

January – February 2018

mndnews



**Always remain
hopeful, fight and
never give up**

www.mnd.asn.au

Newsletter of the Motor Neurone Disease Association of Victoria

mnd 
Victoria

MND Victoria

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*Working towards a world
without motor neurone disease*

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

Contents

From the desk of the CEO	3
Support Services/New staff	4-5
Kokoda Trail 2018	5
Volunteer news/opportunities	6-7
Cornflowers	7
Your stories	8-13
Group programs	14-15
Research update/opportunities	15-18
Awareness and Fundraising	19-22
Donations	23
Bendigo Walk Photos	23
Events Calendar	24

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

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

Coordinator Operations: Georgina Diacos

Coordinator Equipment Service: David Harkin

Equipment Officer: Kathy Walker

Coordinator Volunteer Programs: Deb Olive

Coordinator Information & Resourcing:
David Kerley

Information & Resourcing Officer: Alison Jones

Information and Development Officer (digital communications): Heidi Bryce

From the desk of the CEO

2018 has started, and while some MND Vic staff are enjoying a well-earned break, the organisation continues to do what it does best – provide and promote the best possible care and support for people living with MND. Until there is a cure, there is care!

In December 2017 I attended a series of meetings on ALS/MND in Boston. The International Alliance of ALS/MND Associations is the global body of organisations which work with people living with ALS/MND, and it holds an annual meeting each year for organisations to share the issues they face and the support they provide. It elects a Board of Directors – this year, Carol Birks stood down as Chairwoman, and Steve Bell from England became the new Chairman, and David Ali (Chairman of MND Australia and member of the MND Victoria State Council) was elected to the Board. Carol reported on the significant growth of the Alliance, with 14 new countries now represented.



Attendees heard a range of presentations regarding support for people with ALS/MND and their carers from a range of countries, partnerships and collaborations (I presented on the new Alliance mentoring program), and research and science. The members discussed the strategic plan for the next four years, and identified a range of key issues for the Alliance to pursue.

An “Ask the Experts” session enabled some of the researchers attending the Symposium to present and respond to questions from people living with ALS/MND.

The Alliance also presents the Allied Professionals Forum, a full day of presentations from social, health and allied care professionals sharing what they do that makes a difference for people living with ALS/MND. Key themes include organisational planning and change, resource guides, peer

support, genetic counselling, respiratory care, use of medical marijuana and assistive technology.

And then there were three days of science and research, broken into two streams of science and clinical care research.

The big question – are we any closer to finding cause, treatment and cure? There is a growing number of exciting and well-founded clinical trials that are testing drugs to slow the course of the disease. Further discovery of genes involved in ALS/MND continues. Improvements in animal models are helping detect impact of interventions and agents. And we have the brightest and best researchers and clinicians working on learning more and searching for those elusive causes, treatments and cures.

We are closer – every piece of research, successful or not, brings us closer to understanding this disease and developing interventions to slow, stop and cure ALS/MND. We are learning more and more about the way cells live and die, and the influences that cause them to die.

Australia is a significant player in world research, and our basic and applied scientists are leading the world in some areas. What is more important than leading the world is collaborating with the world. The ALS/MND research community demonstrates every day the importance of collaboration, of shared discovery and global application of learning. They will succeed.

Until next time.

Rod Harris

CEO, MND Victoria



Renewal of 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 for more information on MND Victoria membership.

From Support Services



Hello and welcome to our first newsletter in 2018. It seems that it was only a few weeks ago that I was wishing everyone a happy 2017 and here I am again doing the same for 2018. I hope that you enjoyed the Christmas New Year period and look forward to some happy times in 2018.

In December we welcomed **Georgina Diacos** as Coordinator Operations, replacing **Alia Turnidge** who has left us to seek further opportunities of the travelling kind. Georgina has a business degree and post graduate qualifications in human rights. She brings diverse experience and skills which will greatly enhance the ongoing development and implementation of our new client relationship management system and our communication with NDIS and other government bodies. Georgina is based at Canterbury and works Monday – Friday.

Just as Georgina was commencing, **David Kerley**, Coordinator Information and Resourcing, advised me that he was resigning effective 23 February. David has worked with us for more than seven years, first as the Information and Resourcing Officer and then moving into the Coordinator position when the opportunity arose. Many of you will have spoken with him on the telephone or engaged with him through email or social media. David has developed a wealth of knowledge about MND, the disability and aged care sectors and services available to support people living with MND. David has been a vital part of the Support Services team and will be greatly missed. He also is planning on doing some travelling with his young family and is looking to settle in a regional area. We wish him well and hope for many exciting opportunities.

The Administration team has also had some recent staff changes. We said farewell to Administration Assistant, **Babita Narayan** and welcomed **Isabelle Lloyd** and **Rebecca Moussa** in her place. Isabelle and Rebecca are 'job sharing' the administration assistant role. Both Isabelle and Rebecca commenced their association with MND Victoria as volunteer receptionists during 2017 and have now progressed to permanent employment. It is a great testament to their capabilities that they have moved

so quickly from a volunteer position to that of a permanent staff member. We wish our three new employees great success, satisfaction and happiness in their new roles.



Rebecca and Isabelle

The NDIS roll out continues in 2018 with the following regions soon to be included. A person may meet the access requirements to become a participant of the NDIS up to 6 months prior to this date.

Hume Moreland

The NDIS will become available in the Hume Moreland area from 1 March 2018.

The Hume Moreland area covers the local government areas of

- Hume
- Moreland

Bayside Peninsula

The NDIS will become available in the Bayside Peninsula area from 1 April 2018. The Bayside Peninsula area covers the local government areas of

- Bayside
- Frankston
- Glen Eira
- Kingston
- Mornington Peninsula
- Port Phillip
- Stonnington

Southern Melbourne

The NDIS will become available in the Southern Melbourne area from 1 September 2018. The

Southern Melbourne area covers the local government areas of

- Cardinia
- Casey
- Greater Dandenong

Western Melbourne

The NDIS will become available in the Western Melbourne area from 1 October 2018. The Western Melbourne area covers the local government areas of

- Hobsons Bay
- Maribyrnong
- Melbourne
- Moonee Valley
- Wyndham

Please contact your MND Advisor or Janette McDonald at Canterbury for more information and all pre-planning advice regarding accessing the NDIS and developing and implementing a plan. Aspects of accessing the NDIS and the planning process can be confusing for us all. Our experience is that when our clients have a well thought out and

appropriate NDIS plan, their support needs are generally well met.

Best wishes for 2018. As always we welcome your feedback.

Julie McConnell

Manager Support Services



MND Information Session

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

At 7pm on Tuesday, 20 March at MND Victoria, 265 Canterbury Road, Canterbury.

Please RSVP by 5pm, Monday, 19 March.
Phone: (03) 9830 2122, 1800 806 632 or
Email: info@mnd.asn.au

The following session will be held on Wednesday, 2 May at 7pm in Canterbury.

COME TREK KOKODA WITH ME THIS AUGUST

DALE VINE FROM THE BLOCK HAS COMMITTED TO OUR 2018 ULTIMATE ADVENTURE!

WALK TO D'FEET MND

ENQUIRIES - dwoodrow@mnd.asn.au

Volunteer news!

By Deb Olive, Coordinator Volunteer Programs

Thank you to everyone who has welcomed me to the role of Coordinator Volunteer Programs here at MND Victoria. I am delighted to have joined this organisation and to be able to contribute to its important work. The commitment of our volunteers has impressed me and I look forward to becoming a valuable member of the team.

2017 End of Year Celebration

International Volunteer Day is celebrated on 5th December each year. Proclaimed by the United Nations in 1985, it is a day to recognise the contributions of volunteers across the world and the difference they make to community. It is estimated a billion people across the world volunteer each year. Can you imagine what our world would be like without their contributions?

At MND Victoria we understand the significance of the contributions our volunteers make to our work and most importantly to people living with MND and their families. On 5th December, MND Victoria took time to celebrate the contributions of our volunteers at a Christmas celebration at the Canterbury office. We were pleased to welcome 35 of our volunteers and to take a little time out to thank them and acknowledge their contribution.

Service Awards Recognition

The contributions of a number of our volunteers were recognised at the end of 2017 with Gary Covington and Tremora Howells recognised for 10 years of service to MND Victoria and Simon Morgan recognised for 5 years volunteering. This ongoing support and commitment, often provided behind the scenes, adds to the level of care and

services MND Victoria is able to provide for people living with MND in the community.

Thank you once again Gary, Tremora and Simon and to all of our volunteers who, through their contributions, make such a difference every day.



Gary Covington receiving his 10 year award

Volunteer opportunities

Relief Reception Volunteers

Our volunteer receptionists are our frontline contact people at the MND office in Canterbury. We would like to identify and skill up a small pool of volunteers who are able to provide backup support to our reception team during busy times and when our regular reception volunteers are on leave.

Time required: Reception shifts are 3.5 hours morning or afternoon. Times required would vary according to needs.



Our volunteers at their end of year celebration

Skills required: Excellent communication skills. Interest in learning lots about MND Victoria and in developing office and administration skills.

Hairdresser

We are really pleased we now have a volunteer hairdresser in the South East Metro area. Any clients in the area who would like to access a haircut, please contact your MND Advisor.

We are still seeking experienced hairdressers to volunteer in the North and West Melbourne Metropolitan areas to provide clients with limited mobility access to a trim in the comfort of their own home. This role will require volunteers to provide their own equipment and may involve travel outside their local suburb/area.

Time required: Appointments will be organised to suit the needs of clients and the availability of the volunteer.

Home Visitors

We are seeking volunteers who are able to provide social companionship for clients living at home. Volunteers visit clients in their home and provide clients with opportunities to maintain social involvement and activities of interest. This role will suit someone who enjoys getting to know, and spending time with, people.

Time required: 2-3 hours per fortnight. Volunteers will be matched with people in their local area.

Email: volunteer@mnd.asn.au or 03 9830 2122

The Cornflower—a sign of hope and resilience



“Thought you may like this photo of a pot of cornflowers my grandchildren and I planted two years ago after my husband was diagnosed with MND.

We wanted to show the grandchildren why the cornflower was chosen as the symbol of MND and here is the proof it "never gives up" - a final flower watching over new seedlings emerging from the recently dropped seeds.

Hope you enjoy the photo as much as we enjoy watching the cornflowers grow season after season.

Best wishes, Gleeson family.
Heathcote, Vic.”

Stefanie writes via Twitter: “i am my own number one fan for growing these cornflowers from seeds! (don't forget to support your local mnd/als organisation ♥) thanks for the seeds [@MNDVic](https://twitter.com/MNDVic)!!!!”



Cover story

Always remain hopeful, fight and never give up

By Grace-Ann

An experience that had a significant impact on my life would be the passing of my Uncle Graham. I had never experienced a death before this, so it affected my life majorly. He had Motor Neurone Disease. The reason his death impacted me so greatly was because he had become such a large influence on me. I had looked up to him for so many years. I had admired his strengths and determination in his fight with MND.

Throughout his fight he suffered a great deal, which hurt our whole family enormously. Through this he has become a role model to me. During the pain and the suffering, he never lost his hope, his humour or his cheeky grin! That grin became his trademark and it is something we will all remember him by. He taught me that even when times become challenging, it is important to stay true to who you are and to never change.

He possessed many qualities that I aspire to have; qualities of hope, humour, strength and persistence. This has helped me develop as a person. To have aspirations of qualities that you admire and you see first hand how they help and inspire others, develops a drive to embrace these certain qualities. This circumstance helped me to realise not only how lucky I am to have the amount of love and support I have, but how much love and support I can give to others. It helped me realise my strength. That I could not only take care of myself during this tough time, but that I could help and support others during my time of grieving.

Even though this experience may have been painful and not pleasant, I have learnt from it. I learnt from Uncle Graham to always remain hopeful, to fight and never give up. I learnt to be grateful for what I have; family, friends. But I have most importantly learnt that hard times are inevitable. That everyone goes through times they want to give up; times they feel worthless, as if there is no hope. I feel that it is the perfect time to think about what we have; whether it be the time we have, the memories we have, or something as simple as; I have my family, I have my friends. I am surrounded by love and support and that's all I



need. I learnt that whatever I may be going through I will always have someone to talk to, someone to help me get through the hard times, that I am not alone.

Death can be a sensitive topic and one most don't want to share or talk about, but I feel that everyone will experience deaths and although not enjoyable, through them we learn how to adapt, how to mourn, how to help others and importantly; how to help yourself. To maintain mental health and to take care of yourself is such a critical lesson to all aspects of life. When we share our experiences and feelings, we can help others to embrace it and to cope. We make it OK to be feeling the way we are feeling and not to suppress those emotions.

When I read the above prompt, I knew straight away this is what I wanted to write about. Many people will have that stand out moment in their life that they are shaped by and as a result develop as a person. This was my stand out moment. It so drastically changed my life, because I knew that my Uncle Graham was the sort of person I aspired to be. Due to this, I live everyday thinking of the qualities I long for and the inspiration I got from my Uncle. This experience not only significantly impacted my life, but also helped me develop as a person and become who I am today and the person I will become tomorrow.

Your stories

Karen and Geoff's MND Story

By Geoff Finnigan

Not only is this disease so horrible to endure for the sufferer of MND. But the other side of the coin is the partner and family trying to cope with the emotional issues that are created.

I myself have trouble coping at times. Emotional feelings ebb and flow, relationships can be irreparably damaged at times. From talking to other people who have lost their partners through traumatic illnesses, a common feeling is that we must control our emotions, and quite often we cannot. We have lost our partner, we seek affection, we want clarity in our new life's journey.

We want understanding, compassion BUT NOT SYMPATHY. Don't take our grief away from us.

This is our journey this is our grief, no one else's. We don't want platitudes, advice. And we don't want anyone to interfere with our grief, or assume they understand, they cannot. It is a journey that we have to travel alone, not even family members can help.

Sure counselling helps, but it is the nights that are the worst, silence, loneliness, sleeping by yourself after so many years as a couple. Those are the worst times, your mind works overtime trying to make sense of it all.

But life has to go on, sure it does, but at times it is so f g hard.

I have at times worried I am doing Karen a disservice, am I writing for my own personal emotional release or am I paying homage to Karen. I still don't know for sure, but I do feel that these words are keeping Karen's spirit alive.

I wake just before dawn when I get that urge to write. The last time this happened I had a vision ... this vision is of me standing in front of an audience. Beside me to my left is Karen, she is standing behind me and she is telling me "Go on Geoff, tell them!"

KATIES STORY: Karen's family nickname was Katie, that nickname meant a lot to her. Her siblings always referred to her as Katie, and she took offence to anyone outside of her family, calling her Katie.

Karen was born Karen Bethia Hulley to Ted and Jean Hulley on the 22nd January 1954 in Morwell Victoria. The eldest of three girls and sister to four boys. Being the eldest girl, Karen helped raise her sisters as well as protect them from the boys when sibling pressures came to the surface. The family stability was disrupted by continual moves by Ted and Jean to obtain work stability. In those early years Murrumbidgee was a childhood memory, then Reservoir became a stable home environment in her early teenage years, and eventually the family moved to Markwood when Karen started nursing.

EDUCATION: Karen attended Merrilands High School in Preston, Victoria. On graduation she turned her thoughts to her life's vocation.

Karen wanted to be a Ballerina as a young girl but her dad, Ted, said she had clumsy feet so she turned her attention to being a nurse. At the age of 16 she enrolled as a nurse at the Preston and Northern Community Hospital, commonly known as PANCH. She stayed at the hospital's boarding facility as was required by PANCH along with other first year nurses.

Whilst on duty one night she had a blood vessel burst inside her brain. A Neurosurgeon, who had sped across Melbourne from the eastern suburbs in the early hours of the morning, managed to successfully save her life.

Karen's life was saved, but she was left to deal with Grand Mal seizures due to scar tissue within the brain from the operation, and as a consequence suffered epilepsy. After a period of convalescence and drug treatment to control the seizures, she returned to PANCH and completed her training as a Divisional 1 Nurse.

WORK: Karen found that the responsibilities of a division one nurse in a busy community hospital environment taxing and stressful. Her inability to think quickly was a legacy she had to endure for the rest of her life. She told me that she preferred to be told what to do, not to be responsible to act quickly when required, whilst in charge of a ward.

In addition she had to endure the discrimination and ignorance that ensued by suffering epilepsy.

In 1972 Karen and I met, I was to be her husband for 42 years.

At that time Karen left PANCH Hospital and started working at various private hospitals on night duty. Her confidence as a divisional one nurse

slowly returned and she eventually learned to cope with the demands of community nursing.

Karen, as a Divisional 1 Nurse, worked in various positions over her working life. Public hospitals, private hospitals, nursing homes, a blood collector for Melbourne Pathology. Whilst living in Melbourne she started her own business as a masseur. She also applied Bowen Therapy and Reiki techniques to clients.

When we moved to Wangaratta in 2004 and established our Lavender farm B&B business in Oxley, Karen started working at Wangaratta Private and eventually became in charge of the day stay unit at Wangaratta Private Hospital.

Karen loved the interaction with patients, especially the ability to talk to them. She was a well respected member of the hospital team. Living in Melbourne Karen had become a sports trainer, a masseur, a Reiki master and a Bowen therapist. She was heavily involved with the Anglican Girls Friendship Society Leadership team whilst supporting our two girls.

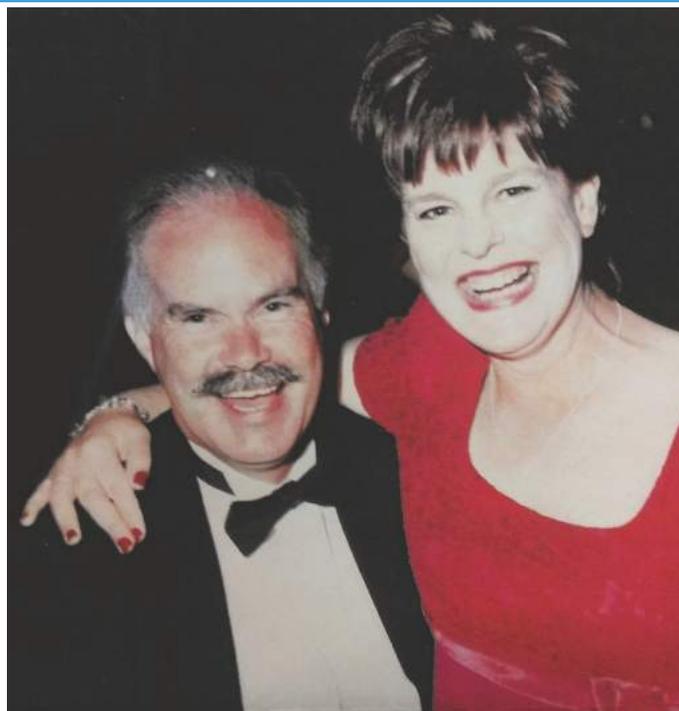
Favourite songs/music: Karen's music taste was varied—she loved Elvis, Country music, Traditional Irish Music, Dolly Parton and most popular music.

Special friends: Karen had many special friends, she was the kind of person who would make friends easily.

She had one particular friend and that was Judy. Karen met Judy when both of them had children at kindergarten whilst living in Epping. It was a friendship that lasted until Judy died of cancer in 2008. Throughout Judy's struggle, Karen would drive down to Melbourne from Wangaratta after working the day stay unit at Wang Private to support Judy. The death of Judy impacted on Karen immensely. She had lost her dearest friend, and I noticed a change in Karen, a sense of sadness and loss would pervade her thoughts.

Fran Pryor was another special friend, Fran worked with Karen in the day stay unit of Wangaratta Private Hospital. Fran became very supportive when Karen had to stop working. Fran would come around to our house every Tuesday and sit and talk to Karen whilst I went into town to do shopping and collect the mail.

I know Karen cherished those days with Fran, the knowledge that she was dying, was not important, it was the friendship that had grown between each



other that was the important factor. I am very much indebted to Fran for her kindness and support.

Hurdles and Heartaches: One hurdle that Karen had to overcome was the stigma of Epilepsy. It affected her relationship with fellow workmates as they failed to understand the impact of the brain surgery, and the possibility that Grand Mal Seizures might happen, although Karen's epilepsy medication provided stability.

She had to deal with the stigma of being an epileptic. Although a person eventually of strong character, she wasn't when I first met her. Her family gave her little support in those early years and her confidence was low. As she grew into married life at 20 and bearing three children she overcame her lack of confidence. I suppose having three children you develop confidence.

Our first born son Timothy, was involved in an incident at PANCH, at the age of four days. He was rushed to the Royal Children's Hospital burns unit. We would drive from Epping to the Royal Children's Hospital every morning where Karen would change his dressing and stay with him all day until I came to pick her up at night.

In April 2014 Karen was diagnosed with a form of MND called Pseudobulbar Palsy.

Regrets: Karen was a happy soul by nature, but the one regret she had was that she would not be alive to see her grandchildren grow up and marry. I don't know if you believe that there is an afterlife. Karen did, our eldest daughter does and I do.

I would like to share with you, some words from her Reiki reading by our eldest daughter on the day of her passing.

"Darling, there you are, I've been waiting for you all day. I know you've been busy with your work. I am ok. I'm really ok. It was easy, so easy. You said it would be. You said I'd wake up and be surprised that it had happened.

"And it did. I didn't really expect it. I didn't know what to think. But I couldn't really think. I was so tired, bored, exhausted. There's not much to live for once you reach that point.

"It's hard. I want to stay part of your lives. I want to meet Mika. I want to see my boys grow up. I want to hold them and play with them and make silly jokes and make more quilts. I know it's time, it's time to end this suffering, the pain, the constant discomfort, I need it to end, I could not stand it any longer. But I will miss you"

"There was nothing worse than this disease. Nothing worse ... At least (now) I don't need to be rolled or have my mouth wiped or eyes wiped or bum cleaned. Oh, it was awful. All of it. I am so relieved it's over. And that I'm still here, somehow ...

"All I need to do is turn around and the way is clear ... I know which way to go. I am not sure where it will take me but the pull is strong, the direction is clear. I just need to be ready. And I'm not ready yet, not yet. Not until the funeral, not until I see you all together, can be sure you'll be OK.

Then I'll go. And I will, I know where I need to go. And I know I'll be OK, I'll be safe."

Karen had photo books made for each of the grandchildren so that they would remember her. Unfortunately she couldn't make the birth of her first granddaughter, she passed away on the 6th of June 2016 and our granddaughter, Mika Katie, was born on the 16th of August 2016. Karen's time had come, the struggle for survival was too great.

She worried that the grandchildren would forget her and it was very important that those photo books were made. I put her mind at rest when she said to me, "will they remember me?" I reassured her that they would not forget her, and they haven't.

Sports, successes: Karen was a high achiever. As a member of the Victorian Road Runners Club she was awarded the Silver Shoe Award for clubman of the year in 1985. Apart from running many fun runs

over the years she completed the Honolulu Marathon in 2001. That same year she gave a speech to Epilepsy sufferers at the Epilepsy foundation of Hawaii.

Karen had a couple of falls as her mobility decreased. She was using the wheelie walker when she had a frightening incident. I heard a crash, she had tried to walk to the toilet, her legs gave way and she put her head through a plaster wall in the bed room. No tears did she show. At this stage, it was clear that she needed to use the wheelchair in the house. Karen was still fighting, still trying to show her independence.

Karen wanted one last trip so I paid for our eldest daughter to accompany Karen on a trip on the Ghan. I couldn't bring myself to go, our daughter had been overseas for 10 years, she needed time with her mum. Karen fell over in the street going to catch the train. She split her head open, and had to go to hospital to get stitches inserted. They managed to get the stitches inserted just in time to catch the train. She said, "don't tell your father" - they didn't tell me until they got home.

Personal care: As far as I was concerned it just had to be done, she was my wife, I wasn't going to abandon her to a nursing home, that would have destroyed her. I learned to cope, we had been married 42 years and Karen being a nurse understood. It would have been less dignified if she hadn't been.

When Karen was confined to bed, I had a monitor in her room and my room. She would make a sound during the night and I would go into her room and tend to her needs be it rolling her over, or adjusting the bed linen.

The most distressing time for me was when I heard her become distressed. I went into her room, her face was bright red. I asked—have you had a bowel movement? She indicated with tears in her eyes, yes. I had to clean her, I reassured her, I showed no emotion, but my heart was being torn apart. So distressing to have to clean your wife's bottom, this bloody disease strips all dignity away. This disease is so terrible, it takes away managing bodily functions - such a bastard of a disease. That first time was the worst, after that I was OK.

I was worried about her PEG feeding tube - concerned that it would fall out. When it did once it was panic stations, Karen was distressed. It was 9 o'clock at night - I called the Ambulance, her

catheter had come out as well! The ambulance didn't have a ventilator. They told me that they hadn't done this before. Luckily I had purchased a battery powered converter unit for her ventilator. We used that to get her to hospital and home again.

NURSING CARE: Karen loved the interaction with the nurses, and I loved it too. Initially I was jealous for a while when Karen's care became critical. The nurses would say to me, "go and have a rest we will look after Karen", I sort of resented it a little bit at first, then I realised that I was being selfish.

There was JOY in Karen's eyes when the staff came, even when unable to move her limbs, her eyes and facial expressions were classic to watch as the nurses joked and teased her. They gave her dignity, I am so grateful to them for that.

The palliative care team educated me around moving Karen to prevent pressure sores developing and keeping her skin moist. I'd rub oil into her sore muscles. Later Karen was struggling with muscle aches and pains. There was no muscle left to massage so I resisted Karen's request to call the masseur.

I cannot emphasise enough, my sincere appreciation to all staff who looked after Karen. You were our lifeline. I will never forget your dedication and kindness. You restored her dignity that this bloody disease took away.

SUPPORT GROUP: Talking is very therapeutic for me. I was part of a support group. It was for current carers and recently bereaved carers. There was a commonality between emotions - I sometimes would hold court so to speak and ramble on a bit. The others in the group understood ... it felt like we were in a parallel universe, people were going about their business as usual, but I/we were not. So many emotions, so many feelings.

I was feeling frustrated and helpless. With the knowledge of the disease, its prognosis - it seemed like I had nowhere to go. There was no one I could turn to and find help. No way to find help to try to come to terms with the diagnosis.

Eventually we found out about MND Victoria and especially Sue Sweeney. Then the Palliative care team at Wangaratta Base Hospital, Denise Ritchens and all the nurses became very important as did Jackie Creek who took over from Sue Sweeney. There were so many nurses and support personnel involved with Karen's critical care.

Karen stayed at home and I cared for her for two years. It was not fair, I had so many questions, about MND, about the meaning of life. Why Karen? She never had a bad word to say about anyone, always happy.

I was challenged by Karen's faith in her god, and her spiritual beliefs. I could never challenge her beliefs, nor would I. How could this god be so cruel? Why my dear Karen had to suffer so much.

Karen donated her brain to the Florey Institute for research into causes of MND. She had that written into her will! As always, Karen thought of helping others. On the day Ben from Mason funerals took Karen down to the Institute, I got a phone call from him—that night. He said ... "Karen is back home"! That small gesture meant a lot to me, and still does.

Karen's death has taken a toll on our family. Relationships are still fractured. Group gatherings are tricky unless the grandkids are there. They are the distraction, they help make light of the gathering. We tend to gloss over reminders of Karen when we are together, sweep them under the carpet so to speak, the feelings are still very raw, we have not sat down and talked over our loss as a family, we are all coping in different ways and sometimes it is better not to say anything.

It was 4 or 5 months after Karen died, I had visited Catherine at her home and we joked and talked about many things. Henry, Catherine's little boy came into the lounge room with Karen's iPad. Karen had given it to Henry when she could no longer use it.

Catherine sensed that me seeing the last tangible thing of Karen's brought back sad memories and she quickly ushered him out of the room with the iPad. Little insignificant things such as an iPad affect me.

Christmas 2016 was very hard, we all had planned to be at Catherine's place for lunch, but a week before Christmas, Catherine rang to say that she couldn't deal with Christmas. The week prior we got together for Henry's birthday. The day was filled with sadness, thank goodness that the grandkids were there to distract our thoughts.

It's now 16 months since Karen passed away. When Catherine calls my mobile, she hears Karen's voice, in the past it upset her, now only fond memories flood back. It is a positive thing. She has reframed it - hearing mum's voice now is a pleasant reminder.

With my son Tim, he misses his mum. When his boys are at school, he has time to think. When we are all together he does not show his emotions. They were always very close.

TRIGGERS: There are so many triggers that bring back memories. I drove down to Melbourne just the other week. And driving on the Hume Highway, that we had travelled oh so many times in the past. Stopping off at the Euroa service centre, for coffee and an egg and bacon roll. Or just reflecting on our life together as the countryside passed by.

My son in law Troy, said to me when I went to their place for lunch, that he had put an Elvis Presley record on for Karen on Mother's Day. Little Henry remembered Grandma and the many antics she would get up to with him.

Most of these triggers are sad for Karen's loss of life, she deserved better. She said she was going to see me out and live to 86!

Karen passed away on June 6, 2016 so her memory is very much in my thoughts this time of the year.

I was invited to the Neale Daniher MND symposium at the Florey Institute in Melbourne which I attended. To watch Neale struggle to hold a cup of coffee with both hands made me feel sad for him. Although he is upbeat at the moment, this disease is going to test his resolve in the future. And I wish I could help him.

There are too many triggers to talk about here. Life will never be the same now that Karen is gone. How can it be, I'm 70.

Get on with life, people expect it of me, and I will, but it is so damn hard at times. I wish I could spend just one more day with Karen, and know that she is ok.

Support services for carers of people with MND

- Carers Victoria—(03) 9396 9500
www.carersvictoria.org.au
- Carer Gateway—1800 422 737
www.carergateway.gov.au
- CareSearch—www.caresearch.com.au
- BrainLink—1800 677 579
www.brainlink.org.au
- MND Victoria—(03) 9830 2122
www.mnd.asn.au

Ballarat Support Group Christmas Gathering



On Saturday November 11th 2017 Marion and Andrew hosted a BBQ for all members and friends of the Ballarat Support Group at their lovely home and gardens at Smythesdale. All members brought salads and sweets to share and Andrew cooked up a storm on the BBQ. While Andrew was doing all the hard work, Marion showed us around her lovely garden and the outstanding work that Andrew had put into their rose garden. Most of them were in full bloom and looked wonderful. Their dogs entertained us by constantly fetching and bringing back a tennis ball. Marion commented that they were exhausted the next day and hardly moved. The group had their Christmas breakup on 24th of November and meets each month on the last Friday of the month and will resume on January 26th at 1pm at the Ballarat Leagues Club

The Ballarat Support Group is an informal group for people with the condition, family members and past and present family carers.

If you would like to find out more, please call MND Victoria on 03 9830 2122 or info@mnd.asn.au

Write your MND Story



Designed by Freepik

We'd love you to share your MND story. Please email your text and a photo to: info@mnd.asn.au by 28 February 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.

What past participants say about Living Well:

“It was a great couple of days, right to the point. I left happy... in a good frame of mind”

“...it has been very enlightening and informative. It also gave me a rare opportunity to meet with others in similar situations and learn from each other”

“We enjoyed it and we got more than we gave.”

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.

Previous participant comments include:

“I thought the depth of the conversation and sharing was engaging and very meaningful.”

“I’ve surprised myself by how much I got out of the bereavement session.”

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 of how to go about it, then contact us and we can talk you through your options.

Please email: info@mnd.asn.au or phone: 03 9830 2122.

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 out each other: <https://www.facebook.com/groups/340781642962036/>

Research update

MND Australia Research Conference 2017 Summary

By A/Prof Brad Turner, The Florey Institute

Over 160 dedicated MND researchers and supporters gathered at the contemporary and architecturally spectacular Charles Perkins Centre, University of Sydney, to attend the 13th MND Australia Research Conference in November 2017.

This year's Conference showcased major research achievements funded by the MNDRIA coinciding with the \$25 Million, 25 Milestones Report, a *Roadmap for the Future* and research outcomes from MNDRIA sponsored projects. The Conference was launched by The Hon. Dr David Gillespie, Federal Assistant Minister for Health, who remarked on the recent significant investment of Government and MNDRIA funding for MND. A/Prof. Justin Yerbury (Uni Wollongong) was awarded the



Betty Laidlaw MND Research Prize for his outstanding contributions to MND research and Dr. Mary-Louise Rogers (Flinders Uni) received the Charcot Grant for her top-ranked Grant-in-aid for 2018. Janet Nash, Executive Officer Research, was presented with a trophy for her 25 years of service to the MNDRIA and "in recognition of dedication and extraordinary contributions to building and sustaining MND research in Australia". Thank you for your limitless energy and patience throughout, Janet!

The Conference commenced with two excellent keynote presentations highlighting the significant impact of MNDRIA-funded research on a global scale. A/Prof Ian Blair (Macquarie Uni) summarised the staggering progress in genetic discovery in MND. While it took over a century to find the first culprit gene for MND, recent next-generation DNA screening technology has narrowed this gap to years. As a result, 10 MND genes have been discovered from MNDRIA-funded projects, notably the MND Australia Ice Bucket Challenge Grant. Aside from shedding light on the causes of MND, these genes have revealed shared molecular origins of MND and frontotemporal dementia, dissolved barriers between inherited and sporadic MND, and inspired a generation of innovative experimental

models to tackle MND in the laboratory. Next, Prof. Steve Vucic (Uni Sydney) summarised over a decade of clinical research by Prof. Matthew Kiernan and their team, providing compelling evidence that MND is fundamentally a disorder of electrical circuits in the brain, leading to subsequent spinal cord and muscle damage. Importantly, electrical overload in the brain of MND patients can be detected by a sensitive and non-invasive technique called "TMS" which Prof. Vucic and colleagues have recently commercialised, which may provide a powerful tool to diagnose and track MND in the clinic.

A/Prof. Tracey Dickson (Menziess Institute) opened the *Roadmap for the Future* session, outlining the important contribution of experimental model systems such as flies, worms, fish and mice to MND research. Although these simple organisms have obvious inherent limitations, their implementation and interpretation in MND research is continually improving. Human-based models of MND were presented, ranging from stem cell reprogramming to mini-brains "on-a-chip", suggesting we are at an exciting advent of highly relevant and digital models for rapid drug screening in MND.

Dr Peter Crouch (Uni Melbourne) summarised his team's 10-year journey in the making with positioning CuATSM as a possible therapeutic option for MND which is currently under clinical trial in Australia. Dr Michelle Farrar (Uni Sydney) provided an overview of "Spinraza", the first approved therapeutic for the fatal childhood motor neuron disease, spinal muscular atrophy (SMA), only approved in Australia last week. While Spinraza continues to demonstrate unprecedented and remarkable benefits in children affected by SMA, this was tempered by the future realities of implementing such an expensive drug and its challenging route of delivery directly into the spine. Lastly, Dr Anne Hogden (Macquarie University) provided insights into how we can best translate research into practice, reminding us that making research useful to MND patients and their families is the big picture goal of research.

After lunch, several MNDRIA currently funded projects were highlighted. While MND typically presents in late-life, the disease process may span years and decades before symptom onset. A/Prof Brad Turner (Florey Institute) outlined his team's approach to understand the molecular processes of

this critical early time period which could provide fresh insights into motor neuron vulnerability.

Dr Chris Bye (Florey Institute) presented evidence for spread of pathology in brains of MND mice which received healthy nerve cell grafts, suggesting a biological mechanism for the characteristic spread of pathology, and perhaps symptoms, in MND. 'Could MND result from accelerated ageing of chromosomes?', was a question posed by A/Prof. Julie Atkin (Macquarie Uni) who found the ends of chromosomes called "telomeres" were shorter in MND affected cells. This suggests DNA instability and damage may contribute to the disease process in MND.

Next, A/Prof Anna King (Wicking Institute) showed TDP-43 triggered abnormal branches and connections in motor neurons, reinforcing the notion that MND is a disorder of connectivity in the nervous system. A/Prof Trent Woodruff (Uni QLD) provided an update on targeting the blood-related complement system in MND, revealing a novel role for the "C5aR1" molecule in muscle and extending the role of the complement system to muscle. Lastly, Dr Albert Lee (Macquarie Uni) summarised his efforts to understand the biology of CCNF mutations, a newly identified gene responsible for MND, revealing these mutations interfere with self-cleansing of damaged proteins in motor neurons which is a unifying pathological pathway implicated in MND.

In the final session, Dr Adam Walker (Macquarie Uni) presented his findings on protein signatures detected in affected tissues of a novel TDP-43 mouse model of MND, revealing widespread protein disturbances that may point to early disease pathways. A/Prof Ron Sluyter (Uni Wollongong) reported on effects of targeting the "P2X7 receptor" linked to inflammation and motor neuron death in MND mice using an improved brain-penetrating drug.

Dr Shyuan Ngo (Uni QLD), this year's recipient of the Charcot Grant, revealed new insights into the link between abnormal whole body and muscle metabolism occurring in MND patients. Dr Ashley Crook (Macquarie Uni) highlighted current issues and dilemmas with genetic testing in inherited MND, weighing up costs and benefits and existing barriers in the event of mutation detection. Lastly, Dr Mehdi Van den Bos and Dr Nim Geevasinga (University of Sydney) summarised encouraging progress with

developing and enhancing TMS with MRI to probe brain dysfunction in MND.

The evening Poster Session provided an engaging mix of clinical, healthcare and scientific research presentations and discussions inspiring collaboration outside the platform communications and the best Poster Prize was awarded to PhD

student Samantha Levin (University of Queensland). Overall, the 2017 MND Australia Research Conference showcased world-class research achievements driven by a dedicated MND workforce built up over the last 30 years of MNDRIA research investment, determined to change the future of MND.



The Annual International ALS/MND meetings are organised by the MND Association of England, Wales and Northern Ireland in partnership with the International Alliance of ALS/MND Associations.

Experts from research and medical communities as well as ALS/MND associations and people living with ALS/MND come together each year to share new understandings about ALS/MND. All share a common goal to move us closer to finding effective treatments and ultimately a cure. The Symposium is preceded by the International Alliance of ALS/MND Associations annual meeting, an Ask the Experts session and the Allied Professionals Forum. This year the meetings, held from the 4 to 9 December and hosted by Alliance members ALS TDI and ALS Hope, attracted 1,640 delegates.

There was much discussion during the meeting on the impact of the FDA approval of edaravone (Radicava) in the USA in May 2017, which is the first therapy shown to slow progression for ALS/MND, in a sub-set of people, to be made available in the US in over 20 years. Dr Jonathon Glass highlighted the problems encountered in the US related to accessing infusion suites and insurance companies' response related to the eligibility criteria data since the drug became available in August. In his clinic they are yet to be successful in having a

patient approved for therapy. Meetings were held by Mitsubishi Tanabe to discuss plans for seeking approval in other countries. At present the company does not have plans to seek approval in other countries nor undertake further research to ascertain impact on survival.

Ask the Experts

The International Symposium offers the host organisation a unique opportunity to invite international ALS/MND experts to provide updates to people living with ALS/MND in their region. These sessions are recorded and live streamed.

First speaker Dr Jonathon Glass, Emory ALS Center, Atlanta, covered ALS and frontotemporal dementia, gene discovery, anti-sense oligonucleotides as a potential therapy for C9orf72, advances in the development of biomarkers and the proteomics approach to ALS/FTD .

Dr James Barry from Massachusetts General Hospital, Boston, talked about clinical trial process and design and the continued search for reliable biomarkers.

Final speaker Dr Steve Perrin, CEO, ALS TDI, Boston, provided an overview of innovations in telemedicine applications for ALS/MND and the merging of telemedicine with precision medicine programs. Steve highlighted that good pre-clinical

work and reliable biomarkers are vital to increase likelihood of success of clinical trials. To date clinical trial success in ALS has been about 0.1%.

15th Annual Allied Professionals Forum

The Allied Professionals Forum sessions enabled the sharing of ALS/MND care and support innovations to help guide practice worldwide. The presentations covered a wide variety of topics on resource development, carer and family support, cannabis use, respiratory care and innovative approaches to assistive technology provision.

28th International Symposium on ALS/MND

Over the three-day event the concurrent scientific and clinical sessions covered biomedical research, diagnosis and prognosis, causes of ALS/MND, clinical trials and treatments and improving well-being and quality of life and more.

Opening address from Jeffrey Rosenfeld set the scene by highlighting the need for the research community to look at new ways to tackle the heterogeneity of the disease.

Research highlights from the Symposium included the discovery of two new genes linked to MND and the use of antisense oligonucleotide-based therapies, which is looking hopeful for people with SOD1 and C9orf72 mutations. Presentations on expanded/pre-approval access to potential therapies stimulated discussion. As always the inimitable Richard Bedlack entertained whilst challenging us all to reflect on our views and practice. The multi-step process of MND progression and factors such as genetic mutations that may shorten this process was a feature of a number of presentations.

Clinical highlights included presentations on carers and cognitive change, telemedicine, app development and much more.

There were a number of sessions that covered Clinical Trials highlighting the worldwide research focus on the search for an effective treatment but also the complexities associated with this search.

We were all disappointed to learn that the phase three trial of tirasemtiv was negative but will watch with interest the current investigation by the European Medicine Agency (EMA) on Masitinib which has shown a slowing of progression in a phase 2/3 trial. Further confirmatory clinical trials will be conducted to provide more necessary

information (including higher dosage effects) to the EMA.

Once again, the Australian contingent of researchers made their mark. The MND Research Institute of Australia (MNDRIA) is proud to have funded nine of the Symposium presenters including Beryl Bayley MND Research Fellow, Dr Parvathi Menon from University of Sydney. Parvathi reported that cortical hyperexcitability is a regional phenomenon in MND, most prominent in cortical areas representing the hand region.

Dr Marco Morsch from Macquarie University presented some elegant research using zebrafish to visualise microglial activation in real time highlighting the ability of microglial cells to uptake TDP-43 and showing if this does not happen there is abnormal dispersal of TDP-43 into neighbouring tissue. Dr Frederik Steyn of The University of Queensland - UQ discussed the association of hypermetabolism with lower motor neurone burden and functional decline. Dr Nimeshan Geevasinga from University of Sydney studied 305 people with MND and found cortical excitability scores may be a useful novel biomarker for diagnosing MND.

Congratulations to Dr Mehdi Van Den Bos from University of Sydney, who stood out in a field of 450 to be awarded a prize for his poster 'Imbalance in cortical inhibition-excitation networks underlies the development of cortical hyperexcitability in ALS'.

Links to all presentations and videos from the meeting are at: www.alsmndalliance.org/2017-meetings Further research from the Symposium will be published in future editions of MND News.

Research opportunities

Donate to the Tissue Bank of Victoria

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: <https://www.florey.edu.au/vic-brain-bank> or Phone: (03) 8344 1900, Mobile: 0438 530 372 Email: fairlie.hinton@florey.edu.au

Awareness & Fundraising

“When you're surrounded by people who share a passionate commitment around a common purpose, anything is possible.” Howard Schultz, 1953.



It's the start of a brand new year and once more I'm excited about the prospects ahead for MND Victoria. I totally agree with Howard Schultz's observation and I can honestly say that here at MND Victoria we are surrounded by people who share a passionate commitment and a common purpose – to help Victorians living with MND to live the best life possible as their MND progresses.

By the time you receive this Newsletter you will no doubt have seen all the publicity around the Australian Open Tennis and its support of FightMND. While we applaud their support and commitment to research into cause, treatment and cure ***it's imperative that we don't lose sight of the needs of people living with MND today!***

I expect that many, many people will mistakenly think that funds raised by FightMND are shared with MND Victoria. This is absolutely not the case – FightMND and MND Victoria are separate organisations which address different needs.

MND Victoria was established in 1981 and its mission then, as now, is to provide and promote the best possible care and support for people living with MND. This involves allocating an MND Advisor to each person with MND who elects to join the Association, providing a wide range of assistive technology devices at no cost to the person with MND, to help them retain and maintain their independence, presenting information sessions to people with MND, their families, friends and healthcare professionals on how best to live with and care for someone with MND.

To deliver the services listed above, the Association must raise over \$3.5 million each year from its various fundraising activities as we receive only 25-30% of our funding from Government sources, including the NDIS. We can only do this if you continue to support our efforts.

Here are some of the many ways that you can support MND Victoria:

- ◆ Join **Dale Vine (The Block)** by taking part in the Kokoda Walk for MND – our goal is to raise \$150,000 (see page 5 to find out how you can be involved)
- ◆ Get together with friends, work colleagues and family to participate in one of the many challenge events such as **Run Melbourne, Stadium Stomp, Melbourne Marathon, Tough Mudder, City2Sea** to name but a few options in Victoria
- ◆ **Start your own** Challenge event – set yourself a goal, perhaps walking, running, swimming or cycling 100 kms in a month, start a MyCause page and get people to sponsor you
- ◆ Hold a **Drink Tea for MND** morning or afternoon tea at work, school, in your local community centre, or at home
- ◆ Consider joining a Workplace Giving Program (contact knightingale@mnd.asn.au for more information)
- ◆ Hold a morning tea or lunch or dinner and invite your family, friends and colleagues along
- ◆ Contact your local Bunnings, Coles, Woolworths or other store or shopping centre and ask them if you can host a **BBQ** one Saturday or Sunday
- ◆ Participate in one of our many Walk to D'feet MND events <https://www.mycase.com.au/events/walktodfeetmnd> or even consider starting one in your local area
- ◆ Purchase **MND Merchandise** and help promote awareness <https://www.mnd.asn.au/gear>
- ◆ If you belong to a sporting club – **Bowls, Netball, Cricket, Football** – ask them to sponsor MND Victoria this season.
- ◆ Are you a golfer? Why not talk to your Club about running an MND Victoria **Charity Golf Day?**
- ◆ Support our **fundraising appeals**
- ◆ Consider naming MND Victoria as a recipient of a **bequest** in your Will

These are just some ideas for you to consider. Daniel Woodrow, Fundraising Officer, and I will be very happy to talk to you about how the Association can support your fundraising efforts. Contact us by email: fundraising@mnd.asn.au or call 03 9830 2122

Please consider how you can support the Association so we can ensure that people in Victoria who are living with MND can continue to get the support they need to help them as they face each day. As Howard Schultz said – *“When you're surrounded by people who share a passionate commitment around a common purpose, anything is possible.”*

Until there's a Cure there's Care.

Kathy Nightingale, Manager Fundraising

Around the State

The Royston fundraiser:



A huge thank you to The Royston Hotel in Richmond which hosted a fantastic event late last year in honour of their favourite customer who has recently been diagnosed with MND. A large number of their awesome local suppliers donated stock so that every dollar spent was donated to MND Victoria. The pub was chockers from the time the doors opened with everyone enjoying the festivities knowing every meal and drink they purchased was helping a very important cause. We thank all those who attended, who supplied stock and raffle prizes, the staff who worked incredibly hard and the management for deciding to put on the event! In the end \$7,635 was raised. An amazing result!

MND 300:

Over Easter this year an amazing team of individuals are coming together to run from Wangaratta to Melbourne. These guys run for fun, and run very long distances. This time they want to help all those in Victoria living with MND by raising a large amount of money by running 300km in their Funky Trunks! The motivation and dedication of this team is phenomenal. If you can help with

accommodation in either Benalla, Euroa, Alexandra or Healesville that would be awesome. They would also appreciate any fundraising or sponsorship support. Perhaps you could consider holding a BBQ at one of their rest stops? If you can help, or would like more information, please get in touch with Daniel at dwoodrow@mnd.asn.au or 03 9830 2122. The dedication this team have is huge and we encourage as many people as possible to support them over the next few months. Keep an eye out on our social media platforms as we showcase their journey. To donate directly to their cause go to: <https://www.mycause.com.au/page/148766/mnd-300>



Share the love!

Liking, sharing and commenting on MND Victoria's social media posts is a super simple way to support us and spread the word about the importance of care and support for people living with MND.

FOLLOW US ONLINE AT:

 www.facebook.com/MNDVic

 www.twitter.com/MNDVic

 www.instagram.com/mnd_vic

14th Melbourne Walk to D'feet MND, Princes Park, Carlton



Once again, we had the most amazing weather for the Walk, and walkers and wheelers turned up early to enjoy a coffee and catch up with friends before the official start at 10am.

The presence of **Razor the Raptor** was a great hit with everyone, and was a commanding figure at the start of the Walk. Although numbers were slightly less than last year, it did not seem so; at one point the MND crowd stretched about two thirds of the way around the track, a wonderful sight to see.

We are most fortunate to have the **Boroondara Central Lions Club** provide the sausage sizzle, they have attended every Walk and have promised to be there again in 2018. Our two coffee carts, **Cappuccino Express** and **Espresso Mobile Café** also regular attendees, are especially appreciated by the volunteers who turn up early to set up for the day.

We had some great raffle prizes this year, all generously donated.

Winners were as follows:

1st \$500 voucher for Silvan Pumps and Sprayers – Megan Collis

2nd \$350 worth of Lorraine Lea Linen – Paul Lewis

3rd \$200 voucher for Kew Skin Therapy – Jenny Ambridge (Jenny generously donated this prize to be re raffled – it was won by David Kerley)

4th High Tea for two, value \$118 at The Westin – Pam Sanders

5th Puffing Billy Family pass – Nicole Clayton

6th MND Big puppy – Amanda Anderson

The raffle raised over \$1500, and the total funds raised was approx. \$150,000 a very pleasing result for one morning's work!

MELBOURNE WALK PRIZES

#1 Individual fundraiser: \$3,202.50 Lauren Maher

#1 Team Fundraiser : \$7,645.25 Team DK

#2 Team Fundraiser: \$7,334.55 Team Jo Q

#1 Team with most members: 95, Team Jo Q

#2 Team with most members: 65, Make our Mark

Best Dressed Team: Team Jo Q

As well as those already mentioned, I would like to acknowledge the support of **Melbourne City Council, Ikon Stadium, Photography by Lissa and Laz, Hire Intelligence, Jo Stewart (Yoga), Angela Lumicisi (soloist)** and lastly, all the volunteers and staff of MND Victoria, without whom the Walk would not happen – A BIG THANK YOU!

Although I mentioned last year that I would be stepping back from running the Walk, I'm still involved! Working with Joe Mantella is such a pleasure and sharing the load as we do, means that I am happy to stay on for a while longer! A BIG THANK YOU to you too Joe!

The date for this year's Walk is 18 November 2018 – I look forward to seeing you there!

Marian Lowe

Melbourne Walk Photographers

Once again we were very fortunate to have Lissa and Larry our official photographers at the Melbourne Walk to D'feet MND in November. Larry and Lissa volunteer their time and talent to MND Victoria. Recently I asked Larry why they support MND Vic and he was happy to share his reasons.

“To be honest, it started with the 'Ice Bucket Challenge' trend a few years ago. Initially, like most people doing the challenge, it was fun and games. Before then, we had no idea there was such a thing as MND, but after learning much more and meeting with some of the battlers, we have really grown to understand

the gravity of what it can do, but also appreciate MND Victoria's ongoing support for the community.

Our first year of being involved with the Walk to D'feet event really opened our eyes to how many people MND can affect. Not only the ones battling, but their loved ones too, and seeing all of the hope and support come together to raise spirits of all involved, just really puts everything in perspective. Being able to be a part of that, for us, is a real privilege.”

You can see more of their great work at:

lissaandlazz.com.au

BENDIGO WALK PRIZES

#1 Individual fundraiser: \$725 Anne Block

#1 Team Fundraiser: \$14,785.75 Team Mez

#2 Team Fundraiser: \$10,884.20 Team Hunts

#1 Team with most members: 63, Team Mez

#2 Team with most members: 60, Shena's Army

Best Dressed Team: Team Mez

Bendigo Walk to D'feet MND, 26 November 2017



Donations received

In memory donations

Peter Anderson
 Alan Anstice
 Ray Bayly
 Dr Graeme Bertuch
 Crockett Cooke
 Pam Davidson
 Ruth Ewart
 Peter Eynaud
 Angela Giannekas
 Leona Harmor
 Father Geoff King SJ
 Gunda Lampe
 John Lines
 Margaret Lyons
 Karon Macpherson
 Daniel Martinez
 Ann Matterson
 Trevor Nance
 Barb Phillippi
 Alison Smithies

Maria Tarquinio
 Julie Zoch
 Timothy Steadman
 Malcolm Duff
 Norm Ducksbury
 Graeme Williamson
 Ken Grubb
 Terry Lewis
 Gordon Lynch

Group Donations

The Scots Glen Singers Inc.
 Western Heights Tuesday
 Morning Badminton Club
 City South Football Club
 Highvale Retirement Village
 Social Club
 Mitcham Scottish Society Inc
 Shepherds Australia
 1971 Monash Graduates

Equipment Donations

Thelma Featherston

Christine Tyrrell

Bequest Donations

Estate of Dorothy Cook

Trust and Foundation donations

Electrical Trades Union
 Norwood Secondary College
 Lions Club of Macarthur & District
 Wodonga Salvation Army Branch
 The Village Glen
 Rochester Golf Club
 Lodge of Euclid

Corporate Donations

Medico Legal Communications
 Simon Denton Industries
 Dromana Dental Clinic Pty Ltd
 Hog Servicing Pty Ltd
 Costanzo Harris Pty Ltd
 Arbour Electrical
 Charity Greeting Cards
 Prospect Accounts

**Join us in Benalla on Sunday 25 February 2018
 from 8.30am to Cycle, Walk, Relay and/or Run. Sign
 up at: www.act2dfeetmnd.com**



**AND Geelong at 10.30am on 25 March 2018
 Sign up at: www.mnd.asn.au/walk**

Newsletter Issue	Copy to Editor by	Newsletter Mail Out Date
March—April 2018	28 February 2018	3 April 2018

Contributions to the newsletter are invited

MND Victoria members are invited to contribute personal stories, anecdotes, letters, or 'Handy Hints' to 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 send to the Newsletter Editor, MND Victoria, PO Box 23, Canterbury Victoria 3126, or email: info@mnd.asn.au

MND Victoria Events Calendar 2018

Date	Description	Contact/tickets
Tuesday, 13 February 2018	Ocean Grove Rotary Club MND Event	Email: fundraising@mnd.asn.au
Sunday 25 February 2018	Benalla Act to D'feet MND	www.act2dfeetmnd.com
17-18 March 2018	Wandin Park Equestrian Event	Email: fundraising@mnd.asn.au
Tuesday, 20 March 2018	MND Information Session, Canterbury	Email: info@mnd.asn.au
Friday, 9 March 2018	MND Golf Day, Mandalay Golf Course	www.trybooking.com/SXDV
Sunday, 25 March 2018	Geelong Walk to D'feet MND	www.mnd.asn.au/walk
30 March—2 April 2018	Wangaratta to Melbourne Run	Email: fundraising@mnd.asn.au
Monday, 2 May 2018	MND Information Session, Canterbury	Email: info@mnd.asn.au
Sunday 6 May 2018	MND Week 2018 begins	Email: fundraising@mnd.asn.au
Friday, 11 May 2018	Blue Cornflower Day	Email: fundraising@mnd.asn.au
Monday, 21 May 2018	National Volunteer Week begins	Email: info@mnd.asn.au
Thursday, 21 June 2018	Global MND Awareness Day	Email: fundraising@mnd.asn.au
Sunday, 22 July 2018	Stadium Stomp (MCG)	Email: dwoodrow@mnd.asn.au
Sunday, 29 July 2018	Run Melbourne	Email: dwoodrow@mnd.asn.au
26 August—4 September 2018	Kokoda Trail 2018	Email: dwoodrow@mnd.asn.au
Sunday, 14 October 2018	Melbourne Marathon Festival	Email: dwoodrow@mnd.asn.au
Saturday, 20 October 2018	Cox's Bridge to Cox's Place Cycle	Email: dwoodrow@mnd.asn.au
Sunday, 18 November 2018	Melbourne Walk to D'feet MND	Email: fundraising@mnd.asn.au
Sunday, 25 November 2018	Bendigo Walk to D'feet MND	Email: fundraising@mnd.asn.au

For further information and the latest events list, please visit our website: www.mnd.asn.au/whats-on/
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