MND NEWS

september/october
2018

The newsletter of the Motor Neurone Disease Association of Victoria

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

INSIDE THIS EDITION:

mnd
Victoria

www.mnd.asn.au

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MND Victoria

265 Canterbury Road (PO Box 23)
Canterbury VIC 3126

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

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

Facebook: www.facebook.com/MNDVic
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ABN 44-113-484-160

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SUPPORT GROUPS

Western Metro

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

Barwon Region

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

Ballarat Region

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

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Information & Resourcing Officer: Sarah Wilkie

FROM THE CEO

The year is well under way and we have taken the leap into spring – hopefully the weather will catch up soon!

Most of the MND Victoria team were in Adelaide recently for the biennial **Support Services Meeting** and the **9th National MND Conference**.

The Support Services meeting was excellent, with all attendees sharing their successes and failures in dealing with the transition to the NDIS. I must say that the leadership provided by MND Australia, MND NSW and MND Victoria in prosecuting issues that were inhibiting access to the NDIS has been a significant contribution to the experiences of us all. That is not to say that all problems are solved, however there are fewer of them and we are on a faster track to have the remaining obstacles addressed.

It is also great to witness the care and support the Support Services teams have for each other, and the increased communication between teams. This will continue in the months ahead.

Similarly, the National MND Conference was excellent with a wonderful range of speakers addressing MND topics. These presentations are now available at: **www.mndaust.asn.au/News-and-media/Summary-of-the-9th-National-MND-Conference** All up, two great meetings focussed on MND and improving services.

The **Annual General Meeting** is coming up and those eligible to vote ie members of MND Victoria, will be receiving notification of the event, applications for postal voting, and a copy of the 2018 Annual Review. The Annual Review is also on **www.mnd.asn.au**, and the audited financials will be available at the AGM. They will also be uploaded to the website.

We have invited **Assoc Professor Bradley Turner** to address the AGM to speak about his MND research, which focuses on producing motor neurones from skin biopsies from people with MND by extracting stem cells and converting them to motor neurones. They will then use an automated testing process to see if any of the 50,000 currently available and approved drugs have an effect on the motor neurones. The aim is to enhance the identification of drugs for possible personalised medicine.

The **2018 Walk to D'feet MND** calendar kicks off on 4 November at The Village Glen, Rosebud. Register on site on the day. For information on all our Walk to D'Feet events, including our biggest Walk on **18 November at Princes Park**, check out our website: www.mnd.asn.au/events/walk. These are fantastic events and I look forward to seeing you at one of these.

Keep safe and don't forget the sunscreen as the warmer days roll out. Until next time, **Rodney Harris**

INFORMATION SESSIONS

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

At 7pm on Wednesday, 24 October at MND Victoria, 265 Canterbury Road, Canterbury.

Please RSVP by 5pm, Monday, 22 October.
Phone: (03) 9830 2122, 1800 806 632 or
Email: info@mnd.asn.au

The following session will be held on Thursday, 6 December at 7pm in Canterbury.

SUPPORT SERVICES

This is my first newsletter contribution since joining the organisation as the Support Services Manager in mid-July. I am thrilled to be joining an organisation that provides such great support to the people it serves.

I was very lucky to have a month's handover period with Julie McConnell, the outgoing Manager, which has assisted me enormously in quickly settling into the role, and I extend huge thanks to her. She has done a fabulous job in building a wonderful team and developing services to support people with MND over the 10 years that she has been in the role. I wish Julie all the very best in her retirement.

To tell you a bit about myself, I studied Occupational Therapy in Adelaide (quite some time ago!). After qualifying, I lived and worked overseas for over 20 years, returning to Australia in 2010 and settled in Melbourne with my family. Since returning, I worked at MS (Multiple Sclerosis Limited) for 6 years managing some of their support services including Information Services, Education, Peer support and Volunteer programs. I also worked for 18 months at the Brotherhood of St Laurence managing the NDIS Local Area Coordination (LAC) roll out in two Local Government areas in North East Melbourne. Immediately prior to joining MND Victoria, I worked for Young People in Nursing Homes National Alliance, doing some project work funded by the Dept. of Health and Human Services, looking at the interface between health and disability services.

The disability and aged care spaces are ever changing and presenting new challenges in how people receive supports and services. We are working hard to ensure we keep abreast of the changes in order to support people with motor neurone disease.

The **2018 National MND Australia Conference** and **National Support Services Day** held on the 30th and 31st August were a great opportunity for the team to meet staff from all of the other State Associations, share best practice and keep abreast of new issues in research and practice. Twenty of us headed over to Adelaide for the conference and have returned to the office with ideas on how to improve the way we work and the services we offer.

Following is a snapshot of some of the key achievements/activities by our Support Services Team since our last newsletter:

1. **Alison Jones, our Coordinator of Information and Resourcing** is on the Steering Committee which is reviewing the curriculum of the personal carer training about non-invasive ventilation (NIV). This will be hugely beneficial in ensuring that the needs of people with MND will be considered in this vital training.

2. **Our three newest MND Advisors**, Melissa Kettle, Fran Hurst and Rachel Ritchie are settling well into their MND Advisor Support Coordinator roles and have been getting to know all of the clients in their areas.

3. Our **Equipment Service Team** is consistently issuing over 200 pieces of equipment a month from our equipment library.

4. We are thrilled to have been able to purchase a number of **iPads** which can be provided to people with speech difficulties or to those who live remotely to assist in enabling communication with key people that are supporting them – family, friends and health professionals. Speak to your health professional or your MND Advisor if you are interested.

NDIS update

Soon we will not need to include these updates in the newsletter as the NDIS will be fully "rolled out" in Victoria by June 2019!

The regions left to phase into the NDIS are:

- Southern Melbourne – from 1 Sept 2018
- Western Melbourne – from 1 Sept 2018
- Brimbank Melton – from 1 Oct 2018
- Goulburn, Outer Gippsland and Mallee - from 1 Jan 2019.

Please talk to your MND Advisor or call our Information Line if you have any queries about accessing the NDIS.

I am looking forward to learning more about the organisation and meeting many of you over the coming months. In the meantime, please don't hesitate to get in touch if you have any feedback.

Jo Whitehouse, Manager Support Services

NATIONAL MND CONFERENCE: MND CARE INFORMING, INFLUENCING, INNOVATING

By Alison Jones, Coordinator Information & Resourcing

'MND Care: Informing, Influencing, Innovating' was the theme for the 9th National MND Australia Conference held in Adelaide on 31 August 2018. Over two hundred delegates from various organisations around the country attended to learn more about a range of issues related to MND.

David Ali, the National President of MND Australia, provided a warm welcome and introduction followed by the Honourable Stephen Wade, MLC, the SA Minister for Health and Wellbeing, who officially opened the conference.

The program commenced with presentations from **Nicholas Bowman** and **Greg Downton** who each have MND and provided their personal perspectives on living with the disease. Both were compelling speakers who shared openly and honestly about the struggles and challenges they face on a daily basis.

Susan Mathers *(photo right)*, Consultant Neurologist at Monash Medical Centre and Clinical Director at Calvary Health Care Bethlehem in Melbourne, was the first keynote speaker and she discussed the importance of patient-centred care when dealing with a progressive neurological disease such as MND.

INFORMING

Sarah Solomon, Occupational Therapist (OT) from Calvary Health Care Bethlehem, works with people with MND on a daily basis and has had a member of her own family diagnosed with MND. She spoke about adjusting and adapting to rapidly changing function and her presentation illustrated how skilled and innovative OTs are in dealing with the constantly evolving needs of people with MND.

Samar Aoun, *(photo page 6)* Professor of Palliative Care from the School of Psychology and Public

Health at La Trobe University, was another keynote speaker and she touched upon a number of research projects which support the integration of a palliative approach early in the management of a person with MND. Palliative care is concerned with maximising the quality of life for someone with a life-limiting illness and their family.

Mark & Jenny Whitley, Social Workers from MND Queensland and Ozcare respectively, jointly presented on having the difficult conversations with people with MND regarding end of life care. The importance of planning ahead was emphasised, as leaving these discussions until later when a person's disease has progressed may result in them being less able to participate in important conversations and decisions.

Mary-Anne Vass, Registered Nurse also from Calvary Health Care Bethlehem, presented on identifying patient / client needs early via a triage call. This enables planning to be undertaken in advance to anticipate needs and ensure they are met.

Christine Batten, Social Worker from the Tasmanian Health Organisation Palliative Care Service, talked about fostering a multidisciplinary team approach to MND. Many different health professionals are involved in caring for someone with MND and this has been shown to enhance the quality of care delivered.

Samantha Mitchell, Speech Pathologist from Goulburn Valley Health, spoke about providing a regional approach to MND care and identified challenges such as distance that can adversely impact on the ability of health professionals to provide optimal care.

INFLUENCING

Anna Connolly, Occupational Therapist from Northern Health, addressed issues pertaining to the National Disability Insurance Scheme (NDIS). This Australian Government initiative, which is still being rolled out in many areas, has significantly changed the landscape for disability service providers and their patients / clients who are grappling with the many complexities of the system.

Kristina Dodds, Education and Carer Support Coordinator from MND NSW, spoke about the importance of supporting NDIS participants who are living with MND via an integrated approach. Only people under the age of 65 are eligible to access the NDIS with people over the age of 65 falling into the aged care system which is an inequitable arrangement being campaigned against by MND Associations.

Paul Cafarella, Health Psychologist from Flinders Medical Centre (SA Health), presented on supporting wellbeing in MND patients, carers, social networks and health professionals. When a diagnosis of MND is made, it touches the lives of many people, not just the person with the disease, and supports need to be put in place to guard the wellbeing of all concerned. The caring role is very demanding hence the importance of carers having regular respite to look after their own mental health.

Rod Harris, CEO of MND Victoria, addressed the controversial topic of voluntary assisted dying (VAD) and the associated legislation which will come into effect in Victoria in June 2019. MND Victoria does not hold a position either for or against VAD but wants to ensure that people with MND are not discriminated against in regard to their ability to access the provisions of the legislation. Other states will watch with interest how the implementation process is managed in Victoria.

INNOVATING

Alicia Gibb, Occupational Therapist from NSW Health, talked about the impact of assistive technology on quality of life for people with MND. Having access to the right equipment at the right time can make a world of difference to someone living with MND.

Given the rapidly progressing nature of the disease, responsiveness to these changes is critical for both the person with MND and their carer/s.

Anna Fulford, Physiotherapist from the Palliative Care Team at Port Kembla NSW, shared her learnings from a project involving one of her patients which saw the development of an online reference guide 'I have MND. Now What?' This innovative resource is currently aimed at people living with MND in NSW, the ACT and NT but may be modified by other states in the future to include links relevant to other areas.

Peter Allcroft, Physician from Southern Adelaide Local Health Network, provided details of a trial of suprascapular nerve block for shoulder pain in MND. Shoulder pain and stiffness affect many people with MND as weakness in the muscles around a joint allow excessive strain to be transmitted directly through the ligaments and soft tissues. The loss of postural control which occurs when muscles are weak can be especially problematic when a person with MND is unable to reposition themselves, so this trial is a promising development for many who are experiencing shoulder pain.

Shyuan Ngo, *(photo below, left)* Scott Sullivan MND Research Fellow at the University of Queensland, was the final keynote speaker who addressed advances in research. Shyuan is part of the group researching Appetite and MND as featured in the last edition of MND news. Considerable work is being done by many researchers both here in Australia and overseas to understand MND better and ultimately, to find a cure.

Group Programs

Living Well

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

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

Living Through

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

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

Living On

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

How do you get involved with the groups?

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

Meeting others

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

This can be done through:

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

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

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

Facebook support groups

MND Carers Australia

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

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

MND Angels Australia

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

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

Kennedy's Disease Facebook Group

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

Kennedy's Disease (also known as Spinal and Bulbar Muscular Atrophy) is a condition that has similar symptoms to MND. One of our members has shared a Facebook group for Australians with, or affected by, Kennedy's Disease. The group aims to help raise awareness within our communities and to help each other out: **https://www.facebook.com/groups/340781642962036/**

Support services for carers of people with MND

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

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

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

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

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

WRITE YOUR MND STORY

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

Please email your text and a photo to: **info@mnd.asn.au** by 7 November for our next edition.

VOLUNTEER NEWS!

MND Australia campaigns to ensure everyone living with MND in Australia has access to the care and support they need. Campaigning aims to reach the people who have the power to change things – by increasing their understanding of the disease and its impacts.

To achieve this we mobilise supporters, create alliances, work with the media and lobby decision makers to create positive change. As part of our commitment to campaigning, MND Australia and MND Victoria are working together to develop and support volunteering roles in campaigning.

New volunteer role coming soon!

We will be launching an exciting new Campaigns Champion role in early October. Volunteers will have the opportunity to be involved in a wide range of campaigning activities, including promoting our national campaign to Make Aged Care Fair, both on and offline; influencing your Federal and State MPs and building awareness and momentum for positive change in your State.

This role would suit someone who is passionate about creating positive change for people living with MND, has good communication and networking skills, access to the internet, and is able to commit a couple of hours a week. If you would like to express an interest in this role please email **volunteer@mnd.asn.au** or **mndaction@mndaustralia.org.au**

Walk to D'feet MND

Volunteers are crucial to the success of every Walk to D'Feet MND. In the lead up to the Walk to D'Feet MND, volunteers are busy at our Canterbury office organising and sending out the t-shirts and merchandise which are so much a part of every MND Victoria event. It is through the support of volunteers, who give up their time to assist in these ways, that MND Victoria is able to ensure events run smoothly and successfully.

In regional areas volunteers and community members come together to arrange and run walks in their local areas. The amount of work contributed and the impact cannot be overestimated.

In coming months a Walk to D'feet MND will be held in -:

- **Rosebud,**
- **Bendigo,**
- **Echuca and**
- **Geelong.**

Volunteer support will be very welcome. You can sign up to assist, just for the Walk to D'Feet MND, by contacting **volunteer@mnd.asn.au** You can also ring 9830 2122 to express your interest in assisting with a Walk.

The **Melbourne Walk to D'Feet MND** will be on **Sunday 18th November 2018**. We are building our team of volunteers to help on the day with t-shirts, registrations, merchandise and course stewards. If you would like to be involved call 9830 2122 and ask for Deb or email **volunteer@mnd.asn.au**

CURRENT VOLUNTEER OPPORTUNITIES

The following volunteer roles are currently available:

Massage Volunteers - Melbourne (Northern Suburbs) and Seymour

Our massage volunteers provide hand and foot massage for people living with MND. The aim of the massage is to assist with relaxation and comfort.

We currently have clients in the Northern Suburbs of Melbourne and on the Mornington Peninsula area who are hoping to be matched with a massage volunteer who may be able to provide them with a weekly, fortnightly or monthly hand and /or foot massage in their home or place of residence.

Time required: Our experience has been that each massage visit takes approximately one hour plus travel time. Massage volunteers let us know how much time they have available – some massage volunteers visit one client each month, others support a number of clients on a regular basis.

Skills required: Massage volunteers are not required or expected to come with skills in massage. MND Victoria provides training and resources to prepare volunteers for their role in hand and foot massage.

Relief Reception Volunteer

We still have a need for one or two relief reception volunteers. Our volunteer receptionists are our frontline at the MND Canterbury office. We are seeking to develop our small pool of relief reception volunteers, able to provide backup support to our regular reception team.

Time required: Reception shifts are Monday to Friday for 3.5 hours in the morning or afternoon.

Times required would vary according to occasional vacancies in our reception roster.

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

Life Story Volunteer

We are growing our team of Life Story Volunteers across Victoria. In this volunteer role you will work with a client to record stories from their life. Recordings are transcribed and developed into a book which the client and their family have to keep and share as they desire.

Life Story volunteers come with an interest in listening and a willingness to create a book which reflects the individual's story. Life Story volunteers do not need to have prior writing or publishing experience. MND Victoria provides training and equipment for this role and covers the cost of producing each Life Story in a booklet form.

Time required: Volunteers will visit with each client for approximately 6 one hour sessions to record their story over a period of weeks. Transcribing and editing generally takes up more time but can be done at home at times that suit the volunteer.

Skills required: Interest in others and in engaging with clients to learn about their life and history. A level of computer skills will be required to enable transcribing of the client's life story and production ready for printing.

Capacity to work through a short term project with a client gives a sense of satisfaction and completion.

Hairdresser - Northern Suburbs

We are seeking an experienced hairdresser to visit clients living in the northern suburbs of Melbourne. Volunteer hairdressers provide a client with MND with a trim in the comfort of their own home.

This role is suitable for a qualified hairdresser with their own equipment and will involve travel within the area.

Time required: Appointments will be coordinated with the client and volunteer to suit their needs and availability.

* * *

For more information about any of these roles or other opportunities to volunteer with MND Victoria, please contact Deb on: (03) 9830 2122 or email **volunteer@mnd.asn.au**

Is the answer in the atoms?

By A/Prof Dominic Hare, Head of Atomic Pathology Laboratory, The Florey Institute of Neuroscience and Mental Health; Dr Kai Kysenius, Postdoctoral Researcher and former Sigrid Jusélius Fellow, Department of Pharmacology and Therapeutics, University of Melbourne; and Dr Bence Paul, Senior Lecturer, School of Earth Sciences, University of Melbourne.

When we think of what we're made of, we tend to think of flesh, blood and bone. Biologists and neuroscientists dig deeper and see the world as a network of cells in a constant state of flux, while biochemists, geneticists and their contemporaries look even closer to see the building blocks of life - proteins, and the DNA that controls how those proteins are built, making us who we are.

But really, deep down, we are made up of the cosmos and the remnants of the Big Bang. Everything is made of atoms, be it the food we eat, the glass that holds the water that we drink, the screen or paper you read this on, and, most importantly, you yourself. And so are the cells and the DNA that make us human.

The jigsaw puzzle of elements that form life is another level of complexity we are seeking to understand. As of 2014, 28 chemical elements of the periodic table were shown to be essential for all life. In fact, the assembly of these elements in the molecular soup of nature is what gives rise to life, and also how disease begins.

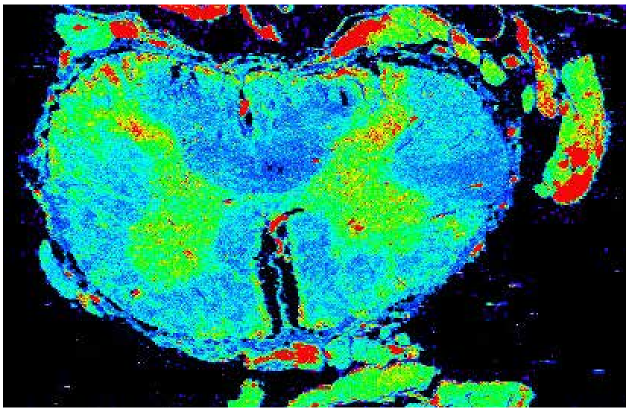
A gene is a bit of DNA that codes what we are made of, like a recipe for life. Our genes are precise mixtures of the elements carbon, nitrogen, hydrogen, oxygen and phosphorus; to make proteins we need to throw sulfur and selenium into the mix. Add to that, we're around 60% water which is full of dissolved essential elements like iron, calcium, magnesium, copper and zinc. We know that these elements are vital for the function of proteins, cells and organs. Although these elements might be tiny molecules, an imbalance of them can have fundamental consequences, like anaemia resulting from iron deficiency. A subtle shift in this element away from normal causes a cascade of rampaging events in our bodies, disrupting the balance of other essential elements along the way. In the end, the trail of destruction left behind can be defined by an 'elemental signature' that goes beyond just iron.

Motor neurone disease is no different. For some, it is in their DNA, and thanks to our understanding of the human genome it is possible to find it early. But the elemental signature that really matters is the one left behind when cells start dying, regardless of genetics. As the disease progresses, more cells die and symptoms worsen, but this identifier spreads throughout the body, amplifying the elemental signature and reflecting the devastating effects of MND.

Why does it matter so much? Because detecting these changes early, when the elemental signature is weak, could be key to the detection of MND and stopping it in its tracks. Deciphering the elemental code will allow us to both better understand precisely how, when, why and where things go wrong.

MND is highly complex, with no one element there to be caught red-handed. The changes in elements are much more subtle, like looking for a needle in a haystack.

Fortunately, recent advances in technology have given us a literal metal detector that can uncover that needle from the hay. Atomic absorption spectroscopy was invented by Sir Alan Walsh at the CSIRO here in Melbourne in the 1950s, and in the 1980s a new technology was developed using mass spectrometry. This has been refined to the extent that today scientists can detect nearly the entire periodic table of elements



at levels equivalent to a drop of ink in 30 Olympic-sized swimming pools. Originally, this technology was used by the mining sector and environmental sciences to precisely detect the elemental composition of the earth. But the sensitivity and precision of this technology can be applied to how we research MND, allowing us to detect those subtle changes that can predicate disease progression.

Just like the underlying causes of MND, we don't know what the elemental changes look like yet, and just how subtle they really are. The only way to know is to measure the elements in as many MND-related samples as possible - from the genetically altered mice that are used to understand the molecular changes that happen and examine potential new therapeutic drugs, to the blood and spinal fluids from MND patients, and samples of the brain and spinal cord from those who have lost their battle. Scientists need to know what to measure these changes against, but no two people are alike, and MND has many different forms. This complicates the search even more, making things like age, sex, the environment, disease duration, and genetics all relevant factors to consider.

This sounds challenging enough for one person, so an analytical chemist, a neuroscientist and a geologist have joined forces in the search for the elemental signature of MND, with the help of modern computing. We've collected an extensive array of data, which accounts for the innumerable variables that make each case unique. There are just too many numbers to crunch in this wealth of data using standard tools, so we've turned to machine learning. This is a type of artificial intelligence where a high powered computer adapts its program to make finding critical information more efficient. In our case, a specialised mass spectrometer measures sample after sample, and the data is fed into a carefully-crafted algorithm that runs thousands upon thousands of complex calculations to spit out the unique numbers we're looking for.

Patience here is a virtue as the data is vast and complex. With a disease as serious as MND, there's little room for error if this marker will have use in finding a cure or detecting it early. To make the most of the opportunities technology has afforded us, building a library of data is our first priority so we can hit the ground running. And once we do, the beauty of machine learning takes over. Every additional sample fed into the algorithm makes it a little bit better. Our hope is to see this idea evolve into information MND researchers the world over can use and contribute to, or even use as inspiration to integrate their own areas of scientific expertise, to expand our search for a cure.

Discoveries today are made by teams of people with skillsets that span multiple disciplines. Chemistry, neuroscience, geology and information technology might not seem like the most likely combination of science to understand MND, but as the elemental signatures of the disease have already told us, the right combinations matter.

The authors would like to thank the late Jenny Simko and her family for their generous support through the Jenny Simko MND Research Grant program of MNDRIA, and Dr Amy Reichelt from University of Western Ontario in Canada for her assistance in writing this report.

HOW CAN I HELP MND RESEARCH?

ALS Quest Survey

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

ALS Quest is a University of Sydney project and the survey is available to complete online at: **www.alsquest.org** Both people with and without MND can fill in the survey - it will take around 90 minutes to complete.

Participate in Familial MND research

Professor Garth Nicholson and his research team based at the ANZAC Research Institute, Concord Hospital Sydney, are studying gene variations in familial motor neurone disease. Professor Nicholson and his collaborators are keen to obtain DNA samples from patients with familial motor neurone disease.

To assist this research, a single blood sample is required together with your consent to take part in the research and, where necessary, your permission to obtain a copy of clinical information from your treating physician. The blood sample can be taken locally and then sent to Sydney for analysis. If you are interested in donating, then phone (02) 9767 6796 or email molmed@med.usyd.edu.au for further details.

Donate to the Tissue Bank

People with a diagnosis of MND confirmed by a neurologist are needed to donate tissue to MND research.

If you are interested in donating, or if you are just interested in finding out what tissue donation involves, please contact Fairlie Hinton, Coordinator, Victorian Brain Bank or find out more on The Florey's website: **www.florey.edu.au/vic-brain-bank** Email: fairlie.hinton@florey.edu.au Phone: (03) 8344 1900 Mobile: 0438 530 372

Join the Australian Motor Neurone Disease Registry

The MND Registry is an ambitious project to register and collect data from every person diagnosed with MND in Australia. It contains de-identified data from people diagnosed with MND including information about the diagnosis, symptoms, treatment and management. This information is made available to researchers studying MND. The MND Registry provides people living with MND with an opportunity to actively contribute to research and learn more about the disease. The participant's neurologist will fill out a case report form detailing the treatment and health situation at the time of the visit. There are no extra tests, procedures or treatments involved. People are free to decline or to withdraw from the study at any time.

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

4TH MND CONNECT ››

Join us for an interactive forum connecting people impacted by MND with Australia's leading MND researchers in Melbourne.

The 4th annual MND Connect meeting for the MND community will be held at the **Ian Potter Auditorium, Kenneth Myer Building, The University of Melbourne, from 10am-3pm on Saturday 10th November 2018.**

People living with Motor Neurone Disease (MND), their friends and family, health and community care professionals, researchers as well as the broader MND community are invited to attend MND Connect 2018.

Find out more and register at: **www.mndaust.asn.au/Discover-our-research/grants-and-research-meetings/4th-MND-Connect**

YOUR STORIES ...

From a quick ice bath to a cool slog across the English Channel

By Justin Phillips

In August, three other ragtags and I will be swimming the English Channel. Taking the Ice Bucket Challenge from 10 secs to 12 hours ... from a quick ice bath to a cool slog across the Channel.

When a friend first floated the idea of swimming the English channel I think I said 'Isn't it cold, I get pneumonia opening a fridge door'! But after the third glass of red and just a little bit of encouragement, my trepidation over the fact I hadn't swum more than a lap in a warm Bali villa pool in over 18 years seemed to recede. I daydreamed ... the feeling of the excitement and magnificence of swimming onto 'le plages de sable blond', su Hauts-de-France ... when the reality and enormity of the challenge ultimately set in a few weeks later, it switched to pure dread.

The Dread. It only grew larger ... after our coach said "so I expect you to be doing a minimum of 12 kms per week from January onwards". Oh. You're not allowed to wear a wetsuit. Really? You will be expected to train without a wetsuit in the bay until it gets below 12 degrees ... "that's for safety" ... clearly not for sanity!

Apparently there is often a bit of swell in the channel, "yes, the average swell in the middle of the channel is about 2 metres" ... no one told me this before my first deposit ... @#%$! Oh and you need to swim 2 hours below 15.5 degrees to qualify. What, I have to qualify? You don't just pay your money and swim? When does the misery end? Not yet. Only after you cross 33km (most swimmers average closer to 40kms due to the currents) of one of the busiest shipping lanes in the world (600 tankers and 200 ferries use it each day), not to mention the multiple blooms of jellyfish!

The pain is intense. Jumping into the freezing water, it hits you like a wad of wasabi, but from the outside in. After practice, swimming in waters below 12 degrees doesn't really get any easier, you just know the process. It takes your breath away. Your fingers, hands and feet start to burn and the sensation rolls up your arms and legs. When the cold water hits your head, it feels like a cross between being hit with a firm mallet and being squeezed in a hot, burning vice. It stays that way for three minutes or so, and then thankfully the numbness sets in, but the shortness of breath stays. But after a short while, the burning sensation in the fingers and arms returns. You can continue, and let the effects of hypothermia take hold. You can hop out. You can choose. MND sufferers can't. While the Channel is not going to be that cold this year, it is part of the preparation, 85% mental and 15% physical. You need to know your limits.

In the back of mind, I always knew I had to push myself harder as others in my family had done before but could no longer do. My late uncle Bruce, a former professional runner was diagnosed with motor neurone disease a few years ago now.

MND is cruel. There is no halfway house. There is only "how long have you got?" Sufferers don't have a choice and don't have options. So, in doing the swim, I thought I may as well also try and give something back.

On 17 or 18th August, our Channel crossing as a relay begins.

Our journey

We will be on a boat called Pathfinder. No world record attempts, just 4 middle aged blokes trying to get to the other side. We will likely start at 2.30am, leaving just south of Dover, swimming the first 3 hours in the dark (and cold) before the sun rises. We are hoping to land in Cap Gris Nez around 2.30pm (English time) before taking the trek back across the channel in the same boat.

A snippet on my Uncle

In 2014 my uncle, Bruce "BT" Cox (or "Doc" in the Sale Football club where he was trainer for many years) was diagnosed with motor neurone disease and it was his wish that we raise awareness of this most heinous of illnesses and support Motor Neurone Disease Victoria. He was a local country legend within the Sale, Loch Sport and Gippsland Communities, mainly because he always had a smile, did endless volunteering and was a tireless worker. He had always been such a strong man and a bit of an athlete, almost until the day he was diagnosed. Won numerous "Gifts" (professional running races) including the prestigious Stawell gift in 1965 and one of the only winners of the junior gift (that apparently stopped running after 1960?). But importantly never one to shy from a good challenge, always up for raising money for charity, including riding from Cairns to Sydney to raise money for Cancer and other events too numerous to name. He passed away in March 2016.

* * *

A HUGE congratulations to Justin and his team on completing the Channel crossing. We would like to thank everyone who has supported them, they have raised an amazing $4730!

HEATHCOTE BOWLS CLUB

MND hit the Heathcote community hard a number of years ago when a local favourite was diagnosed with the disease. Dennis Gleeson was known by just about everyone in the small town and it didn't take long for the community to rally behind him.

A group from the bowls club decided to organise a 24 hour bowls event a few years ago to raise money for Dennis and MND Victoria. This brought in over $20,000 and was the start of an annual event. Each year this group, now known as the Never Give Up group organise a fundraiser on Australia Day at the Bowls club. With the successes they have had, they decided to organise further fundraising and awareness events. On Friday the 17th of August they managed to sell out the Heathcote Golf Club where they remembered Dennis who passed away only a few days earlier.

The aim of this event was to further educate the local community about the disease and how important it is to raise funds for MND Victoria.

Daniel, our Fundraising Officer took on the role of MC. He said it was a brilliant night and was blown away by the generosity of everyone.

We are so thankful to have such passionate supporters. We can't wait for further events up in the Heathcote area!

Our Kokoda Team #NeverGiveUp

This just got real!!! Flying in to Kokoda ... Stav

Incredible experience and tough slog through the most difficult of conditions. Dan+Stace

Thank you to all our Sponsors and friends who have supported us... Stav

Forever grateful to my team who pushed me every day to keep going...Konnie

A very BIG thank you to all our friends for their help towards MND. Ody

We did it!
Courage
Endurance
Mateship
Sacrifice
Vince

pushing my body to its limits, I can not believe what I have just accomplished...Bec

Heading Home From a life changing experience. Stav

MND VICTORIA LARAPINTA TREK 2019

Larapinta, Northern Territory | 16–22 September 2019

The MND Victoria Larapinta trek 2019 will help provide the best possible care and support for people living with MND.

The Larapinta Trail is regarded as one of Australia's premier walking tracks. From the old Alice Springs Telegraph Station to the peak of Mount Sonder, the trail stretches 223 kilometres along the backbone of the West MacDonnell Ranges. Over 5 days of trekking, you will cover 60 kilometres of this iconic track.

Nothing short of extraordinary, you will stand on ancient escarpments and gaze out upon the ochre-coloured landscapes of Central Australia. You will follow Aboriginal Dreaming tracks and trek beside one of the world's oldest river systems.

By day, you will experience the diversity of desert habitats and visit sites sacred to the Arrernte people. At night, you will fall asleep to the sounds of native wildlife under a blanket of stars.

Best of all, you will raise vital funds for MND Victoria to provide the best possible care and support for people living with MND.

Download your info pack or register now to secure your place: **www.inspiredadventures.com.au/events/mndvic-larapinta-2019/**

Join us today, because until there's a cure… there's care.

FUNDRAISING

"I wish to donate the proceeds of our fundraiser to MND Victoria in memory of Margaret our dearest Mum who had MND and was so wonderfully supported by MND Victoria, in particular the regional advisor for the Inner Eastern region. I will always remember Lesley's (MND Advisor) kindness and compassion and gentle way with my Mum who had every confidence in her." (Client's reason for fundraising for MND Victoria).

As you may have read in previous editions of the newsletter, MND Victoria has implemented a Client Relationship Management System (iCase) to more effectively and efficiently manage client and supporter information. We have just completed the migration from our old Donor Management system to iCase and while there have been a few teething problems, we are confident that going forward it will enable us to develop stronger relationships with our donors and supporters.

In conjunction with the migration to iCase during September and October, we will be undertaking a Donor Survey so that we can better understand what motivates you, our donors, to continue supporting the Association. We want to ensure we meet your unique communication needs so we can provide you with as much, or as little, information as you want to maintain your connection. We hope the survey will enable you to give your feedback about why you support the work of MND Victoria because your on-going financial support has a huge positive impact on the daily lives of 400+ people in Victoria living with MND. Your financial support, through your donation to one of our appeals, organisation of or participation in a fundraising event, challenge event, or one of our Walk to D'Feet MND events or donation in lieu of a gift for your birthday or anniversary, enables us to purchase much needed assistive technology devices such as hoists, wheelchairs, power lift arm chairs to name but a few. These items, which are provided at no cost to the person with MND, help them remain safely in their home and relieve them of some of the financial burdens associated with the disease. This is particularly important for those aged over 65 when first diagnosed, as they cannot access NDIS funding so the financial stress for them late in their lives can be overwhelming.

Anyone who has been impacted by MND knows that access to the right equipment, at the right time, and at no cost to the person with MND, contributes to a better quality of life for everyone in the family.

I'm glad to say the new financial year is in full swing and our many supporters and fundraisers are already doing an incredible job of raising awareness and funds. By the time you read this article, the Kokoda Walk to D'feet MND team will be back at work and, hopefully, fully recovered from their trek. I'm delighted to say that their current fundraising total is $50,013. As you have already read, we have just launched the 2019 Larapinta Walk to D'feet MND, a much less challenging walk.

We encourage you to get your family, friends and work colleagues together and register for one of the Walk to D'feet MND events which start taking place in November: **www.mnd.asn.au/walk** As well as providing the opportunity for hundreds of people impacted by MND to get together and celebrate the life of someone currently living with the disease or someone who has died from the disease, the Walks are our biggest fundraising event and our goal this year is to raise $300,000 for care, support and research.

P.S. If you missed out on my article Ten Frequently Asked Questions About Fundraising / Donations, please email me at: **knightingale@mnd.asn.au** and I will send you a copy.

Kathy Nightingale

Manager Fundraising

SNOWFEST WARRAGUL

A Friday evening in late July saw Warragul buzzing! 10,000 locals, snow everywhere, music pumping and a whole heap of fun everywhere you looked. It was the **Warragul Business Group's** annual Snowfest event.

Over the years, money had been raised for various local charities through key figures in the community being dunked into a tank full of ice. This year only one charity was chosen.

Unfortunately MND has hit the local community hard over the last few years so MND Victoria was the beneficiary of all funds raised.

Daniel had a chat on stage about the impact MND has had on those in and around Warragul as well as explaining how important MND Victoria's services are. He then got dressed into his wonderful blue morph suit and made his way to the dunk tank. It took a while for the kids to hit the target but eventually he found himself covered head to toe in ice water. He will do anything for a great cause . . .

WANGARATTA TO MELBOURNE RUN, 12-16TH SEPTEMBER!

Dave and his mates are running 300km in just FIVE days to raise money for motor neurone disease research and to support people living with MND today and into the future. Dave knows the impact of MND as his Mum died from MND some years ago.

So a run? 300 kilometre run!! Are these guys crazy? Yep!! And they love it!! So why exactly are they doing this? Well, because they have a ripper crew that are keen to put an end to motor neurone disease. 50% funds raised will be allocated to research and the other 50% to help people living with motor neurone disease.

The team's running uniform and sponsor is Funky Trunks! Yep ... You guessed it, the guys are running 300km in their bathers. Their goal is to raise $20,000 - you can check out their MyCause page and donate at:

https://www.mycause.com.au/page/148766/mnd-300

SUMMER IS ON THE WAY!

Our super comfy **ALL NEW Walk to D'feet MND flip flops** are perfect for the beach and lazy summer BBQs—raise awareness wherever you go this summer!

Only $29 each (inc post) sizes:
Extra Small: W 80mm x L 190mm.
Small: W 100mm x L 250mm.
Medium: W 110mm x L 275mm.
Large: W 120mm x L 290mm.
Extra Large: W 120mm x L 305mm.

Please measure your foot before ordering.

Check them out in our MyCause store:

www.mnd.asn.au/gear

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

**** The PERFECT Christmas stocking filler ****

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

Ensure your bestie is looking FAB at our Walk to D'feet MND this summer!

Our Doggie Bandanas are only $8 each ... MND Dog Leads are $12 each (small, medium or large length)

Check them out and all our other MND gear at:

www.mnd.asn.au/gear

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

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

OUR HOODIES OUT AND ABOUT . . .

In the last few months, our #NeverGiveUp hoodies have been spotted in Broadbeach, the Freedom Monument in Riga, Latvia, at a rugby game in Hawaii and back home, and of course(!) they were out in force at the National MND Conference in Adelaide.

Grab your hoodies online at: **www.mnd.asn.au/gear ...** Perfect for raising awareness on cooler spring evenings, for travel and showing support at your local rugby match!

Donations Were Received … Thank You!

In memory of

Peter Lowe
Anne Di Nardo
Panagiotis Papoutsis
Bruce Peucker
Wendy Gillam
Dot Dickson
Martin Williams
Nicole Hall
Peter Miller
Peter Patti
Ron Boyd
Graeme Welling
Ellen Drury
Harold Baker
John Cannington
Kae Jones
Rosie Grey
Kim Muckner
Bonny Alford
Gottardo Mantovani
Joy Blakeley
Peter Konstantinidis
Michael O'Brien
Madelyn Farrugia
Annie Melican
Ivan Juracich
Rita Elaine Gall
Anthony Kellaway
Brian Lovell
Alan Nuthall

Research in Memory

Jim Hendricks

Equipment donation

Ron McCann

Trusts

Joe White Bequest
Lord Mayor's Charitable Trust

Clubs

Ruby Red Dancer
Lions Club of Korumburra Inc.
Orbost Hockey Club
Inner Wheel A62 District
Maroondah City Council

Schools

Lilydale High School
St James Primary School
Little River Primary School
Axedale Primary School
Trinity Grammar School

Organisations

Norton Rose Fulbright Australia
Pratt Interiors
Geelong Croquet Association Inc.
Garth Lisle Property Consultants
The Good Food Collective
The Australian Pilates Method Association
O'Brien Real Estate Foundation

Corporate

Barwon Health - Progressive Neurology Clinic
Edgewise Insurance Brokers Pty Ltd
The Phoenix Hotel
Specsavers Pty Ltd.
Ritchies IGA
Home Loan Saint Pty Ltd.
Robinson Gill Pty Ltd.
ME Bank
PhoneCycle
Patrick & Gill Weiner's Bedshed-Nunawading

Support Groups

Barwon Support Group
The Maroondah Catenian Men's Group

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

MND Victoria Membership

Have you renewed your membership for 2018?

You will have received a reminder if your membership is due for renewal. Please keep up your membership—we need you.

Please phone the office on: 03 9830 2122 or email: info@mnd.asn.au for more information on MND Victoria membership.

Contributions are invited!

MND Victoria members are invited to write stories, anecdotes, letters, or 'Handy Hints' for the newsletter. We cannot guarantee that all contributions will be published as this is dependent on available space, but every effort will be made to do so.

Please email your text and photo to: **info@mnd.asn.au** by 7 November for the next edition, to be mailed on 4 December 2018.

Get Involved in an Event near you!

Date	Event	Contact
Saturday, 6 October 2018	**Daylesford Dunking Derby**	Email: dwoodrow@mnd.asn.au
Monday, 15 October 2018	**MND Victoria AGM**	RSVP to: info@mnd.asn.au
Saturday, 20 October 2018	**Cox's Bridge to Cox's Place Cycle Event**	Email: dwoodrow@mnd.asn.au
Sat/Sun, 20-21 October 2018	**Tough Mudder**	Email: dwoodrow@mnd.asn.au
Sunday 21 October 2018	**Tee-Off MND Charity Golf Day**	Email: dwoodrow@mnd.asn.au
Wednesday, 24 October 2018	**MND Information Session**	Email: info@mnd.asn.au
Sunday, 4 November 2018	**Village Glen Walk to D'feet MND**	Email: fundraising@mnd.asn.au
Saturday, 10 November 2018	**4th MND Connect Meeting**	Email: info@mnd.asn.au
Saturday, 10 November 2018	**Show 'n' Shine Movie Night**	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
Sunday, 2 December 2018	**Echuca Walk to D'feet MND**	Email: fundraising@mnd.asn.au
Thursday, 6 December 2018	**MND Information Session**	Email: info@mnd.asn.au
Sunday, 24 March 2019	**Geelong Walk to D'feet MND**	Email: fundraising@mnd.asn.au

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

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

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