MND NEWS

July/August
2019

The newsletter of the
Motor Neurone Disease
Association of Victoria

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

$352,200 FOR MND RESEARCH IN 2018-19!

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MND Victoria

265 Canterbury Road (PO Box 23)
Canterbury VIC 3126

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

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

Facebook: www.facebook.com/MNDVic
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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 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

Digital Communications Officer: 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
Leanne Conway
Fran Hurst
Sam Mitchell
Lauryn Matheson
Trish Duffy
Melissa Kettle
Rachel Ritchie
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

I hope you are all keeping warm in this cold winter weather. The end of another financial year sees us reflecting on the past 12 months, preparing for the next, and taking stock of where we are now.

Our AGM will be held on 28th October at our Canterbury Road offices and this is an opportunity to update our members about our achievements across the past year. We encourage members to attend. You will find an invitation with this newsletter.

Having been with MND Victoria for nearly three months now, I have had some great opportunities to meet with just some of the amazing people who interact with our organisation. Meeting with people who have been newly diagnosed with MND and their families and friends at a recent information session was both confronting and encouraging and I was humbled by the determination and courage shown.

I have met with many of our volunteers – performing so many great works for us, tirelessly, positively and enthusiastically, and am so grateful for all they do to support the Association and our work. You will see in this magazine our celebration of three long serving volunteers who are retiring from their work with MND Victoria – our heartfelt thanks to Mavis Galliene for 39 years of service, Alison Phillips for 34 years of service and Bronwen Pizzey for over 16 years of service.

I have attended a number of fundraising events, planned and delivered by supporters of the Association and raising significant funds – without which we would be unable to provide the level of information, advice, support, assistive technology and contributions to MND research, that we do. At the end of the 18/19 financial year, as a result of the amazing fundraising efforts of many of our supporters, MND Victoria has contributed over $350,000 to research through grants administered by the MND Research Institute of Australia and grants direct to researchers and allied health professionals to attend the International Symposium in Perth in December. For more information on the researchers we are supporting see pages 16-17.

I have met with those who help us to advocate for better services, better funding for support and research and to help raise awareness of Motor Neurone Disease and its devastating impact on those who have it, and their families and friends.

Our advocacy to "Make Aged Care Fair" continues in lobbying governments to give equal access to support and services for those diagnosed who are over 65 years old, as is available to those eligible for the NDIS – you can support this campaign by going to **www.mndaction.org.au**.

We continue our conversations with the NDIA about the importance of timely and specialist assessment and planning for the needs of people with MND. We also advocate for continued improvement to the funding and support of high quality palliative care services.

Finally, I have had the time to get to know the staff at MND Victoria and have been really encouraged by their dedication, commitment and professionalism in all areas of the organisation.

Many thanks to all who contribute to MND Victoria – clients, families, volunteers, fundraisers, advocates and staff. I look forward to meeting with, and hearing from, many more of you. Together we will continue to make a difference in the lives of those affected by MND.

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

Kate

SUPPORT SERVICES

Support Services Staff Update

The team is GROWING!

We welcome **Eric Kuncoro** to the Support Services team in July. Eric replaces Georgina Diacos as the CRM Administrator and Coordinator of Operations.

Eric comes to us from the education sector and has a wealth of experience in managing data bases and technology. He was able to troubleshoot issues with our Commonwealth data reports in his first week with us!

We also welcome **Jenny Fuller** who is our newest MND Advisor and Support Coordinator. Jenny will be working in **Hobart** three days a week. Jenny has a background in palliative care and is experienced in supporting people with MND.

We are in the process of recruiting two more MND Advisors and Support Coordinators – one in Launceston and one to support our work in the North West region of Melbourne – we will have a total of 14 staff in this team when we have recruited these staff.

Our Support Services Team is supporting 489 people, 222 who are under 65 and either are participants of the NDIS or in the process of becoming so, and 267 who are over 65 and engaging with My Aged Care or other services.

Annual Quality Survey

Thank you to everyone who has responded to our annual survey about the services we provide. We have had 102 responses and will be collating the feedback to report in the next newsletter.

Ballarat Health Professional Forum

We are pleased to announce our next MND Health Professional Forum will be held in **Ballarat on Friday 11 October 2019 from 10am-4pm**.

There will be presentations from a range of local health and community professionals, Barwon Health and MND Victoria. We are currently developing the program so please let us know if there are topics you would like covered.

Please let your colleagues know about the forum. You can join our health professionals' email list for further information and registration details. Please forward your contact details to: **info@mnd.asn.au**

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

Jo Whitehouse, Manager Support Services

jwhitehouse@mnd.asn.au or 0402 183 140

INFORMATION SESSIONS

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

7pm on Tuesday, 27 August at MND Victoria, 265 Canterbury Road, Canterbury.

Please RSVP by 5pm, Monday, 26 August 2019.
Phone: (03) 9830 2122, 1800 806 632 or
Email: info@mnd.asn.au

The following session will be held on Wednesday, 9 October at 7pm in Canterbury.

YOUR STORIES …

RIVERS OF GRATITUDE

By Simone Senisin

My beautiful partner John passed away peacefully at home on February 5th, 2019 surrounded by family and friends. I draw strength and peace from his courage and love. The rivers of grief will never stop flowing, they are joined by rivers of gratitude and love. This coming Sunday, June 9th marks what would have been our 29th anniversary. Not ones for any pomp and ceremony, we would have acknowledged it with a few quiet beers and probably a bit of our favourite music. As per John's wishes there wasn't a funeral, however we had a wake at home for our family & friends. John's humour, generosity and grace were ever present in his journey with MND.

I would like to thank his GP, the palliative team, the PNC team at Belmont and MND Vic for their support ... John could die as per his wishes ... so crucial for his dignity. I am forever grateful for the support of our family and friends. John donated to the Florey Institute. I urge all people with MND to consider giving this gift so that, hopefully future generations, one day, may not have to endure the brutality of this disease. I would also like to share a reflection I wrote last year on Sunday, Sept 16, 2018: 6.20am:

MND TAKES YOU QUICKLY FOR A REASON

John was diagnosed with MND in 2017. I won't bore you here with the details of when his symptoms began and all the other predictable questions that people ask about this disease ... repeatedly outlining the months of creeping suspicion that something was wrong to the horror of diagnosis ... the ritual merely reinforces the fear and terror espoused by MND. I mechanically answer such questions ... on the surface people's intentions are genuine concern for the person being asked about, down where the spirit meets the bone, it is about self-preservation. I get it, part of the human condition.

Sept 18 is a significant date for us. We purchased our little piece of Brunswick on that date (1993). As it happens, I was sitting an AMEB piano exam so Dad and John went to the auction that wasn't an auction.... this was our version of cementing our 3-year courtship and trial living together in a rental near the Tip-Top factory in East-Brunswick.

This Tuesday, September 18, John and I are seeing his GP so that he can complete his Advance-Care-Plan. John is to have no treatment, no funeral ... he wants to die at home and have a wake. He is a no-fuss bloke but the most courageous and graceful person I know. He is also the smartest person I know.

John can also be bloody stubborn, a self-confessed family trait, an affectionate bond; the depth of which is only understood with his siblings, apparently gifted to them by their mother. Many times over the last 2 weeks I have pleaded with John to 'stop being a bloody Carmichael!' I laugh at myself!

John is out on the recliner provided by the MND library. This is where he has spent the last 2 nights coughing a dry methodical cough and the occasional dry-wretch. Each breath is accompanied with a faint groan. John tries to reassure me that he is in no pain .... he is being a 'bloody Carmichael'. I don't want to lose him and I don't want him to suffer .... my vulnerable inner-child, my raging inner-adolescent and my kind, generous, empathetic and humorous adult-self share this space with John, each grieving for him, with him, for me, for us. My heart physically warms and pains in my daily endeavour to get a smile. His laughter is silent now, as are his tears .... each emotion indistinguishable from his expression. His smile remains the same.

'You were given this because you are strong'. My sister's words when I first told her about John. 'You are doing a great job, I don't know how you are doing this ... what are you doing for yourself ...? I don't know if I could do it" ... common, repetitive strains from those who love us hoping to foster whatever strength and courage I need? I get it, part of the human condition. I don't know what sort of job I am doing, I am trying to be brave, every day.

Yesterday John was snoozing on the recliner with a Top-End tourist brochure in his hand from The Age. A week ago his beloved camper trailer left our driveway for the last time .... a deeply symbolic loss. I told him we were lucky to have had the opportunity to explore up North. He smiled and surrendered the brochure to the recycle bin. I smiled and walked outside to the garage to hurt and cry. I must remember to pump the tyres of his treasured bikes later today.

John is using the MND-library funded shower chair for the first time this morning. John will donate his brain and spinal cord to MND research. MND is the most insidious disease of daily loss, unrelenting and cruel. John has not complained once ... what grace. John is the strong one. John is the generous one. John is the protector and educator.

I so love this 'bloody Carmichael' and have been loved in return. I am the grateful one.

TC's MND Poem

By Terry Cockett, April 2019, Clifton Springs

I used to be a cyclist and loved riding my bike, under green trees and the blue of the sky.

On a ride one day, I saw evidence, that a horse had recently been by.

So, green and blue, and a bit of horse poo, it was a beautiful day for a ride.

I thought, "I'd like to be doing this in ten years' time, but by then I'll probably have died."

That's because I've been diagnosed with MND, and that bad news nearly made me cry.

"Diagnosed" can be quite an unfortunate word, as it begins with the syllable "die".

I can't ride my bike outdoors any more, my poor balance means I'm likely to fall.

So I ride with the bike on a trainer now, in front of a big TV on the wall.

As the name MND suggests, my neurones are no good.

I've lost control around the tongue and the mouth, because they're not working as they should.

Communication is a real concern, as my speech has completely gone.

The only way I can talk to people, is through an iPad program called ClaroCom.

Holding my head up has also become quite hard, as my neck muscles have gone very weak.

The head just keeps flopping forward now, and I find myself staring down at my feet.

Saliva build-up in my mouth, is a significant problem too.

If I'm not careful, I dribble all down my front, wetting my shirt, my lap and my shoes.

I recently had a PEG inserted, because I'm struggling to swallow my food.

Now it's so easy, my meals are all liquid, and I just pour the stuff into the tube.

Keeping a sense of humour and a cheerful outlook, are the most important aims in my life.

I'm trying to be positive because I don't want, to spoil things for my wonderful wife.

So, MND can be difficult and depressing, I know, and sometimes I feel like tearing my hair.

But, fellow sufferers, we should try not to give up, and remember, until there's a cure, there's care!

MND – THOUGHTS FROM A WIFE AND CARER

By Mary Cockett

Slurred speech, was it from too much to drink?

Friends start to notice and say "maybe a stroke", "Parkinsons starts like this".

Oh dear! Better get it checked out. Ask Doctor Google. Google knows everything.

Off to the doctor – a referral to the Neurologist says "Maybe MND?" Shock! I didn't think of that – don't know that much about it.

A barrage of tests, MRI, 15 blood tests, lumbar puncture, nerve conduction test, breathing tests.

The diagnosis confirmed by two neurologists - MND, because everything else has been ruled out. I thought as much and was prepared but Terry was in shock.

Maybe only 2-3 years left to live, degenerative, won't be able to walk or ride his bike, or play his guitar, be stuck in a wheelchair, or a bed, can't eat, can't breathe, may choke, what will the end be like? A million thoughts. Grief.

Can't sleep. Too much to think about – there goes Terry's life and our life together, Loss! We will face it together and cope together.

He was always so healthy, A-grade squash, cyclist, golfer, healthy eater. "Eat well, keep fit, die anyway" – it says on Terry's t-shirt. Not fair, he is the healthiest of all his friends by far. They will say "so much for that". They will continue to eat their chips and do no exercise.

Not fair. Thoughts of Neale Daniher – Fight MND. Good on you Neale. Fight how? - nothing to do but take one pill that may extend your life by a few months at best. No cure, only care.

Three months into our MND journey – I continue to work three days a week, things are still pretty normal so I keep working while I can – keep things normal as long as we can. I will know when to stop. Who do we tell? Terry does not want pity or sympathy. We just tell close friends and family – the ones who have already noticed that things are not right. They are all very supportive.

The symptoms continue, biting the tongue because it is losing flexibility, then hard to talk because the tongue is swollen. More food goes down the wrong way and the choking begins. I can't speak highly enough of the medical care we are offered. We start bi-monthly appointments at the Neurology clinic – so many specialists, dieticians, speech therapists, social workers, more neurologists – all so friendly and caring. Good advice re eating and swallowing, makes life a bit easier.

We love good red wine and can still enjoy food and wine together. We still socialise and go on weekend holidays with friends. Terry is in no pain, we ease into our new life of managing each day – life is still good and relatively normal. Terry stays positive – fights this MND.

After 6 months, speech is almost gone and we bought an I-pad and use the program ClaroCom to communicate. Terry uses humour to help him cope, and he has adapted and written verses for 2 Greg Champion songs to suit his purpose. He has recorded them on CD – When I Kick the Bucket, and The Organ Donor's song. They are very funny and he gets a lot of joy out of playing them for his friends.

He still rides his bike 100km per week – wants to keep his heart and lungs as fit as they can be. Very important. He is no longer a MAMIL – Middle Aged Men in Lycra. He says he is now a FOSSIL – A Fading Old Sickie Still In Lycra.

We have told more people now – a generic email to all our other friends and family. It was time. Everyone wants to come and visit. You can't blame them. Terry just groans and wants to be left alone to fight this disease. We make the visiting as painless as possible, with small groups of friends for a quick coffee. We are getting through them.

The voice is totally gone now and eating very difficult – often takes 45 minutes for a simple meal. Time for a PEG as he has lost over 6kg. Dreading it and has put it off as long as he can – He thinks "how do I sleep with a PEG in, I might pull it out". More things to worry about.

One year in - PEG is in and it is wonderful. Terry sleeps with a t-shirt on and has a lanyard around his neck to tie the PEG to. The weight slowly comes back on. Free food for life. Yummy vanilla Resource – 5 times per day. It is quick and easy – he can do it in the car or anywhere. What a relief. No more choking or spending so much valuable time eating the tiniest pureed meal.

Medications were very hard to take orally and it could have meant choking when he tries to get the pill to the back of his throat. Taking pills takes more than an hour of his day and quite dangerous I thought. That's it – enough – I go shopping – buy a mortar and pestle – now all pills are crushed and taken through the PEG – so easy – no more stress.

Terry's neck is getting sore and his head is drooping – the wooziness begins and no more outdoor cycling – balance is affected and not safe any more. Bring the bike inside and cycle in the lounge room while watching the tv. I persuade him to drop down to 50km per week instead of 100km – he is dropping weight again and so so tired.

I forgot to mention the saliva – the dreaded saliva. Terry's comment on his iPad – "I dribble and drool like a bloody old fool". It has been ongoing almost since the start, all day. Thin and runny by day, thick and gluggy at night, gets stuck in his throat, especially at bed time.

MND Victoria has lent us a nebuliser to use each evening and it helps. Also taking Entrip to dry up the saliva. Both of these help at night. They, and the new diet, can cause constipation – great – another pill – Coloxyl now and again to fix that up. All in the wonderful PEG.

The appointments continue with the Neurology clinic, all the favourites plus now the physio and the O.T. So much is offered. A soft neck brace is suggested and given. Helps but he is a stubborn thing and doesn't wear it as often as he should.

So much paperwork – disabled parking certificate, advance care directive, respite application, home care package application, carers application – it goes on. Saying this, we have no end of assistance from social workers, aged care, and MND Victoria, they have done all the hard work for us. They ring us and visit at home making sure we have all we need. Chris the neurologist discovers a lot more "fasiculations" (a great MND word) in our last visit – more common on the left side, and a weakening in his left hand and foot. Everything with Terry has always been worse on the left side.

Oh no! If he can't play his guitars (he has 10 of them), he will be shattered. He has a music studio and still produces songs that the old "Thyme" band members come and record. Terry used to sing harmony on these tracks while he could, (now he makes me do it "Grrr") but he still plays guitar on all his tracks.

No more playing the recorder now either – he can't blow or suck – so no straws either. The tiredness and instability are winning. He can't do his balance exercises any more and can only walk a hundred metres or so, but is extremely slow and has to concentrate very hard – he holds his head up with a hand under his chin.

We start looking at portable mobility scooters. I think it is time. Terry is almost convinced. We tried some out and he liked them. We did the Walk to D'feet MND last weekend and we borrowed a wheel chair and his friends pushed him the 3km. It was great. My local gym, Curves Drysdale, helped with the fundraising and did an ice bucket challenge. They raised $2500 and Terry went along and was bit of a mini Neale Daniher for a week. He kept saying to keep him out of it, but I told him it was for a worthy cause – so suck it up Princess. A few pictures and an article in the paper were great and helped with the fundraising – $3460 between family, friends and the gym.

We live in a 2-storey house – I bought BIG thick rubber mats to put at the bottom of the three staircases. Have to look at a lift now as we don't want to move. Wednesday is my last day at work after 14 years at the local Council – will be sad to go but it is time. Terry's dad is 99, living in his own home by himself – and Terry is an only child so he drives 30 minutes in and out of Geelong every day. Terry gets very tired and I don't consider this to be safe some days, so time for me to assist.

Terry does not eat out any more and no longer drinks wine – wine has been his major interest for 40 years and our social life revolved around wine dinners, wine groups and wine holidays (mostly). It has put a huge hole in our social life – fewer dinners out and social occasions. Terry can only sit 30 minutes before his neck gets sore and he needs to leave. He is happy to stay home mostly now or put in a short appearance. We will be socialising more at home – the pizza oven will get a workout.

So many people ask how Terry is by phone, email, Facebook and text message. I started to answer them all personally but too time-consuming and repetitive so I copied them all in on an email and wrote an entire page – a breakdown as to our journey and where we are now and how best to handle visiting etc, with a big reminder to "don't forget about me either." I can still eat out and drink wine.

That is where we are at now. Sixteen months into the MND journey. The great unknown is ahead and everyone who has MND has their own different journey. No two are the same. Good luck on your journeys ... to be continued in a few years.

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 living in Victoria 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/3407816ß42962036/

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

REGIONAL FOCUS

The Bocker family have been fundraising in **Warrion** — a small town with a big heart over the past few years! One year they ran a Bush Dance and Dinner which raised over $4,000 for MND Victoria!

MOST PEOPLE IN THIS REGION ATTEND THE **BARWON CLINIC** WHICH RUNS TWO DAYS A WEEK. NEUROLOGISTS ARE AVAILABLE ONE DAY PER WEEK.

The Barwon region was one of the trial sites when the NDIS began in 2013.

The furthest town to which Trish drives to visit clients is **260 kms** away.

IN THE LAST YEAR TRISH PROVIDED 1033 HOURS OF SUPPORT TO PEOPLE WITH MND.

Beck Mason is a Portland local who has been fundraising for MND Victoria all throughout South West Victoria since her best friend was diagnosed with MND over five years ago. Beck has become part of the MND Victoria family through her incredible passion and dedication to help raise funds to provide care, support and equipment for people with MND. Beck has hosted many fundraising events in Portland, been a major part of the Geelong Walk to D'Feet MND, secured local business sponsorships and spent hundreds of hours selling MND Victoria merchandise and collecting donations. Beck's biggest achievement was taking on our Kokoda challenge. This life-changing experience has spurred her on to do even more for MND! Beck is taking on our Larapinta trek in Outback Australia this year and has now managed to eclipse $100,000 total raised for MND Victoria. This is a phenomenal effort and we can't thank Beck and her team of amazing supporters enough.

160 PEOPLE ATTENDED MND VICTORIA PRESENTATIONS FOR LOCAL HEALTH PROFESSIONAL SERVICE PROVIDERS IN THIS REGION DURING 2018

The **Portland Gorae Cricket Club** held a Summer Ball earlier this year raising over $3,500!

The **Torquay Pharmacy** have been supporting MND Victoria for many years now with a donation tin in their shop.

The **Geelong Walk to D'feet MND** has been held every year since 2012, organised by a group of dedicated volunteers. More than 600 people attended the Geelong Walk in March 2019. The previous year more than $70,000 was raised - which was the biggest year ever!

**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 **

TRISH - MND ADVISOR + SUPPORT COORDINATOR

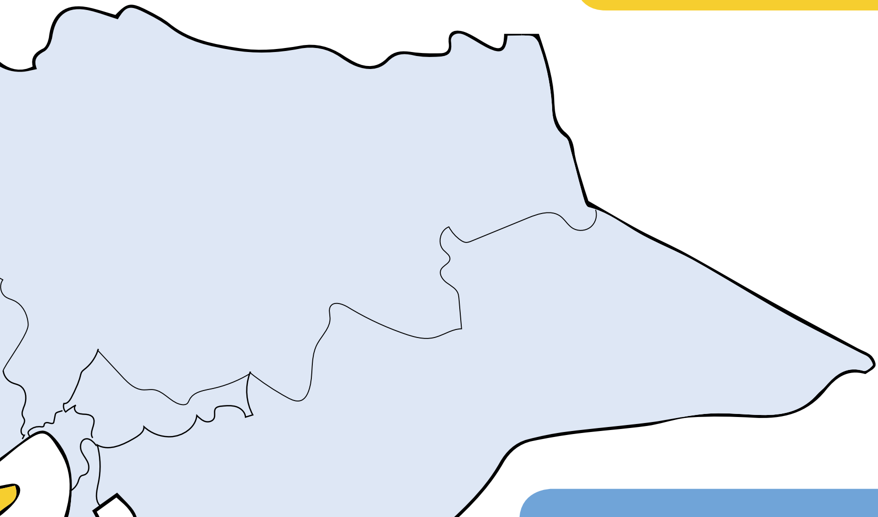
2.5 YEARS AT MND VIC!

28 PEOPLE WITH MND CURRENTLY LIVE IN THIS REGION

7 VIC LOCAL GOVERNMENT AREAS

TRISH TRAVELS APPROX 26,000 KMS EACH YEAR

The **Barwon Region Support Group** commenced in 1990 and has been active since then providing a regular forum for support, information sharing, awareness and fundraising. The Barwon Support Group is one of the longest running groups and we recognise the commitment of all who are, and who have been, involved over the years.



Ocean Grove Rotary Club ran a very successful event for MND Victoria last year at the Bowls Club raising over $13,900 in memory of Maurie Fowler.

12 clients in this area access the NDIS, however 18 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 at: **www.mndaction.org.au**

The RockOff MND live music event was inspired by Jenny Simko, who was diagnosed with MND in August 2014. This event has been an incredible success raising approx $700,000 for MND research over the past five years. The Simko family also run a very successful golf day, Tee Off MND, each year.

Chris Hall is one of our major fundraisers in the Geelong area. He started **Wheel4MND** in 2015 and since then has raised an amazing $28,800! Chris has been aiming to wheel 50km a month in his wheelchair to raise funds for MND Victoria and has organised many fundraisers over the past four years, selling MND merchandise. He is going to shave his beard if he raises $500 by the end of August – search **Wheel4MND** on Facebook to follow Chris' adventures!

Volunteer News!

MND Victoria acknowledges the support and commitment of our entire volunteer team which now numbers more than 130 across the State. Many of our volunteers have a long term commitment to the organisation.

This issue we say "farewell" and "thank you" to three of our very dedicated and long term volunteers.

Mavis Gallienne has been volunteering with MND Victoria for **39 years**. Recently Mavis indicated she would be retiring from volunteering. We acknowledge and thank Mavis for her contributions to MND Victoria and on behalf of people living with MND.

Details of Mavis' contributions were highlighted in MND News of August 2015. The following brief extract captures some of Mavis' involvement:

- Her role as a family member and carer for her sister;
- As a member of the Gippsland Support Group;
- As a member and State Councillor of MND Victoria;
- As inaugural Chairperson of the MNDA; and
- As Board Member, Chairperson and Treasurer of the International Alliance.

In all of these roles, she has demonstrated her commitment to people living with MND and applied her vision and strength to improve the quality of life of people with the disease wherever they live. Her work has always been as a committed volunteer.

On behalf of all of us Mavis – thank you – your volunteering has made a world of difference!

Alison Phillips commenced volunteering with MND Victoria in 1985 ensuring support and information was available in Bendigo and surrounding areas for people impacted by MND. Alison's commitment and contributions were actively seen through her involvement with the Bendigo Support Group for **30 years** and are recognised in the community and at MND Victoria. Thank you Alison for all you have given in support of people living with MND.

Bronwen Pizzey has also been an active and long term volunteer with MND Victoria, volunteering with us for more than **16 years**. In that time Bronwen has taken on a range of roles within the office and in the community supporting clients and their families.

Bronwen's commitment, her energy and her positive approach to everything she has been involved in has been appreciated by staff, volunteers, clients and their family members. Bronwen retires from volunteering with MND Victoria to give more time to her family commitments. All we can say is Bronwen's grandchildren are very lucky to have such an awesome "nan" to spend time with. Bronwen – always positive, noted as she leaves her volunteer involvement with MND Victoria – "I enjoyed every position I held. The staff became friends and I always found interaction with clients and their families very meaningful and fulfilling".

Thank you Mavis, Alison and Bronwen!

Barwon and South West Volunteers

In this issue, we are featuring the services MND Victoria provides in the Barwon and South West Regions of Victoria. We are very well supported by our volunteers in this region.

As noted elsewhere, our Barwon Region Support Group is active and has been a constant source of support and engagement for people with MND since it commenced in 1990. With the guidance of Ian Parton, Chairman, the Support Group is also regularly engaged in awareness raising and fundraising activities in the local area.

Since 2012, the Barwon Walk to D'Feet MND has been a regular feature on the local calendar and has been organised and managed successfully by a committed team of volunteers.

The support offered by volunteers across this large region is remarkable. While distance can at times be a barrier, we are fortunate to have volunteers who are able to offer support to clients and their families, including Hand and Foot Massage, Hairdressing, Life Stories, Social Visitors and Bereavement Calls.

MND Volunteers—many talents and many ways to become involved

Heidi has volunteered with MND Victoria for over five years. Heidi became involved because her daughter mentioned we needed volunteers with data management skills. Heidi saw an opportunity to utilise her skills to support our work.

Heidi's commitment sees her come into the organisation each month to manage data entry of reports provided by our volunteers who work with clients. This helps us stay connected with our volunteers and to understand the contributions volunteers are making every month. Thank you Heidi for sharing your skills and experience with MND Victoria. *(Photo below of Heidi working with Deb on data entry and analysis.)*

VOLUNTEER OPPORTUNITIES

Massage Volunteers

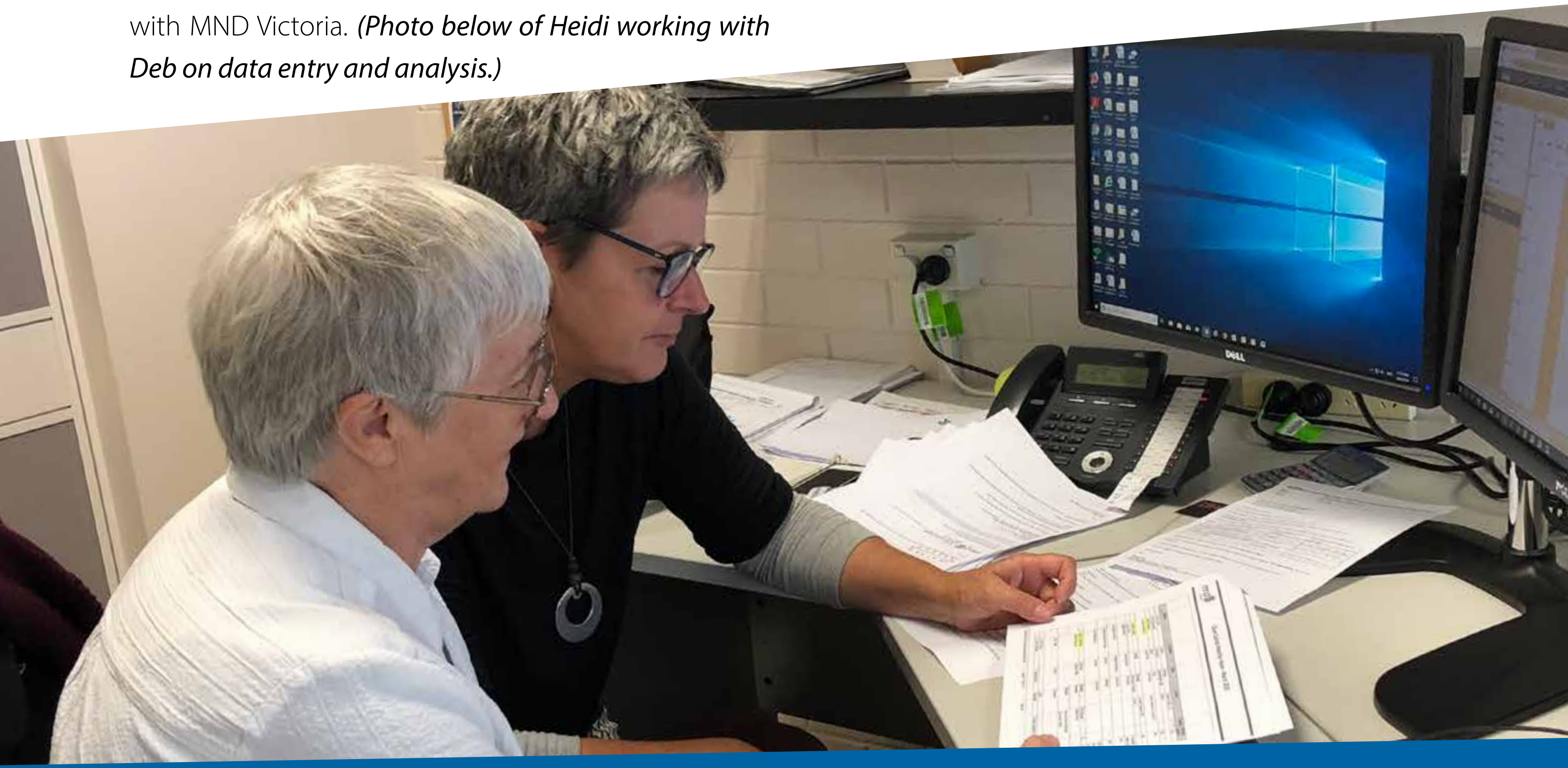
We are looking for volunteers to join our team of Massage Volunteers. Massage Volunteers provide hand and foot massage helping with comfort and relaxation for people living with MND. We currently need more Massage Volunteers in locations across the State. We are planning a training session in the coming months – so you do not need to have experience with massage. Being available to spend time one on one with our members in their community is what makes for a successful Massage Volunteer.

For more information please call 1800 806 632 or email **volunteer@mnd.asn.au**

Visitors for Social Support

Social Support Visitors are volunteers who meet with a person living with MND in their local area. Volunteers may meet for a coffee or a walk and share interests, conversation – maybe even a crossword! If you would be interested in helping someone with MND stay socially connected – we'd love to hear from you. Training and ongoing support will be provided.

For more information please call 1800 806 632 or email **volunteer@mnd.asn.au**



THE DIFFERENCE THIRTY-EIGHT YEARS AND A DIAGNOSIS OF MND MAKES . . .

Hello, my name is Hilary and I have the privilege of volunteering with MND Victoria.

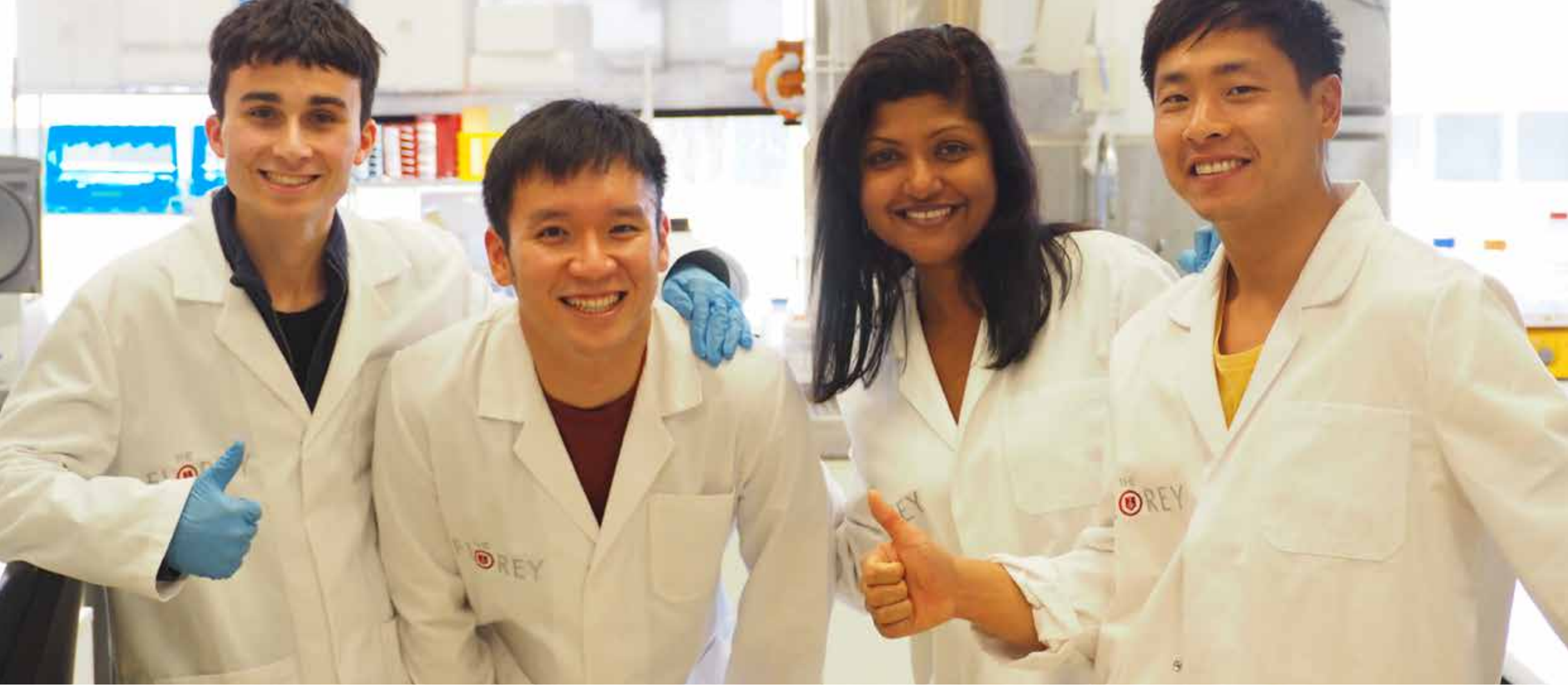
In late 2017, my lovely brother-in-law became unwell and after numerous tests it was eventually confirmed that he had MND, bulbar onset.

Life for my brother-in-law, sister and nephews has become the daily challenge all those affected by MND are all too familiar with. Whilst they are living with the awful reality of MND, I have found that being thousands of kilometres away and unable to assist in any meaningful way is upsetting too.

The only way I could think of showing my support was to become involved with an organisation like MND Victoria. Subsequently my husband, daughter Eleanor, son Kendrick and I have Walked to D'feet MND, organised a Family Team to raise funds for "243 for MND", organised to "Drink Tea for MND", requested a donation be made to MND Victoria rather than a gift when Tony turned 6 and I am a Reception Volunteer on Friday mornings. The staff at MND Victoria are a wonderful bunch to work with and I am inspired by their professionalism, compassion and empathy. Until there's a cure there's care and I would like my brother-in-law, sister and nephews to know I (we) care!

The picture (below) was Christmas 1980 and the second (above) was Christmas 2018, the whole family had gone back to the UK to see Andrew and our English family.

We had a wedding celebration / blessing ceremony at their local church (our English family were not able to come to Eleanor's wedding in Australia in April this year). The ceremony took place on our Grandparents' wedding anniversary and Andrew walked Eleanor down the aisle (he has three boys so would never have done this). When the vicar asked who gave her away, we had to wait while Andrew typed I DO into his voice synthesiser, when he hit play the voice boomed out around the church because he had turned it up to full volume. It was a very special experience.



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 3 times/week for 12 weeks in Footscray. 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 diagnosed with MND in Australia. 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**

$352,200 RAISED FOR MND RESEARCH IN THE PAST YEAR!

In the 2018-19 financial year, MND Victoria has raised $352,200 for MND research.

A HUGE thank you to all our donors and supporters—it is only due to your hard work fundraising and generous gifts that this is possible!

Associate Professor Seth Masters, The Walter and Eliza Hall Institute of Medical Research, VIC

Superball XI MND Research Grant

Targeting cGAS/Sting to block neuro-inflammation in MND

This project examines this critical innate immune pathway in greater detail using models of MND and will validate a biomarker of the pathway in patient samples. Small molecule inhibitors will also be tested in model systems, which could potentially benefit patients with MND who display elevated levels of the neuroinflammatory biomarker.

Dr Rachel Tan, University of Sydney, NSW

Benalla Act to D'feet MND Research Grant

Prions, RNA binding proteins with prion-like domains and motor neuron degeneration

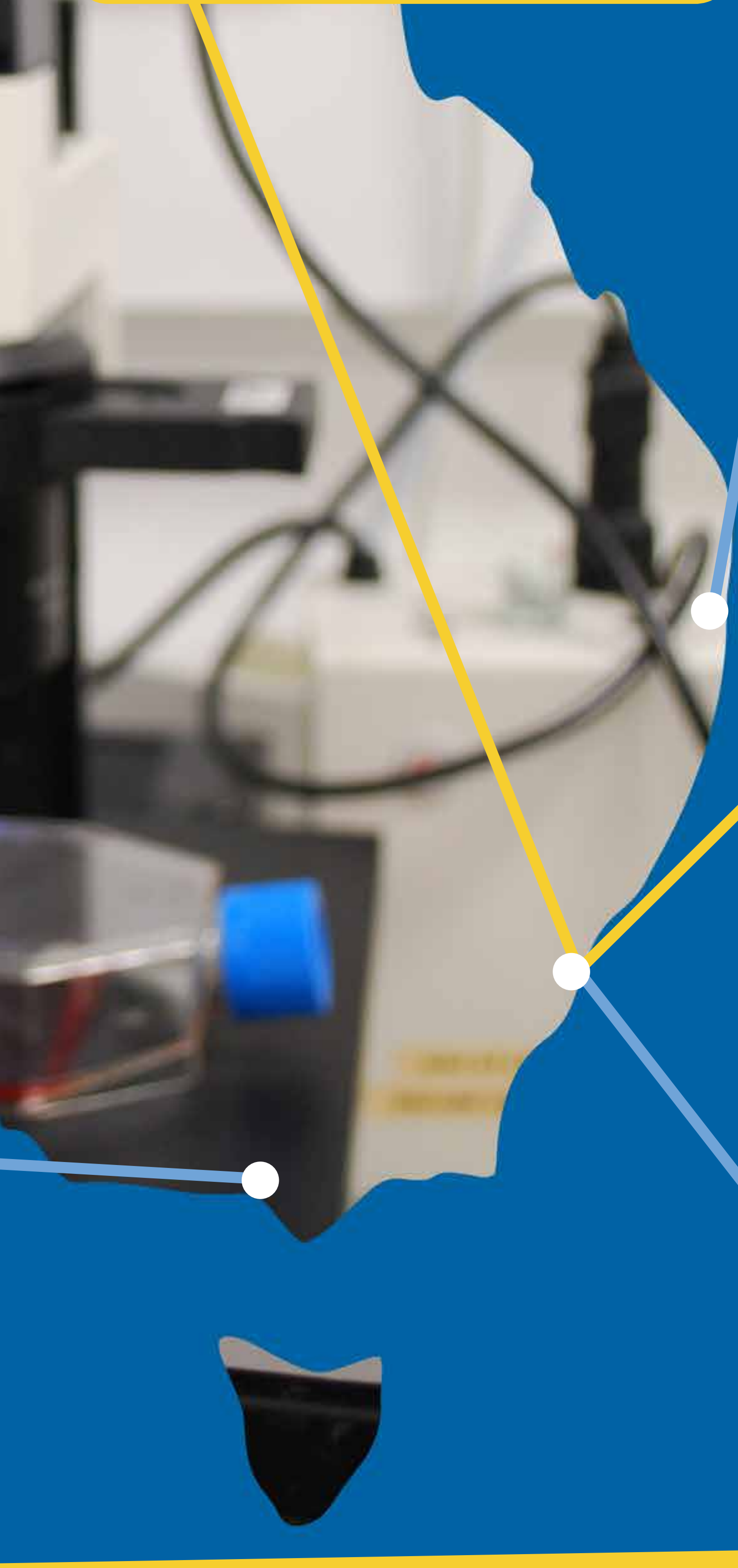
This project will assess this in tissue from patients with MND, with the purpose of determining whether targeting PrPC is a viable therapeutic strategy for sporadic MND.

Professor Pamela McCombe, University of Queensland, QLD.

Jenny Simko MND Research Grant

Immunogenetics of motor neurone disease - a pilot study

This study examines the genetics of the immune-related genes in MND to see whether this can be correlated with disease severity.



Associate Professor Nimeshan Geevasinga, Western Sydney Local Health District, NSW

Jenny Simko MND Research Grant

Utilising novel MRI connectomic analysis to explore pathophysiological changes in ALS

This project hopes to integrate MRI imaging with our expertise in neurophysiological and clinical evaluation of ALS patients with a view to learning more about the progression of ALS. Understanding the degenerative process in the brain may help to target specific pathways for therapeutic purposes.

Professor Julian Trollor, University of New South Wales, NSW

Mavis Gallienne and Graham Lang MND Victoria Research Grant

Using big data to understand the health status and service use of people with motor neurone disease

This study uses linked data from a large sample of people with MND in NSW to describe and understand the mental health needs of people with MND, and how they use mental health services to understand the specific needs of people with MND.

INTERNATIONAL SYMPOSIUM ON ALS/MND, PERTH 2019

MND Australia, in partnership with MND WA, is proud to host the International ALS/MND meetings in Perth in 2019. This will be an opportunity for the Australian MND community to come together with their peers and leading international researchers from around the world to present and debate key innovations in their respective fields. All meetings will be held at the Perth Convention and Exhibition Centre.

On Sunday, 1 December members of the International Alliance of ALS/MND Associations will gather for the AGM and yearly meeting. This meeting is an opportunity for ALS/MND support and advocacy organisations from around the world to share best practice and ideas for better supporting people living with ALS/MND in their communities. Observers are welcome to register to attend this meeting.

Ask the Experts on Monday, 2 December is a free session specifically for people living with MND, their friends and families and the wider MND community. This will be a unique opportunity for the Australian MND community to hear about the latest research advances from leading national and international researchers and clinicians.

The Allied Professional Forum is a full day meeting on Tuesday, 3 December where health and community care professionals from around the world present on evidence based and best practice models of care and support for people living with MND, their carers and families. All are welcome to register to attend.

The 30th International Symposium on ALS/MND will run from Wednesday, 4 to Friday, 6 December. Concurrent platform and poster sessions will focus on scientific and clinical advances. We expect to see many MNDRIA funded researchers presenting their findings this year. All are welcome to register to attend. NB. Early bird rate for the symposium closes on 27 August.

For more information on all these meetings and links to registration pages, visit the MND Australia website: **www.mndaust.asn.au/Discover-our-research/grants-and-research-meetings/International-Symposium-on-ALS-MND/International-Symposium-on-ALS-MND-2019**

Carol Birks, CEO, MND Australia

FUNDRAISING

Every day is a new beginning. Treat it that way. Stay away from what might have been, and look at what can be.

Marsha Petrie Sue

July 1 is the beginning of the new financial year and thus once more the beginning of our Supporter Development activities for another 12 months. But before we focus on the future I'd like to say **a very big thank you to everyone who has supported MND Victoria in the past**. Your enthusiasm, determination, energy and creativity has been such a great encouragement for all of us – not just the staff and volunteers at MND Victoria but the MND Community as a whole.

As most of our readers know only too well, families living with MND face so many challenges and it can be a great encouragement to them to hear about activities being undertaken to raise funds for equipment and service delivery. Equipment provided by MND Victoria plays a pivotal role in allowing people with MND to continue participating in family and community activities for as long as possible.

We have been very encouraged by all the fundraising activities that our supporters have undertaken this past year. We've highlighted many of these in previous newsletters. In this issue I'd like to particularly thank all those who participated in the following:

- **243 for MND** which ran from MND Awareness Week through to 30 June. This challenge event **raised $11,549** – enough to purchase both a power wheelchair and a manual wheelchair. How good is that!
- **Global MND/ALS Day, June 21**. Several different events took place leading up to and around Global Day including BBQs, Film Nights, Netball & Football events. The Warrnambool branch of Bendigo Bank promoted MND in the weeks leading up to Global Day and successfully sold a range of MND Victoria merchandise as well as taking donations ***(photo below)***.

- **The 2019 Tax Appeal**. Over 620 people who saw Ian's MND story as part of the Tax Appeal were moved to donate to this Appeal and as of 9 July, $136,035 had been raised ensuring we can continue delivering care and support to families living with MND.

So – on to new beginnings. I'm happy to say that July has begun on a very positive note with a number of fundraising activities planned for this month. Plus there are on-going fundraising activities by those taking part in the **Larapinta Walk to D'feet MND** event in September, the **New York City Marathon** in November and the **Global Charity TV project**. And don't forget it's nearly time to kick-off our annual **Walk to D'feet MND** events.

HOWEVER, we need to keep the momentum building as funds raised from these activities underwrite our service delivery, including Assistive Technology device purchases which allow people with MND to remain participating in family and community activities.

There are no fundraising ideas too small – or too crazy – and the team here are ready to assist you get yours off the ground. Please contact **fundraising@mnd.asn.au** to discuss how you can raise awareness and funds to help care for Victorians with MND.

MND Victoria Cares ... Always Has, Always Will.

Kathy Nightingale, Manager Supporter Development

Jan Dance Photography Exhibition

For many years now, Jan Dance has been supporting MND Victoria by dedicating all her exhibitions to her sister who died from motor neurone disease. Jan donates a portion of every sale to support people living with MND through MND Victoria. Her latest exhibition has been showing at Kindred Art Space in Frankston since opening during MND week in May.

MLC Year 7 Fundraiser

One of the Year 7 classes at MLC hosted a fundraiser for MND Victoria for MND Global Day. They listened to an inspiring presentation about MND and sold MND merchandise raising valuable funds for MND Victoria!

Scrunch MND

Our new CEO Kate has been visiting a range of fundraising events around the State. In early July, she visited Steph's 'Scrunch MND' stall at the Lilydale Craft and Produce Market. Steph is one of our ambassadors as part of our Charity TV team. She has already raised an incredible $8,053 through her scrunchie sales and other events. *(Photo of Steph with CEO Kate Johnson below)*

Werribee Football Club Ladies Lunch

Kate also visited the Werribee Football Club Ladies Lunch held on 6 July. Through the raffle ticket sales and donations to the charity tins, WDFC successfully raised $1200—an amazing result! *(Kate with the organising team below & MND cookies bottom pic!)*

WILLS AND BEQUESTS

Something most of us don't think about!

Results from a survey undertaken by Finder in October 2018 indicate that **more than half of Australian adults don't have a Will**, with the main reason being they haven't got around to it yet.

"Most people don't like to think about their death and fewer still enjoy paperwork, but if you die without making a valid will, your assets could be distributed in a way you would not have chosen." (Kate Browne, Finder).

MND Victoria has been fortunate over many years to have been the recipient of Bequests from people with MND, volunteers and financial supporters. These gifts are invested in the MND Care Foundation to ensure that the Association will always be able to deliver the care and support so vital to people living with MND, regardless of market conditions such as the global financial crisis in 2007/8. Interest from funds in the MND Care Foundation is invested in MND Victoria so that we can continually upgrade and update our assistive technology library, and underwrite new programs.

The Association's mission is to provide and promote the best possible care and support for people living with MND. We understand that provision of the right equipment at the right time alleviates social isolation and potential financial hardship. We know that the "right" equipment doesn't just mean it serves its purpose – it must also be in excellent condition which is why we are continually reviewing, repairing and replacing equipment which does not meet our quality and safety standards.

If you're one of the 54% of Victorians who have not yet made a Will we certainly encourage you to do so to ensure that you can extend your wishes and provide for the people and organisations you care about, well beyond your lifetime.

If you would like more information about leaving a Gift to MND Victoria in your Will please email: **fundraising@mnd.asn.au** *or phone:* **03 9830 2122**

THE SONG WILL REMAIN

In 2009, when Dot Dickson was active in the Victorian croquet community, she created a tournament for players of any standard to enjoy a day on the courts at the Victorian Croquet Centre in Cairnlea. Dot's goals for the day were that players should enjoy themselves and meet players from other clubs. It proved to be very popular. So Dot continued running these tournaments each year.

When Dot's MND made her too ill to be able to continue organising these One Day Challenges, Kaye Molyneux from the Monash Croquet Club, supported by Brian Rowe from Dot's club, Essendon, generously took up the responsibility of continuing what Dot had started.

This year's tournament was held on 6th June. It has now been named to honour Dot's contribution to Croquet in Victoria. Tournament Director, Kaye, has also used the opportunity to promote awareness of MND and raise funds for MND Vic so they can continue to support people as they had done for Dot. This year the players raised $877.50.

If you play the golf version of croquet, plan to participate next year – probably in June. Look out for notices in newsletters. If you don't play, but know someone who does, tell them about Dot's One Day Challenge golf tournament and encourage them to support it. They will enjoy it.

Participants gather for a photo opportunity on the day, trying to form a "dot" to be photographed:

Dot died on 14th June 2018. At her funeral service, a song played included the line, "The singer may die, but the song will remain". The One Day Golf Croquet Challenge is one of the verses of Dot's song.

Our Hoodies Now Out In Black!

Our super stylish + cosy Never Give Up hoodies are now available in BLACK: www.mnd.asn.au/gear

$75 including postage

All proceeds provide VITAL care + support for people with MND and fund research.

Grab your winter MND gear at: www.mnd.asn.au/gear

Kids MND Gear!

We now have pale grey kids hoodies in stock with our Never Give Up branding and logo.

ALL NEW super cute babies onesies are also available, check them out online at:

www.mnd.asn.au/gear

All our merchandise is available via phone order as well: ***03 9830 2122*** *or you can pop into our office, 265 Canterbury Rd, Canterbury 9am-5pm from Monday to Friday to try on sizes.*

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

DONATIONS WERE RECEIVED ... THANK YOU!

In memory of

Angela Batties
Anna Green
Bruce Bowditch
Bruce Hallows
Carol Inella
Cassie Secombe
Christopher de Krester
David Greenwood
David Liesrsch
Dianne Brown
Dot Dickson
Douglas J Smiley
Eric Ludwick
Francis Pearn
Gemaine Mariolle
Geoff Blake
Geoff Woodrow
Graeme Furphy
John Jarvis
John McIntosh
John Ray
Joy Allen
Kath Chandler
Kenneth Davis
Kevin Pragam
Madelyn Farrugia
Margaret Bolton
Marlene Stanway
Martin Williams
Mary Bussau
Max Hall
Michael Factor
Michael Leach
Michael O'Brien
Norm Henkel
Pamela Davidson
Richard Anchen
Roger Stokes
Sandra Rennie
Sylvia Ellis
Terry Anderson
Terry Beat
Toni Patch
Tony Page

Research in memory of

John Mayger

Organisations

All Souls Opportunity Shop
Barwon Health Progressive Neurology Clinic
Coles Bay Hotels Pty Ltd
Hayden Real Estate
Journey With Spirit
Lalor & Thomastown Combined Pensioner Association
Melbourne Doll Show
Mornington Mazda
The HRKAC Group
Trevor P Weichmann & Associatates Pty Ltd
Wandin Park Association
Lodge of Euclid
Pearce Webster Dugdales
Gym & Tonic
Kew Skin Therapy

Clubs

Ruby Red Dancer
Quambatook Craft Group
The Lagen Social Club
Lions Club of Ararat
Portland & Districr Dance Inc.
Lions Club of Blackburn North
Sale Bridge Club
Lions Club of Carnegie
Midlands Golf Bowls Club
Hoppers Crossing Apex Club
Craft Ladies of the Combined Probus Club of Monash Central
Lions Club of Geelong Breakfast Inc
Mornington Football Club

Trusts

The Mulgrew Family Endowment
George & Edith Ramsay Charitable Trust
The Cuming Bequest
AL & T Brorsen Family Foundation
Crown Resorts Foundation PAF
Australian Communities Foundation
Dimmick Charitable Trust
GW Vowell Foundation Pty Ltd.
The Lord Mayor's Charitable Trust
Kate Jones & Stephen Alomes Fund
O'Sullivan Family Gifts
The Pethard Tarax Charitable Trust

Corporate

Specsavers Pty Ltd.
Express Insurance Brokers Pty Ltd.
Maroondah City Council
Computershare Plan Co Pty Ltd
CPU Share Plans Pty Ltd

Bequests

The Estate of the Late Shirley Marguerita Bull

Schools

Gisborne Primary School
Cathedral College Wangaratta

Churches

Swan Hill Parish Centre

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 4 September for the next edition, to be mailed on 1 October 2019.

GET INVOLVED IN AN EVENT NEAR YOU!

Date	Event	Contact
Tuesday, 27 August 2019	MND Information Session	Email: info@mnd.asn.au
16–22 September 2019	Larapinta Trek - Challenge event	Email: fundraising@mnd.asn.au
Sunday, 5 October 2019	Lakes Entrance Walk to D'feet MND	Email: fundraising@mnd.asn.au
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	Email: fundraising@mnd.asn.au
Monday, 4 November 2019	MND Victoria's New York Marathon Challenge	Email: fundraising@mnd.asn.au
Sunday, 17 November 2019	Melbourne Walk to D'feet MND	Email: fundraising@mnd.asn.au
Thursday, 21 November 2019	MND Information Session	Email: info@mnd.asn.au
Sunday, 24 November 2019	Bendigo Walk to D'feet MND	Email: fundraising@mnd.asn.au
4–6 December 2019	MND/ALS International Symposium, Perth	Email: info@mnd.asn.au

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

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

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