MND NEWS

november/december

2018

The newsletter of the Motor Neurone Disease Association of Victoria

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

INSIDE THIS EDITION:

mnd Victoria

www.mnd.asn.au

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Reg. Assoc. No. A7518

SUPPORT GROUPS

Western Metro

Last Monday each month at 12.30 pm in Footscray
Mrs Christine Robson, (03) 9379 7715

Barwon Region

St David's Hall, Aphrasia St, Newtown
First Monday every second month at 12 noon
Rev. Ian Parton, (03) 5241 9344

Ballarat Region

Meets at various locations around Ballarat
Contact: MND Victoria on Tel: (03) 9830 2122 or 1800 806 632

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FROM THE CEO

Christmas and the festive season are rapidly approaching, with all the joy and sadness they bring. It is a time for reflection, about those who have been overwhelmed and those living with MND, and our collective hopes for successful research and a world without MND. My thoughts are with you all.

On 9 November, I attended the **MND Australia Research meeting** – "Investing in Innovation, Partnering for Progress" - to hear about the wonderful research funded by MND Australia into cause, treatment and cure for MND. Included in the presenters were six researchers funded by named research grants through MND Victoria. There were also 38 posters presenting research in progress or research findings, again demonstrating the wide field that is research and progression to knowledge, treatment and cure.

The coming together of so many Australian researchers, both presenting and in the audience, highlights the depth of talent and knowledge that is aimed clearly at MND and its defeat. MND Victoria believes that without research, there can be no cure. But until there is a cure, there is care, and that is our focus – to support people living with MND until treatments and cure is found.

On 10 November, I attended **MND Connect** – an opportunity for people with MND, carers, families, friends and health care professionals to hear about research and its progress. Its aim is connecting people impacted by MND with Australia's leading MND researchers. The day also included an opportunity to see the very latest progress via a tour of A/Prof Bradley Turner's laboratory and robotic testing process.

In early December I will be attending the **International Alliance of ALS/MND Associations meeting** and the **ALS/MND International Symposium** in Glasgow. At the Alliance meeting, I am presenting on our advocacy efforts in relation to the Voluntary Assisted Dying legislation as a model of how advocacy and influencing can deliver change and remove discrimination from legislation.

Over the festive season, ***MND Victoria will be closed from 25 December to 1 January inclusive***. There will be a reduced service available on 24 December.

Pam and I wish you all you would wish for yourselves at this time. Along with all of the staff at MND Victoria, we look forward to working with you to help people live better for longer while fighting MND. Our thoughts will be with all whose partners, friends and relatives were overwhelmed by MND, and we look forward to finding cause, treatment and cure. And until then, we will provide and promote the best possible care and support for people living with MND.

Until next time, **Rod**

INFORMATION SESSIONS

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

**7pm on Monday, 21 January at MND Victoria,
265 Canterbury Road, Canterbury.**

Please RSVP by 5pm, Friday, 18 January 2019.
Phone: (03) 9830 2122, 1800 806 632 or
Email: info@mnd.asn.au

The following session will be held on Tuesday,
5 March at 7pm in Canterbury.

SUPPORT SERVICES

I feel like I have been working for the Association for years, not just months – in a good way! – the staff, volunteers and the MND community have been so welcoming and supportive in helping me settle into the role. Thank you!

There is lots to share – here is a snapshot!

NDIS

The NDIS continues to roll out across Victoria and Tasmania, with final roll out expected by the middle of next year…it's been a long few years since the full scheme roll out commenced in July 2016 and our team of MND Advisors and Support Coordinators have become very experienced in the process, learning such a lot about all the NDIS "stages" from Access to Pre-planning, Planning to Implementation and Review!

There is almost a completely new vernacular for the NDIS! The NDIS continues to evolve and develop and with that come new processes and procedures which are time consuming to keep abreast of, but the team is doing a great job.

The Support Services team is currently providing support coordination services to 119 people in Victoria and two people living in Tasmania. 108 Victorians are accessing our NDIS equipment bundles. We expect these numbers to rise over the coming months as the last few areas in Victoria and age groups in Tasmania phase into the scheme.

In Victoria, the next (and final!) areas to phase in are Goulburn, Outer Gippsland and Mallee - all from 1 Jan 2019…so if you live in any of these areas, please speak to your MND Advisor or call our Information Team about accessing the scheme. In Tasmania, people aged 50 to 64 will also commence phasing in from 1 Jan 2019.

On the 20 September, along with Carol Birks from MND Australia and Graham Opie from MND NSW, I attended the Joint Standing Committee on the NDIS to talk to them about difficulties that people with MND experience in accessing Assistive Technology (equipment). It was a short meeting, but we were invited to submit a paper to the Committee specifically about the issues that we had raised, which we hope will be taken into consideration when the committee make their final recommendations—their report is due on the 29 November 2018.

Aged Care

Engaging withthe Aged Care system continues to be frustrating to engage with. The Support Services team share the frustrations of many people over 65 who are finding it difficult to access support and services through the Aged Care system which we believe is unfair and inequitable.

If you haven't already, please join the campaign to Make Aged Care Fair at: **www.mndaction.org.au** – or call our Information team for further information on the campaign.

Christmas break

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 Rosanne Gibb, Physiotherapist on (03) 9595 34 86.

Equipment

We have been able to order over $100,000 of equipment to replenish some of the stock in our equipment library in recent months. The equipment team regularly need to decommission equipment as it gets old or damaged, so it's great when we have funds available to order new stock.

A reminder that we have a number of iPads available which can be provided to people with speech difficulties or to those who live remotely to assist in enabling communication with key people who are supporting them – family, friends and health professionals.

Speak to your health professional or your MND Advisor if you are interested.

New staff

We are in the process of recruiting a new part time MND Advisor/Support Coordinator to the team who will be based in Hobart commencing in the New Year.

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

YOUR STORIES …

By Gheslaine Waters

My dad and hero Geoffrey Waters passed away on 1/11/2018 after battling MND, progressive bulbar palsy.

I would just like to thank you, MND Victoria, for the immense help and dedication you have for those who suffer from MND and their families. Thanks to you, my dad had access to equipment and care that made living with MND easier.

My dad was an amazing person, and any person who knew him can testify to that. He never smoked, never drank alcohol, never gambled; he was a kind musician who loved to sing, swim and nurtured the outdoors.

This disease is cruel and terrible and no one deserves to go through it.

Over the last few years he became slower, his speech became a mumble, and then he lost his voice completely. No matter what the doctors told him of his prognosis, he was determined to try everything they told him to make his life more comfortable.

After reaching a breaking point in his disease, his body finally gave up on him and despite his brain and senses being perfectly normal, he removed his NIV and passed away.

I will never forget him and his incredible strength and bravery, right to the very end of his battle. He still kept his sense of humour and continued to worry for my family before he passed. My whole heart is broken knowing that beautiful people like my father suffer from a cruel and aggressive disease such as MND.

Once again, thank you for all your help and I will do everything in my power to support your amazing Association.

SAVING ALL THE TEARS

By Gemma Schofield

Walking in your shoes has never been easy
Hearing all your cries is shouting so loud.
I must have seen those million smiles and never seen them shine.
But wishes can't be choosing the life you should have found
I'm saving all those tears
Saving all the tears.

I try to bring the memories and images emerge.
Always steps behind you imagining you'd turn.
A voice of strength but yet so stern.
I couldn't reach the heights that you so wanted me to yearn.
And now will never know the labours you have learned.
I'm saving all those tears,
saving all those tears.

Age will never marry you or strip you of your goals.
Your proud and lonely messages that always moved a crowd
No give or take, surrender was never on your lips.
No need for that, you thought as possibilities abound.
You're saving all those tears
Saving all the tears

Your presence is required, for us it's always been
a given not a taken to heights we've never seen.
You always made the journey alone and not with care.
For those who see the person and not the woman here.
A proud and stubborn legion your legacy allowed.
They're saving all those tears
Saving all the tears.

I try to think of sunshine but greyness always clouds
The memories of songs and things, of dances in the crowd.
I think of people who touch your life,
The many you have found.
It brings you joy and happiness to know they see you now.
We are saving all the tears
Saving all the tears.

I'm giving all my tears,
Giving all my tears.

[Gemma wrote this poem which was made into a song for her sister Kirsty Gough and was sung at Gemma's wedding in June 2018 for Kirsty. It is about Kirsty and Gemma's memories as her younger sister growing up in her shadow, and what she has observed since her diagnosis from her and her friends and family.]

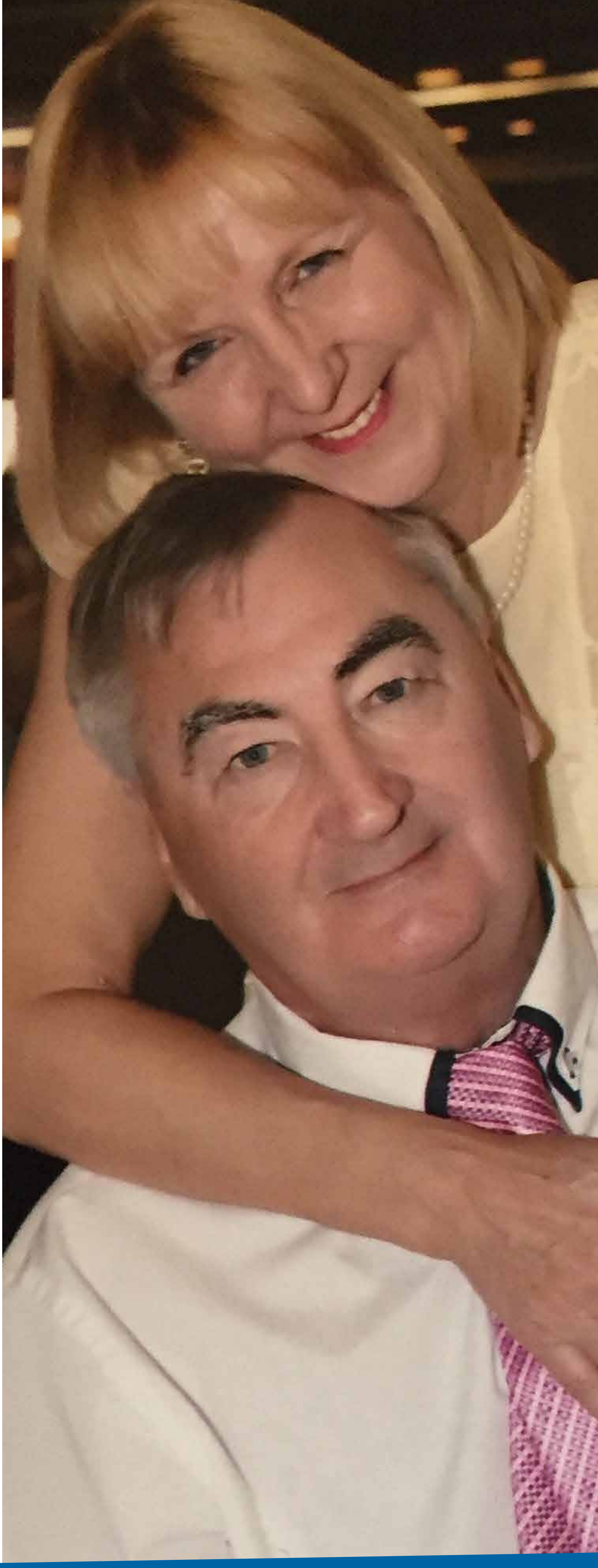
The Overseas Experience

[Please note, the trial mentioned in this article may not be available in Australia.]

Hello readers, my name is Les Wood and I am an MND sufferer. Well actually I don't really consider myself a sufferer in the general sense of the word. Please let me tell you about myself, but take note that I am not a journalist or rich in the written word, so please excuse any written errors.

I am aged 65 and retired, with this disease being the reason. Around ten years ago, I attempted to do a short run to catch a bus literally 100 metres away. Unfortunately I couldn't go above a brisk walking pace: though at 55 I wasn't an athlete, I considered myself active as my job at a prison as an electrician was quite physical, so the task was, or should have been, easily within my scope. I put this modest failure down to having just made a two hour car journey so the next day, whilst on vacation, I attempted the short run again having kept my previous day's failure to myself. Unfortunately, it was the same result. My legs just would not work as I wished, though walking wasn't a problem. I put this down to my age and thought maybe I had a touch of arthritis so I just got on with life.

Over the next 6 months or so I noticed that everyday tasks, mainly whilst at work, were becoming more and more difficult, to the extent that I was often seeking assistance from the other tradesmen At this time I had cause to visit my GP for a routine diabetic check up, on completion my GP asked how things were and if I had any other issues that required looking into. So I told her about my work difficulties and that my walking was by now starting to be a little bit laboured. The doctor got me to walk around her office but this proved nothing as the office was quite small and I could only go a few steps. She then asked me to walk with my toe touching my heel each step, rather like we see on TV when a police officer is trying to determine if someone is drunk or not. "No problem" I said, "this will be easy" as I promptly almost fell into her arms. I attempted this three times and each time could only manage one



step. I wasn't too concerned as I thought maybe there are a lot of people who can't do this simple task. The look on my doctor's face told me she was concerned even if I wasn't.

My doctor quickly had me visiting a local Neurologist who, on hearing my family history that I had a 49 year old sister who had died of MND some 25 years previously, did an examination and referred me to a Senior, later to become a Professor, at a major hospital that had better facilities for testing for neurological problems. I wasn't concerned about it being MND as I said to the Neurologist that two in one family is almost impossible as MND is not hereditary. I nearly fell off my chair when he said that actually around 10 % of cases are hereditary or, as he called it, familial.

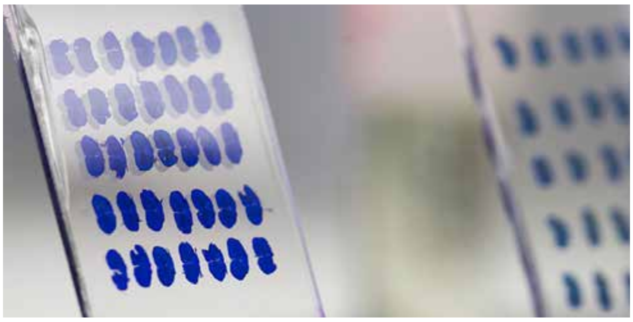
Since that day, my eldest sister was diagnosed with MND but, before she could be put on the doctor's list she died of breast cancer so that is now three of eight children with MND. Although MND is hereditary, my father died of cancer aged 66 and my mother died a couple of years ago aged 92. After almost two years of exhaustive tests, I was diagnosed with MND on August 12 th 2012.

The 90 minute journey home was just a blur. I started having three monthly check ups at the hospital where I received my diagnosis. On the same day, there was a lady in a wheelchair who had been given the same diagnosis and, on each three monthly Wednesday visit, she was also in the waiting room. We always smiled at each other but, on each visit, she appeared to my untrained eye to be deteriorating rapidly. I think I saw her four times and I could tell she was in a very advanced state. I never saw her a fifth time.

During one of my visits, my consultant told me that a drug company in America was looking for patients with the SOD1 type of MND. There are approximately 2% of patients with this gene. "We are looking for people to join a trial to test a new drug" he said. I would have to have a lot of tests to see if I was suitable and, if accepted, I would be the first person in Britain to try this drug. After a great many hiccups along the way, the trial started two years later with eight patients for one year in groups of two.

My group, being the first, was to be given a dose of 20 ml., the next 40 ml., then the next group 60 ml. and the last 80 ml. As this was a clinical trial 25%, or in this case two of us, were to be given a placebo. Apparently, when conducting a trial, they have to do this under health regulations. To this day, no one knows who got the placebo. So, after one year,, this is no longer classed as a trial but is now a treatment, though I suppose the American drug company which is funding this research will say it's still a trial.

Just as in the first phase, I attend the hospital one day each month and start off with a lot of tests and examinations, usually with the same doctors and nurses, so I have got to know them very well and we always have a bit of a laugh along the way. Then around 12 noon I am given the experimental drug. I have been upped to 60 ml. now. This unnamed drug is given via lumbar puncture and, at the time of writing, I have received around seventeen treatments including the initial trial of ten injections.



During one of my many chats with one of my doctors, he could tell I was feeling down. I told him that I was in a particularly low mood that day as I felt I had little hope of any real future. He gave me a real talking to and said "concentrate on what you can do rather than what you cannot do." I can tell you at this point that, after my diagnosis in 2012, I immediately resigned from my job as I thought there is no way I am spending half my life working when I could be at home enjoying life. It was a decision I was later to regret as the loss of earnings has a massive impact on one's life and I had another seven years to go before I could receive my Government pension.

My fabulous wife Valerie retired six months after I did as I was not too well at all and had a few falls in the house whilst she was at work. This was another major blow to our finances as she was a senior nurse running her own clinic and was receiving double the salary I was earning at the prison. So the impact was enormous, but as much as I tried to persuade her that I could manage, she wasn't having any of it. Anyway, I feel that this treatment is having a dramatic effect on me; well, to be honest, on both of us, as we are doing what the doctor advised and moving on.

One of my interests in life has always been horse racing so, after quite a handsome win, I decided to buy a few shares in some yearling racehorses. No horse is allowed to race until it is two year's old, so we spent the first 12 months watching their progress, often travelling to see them in their stables and staying in a nice hotel for a few days. Luckily, one of the horses was very good and won some valuable races. Unfortunately, or some would say fortunately, we received a very good offer for her and the trainer strongly advised us to accept which we did.

I now own shares in six horses, three of which will not be eligible to race until 2019, although we will visit them whenever we can. Our horses have won ten times in total, so we are extremely pleased. Some owners never have a winner so we are very lucky. One of the doctors on my monthly visits is always eager to see how the horses are going and often has a chuckle when I tell him about some of the days at the stables or the races.

My next treatment was on November the 6th, I had my monthly dose increased to 100 mils, this is the maximum allowed and to me is fantastic news. Although it is far from a pleasant treatment and means a 10 to 12 hour stay in hospital, I feel that I am benefitting immensely from the treatment so, as long as they will continue to give me the drug, I will continue on taking it. I was stressed at the beginning because it is not a miracle cure and must never be considered as such. Although I have been diagnosed for six years and had the disease two or three years before diagnosis, I consider myself very fortunate to be on what has turned out to be an extension of life that I certainly never expected. Many people, myself included, thought that no one is trying to find a cure for this terrible disease. I now realise that nothing could be further from the truth as I, and the other fifty or so involved in trials around the world, give testament to.

I'm sure readers will realise that my journalistic skills fall a long way short of those of a skilled writer, but what I am writing is the truth as I see it, with maybe a couple of incorrect dates (but only by a couple of months or so). I have not mentioned the names of any doctors or nurses as I feel it would be inappropriate to do so without their permission. Although I'm sure I can name the hospital … it is the Hallamshire Hospital, Sheffield, England. I can tell you that I am proud to be able to say how fortunate I am to be looked after by such a fantastic team of medical staff, and I must also mention all the staff that we rarely come across, such as scientists, secretaries etc. The list could go on for ever.

So, in conclusion, thanks to Hallamshire Hospital and their world class team and the drug company which has spent large amounts of money developing this drug and bringing it into trial. Who knows, if it turns out to be successful, then maybe they can develop it to suit other faulty genes. I have included a few photos so that you can put a face to my story.

So it's goodbye from me, I will try as best and honestly as I can. Good luck to all patients with this horrendous disease. Stay strong, I am sure one day we will beat it.

Write your MND Story

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

Please email your text and a photo to: **info@mnd.asn.au** by 9 January for our next edition.

GROUP PROGRAMS

Living Well

'Living Well' is a group program for people with MND and their carers. Participants have the opportunity to share knowledge and discuss topics relevant to living with MND.

The format of the program varies to suit the needs of participants and may include readings, group discussion, video presentations and guest speakers. Additionally, participants provide each other with support and are able to share ideas and solutions of their own.

Living Through

'Living Through' provides an opportunity for newly bereaved carers and family members to meet with others who share similar experiences in an informal and friendly environment.

Participants hear from a guest speaker who presents on typical grief experiences. They also have the opportunity to share advice with one another and have access to bereavement support resources.

Living On

'Living On' is a four week program designed for former carers. It provides the opportunity for people who have been bereaved for 12 months or more to meet in a facilitated group to explore positive ways of moving forward whilst finding ways of retaining treasured memories.

How do you get involved with the groups?

MND Victoria will contact potential participants for the Living On, Living Through and Living Well programs shortly before the groups are run. However, you are more than welcome to contact MND Victoria to register your interest: Phone: (03) 9830 2122 or 1800 806 632 or email: **info@mnd.asn.au**

Meeting others

Are you interested in having contact with others living with MND? MND Victoria can assist people with MND, carers, family members and friends to get in contact with others in similar circumstances.

This can be done through:

- MND Victoria group programs
- Ongoing support groups
- Facilitating contact either in person, by phone or by email
- Referring to external online support groups.

If you would like to be in contact with others, but are uncertain on how to go about it, then contact us and we can talk you through your options.

Phone: (03) 9830 2122 or 1800 806 632 or email: **info@mnd.asn.au**

Facebook support groups

MND Carers Australia

An online support group for Australian MND carers to discuss issues they face. MND Carers Australia is independent from MND Victoria, but has asked us to promote their group. To access the group you will need a Facebook account.

A message from MND Carers Australia's administrators: MND Carers Australia's focus is to support the primary carer of someone with MND. The primary carer faces many challenges. They often feel isolated, feeling like no-one understands what they are going through. Only one family member is allowed in the group as the primary carer needs a safe place to discuss any and all issues they may face. This is a private group where you can feel supported, ask questions and vent about the difficulties you face as the primary carer of someone with MND. We hope you will be proactive in the group and gain knowledge from others, but we understand everyone will be at a different point on the MND road. If you would like to join, go to Facebook and search for: "MND Carers Australia" or visit: **https://www.facebook.com/groups/1408400102747388**

MND Angels Australia

An online support group for people in Australia whose partners have died from MND. MND Angels is independent from MND Victoria, but has asked us to promote their group. MND Angels offers participants an opportunity to share experiences and support one another. To access the group you will need a Facebook account.

If you would like to join, go to Facebook and search for: "MND Angels Australia" or visit: **https://www.facebook.com/groups/1512117609036086**

Kennedy's Disease Facebook Group

Did you know that MND Victoria also provides support for people living in Victoria with Kennedy's Disease?

Kennedy's Disease (also known as Spinal and Bulbar Muscular Atrophy) is a condition that has similar symptoms to MND.

One of our members has shared a Facebook group for Australians with, or affected by, Kennedy's Disease. The group aims to help raise awareness within our communities and to help each other out: **https://www.facebook.com/groups/340781642962036/**

Support services for carers of people with MND

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

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

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

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

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

HEALTH PROFESSIONAL FORUM IN TASMANIA

Join us on **Friday 1 March 2019** in Tassie at the **Launceston Conference Centre** for a forum specifically for health and community professionals.

The theme of the forum is '**Navigating MND: Charting a course for health professionals**'.

To join our email list for health professionals and find out about future events and conferences please contact: **info@mnd.asn.au**

Or follow us on Facebook for updates: **www.facebook.com/MNDVic**

Volunteer News!

Walk to D'Feet MND

Once again our Walk to D'Feet MND was a great success due to the support of community, and especially because of the practical assistance and support provided by almost 50 volunteers and staff. Thank you to everyone who contributed assisting with registrations, merchandise, selling raffle tickets, helping in the activity and BBQ tents and as course stewards. We hope all involved enjoyed the day.

International Volunteer Day - Wednesday 5th December 2018

International Volunteer Day (IVD) was introduced by the UN General Assembly in 1985 and is held on 5 December each year. It provides an opportunity for organisations such as MND Victoria to celebrate our efforts throughout the year.

MND Victoria acknowledges our volunteers and also the contributions of volunteers in thousands of community organisations across the state who make such a difference to their communities.

VOLUNTEERS BUILD
RESILIENT COMMUNITIES

Volunteer & Christmas Celebration

On Tuesday 4th December, a large group of our volunteers came together at MND Victoria head office in Canterbury to relax and enjoy each other's company and to celebrate their combined volunteer efforts over the past year. The event also provided an opportunity to recognise a number of our long serving volunteers for their contributions. Ann Simeone was recognised with her 10 year service award. Katharine Barnett and Helen Streeter were both recognised for 5 year's service with MND Victoria.

We congratulate Anne, Katharine and Helen and thank all of our volunteers for their dedication and commitment to this organisation and the work we do.

At the end of a busy year I wish you happiness this festive holiday season.

Volunteer Roles available in 2019

Campaigns Champion

Join us as a Campaigns Champion in 2019 and help to build momentum for change for people living with MND. Campaign Champions are involved in a range of campaigning activities including meeting with, and influencing, local, State and Federal MPs and community groups to raise awareness and understanding of the issues people living with MND face every day.

The Campaigns Champion role suits people who like to engage with others and is perfect for people who seek a volunteer role which is flexible and dynamic. If you have a couple of hours a week to make a difference, this role could be for you.

Full training and ongoing support are offered to Campaigns Champions as well as opportunities to connect with other volunteers and to share and learn from each other's experiences and successes. Contact volunteer@mnd.asn.au or mndaction@mndaustralia.org.au to learn more or read the Role Description at: www.mndaction.org.au/MNDAction/media/Resources/Role-Description.pdf

Massage volunteers

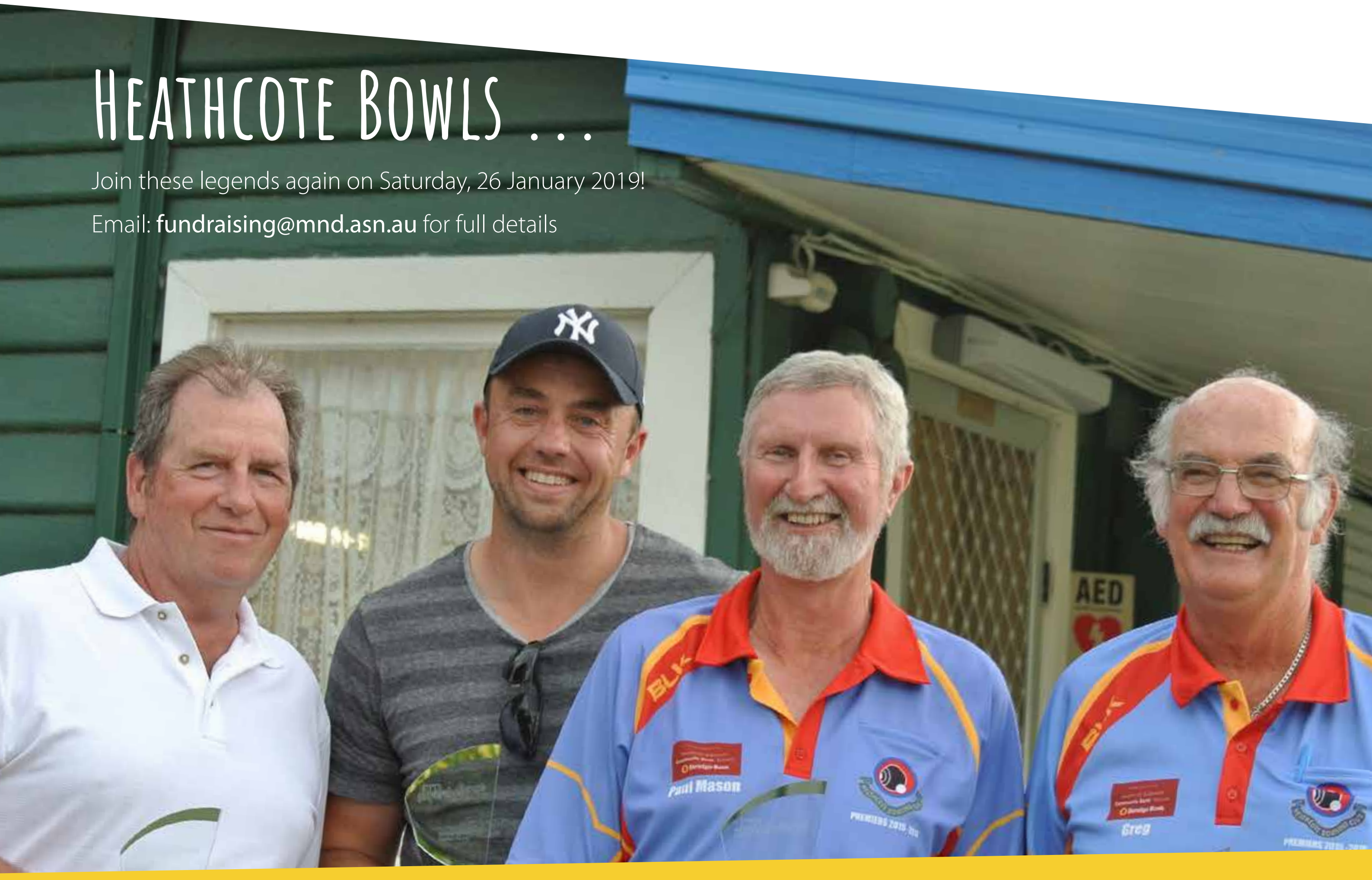
Client requests for hand and foot massage are certainly the most common requests we receive at MND Victoria. We are always seeking more Massage Volunteers to support clients across the State. To be successful in this role you do not need to come with any massage experience or qualifications. We will provide you with the information and training to prepare you for this role. It would suit people who have 2-3 hours per week or fortnight to spend time with a client in your area providing gentle hand or foot massage.

Please contact: **volunteer@mnd.asn.au** for more information.

HEATHCOTE BOWLS ...

Join these legends again on Saturday, 26 January 2019!

Email: **fundraising@mnd.asn.au** for full details



RESEARCH UPDATE

THE 14TH ANNUAL RESEARCH CONFERENCE

On 9 November, MND Australia presented the 14th Annual Research Conference, with the theme "Investing in Innovation, Partnering for Progress".

Over 100 researchers, students and other MND focussed attendees heard from 20 presenters about their research , what they did, what they found and how that impacts on the future of research and MND.

Themes of presentations were:

- Investing in innovation and partnering, where we heard about supporting researchers at all stages of their careers, and partnering nationally and globally;
- Understanding causes, including genomics, mechanism and excitability, the neuromuscular junction, and cyanobacteria toxin;
- Treatment development and trials, including protein degradation, drug testing, growth factors, copper availability and the Lighthouse Project;
- Enhancing clinical research, including inflammation, loss of appetite and weight management, swallowing exercises and diet, lung volume and breath-stacking, and brain controlled communication.

All presenters had been funded by MND Australia through its research arm, MNDRIA, and five presenters were funded by named grants via MND Victoria.

Following presentations, there was a poster session with 38 posters on a wide variety of research directions, with the authors standing by to explain their research and its impact on cause, treatment and cure of MND.

Access to the program and abstracts is available via a link at https://bit.ly/2qKlPaw

>> MND CONNECT 10 NOVEMBER, 2018

To further promote research and its impact, MND Australia and MND Victoria presented the 4th MND Connect meeting in Melbourne on Saturday, 10th November 2018 at the Florey Institute of Neuroscience and Mental Health.

The theme was "MND: one disease, many faces" with the aim of sharing the wonderful MND research carried out in Australia. It offered people living with MND, their families, and a general audience the opportunity to learn more about MND research and care strategies.

Dr Susan Mathers *(photo above)* from Calvary Health Care Bethlehem, opened MND Connect with a great presentation on the theme, and was followed by a presentation by Maria Nanfra on her and her family's experience of being a carer.

Maria spoke articulately and passionately about caring for her mother who was diagnosed with MND four years ago and her father who is also unwell. She highlighted the importance of carers looking after their own health and wellbeing by taking up opportunities for respite from the 24/7 role of caring for others.

Maria also commented on the unfairness of the current system whereby people under 65 years have access to the National Disability Insurance Scheme (NDIS) and those over 65 years do not. Instead, these older people are forced to rely on aged care services that are designed to support people who are frail aged, not those who have a rapidly progressing complex condition like MND.

Dr Thanuja Dharmadasa from The University of Sydney presented on 'The MND jigsaw: patterns within the puzzle'. Dr Dharmadasa's presentation discussed MND disease heterogeneity and explored what we currently know, highlighting the key implications that this may hold for patients regarding their disease. New techniques, which hope to improve diagnosis, better predict disease spread, and enable more accurate prognoses for all patients living with MND were discussed.

A/Prof Gail Robinson *(photo above)* from The University of Queensland (who wrote for us in our May/June 2018 edition of MND News) spoke about 'Cognition and behaviour and MND' giving an overview of cognitive and behaviour change with a focus on language and frontal executive functions.

Roxanne Maule a speech pathologist from Calvary Healthcare Bethlehem, presented on 'Lessons learned from super heroes in considering the management of bulbar symptoms in MND'. Roxanne gave an overview of bulbar symptoms in MND and their management, and used parallels drawn from graphic novel super hero culture to highlight the role of the team with a focus on the speech pathologist. She highlighted how the advances in technology have made a huge impact for people living with MND, particularly in the area of communication technologies.

Prof David Berlowitz, *(Photo above)* from the University of Melbourne spoke on 'Breathing life into MND' and how multidisciplinary care is the most important contributor to increased survival for people with MND. His team have demonstrated that non-invasive ventilation (NIV) improves survival overall by a median of 13 months.

The afternoon session was chaired by **Dr Shyuan Ngo**, from University of Queensland and covered the following presentations:

A/Prof Ken Rodgers from the University of Technology, Sydney presented on Genes and the environment: The Different Causes of MND. It is now known that, even if you don't have a family history of MND, certain inherited genes can make you more susceptible to the disorder. There are three groups of people with MND: those with a family history of disease (~10%), those with no family history but with a genetic susceptibility (~10%), and those with no family history and no known genetic susceptibility (~80%). Professor Al-Chalabi, from Kings College, London, used a mathematical model of cancer from 1954 to analyse MND patient data collected from around the world and estimated that 6 steps were required to cause MND. In the case of familial MND however, fewer steps (2-5) were required and, as a result, the age of disease onset is on average 5 years earlier than the sporadic form. The steps which could include everything from smoking, head injury, military service and welding, to exposure to pesticides, herbicides, heavy metals and algal blooms.

Next up, **Dr Peter Allcroft** from Flinders Medical Centre presented on 'Multidisciplinary care and palliative care'. He spoke of Palliative care's aim to improve quality of life for patients and their families, and to prevent suffering, with a specific focus on care for patients with

MND and their families. There is growing evidence that early referral to a specialist palliative care service improves quality of life, prolongs life, results in fewer unplanned admissions, and enables preferred location of dying to occur.

Emeritus Prof Margaret O'Connor from Monash University presented on 'Voluntary Assisted Dying', Prof O'Connor outlined the requirements of the legislation and discussed aspects that require careful consideration for an individual seeking VAD. Implementations for clinician involvement were also discussed.

A/Prof Bradley Turner *(photo above)* from The Florey Institute of Neuroscience and Mental Health, spoke on 'The Role of Stem Cells in Screening Drugs as Potential Therapies'. "Induced pluripotent stem cells" (iPSCs) are revolutionising MND research. This technology allows MND patient skin cells to be genetically "reprogrammed" and used to grow patient-matched motor neurons in the laboratory. This approach provides a powerful tool capable of accessing motor neurons from living MND patients and modelling all forms of the disease, especially sporadic MND, for the first time. Drug libraries containing 1000's of clinically approved drugs will be tested to identify candidate agents capable of improving motor neuron survival for subsequent preclinical and clinical development.

A/Prof Rob Henderson, from The University of Queensland, and Royal Brisbane & Women's Hospital gave a 'Clinical Trials Update'. A/Prof Henderson spoke of the challenges in conducting trials in MND, current clinical MND trials in Australia and future trials.

A/Prof Henderson explained that most clinical trials for MND don't reach stage 3 which involve large groups of trial participants and are very expensive to run. He also discussed the use of re-purposed drugs which have already been approved for use in other conditions and are therefore tried, tested and safe. For people who are interested in trying alternative therapies, A/Prof Henderson advised them to carefully consider the cost, time involved and possible side effects.

The event concluded with a lively panel discussion and then Lab visits led by Associate Professor Bradley Turner from The Florey Institute of Neuroscience and Mental Health.

A huge thank you to everyone who presented and especially the speakers who travelled from across the country to present to people with MND, their families and friends in Melbourne.

Thank you also to MND Australia for organising this event and the State Associations for their assistance in the planning.

A link to the program and abstracts is available via a link at https://bit.ly/2B5AuDs

This was a great event, missed by many.

2019 RESEARCH GRANTS ANNOUNCED ...

MND Australia's research arm – the MND Research Institute of Australia (MNDRIA) - has awarded almost $4 million for new research projects commencing in 2019.

Following review of grant applications by the MNDRIA Research Committee, 28 new research projects across all Australian States will be supported next year in addition to funds previously committed to support an innovative, national NHMRC partnership grant (2019 – 2023) and the Australian MND Registry.

The Betty Laidlaw Prize for an outstanding mid-career researcher was awarded to Macquarie University researcher Dr Marco Morsch for his project Targeting the nucleo-cytoplasmic transport machinery in sporadic and familial ALS.

"It is an immense honour to be the recipient of the Betty Laidlaw Prize 2019 from MNDRIA and the Laidlaw family. These funds will allow three mid-career researchers to establish a novel and innovative research stream that investigates the basic cellular mechanisms on how disease proteins get misdirected within motor neurons. Understanding this critical step in the development of MND will hopefully get us one step closer to finding a cure".

Two postdoctoral fellowships for early career researchers have been awarded: the Bill Gole MND Postdoctoral Fellowship (2019 - 2021) to Dr Rosemary Clarke from The University of Tasmania and the Beryl Bayley MND Postdoctoral Fellowship (2019 – 2021) to Dr James Hilton from The University of Melbourne.

Twenty five Innovator Grants were awarded. The Charcot Grant, awarded annually for the highest ranking application, went to Professor Julian Gold (The Albion Centre, Sydney) for a phase 3 clinical trial of Triumeq.

A further 24 Innovator Grants will support projects in three areas of research: understanding the causes of MND; treatment development and clinical trials; clinical and healthcare research.

MNDRIA funds only the best research and researchers from across Australia. If more funds were available, grants could be awarded by the expert MNDRIA Research Committee to a greater proportion of the many excellent applications that are received each year.

HOW CAN I HELP MND RESEARCH?

Participate in Familial MND research

Professor Garth Nicholson and his research team based at the ANZAC Research Institute, Concord Hospital Sydney, are studying gene variations in familial motor neurone disease.

Professor Nicholson and his collaborators are keen to obtain DNA samples from patients with familial motor neurone disease. To assist this research, a single blood sample is required together with your consent to take part in the research and, where necessary, your permission to obtain a copy of clinical information from your treating physician. The blood sample can be taken locally and then sent to Sydney for analysis.

If you are interested in donating, then phone (02) 9767 6796 or email **molmed@med.usyd.edu.au** for further details.

ALS Quest Survey

The ALS Quest survey is an anonymous online questionnaire looking at environmental risk factors for MND. It asks a series of questions about a person's lifestyle, work history and family history with the aim of discovering clues as to what factors trigger MND.

ALS Quest is a University of Sydney project and the survey is available to complete online at: **www.alsquest.org** Both people with and without MND can fill in the survey - it will take around 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 or find out more on The Florey's website: **www.florey.edu.au/vic-brain-bank** Email: **fairlie.hinton@florey.edu.au** Phone: (03) 8344 1900 Mobile: 0438 530 372

Join the Australian Motor Neurone Disease Registry

The MND Registry is an ambitious project to register and collect data from every person diagnosed with MND in Australia. It contains de-identified data from people diagnosed with MND including information about the diagnosis, symptoms, treatment and management. This information is made available to researchers studying MND.

The MND Registry provides people living with MND with an opportunity to actively contribute to research and learn more about the disease.

The participant's neurologist will fill out a case report form detailing the treatment and health situation at the time of the visit. There are no extra tests, procedures or treatments involved. People are free to decline or to withdraw from the study at any time.

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

Walk To D'feet MND In A town Near You This Summer!

BENALLA: 8.30am Sunday 24 February 2019 at Benalla Lake Foreshore. Walk, cycle, relay or run to D'feet MND! Sign up at: **www.act2dfeetmnd.com**

GEELONG: 10.30am, Sunday 24 March 2019 at Barwon Valley Fun Park, Barrabool Road, Belmont. Show your support for people with motor neurone disease by walking with us, register online at: **www.mnd.asn.au/walk**

ALL proceeds provide VITAL support for people with MND and fund research.

FUNDRAISING

"You never change your life until you step out of your comfort zone; change begins at the end of your comfort zone." Roy T. Bennett, Author

As I sit down to write this article for our last newsletter of the year I am delighted to once more be in the enviable position of saying thank you to so many of our incredible supporters who regularly step out of their comfort zone to raise awareness and funds for people living with MND. Even when you are passionate about a cause, it's not always easy to ask your family and friends to support your event, but thankfully our committed fundraisers do this time after time.

Earlier this year Daniel, Heidi and I were privileged to sit down and talk with four people living with MND who access our services. It certainly brings home the stark reality of this disease and how even the smallest day to day activity can become a huge challenge, and how vitally important it is for them to access our services to help them overcome these and live as independently as possible for as long as possible.

An MND diagnosis is devastating. It changes everything. Families are faced with making decisions about on-going care including how they will finance their ever changing care needs. Knowing that MND Victoria's mission is to support them as they navigate through the complex health care system and provide them with vital assistive technology often relieves them of the emotional and financial burden they would otherwise face. Families can concentrate on creating memories and enjoying each moment with family and friends.

We can only continue to deliver services to the 400 plus Victorians living with MND every day thanks to the continued financial support of our generous donors.

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.

Sadly, three of the four people Daniel, Heidi and I met in April have already died from MND, highlighting once again that this disease is relentless.

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 Fundraising

EVENTS WRAP UP!

Tee Off MND

The annual Tee Off MND Charity day was held at Clifton Springs Golf Club on a perfect Sunday morning in October. We are so thankful to Russell Lowe and his amazing team of helpers who make this a hugely successful event each year.

Lamington Drive/MND 300

Leonie Bourke supported her son and some mates whilst they ran 300km from Wangaratta to Melbourne in September.

She wanted to help their fundraising campaign so she enlisted the help of some friends, and a number of volunteers from The Wangaratta Quilters Club, to make 500 DOZEN lamingtons. It took them a day to make them all and a day to sell them all.

After the dust settled, it was revealed another $3000 was raised bringing the MND 300 total close to $30,000! What an amazing achievement from everyone involved.

Shave the Fluff Off

Six months ago a group of mates were sitting around a table when Mark Glenister told Tony 'Broomie' Broome if he could grow facial hair until grand final day, he'd give him $1000 for the charity of his choice. Tony did grow a mean beard, Mark donated his $1000, and after a little event at the Bemm River Hotel with raffles and auctions and a very public haircut and shave, a further $3000 was raised! MND has hit Tony's family hard and he was delighted he could do his bit for others living with this horrible disease.

Rosebud Walk to D'feet MND

The Rosebud Walk to D'feet MND was held on Sunday, 4 November at the Village Glen with approximately 50 walkers.

The event has been growing each year and this year they raised an incredible $10,300!

CASTING CALL

We've just been announced as the official charity partner of a national TV show. MND Victoria is now working with the Producers of the show to find 12 people to be cast as television STARS!

Those selected will go on a life-changing and unforgettable adventure while being filmed by an award-winning crew. This groundbreaking TV show – featuring YOU – will screen nationally on a major television network in 2020.

This is a once-in-a-lifetime opportunity, so let us know if you (or someone you know) would like to take part.

Simply attend our 30 minute "casting" session on Wednesday 12th December 2018 at 6pm at the Adina Apartment Hotel Melbourne, 189 Queen Street, Melbourne. This life changing television opportunity is for ANYONE and EVERYONE… so bring your friends and family! (Over 18 yrs)

Please share this opportunity with anyone you know who may be interested.

See you on 12 December (spots are limited so get in first!). Proceeds from this national TV show will support MND Victoria. We thank Charity TV Productions for this exciting opportunity!

ROCK OFF MND BACK IN 2019!

The Rock Off MND live music event is back on **Saturday, 2 March 2019** at Deakin Waterfront, Geelong!

We are super excited for next year's headline act The Black Sorrows ...

Grab your tickets at:

www.rockoffmnd.com.au

Thanks to everyone who supported Rock Off MND in 2018 , an incredible $141,970 was raised for MND Research.

Let's make next year even bigger - grab all your mates to be a part of this hugely successful event to support MND research!

Walk to D'feet MND Sign Up: www.mnd.asn.au/walk

Our Blue Cornflower range of jewelery is the perfect gift to remember a loved one this Christmas.

Earrings or necklaces are $29 each, keyrings also available in silver or black for $19 (postage included!).

Made by a local artist! Check them and all our other MND gear out at:

www.mnd.asn.au/gear

Or phone: **03 9830 2122** to order!

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

Our MND Gear ... Travelling The Globe!

Our Flip Flops have made it all the way to Paris! Our hoodie was spotted in Switzerland and Queenstown and our Walk to D'feet MND tshirt hiked the Great Wall of China! Grab all your MND gear online at: **www.mnd.asn.au/gear ...** perfect for raising awareness wherever you travel!

DONATIONS WERE RECEIVED … THANK YOU!

In memory of

Ken Davis
Beryl Worthy
John Ryan
Eugenie Agullo
Joy Blakeley
Dean Olsson
Bill Hicks
Tom Critchley
Horst Zwicklert
Margaret Williams
Myra June Lloyd
Gavin McCann
Nick Harding
Anne Di Nardo
Gary Spark
Lorraine Ralston
David Bloom
Maree Jones
Judith Cribbes
Murray Swinton
Bev & John Kloprogge
Max Sartori
Carol Eden
Paul Tsakissins
Ivan Juracich
Nicole Hall
Andrew Bowman
Peter Patti
Panagiotis Papoutsis
Margie Parsons
Marion McCabe
Jane Lowe
Belinda Horsley
Stephen Fullarton
Rita Gall
Luke Emery
Mark Olsson
Madelyn Farrugia
Bruce Nelson

Research in Memory

Norman Jarvis
Graeme Ross

Bequests

The Estate of Helen Jean Burgess

Organisations

Torquay Laurel (Legacy) Group
Warragul Business Group
Maribyrnong Aquatic Centre
Muscle Essence Massage
Gaji Hair Designs
K4 Constructions
The Royal Hotel Benalla
McDonald Upton Real Estate
Tocumwal Golf Resort
Australian Hellenic Gold Federation
GROMER Group
Simply Helping- Eastern

Clubs

Ruby Red Dancer
The Country Women's Association of Victoria
Country Women's Assocation of Victoria - Caniambo Branch
Drouin Country Women's Association
Belgrave Football Netball Club
Young Generation Senior Filipino Citizen Club
Lions Club of Geelong Breakfast Inc
Essendon Football Club
Riverina Dragons Supporters Group
Jerilderie Hospital Auxiliary
Tatura Lawn Tennis Club
Centre Quilters Inc.

Schools

Carnegie Primary School
Keilor Primary School
Foster Primary School
Menai High School
Monash University Education Innovation Team

Corporate

Express Insurance Brokers Pty Ltd
Specsavers Pty Ltd
Trevor P Weichmann & Assoc P/L
Ritchies IGA
Garth Lisle Property Consultants
WAW Credit Union
Camden Lane Pty Ltd
Melbourne Health Biochemistry
Drive Melbourne
TB White & Sons Pty Ltd
Law Image Service
Fraser Partners Bo Peep
O'Brien Real Estate
Fit n Firm Berwick

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

MND Victoria Membership

Have you renewed your membership for 2018/2019?

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 text and photo to: **info@mnd.asn.au** by 9 January for the next edition, to be mailed on 5 February 2019.

GET INVOLVED IN AN EVENT NEAR YOU!

Date	Event	Contact
Monday, 21 January 2019	MND Information Session	Email: info@mnd.asn.au
Saturday, 26 January 2019	Heathcote Bowls Event	Email: fundraising@mnd.asn.au
Sunday, 24 February 2019	Benalla Act to D'feet MND	www.act2dfeetmnd.com
Friday, 1 March 2019	Tasmanian Health Profesisonals Forum	Email: info@mnd.asn.au
Saturday, 2 March 2019	Rock Off MND - live music event	www.rockoffmnd.com.au
Tuesday, 5 March 2019	MND Information Session	Email: info@mnd.asn.au
Sunday, 24 March 2019	Geelong Walk to D'feet MND	Email: fundraising@mnd.asn.au
Wednesday, 17 April 2019	MND Information Session	Email: info@mnd.asn.au
5–11 May 2019	***** MND WEEK 2019 *****	Email: fundraising@mnd.asn.au
Sunday, 5 May 2019	Service of Hope and Remembrance	Email: info@mnd.asn.au
Tuesday, 7 May 2019	Ask the Experts - MND Research Forum	Email: info@mnd.asn.au
Friday, 10 May 2019	Blue Cornflower Day	Email: fundraising@mnd.asn.au
20–26 May 2019	National Volunteer Week	Email: volunteer@mnd.asn.au
Friday, 21 June 2019	Global MND Awareness Day	Email: fundraising@mnd.asn.au
16–22 September 2019	Larapinta Trek - Challenge event	Email: fundraising@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