No 264 May 2018

Mornington Peninsula Post-Polio Support Group

Next meeting: Saturday, May 12, at 11am at the Information office, Mornington, cnr Main and Elizabeth Sts, rear of the building. The next social outing could be dinner or lunch on May 22, depending on weather and availability. For the record: meetings are held on the second Saturday of raw month, with outings - lunch or dinner - on the third Tuesday unless the meeting date is mid month. Please contact the secretary for confirmation, venue and details, or if you need a lift.

In this edition

Most of us being too old for support from NDIS need to apply for an Aged Care assessment and package. While there is a significant waiting list, more funding is expected in the Federal budget. For information on the packages and how to get them - p3/4.

The Australian Electoral Commission has proposed to change the name of the seat of Melbourne Ports to Macnamara in recognition of the work of scientist and polio specialist Dame Jean Macnamara. Seeing this as a fine opportunity to raise awareness of post polio syndrome submissions have been made in support of the change. Those submissions from P5-7.

Polio virus apparently killed dopamine producing neurons in the brain but researchers are finding new ways to restore memory.

Meanwhile another happy band of researchers have found that a low mental energy may affect walking patterns. P8

Stay alert out there - Ed

Daughter of Dame Jean Macnamara, Merran Samuel with the portrait of her mother by Peter Churcher. Merran has been delighted by the recognition of Dame Jean by the AEC Commissioners.

Secretary's notes

AT the April meeting Treasurer and Secretary reviewed the membership lists to ensure we were not continuing to send newsletters to people who have moved, resigned or are deceased. The list remains surprisingly healthy thanks to new members.

We hope to find many more local polio survivors with the appointment of a Community Worker by Polio Australia and Polio Network Victoria for Victoria under a pilot plan, thanks to funding from Jill Pickering. The appointee is Stephanie Cantell, who comes from an Occupational Therapy background. Her role will be to work with the post polio community, attending meetings and workshops to help find people who have not come forward, raising public awareness of post polio.

Thanks to Bruce's accounting, a clear income for the book with postage costs separated allowed us to move to give a further $1500 to PNV for this year's Polio Day. We have now contributed a total of $2500 with a healthy balance continuing to grow.

The Secretary has nominated our group for a Delys Sergeant Age-Friendly Award through Mornington Peninsula Shire for the book project. Aim is to further raise awareness of post polio - and sell more copies of course! Had a cheery response congratulating us on the effort.

Convenor Ian Bladon encouraged those attending the April meeting to talk about what they did over Easter. After that Wendy Bladon talked about her impressions of the Bayside meeting on Dealing with the System: Aged Care Packages etc. Wendy was most impressed by the number of polios attending (around 50) and the speakers. Ian has been to Polio Services Victoria and was impressed by the efficiency and friendliness of the team. He had a two hour appointment so was thoroughly assessed. We encouraged Graeme to make an appointment as his left leg is much weaker. He has been reading Polio Paradox, excited by the wealth of info.

No-one was available for the April lunch which was subsequently abandoned with the Secretary diverted to Frankston Hospital with her Ian. He had a fall, leg infected, then pneumonia, but is home and much weller now. We discussed briefly the benefits of lunch or dinner outings during winter. We could also consider morning or afternoon teas at different locations to reduce effort.

Polio Network Victoria meeting:

Fran attended the April meeting of PNV at West Footscray in her role of editor of *Polio Perspectives*. The first stand alone edition has been printed and should be in the post directly. Given challenge of travel in winter months it was decided to hold PNV's meeting via teleconferences for the June and August.

Site visits are to be undertaken for this year's Polio Day, due to be held in the metropolitan region after last year at Bendigo. The theme is We'e Still Here with speakers likely to tackle the mire of Aged Care Packages (18 month waiting list for assessments).
See story P3/4

Susan Shaab was the Post Polio Victoria representative at the meeting. Susan said PPV has received a Continuity of Support grant from DHS to buy equipment and help with publication of the newsletter.

The PNV meeting also decided to apply to take part in this year's Seniors Festival in October at Fed Square to help raise awareness.

Budget to focus on funding more at-home aged care

By ABC political correspondent Louise Yaxley May 2

Cutting the waiting list for older Australians needing aged care in their own homes will be a focus of next week's federal budget.

More than 100,000 people are waiting for an aged care package, which provides up to $50,000 to spend on a range of services at home, rather than needing to move to a nursing home.

Home-care package levels

Basic care needs yearly subsidy up to approximately $8,000
Low level care needs - subsidy up to approx $14,500
Intermediate care needs, subsidy up to approx $32,500
High-level care needs subsidy up to approx $49,500

(The yearly subsidy value is paid by the Government to a provider chosen by the individual. The maximum Government contribution increases each year.)

Source: myagedcare.gov.au

Most of those people are waiting for one of the two highest-level packages and the delay can be for more than a year. Some of that group have been given a lower level of services as an interim measure, which means they receive either $8,000 or $15,000 a year.

Federal Labor has been highlighting the plight of people with dementia who are among those with the need for high-level services.

ABC News understands the budget will focus on about 60,000 people who have been approved for support but have not received any funding.

Aged Care Minister Ken Wyatt has described home care as an "absolute priority”.

"As a Government, we have heard very clearly from senior Australians across the country that they want to receive aged care services in their homes," Mr Wyatt told the National Press Club.

Demand for home services growing

The demand for services at home is growing much faster than for places in residential aged care facilities. Canberra pensioner Val Dobson, who has bad arthritis and heart problems, waited a year for her home care package to be approved.

Sector expectation for older Australians to pay more

However, the review of aged care report prepared for the Government last year warned it is not easy to accurately measure the demand for aged care places.

The report said:

While accurate assessments of demand are yet to be developed, the available evidence, including advice from sector stakeholders, reliably shows two things:

- There is a need for more high-level care at home
- Meeting projected future demand will need additional investment by government beyond that currently planned

But funding that will be a test for the Government, which already spends $20 billion a year on aged care. Within the sector, there is an expectation aged Australians will be asked to pay more.

Leading Age Services Australia's Sean Rooney said: "Part of the cost of providing care for older Australians needs to be met by the people receiving those services.”

Council of the Ageing's Ian Yates said: "We have a situation where either the Government has to pay more, or the users of the service has to pay more, or probably some of both.” The clear preference for older people to stay in their own homes rather than move to a nursing home has increased the demand for respite services for family members who have been caring for them.

Commonwealth Home Support Package - details

https://www.myagedcare.gov.au/help-home/home-care-packages

Approx 30%-40% of the subsidy will be deducted in Admin/ Advisory Fees. Rate for services vary between Service Providers and types of service/care.

Example of average costs a service provider for a fully managed **Level 2 Package** (subsidy $14, 500pa)

Weekly Subsidy	$ 284.55
Administration Fee	$ 51.22
Core Advisory -	$ 42.68
Available per week	$ 190.65

The annual benefit for a level 2 package is approx $9900 you do not have to spend it all in one year and can preserve some funds to purchase/ rent / pay out of pocket expenses for items such as Calliper repairs/ replacement, power chairs, adjustable beds SWEP Client contributions.

First Step

To find out if you are eligible for a home care package or any other help at home services, call My Aged Care on 1800 200 422.

The My Aged Care contact centre will ask you a series of questions to determine if you need an assessment by an Aged Care Assessment Team (ACAT).
Be honest tell the operator on the phone all about your condition, your prognosis and your living arrangements and ask for a commonwealth home support package
If you do not pass this gate keeper no next step.
Next step maybe a phone call from:

- *Local contractor/council worker to assess your needs. Fail this test no home assessment. So be fully honest about about your condition, your prognosis and your living arrangements and ask for a commonwealth home support package*
- *Local contractor may arrange home visit reiterate about your condition, your prognosis and your living arrangements and ask for a commonwealth home support package*
- *ASK for an Aged Care Assessment Service **ACAS** Review to assess the level of home support*

Next step should be a letter from the local contractor/council worker to confirm what was discussed a confirmation that ACAS will be in contact
Next step should be a phone call from ACAS to arrange a home visit
reiterate about your condition, your prognosis and your living arrangements and ask for a commonwealth home support package

Next step should be a home visit from ACAS
The person from ACAS will be knowledgeable about heath condition and I strongly suggest honesty and that you reiterate about your condition, your prognosis and your living arrangements and ask for a commonwealth home support package. Show them your home, where you sleep, your garden, your challenges.
When asked what you would like from a package. Be specific if you can about personal care, and I also strongly recommend that you explain what is hard/ impossible/dangerous for you around the home, whether is is toileting, shelling the peas or just exiting the front door.
The range of services are extensive and include such things as showering, taxi vouchers, gardening, help with shopping and getting to medical appointments – a myriad of things to enable you to say out of residential care in your own home.

Next step should be a letter from MY Aged Care confirming assessment from ACAS and their recommendations
Next step if a commonwealth home support package is recommended
•A contribution assessment by Centrelink - Most pensioners will not have to contribute to the their package. Some self funded retirees may need to make a contribution - but what ever the contribute will be capped and most like the benefits will out weight the costs.

Next step will be a long wait for the assignment of a Commonwealth Home Support Package - **1 - 2 years is not an uncommon wait so get on the list now!**

Once a package is assigned you will have 58 days to nominate a service provider .
From: https://www.myagedcare.gov.au

Submissions to the Australian Electoral Commission for the new seat of Macnamara

Among the redistribution and renaming of Federal seats, the seat of Melbourne Ports is proposed to be renamed after Dame Jean Macnamara, renowned scientist and polio specialist. Dame Jean's daughter Merran Samuel was keen for the polio community to support the move. Individuals and polio organisations (Polio Australia, Polio Network Victoria, Post Polio Victoria) have made submissions as this is rare recognition for Dame Jean and those of us who she rightly predicted "will pay for this later". The following submissions offered insight into her contribution:

From Peter Willcocks - Bayside Polio
Dear Commissioners,
My submission is in favour of the renaming of Melbourne Ports to Macnamara.
I applaud the commission for making the recommendation for change. The electorate of Melbourne Ports' prime industry is no longer that of shipping.

The renaming of Melbourne Ports to Macnamara is an inspired opportunity to raise awareness of the work of Dame Jean Macnamara. She was not only a medical practitioner, a scientist, a polio specialist but most importantly an advocate for social change. She created awareness of social inclusion and educational opportunities for those deemed at the time less academically capable.

I am one of the tens of thousands of Australians who had paralytic polio. I am indeed in her debt, not so much for her work as a doctor but more from her way of doing things that recognised polio survivors as people who can live a full life. Prior to her inclusiveness, women who had polio were discouraged from marriage and having children, boys were discouraged from 'men's' work and study. As disabled we were directed to nonchallenging sedentary tasks.

I am fortunate to have discovered some of the work of Jean Macnamara as part of study some years ago into the social and economic impact of infectious disease in Victoria.

The young Jean Macnamara graduated with a Bachelor of Medicine and Bachelor of Surgery from Melbourne University in 1922. The network had begun, she graduated with other notables of 20th century Dame Kate Campbell (Paediatrician), Lucy Bryce (Haematologist and medical scientist), Jean Littlejohn (Ear, nose and throat surgeon) and Sir Macfarlane Burnet (Nobel prize 1960 for medical research).

One of the significant differences in the career of Dr Macnamara was her personal commitment to people who had polio which began in 1925 as medical officer responsible to the Poliomyelitis Committee of Victoria. In 1925 it was accepted that there was no cure for polio, treatments varied many of which resulting in lasting legacies of pain, crippling and isolation; children that had polio were treated as victims and in the main deemed of little potential for employment to be hidden from society.

By 1938 Dr Macnamara was widely published, had developed research partnerships not only in Australian but also in America and England. She had inspired our top scientists, politicians, fund raisers, fellow practitioners, trainee physios and the very people care was direct at, those that had polio to find a cure to find a vaccine. Though 'a cure' still alludes us, it was due in some part to some of her earlier research into the virus that led to that great day in 1956 when our first Jonas Salk polio vaccinations began in Victoria.


Dame Jean Macnamara, portrait, Peter Churcher.

In 1937-8 there were 2276 notifications in Victoria of poliomyelitis. Of the many articles on and by Dame Jean Macnamara, the following 1938 article in 'The Gippsland Times' shows the extent of depth of her reporting, of the esteem in which she was held and her worthiness of the renaming of Melbourne Ports to Macnamara.

"Victorians on their mettle - This is the first epidemic (1938) in Victoria in which we have the facilities to give each child anything like ideal treatment. In the past – 1931 for example we had to choose between giving a few a splendid chance and neglecting the remainder or trying to ensure that everyone was cared for as well as we could. We then chose the last-mentioned alternative..."

Your sincerely, Peter Willcocks

Re: Renaming of Melbourne Ports to Macnamara - from Polio Australia

Dear Commissioners,

On behalf of Polio Australia, this submission is **in favour** of the renaming of Melbourne Ports to Macnamara. Polio Australia is the national peak body representing polio survivors throughout Australia, most of whom have benefitted from the work done by Australian medical doctor and scientist, Dame Jean Macnamara, either directly or indirectly.

'Dame Jean' was best known for her contributions as a consultant and medical officer to the Poliomyelitis Committee of Victoria 1925-31. During the 1937-38 polio epidemic, she worked with Frank Macfarlane Burnet to discover that there was more than one type of poliovirus (British Journal of Experimental Pathology, 1931). Although the Salk and Sabin vaccines would not be available until after the mid-1950's, Dame Jean's contribution to this eventuality was significant. At this time, Australia is polio free, purely thanks to ongoing immunisation.

Whilst the two polio vaccines marked the end of polio epidemics, there are many thousands of children (predominantly) who contracted polio during the regular epidemics of last century. A great number of those who survived disease have clear memories of Dame Jean's ministrations, which impacted greatly on their recovery, family life, and education and career prospects. These early interventions have had a ripple effect throughout the community, with a significant number of Dame Jean's patients going on to live long and successful lives, producing legal professionals, accountants, teachers, social workers, disability advocates, to name a few.

Polio Australia's demographic comprises thousands of polio survivors who are now living with the Late Effects of Polio, a chronic and often debilitating condition which is little understood by today's health practitioners. We can only imagine what Dame Jean would have done in relation to researching, educating, and treating this 'second wave' of polio-related morbidity.

However, acknowledging and celebrating the Macnamara namesake through the renaming of this federal electorate seat, goes a long way towards both recognising her historically significant achievements, and raising the awareness of a disease that continues to affect people today. This is not a history we would every wish to repeat.

Maryann Liethof , National Program Manager, Polio Australia

The 'Scratch Pad memory'

Dr Richard Bruno notes: Polio Survivors, like Parkinson's patients, make too little Dopamine, the Poliovirus having killed Dopamine producing neurons in the brain activating system and impairing attention. Along with attention problems, this study may help us understand why Polio Survivors report trouble with immediate or "Scratch Pad" memory.

"…dopamine neurons play a critical role in the formation of episodic memory, which allows people to remember such things as where they parked the car in the morning and what they had for dinner last night."

Study Sheds Light on How "Dopamine Neurons" Contribute to Memory Formation in Humans

Newswise — Los Angeles May 2, 2018 — Research from Cedars-Sinai sheds light on how the human brain rapidly forms new memories, providing insights into potential new treatments for memory disorders. A new study examined neurons that produce dopamine, a compound that acts as a transmitter for nerve impulses. It found that these dopamine neurons play a critical role in the formation of episodic memory, which allows people to remember such things as where they parked the car in the morning and what they had for dinner last night.

The study, published in the journal *Current Biology*, was co-authored by Ueli Rutishauser, PhD, the senior author and an associate professor in the Department of Neurosurgery at Cedars-Sinai. In the study, investigators observed the response of individual human dopamine neurons in patients undergoing deep brain stimulation surgery to treat Parkinson's disease. The patients watched a sequence of images: Some had never been seen before and were thus "novel"; others were repeated and were therefore "familiar."

For each image, the patient pressed a button indicating whether it was novel or familiar. This allowed investigators to track the formation of new memories, because an image was only novel once. Afterward, it formed a memory.

"What we discovered was that a subset of the dopaminergic neurons responded only when an image was novel, but not when it was familiar. In other words, it indicated if the image was new, but not if something was familiar," said Jan Kaminski, PhD, first author of the study and a project scientist at Cedars-Sinai. "This is an important new scientific discovery, because it has so far remained unclear how the dopaminergic system contributes to episodic memory formation."

This research was conducted while Parkinson's patients were having a deep brain stimulation device implanted to reduce their symptoms. As part of this procedure, during which patients are awake, an electrode is lowered into the brain to precisely localize the deep brain stimulation electrode. The target of the electrode is deep inside the brain, close to where the dopamine neurons are located.

"This procedure is one of the rare opportunities for researchers to observe the activity of dopamine neurons in an area of the brain called the substania nigra in an awake human being, a type of recording only possible because the patient is undergoing a neurosurgical procedure," said Adam Mamelak, MD, professor of Neurosurgery at Cedars-Sinai and a co-investigator of the study. "This setup provides extremely valuable new insights into how humans form memories."

While not directly tied to research on specific ailments, the findings provide new information relevant to the understanding of certain diseases, Rutishauser said. "Dopamine neurons degrade in neurodegenerative diseases such as Parkinson’s, which in addition to motor symptoms is often also accompanied by cognitive issues such as memory problems," he said. "What this paper shows is that dopamine neurons activate for novel stimuli. This short 'burst' of dopamine is what triggers learning."

A common treatment for patients with Parkinson's, for instance, is to take medications that increase dopamine to a steady level. But those drugs do not facilitate the short bursts that help in the formation of memory. "Our work reveals new avenues for treatments that can be explored, including those that restore short bursts of dopamine or that otherwise increase activity analogous to what dopamine is thought to do," Rutishauser said.

Mental, Not Physical, Fatigue Affects Seniors’ Walking Ability

Newswise — Low “mental energy” may affect walking patterns in older adults more than physical fatigue. New research about the relationship between walking ability and self-reported mood was presented (April 27) at the American Physiological Society (APS) annual meeting at Experimental Biology 2018 in San Diego.

Researchers from Clarkson University in New York observed a group of older adults (average age 75) while they performed physically and mentally tiring tasks. The volunteers performed the physical task—a timed walking test at normal speed for six minutes—before and after the cognitive components. LED sensors embedded in the five-meter walking track captured gait speed and stride length. The cognitive portion of the test consisted of several math subtraction activities and visually identifying specific numbers and sequences on a computer screen. The volunteers reported their mood, motivation and energy levels after both the physical and cognitive tests. Vocabulary used to capture the participants’ mood included “a list of mood components such as tense, worn out, energetic, confused [and] lively,” explained Abigail Avolio, first author of the study.

The research team used a well-known correlation formula (Pearson correlation coefficient) to determine the relationship between self-reported mood and physical performance. There was no change in gait in relation to mental fatigue in the first 30 seconds of the follow-up walking test. However, walking speed and stride length later in the test period decreased significantly in people who reported more cognitive fatigue, but not in response to lagging physical energy levels.

More study is needed “to further evaluate why feelings of physical energy and fatigue are not related to gait,” the researchers wrote.

People prescribed medicinal cannabis will have access within two days under streamlined process

By ABC political reporter Isabella Higgins Posted 13 Apr 2018

Australians prescribed medicinal cannabis will now have access to the drug within two days, after a meeting of state and territory health ministers in Sydney.

Patients have been waiting months for access to the drug, under current legislation which sees a double-approval process from both state and federal regulators.

On Friday, all state and territories signed up to the national scheme, which allows the approvals process to be streamlined through one national body.

"Faster access, better access ... there will be a one-stop shop for accessing medicinal cannabis," Federal Health Minister Greg Hunt said.

"The decision as to whether or not to prescribe is rightly in the hands of medical professionals, but once that decision is made, access will then be provided within what we expect to be a 48-hour period.

Who can get medicinal marijuana?

"In many cases, as low as 24 hours." The single approvals process, through the Therapeutic Goods Administration (TGA), started operating in New South Wales last month.

Mr Hunt argued it had been a very successful trial. "We've already seen, in New South Wales, the time for prescriptions drop dramatically from two months to two days in that system," he said.

"This is an important day for patient access. Now time should not be a matter of concern once a doctor has made his or her prescription."

A polio survivor who has used CBD oil reports :

- First deep and fully rested sleeps had in 30 years.
- Relieved restless leg issue at night
- Helps concentration during the day – clearer focus
- Wake up feeling alive! (not feeling the need to turn over and go back to sleep)
- Generally more vitality
- No side effects that aware of
- Heals a number of other ailments, however, sleep deprivation, restless leg and fatigue have been biggest enemies.

Please note the statement below. This item should not be read as an endorsement of any product but seen as a coming opportunity to benefit prescribed use of properly manufactured oil rather than experimentation with 'street corner' purchases.

The aims and objects of our group are to gather and disseminate information on Post-Polio Syndrome and Late Effects of Polio, to support each other in anyway we can. Opinions expressed in this newsletter may be those of the writers only. We do not purport to be medically qualified. Consult your doctor before trying any medication or new form of exercise. Give relevant information to your doctor and help them to help us. We do not endorse any product or services mentioned.

Polio’s motorcycle ambassador – Bob Mutchler

Bob Mutchler became a resident of Folsom (California) in 1980 and has given much to his community, locally and internationally. From teaching all ages to donating to Polio eradication, Mutchler has lived a heck of a life and has stories to share. “I was born at an extremely young age,” Mutchler jokingly said.

At nine months old, he contracted poliomyelitis, also known as polio. “I spent the next three years in and out of an iron lung until I was 4,” he said. Mutchler has had many businesses, including Bob Mutchler Piano Tuning and Repair, which he still operates, as well as teaching part time. At the age of 35, the fourth-generation piano technician started to develop severe weakness and muscle pain, so he went to a neurologist, who informed him he had Post-Polio Syndrome (PPS). PPS is a condition that affects polio survivors years after recovery, causing new weakening in muscles previously affected by the polio infection.

“At the time, doctors didn’t know a whole lot about polio. He told me I could expect to be in a wheelchair or flat on my back in a couple of years,” Mutchler said. “Then I went to see a second neurologist who gave me the same diagnosis, and after the third, I decided they knew some things more than I did.”

After being told he only had two productive years left, Mutchler did the logical thing – he bought a motorcycle. After three days of owning the bike, he embarked on a 7,000-mile ride for seven days through the southern states.

“Upon arriving home, I realised I felt better, both emotionally and physically, than I had for many, many years,” the 70-year-old said. “Now, 35 years later, and those three neurologists have died and I am still riding my motorcycle.”

Because of the stigma attached to polio, growing up, Mutchler had very few friends. “No one knew what caused it and parents didn’t want their children playing with me because they didn’t know if I was contagious or not,” he said. “I was defensive about saying I had polio. I wanted to distance myself from it. But when I started riding motorcycles, I started riding for Project DARE (Development through Adventure, Responsibility and Education). I became a spokesman for them.”

Then he joined Rotary International. In 1998, Mutchler claimed his allegiance with PolioPlus. The motorcycle aficionado decided to ride his motorcycle to 48 state capitols, and after generating major media coverage, the next year he named it the PolioPlus Motorcycle Ride and rode through all the Canadian provincial capitols.

In 2000, Mutchler went to Ghana on a national immunisation trip to help immunise eight million children. “I felt a tugging on my pant leg only to look into the big brown eyes of a boy about 12 years old. He was crawling on the ground because he had polio – his legs were drawn underneath and he was unable to straighten them out. With a big smile, the boy said, ‘Thank you for saving my baby sister so she doesn’t have what I got.

“At the time, I considered quitting the motorcycle, but at that point, I realised my pain was so insignificant and I needed to keep riding and spreading the word.”

To donate to PolioPlus, go to rotary.org. To purchase Mutchler’s book, contact him at *rpmutchler@aol.com*.

– Rachel Zirin, Senior Reporter *Folsom Telegraph*