

# MND NEWS



The newsletter of the  
Motor Neurone Disease  
Association of Victoria

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



[www.mnd.asn.au](http://www.mnd.asn.au)

may/june  
**2018**



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ABN 44-113-484-160  
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

# STAFF

**Chief Executive Officer:** Rodney Harris

**Manager Finance & Administration:** Megan Crellin

**Administration Assistants:** Isabelle Lloyd, Rebecca Moussa

**Manager Fundraising:** Kathy Nightingale

**Fundraising Officer:** Daniel Woodrow

**Digital Communications Officer:** Heidi Bryce

**Manager Support Services:** Julie McConnell

**Coordinator MND Advisor Service:** Janette McDonald

## MND Advisors:

Ruth McEvoy

Elizabeth Crask

Lesley Burcher

Eric Kelly

Lauryn Matheson

Jenny Waites

Trish Duffy

Leanne Conway

Melissa Kettle

**Coordinator Operations:** Georgina Diacos

**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 CHAIRMAN



**I am writing this article to advise the news that our CEO, Rod Harris, has decided it is time to retire following 24 years as CEO of MND Victoria.** Interestingly, whilst I was expecting this article to be sombre in its content, I am also feeling quite uplifted following my attendance at yet another well organised, successful and thought-provoking Service of Hope and Remembrance – my favourite MND event every 12 months. There are two main messages from our Service; reflection and hope, and I will use these messages to do my best to discuss Rod’s significant impact on our organisation.

When I reflect on Rod’s numerous contributions over the many years, I have been involved with the Victorian State Association, the one consistent benefit and value has been to those with MND, their families, carers and supporters. This core group within our MND community have been the motive for Rod’s passion, incredible commitment and energy.

Rod received an Order of Australia (OAM) for his work to ensure that palliative care was available to everybody and helped embed MND in the psyche of palliative care. Palliative care is, in Rod’s words: “no longer a cancer service, (it) is now a service for all people who need and want it”. Rod, and his forever supportive partner Pam, often represent MND Victoria at fundraising functions throughout the week and weekends, whenever there is an opportunity to spread the word and raise some funds to support those with MND.

Rod’s passion is also extended to his team at MND Victoria. Rod’s considerable leadership skills have earned him the respect of his staff, notwithstanding continual change and ongoing challenges – the transition to NDIS and MyAgedCare rollout together with the implementation of our new client management system have been just some of these significant changes and challenges.

An articulate communicator, Rod has been able to successfully influence many aspects of State government, including the relatively new and evolving NDIS program. Rod’s significant experience gained by his years with MND Victoria, together with his role as Board member and Chairman of the International MND Alliance, has provided the confidence to ensure many successful negotiated outcomes, all of which have (and will continue to) benefited those with MND.

These have been just some of my reflections – there will be many more to come. So where does hope come in? At our Service for Hope and Remembrance we spoke about the future concerning new advances in treatment for people living with MND, finding the cause and of course, an ultimate cure for MND. Rod has always been intensely supportive of research, most particularly research relating to care and support of those with MND. Communication from the MNDRIA has improved markedly due to Rod’s insistence that reports from Researchers and Scientists are written in “plain English” and Rod’s continued backing of the MND Tissue Bank of Victoria has ensured its ongoing survival.

Thankfully we will have to put up with Rod for some months to come so that he can assist us to recruit the most appropriate replacement CEO. Whilst Rod thinks this will be an easy task we are all very much aware that Rod leaves some very large shoes to fill.

There will be many opportunities for us to reflect on Rod’s achievements and contributions before Rod retires and his passionate support of research will ensure that future generations of MND patients will have more improved treatments and a cure for this dreadful disease.

**David Lamperd, Chairman,  
State Council, MND Victoria**

# FROM THE CEO



**As forewarned in the last newsletter, MND Australia and the State Associations have developed a campaign to influence Government in Aged Care – to Make Aged Care Fair for people with MND.**

The development of the NDIS has meant that responsibility for those over 65, when diagnosed, has been transferred to Aged Care – a service focussed on people who are frail and experiencing dementia. Aged Care does not recognise that people with a disability over 65 may not be frail, nor experiencing dementia, but need assistance with home care, assistive technology and home modifications to regain, retain and extend their independence in their community, and live better for longer. And this especially applies for people with MND.

We want to Make Aged Care Fair. We want the entitlement to support which is a fundamental right under the NDIS to be extended to those over 65. We want people with MND to be able to access assistive technology to keep them and their carers safe, and to extend their independence and mobility. We want them to be able to access care and support that will enable them to remain at home for as long as they wish. And we want them to live better for longer.

We need your support and commitment to achieve this. We need you to visit: [www.mndaction.org.au](http://www.mndaction.org.au) and register to receive more information. We need your commitment to take action by contacting your

State and Federal politicians to tell them that you want to Make Aged Care Fair for people with MND.

To assist, MND Australia has developed the MND Action website. I expect it to be live when you read this. We need you to use the website to send an email to your State and Federal politicians and tell them that you want them to Make Aged Care Fair for people with MND. Material on the site will assist you to get the message across.

## **Please take action!**

As I write this, MND Week is coming to a close. Our Service of Hope and Remembrance was a wonderful event attended by over 50 people who shared their experience with MND and their hope for a world without MND.

Our 'Ask the Experts' event was a terrific experience, presented by Associate Professor Brad Turner and his team at The Florey Institute, incorporating three presentations about research, followed by lunch, and then demonstration-based tours of the lab. It was amazing to see motor neurones alive and wriggling that have come from the recent program of skin sample collection, and to hear of the plans to test over 50,000 drugs and compounds that are currently available.

You will have read David Lamperd's article on my retirement. All I wish to say is that it has been an honour and a privilege to work with, and for, people with MND over the past 24 years. I have been very lucky to work with a wonderful team, past and present, who help people live better for longer while fighting MND. I have met, and continue to meet, inspirational people who have helped drive me forward in my work. I thank the MND Victoria State Councils, past and present, for their trust and giving me the opportunity to be a part of this wonderful organisation and the people it serves.

Remember, please take action – we will not Make Aged Care Fair and provide effective and adequate support for people with MND unless we all take action at – [www.mndaction.org.au](http://www.mndaction.org.au)

Until next time ...

**Rod Harris, CEO**

# SUPPORT SERVICES



We are once again coming to the time of year where our services and supports are audited against the Department of Health and Human Services (DHHS) and ISO 9001-2015 standards. This year the audit is scheduled for mid-June. As with previous audits, the auditors will be seeking input from our clients and families to ascertain if we are delivering our support and services according to the standards and your expectations. If you or a family member would like to speak with one of the auditors either in person, via the telephone or email, please contact Georgina on 98302122 and she will make a note for the auditors.

The NDIS continues to confuse and frustrate whilst at times amaze. It is confusing and frustrating because each NDIA planner or Local Area Coordinator seems to have a different understanding of the process required for a person to become a participant and then develop and complete a plan. This uncertainty makes it very difficult for the MND Advisors to provide you with the correct advice when even NDIA staff do not have the same understanding amongst themselves, or even the same information. All NDIA staff are new and many have not worked with disability before and certainly not people living with MND. This of course compounds the difficulties when developing an appropriate plan for someone living with MND. We are finding that recently we are seeing more appropriate plans but the MND Advisors are working very hard with each person to support you to ensure that your plan meets your expressed goals and provides the support to enable

you to live as well as possible in the setting of your choice. In many cases, once the plans are completed and approved, they are amazing in that they provide funds to cover the expressed needs and outcomes that make a difference to lives. Our experience is that when our clients have a well thought out and appropriate NDIS plan, their support needs are generally well met.

We recently welcomed Melissa Kettle (*photo below*) as our newest MND Advisor. Melissa commenced in her role with the Support Services Team on 23 April and spent some time participating in her orientation and induction program. She comes with a wealth of experience having previously worked in many community and clinical settings.

Melissa will be based at the Canterbury office and will cover the north eastern metropolitan local government areas of Yarra, Nillumbik, Darebin and Whittlesea. Her usual days of work will be Monday – Wednesday and Friday. Melissa will work within the metropolitan team of MND Advisors/Coordinators of Supports. As many of our MND Advisors are part-time workers and therefore not always available, our MND Advisors work as a team to provide support as required.



In March, Sandra Nicholls commenced as our newest Equipment Services Officer. Sandra has a strong admin background having worked in banking and finance for more than 20 years. Sandra also has a family connection with MND in Victoria and has experienced our services previously. Sandra has settled in well and quickly become an integral part of the team.

In other staff news and with more than a tinge of sadness, Lesley Burcher, MND Advisor for the inner eastern and southern metropolitan areas, is leaving in June after almost 20 years working at MND Victoria. Lesley has decided it is time for her to look for other opportunities and explore other “ventures”.

In her letter of resignation, Lesley states that “working with people living with MND has been the most rewarding and humbling experience and has contributed to putting my own life and how I live it, into perspective.” Lesley also thanked MND Victoria State Council for ‘their guidance and commitment to providing a stable and secure environment for all at MND Victoria to continue to provide the best possible care’.

With Lesley will go a wealth of knowledge regarding the history of the Association and the early struggles to obtain services and care for people living with MND. Lesley will be greatly missed for many reasons, too many to list here, however she has been and continues

to be a highly valued and valuable member of the MNDV team. Her expertise, knowledge of MND, MND care and both the disability and aged care sectors is irreplaceable. She will be leaving a great legacy when she finishes her time with MND Victoria. I know you will join with me in wishing Lesley every happiness and success in her future “ventures” and life after MNDV.

Lesley is taking annual leave in April/May and will return to work for a short time before commencing long service leave on 30 June. Her last day in the office will be 29 June 2018.

As always we welcome your feedback.

**Julie McConnell, Manager Support Services**

## MND WEEK 2018 EVENTS

MND Week occurs in the first full week of May each year and this year, MND Victoria organised the following two special events to mark the occasion.

**A Service of Hope and Remembrance** was held on Sunday 6 May 2018 at the RACV Club Melbourne. The service was led by Russell Armstrong, Supportive Care Worker from Barwon Health, who reflected on his involvement with people with MND and he gave an overview of the Dignity Therapy program at Barwon Health. Laura Madonna Murray, a music therapy student from Calvary Health Care Bethlehem, sang and played three pieces which added to the ambience of the service. A candle lighting ceremony also took place which acknowledged the many different people whose lives are touched by MND including people living with the disease, those who have passed away, supporters and friends of MND Victoria, health care professionals, volunteers, MND Victoria State Council and staff, researchers and others involved with the global fight against MND. Many of the people who attended took the opportunity to light a candle for someone in their life touched by MND.



A Service of Hope and Remembrance was also held in **Geelong** with Rev Ian Parton leading the service.

**‘Ask the Experts’** was held on Tuesday 8 May 2018 at the Florey Institute of Neuroscience & Mental Health in Parkville and comprised presentations by three researchers followed by tours of the laboratory facilities.

**Associate Professor Brad Turner** gave an update on international & Florey MND research. He explained that 10% of MND cases are inherited and 90% are sporadic (scattered or isolated). Possible risk factors include smoking, playing sport at a professional level, retroviruses, blue-green algal blooms and military deployment in the Gulf War. He spoke about genetics, advising that 70% of MND genes have now been found and that they point to disease pathways and potential treatment clues. He believes that the remaining 30% of genes will be identified over the next 5 years. Part of Brad’s presentation also focused on a new Drug Screening Program that is currently recruiting participants. He explained that MND is highly clinically variable with many different phenotypes (clinical presentations) and that in MND ‘one size does not fit all’ for clinical trials. One of the problems is a lack of effective treatments for MND due to factors including high disease variability, a lack of relevant sporadic MND models, a lack of human models, and until now, a lack of investment in large scale drug screening.

A new \$5M program is now operating at the Florey for sporadic MND which aims to fast track drug screening. The expensive, state-of-the-art equipment involved in this project was demonstrated to participants as part of

the lab tours. There were five stations that participants were rotated through including cell culture, mice, molecular, microscope and stem cells where lab staff spoke enthusiastically about their current work with MND.



**Dr Fazel Shabanpoor** talked about gene therapy for neurodegenerative diseases including MND. He started by advising that the US FDA (Food & Drug Administration) has recently approved the first drug for Spinal Muscular Atrophy (SMA) called Spinraza. SMA has similarities to MND hence the excitement generated by the availability of this new drug treatment. In discussing gene therapy, Fazel explained that this involves replacing a mutated gene that causes disease with a healthy copy of the gene and removing or inactivating a mutated gene that causes disease. He also discussed anti-sense therapy which involves

inactivating a mutated gene that is functioning improperly.

**Dr Tristan Iseli** from Neuroscience Trials Australia provided an overview of clinical trials and MND. He explained that clinical trials are performed for safety and tolerability, to find a dose that works and to find out who it works for. Clinical trials must always be conducted ethically and the risks and benefits weighed up carefully. In addition, the rights, safety and wellbeing of the participants are of utmost importance. People take part in clinical trials for a variety of reasons including to advance medicine, to help improve the lives of others, to help improve their own condition, and in some cases to earn extra money and receive free medical care. It can be a long, complicated process. To illustrate this, Tristan advised that of over 10,000 compounds synthesised in the lab across the industry, only one compound will reach the market as a new drug and that it takes on average 12-15 years to develop a drug at an average cost of up to \$US800 million (from discovery through to approval). There are over 55,000 clinical trials of various types currently in operation globally with around 6,600 of these in Australia.

**Alison Jones, Coordinator Information & Resourcing**

## YOUR STORIES

### Goodbye Friends

*By Stephen Alomes*

Brian was the last to go. He too died from motor neurone disease – that is the disease whereby the neurons stop working and cannot convey messages to the muscles, even while the brain generally remains as sharp as ever. Brian and Carmel, charming and thoughtful people, had come from Queensland some time ago.



Now our 'MND lunch group' has only the partners left after Brian departed; he was older, lasting two years more than the average, around five years. The sufferers have gone, no longer suffering. Leo, the Telstra engineer was a strong man who experienced physical weakening and death. My partner Kate, a researcher, and Lyn, a teacher, could no longer talk to us via their text to speech software. The indefatigable Lyn, speaking through her machine, sought to educate staff and others in the nursing home place where she spent her last years. Geoff the jurist went too. So did Irene, who joked that when so many different helpers came to shower her she might as well have been in a glass cage at the shopping mall. So did Mike, after he and Kay went back to family in Adelaide and Steve, whose partner Colleen is now a sole parent for their young daughter.

Our group evolved after an excellent 'living with MND' workshop run by the MND Association of Victoria. Through it, we met the most wonderful people, as if

the disease had somehow targeted the best and most interesting.

Kate and I had good professional support from the MND clinic at Calvary Health Care Bethlehem, the MND association, our local community health centre, Mercy Palliative Care, which provided ongoing as well as more difficult stages support, and Carers Victoria.

However, that was not enough. We are people who live in a society, not just patients and carers.

Brian knew about the numbers and about organising, which led to our lunch group. Brian and Carmel also set up support through family as well as support services.

However, Kate and I also needed an everyday support group, which we created with friends. We set up our own support group, using the practical advice in the American book, 'Sharing the Care', although avoiding its semi-military titles for co-ordinators. When I needed a break, our friends came and enjoyed time with Kate, who later only chose to go when she could neither communicate nor move.

Facing the need for carer support, some people proudly fly the flag of family 'duty' – 'It is all up to me'. Unfortunately, especially women. However, if carers are to have a life there needs to be more than that.

While over 700,000 Victorians are carers, it is not just secret women's business, an extension of the nurturing, female side, carried out by mothers and daughters, although more of the burden does fall on them. Nor is it just 'secret family business'.

Still today, there are varying systems of support for carers, and the financial support is poor.

Fortunately, like Brian and Carmel, we had resources and time, which many carers do not.

Australia needs more formal recognition of carers, those with family members facing terminal disease, and also those with ongoing problems, whether the product of accident or disability, of specific illness or of decline with age.

Australia today has millions of unpaid or poorly supported carers, some of them children and young people in their 20s, caring for siblings, parents, partners and friends. Today, we need to further enhance formal and informal support for carers and for setting up care networks. Once, support might have come from the

street, the suburb, or the parish church, as well as the family. Today those local and immediate supports have weakened.

The needs of carers must be addressed as well as the focus on the individual and on the contract which shapes the new NDIS, the National Disability Support Scheme, and the continuing debates around the country on palliative care and assisted dying.

As systems now put aside narrow interpretations of privacy laws when families are consulted over ongoing health issues, we need to make some changes. We need a return to our social values and focus on the group, rather than just the individual in the era of the contract state. Fortunately, while Kate and I have always supported voluntary assisted departure, the broader definition of palliative care involves both palliation through an illness to allow the sick and their friends and families to live a life, as well as the last stages.

Brian was a brave man who was knocked over by a twisted bowel, and did not have to endure the totally disabling final stages of MND. In his necessarily black humour, which we all acquired, it may have been, in a way, a better result. He was almost OK when we lunched a few weeks before.

Not everyone has the skills that we shared with Brian and Carmel, who would join me in endorsing a more systematic government approach to supporting carers and to facilitating support networks.

While Victoria has improved carer support, and we await the government's carer statement this year, we need a lot more. Even the economics are simple. Carers save governments billions but the absence of support also takes many of them out of the workforce. We desperately need improved support for carers and for providing facilitators to help people set up support networks.

Goodbye Brian, goodbye friends. We'll lunch again and Carmel, Vin, Chris, Maureen and I, and sometimes Bryan and Colleen, will drink a toast to you and to Irene, Leo, Lyn, Geoff, Mike, Steve and Kate, and to improved support for carers across Victoria and Australia.

*\* Stephen Alomes is an Adjunct Professor in the Centre for Global Research, RMIT University. His story of Kate Jones is at <https://www.theage.com.au/national/versatile-researcher-revealed-the--personal-stress-of-politicians-work-20150514-gh1up9.html>*

# YOUR STORIES



## My Journey with MND Victoria

Hi my name is Ailish, and I am a social work student at Deakin University. For the past three months I have been completing my Field Placement at Motor Neurone Disease Victoria and by the time I finish I will have been working here for approximately five months.

I knew of Stephen Hawking's journey with ALS before I started my placement but I would say I knew very little about the disease. When receiving my placement agency, as any student would, I researched the disease extensively. I was taken aback by the immense struggle I imagined would be faced by people with MND, their friends, family and carers.

In my time at MND Victoria so far I have had the chance to engage with individuals whose resilience in the face of adversity is inspiring. The strength of the human spirit can know no bounds. Very quickly I developed a passion to help those whose journey in life encounters MND and advocate on behalf of their needs. I feel blessed to be a part of an organisation where every worker demonstrates an intense dedication to their work and, no matter the challenge, they show up each day to help in every way they can. Until there is a cure, there is care.

## Cosmologist, space traveller, hero!

On the 14th of March this year, one of the greatest scientific minds of our time passed away. Stephen

William Hawking was born on the 8th of January 1942 (exactly 300 years after the death of Galileo). At the age of 21 (in 1963), he was diagnosed with a rare, slow-progressing form of Amyotrophic Lateral Sclerosis (ALS)- also known as Motor Neuron Disease (MND) and was given two years to live. An astonishing 55 years later and Hawking has left quite a legacy.

## Academic Life

In October 1962, Stephen arrived at the Department of Applied Mathematics and Theoretical Physics (DAMTP) at the University of Cambridge to do research in cosmology, there being no-one working in that area in Oxford at the time. After gaining his PhD (1965) with his thesis titled 'Properties of Expanding Universes', he became, first, a research fellow (1965) then Fellow for Distinction in Science (1969) at Gonville & Caius College. In 1966 he won the Adams Prize for his essay 'Singularities and the Geometry of Space-time'. Professor Hawking moved to the Institute of Astronomy (1968), later moving back to DAMTP (1973), employed as a research assistant, and published his first academic book, The Large Scale Structure of Space-Time, with George Ellis. During the next few years, Stephen was elected a Fellow of the Royal Society (1974) and Sherman Fairchild Distinguished Scholar at the California Institute of Technology (1974). He became a Reader in Gravitational Physics at DAMTP (1975), progressing to Professor of Gravitational Physics (1977).

## MND INFORMATION SESSIONS

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

**At 7pm on Thursday, 14 June at MND Victoria, 265 Canterbury Road, Canterbury.**

Please RSVP by 5pm, Tuesday, 12 June.

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

Email: [info@mnd.asn.au](mailto:info@mnd.asn.au)

The following session will be held on Monday, 30 July at 7pm in Canterbury.

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

He then held the position of Lucasian Professor of Mathematics (1979-2009). The chair held by Isaac Newton in 1663. From 2009, Stephen was employed as the Dennis Stanton Avery and Sally Tsui Wong-Avery Director of Research at DAMTP and founder of the Centre for Theoretical Cosmology at Cambridge.

Professor Hawking received over a dozen honorary degrees and many awards, medals and prizes including: the Commander of the Order of the British Empire (1982), the Wolf Foundation prize (1988), Companion of Honour (1989), Copley Medal (2006), the Presidential Medal of Freedom (2009), and the Fundamental Physics prize (2013). He was a fellow of the Royal Society and a member of the US National Academy of Science. Professor Stephen Hawking is regarded as one of the most brilliant theoretical physicists since Einstein.

Professor Hawking has written at least 19 books. In the book *My Brief History* he turned his gaze inward for a revealing look at his own life and intellectual evolution. The book recounts Hawking's improbable journey, from his post-war London boyhood to his years of international acclaim and celebrity. Writing with humility and humour, Hawking opens up about the challenges that confronted him following his diagnosis of MND aged twenty-one. Tracing his development as a thinker, he explains how the prospect of an early death urged him onward through numerous intellectual breakthroughs, and talks about the genesis of his masterpiece *A Brief History of Time* – one of the iconic books of the twentieth century.

## Motor Neurone Disease

In 1963 Stephen was diagnosed with ALS, a form of Motor Neurone Disease, shortly after his 21st birthday. In spite of being wheelchair-bound and dependent on a computerised voice system for communication, Stephen continued to combine family life (he has three children and three grandchildren) with his research into theoretical physics, in addition to an extensive programme of travel and public lectures. Thanks to the Zero-G Corporation, he experienced weightlessness in 2007 and always hoped to make it into space one day.

Over 420, 000 of the world's people are living with MND and approximately 140, 000 cases are diagnosed worldwide each year. That's 384 new cases every day.

Closer to home, more than 2, 000 people are living with MND in Australia, 58% who are under the age of 65.

## Assistive Technology

Since 1997, Stephen Hawking's computer-based communication system was sponsored and provided by Intel® Corporation. A tablet computer mounted on the arm of his wheelchair was powered by his wheelchair batteries, although the tablets internal battery kept the computer running if necessary.

His main interface to the computer was through an open source program called ACAT. This provided a software keyboard on the screen. A cursor automatically scanned across this keyboard by row or by column. Characters could be selected by moving his cheek to stop the cursor. His cheek movement is detected by an infrared switch that was mounted on his spectacles. This switch was his only interface with the computer. When a sentence was built, it would be sent to a speech synthesizer.

### **Professor Hawking you will never be forgotten!**

We are comforted by knowing you live on in many alternate futures according to the many-worlds interpretation of quantum mechanics!

~R.I.P.~

## WRITE YOUR MND STORY

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

Please email your text and a photo to: [info@mnd.asn.au](mailto:info@mnd.asn.au) by 4 July 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](mailto: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 of 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](mailto: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"

## 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".

## Kennedy's Disease Facebook Group

Did you know that MND Victoria also provides support to 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](http://www.carersvictoria.org.au)

**Carer Gateway**—1800 422 737  
[www.carergateway.gov.au](http://www.carergateway.gov.au)

**CareSearch**—[www.caresearch.com.au](http://www.caresearch.com.au)

**BrainLink**—1800 677 579 [www.brainlink.org.au](http://www.brainlink.org.au)

**MND Victoria**—1800 806 632 [www.mnd.asn.au](http://www.mnd.asn.au)

# VOLUNTEER NEWS!



*By Deb Olive, Coordinator Volunteer Programs*

## National Volunteer Week

National Volunteer Week 2018 was a week to recognise the contributions of more than 6 million people just like us who volunteer each week across Australia.

MND Victoria said thank you to our 133 volunteers during National Volunteer Week (NVW) 21-27th May. With volunteers supporting the work of MND Victoria across the state, NVW is a time to acknowledge the care and support provided by these dedicated individuals. Thank you to each and every one who helps out – Giving a Little does Change a Lot!

On 22nd May, 50 of our volunteers were able to come together for a thank you event at the MCG. The contributions of all of our volunteers were recognised.



Rod Harris CEO and Julie McConnell Manager Support Services presented Years of Service awards to a number of volunteers including – Bronwen (15 years); Helen and Barbara (10 years), Lesley, Margaret, Nick and Marilyn (5 years):



A number of volunteers receiving the 5 year service awards were not able to attend the event – we thank and acknowledge – Brenda, Joan, Effie, Jennifer, Heidi, Jenny and Mim.

## Our Reception Team

Each day MND Reception at Canterbury manages all calls and enquiries coming into the organisation. Our Receptionists come from a wide variety of backgrounds. Some have been in the role for a number of years, others a very short time. They share a commitment to helping and all of our Reception team are volunteers.

Our Reception Volunteer team is made up of 10 regular Reception Volunteers and four Relief Reception Volunteers. Reception Volunteers work half a day each week – you can imagine how much changes from week to week for them. They do an incredible job responding to each enquiry whether about membership, mail, merchandise, or other matters.

Next time you contact our Reception team know they are doing their very best to assist you.

## VOLUNTEER OPPORTUNITIES

**MND Friendship Group Coordinator Melton area** – several people living with MND in the Melton area are seeking to meet up socially on a regular basis. To help make this happen, we are looking for someone who can be the point of contact assisting with coordination of this group. The role will involve contacting group members, coordinating times and dates for get togethers and welcoming new members to the group.

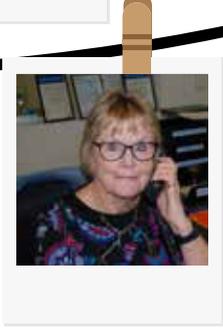
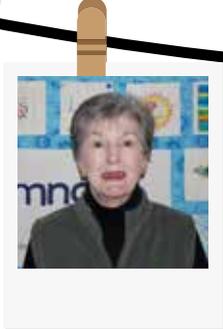
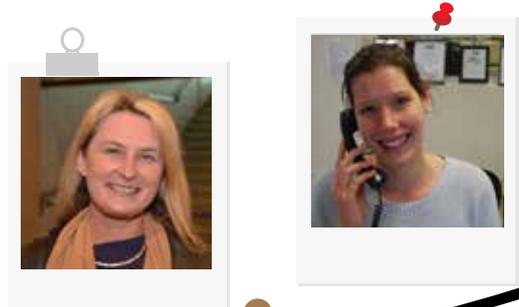
**Time required:** The role will involve 1-3 hours per month liaising with group members as well as attending friendship group get togethers (1-2 hours) at a local venue.

**Skills required:** Access to email or phone to contact and connect with group members. Interest in assisting people to stay connected with others in their local community.

**MND Friendship Group Werribee** – we are almost ready to launch our Werribee Friendship group. Please contact your MND Advisor if you live in the Werribee area and would like information about this group. Thank you to Leanne for taking up the volunteer role to facilitate this group.

Please contact Deb: [volunteer@mnd.asn.au](mailto:volunteer@mnd.asn.au) or phone 03 9830 2122 if you are interested in any of these roles.

## MEET SOME OF OUR RECEPTION VOLUNTEERS!



# RESEARCH UPDATE



## Studying the genomes of single neurons to understand MND

*By Associate Prof Justin P. Rubio, Department of Pharmacology and Therapeutics, University of Melbourne, The Florey Institute of Neuroscience and Mental Health.*

There are 40 trillion cells in our body and each has inside it the genetic code for life, the DNA genome. While as a species humans look quite diverse, we are actually very similar at the genomic level. What distinguishes our own DNA from other people's are the natural variations in its code that we inherit from our parents. Most of this genomic variation doesn't significantly impact our health, but sometimes it does. From research conducted so far, we know that genomic variations (otherwise known as mutations) in certain genes can predispose a person to developing MND in about 10% of cases, however, we are at a loss to explain the origin of the other 90% of MND in the community, including why it is so clinically variable.

In recent years, the cost of genomic research has come down substantially, and we are now able to generate the entire sequence of a person's genome for around \$2,000. This is in stark contrast to the cost of the first human genome sequence, completed in 2003, which cost USD \$100 million. This drastic reduction in cost has fuelled the emergence of "single cell genomics", a relatively new field of research that

seeks to understand complex biology by studying the genomes of individual cells.

In recent years, published research has shown that individual cells in our body, including neurons in our brain, develop literally 1000s of mutations in their genome over and above what we inherit from our parents. These "somatic" mutations can be shared between many cells, a few cells or be unique to a single cell, and together, constitute a "barcode" that can be studied to understand the origin and life story of the cell.

Our research seeks to apply single cell genomics to MND as we believe it will provide insight into the complex biological processes involved in the development and progression of disease. Our research is reliant on people with MND who donate to the Victorian Brain Bank, as we use this post-mortem tissue to isolate and study the individual genomes of motor neurons and construct their life stories. If we can piece together the life stories of many motor neurons from different people who had MND, we hope to be in a better position to develop effective medicines.

Each of the 40 trillion cells in our body has deoxyribose nucleic acid (DNA), nature's ultimate data storage molecule, and the genetic code for life. DNA is a long molecule packaged into the cell's nucleus, like a piece of string, and it is comprised of four DNA bases, known as Adenine, Cytosine, Guanine and Thymine. Different arrangements of 3 billion of these DNA bases comprise the human genome, with about 1% of this arranged into specific sequences that encode about 20,000 genes. These genes encode proteins, which do a lot of the work in our cells, helping them to carry out their designated functions and keeping us healthy. Alterations to the DNA code of certain genes (termed mutations) can alter cell function and sometimes lead to diseases, such as MND.

***A/Prof Rubio's research is funded by MND Victoria through the Jenny Simko MND Research Grant.***

***If you attended the Rock Off MND event in Geelong, then you have personally contributed to support this research - THANK YOU!***

# RESEARCH ...



## Neuropsychology MND research at the University of Queensland

*By Associate Professor Gail Robinson, PhD, Consultant Clinical Neuropsychologist, NHMRC Boosting Dementia Research Leadership Fellow, UQ Neuropsychology Research Clinic*

Neuropsychology is focused on the cognitive (or thinking), behavioural and emotional changes that arise due to alterations in the brain or central nervous system. We now know that changes in cognition, behaviour and emotion can occur in as many as 50% of those diagnosed with MND. At the University of Queensland (UQ) the focus of our neuropsychology research is to understand more about specific changes in cognition, behaviour and mood, especially in relation to different types of MND, and the effect on family, friends and carers.

First, identifying the pattern of neuropsychological changes in MND, and differences between MND types, will refine what we understand about the range of cognitive and behavioural changes. In order to do this we invite everyone who receives a diagnosis of MND to have a detailed neuropsychological assessment that targets specific cognitive domains (e.g., language, memory, executive functions, emotional processing) and behaviours like disinhibition or apathy. As changes are frequently quite subtle, it is family or carers that often notice changes, rather than the

individual with MND. Therefore, we also ask family and carers to fill in questionnaires about changes as well as individuals with MND. From the pattern of cognitive testing and the information from questionnaires, we compile a neuropsychological profile of strengths and weaknesses for every individual. This informs our research and is the basis for feedback to families, carers and the individual with MND. In addition, we recognise that MND affects not only the individual with MND but also their family, friends and carers. One component of our research is to detail the burden of care for those involved in order to determine what is needed to support those affected, including the main carer. This will inform the health system more broadly about MND-specific care needs.

Second, with the support of the MND Research Institute of Australia, we are currently developing an online version of a carer's behaviour rating scale, the Online Carer's Questionnaire (OCQ). The OCQ is designed to measure behavioural and cognitive changes that are observed by carers and it involves filling in a questionnaire via the internet at home (rather than coming to a hospital clinic). The OCQ is based on a widely-used screening tool in MND, the Edinburgh Cognitive and Behavioural Screen, which was developed by Prof Sharon Abrahams and colleagues in Edinburgh (UK). We will first validate the OCQ with the help of individuals attending the Brisbane MND clinic, which is led by neurologists Dr McCombe and Dr Henderson.

Once we are confident the OCQ is useful in assessing changes in behaviour and cognition, we will make it available to use by anyone with MND across Australia (i.e., in rural, regional and city settings) and then by the international ALS research community. Our research is a collaboration between the Brisbane MND Clinic and MND researchers at UQ, including genomic expert Prof Naomi Wray who leads the sporadic ALS Australia Systems Genomics Consortium (sALSA-SGC). Our research team includes international ALS experts Prof Abrahams (Edinburgh) and Prof Al-Chalabi (King's College London), which will enable us to validate the OCQ in the UK and then make it available to the international ALS community. As MND is a complex and heterogeneous disease, we are aware that a good standardised and validated online measure of

behaviour and cognition like the OCQ is urgently needed to contribute to defining the biological basis of MND, along with genetic data that is now being collected world-wide via biological samples (e.g., saliva and blood).

MND research at UQ in Brisbane is highly collaborative and focused on detailed research studies of clinical neurological features, genetic characteristics, neuropsychological features, brain MRI neuroimaging studies, and metabolic studies, among others. In the last 5-10 years, there has been exponential growth in the Brisbane MND research community, with increased collaboration and organisation starting to see MND research flourish. We are committed to understanding the complexity and nuances of this disease in order to continue the search for the so

far elusive cure. At the same time, quality of life and support for both the individual with MND and family, friends and carers are high priorities. We are motivated and spurred on by the courage and determination of the many individuals we meet - we have been inspired and will do our best in this endeavour.

#### **UQ MND Clinical Neuropsychology Team:**

*Gail Robinson – Head; Amelia Ceslis – current Registrar; Rosemary Argall – past Registrar; Amelia Hobson – Doctor of Psychology student.*

***A/Prof Gail Robinson's research is funded by MND Victoria through the Mavis Gallienne and Graham Lang Research Grant - your fundraising and donations to MND Victoria have made this research possible!***

## MY EXPERIENCE OF RILUZOLE

*By Stuart W Smith, Warrnambool, Vic.*

I was diagnosed with MND in late October 2017, and commenced Riluzole on 23rd November. After commencing Riluzole, I found I was fatigued, needed an afternoon nap and went to bed at 9pm.

In late January, I started feeling breathing difficulties, especially walking up hills. This deteriorated significantly in early February. I saw my GP on Wed 7/2/18 and had Chest XR on Friday 9/2/18. It was clear that in view of breathing difficulties, my GP sent me to the local Emergency department. There my oxygen measurements on my finger were reduced to low 80's. I had a CT PA of my chest which confirmed an inflammatory reaction wide-spread through my lungs.

This was similar to a Mycoplasma pneumonia. However I had no fever and a minor cough only. I was hospitalized on oxygen and antibiotics.

On the Monday I was seen by a Physician, who examined me, reviewed the CT, but felt I was not suffering from an infection and so began reviewing the medical literature of Riluzole.

He confirmed there were 4 cases written up of a Pneumonitis, lung inflammation, related to Riluzole. Hence he stopped the Riluzole and the antibiotics.

I was able to be discharged and my health started improving. After 2½ weeks I had further improved and was able to walk up hills. (Initially I was restricted to flat terrain and short distances.)

Thus no more Riluzole. I now find I don't require an afternoon nap and am able to go to bed later. I also feel more refreshed in the morning after a sleep.

## 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 Ms Fairlie Hinton, Coordinator, Victorian Brain Bank or find out more on The Florey's website:

**[www.florey.edu.au/vic-brain-bank](http://www.florey.edu.au/vic-brain-bank)**

Email: [fairlie.hinton@florey.edu.au](mailto:fairlie.hinton@florey.edu.au)

Phone: (03) 8344 1900

Mobile: 0438 530 372

# YOUR STORIES



**Gavin McCann was diagnosed with motor neurone disease in January 2015. Being told this news is devastating for anyone. Gavin however, used this news to live out his long time dream. He didn't once complain what was going to happen to him. He instead bought a boat. From that day on, Gavin says "I live with a smile on my face every single day".**

Gavin is certainly unique. Not only did he just buy a boat, he lives on it. After initially docking the boat in Apollo Bay, which was close to his home in Colac, he came across Bill, who suggested he take his boat across the state to the Gippsland Lakes at Paynesville. Why you may ask? The winds down at Apollo Bay really didn't suit being on a boat as you start losing the strength in your legs.

Bill introduced Gavin to the Paynesville Motor Cruiser Club and the many locals associated with it. Gavin has found himself a new family, a community which has got behind him to help him live the best life possible.

Living on a boat with MND at first thought sounds incredibly risky, maybe even naïve. Gavin dispelled all those thoughts quite quickly, maybe it was his infectious smile and positive outlook? Nevertheless, he explained that boats are compact, he can reach everything in each part of the boat, even if he has to lean on walls. It has hand rails everywhere and even rails on the roof to hang on to. There is no glass in the shower or anywhere else. He continued to explain he can live independently on his boat whereas if he has

to make the trip back to his home in Colac, he needs constant help from his wife.

I think it is fair to say that doing the washing doesn't excite anyone. Gavin is an exception. The washing machines are in a facility on the other side of the marina. How does Gavin manage to do this? He jumps on his jet ski with his washing basket, heads on over and then spends the next hour just cruising through all the canals until the washing is done.

Gavin has constant ideas on how to adapt his boat to accommodate the progression of MND. The community around him help in every way they can to implement these ideas and modify his boat accordingly. There is nothing the power of community can't accomplish in situations like Gavins.

Everyone at the Motor Cruiser Club has been so touched by Gavin's story that they are throwing a fundraising event in his honour in April. A traditional ice bucket challenge with a twist. On the boat with many people suffering the fate of ice cold water dunked on them by a special creation by Gavin. There will be live bands, hundreds of people watching from the balcony and the support of the whole community.

*Vita brevis est edite primum secundam.* This is the quote on the front of Gavin's boat. He says it translates to 'life is short, eat the first seconds'. Gavin is adamant that he will keep maximising the time he has left. He only gets off his boat every couple of months when he needs to head back to Geelong for specialist appointments. He understands what motor neurone disease is doing to him but he intends on 'living the dream' right to the very end!



# FUNDRAISING



## Do you genuinely know how your support impacts the lives of people living with MND?

I'd like to take a few minutes to highlight how some of the people living with MND have benefitted from the services delivered by the Association.

**Barry was diagnosed with MND at age 71 – just when he and his wife Carol thought they were going to enjoy their well-earned retirement.** They had no idea how MND would progress or how it would impact them, but thanks to MND Victoria their questions were answered efficiently, professionally and compassionately by their MND Advisor who met with their whole family in Barry and Carol's home to educate them on MND. Their MND Advisor meets with them regularly and ensures they are linked to all available local support services. As Barry was aged over 65 when diagnosed, he is unable to access the NDIS so the services provided by the Association, such as a range of mobility equipment, are vital to maintaining Barry's independence and allowing him to remain safely living at home. All these services are provided at no cost to them.

**Brett was a good looking man who dressed immaculately in full business man's attire of suits, cufflinks and great ties. Approaching 40 he was in the prime of his life doing a job he absolutely loved. Married with a young daughter he was fit, active, loved life and lived it to the full.**

Around July 2014 he first started getting symptoms, but he and some of his mates went to Las Vegas which was very fortunate because, by September, an overseas trip was unimaginable.

Brett was diagnosed in the November and he and his family were advised by the neurologist that as Brett's disease was progressing very fast his life expectancy was about nine months.

MND Victoria provided them with an MND Advisor who organised for equipment to be delivered so that it was available the minute it was needed. Throughout his short journey with MND, the Association provided a hoist to safely transfer him, a shower commode, an electric riser chair, a manual wheel chair, an electric power wheelchair as well as other items. All were delivered and maintained at no cost to Brett or his family. Without those aids it would have been impossible for Brett to have remained at home and, like most people with MND, home was where Brett wanted to be.

**Liz's life with MND was, mercifully, quite short. Liz was just 54 years old when diagnosed in June 2016. Nine months later she died in her partner Rob's arms.**

Liz first contacted MND Victoria in September 2016, the Association helped make life more bearable for Liz. Her MND Advisor worked tirelessly to source agencies to provide workers to be trained in Liz's care to fulfil Liz's goal of living, and dying, at home. There's no way they could have achieved this without the knowledge, expertise and unwavering support of the Association. For people living with MND, the intricacies of navigating the healthcare system can be overwhelming. Of course family and friends helped care for them too, but according to Rob it was the care and support provided by the Association that enabled Liz to remain living, and dying, at home.

**Joy was diagnosed with MND in January 2017. Like Barry, she was over 65 when first diagnosed, so access to services from NDIS was never an option for her.** They were encouraged to contact the Association which had been supporting people with MND for over 35 years and could provide them with advice through their information service as well as an MND Advisor to connect them with health professionals and community support in their area and, most importantly, provide them with equipment that would help Joy stay active

and in control of her life. MND Victoria has provided Joy with a variety of equipment including a four-wheel walker, electric riser chair and over-the-toilet frame. All these items, the information and MND Advisor service are provided at no cost to Joy.

**You might be wondering why I'm sharing these stories with you. It is simply so that you are aware that MND Victoria is the ONLY organisation in Victoria delivering care and support to people living with MND, and we've been doing this for 37 years.**

The Association has supported thousands of people living with MND and yet we receive only 25-30% government funding. Every day we have to seek ways to raise funds to ensure that people living with MND can, and do, access our services so that they and their families can continue to participate in family and community activities and reduce the risk of social isolation. Each year we must raise over \$3.5 million.

If you live in Victoria you are probably aware of the recent establishment of FightMND and their awareness and fundraising activities. These are to be applauded but, and it's a big but, the funds raised by FightMND do not contribute to the services delivered by MND Victoria so they are not helping the people living with MND now. And while we'd all like to see a cure for this terrible disease we can not, and must not, ignore the needs of those living with MND today and in the near future while research for a cure continues.

So, if you are thinking of holding a fundraising event or participating in a challenge event to "raise funds for MND" can I please encourage you to put your efforts into supporting MND Victoria. We'd love to support your efforts. Contact us by email: [fundraising@mnd.asn.au](mailto:fundraising@mnd.asn.au) or call 03 9830 2122

**Until there's a Cure .... there's Care.**

**Kathy Nightingale, Manager Fundraising**

# COMMUNITY FUNDRAISING EVENTS

## Orbost Croquet Club

Christine Eaton is the President of the Orbost Croquet Club. She is currently living with MND and has lost many other family members to the disease in the past. The croquet and bowling club decided to put on a fundraiser in honour of Christine and her family. This was an incredibly special day where the wider Orbost community got involved as well as a number of other croquet clubs from around Gippsland.

The day started with an exhibition croquet match between some local 'legends' which, from all accounts was a fantastic spectacle. The local Lions Club put on a BBQ, volunteers sold plenty of merchandise and the 100 people in attendance enjoyed a friendly game of croquet and bowls. The day concluded with a phenomenal selection of cakes for afternoon tea.

Our Fundraising Officer, Daniel had the pleasure of speaking to everyone who attended the day and was then presented with a novelty cheque which showed how much hard work went into the event!

## Jacquie Carrington

When Jacquie contacted us saying she wanted to invite a few friends over to her house in Brighton to raise a few dollars for MND Victoria, we didn't expect 80 women to turn up with a bottle of wine each and have a fantastic time in her living room on a Tuesday night. That's exactly what Jacquie managed. She worked tirelessly over the space of 3 months to arrange some amazing raffle prizes, auction items, catering that had to be seen to be believed and the event in general.

Jacquie lost her aunt from MND and since then has been wanting to do something to help others. This was her time to shine and shine she did! The items she received for her raffle and auction were incredible and we send a huge thanks to all the businesses that provided these. She convinced a good friend to be the MC for the night and another to donate time to be the auctioneer. All her friends had a fantastic time and the \$20 entry they paid to attend the event was a simple way to boost Jacquie's fundraising efforts. After

all was said and done, Jacquie's event, that she single handedly organised, raised \$7500!

We are so thankful to Jacquie and her friends for making this a night to remember! We look forward to welcoming Jacquie as a new volunteer for MND Victoria in the near future.

## Alamein FC

On a very wet and windy Sunday the 15th of April, Alamein FC hosted South Melbourne FC in a major Premier League soccer clash. It was also a major day off the field with Alamein putting on a fundraiser for MND Victoria. This event came about due to the club feeling the impact that MND has on families with a star player's father being recently diagnosed with the horrible disease.

They wanted to give back to the organisation that provides all sorts of support to the family. They organised raffles, auctions, merchandise selling, junior players who walked around the grounds tin rattling and encouraged donations from all spectators. Our very own Sarah from the information team attended the day and joined the FNR radio team to speak on the soccer focused radio station about the work of MND Victoria, and to raise further awareness around the disease and how important care and support is to those living with motor neurone disease.

We are very thankful to everyone involved. The total amount raised was \$4037 and they have indicated they would like to continue supporting MND Victoria at various other events in the future.



# BLUE CORNFLOWER DAY

Blue Cornflower Day was during MND Week on Friday, 10 May. These cornflowers were made by staff on the **Acute Neuro-sciences Unit, University Hospital Geelong**:



The **Coles Bairnsdale** team had a fun day dressing up to raise funds and awareness - the customers loved it!



## Qenos Contractors

A huge thank you to Qenos Contractors' staff who choose a charity to donate to when they achieve their quarterly safety performance targets. This quarter, they donated to the MND Superball which is a fundraising event for MND Victoria. This year's event is on Saturday, 16 June 2018 at the Pullman Albert Park. Contact: [russellhigginsconsulting@gmail.com](mailto:russellhigginsconsulting@gmail.com)



# MND HOODIES!

Our MND hoodies are super warm and comfy and best of all ... your purchase helps support people living with MND and funds research.

WOW! What a hoodie!

Grab yours online at:

[www.mnd.asn.au/gear](http://www.mnd.asn.au/gear)

Or phone: 03 9830 2122

*Our hoodies are a fitted style, so please order 1-2 sizes up if you prefer a roomier hoodie.*

"SO COMFY & COSY"

Karen, via Facebook



## >> MND VICTORIA TRAVEL CUPS >>

**Love your coffee AND the environment?**

**Why not invest in one of our MND Victoria travel cups?**

Raise motor neurone disease awareness with EVERY trip to the cafe + reduce your impact on the environment!

Check out our travel mugs and all of our other MND gear at:

[www.mnd.asn.au/gear](http://www.mnd.asn.au/gear)

Or phone: 03 9830 2122

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

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

"IT'S THE BEST TRAVEL MUG I HAVE HAD!"

Jen, via Facebook



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

# KOKODA CHALLENGE - MEET BECK MASON!

Introducing our first Kokoda Challenge participant!



The term 'legend' gets thrown around a lot, however Rebecca Mason more than deserves that title.

Beck lives in Portland but makes the trip up to Geelong on a regular basis to be with her best friend who is living with MND.

It may be for a couple of hours, couple of days or weeks, she will do whatever she can to make life easier and enjoyable for her friend and family. This care and support is invaluable and is really indicative of the quality of person that Beck is.

Beck is also what we would like to call a 'Champion Fundraiser'. For the last couple of years she has led her team known as Sisters and Brothers United in the annual Geelong walk. She organises fundraising

events, spends her weekends selling MND merchandise, negotiating with local businesses to provide sponsorship and raises significant awareness throughout South West Victoria. **She and her team have raised in excess of \$70,000 in the last couple of years for all Victorians living with MND!**

Beck signed up for Kokoda as soon as registrations opened and although she wouldn't describe herself as an avid hiker, or even a once a year hiker. She decided this was a challenge she didn't want to miss out on. A personal challenge and one she knows will significantly help all Victorians living with MND. She is pictured here on her first training hike. In Bali of all places! Her passion and determination will be infectious for the Kokoda group this year and we can't wait to see Beck complete this enormous challenge.

How Beck finds the time to fit everything in is astonishing (she also works and has her own family). We are absolutely honoured to have her as part of MND Victoria and our Kokoda challenge this year.

**The Kokoda Challenge is running from 26 August to 4 September 2018!**

If you'd like information on how to take part in this year's trip please contact Daniel, phone: 03 9830 2122 or email: [dwoodrow@mnd.asn.au](mailto:dwoodrow@mnd.asn.au)

## GEELONG WALK TO D'FEET MND!



# DONATIONS WERE RECEIVED ...

## In memory of

Annette Pittard  
Barry Clark  
Cheryl Brian  
Ciro Gulano  
Mary (Bonnie) Dickson  
Susan Turner  
Heather Thompson  
Ian Aitken  
Nandor Kaszonyi  
Patricia Balsillie  
Peter Andressen  
Bill Thomson  
Harvey Sykes  
Mr William Cumming  
David Price  
Mrs Betty Cristina  
Mary Bussau  
Stephen Lucas  
Barbara Smith  
Albert Church  
Mr Noel Smyth  
Mrs Anne Sinclair  
Mr Peter Farnham  
Dr Peter Meehan  
Charlie Anderson  
Gayle Higgins  
Mr Geoff Kennedy  
Mr Allan Looney  
Mr Neville Johns  
Mr Peter Lowe

Robert Dean  
Eugene Marek  
Vic Robertson  
Mr Ronald Bayston  
Mrs Margaret Course  
Mr Peter Farnham  
Dr Robert Hudson  
Mr Ray Musgrove  
Mr Peter Andressen  
Jackie Barling  
Tim O'Callaghan  
Marg Parsons  
Jeff Renkin  
Mrs Norma Hooker  
Margaret Lyons  
Christine Handson  
Martin Willams  
Jeff Renkin  
Derek Turner  
Lorna Eastwood  
Peter Lowe  
Kimberly Lock  
Ken Davis

## Corporate

P & Y Bickley Consultants Pty Ltd  
BrainLink Services Ltd  
Edgewise Insurance Pty Ltd

## In Memory Research

Jeff Bibby  
Philip Gulle

Jim Hendricks  
John W Smith  
Kenneth MacDonald

## Bequests

The Estate of the Late Albert G  
Duncan  
The Estate of the Late James Holt

## Trusts & foundations

Lilydale Cricket Club  
Toorak-Prahran Cricket Club  
Calvary Health Care Bethlehem  
East Gippsland Insurance & Orbost  
Travel Centre  
Montgomery Foundation Pty Ltd  
Nexus Primary Health  
Perrys Stockfeed and Saddlery  
Rotary Club of Ocean Grove  
Ruby Red Dancer  
F45 Maribyrnong  
Orbost Croquet Club  
Mona Georgina Harris Perpetual  
Charitable Trust  
Anglican Parish of Orbost  
Lions Club of Orbost  
Bairnsdale Croquet Club Inc  
Maffra Croquet Club Inc  
Friends of Orbost Op Shop

## MND Victoria Membership

Have you renewed your membership for 2018?

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](mailto: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 & photo to: [info@mnd.asn.au](mailto:info@mnd.asn.au) by 4 July for the next edition, mailed on 7 August 2018.

# GET INVOLVED IN AN EVENT NEAR YOU!

Date	Event	Contact
Thursday, 14 June 2018	MND Information Session	Email: <a href="mailto:info@mnd.asn.au">info@mnd.asn.au</a>
Saturday, 16 June 2018	Superball XI MND Charity Ball	Email: <a href="mailto:russellhigginsconsulting@gmail.com">russellhigginsconsulting@gmail.com</a>
Thursday, 21 June 2018	Global MND Awareness Day	Email: <a href="mailto:fundraising@mnd.asn.au">fundraising@mnd.asn.au</a>
Sunday, 22 July 2018	Stadium Stomp (MCG)	Email: <a href="mailto:dwoodrow@mnd.asn.au">dwoodrow@mnd.asn.au</a>
Sunday, 29 July 2018	Run Melbourne	Email: <a href="mailto:dwoodrow@mnd.asn.au">dwoodrow@mnd.asn.au</a>
Monday, 30 July 2018	MND Information Session	Email: <a href="mailto:info@mnd.asn.au">info@mnd.asn.au</a>
26 August - September 2018	Kokoda Trail - Challenge Event	Email: <a href="mailto:dwoodrow@mnd.asn.au">dwoodrow@mnd.asn.au</a>
30 - 31 August 2018	9th National MND Conference	Email: <a href="mailto:info@mnd.asn.au">info@mnd.asn.au</a>
Sunday, 14 October 2018	Melbourne Marathon Festival	Email: <a href="mailto:dwoodrow@mnd.asn.au">dwoodrow@mnd.asn.au</a>
Saturday, 20 October 2018	Cox's Bridge to Cox's Place Cycle	Email: <a href="mailto:dwoodrow@mnd.asn.au">dwoodrow@mnd.asn.au</a>
Sunday, 4 November 2018	Village Glen Walk to D'feet MND	Email: <a href="mailto:fundraising@mnd.asn.au">fundraising@mnd.asn.au</a>
Sunday, 18 November 2018	Melbourne Walk to D'feet MND	Email: <a href="mailto:fundraising@mnd.asn.au">fundraising@mnd.asn.au</a>
Sunday, 25 November 2018	Bendigo Walk to D'feet MND	Email: <a href="mailto:fundraising@mnd.asn.au">fundraising@mnd.asn.au</a>

For further information and the latest events list, please visit our website: [www.mnd.asn.au/events](http://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](mailto: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](http://www.mnd.asn.au) or follow us on:**

[www.instagram.com/MND\\_Vic](http://www.instagram.com/MND_Vic) | [www.facebook.com/MNDVic](http://www.facebook.com/MNDVic) | [www.twitter.com/MNDVic](http://www.twitter.com/MNDVic)