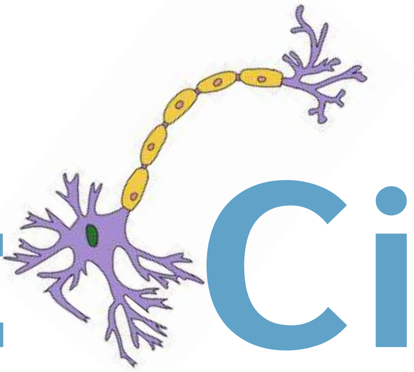
Winter Edition 2020



Short Circuit

Amargosa Opera House

Short Circuit readers will recall a previous article last year featuring Palm Springs in Southern California. While researching the town, I stumbled across an interesting site in Death Valley which is 500 kilometres (300 miles) from Palm Springs. Imagine driving for miles on desert roads in one of the hottest places on earth; you are greeted by little vegetation, expanses of mountains and hot sand until you arrive at Death Valley Junction. Here you will come across the renowned Amargosa Opera House. The theatre is lined with art, there is both a 16-room hotel and café in the classic Spanish Colonial Revival architecture which is common to the region.

The Amargosa Opera House was originally called the Corkhill Hall and was built by the Pacific Coast Borax Company, designed by architect Alexander Hamilton McCulloch, and constructed between 1923 and 1925. Originally, 350 people called this mining community home. But like many small mining towns, after the mines were closed, the town went into decline in the 1940's.

..continued page 2

Leisure Options

Leisure Options is a family owned and operated business offering holidays for people that require assistance and support during their travels.

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My COVID-19 Story

My name is Lydia. I'm forty-seven and have a twenty-seven-year history of MS. When I was diagnosed with MS, I was a medical student.

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DMT & COVID-19

Exposure to DMT not linked with increased risk of severe COVID-19

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Amargosa Opera House - Death Valley

While the town has now gone, the Opera House remains and has taken on a life of its own. In 1967 Marta Becket, a ballet dancer from New York, was travelling across the United States with her husband. Their car had a flat tyre in the township and Marta chanced upon the abandoned theatre. Deciding that the theatre would be a perfect venue, she leased the premises and repaired the Hall. Thus, the Amargosa Opera House was born.

The magnitude of the task Marta faced cannot be understated. The existing structure had been neglected, and Death Valley Junction is a highly unlikely place to start a new business venture, especially light theatre. Often in the early years there was no audience. Her first performance was presented in 1968 to a dozen or so theatre goers. However, the lack of patrons proved to be no obstacle for Marta, who proceeded to paint an audience on the walls of the Opera House. The stunning pictures are still there today.

In 1970, National Geographic journalists were on an unrelated mission, and seeking relief from the oppressive heat, sat down in the Opera House, and witnessed Marta’s performance. Impressed with the buildings, paintings and performance, international attention followed when an article featured in the magazine. Marta established the non- profit Amargosa Opera House, Inc. to continue the preservation of the property.

Marta continued to perform until 2012. In her final years, Marta would have “sit down shows” where she would reside on the stage and talk about her life and take questions from the audience. Today, the Opera House has regular guest performances and is a well-known destination for people who are visiting Death Valley. The hotel is available for bookings, and visitors can visit the café for meals and refreshments. We would love to visit!

The most important story is that of Marta's miraculous, ceaseless creative outpouring for nearly 50 years -- her resilience year after year facing the dual adversities of nature and man -- and striving to ensure that her legacy in Death Valley Junction lives on through the goodwill and generosity of patrons.

The General Manager for the Amargosa Opera House is Ms. Bobbi Fabian, and I have taken the opportunity to ask Ms. Fabian some questions. How long had she been the GM of the Opera House and what attracted her to the position; what are the challenges and benefits of desert living; where do her performers and guests originate from; and when is the off season, and what happens during that time?

Continued...

Bobbi told me she initially moved there in 2015 to open the café. She had been coming to Death Valley for about 10 years and loved the place, always feeling like she was coming home. She renovated the café and opened in 2016. Then in mid-2017, she was asked to be interim general manager, and soon after became full-time GM. Bobbi has always lived onsite and it's difficult to advertise for the position; not many people would realize what goes into taking care of a 260-acre town, and she was the obvious choice when the board of directors was looking for someone.

The main challenge is the weather. The heat in summer is quite intense but the rain is something that many people do not associate with the desert. When it rains there, it can easily flood, and they have several issues when it comes to heavy rains. However, there are several benefits which include the quiet and isolation. Bobbi says she is an introvert so very much enjoys the peace and solitude. And the sunsets and changes of seasons on the desert landscape are incredibly beautiful to observe.

Bobbi said that in the last two seasons, they have featured a diverse range of performers, predominately from the western region of the US – California, Nevada, Oregon, Arizona. There is never really an "off season". The opera house performance season is from October through May, and tours of the opera house run all year. Also, the hotel is open all year while the café is open roughly October through May.

They usually have a large influx of Europeans during the summer (July-September) and that can be the busiest time, so, really, they are busy all year!

In 2020, we are all living with the Covid-19 worldwide pandemic. Like many businesses, the Opera House, Hotel and Café has had to close its doors and is dependent on donations during this period for its ongoing survival. We hope this article will stir some interest and travel dreams for all of you, when international travel resumes. Until then strap your wings to your armchair, put on our flying goggles and take off for a virtual adventure.

Written by Chris Platford

All location photos are by Kurt Moses (published with permission)
www.amargosaoperahouse.org

Tell us how you cope with your MS or what you've achieved despite your MS. We will publish the best stories in Short Circuit to inspire others.

The best story published will receive a $200 voucher.

TELL US YOUR STORY

Presidents Letter

Winter 2020

How have you been coping with the COVID19 crisis? I have found some unexpected benefits of the crisis. For example, I hope you have been taking full advantage of the services offered by the MS organization. There are numerous opportunities for getting together in telephone groups. I have joined a couple of telegroups, one with the people I normally go swimming with every week and another with other people with MS who are over 65. They are very easy to join, call MS Connect for more details on 1800 042 138 or msconnect@ms.org.au.

Perhaps you have been getting together with friends or families on-line using ZOOM or a similar video link software. Once again this is something my wife and I have been doing; we have been linking up with our grandchildren every week and we have been linking with distant friends and having “on-line drinks”. As a result of the crisis we are seeing distant family and friends more often than before.

Another unexpected benefit of the crisis has been the growth of tele-medicine I have had telephone consultations with my GP and with my neurologist and I have booked a telehealth appointment with my continence specialist. MS is also offering telehealth services by videocalls with health professionals including physiotherapy, occupational therapy, continence assessments and exercise physiology. You can access these services with your existing NDIS funding. Again, to find out more contact MS Connect.

I hope that these telelink and telehealth opportunities continue once the crisis is over. But I recognise that many people with MS have reduced dexterity in the hands and can’t use a keyboard or a conventional mouse. If this is you then maybe an ergonomic mouse and keyboard could help. Go to Ergonomic Trends for more information.

Some of you may have noticed a bit of good news from MS-UK recently announcing that an early study from Italy suggests people with multiple sclerosis (MS) may not have a higher risk of getting a severe COVID-19 infection. Although the researchers said caution must be taken because it is still too early in the pandemic to draw solid conclusions, the results should bring some reassurance for those of us living with MS. However, this does not mean we can let our guard down!

All people with MS are still advised to pay particular attention to guidelines for reducing the risk of infection with COVID-19. Older people with MS, and those with additional health complications, mobility issues and those taking some MS treatments should take extra care to minimise their exposure to the virus.

Finally, I know many of you will have been disappointed that we were not able to run our annual **Living with MS conference** this year. You will be pleased to hear that we intend to put on a presentation in conjunction with our AGM, on November 16th , and that it will be videocast so that you will be able to watch it even if you are not able to attend the event. Look out for more information on this as it becomes available.

Keep well and keep safe,

Nigel Caswell.

MOBILITY SCOOTERS for HIRE & SALE

I have found a fantastic company in Reservoir and family owned. My small Shoprider mobility scooter I use inside had problems and I needed to hire a replacement scooter urgently. I found Mobility Scooters for Hire Sale Service and phoned on a Friday at 7pm and the owner organised his son to deliver my hire scooter a Tri-Scout 2, long wheel base and he arrived one hour later at 8pm. He also picked up my trusty little Shoprider to be repaired.

At this time on a Friday night the other companies were all already closed for the weekend. One week later my scooter was returned looking brand new and with new batteries.

OPENING HOURS
Sunday 3-5pm
Monday 9-8pm
Tuesday 9-8pm
Wednesday CLOSED
Thursday 9-8pm
Friday 9-8pm
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To qualify you must:

- Have a Health Care Card/Pension Card or be on a low income (take home income of $45,000 per year for individuals and $60,000 per year for joint applicants)
- Have lived at your current address for more than three months
- Show a willingness and a capacity to repay

For more information visit www.NILS.com.au

Leisure Options

Leisure Options is a family owned and operated business offering holidays for people that require assistance and support during their travels. From humble beginnings in 1994 Leisure Options has grown to become a true industry leader for over 25 years. During this time, the agency remains true to their mission of accessible travel for all, a key to their ongoing success.

As a boutique tour operator Leisure Options is proud to provide a vast array of amazing holidays. Each departure travels in small groups with high staff to traveller ratios, staying in quality accommodations and maximising time at each destination by avoiding extended travel times.

Leisure Options caters for people with all ranges of abilities from the very independent to those requiring 1:1 support. The friendly, compassionate and professional tour leaders work hard to ensure you enjoy a fun-filled, hassle free holiday.

Whether you want to travel with a group, have a dream destination with an itinerary created especially for you or just want some one-on-one time during respite care, Leisure Options can cater for every travel need.

When booking with Leisure Options you can be assured that you are travelling with a fully accredited, award winning travel agency that specialises in catering for all your needs. Proud achievements include multiple Victorian Tourism Awards and the agency is both AFTA and IATA members. The agency's travel industry experience is equally matched by the many years of health and disability experience that the diverse staff bring to the business.

Leisure Options is a registered NDIS provider and can help you utilise your funding towards the support costs of your holiday.

For further information please contact 03 9646 0666 or email mail@leisureoptions.com.au

MAKE THE SWITCH

Switch to a digital subscription of Short Circuit and you could win a $100 gift voucher whilst saving the environment at the same time.

Last editions winner was: Angeline Remy from Brunswick.

THE HARDER
THE BATTLE,
THE SWEETER
THE VICTORY.

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My COVID-19 Story

My name is Lydia. I'm forty-seven and have a twenty-seven-year history of MS. When I was diagnosed with MS, I was a medical student. I was fortunate to be employed as a medical practitioner for 15 years. Then, I became an aged care nursing home resident at the age of 40.

My nursing home is in lockdown because of COVID-19. I have been allowed to leave this facility twice since March twenty-fourth. I was allowed to travel to my grandmother's funeral and to an eye specialist appointment. My mum and my sister are allowed to visit for half an hour per week. We must meet in the dining room separated by a long table. Fortunately, we are allowed to drink alcohol. I drink a pale ale during that time.

I've kept myself constantly busy over this time. I have two physiotherapy sessions per week on Zoom. I've continued my weekly singing lessons on the phone.

I've become addicted to a US true crime podcast called Crime Junkie. I'm also reading an excellent Australian novel called BRUNY. I talk to Mum on the phone every day and I talk to my brother and sister a few times a week on the phone.

I look forward to our monthly teleconference with my MS Coburg group. I'm spending a great deal of time on my desktop. I'm keeping in touch with my friends via email and text. Bless the internet. Jeez, Louise, we're so fortunate that cyberspace exists.I'm trying to go into the courtyard to get some sun most weekday for about twenty minutes.

I think that as MS sufferers, we are used to coping with adversity. Every person who has MS whom I've spoken to seems to be adjusting to the current way of life with remarkable ease. I think the experience of MS makes one tougher. We are more able to manoeuvre through life's difficulties.

Won't it be good when life returns closer to normal. I'm currently singing Joni Mitchell's 'Big Yellow Taxi' with my singing teacher. The line "You don't know what you've got 'til it's gone' is so relevant to now. Relevant to every human on earth. We will definitely never forget 2020.

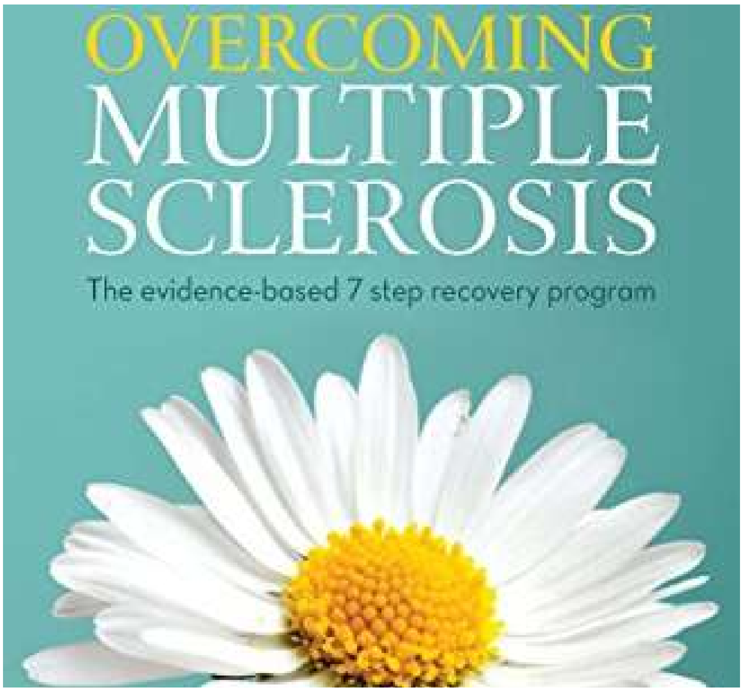
Preventing the progression of my MS

I wish to share a part of my personal journey with MS and the outcomes, but first a bit of history. Myelin is a fatty substance that is essential for the conductivity of our thoughts and instructions from our brain. It is not only found in our brain but also in the spinal column and it forms as a protective sheath around our nerves.

MS occurs when for some, yet an undiscovered reason, our immune system identifies our myelin as a foreign body and attacks it. This causes a lesion and breaks our nerve's ability to pass on the brain's instruction to our muscles.

Approximately 40 years ago two practicing American neurologist's namely Drs. Swank and Doogan were running a clinic for people with MS. They discovered that by changing the consistency of the Myelin to a more oily substance immune system ceased its attack. They commenced recommending their clients omit all foods containing saturated fat and make other minor adjustments to their diet.

The results were remarkable. Drs Swank and Doogan found this stopped their clients' MS progression dead in its tracts. Now to my personal journey with MS; I had a major attack in 1995, I suffered a high degree of fatigue for a week and the legacy of this first attack was a



However, my MS progressed quite rapidly in 1996 to where I needed a walking stick and by 1998 I had to use a walking frame; and by 2001 I was unable to walk and became wheelchair bound. It was then that I obtained a copy of Professor George Jelinek's book on Overcoming MS.

I found it quite profound and exciting. Among many of his recommendations he wholly endorsed the Swank and Doogan fat free diet. George is an MD and embraced the diet immediately upon being diagnosed with MS and has absolutely no symptoms.

It was in 2001 when I commenced the diet and..
I HAVE HAD NO PROGRESSION IN MY MS FOR 19 YEARS. AMAZING!

Your Committee has purchased a number of the books 'Overcoming Multiple Sclerosis' and whilst these books retail for up to $49.95 we are able to subsidise the cost and offer them to you for just $20 including postage.

Allen Maher

To order a copy of Overcoming MS, contact Michelle
M: 0435 085 827
P: 8351 9780
E: treasurer@pwmsv.org.au

How corona virus helped me to walk for MS

When the corona virus caused all swimming pools to close I was devastated. I have had MS for at least 45 years and possibly longer. I am largely dependent on a wheelchair to travel any distance more than 50 metres. At a push I might walk 150m using my walker and but that was my absolute maximum.

Aqua aerobics were my main form of exercise and of course closure of the pools meant this was no longer possible. So I had to find some alternative form of exercise. I decided to try and improve my walking; I would go for a walk every morning before breakfast. I started by just walking 150m each day; I live in a retirement village with large gardens and I walked from my house to a nearby fountain and back. After about a week I felt I could do more, so I added in walking part way around the bowling green next to the fountain.

As an added incentive I registered for the “MS 50km Walk” and set myself the challenge to walk more than 10km and raise $1000 during May. Every morning I walked, and golly it was cold some mornings, and I found I could gradually do more and more.

I walked a total of 14Km and raised over $2,500 during May. But what is even more important to me is I have continued to walk every morning and with the aid of my walker I can do as much as 500metres. Which leaves me completely stuffed but with a huge sense of achievement.

If this story sounds to you like me boasting, well you are probably right. But then I am surprised at what I have been able to achieve, and it wouldn’t have happened if it hadn’t been for the corona virus!

Nigel Caswell

CRISIS RESILIENCE IN PERSONS WITH MULTIPLE SCLEROSIS (C-RIMS)

MS Research aim to understand:
1. Issues experienced by, and information needs of, people with MS during the COVID-19 pandemic and the Australian bushfires
2. Ways to mitigate the impacts of crises in the MS community

For more information on this clinical trial, please visit:
https://mstrials.org.au/c-rims/

People with MS Victoria Inc 2020 AGM

“Living with MS” Conference

Monday 16th November,
10.00am – 1.00pm
The Nerve Centre, Blackburn

2 Key Speaker Sessions

**Technology
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The two speaker sessions will be preceded by a brief annual general meeting; and a light lunch will be served afterwards. Numbers are very limited, but all sessions will be streamed on the internet and you will be able to ask questions.

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Exposure to DMTs Does Not Increase Risk of Severe COVID-19 in MS Patients, Study Finds

This article with thanks from www.multiplesclerosisnewstoday.com

Exposure to disease-modifying therapies does not increase multiple sclerosis (MS) patients' risk of developing a severe form of COVID-19, according to a registry-based study.

However, MS patients who are older, obese, or have severe neurological impairments have a greater risk of developing a severe form of the disease.

Findings were reported in the study, "Clinical Characteristics and Outcomes in Patients With Coronavirus Disease 2019 and Multiple Sclerosis," published in the journal JAMA Neurology.

MS patients are a population of particular interest during the pandemic because most of them are actively taking medications that suppress the activity of the immune system, which may increase their chances of being infected by the severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2).

In its COVID-19 recommendations released in March, the Multiple Sclerosis International Federation stated that "some MS medications might increase the likelihood of developing complications from a COVID-19 infection but this risk needs to be balanced with the risks of stopping treatment."

However, it is still unclear at this point if the use of disease-modifying therapies (DMTs) — medications that reduce the activity of the immune system to keep inflammation in check — increases the risk MS patients have of being hospitalized with a severe form of COVID-19.

To address this question and identify risk factors that could be associated with severe forms of COVID-19 in MS patients, a group of French investigators carried out a registry-based study that included data from 347 MS patients (mean age of 44.6 years) who received a confirmed or highly likely diagnosis of COVID-19 between March 1 and May 21.

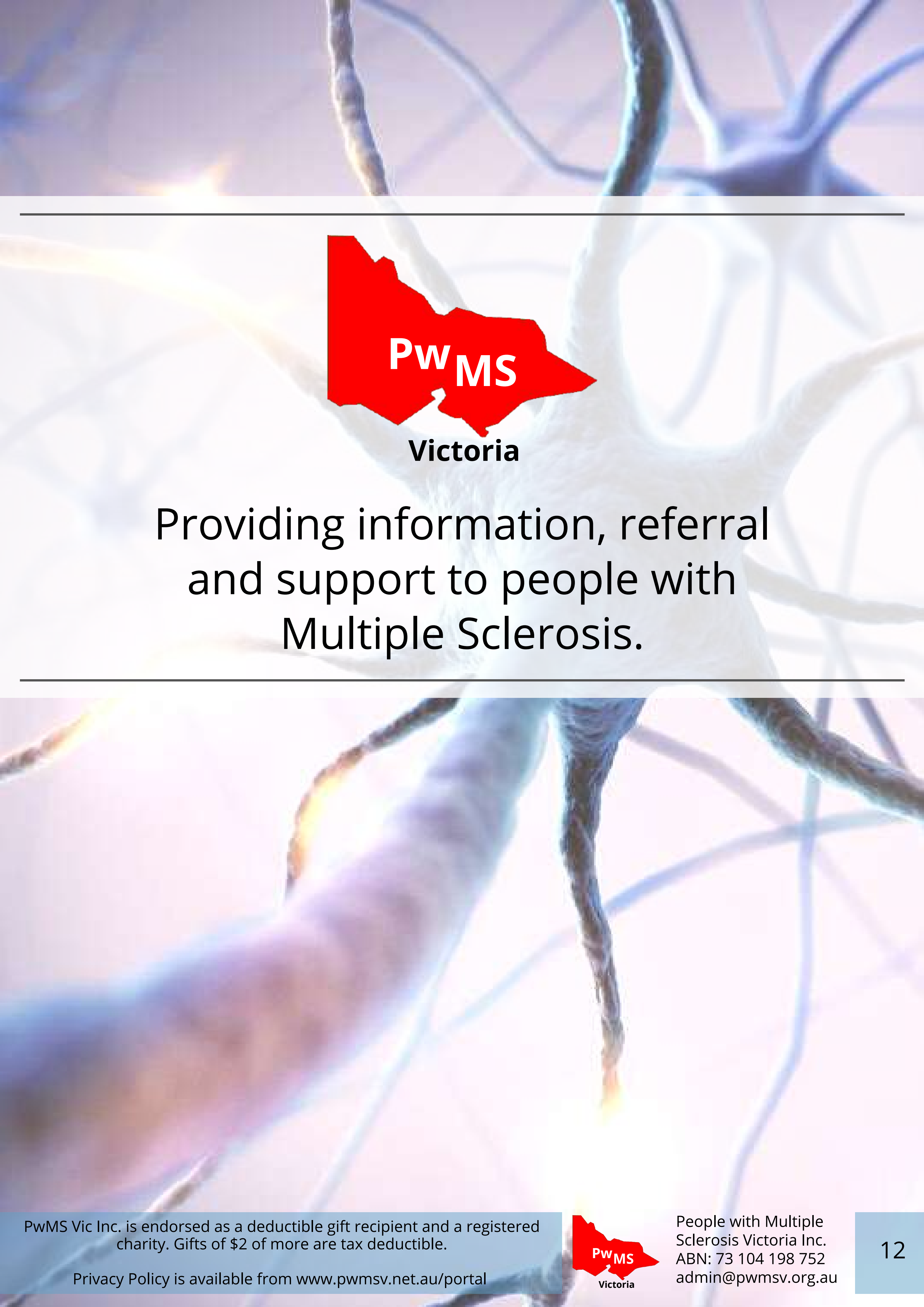
Patient data was part of the Covisep registry, a multicenter registry that contains clinical information gathered from patients followed at MS expert centers and general hospitals, with support from neurologists and members of the Société Francophone de la Sclérose en Plaques in France.

As part of the study, investigators collected a series of demographic and clinical information from patients, including their neurological history, comorbidities, degree of disability imposed by MS, and COVID-19 severity.

The extent of patients' disability was determined using the expanded disability status scale (EDSS). COVID-19 severity was evaluated using a seven-point ordinal scale, with a cutoff threshold at three, meaning that those scoring three or higher had a severe form of the disease. (A score of 3 means hospitalized but not requiring supplemental oxygen, while a score of 7 represents death.)

Statistical analyses were used to evaluate possible relationships between the different characteristics analyzed and COVID-19 outcomes.

To read further on this article by Multiple Sclerosis News Today, visit the article link here: https://multiplesclerosisnewstoday.com/news-posts/2020/06/29/



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