

MND NEWS

November/December

2019



The newsletter of the
Motor Neurone Disease
Association of Victoria

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



LARAPINTA
TREK RAISES
\$106,043!

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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

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

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 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	Jenny Waites	Lauryn Matheson
Trish Duffy	Melissa Kettle	Michelle Sharples
Fran Hurst	Sam Mitchell	Jenny Fuller (Hobart)
Julie Wilson	David Cox	Emma Wilkinson-Reed (Launceston)
Lesley Burcher		

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



December in Australia brings summer and the festive season. Christmas is a time for family and celebration – but it can also be a difficult time for many, including people in need of care and support and those who have lost a loved one.

It can be a time when services are reduced and less formal support is available. I encourage you to speak up and ask for the help and support you might need from family and friends across this time. If someone says “Let me know if you need help with anything,” take them up on it - have a list of ways in which people might make this time a little easier for you and your family. Could they cook you a meal, do some shopping or gardening, pop in for a cuppa and a chat? Often people really want to help, but don't know how best to do so. Don't be afraid to ask.

MND Victoria held our **38th Annual General Meeting** on 28th October. Many thanks to those members and supporters who attended. Highlighted in the presentations at the AGM were the provision, by MND Victoria, of **support for 655 people with MND** in Victoria and Tasmania across the 2018/19 financial year, our investment of **over \$350,000 in research** into the causes, treatment and cure of MND and our achievements in **raising over 76% of the funds** used for the provision of care and support through fundraising and fee for service activities. Following the

formalities, our guest speaker, **Associate Professor Peter Crouch** provided an update on the Copper ATSM trials and the move to Phase 2 of the trial which evaluates the efficacy of the drug. Peter's presentation was informative and engaging and we thank him for his time and for sharing his knowledge.

If you would like a copy of our Annual Review, please contact the office, email info@mnd.asn.au or visit: **www.mnd.asn.au/about-mnd-victoria/annual-review**

We have seen two 'Walks' happen in November. Our **Rosebud Walk to D'Feet** was held on the 3rd of November and our **Melbourne Walk to D'feet MND** was held on 17th November and both were a great success. Walks are a great way for people impacted by MND to come together, meet each other, support a person living with MND, and remember and celebrate the life of a loved one whilst helping to raise the much needed funds for care and support of people living with MND. We thank the dedicated volunteers who organise these terrific events and everyone who attended.

As this newsletter goes in the mail, a number of the staff at MND Victoria are headed for Perth for the **MND/ ALS Allied Health Professionals Forum**, held in conjunction with the International Symposium. This is an excellent opportunity to hear more about the work of Allied Health professionals supporting people with MND across the globe. Our **Nina Buscombe Awards** have also supported 43 allied health professionals and researchers to attend the conference in Perth. We will provide an update on the forum and symposium in our next newsletter.

MND Victoria's offices will be closed from 25th December to 2nd January.

From our families to yours, we wish you all the best for the festive season. At MND Victoria we look forward to working with you to continue to provide the best possible care and support for people living with MND. Our thoughts are with those whose family members or friends were overwhelmed by MND this year and we look forward to finding cause, treatment and ultimately a cure.

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

Kate

SUPPORT SERVICES



There is a lot to share – here is a snapshot!

Support Services Staffing:

The team is growing and forever changing! A quick snapshot of the changes in the MND Advisor and Support Coordinator Team is:

- **Julie Wilson** (*photo right*) has stepped into a newly created role covering the northwest metro areas of Melbourne.

Julie has been working at Melbourne City Mission for the last 3 years as a Palliative Care Nurse specialist, and prior to that was at RDNS (as it was then, now Bolton Clarke!) for 10 years as a clinical nurse consultant in the palliative care team.



- **Rachel Ritchie**, covering the Metro Outer east area, has left us and **Michelle Sharples** (*photo right*) started in this MND Advisor and Support Co-ordinator role on 11 November. Michelle has

been working in the community disability sector for many years, most recently with Vision Australia.



- **David Cox** commenced with us on 25 November and will be covering the Peninsula and South

East Melbourne metro area. David has been working for South Eastern Palliative Care for over 10 years in a number of roles, including Volunteer Coordinator, Community Welfare Worker and Carer Education Nurse.

- **Lesley Burcher**, who some of you may remember, (she worked for us for 19 years before retiring a year ago!), has returned in a casual capacity to help cover leave and vacant positions.
- **Emma Wilkinson-Reed** joined **Jenny Fuller**, our Advisor based in Hobart to complete the Tassie team on the 14th October and has been starting to get to know the clients in the North and North West regions of Tasmania. Emma is a registered nurse who has been working at the Launceston General Hospital for the last few years and has had experience of supporting people with MND in her nursing role.

Be Bushfire Aware...

It's great that the weather is getting warmer, but it also means we are moving into the fire season.

This message may have more or less relevance to you depending on where you live! Most of you will be prepared, but it is always good to have a reminder! Here are some things to consider:

- Every person and household in a fire danger area should have a fire emergency plan. Information about developing a fire emergency plan for you and your home is available on the internet or through your local government or emergency services office. In Victoria, the CFA Leave Early Plan is available at www.cfa.vic.gov.au/plan-prepare/your-bushfire-plan or by requesting a copy from the **Victorian Bushfire Information Line on 1800 240 667**. Tasmanian residents can access advice regarding the development of a fire plan at www.fire.tas.gov.au or by calling the **Tasmanian Fire Service Information Line on 1800 000 699**.
- Your fire emergency plan should include provision for any special needs "caused" by your MND. This may mean that you need more time to evacuate or leave your home, and should consider leaving earlier. If you are using a ventilator, you will need to ensure that battery backup is available and that you take all of the bits and pieces you will need

if you leave home and cannot return for a period of time. It is recommended that you attend the emergency services department of your nearest safe hospital and seek assistance. Please follow any instructions that have been issued to you by the Victorian Respiratory Support Service (VRSS/Austin Hospital). Similarly, take appropriate foodstuffs and equipment for PEG feeding.

- Emergency Services and the Police (authorities) have advised that it is NOT their role to assist in evacuating people from their homes. You need to make plans that are appropriate for your disability and leave early enough to minimise risk. In Victoria you can, however, request to be considered for listing on the Vulnerable Persons Register (VPR) which is a state government initiative to identify people who are vulnerable due to frailty or physical or cognitive impairment. However, listing on the VPR does not mean that you will be evacuated by the authorities in the event of a bush fire threat. The VPR will be used by the authorities for planning and responding to a range of emergencies where there are the capacity and resources to safely provide assistance. Please talk to your MND Advisor if you think you should have your name listed on the register and they will be able to assist you.
- Take key equipment with you if you are able. If you have an electric wheelchair, take the cushion as it can be used on other chairs. If you are unable to take your equipment, do not worry. As soon as possible, contact your MND Advisor to discuss the replacement of equipment if yours is destroyed or damaged.
- MND Association staff will call you after a fire in your area to ensure that you are safe and to offer assistance to address any unmet needs you may have.

I hope this does not happen to anyone, but please take every step to plan for the worst, and that, in the event a day is declared Code Red (Catastrophic), you will have already implemented your Bush Fire Plan.

Please note that on days declared Code Red (Catastrophic), MND Staff will not make any home visits. Be safe!

Christmas Office Closure

Our offices will be closed between Christmas and New Year. Therapists from Calvary Health Care Bethlehem have kindly agreed to organise any urgent repairs required for equipment on loan from MND Victoria during business hours over the period 27 to 31 December. Please contact Trinh Nguyen: 03 9595 3494

Best wishes for the upcoming festive season which is nearly upon us! Look after yourselves and each other. As always, we welcome your feedback!

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

Hobart Health Professional Forum



Our next MND Health Professional Forum will be held in Hobart on Friday, 27 March 2020 - please save the date!

If there is information or topics you would like covered at this forum, please email: **info@mnd.asn.au**

If you, or your colleagues, would like to join our mailing list to hear about future events and conferences for Health Professionals, please email: **info@mnd.asn.au**

MND INFORMATION SESSION

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

**7pm on Tuesday, 7 January at MND Victoria,
265 Canterbury Road, Canterbury.**

Please RSVP by 5pm, Monday, 6 January 2020.

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

Email: **info@mnd.asn.au** The following session is on Wednesday 19 February at 7pm.

ODE TO MY TONGUE

By *Fiona Ernst*

A note about me and my diagnosis. About 2 years ago I was diagnosed with MND at the age of 60.

I was in the middle of enjoying many new activities but was realising that I was exhausted all the time and stumbling quite often. Slowly I've foregone those activities only to pick up more that required less bouncing around.

What is left is reading, tapping on my PC and Netflix. It has been an eye opening experience in the health domain having hardly anything wrong with me over the decades.

My thanks go to all the teams; MND Victoria for their care, support and equipment, Northern Health for their care, support and expertise and NDIS for their financial support.

My sincere thanks and love go to my wonderful partner John-Paul, my wonderful family and my wonderful friends. I'm not going yet, I still have quite a bit of lung capacity left.

I am not afraid of dying nor the manner in which I go. Life is all about experience and connections.

Remember: We are all visitors to this time, this place. We are just passing through. Our purpose here is to observe, to learn, to grow, to love... and then we return home. Aboriginal Proverb.



Ode to my tongue after having bitten it once too often that day!

Bitten and knotted,
Discoloured, disfigured,
This muscle refuses to move.

It no longer forms
My mellifluous sounds
Nor shuffles the food round my mouth.

I don't mind the staggering,
Nor ragged writing,
But choking and grunting frustrate.

No point remonstrating,
Everyone is powerless
Against the decay of the spark.

Dysarthria is near
No longer to form words
Alas, my chords are near mute.

No matter for now,
That organ has served well
For three score years and more.

I've sung and I've screeched,
I've lectured, I've beseeched,
And to the many I've uttered my love.

Up there I'll not need
That bulbous reed
To let everyone know I am there.

A thought only is needed
To reach their ears so
To gather my loves to me

So thank you dear one for
Being a voice and a pump
For the nourishment of body and soul.

I have no more to say,
How feeble words are
When bliss is not far away.



VALE JOHN LAIDLAW AO, 10.06.32–08.09.19

People with MND, the scientific researchers, and MND Associations have lost a humane, caring and champion philanthropist who was a significant partner in the fight against MND.

Through John's leadership of Yakka, he promoted MND as a cause to his team and workers, and through his generous philanthropy made enormous contributions to MND care and research.

John and his wife Betty have been amazing supporters of MND care, support and research since Betty's diagnosis of primary lateral sclerosis (PLS), a slowly progressive form of MND, in 1984.

Their regular presence at meetings at our former South Caulfield office demonstrated their shared fight that so many people were undertaking. John's visits to Canterbury lifted his interest in, and engagement with, research, and the funding needed to advance the search for cause, treatment

and cure of MND, and to maintain the care and support people needed to live better for longer while fighting MND.

John, and the Laidlaw family, have donated over \$115,000 to MND Victoria care and support, and have invested over \$2 million into MND research through the MND Research Institute of Australia—significant personal financial contributions to benefit many.

In 2016, a \$1 million Betty Laidlaw Research Grant was awarded to neuroscientist, Dr Peter Crouch, to lead a multicentre team working on the drug copper-ATSM as a potential treatment for MND. This drug is moving into Phase 2/3 trial soon.

John will be a significant loss to Betty, his family and the MND community. We extend our heartfelt sympathies to John's family and friends, particularly his adored wife Betty who lives on with MND.

(Photo by MND Australia: John Laidlaw AO with Dr Marco Morsch, last year's Betty Laidlaw Prize winner.)



2019 VICTORIAN SENIOR OF THE YEAR!

Huge congratulations to Margaret Young who has won the '2019 Victorian Senior of the Year' award for her amazing volunteer work with Eastern Palliative Care, Vision Australia and the Smith Family. Margaret, who is now living with motor neurone disease, is truly an inspiration to all those she meets.

Our CEO, Kate Johnson, was delighted to attend the award ceremony held in October 2019.

Margaret wrote the following piece for her acceptance speech, "I love speaking in public. I have been known to wrestle a microphone from a colleague and, as an ex-TAFE lecturer, I could speak for 3 hours non-stop. But that voice has been taken from me by motor neurone disease, and now I must use another's voice, but I still have a lot to say.

At my secondary school, the Principal would regularly say, "Girls, from those to whom much is given, much

will be required." I confess I thought he was an old fossil. Now I find that I am of the same mind.

When I retired, I decided to volunteer and work for, and with, people who are frequently marginalised: people with disabilities, people who are financially disadvantaged and people who are dying. So I volunteered at Vision Australia, The Smith Family and at Eastern Palliative Care (EPC).

Volunteering is often seen as selfless, and indeed one does give a lot of oneself to it. In that regard, I guess I was echoing the philosophy of my school Principal: that is, giving back some of the blessings I have received in my life.

But there were other important aspects: I wanted to be challenged; intellectually and ethically. I did not want to be on the margins of society. I wanted to be engaged and still involved. And I have been.

To single out one of my volunteering roles – sitting with people who are dying is often challenging and sad, but

I have found during my 11 years of being a home visitor, that most people in palliative care are getting on with life, often with enthusiasm and joy. I have also found that it is a privilege to be invited into a dying person's life and to walk a little way with them.

And now I find myself in the same position. A friend asked me the other day "in your situation, where is the gold?" This was a searching question.

Indeed, there is gold to be found: in family, friends, nature, music, art, literature and in my continuing volunteering."

Eastern Palliative Care has been working with Margaret over the last 18 months since she was diagnosed with MND to film her journey. The footage will be turned into teaching videos for staff and volunteers around caring for clients with MND.

Thank you to Eastern Palliative Care for sharing this story with us and the beautiful photographs of Margaret!



GROUP PROGRAMS

Our next **Living Well Group Program** for people with MND and their carers will be running over 6 weeks commencing in February 2020. Participants will have the opportunity to share knowledge and discuss topics relevant to living with MND. They will also provide support for each other and will be able to share ideas and solutions of their own.

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 to register your interest.

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

VOLUNTEER NEWS!



As we approach the end of 2019, two things strike me – the speed with which this year seems to have moved and the unfaltering support provided throughout the year by our dedicated volunteers.

It is with great warmth and pride we say “thank you” to every one of our volunteers. Each contributes their time, skills, commitment and energy to the important role they play within the organisation. Together our volunteers build a community of support which could not exist without them.

In this edition, we acknowledge the fundraising efforts that underpin so much of the work of MND Victoria.

Through 2019 our volunteers have actively contributed to key fundraising events and activities -:

- The **Walk to D’feet MND** held across the state are key events on the MND Victoria calendar. Each walk requires a huge team of volunteers to make the day a success.
- The **Melbourne Walk to D’feet MND**, held on 17th November, saw 55 volunteers and staff working together as a team to ensure a great day for all.



- **Bunnings Sausage Sizzles** have become a regular fundraiser for MND Victoria. The Box Hill Bunnings Sausage Sizzle sees volunteers and staff together cooking up a storm to raise funds. In 2020 our volunteers will once again be found at Box Hill Bunnings on Saturday 15th February.
- Over recent years, the **Wandin Park Equestrian Event** held in March has nominated MND Victoria as the event charity. Over the two-day event, MND Victoria volunteers collect donations from participants and spectators. No matter how hot or cold or wet the day is, MND Victoria volunteers provide a smile and a welcome to all who enter.
- The **“30 Variations”** season in Melbourne saw volunteers collecting donations from patrons.
- In local communities, MND Victoria **Support Groups** led by committed volunteers, were active throughout the year with many different fundraising initiatives and activities in addition to the work they do raising awareness of MND and providing support and friendship to people living with MND and their families.

As the year comes to an end, sending wishes for the festive season and looking forward to continuing our work together in 2020.

Deb Olive, Coordinator Volunteers

VOLUNTEER OPPORTUNITIES

Massage Volunteers Needed – Melbourne Suburbs

Massage Volunteers provide hand and foot massage for people living with MND. We are seeking volunteers in the North, North West suburbs and in the South East suburbs to match with clients for regular ongoing visits.

Volunteers do not need to come with skills in massage as all training and equipment is provided by MND Victoria. Training will commence in the new year.

Please contact Deb, phone 03 9830 2122 or email volunteer@mnd.asn.au for more information.

2019 PREMIER'S SERVICE AWARD – CYNTHIA VINCENT



We are very excited for Cynthia Vincent who recently received recognition for her 27 years of volunteer commitment to MND Victoria with a 2019 Premier's Volunteer Champions Service Award.

This is outstanding and well-deserved recognition for Cynthia who, when her mother was diagnosed with MND in the 1980s, began her volunteer involvement with MND Victoria through the Eastern Support Group. Since then Cynthia has taken up every opportunity to contribute including: visiting local Members of Parliament to raise awareness of MND, organising luncheons, information stalls and other fundraisers, assisting with the MND News mailout and Walk to D'Feet MND, volunteering at Reception. Recently Cynthia has taken on a new role as Bereavement Call Volunteer. In this role Cynthia provides a supportive link to families after the loss of their loved one.

We are so thankful to Cynthia and pleased she has been recognised in this way. Anyone who knows Cynthia will know she is a special person who quietly gets on with the job at hand, never seeking recognition or thinking she deserves a reward for all she has contributed. Congratulations, Cynthia!

ALL THE WAY

By John Ross McGlade

I will not listen to this disease
That's what it wants.
It wants to consume my thoughts,
Every day,
Every time I bathe or eat.
Every time I transfer
From bed to chair
Or back again.
I will not listen
Every time I fall
Or get help.
I will not listen
To the incontinence
Or the cramps or my labored speech.
Nature will do as it pleases,
As it has always done,
It rolls the dice for us all.
I will count my blessings
Having come further than many.
I will not let anger consume me
For I have had a good life
And how long is a piece of string?
I will not listen to this disease
I'm too stubborn.
Too wild,
Too succinct.
I will tell it I don't care,
I will not fight you,
Do as you please!
And in the meantime
I will
Live all the way.



The furthest suburb to which Fran drives to visit clients is **42 kms** away.

5 Local Government Areas make up this broad demographic region.

In the last year, Fran has presented six Health Professional Information Sessions to 140+ attendees at Aged Care Facilities across this region.

IN THE LAST YEAR FRAN PROVIDED 915 HOURS OF SUPPORT TO PEOPLE WITH MND.

ALL CLIENTS 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.

CLIENTS LINK IN WITH MANY OTHER ALLIED HEALTH SERVICES INCLUDING: CONNECT HEALTH, STAR HEALTH, CENTRAL BAYSIDE COMMUNITY HEALTH SERVICE, STEPS NEUROLOGICAL THERAPY SERVICES AND NEUROLOGICAL REHABILITATION GROUP.




We have **19 amazing volunteers** in this region who work in a variety of roles including: Writing Life Stories, proofreading + mailing out MND News, Walk to D'feet MND Support, Events Support, Visiting People with MND, giving haircuts, Information and Resourcing Support, Hand + Foot Massage, Merchandise Support, State Council Members and Admin Support!

THIS YEAR, FRAN PRESENTED AT AN EASTERN HEALTH HEALTH PROFESSIONAL SESSION WITH 45 ATTENDEES ON LINKING PATIENTS INTO THE NDIS.

**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 **



FRAN - MND ADVISOR
+ SUPPORT COORDINATOR

52 PEOPLE WITH MND
CURRENTLY LIVE
IN THIS REGION

26 clients in this area access the NDIS, however 26 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

A HUGE SHOUT OUT TO ALL THE BIG FAMILY TEAMS FROM THIS REGION WHO WALKED TO D'FEET MND THIS YEAR IN MELBOURNE! SPECIAL MENTIONS GO TO JAMELICA, JACKS CREW, TEAM PATTO FROM THIS REGION, AS WELL AS TEAM FAB AND THE PAPARGIRIS FAMILY WHOSE PHOTOS AND STORIES ARE BELOW ...



Southern
Metro



Fabian and Jodie headed up **Team FAB** again this year, looking to beat the \$10,000 they raised last year!

Fabian was diagnosed with MND eight years ago. His wife, Jodie, one of our State Council members says, "**MND Victoria provided information and helped us connect with services and particularly as the disease progressed, they provided amazing equipment that really changed our lives.**"

Two of our State Council members, Jodie and Jeremy come from this region. We are so grateful to all our State Council Members who volunteer their time to provide strategy, advice and support to the CEO and staff of MND Victoria.



The Papargiris family has Walked to D'feet MND again this year, for Con (pictured) who is currently living with MND.

They are one of our biggest teams this year having raised almost \$6,000 already!

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



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

EXPLORETECH PROJECT

You are invited to take part in the EXPLORETECH research project, which explores the views of participants with or without Motor Neurone Disease (MND) on the use of assistive technology.

Use of technology, such as the internet, handheld devices and computers is part of everyday life and offers ways to enhance the life of people living with disabilities. This can range from basic assistive technology, such as adapted keyboards or text to speech application, to sophisticated applications involving brain computer interface technology (BCI). In Motor Neurone Disease (MND), assistive technologies

may compensate for motor and communication impairment, facilitating social interaction. Usually this technology is developed by research and technical teams.

This research will help us to better understand what is important to end-users in their everyday life and guide the development of these technologies effectively to meet end-user needs appropriately.

This study aims to recruit up to 20 people with, and without, MND (relatives/carers). This research is initiated by Calvary Health Care Bethlehem and is funded by The University of Melbourne.

Please contact: christin.bird@unimelb.edu.au to get involved!

\$3 MILLION IN RESEARCH GRANTS ANNOUNCED BY MND RESEARCH INSTITUTE OF AUSTRALIA!

In October, the MND Research Institute of Australia (MNDRIA), the research arm of MND Australia, announced close to \$3 million to fund 23 new research grants to further understand the causes, find effective treatments, and discover a cure for motor neurone disease (MND).

“Understanding the mechanisms and biology of MND is key to developing better treatments,” said Dr Gethin Thomas, MNDRIA Executive Director, Research.

The MNDRIA is part of a national network of MND Associations, and over the last 32 years has committed over \$32 million in research funding to end this terrible disease. The continued funding of research is only possible thanks to the generosity of donors. Every single dollar donated to MNDRIA goes directly towards funding the best research.

Your amazing fundraising has made four of these research projects possible as they are funded directly by MND Victoria. The projects and researchers are:

- 1. Dr Samantha Barton** at the **Florey Institute of Neuroscience and Mental Health** received the **Jenny Simko MND Research Grant** for a project titled, "Could abnormal myelin composition be exacerbating neuronal dysfunction in MND?"
- 2. Professor David Berlowitz** at the **University of Melbourne** received the **Mavis Gallienne and Graham Lang MND Victoria Research Grant** for his project titled, "NIV@Home".
- 3. Dr Susan Mathers** at **Monash University/ Calvary Health Care Bethlehem** received the **Superball XI MND Research Grant** for a project titled, "Identifying and responding to the health literacy needs of people living with MND/ALS – a coordinated national approach".
- 4. Associate Professor Lezanne Ooi** at the **University of Wollongong** received the **Benalla Act to d'feet MND Research Grant** for her project titled, "Targeting cortical hyperexcitability and neurodegeneration in amyotrophic lateral sclerosis".

BALLARAT MND HEALTH PROFESSIONAL FORUM

By Alison Jones, Coordinator Information & Resourcing

Ballarat was the location for MND Victoria's Regional Health Professional Forum held on Friday 11 October 2019. The aims of the event were:

- To increase knowledge about MND to enhance and support practice
- To provide the best evidence currently available for the management of MND
- To reduce the isolation of health professionals in a regional setting and facilitate networking, information sharing and problem solving
- To acknowledge the demands that health professionals face in caring for clients with MND and their families, and to equip them with strategies to support and enhance their mental health and wellbeing

Over 60 people attended the forum to hear expert speakers from Barwon Health, Ballarat Hospice Care, Grampians Regional Palliative Care, Northern Health and MND Victoria present on a range of topics including: nutrition and MND, dignity therapy, voluntary assisted dying (VAD), as well as grief, loss and self-care, and more.

Attendees were especially touched by the opening presentation given by the wife of a client with MND

who spoke openly and honestly about the challenges she has experienced as a carer as well as the supports available that have helped her and her husband in their journey.

The keynote speaker, Dr Matt Ligtermoet, neurologist from the Progressive Neurological Disease Clinic at Northern Health, wrapped up the day with a very interesting clinical update on MND, giving attendees the latest information on the disease and current treatments available.

Some of the feedback received included:

- *'It was a good, well-rounded day covering lots of aspects of care and issues'*
- *'A great day, lots of take home messages, well-organised and very thought-provoking for allied health professionals'*
- *'Very well-organised and informative, keep up the good work'*
- *'Great day, thoroughly enjoyed (it)'*

We thank all the speakers for the time and effort they put into their presentations and for participating in our event.

Our next Health Professional Forum will be held in Hobart on Friday 27 March 2020. Please save the date in your diary if you would like to attend. Further details will be released in due course.

If you are a health professional and would like to join our mailing list to hear about future events, training opportunities, research, resources and more, please email: info@mnd.asn.au

Photo (left to right): Presenter Ingrid Swain from Barwon Health, MND Victoria CEO Kate Johnson and Presenter Jeanette Wallish from Barwon Health



FUNDRAISING



“If you are working on something exciting that you really care about, you don’t have to be pushed. The vision pulls you” Steve Jobs, Entrepreneur, 1955-2011

I am so lucky to be in a position where I can say that Steve Job’s quote truly reflects how I feel about my role at MND Victoria – and that’s thanks to the amazing people who give their time, energy, ideas and support to the Association. Without this support we would not be able to make day-to-day living a little bit easier for those living with MND. And this is not just the person with the disease, but also their family, work colleagues and friends.

So much has happened this year. Our Global Charity TV Ambassadors are well on their way to raising their individual fundraising goal of \$10,000; the Larapinta trekkers had a wonderful time in September and did an outstanding job of raising over \$100,000; just recently three of our supporters participated in the New York City Marathon and have raised over \$30,000 between them. But it’s not just these high profile events that have such a positive impact on us, it’s also the support we receive from primary and secondary school students, clubs, individuals, Corporations, Trusts, Foundations, families and friends who donate to us in memory of their loved ones. While these amounts may be smaller, they all add up and are recognition, by people who have been impacted by the disease, of the importance of supporting MND Victoria’s service delivery.

Those of you who read the MND Newsletter are fully aware of the impact of MND on day-to-day activities. As well as the physical and emotional impact of the disease, there is a big financial impact. That’s why MND Victoria remains totally committed to its mission to promote and provide the best possible care and support for people with MND. This enables families to concentrate on creating memories and enjoying each moment with their loved ones.

As this is the last Newsletter of 2019, I’d like to say thank you to everyone whose excitement propels them to raise awareness and funds for MND Victoria. It’s because of you that we can continue to deliver services to the 400 plus Victorians living with MND every day. Whether your support is through participating in Challenge events, one of the various Walk to D’feet MND events, responding to our Appeals or Donor Updates, being a regular monthly donor, or nominating MND Victoria as a gift recipient in your Will – each of you are a vital part of the MND Community.

I know that this Christmas will be extremely difficult for many of our readers as they remember loved ones who have died or are celebrating with a loved one who is currently living with this disease. I just encourage you to remember that MND Victoria is here to support you through this difficult time. MND Victoria Cares ... Always Has, Always Will.

Kathy Nightingale

Manager Supporter Development

AROUND THE STATE ...

The Great 'Never Give Up' Ride - for those living with MND:

On Friday the 18th of October, **21 legends** jumped on their bikes in **Hoppers Crossing** to begin a 3 day, **300km ride to Tocumwal** in Southern NSW. They were brought together and inspired to take on this epic challenge because a loved one, and friend to so many, is currently battling with this horrible disease.

With their amazing support crew and an incredible desire to complete the challenge together, they got through a brutal first day where they rode 140km



into a headwind. Everyone was hurting badly and wondering what they'd signed up for. Keep in mind, most of the team were social riders at best!

Fast forward to the Sunday, all 21 rode into Tocumwal with the help of the local CFA who closed the roads and escorted them through town.

We thank everyone involved for doing something amazing and inspirational. On top of their cycling efforts, they also raised over \$25,000 for the care, support and vital assistive equipment to support all Victorians living with MND.

We can't wait to see their next challenge!



Melbourne Marathon Festival

At the recent Melbourne Marathon Festival, a total of **34 runners** took on the challenge of either the **10km**, **half marathon** or **marathon** for MND Victoria.

Everyone was running in honour of friends or family who have been impacted by motor neurone disease. Overall, **\$19,000 was raised** for the care, support and

equipment for all Victorians living with MND! It was amazing to see our new running singlets out on the course and finishing with a lap inside the MCG. We thank all those runners and their supporters.

Next year there will be a number of opportunities for runners or would be runners to take on similar challenges for MND Victoria. Keep an eye out for news and we hope to see you running for all Victorians living with MND!

NYC Marathon

On November 3rd the famous **New York City Marathon** was run. Three of the 200,000 entrants were incredible humans who signed up as runners for MND Victoria 12 months ago. **Dean, Stav** (photo below) and **Mike** spent the past year training for the world's biggest and most famous marathon. In the process they **raised over \$30,000!**

Dean and Stav are no strangers to our Challenge events. Stav has taken part in our Great Wall of China and Kokoda challenges and Dean took on Kokoda. This wasn't Mike's first marathon but it was his dream to run this famous event. We are so thrilled he ran for MND Victoria!

Some very sore legs didn't put a dent in the amazing accomplishment and memories all have for the rest of their lives!



Tee Off MND + Jen's Bubbles

The annual **Tee Off MND** was back for another year at Clifton Springs Golf Club. Perfect weather greeted the 80 golfers who put their golf game to the test in the name of MND research. A new addition this year was a **bubbles and brunch morning** for the non golfers.

Both events were a huge success and we thank Russell and his team once again! A record amount of just over \$20,000 was raised which is a huge credit to all participants.



Keep an eye out for our **Benalla Act to D'feet MND date (February)** in the next MND News!

GEELONG WALK TO D'FEET MND - SUNDAY 22 MARCH!

Join our Geelong Walk to D'feet MND at 10.30am on Sunday 22 March at Barwon Valley Fun Park in Belmont.

Our Walks are an easy, fun way to raise awareness and funds for MND Victoria. All funds raised enable us to deliver care and support services to people currently living with the disease as well as fund research into cause and cure.

Grab your friends, family or work colleagues and get started!

To join us today and start fundraising, please visit:

www.mndwalk.org.au



INCREDIBLE LARAPINTA TREK RAISES \$106,043!

A group of hikers is seen on a dirt trail in a dry, bushy landscape. The hikers are wearing various gear, including hats, backpacks, and trekking poles. The terrain is hilly and covered with sparse, dry vegetation. The sky is clear and blue.

We are so thankful to all 18 superstars who took on our Larapinta Challenge in September. It was a week of very hot and dusty conditions where the team took on approximately 60km of the famous Larapinta Trail just out of Alice Springs. 4am wake ups were normal but each day provided new challenges, incredible experiences and great fun!

Everyone spent the best part of 12 months training and fundraising, and ultimately **raising \$106,043** to help support all Victorians currently living with MND.

The group came together as individuals who had all been impacted by MND in one way or another. They leave as one group of great friends who accomplished something special, saw some incredible scenery, bonded over many stories and have contributed in a huge way to the lives of others.

We can't wait for next year's **Great Wall of China** challenge. Please get in touch with Daniel at dwoodrow@mnd.asn.au if you would like further information.

LARAPINTA ADVENTURES

By Marilyn Mackenzie

My daily training almost done
A six month programme, not always fun
Uneven bluestone steps very carefully trod
Mist, frost, sunshine and sometimes bog
10,000 steps a target striven
Many friends have generously given
The target funds to raise client care
Our ultimate goal: Motor Neurone share
The Larapinta Trail, not an easy snare!

A greeting in Alice's Hyatt cool
Too late to cool off in the pool!
Our group a mix of ages broad
One common goal: Motor Neurone reward
A bus to take us to campsite fine
But a 6.30 start to find Todd's singing line
Red dirt a-coating all around
Walking poles, a great assistance found
One casualty in heated climes
Bush ambulance a mercy find
A locked gate almost had us stumped
An hour to wait! But Ranger trumped!
Our leader, Immy strong in facts
Her local knowledge had us rapt
Trees and plants stopped us in our tracks
And geology colours could have us back!
Arente caterpillars clearly present
Namatjira dots were certainly evident
In arid country a desert rose a surprising presence
Early rising's melodic tones
Swags and beds left with scarcely a moan!
'The lion sleeps to-night' a whimsical choice
A 1am rise for Mount Sonder's darkness stumble
The brilliant 6.30 sunrise made us all quite humble!
Lunch wraps, snacks and treats to keep us prime
We were a team to trek Larapinta fine!!



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

**** Please place orders by Wednesday, 11 December to ensure delivery by Christmas ****



BLUE CORNFLOWER JEWELLERY + KEYRINGS!

\$25-35 EACH
(INC POSTAGE)

Our stunning Blue Cornflower jewellery is the perfect Christmas gift! Choose from earrings, necklace or keyring.

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

DONATIONS RECEIVED ... THANK YOU!

Corporations

Specsavers Pty Ltd.
Express Insurance Brokers
Garth Lisle Property Consultants
A.G. Coombs Group Pty Ltd

Organisations

Lorraine Lea Linen
Salvation Army-Wodonga Branch
Trevor P Weichmann and Associates
Garth Lisle Property Consultants
Learning for Life Autism Centre
Hannaton Marinos
G.J Gardner Homes
Frontline Stores Australia
The Phoenix Hotel
Roe's Holding
Greyhounds Entertainment

Clubs

Seymour and District Car Club
Rochester Quilting Patch
Culcairn Women's Bowling Club
The Lions Club of Frankston Inc.
Ruby Red Dancers
The Ballarat Woodworkers Guild

Bequests

Estate of Ronald Arthur Prince

In Memory

Leonie Marston
Tony Werner
Mary-Anne Smith
Roberta Moorfoot
Maria Longo
Gwen Joyce
John Reid
Robyn Larsen
Betty "Patra" Zannis
John Laidlaw
Yvonne Lodwick
Bill Clarke
Dorothy Newton
Ilka Bickford
Margaret McGregor
Haydn Hiddle
Judith Boyle
Des Taylor
Penny Taylor
Robert Back
Danny Reardon

Michael Sellar
Arthur Coates
Don Brennan
Peter Cox
Clarice Robertson
Richard Fuhrmeister
Margaret Stone
Christine Handson
Rosamund Mortimore
Madelyn Farrugia
Ele Yap
Anne Di Nardo
Jim Mantovani
Sofia Sakkas
Margaret Robinson
Sylvia Ellis
Gemma Carnevale
Anna Koromiles
Margaret Stone

Schools

Trinity Grammar School

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 8 January for the next edition, to be mailed on 4 February 2020.

GET INVOLVED IN AN EVENT NEAR YOU!

Date:	Event:	Find out more:
Tuesday, 7 January 2020	MND Information Session	Email: info@mnd.asn.au
Saturday, 26 January 2020 (TBC)	Heathcote Bowls Event	Email: fundraising@mnd.asn.au
Wednesday, 19 February 2020	MND Information Session	Email: info@mnd.asn.au
Saturday, 14 March 2020	Rock Off MND, Geelong	www.rockoffmnd.com.au
Sunday, 22 March 2020	Geelong Walk to D'feet MND	www.mndwalk.org.au
20-22 March, 2020	Wandin Park Equestrian Event	www.wandinpark.com
Friday, 27 March 2020	MND Health Professional Forum, Hobart	Email: info@mnd.asn.au
Thursday, 2 April 2020	MND Information Session	Email: info@mnd.asn.au
3-9 May, 2020	MND Week 2020	Email: fundraising@mnd.asn.au
Sunday, 3 May 2020	Day of Hope and Remembrance	Email: info@mnd.asn.au
Sunday, 3 May 2020	South East Melbourne Walk to D'feet MND	www.mndwalk.org.au
Tuesday, 5 May 2020	Ask the Experts - Research Event	Email: info@mnd.asn.au
Sunday, 21 June 2020	Global MND Awareness Day 2020	Email: fundraising@mnd.asn.au
Saturday, 8 August 2020	MND Charity Ball - Superball XIII	Email: fundraising@mnd.asn.au
12-20 September 2020	Great Wall of China Trek	Email: dwoodrow@mnd.asn.au

For further information and the latest events list, please visit our website at: www.mnd.asn.au/events
 Please email details of events you would like listed on our events calendar to Kathy Nightingale: fundraising@mnd.asn.au We can also provide you with our Event Flyer template to use for your event!



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

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