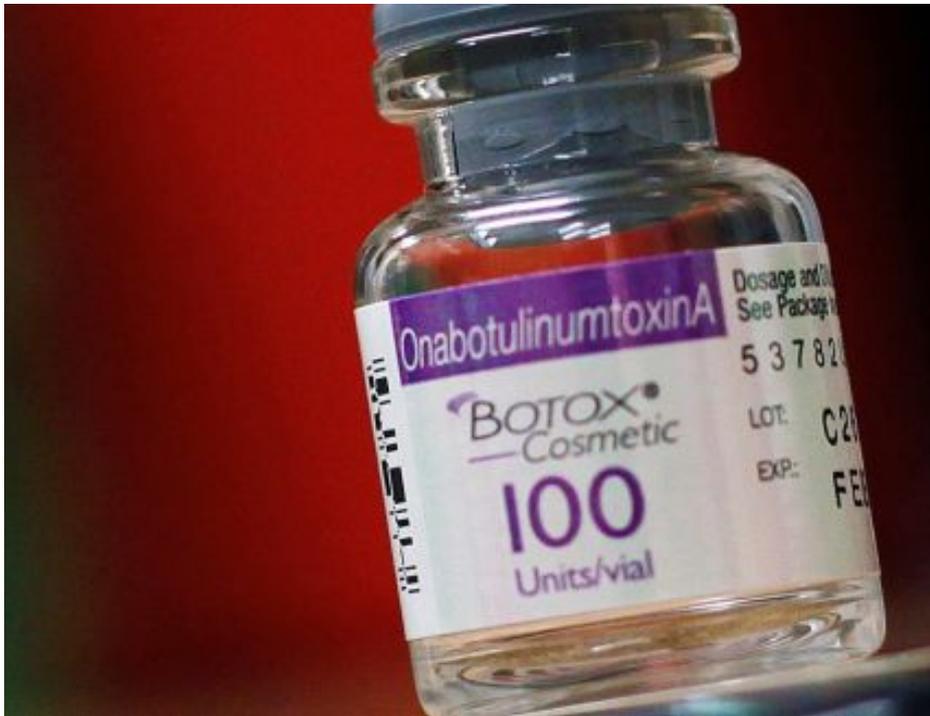




Short Circuit



Botox Approved for wider treatment of Spasticity

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..continued page 3



CLARENCE TRAVEL

Since I was diagnosed with MS in 1993, Stevie and I have travelled almost half a million km around Australia

(Page 2)



PRESIDENT LETTER

Stevie, my wife, and I usually try to get away from Melbourne's cold for a few months during the winter.

(Page 3)



Research opportunity:

"Person with MS" or "MSer"?



Should you be addressed as a person with MS or an MSer? Do you think this varies depending on who is addressing you: ie friend, professional, media? Have your say!

Click on the link or scan the code to complete a 10-15 minute survey:
https://monash.az1.qualtrics.com/jfe/form/SV_er1v2XcWADDa620

RESEARCH OPPORTUNITY

Tell us the most respectful way to refer to your health condition

(Page 5)



Travelling Australia with Nigel Caswel

Since I was diagnosed with MS in 1993, Stevie and I have travelled almost half a million km around Australia. I wrote previously about the Burrup Peninsula in northern WA. Another, very different place we also like is Iluka on the Clarence River, in northern NSW. The Clarence is the second longest inland river in Australia after the Murray, but very different. For the first 100km or so from the mouth at Iluka to Grafton it is hundreds of metres wide and navigable by quite large boats. Maybe the Murray was like this in the days of paddle steamers before we dammed it and diverted most of its flow? The Clarence is still a major source of fish, and the broad flood plain is a rich patchwork of bright green sugarcane and more recent dark green macadamia plantations.

The area was originally home to the Bundjalong and Yaegl peoples and the first European to enter the river mouth was Matthew Flinders in 1799. He noted that the native people lived in seemingly permanent villages of large bark huts with passageway entries (sound a bit like bark igloos). The area was first settled by cedar cutters in the 1830s around present day Grafton, and by 1874 had its first sugar mill at Harwood; which is still operating. The oldest operating sugar mill in Australia and the only one(?) to have a refinery attached, producing Sunshine Sugar.

The river soon became a major source of fish and by

the 1900s half the fresh fish sold in Sydney was coming from the Clarence, and the river still has the second largest fishing fleet in NSW. Half of which is based at Iluka, where we stay, meaning there is fresh caught fish on sale at the Fisherman's Co-op every day. Iluka is the smallest hamlet on the lower Clarence and home to an "amazing it's still standing" pub "Sedger's Reef" which has been serving beer since 1874. We love Iluka because it is quirky, small, quiet, friendly, and well serviced and we have a regular spot on the river from where we can watch the dolphins, pelicans and terns and wonderful sunsets

Grafton, known as the Jacaranda City, is the oldest town on the Clarence and has many heritage buildings. It is famous for its jacarandas and infamous for some of the wildest protests against fluoridation of water supplies, (in 1964 someone tried to blow-up the fluoride plant just before it was due to open). Maclean is another old river port we enjoy visiting which now claims to be the Scottish capital of Australia. Its 200 or so power poles are all painted with Scottish tartans; its streets have Scottish signs; and its highland games are over 100 years old. And then there is Yamba, just a ferry ride across the Clarence from Iluka. It is a very popular holiday centre with excellent beaches and surf; regular weekly markets; and lots of out-door cafes which are patronised by flocks of blue faced honey eaters.



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People with Multiple Sclerosis Victoria Inc.
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Presidents Letter

SPRING 2021



Me riding Gandalf

Stevie, my wife, and I usually try to get away from Melbourne's cold for a few months during the winter. We didn't last year because of COVID. This year we did, but found ourselves locked in NSW, but fortunately we were able to enjoy some sunshine and warmth never-the-less. So, I thought I would talk about some of my experiences travelling with a disability.

I was diagnosed with Primary Progressive MS in 1993 after many years of unproductive tests and depressing uncertainty. It has subsequently become clear that my MS journey began much earlier and that I have had progressive MS for at least 45 years. I am fairly severely affected from the waist down and use a walker or mobility scooter to get around. We have not let this prevent us travelling Australia.

We travel in a small motorhome christened Aphrodite which we have had converted so I can drive it "hands only" and Stevie drives it as a conventional automatic. I made the decision to convert to hands-only driving without waiting to be told I had to. It was a difficult process because the authorities are not used to someone making this choice voluntarily. And I had to get myself declared "unfit to drive conventionally" before they would allow me to convert!! However, it proved to be the right choice and I have enjoyed many years of driving since.

The first thing one notices when travelling with a disability is everyone is incredibly helpful. In fact, people often offer help when I don't need it and my inclination is to say, "no thanks". However, I believe it is better to accept than decline. Otherwise, the offerors may not be so generous in future. One should not feel that accepting an offer of assistance is any admission of defeat or any reflection on one's ability. It is simply a generous response to a generous offer.

Another thing one quickly discovers is how you can never rely on anyone else's advice as to how accessible some venue is. Able people simply do not notice small steps, not even two or three, and one is quite sufficient to stop a wheelchair or a scooter. So, I regularly carry my crutches with me so that I can get into shops and cafes. I have made carriers for my crutches on the back of my scooter "Gandalf" which essentially consist of a strap around the seat back and a container low down for the crutch-feet to sit in. These cost virtually nothing and hold the crutches as close as possible to the back of the scooter.

Toilets are another problem. Some people have a very strange idea of what accessible means. They seem to imagine that it's OK to fill the approach passage with surplus furniture or that it's not necessary to be able to turn your wheelchair round in the toilet. Have you ever tried to lock a toilet door behind you from your wheelchair! Finding a toilet in an unfamiliar area can be a real challenge. The MLAK system is OK but it could be so-much better if it was more widely advertised, and all public toilets were fitted with MLAK locks so they were accessible even after hours. Also, it is worth knowing about the National Continence Helpline "wallet card". It has the words National Continence Helpline on the front and on the reverse has Toilet Help Card. Can you please help. I have a medical condition and need a toilet urgently. Once again it needs to be widely advertised and distributed.

Despite these "little problems" Stevie and I still enjoy touring this wonderful country we live in; seeing new places and revisiting old ones and showing the "MS monster" that I am still in control of my life.

Maybe we'll see you on the road someday?
Nigel Caswell A.O., President.

Multivitamins Reduce Fatigue, Improving Quality of Life

Multivitamin supplements reduce fatigue and improve quality of life in people with relapsing-remitting multiple sclerosis (RRMS), a new study reports. The study, "Reduction in Fatigue Symptoms Following the Administration of Nutritional Supplements in Patients with Multiple Sclerosis," was published in the journal MDPI.

After 70 days of continuous use, patients taking multivitamin supplements containing vitamins A, B-complex, C, and D improved their blood antioxidant status and experienced up to a 34% reduction in fatigue; and a consequent improvement in their quality of life (QoL).

Effective treatment options for fatigue in people with MS are limited, but nutrition research suggests that dietary interventions can complement pharmaceutical therapy and potentially control MS symptoms and disease progression. Previous studies have shown that people with MS have low levels of vitamins D, B12, and A, contributing to MS severity; and have also linked diets low in folate and magnesium to increased fatigue in MS.

Some vitamins, such as A and C, function as antioxidants. Antioxidants are compounds that neutralize free radicals. When free radicals build up, they cause a condition called oxidative stress, leading to damage of cells and structures. Myelin sheaths that cover neurons are extremely sensitive to oxidative stress.

Adequate antioxidant nutrient intake, therefore, is crucial to prevent oxidative stress.

While observational studies have linked dietary patterns to MS severity, few have examined the possible therapeutic effects of adding multivitamin supplements to the diets of people with MS. Moreover, the impact of multivitamin supplements on fatigue is unclear.

An international team of researchers now sought to investigate the effect of two nutritional supplements containing several vitamins and folic acid on the antioxidant status, fatigue, and QoL in people with MS.

A total of 50 female volunteers with RRMS were recruited to the study. Participants were assigned randomly to two groups. For 70 days, one group (25 participants) took two commercial vitamin-rich dietary supplements — Citozym and Ergozym — while the second group (25 participants) received a placebo made with distilled water, honey, and approved food pigments to have the same color. Citozym contained vitamins C, B5, D, and folic acid (B9), while Ergozym contained vitamins A, B2, B3, B6, B9, B12, and biotin.

Participants' blood samples were collected to assess the total antioxidant status after 70 days. Fatigue symptoms and QoL were quantified using the Fatigue Severity Scale (FSS) and the Modified Fatigue Impact Scale (MFIS), after 5, 10, 20, 35, 50, 60, and 70 days of treatment.

After 70 days, the total antioxidant status levels were found to be significantly higher in the supplemented group compared to the placebo group. Fatigue was reduced in the supplemented group by 34% based on the FSS scale assessment and by 33% with MFIS. Interestingly, fatigue reduction was observed as early as 10 days after treatment with supplements. No significant differences in fatigue scores were observed in the placebo group.

Although previous studies investigating the use of single vitamins for reducing MS symptoms have produced conflicting studies, the researchers noted the data obtained indicates "a significant reduction in fatigue and an improvement in the QoL in individuals who received multivitamin supplementation. These clinical outcomes were accompanied by a significant increase in oxidant capacity and a reduction in inflammatory markers."

Nonetheless, the team noted that "further studies including a larger cohort of patients will be needed to confirm diet's role in this disabling symptom [fatigue] in MS."

For more information go to Multiple Sclerosis News Today 22/07/2021; Multivitamins Reduce Fatigue, Improving Quality of Life

Botox Approved for wider treatment of Spasticity

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In a press release Mitchell F. Brin, MD, chief scientific officer at AbbVie, the drug's maker, said. "This announcement is especially important because spasticity is a disabling neurological condition that can have a significant impact on a patient's quality of life,"

Spasticity, which makes movement difficult, is one of the most common MS symptoms. It can affect walking, balance, and speech, all of which can be hampered by feelings of stiffness and heaviness in the muscles. In the upper limbs, this often

Free Technology Support

Indications are sought from people with MS and/or their carers, as to whether you would be interested if PwMS-Vic was to offer a free technology support service to registered newsletter subscribers.

The proposed service would allow subscribers to have their technology problems assessed and if possible solutions found. The aim is to improve our subscribers' access to electronic communications by way of independent advice in resolving technical issues.

We have two information technology qualified and experienced volunteers with MS on our management committee who could possibly provide this service.

Register your interest by calling or sending an SMS text to Aldo Gianni on mobile 0420 331 629.

translates to a bent elbow, an arm pressed into the chest, or making a fist with the hand curled inward. These effects can significantly impact a person's ability to perform daily tasks and worsen an individual's overall quality of life.

Botox is an injectable preparation of botulinum toxin type A, a toxin naturally made by the bacteria that causes botulism, which blocks nerve activity in the muscles. It is injected directly into the affected muscles, resulting in short-term and localized muscle relaxation.

The treatment is approved for easing upper limb spasticity in patients ages 2 and older. However, it has not been shown to improve an individual's functional abilities related to their upper extremities, or the range of motion at joints affected by stiffness and rigidity.

"Botox has demonstrated efficacy and safety for spasticity management at clinically proven doses," and "This label expansion offers physicians and their patients living with spasticity another important tool as part of a comprehensive treatment plan for spasticity management," said Kimberly Heckert, MD, director of the spasticity management fellowship at Thomas Jefferson University, in Philadelphia.

For more information go to <https://multiplesclerosisnewstoday.com/news-posts/2021/08/02/botox-approved-treat-ms-spasticity-8-more-arm-hand-muscles/>

MS Research Opportunity



Research opportunity:

"Person with MS" or "MSer"?



Should you be addressed as a person with MS or an MSer? Do you think this varies depending on who is addressing you: ie friend, professional, media? Have your say!

Click on the link or scan the code to complete a 10-15 minute survey: https://monash.az1.qualtrics.com/jfe/form/SV_er1v2XcWADDa620



Tell us the most respectful way to refer to your health condition or disability.

Election of committee members for 2021-2023

Every two years nominations are invited for people willing to become members of the PwMS Vic committee. The members of the committee organise and run the organisations activities including the annual conferences the Short-Circuit newsletter, and the website and Facebook page.

They also take an active role in advocating for the rights of and services provided to people living with MS. If you would like to contribute to this very important work or you know someone who you think would make a useful contribution, please complete and submit the nomination form below.

Nominations must be in the hands of the Secretary PwMS-V Inc., no later than 29/Oct/2021

By Email at; cplatfor@bigpond.net.au;

or post at; Nominations, PO BOX 1035 CRAIGIEBURN VIC 3064;

People with Multiple Sclerosis Victoria Inc

NOMINATION FORM 2021-23

I/We.....

Being members of People with Multiple Sclerosis (Vic) Inc. hereby nominate the following member of the said Association, for Election as:

- President: (name)
- Secretary: (name)
- Treasurer: (name)
- Ordinary Committee Member
(name).....

Signature of Nominator.....Date.....

Acceptance by Nominee

I (name).....**Accept the nomination & all the responsibilities of the said position.**

Signed..... Date / / 201

Probiotic supplements could ease disability and lessen depression in MS

Extract from an article in Multiple Sclerosis News Today; by Marisa Wexler MS, August 17, 2021

Probiotic supplements could ease disability, lessen depression, and improve overall health in people with relapsing-remitting multiple sclerosis (MS), according to an analysis of four randomized clinical trials. The findings were in the paper “Effect of Probiotics Supplementation on Disease Progression, Depression, General Health and Anthropometric Measurements in Relapsing-Remitting Multiple Sclerosis Patients: A Systematic Review and Meta-analysis of Clinical Trials,” published in the International Journal of Clinical Practice.

The human body is home to billions of bacteria, many of which live in the digestive tract. These bacteria — collectively called the gut microbiome — play vital roles in both health and disease, many of which are only beginning to be understood.

Emerging research suggests that regulation of gut microbiome can be affected by autoimmune diseases like MS. This raises the possibility that steps to normalize this microbiome could be a treatment approach. One such way is taking probiotics, which are specific bacterial strains thought to be beneficial for the health of the microbiome, as a supplement.

Whether and how probiotic supplements might benefit MS patients has been investigated in clinical trials, though most have been small and of short duration, limiting their ability to draw robust conclusions. A team of researchers in Iran conducted a meta-analysis of clinical trials of probiotic supplements in people with relapsing-remitting MS (RRMS). In this type of analysis, researchers pool data from multiple published studies and analyze them collectively. Because of their varied study data, meta-analyses generally have more power to find meaningful conclusions than do individual studies.

Results showed that probiotic supplementation led to a significant decrease in Expanded Disability Status Scale (EDSS) scores, and also led to significant improvements on the Beck Depression Inventory- II , a measure of depression severity, and on the 28-item General Health Questionnaire, which assesses overall health, including mental well-being.

Based on the results, the researchers suggested that probiotic supplements might benefit some MS patients. However, they stressed that their analysis was limited by the small amount of data published, and more research is needed.

To read the full article go to <https://multiplesclerosisnewstoday.com/news-posts/2021/08/17/probiotic-supplements-benefits-rrms-meta-analysis-reports/>

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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.



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

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