.

Further information about the project is available on the MND Australia website:

www.mndaust.asn.au/Discover-our-research/Latest-research/Clinical-trials/The-Lighthouse-Project



VOLUNTEER NEWS!



MND Victoria Volunteers Care

MND Victoria volunteers come from many different backgrounds and bring many skills and experiences to their work with the organisation. All of our volunteers share the quality of caring for others and many come to volunteering with MND Victoria following their own experience with a friend, relative or loved one with MND.

Colleen (*photo below*) has been volunteering with MND Victoria for three years and is now active in a number of roles including mailout days for MND News, administration support within our volunteer programs and being one of our team of Bereavement Call volunteers.

In her Bereavement Call role Colleen works from home to make a call to family members of clients who have passed away. Colleen's call lets that person know MND Victoria is still thinking of them, provides an opportunity



to check in on how they feel they are going, and offers links to further support if needed. Colleen notes that listening to people's stories is always worthwhile.

When asked why she volunteers – Colleen says that she has skills and time and motivation that she felt could benefit the work of the organisation. She also notes volunteering has benefits for herself and her husband. Colleen comments – "I am a carer for my husband and I need to get out and he needs me to get out – we both need that space – it's just a win-win."

We feel honoured to have Colleen as one of our fabulous team of volunteers.

VOLUNTEER OPPORTUNITIES

Walk to D'Feet MND



Preparation and planning is underway for our Melbourne and regional Walk to D'feet MND events. Once again, volunteers are busy at our Canterbury office responding to orders for t-shirts and merchandise for each of our walks. The Melbourne walk and walks in regional areas are only possible because of the time and commitment given by teams of volunteers who are dedicated to raising awareness, raising funds and supporting and acknowledging loved ones.

If you would like to be involved as a volunteer at one of our walks please contact us.

The Melbourne Walk to D'Feet MND is on Sunday 17th November 2019. There are still spaces available to be involved as a volunteer on the day. You can even combine volunteering and participation in the walk.

Volunteer roles are available include assisting with registrations, t-shirts, merchandise and as a course steward. If you would like to be involved, call Deb on 9830 2122 or email volunteer@mnd.asn.au

Outer Eastern and Yarra Ranges Region Massage Volunteers and Life Stories Volunteers needed.

Requests are growing in the Outer Eastern and Yarra Ranges Region for volunteers to assist clients with hand and foot massage and life stories. We have a number of very dedicated volunteers in the area but, even with their support, we currently have a waiting list for people seeking regular massage and assistance to write their life story.

If you have a love of writing and are interested in people's stories, our Life Stories volunteer role may be for you. Life Stories volunteers are matched with a client to work with over a number of months, capturing their stories and developing them into a personalised book which is printed just for them and their family. MND Victoria provides training and ongoing support for our Life Stories volunteers.

Massage Volunteers are matched with a client who they meet with regularly to provide a gentle massage of their hands and sometimes their feet. Again MND Victoria will provide you with training to be a Massage Volunteer and ongoing support in your role.

For more information about becoming a Life Stories Volunteer or a Massage Volunteer with MND Victoria call 1800 806632 or email volunteer@mnd.asn.au

Deb Olive - Coordinator of Volunteer Programs

HAVE YOU CONSIDERED LEAVING A GIFT TO MND VICTORIA IN YOUR WILL?

The financial impact of MND on families is huge. Careers end for the person with the disease as well as their partner or parents who often choose to become full time carers. For those aged over 65 when they are diagnosed, the financial impact is even greater.

Your gift (bequest) to MND Victoria in your Will is a lasting legacy which will make all the difference to people living with motor neurone disease.

Making a Will is an important way to secure the future of your loved ones. Once you have done this, if you then leave a bequest to MND Victoria, you are making a promise to be there for those families who will be impacted by the disease in the future.

Please contact our Supporter Development Manager, Kathy, for further information: fundraising@mnd.asn.au

INTERNATIONAL SYMPOSIUM ON ALS/MND, PERTH 2019

The International ALS/MND meetings will be held in Perth from 1-6 December 2019.

'Ask the Experts' on 2 December, is a free session for people with MND, their friends and families and the wider MND community to hear about the latest research and clinical developments.

The Allied Health Professional Forum is on Tuesday, 3 December, followed by the International Symposium on ALS/MND which will be held from 4-6 December.

www.symposium.mndassociation.org



A NUMBER OF VOLUNTEERS WHO REGULARLY WORK AT THE CANTERBURY OFFICE TRAVEL FROM THE YARRA RANGES AND MAROONDAH REGIONS. JOHN AND MARIAN, TWO OF OUR LONG TERM VOLUNTEERS, HAVE MADE THE TRIP SO REGULARLY, THEIR CARS NOW DRIVE HERE ON AUTOPILOT!

More Massage and Life Story volunteers are needed in this area, please email: volunteer@mnd.asn.au to find out more!

The furthest town to which Rachel drives to visit clients is **107 kms** away.

IN THE LAST YEAR RACHEL PROVIDED **743 HOURS** OF SUPPORT TO PEOPLE WITH MND.



Steph is the first of our 12 Charity TV Global ambassadors to reach the \$10,000 fundraising milestone and we are incredibly thankful and proud of her achievements thus far. Steph has worked so hard selling scrunchies and other MND Victoria merchandise at various local markets and netball centres, hosting movie nights and using all of her networks to generate donations. Steph is doing this in honour of a great family friend who has the disease and she knows her efforts are truly valued. Steph can be found most weekends out and about in the Eastern suburbs adding to her already incredible fundraising tally.



10 VOLUNTEERS WORK WITH PEOPLE WITH MND IN THIS REGION. THEY VISIT PEOPLE WITH MND, WRITE LIFE STORIES AND GIVE HAND + FOOT MASSAGE.

MOST PEOPLE IN THIS REGION ATTEND THE STATEWIDE PROGRESSIVE NEUROLOGICAL DISEASE SERVICE AT CALVARY HEALTH CARE BETHLEHEM. THE CLINIC OFFERS A RANGE OF MULTIDISCIPLINARY ASSESSMENT, EDUCATION & MANAGEMENT SERVICES.

**All services and equipment needed by people with MND can be accessed in all rural areas of Victoria - please discuss your needs with your MND Advisor + Support Coordinator or Allied Health Professional **

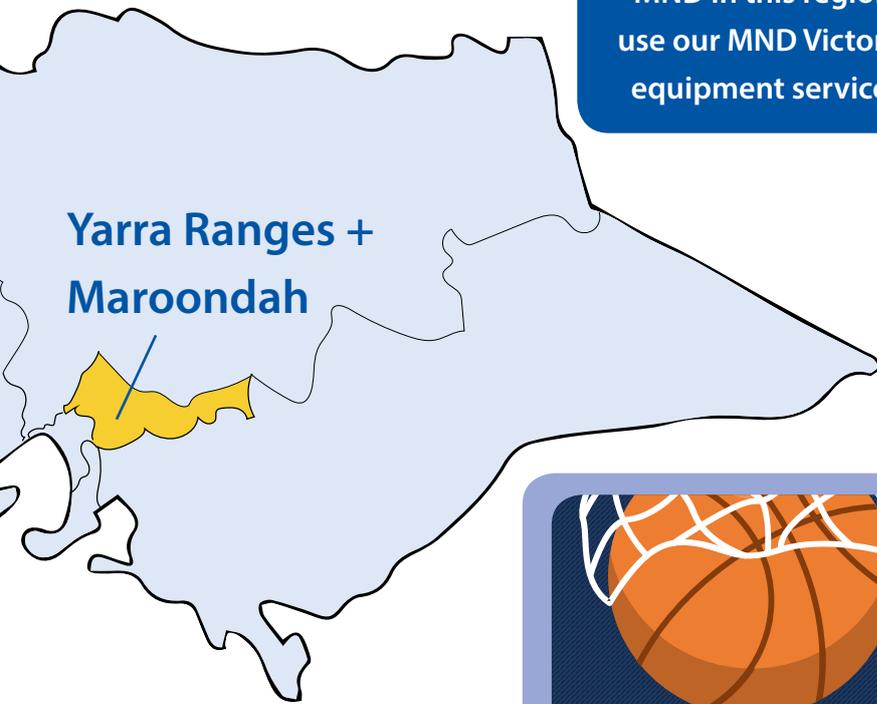


RACHEL - MND ADVISOR
+ SUPPORT COORDINATOR

36 PEOPLE WITH MND
CURRENTLY LIVE
IN THIS REGION

14 clients in this area access the NDIS, however 22 clients are stuck with the 'My Aged Care' system which fails to meet the needs of people with MND. Please join the campaign to Make Aged Care Fair: www.mndaction.org.au

80% of people with MND in this region use our MND Victoria equipment service.



Yarra Ranges +
Maroondah

Last year, we had the pleasure of being invited to speak at Maroondah Rotary's monthly meeting to talk about MND and how important the services provided by MND Victoria are to everyone living with the disease. Certain members of the Rotary club have supported the work of MND Victoria for a number of years. We are very thankful for the invitation and we were very fortunate to be presented with a \$2000 cheque at the conclusion of the evening.



Local member for Ringwood, Dustin Halse, and some fellow MPs, hosted the 'Shoot Hoops for MND' Day down at Norwood Secondary College. They were joined by some Ringwood Hawks basketball players to raise some funds and awareness for MND during MND Week in May. A lot of fun was had during the hour long event where money was pledged for every basket scored. We thank Dustin and his team for making a difference to Victorians living with motor neurone disease.

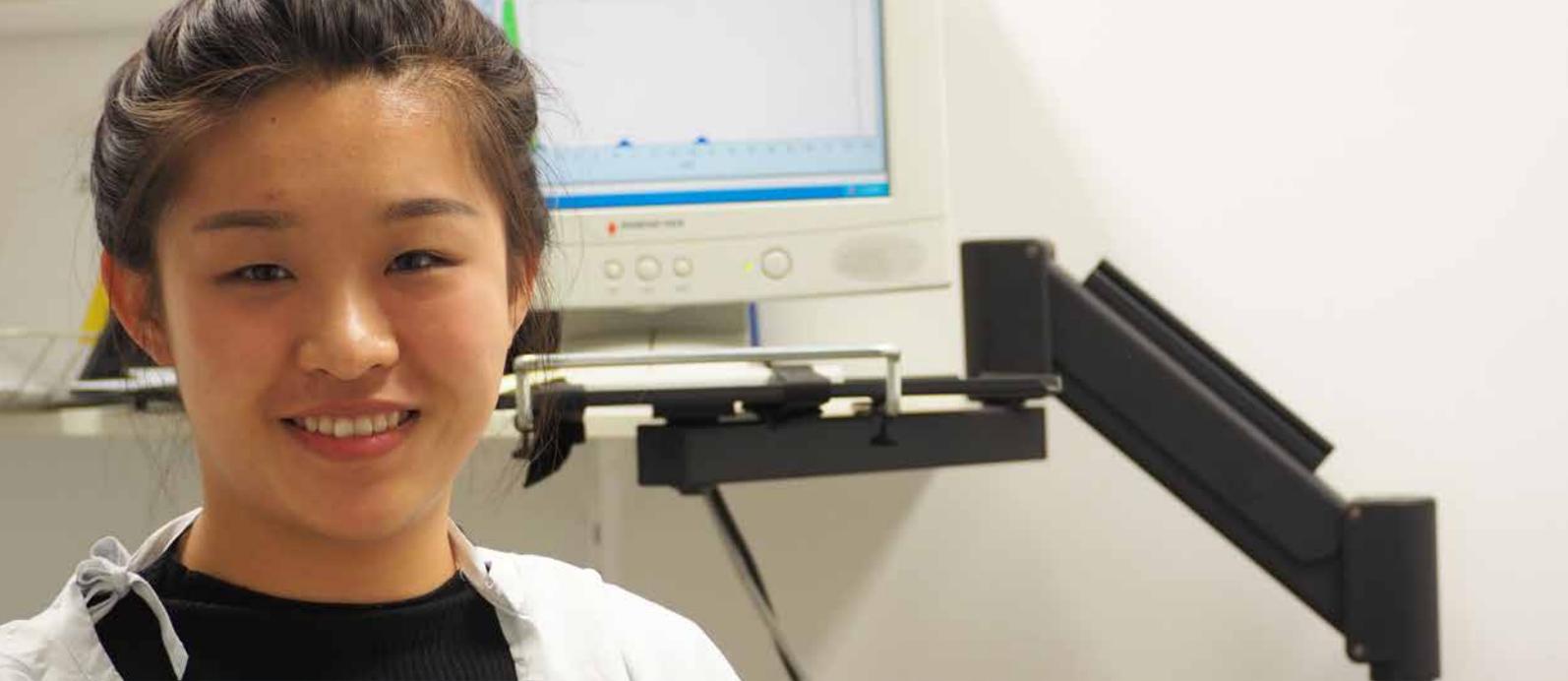


Lilydale Cricket Club has hosted the 'Lilydale Little Chill Ladies Day' for MND for the past 2 years. This is in honour of a club legend who passed away last year from MND and is a great day out where awareness and funds are raised for MND Victoria. We are so thankful to the club, the local community and the amazing organisers who put on a fantastic event!

If you live in this area (or anywhere in Victoria!) and would like to hold a fundraiser at your local sporting club, school, workplace, or with your friends and family, please contact our fundraising team for support and to get started: fundraising@mnd.asn.au



Our Volunteers have been involved at the **Wandin Park Equestrian** event for six years now where donations are taken upon entry to support people living with MND.



HOW CAN I HELP MND RESEARCH?

Exercise and MND study

Researchers from the Institute for Health and Sport (Victoria University), in collaboration with neurologists at Western Health, want to better understand the role of personalised exercise training in patients with MND. Patients will participate in a supervised exercise training program in Footscray three times a week for 12 weeks. For further information about this project, please contact: Dr. Alessandra Ferri, Ph: 03 9919 4756 or email: alessandra.ferri@vu.edu.au

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

IDENTIFYING AND ADDRESSING THE SUPPORT NEEDS OF FAMILY CARERS OF PEOPLE WITH MOTOR NEURONE DISEASE

By Professor Samar Aoun, Public Health Palliative Care Unit, La Trobe University, Melbourne. Perron Institute for Neurological and Translational Science, Perth.

Family carers of people with MND often describe their caring experiences as unrelenting due to the progressive nature of the disease and the hopelessness of recovery compared to cancer. Studies have reported that family carers suffer from anxiety, depression, strain, burden, fatigue, impaired quality of life and reduced social contacts. Whilst management of physical symptoms in MND is paramount, attending to such family carers' psychosocial factors is crucial to prevent deterioration in their health and wellbeing. Most individuals with MND live at home, where their psychosocial functioning is intimately connected to the extent and quality of support they receive from family members.

Notwithstanding the physical, psychological and emotional burden of the disease on MND family carers, the Deloitte Access Economic Report (2015) has quantified the economic disadvantage on families supporting people with MND, who provide an estimated 7.5 hours of informal care per day to people with MND. The productivity loss due to such informal care in Australia was estimated to be \$68.5 million in 2015, with individuals shouldering most of these costs (\$44.0 million), and with government bearing the rest (\$24.5 million).

This further highlights the disadvantages in all aspects that MND family carers shoulder during the disease journey. Therefore, it is imperative that MND Associations identify and address the support needs of family carers as distinct from the patients and in a consistent and systematic manner.

A pilot study, conducted in collaboration with the MND Association in WA, revealed that the top five support needs reported by family carers were: **knowing what to expect in the future (83%), knowing who to**



contact if concerned (71%), equipment to help care (66%), dealing with your feelings and worries (58%) and having time for yourself in the day (58%).

The proposed solutions (action plan) put in place by the care advisors for “**knowing what to expect in the future**” consisted of discussions around end of life issues, advance health directives and future care and the role of palliative care.

For the second priority on “**knowing who to contact if concerned**”, discussions centred around ambulance cover, referral to palliative care services, and a contact number at night/weekend.

For the third priority on “**equipment to help care for your relative**”, information was provided on the Association's equipment pool and possibility of financial help for hire of equipment if required; a bedside commode being provided to aid with deteriorating mobility; and liaison with a disability service to provide the next level of bathroom modifications.

The solutions put in place for “**dealing with your feelings and worries**” consisted of information on various avenues for counselling and encouragement to attend the Association’s carer luncheon for social support.

For the fifth priority on “**having time for yourself in the day**”, care advisors liaised with service providers to increase hours available for respite, discussed strategies for creating time for the carer, and encouraged the carer to allow more people to help with relative’s care, giving carers more time for themselves.

Carers found that this approach has adequately addressed their needs in a timely manner and it

gave them a sense of validation, reassurance and empowerment. Care advisors advocated this approach as an improvement to standard practice, allowing them to more clearly assess needs and offer a more structured follow-up and a focus on the carer and family.

Where to from here? There is currently planning for a national collaborative initiative to implement such a supportive model of care for family carers in all MND Associations and MND Clinics. So stay tuned! After all, until there is a cure, there is care.

A huge thank you to all the carers who completed the survey for this research project.

BENDIGO WALK TO D'FEET MND

10.30am Sunday, 24 November 2019 at Lake Weeroona Park

Show your support for people living with motor neurone disease and raise funds for care, equipment and research at our Bendigo Walk to D'feet MND!

This is an easy approx 3km flat walk, wheelchair, pram and dog friendly ...

Find out more and get started: www.mndwalk.org.au



FUNDRAISING



"I believe that we all have a responsibility to give back. No one becomes successful without lots of hard work, support from others, and a little luck. Giving back creates a virtuous cycle that makes everyone more successful." Ron Conway, USA, 1951-

When we ask our supporters why they want to raise funds for MND Victoria, the most frequent response is that they "want to give back" to the organisation that helped and supported their loved one through their MND progression.

MND Victoria was established in 1981 to provide care and support to people living with MND. Thirty-eight years later this is still our major goal and we are continually enhancing the services we provide. These services include supporting individuals and families as they negotiate access to support from the NDIS and Aged Care systems. In addition, access to MND Victoria's assistive technology devices can make life more tolerable and safer for people living with MND, as they are empowered to maintain their independence and participate in family and community activities.

Comments from our recent Quality Survey reflect how vital this care and support is to people facing the daily challenges of MND. **"What has amazed me is the quality of all staff, both early after diagnosis and ongoing assistance when required" and "All equipment given to us has been a wonderful help. We would not have coped without the equipment service".**

Empowering people with MND to live the best quality of life possible during disease progression means ensuring access to these vital services as soon as possible once identified. Fundraising, through a variety of activities, continues to underpin the Association's finances, and fundraising, paid services and investment contributed 75% of total income in the past year. This is why the Supporter Development team exists – to raise awareness of our fundraising needs and support everyone who raises funds for us. Every dollar raised is important because it helps families today!

Last year I answered some frequently asked questions about "how do we raise funds and where does our donation go?" and I thought it worthwhile to repeat some of these today.

Frequently asked questions about fundraising and 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, it can be as simple as holding a Drink Tea for MND at your work/school to organising a ball – and everything in between. The Supporter Development Team at MND Victoria is ready to help!

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 we can help you set up your fundraising page. PLUS MND Victoria has its own annual Challenge Event. Last year it was Trek Kokoda which raised \$55,000. This year 18 people are taking part in the Larapinta Walk to D'feet MND and we estimate over \$100,000 will be raised from this event. Three really fit people are taking part in the New York City Marathon and each have committed to raising a minimum of \$10,000 for the Association.

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 fundraising activity sponsored by the Association, so we encourage

everyone to put together as big a team as possible and set a challenging fund raising goal. If you're interested in setting up a walk in your local area, 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. Please contact us at: fundraising@mnd.asn.au

4. What is the difference between MND Victoria, MND Australia and Fight MND? Do all donations end up in the same place? We understand that people can be confused between the different organisations focusing on motor neurone disease. Often people think they are all the same organisation – but this is not the case. It is fabulous that MND has so many supporters and organisations focussing on MND, and we all have a shared vision of "a world without MND". However, it is important to know which organisation is which and where and how your donation will be used, so you can make an informed decision.

All aspects of the work of these three organisations are important.

MND Australia was established in 1991 as the national body for people living with MND, with a mission to promote and support international best practice and evidence based care and support for people living with MND and their families throughout Australia. MND Australia does this through its advocacy to government and other bodies for better support for people with MND and through its research arm, the MND Research Institute of Australia, which funds high quality research that aims to identify the cause, lead to better care, treatment and ultimately a cure for MND.

Fight MND was established in 2014 with the purpose of finding effective treatments and ultimately a cure for Motor Neurone Disease. FightMND has done an excellent job in raising awareness of MND, particularly in the general community, as well as raising over \$30 million from individuals, Corporations, State and Federal governments. They have funded a number of Australian researchers and research programs, as well as clinical trials.

Funds donated to MND Australia or Fight MND are not distributed to MND Victoria.

MND Victoria was founded in 1981, with a mission to provide and promote the best possible care and

support to people living with motor neurone disease – including people who have been diagnosed, those yet to be diagnosed, carers, former carers, families, friends, workmates and any other person whose life is, or has been, affected by a diagnosis of MND. We do this through:

- Providing and promoting the best possible care and support to people living with MND
- Improving community awareness and support of MND Victoria
- Being the expert voice for MND and the needs it creates
- Promoting and supporting research into care, support, treatment and cure for MND

MND Victoria is the only organisation that focuses on providing a comprehensive range of care and support to people currently living with MND to help them to live as well as possible for as long as possible.

Donations to MND Victoria help us to continue to provide these essential services at no cost to the individual or their families.

We look forward to the day when there is a cure for MND and until that day we will continue to do everything we possibly can to support those living with the disease because, until there's a cure ... there's care.

AROUND THE STATE ...

Charity TV Global update:



We have 12 Charity TV Trip Ambassadors who are starting to get into full swing with their fundraising campaigns. We are thrilled to have such dedicated individuals making up our team who will be experiencing a week long 'adventure' in March next year. Their goal is to raise a minimum of \$120,000 between them and, with 6 months to go, they are

just about half way which is a tremendous effort! Steph Cross is the first ambassador to reach the individual \$10,000 target. Steph has been working tirelessly selling scrunchies and various MND Victoria merchandise, hosting movie nights and really using her many networks to raise funds and awareness. We can't wait to see our team's fundraising plans come to fruition over the coming months. Our first Charity TV Global campaign is shaping up to be a huge success!

24 Hour Bike Ride and Breakfast:

Robert Pitman was a very popular and respected figure in the Ballarat community. His passing from MND a couple of months ago triggered a wave of support for Robert's family and MND Victoria. Two Ballarat locals and mates of Robert, who wanted to make a difference, were Tavis and Peter. Both knew Robert through their shared love of cycling so they decided they would ride their bikes 600km in 24 hours on August 31st.

They endured ordinary weather and, in particular, very gusty winds, but they managed to complete their goal with the great support of family and friends. Two weeks prior to their ride, they hosted a breakfast to raise further funds and awareness for the disease and MND Victoria in the community.

Tavis and Peter have managed to raise over \$15,000 in honour of Robert. We can't thank them enough for all their efforts. The focus is now turning to an even bigger event in December where they plan to ride with up to 100 others from Ballarat to Lorne!

Terry Johal:

We had the pleasure of meeting Terry at his home to thank him for his fundraising efforts and to learn more about his incredible life.

Terry has lost nearly all of his ability to move and speak but his mind never stops. He decided to create a fundraising page to help the organisation that has helped him since his diagnosis. Through the generosity of friends and family, \$23,482 has been raised which is an incredible result! Terry is also writing a blog about his phenomenal life and his journey with MND. It is an amazing read and can be found at:



**EMBRACE
THE CACTUS**

www.embracethecactus.com "Dealing with the diagnosis of Motor Neurone Disease is hard enough, figuring out what comes next is daunting. There are a variety of medical people to deal with - a multi-disciplinary team of occupational therapists, physiotherapists, speech therapists, dieticians, various nurses, neurologists, respiratory specialists and the list goes on. And there is a range of equipment that is needed, which changes as the disease progresses. MND Victoria helps by providing an Advisor to navigate through the labyrinth. They also provide any equipment needed to help people with MND improve their quality of life. From crutches, walking frames to wheelchairs and specialised beds. And all for free.

The support and help from MND Victoria has been invaluable for my family and me. It would have been so much more painful without the organisation. I would appreciate any funds that you can give so that MND Victoria can continue to help people with MND. Thank you."

Never Give Up Bike Ride:



On 18 October approximately 30 riders will be embarking on a monster challenge by riding 300km from Hoppers Crossing, Victoria to Tocumwal, New South Wales over 3 days. No rider is what you would call 'experienced' but they all have plenty of passion and motivation to ride for all Victorians living with MND. Like many of our amazing fundraisers, MND has directly impacted the families of some of the riders. They understand the difficulties those with the disease face, so a challenge like this is the least they can do to show support for loved ones and raise funds so that MND Victoria can continue to provide care, support and vital assistive equipment for their loved ones and every other Victorian living with the disease. So far, the group has raised just over \$10,000! We wish them well for their ride and thank them for everything they are doing for those living with MND!

CORNFLOWER BLUE GIFT CARDS

\$15 PER
PACK OF
8 CARDS

ALL purchases help provide **VITAL care + support** for people with motor neurone disease and fund research.



CHRISTMAS
GIFT STICKERS
\$5 PER SHEET!



Order yours online today at: www.mnd.asn.au/gear or phone: 03 9830 2122



ALL NEW 'NEVER GIVE UP' TIGHTS!

\$55 EACH (INC POSTAGE)

Perfect for your yoga session, pilates class or our Walk to D'feet MND!

ALL purchases help provide **VITAL care + support** for people with motor neurone disease and fund research.

Order yours online today at:

www.mnd.asn.au/gear

or phone: 03 9830 2122

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



WALK TO
D'FEET
MND



10am, Sunday 17 November 2019 Oval 3, Princes Park, Carlton

Adults \$40, Children \$10 (5-18yrs), Families \$80 (2 adults + 1 child), \$90 (2 adults + 2 children)

3.5km walk on the footpath around Princes Park Carlton (Mel 2B D1). Plus: Free Walk to D'Feet MND T-Shirt, Face painting, Sausage Sizzle, Raffle, Music, Disabled Parking for people with MND.

Awards for: "Best" dressed team, Biggest team, No 1 fundraising team, No 1 individual fundraiser

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

Take this opportunity to 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.



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

Registration Form

Please complete details for each participant and mail form with entry fee by 6 November, to:

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

Save time - register and order Walk T-Shirts on line:
<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 Pre-register by 6 November or register on-site	NUMBER	COST
Adult \$40		
Family (2 adults + 2 children <i>NB Child is aged 5 – 18 years</i>) \$90		
Family (2 adults + 1 child <i>NB Child is aged 5 – 18 years</i>) \$80		
Additional child \$10		
Merchandise: <input type="checkbox"/> Bandanas \$8		
<input type="checkbox"/> Dog Leads [<input type="checkbox"/> Large <input type="checkbox"/> Medium or <input type="checkbox"/> Small] \$12		
My Donation (over \$2 tax deductible)		
	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 received by 6 November. Registrations received after 6 November, T-shirts can be picked up on site.

Please indicate the number of t-shirts required in the box next to the sizes required:

<input type="checkbox"/> 4XL	<input type="checkbox"/> 3XL	<input type="checkbox"/> 2XL	<input type="checkbox"/> XL	<input type="checkbox"/> L	<input type="checkbox"/> M	<input type="checkbox"/> S	<input type="checkbox"/> 14	<input type="checkbox"/> 12	<input type="checkbox"/> 10	<input type="checkbox"/> 8	<input type="checkbox"/> 6	<input type="checkbox"/> 4
Adult Sizes							Children Sizes					

DONATIONS RECEIVED ... THANK YOU!

Corporations

Advanced Orthodontics
Arcare Malvern East Aged Care
Express Insurance Brokers
Phoenix Hotel
Specsavers
PayPal Giving Fund
Australian Government Department of Human Services
Dyson Group of Companies
Garth Lisle Property Consultants
UBS AG
Moonee Ponds Staff Welfare Fund
Les Penna Motorcycles

Associations

Loch Sport Business & Tourism Association Inc

Clubs

Werribee Districts Football Club
Leopold Sportmans Club
Eaglehawk Football Club
Strathfieldsaye Football Club
Craft Ladies of the Combined Probus Club of Monash Central
The Country Women's Association of Victoria
Lions Club of Leopold Inc
Hoppers Crossing Apex Club

Lions Club of Geelong Breakfast Inc
Ballarat Scrabble Club
Roseville Craft Group
Country Women's Association-Yarrawonga Border Branch

Trusts

Pethard Tarax Charitable Trust
Joe White Bequest

Churches

Men's Society Group of St John's Anglican Church

Bequests

The Estate of George Findon Miller
The Estate of Yvonne Lesley Turner
The Estate of the Late Helen Jean Burgess

In Memory

Andrew Stafford
Annie Melican
David Liersch
Donna-Maree Jackson
Frank Keen
Geoff Fletcher
Geoffrey Woodrow
Graeme Furphy
John Jarvis
John Ray

John Reid
Jozef Jablonski
Kevin Pagram
Leonie Marston
Mervyn Arthur Coates
Neville Hesketh
Raymond Bannister
Robert Pitman
Sam Salvatore Calafiore
Sandra McKeann
Stuart William Smith
Sylvia Ellis
Theresa Dal Santo
Tony Werner
Vicki Bowes

Schools

Eastbourne Primary School
Briagolong Primary School
Lang Lang Primary School
Streeton Primary School
Emerson School
St Peter Julian Eymard Primary School
Ouyen P-12 College

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 2019?

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 6 November for the next edition, to be mailed on 3 December 2019.

GET INVOLVED IN AN EVENT NEAR YOU!

Date:	Event:	Find out more:
Wednesday, 9 October 2019	MND Information Session	Email: info@mnd.asn.au
Friday, 11 October 2019	Ballarat Health Professional Forum	Email: info@mnd.asn.au
Sunday, 13 October 2019	Melbourne Marathon	Email: fundraising@mnd.asn.au
18-20 October 2019	#NeverGiveUp Ride from Hoppers Crossing to Tocumwal	Email: fundraising@mnd.asn.au
Monday, 28 October 2019	MND Victoria Annual General Meeting	Email: info@mnd.asn.au
Sunday, 3 November 2019	Rosebud Walk to D'feet MND	www.mndwalk.org.au
Sunday, 3 November 2019 (US timezone)	MND Victoria's New York Marathon Challenge	Email: fundraising@mnd.asn.au
Sunday, 17 November 2019	Melbourne Walk to D'feet MND	www.mndwalk.org.au
Thursday, 21 November 2019	MND Information Session	Email: info@mnd.asn.au
Sunday, 24 November 2019	Bendigo Walk to D'feet MND	www.mndwalk.org.au
4-6 December 2019	MND International Symposium, Perth	www.symposium.mndassociation.org
Sunday, 22 March 2020	Geelong Walk to D'feet MND	www.mndwalk.org.au
Sunday, 3 May 2020	South East Melbourne Walk to D'feet MND	www.mndwalk.org.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