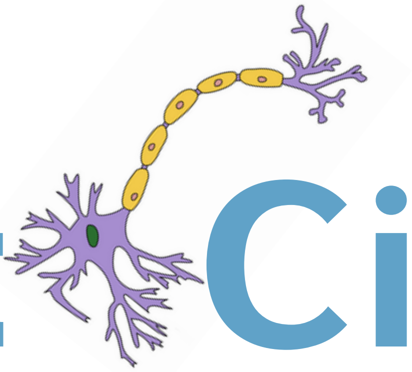
Summer Edition 2021

Short Circuit



Monash Uni, Helmut Butzkueven joins upcoming PwMS Conference

We are excited to hear Helmut talk at the upcoming May 2021 conference. in the lead up, please read a bit more about Professor Helmut Butzkuevens bio.

Professor Helmut Butzkueven is The The Van Cleef Roet Chair of Neuroscience and Head of the Department of Neuroscience, Monash University, and Director of Neurology, Alfred Health.

He is also Chair of the Multiple Sclerosis and Neuroimmunology research unit in the Department of Neuroscience, Central Clinical School. He is an international leader in translational research in the neurological disease, Multiple Sclerosis (MS). He is Managing Director of the MSBase Foundation (www.msbase.org) that funds and administers a global online MS cohort study with more than 70,000 patients enrolled in 130 centres across 36 countries, which has resulted in multiple publications that have directly impacted on patient care worldwide.

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Armchair Traveller

My wife Stevie and I have been exploring Australia for more than 30 years. In 2002 we visited the Burrup Peninsula in the north west of Western Australia, some 1500km north of Perth

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Drugs for Pain Relief?

Early last year my neurologist referred me to a medical practitioner who could prescribe a medicinal Cannabis Oil

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MS Aust New CEO

The Board of MS Australia is pleased to announce the appointment of a new Chief Executive Officer to guide the newly focused and amalgamated MS Australia.

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Professor Helmut Butzkueven completed his PhD at the Walter and Eliza Hall Institute in 2003, and subsequently a post-doctoral fellowship at The Howard Florey Institute. He has received multiple awards for his research and medical leadership, including The Bethlehem Griffith Research Foundation Award, The Australian Museum and University of NSW Eureka Prize and the Research Australia Health and Medical Research Data Innovation Award. Currently, he holds a highly competitive NHMRC Research Leader Investigator Grant, recognising him as a leading medical researcher in Australia.

Research interests

His overarching research theme and clinical interest is the use of registry data, clinical MRI data, cognitive testing, genomics and patient self-monitoring devices and applications to evaluate treatment strategies to optimise the benefit and safety of MS therapies.

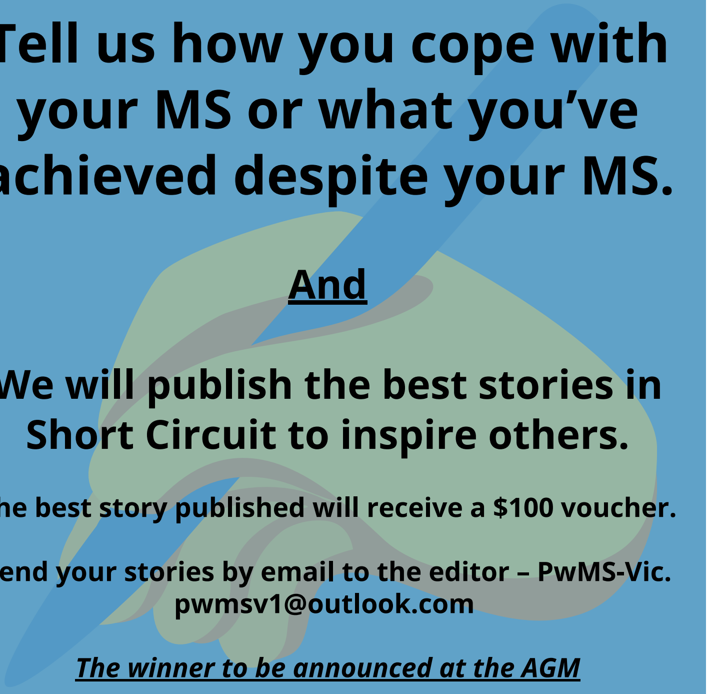
Clinical activities

In addition to his research leadership credentials, Prof. Butzkueven has over 20 years' experience as a clinical neurologist, and is Head of the Multiple Sclerosis and Neuro Immunology (MSNI) Clinic at the Alfred Hospital, Melbourne, Australia. He is also a passionate teacher and mentor of young clinicians and researchers, and is Research Higher Degree Coordinator for the Central Clinical School, Monash University.

Community service

Professor Butzkueven also is a member on the Board of Directors at MS Research Australia. He has a long working history with MS Research Australia, initially awarded a Fellowship in 2006 to investigate protecting nerve cells from MS injury. Most recently he has been an active member on a number of working groups and collaborative platforms as well as volunteering as MS Research Australia's Scientific Conference Convenor.

TELL US YOUR STORY



Tell us how you cope with your MS or what you've achieved despite your MS.

<u>And</u>

We will publish the best stories in Short Circuit to inspire others.

The best story published will receive a $100 voucher.

Send your stories by email to the editor – PwMS-Vic. pwmsv1@outlook.com

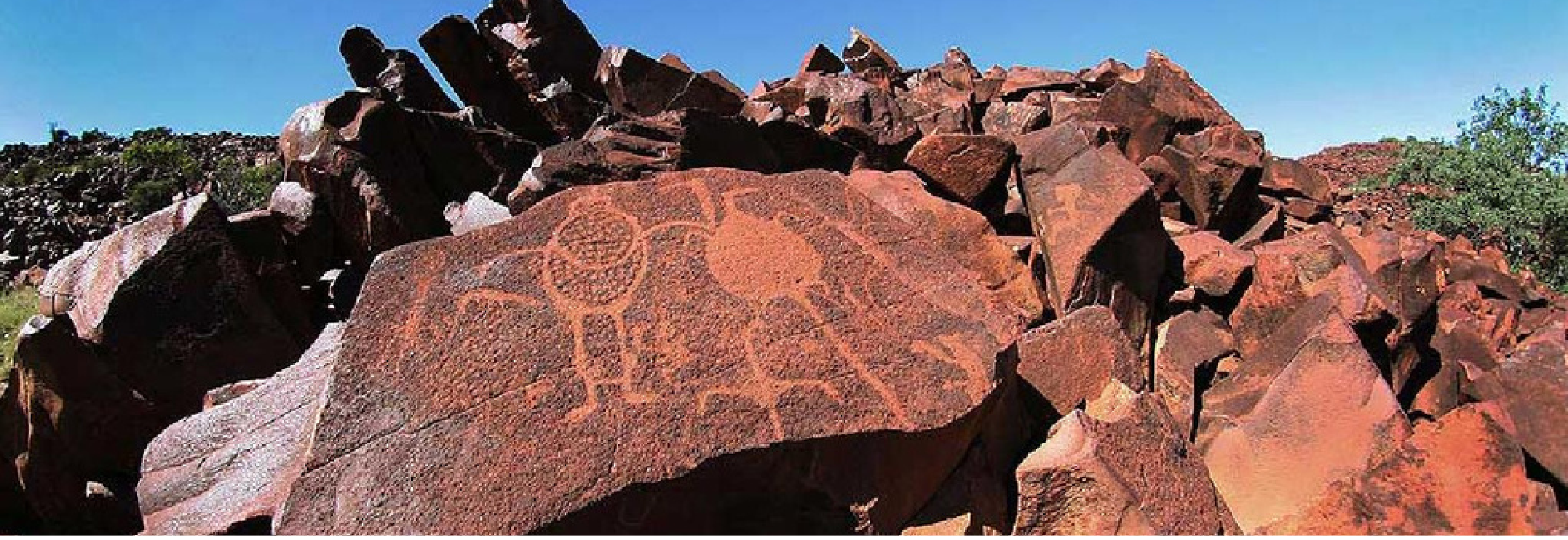
The winner to be announced at the AGM

OPT IN FOR EMAIL

In each issue of Short-Circuit this year PwMS will announce the winning member who has agreed to receive Short-Circuit electronically.

If you are willing to receive your copy of Short-Circuit electronically please send an email to PwMS at admin@pwms-v.org.au giving your name and the email address to which you would like Short-Circuit sent.

Your name will then be entered in the lucky draw.



Armchair Traveller

My wife Stevie and I have been exploring Australia for more than 30 years. In 2002 we visited the Burrup Peninsula in the north west of Western Australia, some 1500km north of Perth.

The Peninsula is living proof of the ancient history of the Indigenous people of the Pilbara where Aboriginal people are thought to have been living for more than 50,000 years. It contains the Murujuga National Park situated about 5 kilometres north-east of the town of Dampier.

The landscape is covered with huge piles of rust-coloured boulders. It is a place of stunning, natural, sculptural beauty and home to one of the most exciting collections of rock art in the world. There are more than 700 Indigenous archaeological sites, including tens of thousands of rock engravings. These engravings are thought to be among the earliest examples of art in the world and showcase what is believed to be the highest concentration of rock engravings at any known site in the world.

When Stevie and I visited we camped in the tiny caravan park in Dampier and ate in the works canteen attached to one of the mining operations. In those days there was very little signage and to find the art sites it was necessary to look out for and follow tracks through the rocks, some of which may have existed for centuries.

I was much more mobile than I am now and by following ancient pathways we found several sites with vivid carvings of people dancing or climbing(?); of fish, kangaroos, wallabies, turtles, and emus. This was an incredibly moving experience. The carvings have been estimated to be as old as 40,000 years. They are very diverse, depicting a record of what was meaningful to the people of the Pilbara and beyond. They provide us with an insight into an ancient world.

The peninsula is also close to significant resources of salt, natural gas, petroleum, iron ore where industries have invested billions of $$ in developments. Trade to and from the Port of Dampier means it is the second largest tonnage port in Australia. Careful, long-term management involving Indigenous groups, industry, government and the community will hopefully see our heritage protected into the future, to the advantage of all Australians.

The Park and the adjacent Dampier Archipelago were included in the Australian National Heritage List in July 2007. Development in the region has created thousands of jobs but it has also improved access to the area making it easier to visit. More information about accommodation, tours, and attractions can be obtained from Karratha Visitor Centre. If you are lucky enough to visit please remember the rock art is sacred for Aboriginal people and its traditional custodians the Ngarluma-Yindjibarndi, the Yaburara-Mardudhunera and the Woon-goo-tt-oo. These are unique and irreplaceable cultural resources for all Australians; help preserve these sites for future generations, avoid touching or stepping on the art and do not mark the art in any way.

Nigel Caswell

Presidents Letter

Summer 2021

FREE “at last”! Free to travel around the state; free to receive visitors in your home; free to party with other people out of doors in a park; free to go out to lunch or dinner or for a coffee; and free to do many other things. Pat yourselves on the back because as Victorians we can rightfully feel proud of what we have achieved. Back in August we were getting 700 new COVID cases per day and this was similar to the UK. Whereas here (up to Christmas) we had more than 50 days in a row with no new cases and the UK is getting more than 50,000 new cases per day.

So, I hope you have been getting out there and celebrating; you deserve it!

But don’t gloat too much and please be careful; as the last few days clearly demonstrate, the virus can easily come back. So keep yourself and your friends and family safe by washing your hands regularly, wearing a face mask as a matter of course, coughing and sneezing into your elbow, keep up to date with the latest COVID rules and if you have attended a “hot-spot” or feel unwell or have symptoms of coronavirus get tested and stay home.

Now were you one of the people who watched the “People with MS – Victoria” on-line seminar on Nov 14th? If not, you missed out on a highly informative pair of speakers; Dr Julia Morahan, Head of Research at Research Australia (MSRA); and Debbie Roberts, CEO of Data for Inclusion (DFI), (a small company which specialises in developing products to support people with differing abilities).

Dr Morahan described the extensive range of research projects being undertaken here in Australia, focussed on the cause, cure, and management of MS. All of which are financially supported by MSRA and many of which are being undertaken in partnership with overseas institutions. She then devoted the second part of her presentation to the new lifestyle guidelines recently published by MSRA. This guide provides a huge amount of information about lifestyle factors we can modify to help improve our lives as we cope with MS.

Debbie Roberts, spoke about a huge range of exciting new technology products designed to make life easier for people with disabling conditions like MS. She said she was inspired into action because of a family member who has MS. Her initial aim was to develop a tool which would make it easy for people to go out and know what to expect; to know what a venue does not have; and to know if it’s suitable or not. Debbie then went on to describe the range of other products and information DFI now offers and is developing or thinking of developing. These include tools designed to help us: save money on medication, communicate with less effort, and be more in control of our lives. The range Debbie described was amazing.

The presentations have been recorded and are available on the PwMS website, for you to watch as many times as you like. http://www.pwmsv.net.au/portal.   I have already watched them both twice and I got as much out of the second viewing as the first.

On the 16th of November we held the PwMS 2020 annual General meeting on ZOOM. There was only a small attendance, but the meeting was conducted appropriately with all the annual accounts, auditors report and annual report being formally adopted. All these can be viewed on our website. We have been fortunate enough to be awarded a grant to host our regular annual “Living with MS” conference in May this year. We will have speakers on the latest treatments and research and managing your money and allowances to get the best out of them. We hope the conference will be back at the Nerve Centre at Blackburn and that we will be able to welcome our regular attendees once again.

2020 has been one hell of year and I wish you all an enjoyable festive season, summer break and a better 2021.

Nigel Caswell, O.A.M. President.

62 Year Old Perspective on Certain Drugs for Pain

Early last year my neurologist referred me to a medical practitioner who could prescribe a medicinal Cannabis Oil product manufactured by a Swiss pharmaceutical company which was approved by Australia's Therapeutic Goods administration.

I was prescribed 5% CBD (Cannabidiol) Oil for pain management at an initial rate of 0.1ml per day and I was asked to gradually increase it until I reached a dosage which produced a substantial reduction in my pain level.

Ingestion of the CBD Oil at the lower doses was ineffective. After the first 6 weeks I contacted my medical practitioner prescriber who suggested gradually increasing it to a maximum of 1ml per day.

I eventually found that there was some but not complete pain relief at the maximum dose and persisted with this protocol for more than 6 months.

However, after 3 months I found that the small reduction in pain came at the cost of my feeling increasingly unwell. After the last round of my biannual blood pathology tests came back with worryingly high liver enzyme levels indicating liver damage it was decided to immediately suspend use of the CBD oil as this was the only change to the daily 10 drug regimen which I had been on for the last 13 years for a variety of conditions.

Within 2 weeks of stopping the CBD Oil I was feeling much better and my liver function indicators have improved although not back to my normal levels which have been steady for an exceptionally long time.It was discovered in the medical literature that in some people with pre-existing drug induced liver impairment the addition of this prescription medication had induced substantial liver inflammation.

Thankfully, a different pain relief drug called Tapentadol was found that mildly improved my pain level without substantially affecting liver function. So I guess the take home message is that so little medical research has been done on the potential effects of Cannabidiol (the non psychoactive component of the Cannabis flowers) that undertaking a personal trial of the drug has to be very closely monitored by your GP.

On a more positive note if you have SPMS your neurologist may have already made you aware of Siponimod (similar to Fingolimod for RRMS) which may substantially reduce the rate of brain and spinal cord degeneration by sequestering lymphocyte (types of white blood cells) populations from blood circulation in the lymphatic system.

The effect is that this would prevent any activated lymphocytes targeting your nervous system from crossing the blood brain barrier. If I meet all the criteria and do start on the protocol I will need to get baselines for various organ system functions to ascertain if the drug induces the possible side effects which may eventuate. I will then provide an update when appropriate later this year.

Thanks for reading, look after yourselves and stay well.

Adolfo Gianni

Media Release - MS Australia CEO Announcement

The Board of MS Australia is pleased to announce the appointment of a new Chief Executive Officer to guide the newly focused and amalgamated MS Australia.

Board President, Associate Professor Desmond Graham, announced the appointment of Mr Rohan Greenland as the organisation’s new CEO.

Associate Professor Graham said, “After a very comprehensive recruitment process, the MS Australia Board is pleased to secure Rohan for the role, commencing on the 14th December 2020. Rohan is an extremely impressive executive, who has dedicated his career to successfully advocating for better health outcomes for everyday Australians.

In a tough environment for the not-for-profit sector, Rohan has the experience required to help MS Australia speak with one voice about care, research and advocacy and brings an established network of stakeholders which will help our message to be heard.

Rohan brings a track record of success, particularly in relation to public health advocacy and stakeholder engagement. The Board is confident he is the best person to advance MS Australia’s core purpose: achieving the best possible outcomes for those living with MS now and in the future by enabling the delivery of care and support; funding research to seek a cure; and advocating for improved health and social outcomes and greater investment into the disease.

Rohan joins MS Australia from Palliative Care Australia where he has been CEO since February 2019. He also worked in senior advocacy roles at the National Heart Foundation for more than a decade; was Director Public Affairs at the Australian Medical Association; and was a political adviser to Australian national and territory ministers.

Mr Rohan Greenland said, “I am deeply honoured and excited to join MS Australia at an important time in its development. Its mission is critical to lives of the 26,500 Australians who are living with MS, to their families and carers, and to the nation as a whole.

MS Australia has an enviable reputation as a charity that supports world-class research, provides much needed and practical assistance to people living with MS and advocates with passion for the people it serves. I look forward to doing all I can to build on that reputation and help achieve its ultimate goal, a world without MS.

”Associate Professor Graham said, “On behalf of the Board, we would also like to acknowledge the hard work and strong leadership of both Deidre Mackechnie the outgoing CEO of MS Australia and John Blewonski who has been Acting CEO of MS Research Australia and extend our gratitude for their significant contributions to the MS community.”

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Survive the Heat

During extreme heat it is easy to become dehydrated or for your body to overheat. If this happens, you may develop heat cramps, heat exhaustion or even heatstroke. Heatstroke is a medical emergency which can result in permanent damage to your vital organs, or even death, if not treated immediately. Extreme heat can also make existing medical conditions worse.

REMEMBER AS A PERSON WITH MS YOU ARE MORE LIKELY TO BE AT RISK FROM EXTREME HEAT.

- Drink plenty of water, even if you don't feel thirsty. (But if your doctor normally limits your fluids, check how much to drink during hot weather).
- Block out the sun at home during the day by closing curtains; open the windows when there is a cool breeze.and keep yourself cool using wet towels, putting your feet in cool water or taking a cool (not cold) shower.
- Stay out of the sun during the hottest part of the day; and cancel or postpone outings.
- If you absolutely must go out, stay in the shade and take plenty of water with you and spend as much time as possible in cool or airconditioned buildings (shopping centres, libraries, cinemas or community centres).
- Wear a hat and light-coloured, loose-fitting clothing made from natural fibres like cotton and linen. Make sure food that needs refrigeration is properly stored.
- Avoid heavy activity like sport, renovating and gardening.
- Watch or listen to news reports to find out more information during extreme heat.

PREPARE FOR EXTREME HEAT DAYS by stocking up on food, water and medicines so you don't have to go out in the heat. Visit your doctor to check if changes are needed to your medicines during extreme heat. Store medicines safely at the recommended temperature. Check that your fan or air-conditioner works well. Have your air-conditioner serviced if necessary. Look at the things you can do to make your home cooler such as installing window coverings, shade cloths or external blinds on the sides of the house facing the sun.

KEEP IN CONTACT WITH FRIENDS AND FAMILY

- Keep in touch with friends and family. Call them at least once on any extreme heat day.
- Encourage any friends with MS to do the same.

If you believe you are showing symptoms of heat stress, seek medical help.

TEPP-46 Might Worsen MS Rather Than Treat It, Study Suggests

Using a small molecule called TEPP-46 to block the non-metabolic function of the enzyme pyruvate kinase M2 (PKM2) in T-helper (Th) immune cells did not lessen disease severity and redirected inflammation and neural damage from the spinal cord to the brain in a mouse model of multiple sclerosis (MS), a study reported.

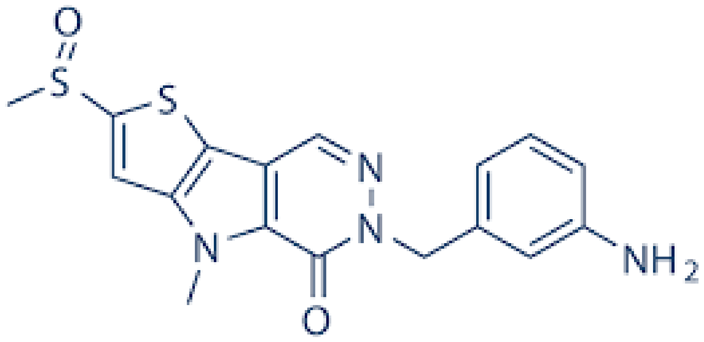
These findings challenge previous preclinical data supporting TEPP-46 as a potential MS therapy, and more studies are needed to clarify the compound's effects.

"It was not at all what we expected," Alban Gaultier, PhD, said in a press release. Gaultier is the study's first author, a neuroscientist with University of Virginia's School of Medicine and its Center for Brain Immunology and Glia.

"The take-home message is that we should be very careful and do more fundamental research before we propose to take this to clinical trials," Gaultier added.

The study, "Modulation of PKM activity affects the differentiation of TH17 cells," was published in the journal Science Signaling.

T-helper cells work by recruiting and activating other immune cells. Two of its subsets, Th1 and Th17, produce pro-inflammatory molecules — IFN-gamma by Th1 and IL-17 by Th17 — that, when present at unusually high levels, are associated with the development of autoimmune diseases such as MS.PKM2 is an enzyme mainly known for its role in glycolysis — the energy-producing metabolic reaction based on the breakdown of sugar (glucose) inside cells. However, increasing evidence suggests that PKM2 has a number of non-metabolic functions dependent on its entry into the cell nucleus, where it interacts with other molecules to regulate genes' activity.



Previous studies highlighted that PKM2 is a key factor of Th17 and Th1 cell maturation and autoimmune inflammation. While some of these data derived from the genetic deletion of PKM2 from Th cells, most were based on PKM2 suppression via TEPP-46.Originally developed to fight cancer, TEPP-46 is a small molecule that selectively prevents PKM2 translocation to the nucleus and, therefore, its non-metabolic and gene regulatory functions.

Notably, previous data showed that treating Th cells with TEPP-46 significantly reduced their maturation into Th17 and Th1 cells, and eased disease severity in a mouse model of MS called experimental autoimmune encephalomyelitis (EAE).However, Gaultier and his colleagues now show that TEPP-46 may in fact promote changes in Th maturation and activity associated with MS development.

Using Th mouse cells grown in the lab, the team found that while TEPP-46 effectively suppressed Th17 maturation and IL-17 production, it also promoted the maturation of IFN-gamma–producing Th1 cells and Th17 cells that produced a molecule called GM-CSF. GM-CSF-producing Th cells are being "increasingly recognized as contributors to MS," the researchers wrote.In addition, TEPP-46 also blocked the maturation of regulatory T-cells (Tregs), immune cells that typically dampen immune and inflammatory responses by suppressing the activity of pro-inflammatory cells such as Th17 and Th1. In MS patients, Tregs often show impaired activity or are found in reduced numbers.

These TEPP-46-induced changes in T-cell populations were found to redirect — by unclear processes — immune cells, inflammation, and nerve cell damage from the spinal cord to the brain in the EAE mouse model.

“In this animal model of MS, most of the inflammation takes places in the spinal cord,” Gaultier said. “By using [TEPP-46] and reprogramming the immune cells, we were able to move the pathology [disease features] from the spinal cord to the brain, which better mimics human disease,” he added.

This approach, while hardly a treatment, “could be very useful” in creating better mouse models of MS, he also added.

Researchers also found evidence that TEPP-46’s effects were not all associated with PKM2, suggesting the existence of other targets, which can lead to unwanted “off-target” effects and side effects.

Overall, these findings do not support TEEP-46’s therapeutic potential and its use in MS, in clear contrast to previous data. As the researchers do not fully understand the reasons behind these discrepancies, they emphasized that further research is needed to clarify them.

This article was first published in the Mulple Sclerosis News Today Newsletter and written by Marta Figueiredo

Marta Figueiredo holds a BSc in Biology and a MSc in Evolutionary and Developmental Biology from the University of Lisbon, Portugal. She is currently finishing her PhD in Biomedical Sciences at the University of Lisbon, where she focused her research on the role of several signalling pathways in thymus and parathyroid glands embryonic development.

People with MS Victoria Inc Annual Confernece

"Living with MS" Annual Conference

Saturday 1st May, 10.00am – 3:00pm
Online Event - Facebook.com/pwmsv

LIVE STREAMED

Saturday 1st May
from 10:00AM

Follow us on
facebook.com/pwmsv

4 Outstanding Speakers

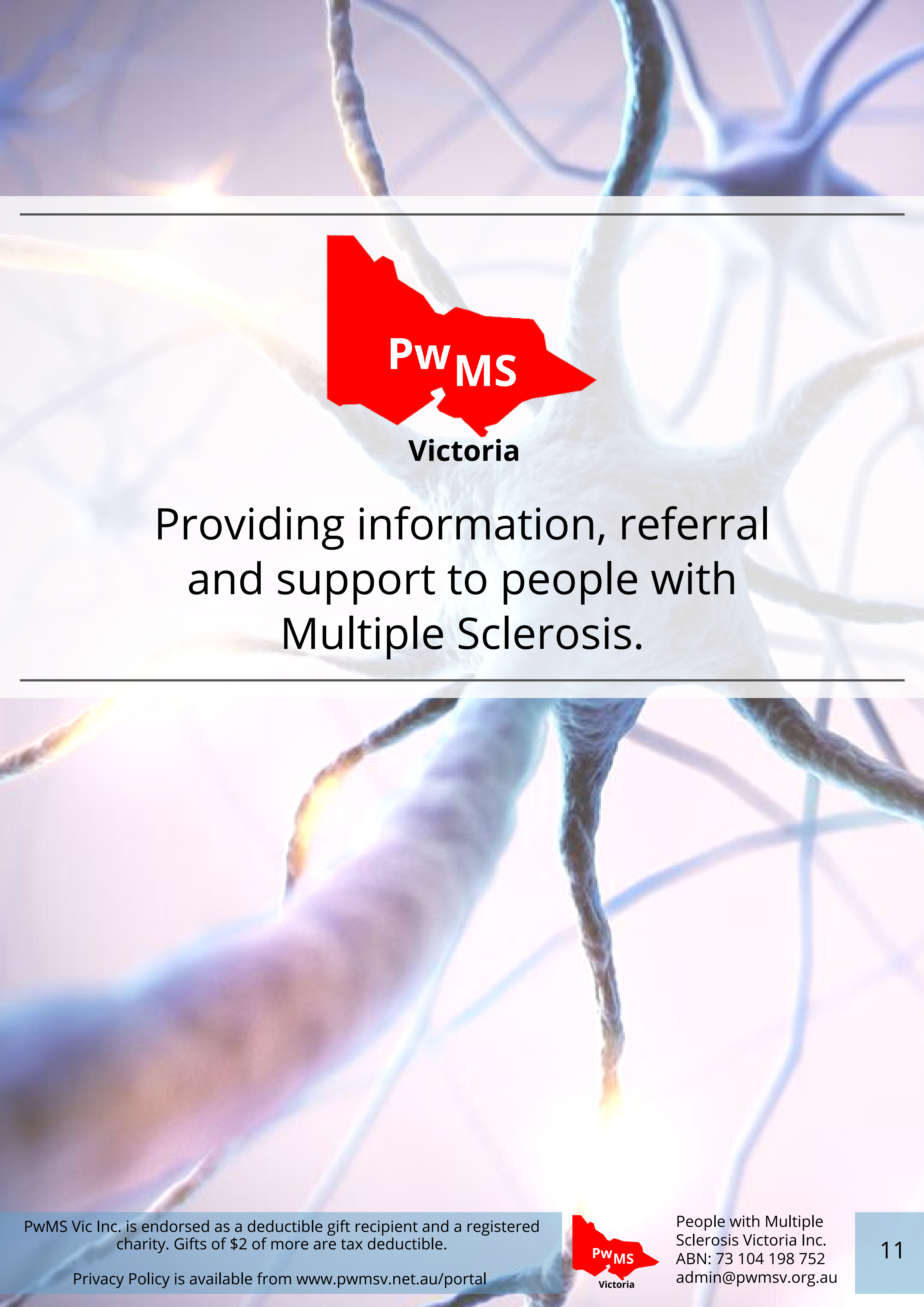
Helmut Butzkeuven
Chair of Neuroscience & Head, Department of Liu, Monash Uni speaking on current treatment & research

John Blewonski
CEO of MS Limited speaking on improvements on services for people with MS

Nicola Beswick & Raylene Carnie
Financial Planner & Financial Counsellor (both living with MS) speaking about effective money management strategies.

SAVE DATE

TICKETS ARE $10 ----- ENSURE YOU SAVE THE DATE
Watch our facebook page for further information or,
Email: msraymond@optusnet.com.au – or- Mob: 0435 085 827



Victoria

Providing information, referral and support to people with Multiple Sclerosis.