



# Armchair Travelling

Each quarter we will try to bring unique places that most Australians have not visited. The Fareo Islands are one such place. The Fareo Islands are located halfway between Scotland and Norway in the middle of the North Atlantic Ocean. The islands themselves operate semi independently but are part of the Kingdom of Denmark. The land mass constitutes about 1,400 km with a population nearing 52,000 Faroese.

The terrain is rugged, there are a lack of trees and the climate is sub polar, overcast, often windy with wet and cool conditions throughout the year. Temperatures average 5'C in Winter and 12'C in Summer. The Summer days during May and August bring "white nights" when light occurs most of the time, and in Winter during November to January, darkness rules. This is not the place to visit for poolside cocktails, banana lounges and beach umbrellas.

..continued page 2



Welcome to a new decade; the 2020's. Judging by the way they've started the 2020's may be just as roaring as the 1920's but for very different reasons.

(Page 3)



#### **Data for Inclusion**

The folks at Data For Inclusion (DFI) believe technology should be easy. They believe that when it isn't, then it's the developers' fault, not the users, who are typically blamed.

(page 4)



delighted to have opportunity to give back to the MS community, considering the amount of support and opportunities I've received from the community before.

(Page 4)

PwMS Vic Inc. is endorsed as a deductible gift recipient and a registered charity. Gifts of \$2 of more are tax deductible.





# **Armchair Travelling to unusual Places**

Getting around the Islands is by road with much of the Island connected by a series of spectacular tunnels though the mountains, between islands (subsea) and ferries between islands not connected by road. While the native language spoken is Faroese, the Danish language and English is also spoken.

Major economic drivers include the fishery industries and tourism. Tourism to the Faroe Islands is actively encouraged with guides for hiking, boat trips, road trips, fishing, bird watching, bike riding among the encouraged activities. There is an excellent web site for tourism provided. https://www.faroeislands.com/

For the Multiple Sclerosis community, the Fareo Islands holds a special significance. Before World

War 2, there were no documented cases of the disease on the Islands. During the War, British troops were stationed on the Islands and after there were four Multiple Sclerosis epidemics in proximity to the British encampments. A conclusion was that somehow the troops had introduced an pathogenic organism to the Island.

For the intrepid traveller, this country might be the ticket for a unique travel experience, oddly connected to Australia by marriage - Mary, Crown Princess of Denmark (soon to be Queen as long as there are no Royal disasters) but if it seems all too much, sit back in your recliner, turn up the air conditioner, switch onto You Tube and become an "Armchair Traveller".

By - Chris & Susan Platford



Make a Tax Deductible Donation\* to PwMS Vic Inc. an endorsed as a deductible gift recipient and a registered charity.

\* All Donations of \$2 or more





# Presidents Letter Autumn 2020

Welcome to a new decade; the 2020's. Judging by the way they've started the 2020's may be just as roaring as the 1920's but for very different reasons. This could be the decade when our climate begins to bite us back very hard for our refusal to take seriously the many warnings we've had, and our political leaders' unwillingness to lead us along a path of environmental sustainability.

The fires this summer have been simply horrifying, and the damage done to people's homes, to small businesses, to native forests and plantations and to our wildlife is truly shocking. I hope that very few of you have been directly affected. I cannot imagine what it would have been like to be caught up in the fires for someone who is already living with a disabling chronic disease.

One of the many lessons authorities have learnt is how badly off rural areas of Victoria are for specialist services. Hopefully we will see an improvement in this area as a consequence. One of the good things has been the way the whole community has responded to help those whose homes or livelihoods have been damaged or destroyed. Let us commit to continuing to support one another for the many years it will take to bring those fire damaged areas back to life. And let us commit to redoubling our efforts to reduce our impact on the environment: use less, waste less and recycle more.

Now we have the challenge of Corona Virus or COVID 19. The Guidelines on how to respond to this are changing by the hour so I will not attempt to detail them here but recommend that you refer to the MS Australia website and read Advice for patients with multiple sclerosis and related disorders regarding COVID-19 outbreak.

Most importantly do not panic and do not make any unilateral changes to your medication without first consulting your neurologist or GP, and protect yourself by observing good hygiene practices;

- avoiding unnecessary public gatherings
- covering your coughs and sneezes with your elbow or a tissue
- disposing of tissues properly
- washing your hands often with soap and water, including before and after eating and after going to the toilet
- using alcohol-based hand sanitisers
- cleaning and disinfecting surfaces

If you develop a high fever, cough, or have difficulty breathing, avoid contact with others and inform your neurologist or doctor without delay.

Unfortunately the Corona Virus outbreak has meant we have had to cancel our annual conference which was to have been held on May 2nd. We had three excellent sessions planned and we hope we will be able to put it on later in the year possibly in November. We are seeking approval to carry forward the grant we received.

Finally let me finish on a positive note; it is exciting to read that MS Research Australia has awarded \$2.4 million in new MS research grants commencing in January 2020. This forms part of MSRA's expected \$4.1 million commitment to MS research funding for 2020. The 19 new projects focus on key areas such as vitamin D, Epstein-Barr virus (EBV), gut health, fatigue and depression, cell therapy and myelin repair. Also there are a number of international research projects trialing treatments which show potential to repair myelin.

Here's wishing you a happy and prosperous 2020's decade.

Nigel Caswell O.A.M., BSc. Eng.



# **New PwMS Editor**

I'm delighted to have the opportunity to give back to the MS community, considering the amount of support and opportunities I've received from the community before.

Living with MS for around 12 years, I've passionately been involved in fundraising and awareness, throwing myself into MS events over the time whilst also continuing to work to support my family.

As work has given me a lot of satisfaction it has also meant that balancing my volunteering engagement has been difficult. When I saw the opportunity to be involved as editor with PwMS it was the perfect fit to allow me to continue to be engaged and volunteer in the comfort of my office or home.

Playing football was my passion before MS. I played with Port Melbourne VFL team for several years before I started getting some double vision, which later turn out to be, you guessed it, Multiple Sclerosis.

My working career has seen me working with groups such as Crust Pizza, Emirates Leisure Retail in senior executive roles and more recently



as CEO for a Non-Profit organisation called Lord Somers Camp & Power House where I lead a social enterprise funded group with a focus on creating a stronger, more inclusive society.

My wife, Leanne has been my major supporter and my young family including daughter Quinn who is 6 and son Max who is 3 keep me laughing and young.

I'm excited to be involved and I hope I can do my small bit in gathering information from a dedicated group of volunteers at PwMS to be read by you, our readers.

# **Making Life Easier with Free Technology**

The folks at Data For Inclusion (DFI) believe technology should be easy. They believe that when it isn't, then it's the developers' fault, not the users, who are typically blamed.

DFI's aim is to provide practical, easy to use technology that helps people retain more control over their lives. They provide tools to support both users and carers.

Each team member in DFI has been personally affected by someone close to them with an illness or vulnerability. This is what inspires their work and commitment to releasing products free of charge.

Debra Roberts from DFI is able to demonstrat the DFI tools that support people with MS. These include support for people with hand tremors, involuntary movements, speech, memory, mobility or vision difficulties.

Debra can show some of the tools that DFI have available now and can give us an advance preview of what's coming.

These include products designed to help you:

- save money on medication
- communicate with less effort
- be more in control
- protect yourself against making mistakes
- remember more for health professional visits
- cook with less effort & less cleanup
- when going out to find out more about the suitability of a venue for your needs



Find out more visit Data For Inclusion at www.getdfi.com



admin@pwmsv.org.au

# **New Treatment Research Underway**

Dr Steven Petratos and his team are trying to turn back the clock in MS. MS is caused when the immune system attacks and damages myelin the insulating sheath on nerve fibres. This damage impedes nerve signals travelling along nerves and leaves the cells vulnerable to degeneration. The disruption of nerve signals results in MS symptoms.



Currently, there are no therapies which can repair or restore damage to myelin, relapsing-remitting MS there are a number of

therapies which can inhibit the immune system, but for progressive forms of the disease there are only limited treatment options. Dr Petratos is looking to repurpose a drug (DITPA) already approved for use in a rare neurological condition. He has already shown that this drug may slow the progression of MS in a laboratory model of MS, and that it might enhance the body's ability to repair the myelin sheath and repair some of the damage caused by MS, which might help turn back the clock in MS.

Dr Petratos will investigate the mechanisms by which DITPA works and how it might help regenerate the myelin sheath, his early work suggests that this drug might help generate new cells which can repair the damage. If this project is successful and the drug is shown to be safe and has a clinical impact, it is hoped that it could enter clinical trials in people. It is hoped that its development could be accelerated due to the fact it is already in clinical use for another disease.

### TELL US YOUR STORY

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

The best story published will receive a \$200 voucher.

Send your stories by email to the editor - pwmsv1@outlook.com The winner to be announced at the AGM





### NNER WINNER WINNER

### **Wendy Smith**

Congratulations Wendy, you're the winner of a \$100 Coles Gift card for switching to e-newsletters.

Fancy switching yourself, and having a chance to win a gift card? Email admin@pwmsv.org.au today!



Victoria

# **Concession Support**

#### **VICTORIAN CONCESSION BOOKLET**

Lists all the concessions currently available in Victoria To receive the booklet phone 1800 658 521 (toll free) and press 5 for General Concessions.

#### **DISABLED PERSONS PARKING PERMIT**

Entitles you to park in a disabled person's parking space Application forms available from your local council.

#### MULTI PURPOSE TAXI PROGRAM WHEELCHAIR / SCOOTER

Entitles you subsidised taxi fares, for information contact CPV Victoria Ph: 1800 638 802 www.cpv.vic.gov.au. Application forms are now filled in by your GP. You will need to make an appointment with your GP.

#### **RACV EMERGENCY WHEELCHAIR & SCOOTER ASSSIST**

Annual charge \$30.00

General enquiries 13 72 28 Roadside assist 13 11 11 Usually it is very easy to get you moving again, but if for some reason they cannot fix the problem, a taxi/maxi taxi will be dispatched to transport you to your home address or chosen destination. A total of eight service calls per annum are available and this includes pumping up tyres on wheelchairs and scooters. Unfortunately this service cannot include assistance in lifting a person out of a wheelchair.

#### **CAR INSURANCE - Notify VIC ROADS 13 11 71**

Also notify your insurance company if you are driving and have MS. If you have an accident they can refuse your claim.

#### PHOTO IDENTIFICATION CARD

The Photo ID card can be used where a signature is required. Contact MSL at the Nerve Centre, 54 Railway Road, Blackburn on 9845 2700 A normal passport photo can be used to fit the space on the application form, nothing larger.

#### **COMPANION CARD**

The Companion Card is for people with significant, permanent disability who can demonstrate they need high-level support from a carer when attending most community activities or events, and that this need is life-long. The card contains a photograph of the cardholder and can be presented when booking or purchasing a ticket at events and venues. The participating organisations will issue the cardholder with a second ticket for their companion at no charge.

Email address: www.companioncard.org.au

If you are unable to download the form, please contact the Companion Card program on 1800 650 611 and request an application form. Mon-Fri 10am-2pm.



#### **CONTINENCE AIDS PAYMENTS SCHEME (CAPS)**

Eligibility for CAPS, clients diagnosed with a neurological condition DO NOT need a PCC/HCC to qualify. To obtain an application form phone the NATIONAL CONTINENCE HELP LINE 1800 330 066. For CAPS application and payment inquiries contact Medicare Australia 13 20 11 select option 2

#### MEDICAL COOLING CONCESSION

Ph: 1800 658 521

The electricity account holder must be PCC/HCC eligible. The Medical Cooling Concession provides a 17.5% discount on mains domestic electricity usage and service costs between 1 November and 30 April for concession card holders with multiple sclerosis and other qualifying conditions.

*Note*: During this period the Medical Cooling Concession is given in addition to the Annual Electricity Concession. For an application form phone your electricity retailer or the Victorian Concessions 1800 658 521 (toll free).

#### **ESSENTIAL MEDICAL EQUIPMENT PAYMENT**

The Essential Medical Equipment Payment is an annual payment for Australians with higher than average energy costs because they rely on essential medical equipment in their home. For more information and to apply visit www.humanservices.gov.au/emep

#### WINTER GAS CONCESSION

Account holder must be PCC/HCC eligible. The concession is available over the winter period of 1 May to 31 October each year. Provides a concession of 17.5% of gas usage and service costs. Phone your gas retailer and give your concession card details over the phone. Please read the Victorian Concessions booklet for more detail. 1800 658 521 (toll free).



### **Concession Support**

#### **MOBILITY ALLOWANCE**

https://www.servicesaustralia.gov.au/individuals/services/ce ntrelink/mobility-allowance A payment to help with travel costs if you can't use public transport. To receive the Mobility Allowance the person must be either working, training or volunteering a total of 32 hours per month. (Volunteering must be with a Charitable Institution.) Entitles you to a Health Care Card. Note: You can't get the Allowance if you have either:

have a plan with the National Disability Insurance Scheme (NDIS), or have a car from the Department of Veterans' Affairs

#### MAIL HOLD AND REDIRECTION

Australia Post provides a reduced fee for redirecting mail to a new mailing address for up to 12 months for eligible cardholders.

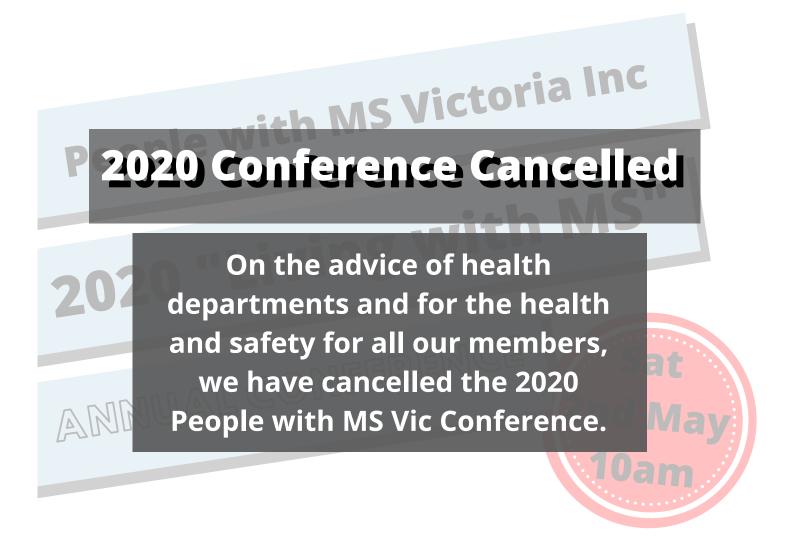
#### STAMP DUTY CONCESSION

Available to first home buyers when they purchase a new or established property in Victoria with a dutiable value up to \$600.000. A sliding scale of partial exemptions is available for properties with a value of more than \$600,000, but not more than \$750,000. This concession is available once in a lifetime. Your conveyancer or solicitor will usually apply for the exemption, concession or reduction. State Revenue Office 13 21 61 Visit www.sro.vic.gov.au

#### **DENTAL SERVICES**

Public dental services are provided through the Royal Dental Hospital Melbourne and 79 clinics across Victoria, operated by community health and rural public health services. For more information and to apply: Dental emergencies, phone Dental Health Services Victoria on 03 9341 1000 or 1300 360 054 (country callers).

General enquiries, phone 03 9341 1000 or 1800 833 039 (country callers). Please read the Victorian Concession booklet 1800 658 521 (toll free) Visit www.dhsv.org.au





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

