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State Council
David Lamperd—President
Katherine Barnett—Vice President
Jeremy Urbach—Hon. Treasurer
David Ali
Duncan Bayly
Christopher Beeny
Barry Gunning
Jodie Harrison-Fitzgerald
Angeline Kuek
Wayne Pfeiffer
Chloe Williams

Support Groups

Western Metro
Last Monday each month at 12.30 pm
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: David Kerley (MND Victoria)
Tel: (03) 9830 2122 or 1800 806 632

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Staff
Chief Executive Officer: Rodney Harris
Manager Finance & Administration: Megan Crellin
Administration Assistant: Vacant
Manager Fundraising: Kathy Nightingale
Fundraising Officer: Daniel Woodrow
Manager Support Services: Julie McConnell
Coordinator Support Services: Janette McDonald

MND Advisors
Ruth McEvoy
Elizabeth Crask
Lesley Burcher
Eric Kelly
Lauryn Matheson
Jenny Waites
Trish Duffy
Leanne Conway

Coordinator Operations: Alia Turnidge
Coordinator Equipment Service: David Harkin
Equipment Officer: Kathy Walker
Coordinator Volunteer Programs: Deb Olive
Coordinator Information and Resourcing: David Kerley
Information and Resourcing Officer: Alison Jones
Information and Development Officer (digital communications): Heidi Bryce
By the time you are reading this, our spring walks have been concluded. Long term weather forecasts indicate great weather for them and I expect that all attending will have fabulous days.

Roll out of the National Disability Insurance Scheme continues, with Eastern Metropolitan coming on line in November.

Amongst people registered with MND Victoria, there seems to be some misunderstandings of the relationship between MND Victoria, the NDIS, and our historical funding from the State Government.

As you know, MND Victoria’s history has largely been self-funding, with about 20% of our funds coming from government. We have always provided our services at no cost to the individual. This has given us independence, a focus on people with MND, while having a baseline of support. Since the introduction of the NDIS, we have gradually been losing our State funding as people transition to the NDIS. This means that our baseline support has been reducing, we are receiving funds from individuals’ support package, and increasing our reliance on the NDIS to meet the costs of service delivery. In particular, this affects our Equipment and MND Advisor/Support Coordination Services.

Eventually, we will rely on the NDIS, with people who are participants choosing MND Victoria to provide these services, to fund our services. This continues our policy of our services to be delivered at no cost to the people with MND, but funded through their NDIS package. This is working well so far, but it is essential for the future that people with an NDIS package of support choose MND Victoria as their provider for coordination of supports and equipment. Equally, it is essential that those services are included in the personal plan developed with the NDIA.

For people over the age of 65, and not eligible for the NDIS, a different issue arises. Previously they have been supported by a combination of fundraising and State government funding, and at no cost to the person with MND. As we lose the State funding, there is more pressure on MND Victoria to generate funds via Aged Care packages, and through fundraising. We have experienced a decline in fundraising over the past two or three years, particularly in our independently run events. These events are still occurring, but the funds raised are going to other MND organisations. This drift of funding makes it increasingly difficult to meet the costs of the 60% of our current clients who are over the age of 65.

We want to continue delivering our services at no cost to all people with MND. We are influencing government regarding the enhanced use of specialist agencies like MND Victoria in the NDIS, and attempting to achieve better recognition of the needs of people over the age of 65 in Aged Care. We hope we will be successful.

In the meantime, can I ask that if you, or your friends, or workmates, decide to raise funds for MND, you ensure that they are raised to support the ongoing delivery of care and support for all people living with MND. Until there is a cure, there is care!

My very best wishes for the coming festive season, and a safe prosperous New Year for all. We all look forward to the discovery of cause, treatment and cure for this rotten disease, and to live as well as we can for as long as we can.

Regards

Rodney Harris, CEO
From Support Services

As I write this newsletter piece it seems, with the hot weather we are currently experiencing, that we have bypassed spring and leapt straight into summer. I hope that you have made preparations to ensure you keep safe and comfortable in the hot weather.

During times of high temperature it is important to keep as cool as possible, drink plenty of water, restrict your outdoor activities to before 10:00 am and after 3:00 pm and stay out of the sun. I trust that those of you in bushfire prone areas have your fire plan in place and are prepared to take early action should the necessity arise. If you have any concerns please talk to your MND Advisor or contact the Canterbury office.

We now have approximately 55 clients who have an active NDIS plan. Within these plans allocations of funding are made that are considered reasonable and necessary to support the stated goals of the participant. These supports can include assistive technology (equipment), assistance with personal care and at home, transport to appointments and activities and a worker to coordinate these supports (Coordinator of Supports).

There are a further 50+ clients who are in the process of gaining access to the NDIS or waiting for their planning meeting. We know that our clients who are eligible for the NDIS are being contacted by a representative of the NDIS with the view to commencing the plan development process, in many cases even if they are not in a current roll out area. It is extremely important that you are well informed, have thought about how you want to live your life and what type of support you need to make this happen and to live as well as possible. During your meeting with the NDIS planner you will be asked many questions. One of these will be about your ‘goals’. This is because all funded supports are measured as to whether they are ‘reasonable and necessary’ to assist you to achieve your goals.

In previous newsletters I have strongly encouraged you to seek support from your MND Advisor when planning for and meeting with the NDIA planner to understand the opportunities available through the NDIS and how to ensure your plan will provide for your needs. I have included here a comment from one of our clients which highlights the benefits they found by having the support of their MND Advisor during the preplanning and planning processes.

“Thanks again for your assistance today with the planning session for NDIS. Your advice was invaluable. There were a number of questions that I would not have been sure how to answer, and your suggestions helped me with the appropriate answers.

I want to reiterate that I really hope this plan keeps MNDA involved as much as possible. The association has been of great help over the years, and I look forward to ongoing and long-term (hopefully) contact with you. I think from what I have seen today the plan will make this possible.”

Our experience is that when our clients have a well thought out and appropriate NDIS plan their support needs are generally well met.

Similarly, for those of you who are 65 or older and required to have your support needs addressed through the Commonwealth Aged Care Programs, your MND Advisor is able to provide information regarding the different aged care packages and assist you to access these.

Whilst NDIS has been rolling out across the country there has also been considerable change in the way aged care programs are accessed and provided. Referrals for support, both at home and in residential accommodation are made through the ‘My Aged Care’ website www.myagedcare.gov.au

As with the NDIS local area coordinators and planners, many of the people working in Aged Care assessment and planning roles do not have specific experience or knowledge of an uncommon disease such as MND. This is of considerable concern to us. It is therefore the best option for you also to have the advice and support of your MND Advisor when considering options for support provided through the aged care program.

In the previous newsletter I advised that Leanne Conway (Coordinator of Volunteer Programs) had recently been appointed as an MND Advisor. The new Coordinator Volunteer Programs, Deb Olive commenced in late November. You will see a photo of Deb elsewhere in this newsletter. Deb will undertake her induction into the role over the coming weeks and looks forward to meeting those of you who are able to attend the end of year celebrations in December.

Alia Turnidge, Coordinator Operations, will leave us at the end of the year. Alia has a strong desire for travel that she wishes to explore. Alia began her time with us about 2.5 years ago in a temporary part-time role to assist the Equipment Team. Her
considerable skills and aptitude rose to the fore and we quickly saw the good sense in harnessing these to assist in several areas, in particular with the development and implementation of our new Client Relationship Management System, iCase. She quickly learnt the crux of our work and was able to provide advice and support to develop iCase to meet our requirements. Her input has been considerable, extremely valuable and greatly valued. We wish her much happiness and every success in her future endeavours.

As always we welcome your feedback.

Julie McConnell
Manager Support Services

**MND Information Session**

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

**At 7pm on Monday, 5 February** at MND Victoria, 265 Canterbury Road, Canterbury.

Please RSVP by 5pm, Friday, 2 February.
Phone: (03) 9830 2122, 1800 806 632 or Email: info@mnd.asn.au

The following session will be held on Tuesday, 20 March at 7pm in Canterbury.

**Christmas break closing hours**

MND Victoria will be close over the Christmas – New Year period from 5pm on Friday, 22 December 2017 and will re-open at 9am on Tuesday, 2 January 2018.

Therapists at Calvary Health Care Bethlehem (CHCB) have been authorised to organise any urgent repairs required for equipment on loan from MND Victoria during business hours over period, 27-29 December. If you have any problems with equipment on loan from MND Victoria during the Christmas-New Year holiday period, please phone Calvary Health Care Bethlehem on: (03) 9595 3485

**Get Ready to Rock Off MND in 2018!**

20 January 2018 at Deakin Waterfront, Geelong

Lead act Kate Ceberano! Tickets online at: www.rockoffmnd.com.au
**Volunteer opportunities**

**Travel reimbursement is offered to all volunteer roles**

**Massage – Volunteers needed in the following areas:**
Bendigo, Bundoora, Campbellfield, Caulfield, East Melbourne, Elsternwick, Essendon, Noble Park, Seddon, St Kilda, Whittlesea

**Time required:** 2–3 hours per week/fortnight

**Preferable day:** Dependent on client

**Duties include:** Visiting client in home to provide gentle hand and foot massage

**Essential skills:** Good communication skills, enjoy working with people

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**Hairdresser/s**

**Hairdressing volunteers are needed in the Melbourne Metropolitan Area:**

**Time required:** As required

**Preferable day:** Dependent on client

**Duties include:** Visiting client in home to provide a haircut

**Essential skills:** Excellent interpersonal skills, enjoy working with people, must be a qualified hairdresser, must have valid driver’s licence and roadworthy vehicle, must have own equipment, willingness to travel outside home suburb area (negotiated).

*If you are interested in applying for any of these positions, please phone Deb, our Volunteer Coordinator on: 03 9830 2122*

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*AND thank you for all your hard work at our Walks!*
In 2017, our 133 volunteers contributed a total of 6,865 hours of support to our work.

Coordinator Volunteer Programs

We are delighted to introduce Deb (Debra) Olive, our new Coordinator Volunteer Programs. Deb has recently relocated to Melbourne from Queensland.

Deb has many years’ experience working in community, government and private sector organisations managing, coordinating, training and supporting volunteers. She is an experienced volunteer program manager with significant experience working with paid and unpaid staff and comes with glowing references.

Welcome Deb!

The Chrysallis

This gruesome gargoyle that u see
Is just a shell that's grown on me
But searching deep you will soon spy
The beating wings of a butterfly

A butterfly, now, wings clipped fast
Unable to fly
Its freedom past
No longer ever flying high
Or blown in the wind
Now to weep or cry

But one day soon that cocoon will split
And of this earthly life I'll quit
Those wings of turquoise blue will soar
And take to the heavens once more.

This gruesome gargoyle that you see
Is just a shell that grew on me
I never dreamed that I would be
A victim of dreaded MND

A dose of flu was all it took
My immune system badly shook
The doctors couldn't find the CAUSE
My voice just went so strangely hoarse

Down to Geelong and more tests done
An Indian Doctor was the one
Who told us that laughing hysterically
Is one of the symptoms of MND

AND it was!

Poem by Pamela Bruce
In November MND Victoria ran an MND Seminar for health and community professionals in Bendigo. The seminar was titled “MND – The Community Responds” and it lived up to its name as it sold out prior to the event!

The seminar featured a range of MND experts from statewide and local providers Calvary Health Care Bethlehem, Austin Health, Bendigo Health and Goulburn Valley Health. Over 80 people attended ranging from nurses, occupational therapists, speech pathologists, physiotherapists, case managers, physicians, students, people with MND and carers.

The program included engaging presentations and lively discussion particularly during the National Disability Insurance Scheme and practice case scenario panels.

Feedback from the day included:

“I really enjoyed the panels which gave us the opportunity to ask questions, and the information related to cognitive change, respiratory change and the personal perspective.”

“I enjoyed the overview of MND, cognitive and respiratory aspects as I came in to this course with limited knowledge in these areas. I found the guest speakers very informative and the content interesting.”

“Great venue. Good food. Good pace. Interesting speakers and plenty new material to get our head around.”

MND Victoria would like to thank all those who took part in the day, particularly our guest presenters.

“The (most valuable aspect of the seminar was the) relevance of all topics and information covered over the day to our practice in a regional service working with people with MND. All information was well enforced by the case studies and the expert panel at the end of the day. Thoroughly enjoyed the day excellent presentations and very well organised.”
Trek Kokoda with MND Victoria in 2018!

Email Daniel: dwoodrow@mnd.asn.au to receive our Information Pack!

“Happy to announce that Aug 26 next year I’ll be joining @mnd_vic to trek Kokoda on a fundraising mission. I’ve always wanted to experience the Kokoda trail and even better that I get to do it with such a great organisation.”

Dale Vine, Former ‘The Block’ Contestant

**Fast Facts:**

Dates: 26 August – 4 September 2018

Total trip cost: $5,650 Ex Melbourne

Package includes:

- Registration Fee: $1,500 (non-refundable)
- Travel & Accommodation

Fundraising Target: $5,000

Trip Duration: 9 nights. 10 days. 7 nights are spent on the track.

Minimum Age: 18 (younger ages considered on application)
My Story about MND and how it has effected my life

I guess that before I talk about MND I need to write a bit about my relationship with my sister, Sue.

I am the youngest of three, Sue was 4 years older than me, and my brother, Jeff, is 2 years older.

Sue and I shared a rare sibling relationship, we never ever fought and we were extremely close. Sue introduced me to the sport of water skiing and we would holiday together every summer, skiing behind a boat that we jointly owned.

Sue never had any children of her own, though this was not due to anything medical. This in itself is a tragedy as she would have been an awesome mother. She was extremely close to my two children and was more than just their Aunty, she was like a surrogate mother to them both. This was also the case with my brothers’ children.

I was fortunate to have grown up in a family that was extremely close and family orientated. We would all get together for lunch on Saturday and dinner one night a week, usually on a Monday. This was never seen as a chore as we all loved spending time together and enjoyed our grandmother’s great cooking. How lucky were we that we could be spoiled in such a loving environment?

Sue started up a business which grew to be huge. My mother and father along with myself worked in the business and all the kids would come and help during the school holidays. The business was selling lingerie through party plan and consultants would join to sell the product. This was Sue’s “baby” and she put her heart and soul into making it a success. I was extremely proud of her achievements and felt that I was the luckiest lady alive as only I could say that I was Sue’s sister.

Sue’s company is still active today with over 2000 consultants Australia wide. (I refuse to name this company for personal reasons).

Now my introduction to MND

I remember the first time I ever heard the words “Motor Neurone Disease”. Sarah Ferguson, the then Duchess of York, spoke of MND. I can’t remember her association but either a family member or friend passed away and she spoke of this. I remember thinking at the time that it was a strange name for an illness as I had no knowledge of Motor Neurones and how they controlled muscles in our body.

I never really thought about MND after this one time. Until…….

As I have already mentioned I worked for Sue. I worked in the warehouse which was in a separate building to where the offices were. One day I went across to the offices to speak to Sue about some work-related matter. She was standing in the foyer with two of her colleagues and was massaging her left hand between the thumb and first finger. I asked her what was wrong with her hand and she replied that she was having issues with her muscle and that her hand was a bit weak. I didn’t think much of this as it seemed to be a minor issue.

Months went by and I noticed that her hand had not seemed to improve at all. When I asked her about it, she told me that she was seeing a specialist and that they were looking at different diagnoses. I still did not know much about MND at this time but just the fact that Sue used the word “sinister” put the fear of God into me. As close as I was to Sue I used to dread every time she would phone me as I was scared of what she might say. To put this into perspective, Sue did not have to phone me often as I would see her on an average of 4 – 5 times a week, so if she did phone, it was always for a very important reason.

After seeing specialists over a period of about one year, finally the cruel diagnosis came through. Sue had MND and there is NO CURE. My beautiful sister had just been given a life sentence at the young age of 54. She was told that in three years she would either be dead or significantly disabled. Sue was never one to give up and she was not prepared to do so now. She considered herself fortunate that she was in a financial position to look
for alternative treatments. She spent hours with a personal trainer where she would stretch and ride an exercise bike for 5 or so minutes and walk on her treadmill. Her biggest goal at this stage was to recover sufficiently to be able to wear her high heels once again. She was like an Australian version of Imelda Marcos and had a huge wardrobe of the most stunning shoes.

Sue never gave up hope and at some time during her illness she was told that she might in fact have Multifocal Motor Neuropathy, a progressive muscle disorder characterized by muscle weakness in the arms and hands, which made sense as her illness had originated in her hand. As opposed to MND, MMN is not a terminal illness. This gave us all a little ray of hope. Sue was subsequently sent off to have treatment at St Vincent’s Hospital in Melbourne where she had intravenous immunoglobulin therapy. She was told that the only way this diagnosis could be confirmed was if the treatment was successful. I went to most of these treatments with Sue and I will never forget the joy we both felt when one of her fingers started to spasm during a treatment. We both believed that this was a sign of improvement and that she really did have MMN. Sadly, this joy did not last long, there were no more signs of improvement and we were told that the spasms she had felt were a one off and not due to the treatment.

Sue saw herself as fortunate that she was in a position to travel the world to seek alternative treatments. Her first treatment was to travel to Cologne in Germany where she sought stem cell treatment. She found out that her body was extremely toxic so all of the stem cells were killed off. She then travelled to a small village in China for a few weeks where she had acupuncture, remedial massage and a cocktail of Chinese herbs. Unfortunately, this also was ineffective.

Still Sue never gave up. She believed that her illness was potentially not incurable and that she could find a way to stabilise and manage her “condition”. She felt that as long as she could still walk and talk she would be able to fight MND every day. I too believed that if anyone could beat this disease, it would be Sue.

As time went on Sue continued to do most of the things that she loved. She went to work every day, driving herself there for as long as she could. She travelled overseas for her work and continued to attend all of the monthly meetings that were held at every capital city in Australia. She loved to spend time with the consultants that attended these meetings and she considered herself lucky that she had such a large “family” whom she loved and who all loved her back.

Not once did I ever hear her complain, feel sorry for herself, or ask why she was given this debilitating illness. I was amazed at her strength and resilience.

As time wore on it became evident that MND was going to win this fight. I hated the thought that I was going to lose my sister, this person that I had always looked up to as my role model and mentor; someone who had always taken such good care of her health and her fitness. I watched her grow weaker and weaker and the weight was just falling off her. This bright vibrant lady was wasting away to just a tiny fragment of herself but still she managed to smile and crack the odd joke here and there. She also said that there would be no way she would ever rely on a wheelchair, that she was going to walk one way or another without having to sit in a chair.

When the end came near, Sue was admitted into intensive care at Cabrini Hospital in Malvern. Finally, and sadly, Sue accepted the fact that she was dying and there was no way she was going to recover. After spending only one day in hospital she told me that she did not want to die here and that she wanted to go home. I spoke to the head of the ICU and he promised that he would do what he could to uphold her wishes. This incredible man managed to put together a team of three medics; one palliative care doctor, one palliative care nurse and an ICU nurse to accompany her. On Thursday, 27th October 2011, after spending only 4 days in intensive care, Sue came home. She was met by her family and closest friends and work colleagues. We all sat with her in her sun filled family room and told her stories of times we spent with her and what she meant to us all. Sue passed away peacefully knowing that she was loved and had been an important part of so many people’s lives.

Sue had many mantras in her life, one was to believe in yourself, another was to never jeopardise your integrity. She was an extremely passionate lady and had an abundance of dignity. I will love her forever and try always to live by her mantras so that she will always be proud of me.

I LOVE YOU SUE AND MISS YOU MORE THAN WORDS CAN SAY.
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 and speak to David Kerley.

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 Angels 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/

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
- MND Victoria - (03) 9830 2122  
  www.mnd.asn.au

“Icky, Sticky Saliva”

Practical Tips on How to Manage Saliva Changes in MND

- Is your saliva **too thick**?
- Is your saliva **too thin**?
- Is your saliva **too dry**?
- Is your saliva **too thick** or **phlegmy**?

There are solutions!
Come along to an education session presented by the Speech Pathologists at Bethlehem Hospital.

What will the session include?
- Practical advice on how to manage your particular secretion changes
- Demonstration on how to use a nebulizer
- The benefits of dark grape juice on secretions
- And much more!

Who should attend?
Clients and their families and/or carers who are interested in practical tips and strategies on how to manage saliva changes.

When/Where?
Tuesday 30th January 2018.  1.00pm -2.00pm
Magnolia Cottage, Calvary Healthcare Bethlehem
476 Kooyong Rd. Caulfield 3162
RSVP: Speech Pathology Department, Phone: 9595 3327
www.bethlehem.org.au

MND Victoria are now on Instagram!
Follow us: @mnd_vic
www.instagram.com/mnd_vic
Research update

**Vale Graeme Bertuch**

It is with much sadness that we report that Graeme Bertuch OAM died from motor neurone disease in November 2017.

Graeme had a varied and interesting career in the medical field, spending 38 years of his career in Ararat as a very highly regarded General Practitioner. Graeme was also a viticulturist, owning a vineyard with his wife Carolyn.

In 2016, Graeme was awarded the Medal of the Order of Australia for his service to medicine and the community.

Diagnosed with motor neurone disease in 2014, Graeme was quick to offer his services to MND Victoria in any way he could help.

We asked Graeme to write the MND Research Updates for MNDnews. Graeme’s medical background gave him a good understanding of the complex research being undertaken in this area and he would write each edition to help others understand the latest developments.

Graeme had a great sense of humor and was very creative; we particularly enjoyed his series of interviews with MND researchers and clinicians.

*This is Graeme’s final article:*

**TRIALS AND TRIBULATIONS!**

Let’s take a look at some PRECLINICAL and CURRENT TRIALS of medication being offered to patients with ALS/MND to understand the thinking of researchers and in which direction they are heading.

**ANTIRETROVIRAL**

The first we will look at is treatment for ‘fossil’ genes, thought to be part of our genetic makeup for millions of years and introduced by retroviruses. A retrovirus is a single stranded RNA virus that invades the host cell and uses its own enzymes to introduce DNA into the host cell. Because this is the reverse of what usually happens it is prefixed with retro. HIV is a modern example of one of these invading retroviruses. These “fossils” called HERV’s [Human Endogenous Retroviruses] were thought to be inactive, as it was thought that they had become defective or mutated over millions of years. They comprise up to 8% of the human genome. There is now evidence to suggest they are not inactive. HERV-K has been found in the brains of patients with ALS/MND and has been directly linked to motor neurone damage. This HERV gene can jump from one part of the genome to another and replicate itself. It ultimately causes disease by making abnormal proteins and then possibly triggering ALS/MND.

There is a study being done in Australia called the Lighthouse Project which is trialling an antiretroviral drug, Triumeq, to see if it can change the quality of life of patients affected by ALS/MND, looking at changes to respiratory and muscle function. Biomarkers are also being measured. The markers P75 and NfL [neurofilament-light chain] have been found to be higher in patients with ALS/MND than in normal controls. These will help to establish whether Triumeq has a positive effect.

**IMMUNOTHERAPY**

A trial of Interleukin-2, which is a form of immunotherapy, has been investigated in France and the UK in a study called MICROCAL. This treatment is usually used to treat cancer [metastatic melanoma and metastatic kidney cancer] by using the immune system. One particular immune cell called a Regulatory T Cell or Treg is thought to play a part in helping to protect nerve cells against damage. The drug Interleukin-2 can increase the levels of T cells in the blood and might be able to protect motor neurones in ALS/MND by reducing inflammation. In this trial lower doses were used, which were expected to alter aspects of the immune system without the side effects experienced by cancer treatment, and then to see if the progression of ALS/MND was altered. Biomarkers will be used to see if the inflammatory
response in the nervous system is modified. The project will be completed in 2019.

COPPER THERAPY
Trials are underway in Melbourne and Sydney with the copper containing compound Cu-ATSM. This is a molecule which for many years has been used in imaging tissues, including the brain, which aren't receiving sufficient oxygen [hypoxic tissues]. Scientists found that it had the ability to deliver copper safely to cells in the body and that copper could prevent the malformation of proteins known to cause neurodegenerative diseases such as ALS/MND. SOD1 protein mis-folding is one of the genetic related causes of ALS/MND. The compound Cu-ATSM was found to extend the life of genetically modified mice to a significant degree. Although mutant SOD1 related disease is only a small fraction of the total causes of ALS/MND in humans, mainly in the inherited disease, the trial will test the reaction in sporadic ALS/MND as there is some evidence to suggest Cu-ATSM will work in all cases.

ANTIOXIDANT
In May, the FDA, the organization that approves drugs for use in America, granted a licence for the drug known as Endaravone [trade name Radicava] for the treatment of ALS/MND. Initially developed as a drug to treat strokes, it has been re-invented for treatment of motor neurone disease. It is an antioxidant drug that works by mopping up “free radicals” in the body, in this instance from the mitochondria [powerhouses of the cell nucleus] in motor neurons. In some clinical trials, Endaravone had been found to slow the progression on ALS/MND, potentially helping people preserve function for longer. The drug is administered intravenously every day for 2 weeks before a two week break. This is repeated indefinitely. Initial studies on the drug did not show any significant benefit, but then a small group was examined within the study who appeared to gain some benefit. These people had ALS/MND for less than 2 years and their disease hadn’t progressed very much. This group represents about 7% of sufferers. The drug has currently not been registered for use in Australia.

ANTIEXCITATORY
Although not subject to any specific trials, Riluzole is included to represent an antiexcitatory/glutamic acid inhibitor. Riluzole is the only drug that can be prescribed in Australia for ALS/MND and has been so since the1990’s. Riluzole has neuroprotective, anticonvulsant and sedative properties and acts by inhibiting the release of glutamic acid from the motor nerve endings thereby reducing overstimulation which leads eventually to death of the motor neuron. Riluzole [100mg daily] is reasonably safe and probably prolongs median survival by 2-3 months.

OTHER NOVEL DRUGS
Over the last few years other drugs have been trialled such as GM604, a peptide which appears to be a neurotrophic factor. Neurotrophic factors play a crucial role in the development of the nervous system and there have been studies of their potential for treatment of ALS/MND. They have been effective in keeping neurons in a dish alive and also in mouse models of neurodegenerative disease but not been demonstrably effective in clinical trials in humans.

PMX205 is a novel drug which blocks a key component of the nervous system involved in inflammation. The complement C5a is thought to speed up the death of motor neurones. PMX205 is an inhibitor of C5a and dampens down inflammation. Research at the University of Queensland has shown slowing of the disease progression in mice which helps the case to take PMX205 towards further clinical trials which are expected to start in late 2018.

Another Queensland initiative has found that a protein called EphA4 plays a role in delaying the repair of damaged neurones. Researchers are looking to develop an EphA4 inhibitor which could be effective in treating ALS/MND.

Lithium was also trialled in 2008 in Italy. Some studies showed a reduction in disease progression but this was not born out by larger studies in the UK and USA. However, a recent review of the studies has found that lithium can improve survival in a small subgroup of people with a gene that is found to enhance survival [UNC13A]. Having this gene increases the probability of one year survival from 40% to 70%. No influence was found in people with the C9orf72 gene.

Small studies in isolation can throw up misleading results and findings on drugs such as GM604, PMX205 and EphA4 need to be reproduced on a large scale over a significantly long time period to establish whether there are any beneficial effects and no significant side effects.
TRIBULATIONS - ARE MOST PUBLISHED RESEARCH FINDINGS FALSE?

Earlier this year Duncan Bayly [MND Vic Board Member living with MND] sent me an article first published in 2005 by J P A Ioannidis which stated that most published research findings are false. This article had caused Duncan some concern. The paper was based on the premise that most research articles do not reach formal statistical significance. “There is increasing concern that in modern research false findings may be in the majority of published research claims. It can be proven that most claimed research findings are false”. This question has significance for the MND “community” as a lot of research is being done giving much hope to the MND affected that treatment is attainable. Do we ask the research community about this hypothesis? If we do and they agree with the paper, then they would necessarily doubt the veracity of their own research. Apart from the statistical proof to support the leading statement, other reasons or corollaries were also advanced. I won’t mention all of them but some will ring a bell.

1. The smaller the studies conducted in a scientific field, the less likely the research findings are to be true.

2. The smaller the effect size, the less likely the research findings are to be true.

3. The greater the flexibility in the way the research is set up [designs, definitions, outcomes] the less likely the research findings are to be true.

4. The greater the financial and other interests and prejudices in the scientific field, the less likely the research findings are to be true.

5. The “hotter” a scientific field [with more teams involved] the less likely the research findings are to be true. This point may explain why we occasionally see major excitement followed rapidly by severe disappointments in fields that draw wide attention. This has certainly been noted in the MND field of research. With many teams working in the same field and with massive experimental data being produced, timing is the essence in beating competition. It must be said, however, that there seems to be international connectivity and sharing in the MND research community that could mitigate this corollary.

So has Duncan cause to be worried? I suppose only time will tell, but given that after intensive research in the last 30 years we are no closer to having a significant treatment despite great strides in identifying the genetic basis of MND: then it is right to ask the question.

Research opportunities

People with MND - call to arms!

The Fight MND Drug Screening Program

We are pleased to inform you of an exciting opportunity for MND patients to directly contribute to helping find a cure for MND.

Earlier this year, FightMND announced its support, together with the Victorian State Government and the Balcon Group Pty Ltd, for a world-first MND Drug Screening Program using MND patient’s own stem cells and motor neurones grown from a simple skin biopsy. The Program is an initiative of the Motor Neurone Disease Laboratory at The Florey Institute of Neuroscience and Mental Health in Melbourne.

The Florey is now pleased to announce a call for volunteers for people with MND to contribute to the FightMND Drug Screening Program. Australian residents diagnosed with MND who are willing to travel to Melbourne to donate a skin and blood sample are invited to register.

The research will examine skin and blood samples from 155 people with MND and 30 controls in this phase of the project. The processing of samples must be completed within 24 hours of them being taken, so sample collection will take place at Calvary Health Care Bethlehem in Melbourne. The program calls for 25 people to donate samples per month.

The process of donating your skin cells is quick, easy and will directly help the team at the Florey to screen thousands of drugs to hopefully identify new potential treatments as soon as possible. Here’s your chance to help cure MND!

To register your interest in participating in this world-first drug screening program, visit the Fight MND website: www.curemnd.org.au/drug-screening-platform

For more information please visit MND Australia’s website: www.mndaust.asn.au/drugscreening

This project has been approved by the University of Melbourne Ethics Committee and all information
As medical tourism has grown around the world, so have the number of the reports highlighting the adverse outcomes from undertaking medical care abroad. Health and safety risks associated with medical tourism have become a major concern to researchers, medical professionals and policy makers worldwide. Due to a scarcity of empirical research on medical tourism, your participation is invaluable in highlighting what patients have experienced following travel to another country or jurisdiction.

If you have any inquiry into our study, please contact us:

**Chief Investigator: Professor Alan Petersen**
School of Social Sciences, Faculty of Arts,
Phone: 0420772356
Email: alan.petersen@monash.edu.au

**Second Chief Investigator: Dr Maho Omori**
School of Social Sciences, Faculty of Arts
Phone: 0415140838
Email: maho.omori@monash.edu.au

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**Can you write your MND story for our next newsletter?**

Please email to: info@mnd.asn.au by 10 January for our next edition.
Awareness & Fundraising

While we are living in the present, we must celebrate life every day, knowing that we are becoming history with every work, every action, every deed. Mattie Stepanek 1990-2004 (Mattie was described by President Jimmy Carter as "the most extraordinary person whom I have ever known").

It’s amazing to realise that 2017 is almost over! Where did the time go? Every day at MND Victoria seems to be busier than the last!

While there’s a lot of excitement in the build up towards Christmas I’m reminded how important the annual Walk to D’feet MND events are to our MND Community. These events provide a place and time to remember loved ones who have died from the disease, support those who are currently living with the disease and help fund research into cause, treatment and cure. While the Melbourne and Bendigo Walks are very difficult times for many of our Newsletter readers and supporters, these events provide significant income for MND Victoria ensuring that people diagnosed with MND have access to care and support so vital to their continued participation in family and community activities.

Recently I was privileged to talk with Rob who shared with me how he and his partner Liz got through the nine months of Liz’s MND journey. Like so many people with MND, Liz wanted to stay living at home and that’s where she also wanted to die. Thankfully, with the support of MND Victoria, Liz died peacefully at home in Rob’s arms. You can read Rob and Liz’s story on our website at: www.mnd.asn.au

You will see from Daniel’s “Fundraising Round-Up” a lot of people have been working very hard to raise awareness and funds for MND Victoria. We can’t thank you enough for your efforts which will become a part of the history of MND Victoria.

I do hope that this Christmas you can share happy memories with family and friends of your loved ones who have died from or who are currently living with MND. And can I please encourage you to continue supporting MND Victoria because Until there’s a Cure .... there’s Care.

Kathy Nightingale
Manager Fundraising

Celebration of Champions

In April we will be holding a Celebration of Champions lunch to thank everyone who has raised over $2,000 through one of our Walk to D’feet MND events in 2017-2018.

Keep an eye out for your invitation early next year.

Around the State

Portland Live Auction Night

Portland Football Netball Club was host of The Sisters and Brothers United Live Auction fundraiser on Saturday the 28th of October.

140 people were in attendance for the evening’s festivities which included live music, delicious canapes, a very popular and busy bar and of course, the Live Auction. There were so many incredible items that had been donated by local individuals and organisations. Once the auction got underway there was some very competitive bidding which was quite entertaining at times and, of course, very beneficial to the cause.

Throughout the whole event it was very evident that so many people cared about the cause and were incredibly generous.

At the end of the night $39,704 had been raised for the Sisters and Brothers United team which goes towards their annual donation to MND Victoria!

A special mention goes to the ETU - Electrical Trades Union of Australia, Victorian Branch, who donated $25,000 on the night! They have been absolutely amazing with their support of the team over the last couple of years!
Lakes Entrance Walk to D’feet MND

The walk season kicked off down in Lakes Entrance on a perfect spring day on October the 1st. The organising team, led by Danielle, put on another fantastic event. There was an enthusiastic stretching session to start the day, face painting for the kids, an ice bucket challenge and much more! Everyone had a great time and the total amount raised was in excess of $10,000. Well done to everyone! There is something special about the walks in regional Victoria. The community certainly get behind them and create an atmosphere you just want to be a part of!
Melbourne Walk to D’feet MND!

The 2017 Melbourne Walk to D’feet was, once again, a great success. The lovely weather meant that everyone could enjoy meeting up with family and friends before and after the Walk. Our newest addition to the Walk, Razor the Raptor, was a big hit with children and adults alike. A full report on the event will be published in the next Newsletter but in the meantime check out some of our photos.

More photos can be seen on our Facebook Page: www.facebook.com/MNDVic #NeverGiveUp
Discover Parks Echuca-Moama Ice Challenge for MND

SARAH Pagram-Waters knows all too well the impact of motor neurone disease. After her father was diagnosed with the terminal illness earlier this year Sarah said working full-time at Discovery Parks Maidens Inn Moama was difficult.

Sarah found the motivation to create an event within her local community to raise funds for MND. Her workplace became the host of a Twilight market at the start of October. There were around 20 different stalls, food trucks, face painting and an ice dunk challenge where all the staff got dunked into a huge ice bucket. That’s a lot of very cold people! In the end $6941 was raised. An incredible result and a huge congratulations and thankyou to everyone involved.

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
Donations were received

Donations were made in memory of:
Arie Domburg
Brian Grau
Daniel Martinez
Geraldine Kelman
John Bountino
John Hammond
Jenny Morgan
John Ray
Ken Grubb
Ken Nathan
Liugina Ciuffetelli
Michael Northwood
Marie Retallick
Mick Taylor
Mark Zacharias
Peter Bennett
Pat Direen
Robert Kraal
Sebastian Caccamo
Sue Sweeney
Paul Thorne
Martin Williams
William Berry
Christine Handson
Peter Andressen
Ken Mckenzie
Alan Phillips
Graham Henry
Jean Lincoln
Giuseppe Piraina
Lindsay Murphy
Ian Ballantyne
Lucia Sassano
Jane Hall
Edna Gritty
Justin Penny
Kay Andrews
Josephine Phillips

Trust and Foundation Donation
Support Group Donation
Lilydale Masonic Lodge NO 108
Lions Club of Geelong Inc
Dana Street Primary School
Dandenong Ladies Probus Club
Belgrave Football Club Club
The Wonthaggi Club
Glen Iris Primary School
Belvoir Special School

Equipment Donation
Colleen Egan
Georgia Dacakis
Sally Edwards

Group Donations
Barwon Regional Support Group

Bequest Donation
Estate of late Dorothea Dunlevie

Corporate Donations
Edgewise Insurance Brokers
Ritchie’s Supermarket
Pet Stay
Specsavers Pty Ltd
Blue Bike Solutions

Christmas cards 2017!

Phone: 03 9830 2122 to order!

Only $6.50 per mixed pack of 10 cards!
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

<table>
<thead>
<tr>
<th>Date</th>
<th>Description</th>
<th>Contact/tickets</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tuesday, 13 February 2018</td>
<td>Ocean Grove Rotary Club MND Event</td>
<td>Email: <a href="mailto:fundraising@mnd.asn.au">fundraising@mnd.asn.au</a></td>
</tr>
<tr>
<td>Sunday 25 February 2018</td>
<td>Benalla Act to D’feet MND</td>
<td><a href="http://www.act2dfeetmnd.com">www.act2dfeetmnd.com</a></td>
</tr>
<tr>
<td>Friday, 9 March 2018</td>
<td>MND Golf Day, Mandalay Golf Course</td>
<td><a href="http://www.trybooking.com/SXDV">www.trybooking.com/SXDV</a></td>
</tr>
<tr>
<td>30 March—2 April 2018</td>
<td>Wangaratta to Melbourne Run</td>
<td>Email: <a href="mailto:fundraising@mnd.asn.au">fundraising@mnd.asn.au</a></td>
</tr>
<tr>
<td>Sunday 6 May 2018</td>
<td>MND Week 2018 begins</td>
<td>Email: <a href="mailto:fundraising@mnd.asn.au">fundraising@mnd.asn.au</a></td>
</tr>
<tr>
<td>Friday, 11 May 2018</td>
<td>Blue Cornflower Day</td>
<td>Email: <a href="mailto:fundraising@mnd.asn.au">fundraising@mnd.asn.au</a></td>
</tr>
<tr>
<td>Monday, 21 May 2018</td>
<td>National Volunteer Week begins</td>
<td>Email: <a href="mailto:info@mnd.asn.au">info@mnd.asn.au</a></td>
</tr>
<tr>
<td>Thursday, 21 June 2018</td>
<td>Global MND Awareness Day</td>
<td>Email: <a href="mailto:fundraising@mnd.asn.au">fundraising@mnd.asn.au</a></td>
</tr>
<tr>
<td>26 August—4 September 2018</td>
<td>Kokoda Trail 2018</td>
<td>Email: <a href="mailto:dwoodrow@mnd.asn.au">dwoodrow@mnd.asn.au</a></td>
</tr>
</tbody>
</table>

For further information and the latest events list, please visit our website: [www.mnd.asn.au/whats-on/](http://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](mailto:funraising@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)