

**POLIO NSW**

*formerly Post-Polio Network (NSW)*

# NETWORK NEWS

*Incorporating – Polio Oz News*

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## Editor's Report:

It is refreshing to see the easing of COVID restrictions and to feel some 'normality' returning to our lives. We only have to look at overseas countries to realise how fortunate we are in Australia. COVID has given us time to realise and appreciate what is really important in our lives.

Membership renewal notices are included with this issue of Network News. On this form we are asking for your **email address**. If you do not have your own email address perhaps consider including a family members email. This address is needed so we can contact you with information about future online webinars or perhaps a support group chat meeting or just to send you any updates of important information. You can still choose to either have your newsletter sent to you by post or email. You can also provide your email address by phoning the office on 9890 0946 or by sending an email to [office@polionsw.org.au](mailto:office@polionsw.org.au)

This issue delivers a number of articles on NSW government initiatives including the Dine and Discover Voucher offer (page 5), schemes from Transport of NSW (pages 5-7) that provide options for 'getting around' and of a system introduced in hospitals across NSW called REACH (page 4) which responds to patients' escalating health concerns.

We have included two articles by Dr. Marney Eulberg - "Brain Fog" (page 8) and "Post-Polio Osteoporosis" (page 13). From PA Polio Survivors' Network, Bruno Bytes Q&A (page 9) covers topics including oesophageal spasm, "good leg", muscle weakness and PPS diagnosis. An interview with Dr. Lauro Halstead is thought provoking and covers "Hold on to Strength" (page 21).

On page 20 is a fact sheet about exercise that was put together by Polio Australia's Clinical Health Educator, Michael Jackson, specifically for GPs.

One of our longstanding Board members tendered her resignation after many years of service to Polio NSW. see Merle Thompson's article on Anne Buchanan's significant contributions (page 2). We wish Anne the very best for her future in 'retirement'.

We hope that you find this issue of Network News informative. Stay safe and well.

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# THANK YOU TO ANNE BUCHANAN

By Merle Thompson, Secretary



In February it was with regret that the Board received a message from Anne Buchanan advising that she was resigning from the Board. Her decision was purely based on her feeling that she had been “serving on the Committee/Board for too long and have nothing further that I can offer in support of Polio NSW.” She concluded her message with “I offer the organisation every good wish for the future.”

Anne’s service to the Management Committee/Board has been extraordinary. Her length of service totals around 19 years. She first joined the Committee on 29 November 1997 and was a dedicated member from then until August 2007 – close to 10 years. At that time Anne was working part-time for the National Australia Bank and she was unable to change her shifts to fit in with our meetings. Later she was able to re-join the Committee and served for another nine years from 23 November 2011 AGM and resigned on 22 February 2021.

Anne and her husband, Gary, were foundation members of the, then, Post-Polio Network NSW. They both became members on 6 April 1989 – the membership approvals on this date were the first after the Network was formed. It was Gary who was the polio survivor. Anne is an Associate Member. Throughout their marriage she was Gary’s carer – a role which became increasingly more difficult as his health deteriorated. Gary died in January 2019.

Anne was always interested in helping other carers and had many informal discussions with other carers at seminars and activities. In this context she became a friend, and you could say, ally, of my sister, Lyn. They had their own little “support group”.

As the only “non-polio” on the Committee it fell to Anne to be a physical help to the other members. She willingly made literally hundreds of cups of teas and coffees for other Committee members, moved chairs for them etc. And this was extended to other members at seminars.

Publicity was Anne’s particular role on the Committee/Board. She placed advertisements in newspapers to promote seminars, wrote articles to send to newspapers and came up with ideas such as bookmarks to promote the organisation. In Polio Awareness Week she set up displays in libraries within her own area and would walk the streets putting posters in shopping centres and at such places as doctors’ rooms and pharmacies.

In addition to her role as a Board member, for many years Anne and Gary jointly compiled “Information Bulletins” containing information on, for example, services for people with disabilities and assistive devices. These were published quarterly from 1993 until 2007.

From a personal perspective Anne’s special friendship means an enormous amount to me. We became closer when she was caring to me after Lyn’s death. She has a sixth sense to know when I need support and we have long, mutually supportive and chatty evening phone calls.

The Board thanks Anne for her service and wishes her well.



# CAN YOU HELP?

It's membership renewal time once again. It is always heartening each year to receive financial support from our members. We receive significantly more than 50% of our income through these generous donations. That is a wonderful endorsement from you, our members, of your faith in what we are doing as an organisation to support you in managing your polio journey.

Each financial year our expenditure is higher than our income resulting in a shortfall averaging \$10,000. This means that our capital funds will continue to diminish each year until we are no longer financially viable.

In an attempt to reduce our expenditure the Polio NSW Board made the difficult decision earlier this year to reduce staffing hours in the office. Although this has been implemented the savings are not enough so we are asking for your continued help through donations.

We have in place a system that allows for an easy donation plan that can be arranged by visiting our website [www.polionsw.org.au/donations/](http://www.polionsw.org.au/donations/) or by calling George at our office. It can be a regular or a one-off donation. An easy option is electronic transfer via internet banking. (See details below.)

All donations over \$2 are tax deductible.

## Direct Deposit

Donations can be made through your internet banking as an electronic funds transfer to our Westpac account. Your donation can be one-off or recurring. Please be sure to include your name on your payment so we can send our tax-deductible receipt to you.

**Bank:** Westpac  
**Branch:** Sydney, NSW  
**BSB:** 032-000  
**Account Number:** 628910  
**Account Name:** Polio NSW Inc

## Credit Card

One-off or recurring credit card donations can be made by visiting this page on our website:

**[www.polionsw.org.au/donations/](http://www.polionsw.org.au/donations/)**

or complete the details below and return this page to: **PO Box 2799, North Parramatta 1750**

<b>Credit Card Number:</b>		<b>Name on Credit Card:</b>	
<b>Credit Card Expiry:</b>		<b>No. on back of Card:</b>	
<b>Donation Amount:</b>		<b>Donation Frequency:</b>	

*Donation Frequency can be: One-Time, Monthly, Quarterly, Half-Yearly, or Annually*

<b>Address:</b>	
<b>Email (if available):</b>	

## Cheque

Please make cheques payable to **Polio NSW Inc** and post to: **PO Box 2799, North Parramatta NSW 1750**. Make sure to include your name and address with your cheque so we can send our tax-deductible receipt to you.



# REACH - Patient, Family & Carer Escalation

## What is REACH

REACH is a system that helps patients, their family and carer/s to escalate their concerns with staff about worrying changes in a patient's condition. It stands for **R**ecognise, **E**ngage, **A**ct, **C**all, **H**elp is on its way. REACH was developed by the Clinical Excellence Commission in collaboration with local health districts and consumers. It builds on the surf life-saving analogy for recognition and appropriate care of deteriorating patients by encouraging patients, their families and carer/s to 'put their hands in the air' to signal they need help. This is consistent with the emergency response systems already in use in NSW Health services.

REACH actively promotes partnership between patients, their family and carer/s, and the treating team, in recognising and escalating deterioration. It encourages patients, their family and carer/s to initially engage with their nurse or medical team, if they are concerned that 'something is not right'. If they continue to be worried they can then escalate their concerns by requesting a 'clinical review' knowing that this should occur within 30 minutes.

Finally, if they are still concerned, an independent review or rapid/emergency response can be activated by the patient, family or carer by calling a unique number made available by the facility. REACH casts the safety net wider by empowering consumers to 'speak up for safety' and provides assurance that help is on its way.

<b>R</b>	<b>Recognise</b>	You may <b>Recognise</b> a worrying change in your condition or in the person you care for.
<b>E</b>	<b>Engage</b>	<b>Engage</b> (talk) with the nurse or doctor. Tell them your concerns.
<b>A</b>	<b>Act</b>	<b>Act</b> - Ask the nurse in charge for a "Clinical Review". This should occur within 30 minutes.
<b>C</b>	<b>Call</b>	If you are still worried <b>Call</b> R.E..A.C.H. Use the bedside phone or ward phone or ask for the hospital's REACH call number.
<b>H</b>	<b>Help is on its way</b>	<b>Help</b> is on its way.

REACH is not in all hospitals in NSW, but staff are still there to help you

<https://www.cec.health.nsw.gov.au/keep-patients-safe/deteriorating-patient-program/reach>



# Dine and Discover NSW

The NSW Government launched the Dine and Discover NSW voucher scheme to encourage the community to get out and about, to support dining, arts and tourism businesses, and to stimulate spending in the economy. This program has now been rolled out across NSW beginning in March and finishing up on June 30, 2021.

## How does Dine & Discover NSW work?

Every NSW resident aged 18 and over will be eligible for four \$25 vouchers worth \$100 in total. The vouchers can be used at participating NSW businesses that are registered as COVID safe.

The Dine & Discover NSW vouchers will be divided into two categories:

- two \$25 vouchers to be used for eating in at restaurants, cafes, bars, pubs, wineries and clubs
- two \$25 vouchers to be used for entertainment and recreation, including cultural institutions, live music, and arts venues.

The vouchers:

- can be used 7 days a week, including public holidays.
- can be used at participating NSW businesses that are registered as COVID Safe
- are valid to 30 June 2021

## How to apply for the vouchers?

To participate in Dine & Discover NSW, you must have a [MyServiceNSW](#) account. You can download the Service NSW app and register for a [MyServiceNSW](#) account.

Further information is available at: [Dine and Discover NSW](#)

# Transport for NSW

Visit: <https://transportnsw.info/travel-info/ways-to-get-around> for transport options available to residents of NSW.

## Community Transport

Community transport is a service for eligible seniors, pensioners, those with accessibility needs or those who have limited access to public transport.

If you need transport to medical appointments or someone to help you with errands, you may be eligible for community transport services.

The service is especially designed to help you get to medical appointments, participate in social activities, do your shopping and maintain independent living at home.

### About community transport services

Contact your local operator via <https://transportnsw.info/operators> to check if their services suit your specific needs. Some of the services available may be:

- Door to door transport to and from your destination
- Flexible pick-up times to suit your needs
- Vehicles suitable for wheelchairs and people with specific mobility needs
- Vehicles that can accommodate small groups
- Trained drivers who can assist you to and from the vehicle
- Assistants who may help carry shopping bags back to your home

Multilingual staff or resources to support your language needs

### **Eligibility**

Community transport may be available to people who have limited transport options and who meet certain eligibility criteria.

You may be eligible if you:

- Are elderly and have limited mobility
- Have a disability or health issues which limit your mobility
- Have language challenges that limit your access to transport
- Live in an area with little or no public transport and don't have access to private transport
- Face other significant barriers to accessing transport

To find out if you are eligible, visit <https://transportnsw.info/operators> to see what services are available to you.

If you are aged 65 years and over (50 years and over for Aboriginal and Torres Strait Islander People), contact [My Aged Care](#) on [1800 200 422](tel:1800200422) for an eligibility assessment.

### **How to pay and book**

Cost varies between operators and areas, depending on available resources, passenger needs, and pick-up and drop-off locations.

## **Taxi Transport Subsidy Scheme**

If you are a resident of NSW and are unable to use public transport because of a severe and permanent disability, you may be eligible to a subsidy of 50% of a taxi fare, up to a maximum subsidy of \$60 and only pay the remaining fare. This includes travel in wheelchair accessible taxis.

### **Eligibility**

To be eligible for the Taxi Transport Subsidy Scheme you must:

- be a permanent resident of Australia
- normally reside in NSW
- not be a member of a similar scheme in another Australian state or territory
- be over school age (preschool aged children, regardless of disability, are ineligible for inclusion in the scheme)
- have a severe and permanent disability in one of the specified categories.

### **Ambulatory/Mobility/Functional**

- Unable to walk or stand. Mobile only in a wheelchair due to a physical disability or
- Restricted to walking inside the home. Mobile outside of home only with a wheelchair due to a physical disability or
- Severe and permanent ambulatory problem that cannot functionally be improved which limits walking to a distance of 20 metres or less without rest and also:
  - necessitates permanent use of a walking aid for all mobility or
  - necessitates the constant assistance of another person for all mobility or
  - is unable to independently ascend or descend three or more consecutive steps of 350mm height.
- Total and permanent functional loss of both upper limbs which renders the person incapable of travelling on public transport without the constant assistance of another person.

### **How to apply**

To apply, you need to fill out an application form and provide supporting documents from

your medical practitioner or treating specialist, so that the severity of your disability or medical condition can be assessed by Transport for NSW independent medical assessors. However, before completing the application, applicants are required to read and agree to the TTSS terms and conditions outlined below.

Participation is not means tested. Receipt of an aged, invalid, blind or any other pension does not automatically qualify you for participation in the TTSS. To get an application form:

- download and print the [TTSS application form \(pdf 558KB\)](https://transportnsw.info/ttss-application-form) via:  
<https://transportnsw.info/ttss-application-form>
- call 131 500 to request a form by mail.

Fill out your personal details then give it to your medical practitioner or treating specialist for completion. Sign and date the form before mailing it back to the address provided or prepare digital copies to submit online at [transportnsw.info/concessions-application](https://transportnsw.info/concessions-application).

### **How it works**

The Taxi Transport Subsidy Scheme is a docket system. TTSS provides a subsidy of up to half the metered fare, to a maximum of \$60 subsidy per trip. Only one travel docket can be used per journey.

When you apply for TTSS you will be sent dockets specific to your needs. When you travel, hand the driver a completed docket for 50% of the fare up to \$60. You pay the remaining fare.

For example: if the metered fare is \$80, you can use the travel docket for \$40 and you pay the remaining \$40 yourself. If the metered fare is \$140, you can use the travel docket for the maximum of \$60, and you pay the remaining \$80 yourself.

Download the information booklet to help answer further questions about TTSS.

[TTSS information booklet \(pdf 424KB\)](https://transportnsw.info/document/1482/ttss-info-booklet.pdf) via <https://transportnsw.info/document/1482/ttss-info-booklet.pdf>

**From November onwards the Taxi Transport Subsidy Scheme (TTSS) is going digital and will gradually transition away from the manual paper travel dockets. to a digital Smartcard.**

## **Wheelchair Book and Ride**

From 1 March 2021, new taxi booking service, [Wheelchair Book & Ride](#), will replace Zero200 as the Government approved centralised booking service for wheelchair accessible taxis in the Sydney metropolitan area.

The service is funded by Transport for NSW and operated by [Spinal Cord Injuries Australia](#).

Wheelchair Book & Ride makes it easier for wheelchair users, who rely on taxis to get around, to secure a booking with an accessible vehicle. The service will connect with a pool of taxi operators across Sydney to find customers their next available accessible ride.

Wheelchair Book & Ride is available for taxi bookings and general enquiries 24 hours a day, seven days a week.

If you are a participant in the [Taxi Transport Subsidy Scheme travel dockets](#) or have a TTSS SmartCard, you can continue to use these for the Wheelchair Book & Ride service.

**NDIS funding support:** Customers should check with the [NDIS](#) for information on funding support.

Bookings can be made by phone or online, with voice recognition software to be introduced in the future. To make a booking, call **13 90 00**

# Brain Fog Versus Something More Serious

Taken from PA Polio Survivors Network February 2021 [www.papolionetwork.org](http://www.papolionetwork.org)

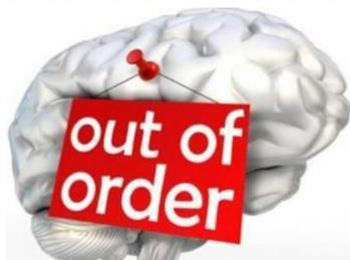
From Primary Care Physician **Dr. Marny Eulberg, MD**



According to healthline.com, “brain fog is a symptom of other medical conditions. It’s a type of cognitive dysfunction involving memory problems, lack of mental clarity, poor concentration, and/or inability to focus”. It may also be called “brain fatigue” which is a good description because just like muscle fatigue an individual episode does not last forever and recovery from the fatigue is possible.

Polio survivors are not the only group of people who have reported brain fog in association with whatever underlying medical condition they have. Individuals with many auto-immune diseases, those with chronic fatigue syndrome, those whose blood sugars drop below 50 or 60 mg/dl, and now, several of the COVID “long haulers” have noted similar problems.

Almost everyone who has had several nights of non-restorative sleep, is physically or mentally fatigued, has gone several hours without eating or has consumed a high sugar snack and “crashed” a couple hours later has had times when they cannot remember a



word that normally would be a regular part of their vocabulary, can’t quickly add up a series of numbers, cannot remember someone’s name, etc. Most polio survivors, who contracted polio in the U.S., are now age 65 or over and some “forgetfulness” is considered normal, such as forgetting where you left the car keys, where you put that item “so I won’t forget” but now you can’t find it, only remember a person’s name after 5-10 minutes into a

conversation with them, or temporarily forgetting where you parked your car in that supermarket parking lot. I’ve seen a floor mat for sale in catalogues that uses the rhyme/song “Head, shoulders, knees and toes” but changes it to say, “Glasses, wallet, keys and phone” and recommends it be placed on the floor leading into your garage or out of your home!

## What can you do to minimize the brain fog or forgetfulness?

- First, recognize that it is a problem for you.
- Second, observe and identify if there are some factors that make it worse for you –
  - Does it happen more later in the day when you are tired?
  - Does it occur when you haven’t slept well?
  - When you haven’t eaten for several hours? etc.
- It may be wise to postpone making important decisions or ones that have long-term consequences in these situations.
  - For example, maybe you should reconcile your bank balance in the morning right after breakfast (if that is the time you are mentally the sharpest).
  - Make lists - just the act of handwriting something builds extra pathways in your brain making it more likely that you will remember it even if you misplaced the list!
- Limit the choices. If you have handicap parking privileges USE them. It will decrease your physical fatigue and markedly reduce the number of possible places where your car will be parked.
- Be patient and kind to yourself. Beating yourself up will only make the problem worse.

## When is it more than brain fog/ brain fatigue/normal forgetfulness?

- If you're concerned, speak to your primary care physician about it.
- If you have the issue, try and schedule your appointment in the morning when you are the least fatigued. Then, remind your primary care physician about polio fatigue/overuse prior to being given any tests.
- A brief screening test that is frequently used by primary care physicians is the Mini-Cog that is available at <https://mini-cog.com> Click on "Standardized Mini-Cog". Note: the symbol "<" means "less than", so when it says "A cut point of <3 on the Mini-Cog" it means that a score less than 3 indicates that a work-up for dementia should be undertaken.

**See Dr. Eulberg's articles on the "Living with Post-Polio Syndrome" page of our website:** [www.papolionetwork.org/living-with-pps-articles-and-video-library](http://www.papolionetwork.org/living-with-pps-articles-and-video-library)  
Do you have a question for Dr. Eulberg? Email us at: [info@papolionetwork.org](mailto:info@papolionetwork.org)



# BRUNO BYTES

Taken from PA Polio Survivors Network [www.papolionetwork.org](http://www.papolionetwork.org)

## How Many Survivors ARE There? It was All in the Family.

**Question:** My sister had paralytic polio and I had what the doctor said was the flu at the same time. Could my "flu" have been a mild case of polio?

**Answer:** If the poliovirus entered the nervous system there was no mild "case." From the research of Dr. David Bodian in the 1940s, the poliovirus killed brain stem (bulbar) neurons even if it didn't affect the spinal cord. And you had to have 60% of your spinal cord motor neurons killed to have any evidence of paralysis!

Here's another stat. We went through the Mayo Clinic's Olmsted County, MN data base. We found data that indicates there are 150,000 Americans who had polio (usually siblings of paralytic polio survivors) who were never diagnosed, not even as having "non-paralytic" polio or the "summer grippe".

Finally, 1909 to 1955 more than 2000 family members in over 1000 households were surveyed in which at least one person had polio. On average if one child in a household became ill he "shared" polio with one other sibling of similar age. I say "he" because more boys had polio than did girls. Just over half of those who became ill were paralyzed, while the others had flu-like symptoms ranging from a fever, sore throat and nausea to a stiff neck and muscle pain. This "minor illness" was caused by the poliovirus but may never have been diagnosed as polio at all, or may have been called "abortive" or "non-paralytic" polio. In three-quarters of the households the first case of polio was paralytic and the second was "non-paralytic". This is why we will never know how many people in North America actually had polio!

The 1987 national health interview survey estimated that there were 1.63 million American polio survivors. But you would've had to know that you had polio to answer "yes" to the survey. What's more, reporting cases of polio was not required until 1955 and was only required to make sure that the vaccine was working. Nobody documented how many people had polio before the vaccine. The federal government was just measuring that the vaccine was actually preventing new cases.

## Bottom line:

- Poliovirus did lots of damage whether or not you had muscle weakness or paralysis.
- There's about a 1-in-5 chance that if you had paralytic polio one of your brothers or sisters had non-paralytic polio and may not even have known it.
- We have no idea – and will never know - how many people had polio.



## Bruno Bytes

First Quarter 2021

From Dr. Richard L. Bruno, HD, PhD  
Director, International Centre for Polio Education  
Bits and Tidbits from the Post-Polio Coffee House

[www.papolionetwork.org/encyclopedia](http://www.papolionetwork.org/encyclopedia)

## On the topic of Esophagus Spasms and Not Everything Being PPS

### **A REMINDER THAT NOT EVERYTHING IS PPS . . .**

Esophagus spasms are not uncommon in polio survivors. At the Post-Polio Institute, we found that low dose Klonopin (clonazepam), taken 30 minutes before eating, is effective in treating spasms of the esophagus muscles that prevent food from going down. But, as always, you have to rule out causes other than PPS that may trigger muscle spasms or swallowing difficulty:

*"I had spasms and choking where food would get stuck in my esophagus, very painful until food went down. Foods that would especially cause the choking were bread and spaghetti. I would even choke on my saliva at times. I also had a lot of coughing. This had been going on for many years. In the last year, I was embarrassed to go out in public because I would get strange looks when I started coughing because of COVID. I thought it was due to a sinus drip.*

*I mentioned choking, spasms and coughing to my doctor four months ago. He said symptoms were caused by acid reflux and not a sinus drip. He prescribed pantoprazole (Protonix). I went in for a check up recently. He asked how were the pills working. I said they appear to be helping".*

## On the topic of Polio Survivors and their "Good" Limbs

### **Now, About Your "Good" Leg**

It's well-known that "good" limbs (those thought to be unaffected by polio) commonly show electromyographic (EMG) evidence of prior poliovirus damage to motor nerves. A large study from India brings home this point. (1) EMGs were performed on all four limbs (not something we recommend) in 116 polio survivors. In 42% of the limbs that survivors said were "unaffected by polio," EMG revealed evidence of poliovirus damage. On manual muscle testing, 26% of the "unaffected" muscles with poliovirus damage had decreased strength.

This study is a reminder that "non-paralytic" polio (NPP) wasn't necessarily "damage free" polio. For example, it was reported in 1953 that 39% of those diagnosed with NPP had measurable weakness on manual muscle testing in at least one muscle group. A 1954 paper - "The Infrequent Incidence of Non-paralytic Poliomyelitis" - documented that 89% of polio survivors who were acutely "persuasively non-paralytic" had "very definite muscle weakness" as long as three years after the diagnosis of NPP.

So, it should be no surprise that more recent studies have documented late-onset weakness and fatigue in NPP survivors. A study of 828 polio survivors found new muscle

weakness and fatigue, respectively, in 38% and 34% of those who had been paralyzed and in 14% and 21% of those diagnosed with NPP. (2)

What's more, a study of 34 sets of twins found PPS symptoms in 71% of the twins who had had paralytic polio but also found "PPS-like symptoms" in 42% who had had no symptoms of paralysis. (2) I wasn't surprised when Post-Polio Institute patients would report that their "good" ("unaffected") muscles were becoming weaker while their obviously polio-affected muscles were not. Taken together, the studies above are reminders that overworking your "unaffected good muscles" could make a good limb turn "bad".

References:

1) Ann Indian Acad Neurol. 2016; 19(1): 44–47

2) Bruno, RL. Paralytic Versus "Non-Paralytic" Polio: A Distinction without a Difference? Am J Physical Med Rehabil, 2000; 79: 1-9.

### On the topic of Muscle Weakness

**Question:** Is the weakness associated with PPS generalized or can it be muscle specific?

**Dr. Bruno's Response:** Both, sort of. Weakness is caused by failure of individual motor neurons, not all of your motor neurons at once. And not all motor neurons were damaged to the same extent by the poliovirus. When you do manual testing of a given muscle, weakness is "specific". When you're doing *your* life, muscle weakness can feel "general," or maybe "generally" in the legs or the arms. Also, it's hard to separate "general" muscle weakness from fatigue, which is caused by brain neurons browning out.

**BOTTOM LINE:** Don't work until you feel "specific" or "general" muscle weakness. Muscle weakness and fatigue are your body's way of saying, "You've done too much!"

### On the topic of Neurons "Sprouting"

A new study found in fruit flies what's been known for 70 years to happen in polio survivors...

*"What happens when a neuron dies? Can other neurons around it pick up the slack to maintain the same level of function? In the fruit fly, each muscle is activated by two motor neurons. Researchers wondered what would happen if one neuron were removed. Would the other neuron compensate for this loss? They found that the remaining neuron expanded its synaptic arbor ("sprouted") and compensated for its missing neighbor."*

**FROM "The Polio Paradox":** Axons Sprouts and Fat Fibers. Remaining, poliovirus-damaged motor neurons did something amazing after the poliovirus infection had run its course. The axons grew, sending out sprouts -- like extra telephone lines -- to turn on the muscles that were orphaned when their motor neurons were killed. Those sprouts took from nine months to 2 years to grow and ultimately activated about 16 times more muscle fibers than were connected to the motor neuron originally.

Yet another important process took place that allowed polio survivors to regain strength. Muscle strengthening exercise and physical therapy caused muscle fibers to grow larger, a process called hypertrophy, enabling the fibers to do more work. Polio survivors' individual muscles fibers have been found to be twice the size of fibers in those who didn't have polio. So, motor neuron recovery, sprouting and muscle fiber hypertrophy allowed polio survivors to get stronger after the poliovirus attack. A 1955 study by British polio pioneer W.J.W. Sharrard found that polio survivors regained nearly 95% of the strength they would ever recover during the first 11 months after the polio attack as a result of sprouting, muscle fiber hypertrophy and learning to use functioning muscles to substitute for those that were permanently paralyzed.

So, where do you stand (or sit) today with regard to your post-polio motor neurons? If you had any paralysis, muscles that you know were affected during the poliovirus attack have on average only 40% of the motor neurons you were born with, neurons that were damaged, are smaller than normal, whose internal “pipes” are clogged, but have sprouted to turn on 16 times more muscle fibers, fibers that are twice the size they were before you had polio. If you have muscles that were not paralyzed or had so-called "non-paralytic" polio, you lost 40% of the motor neurons you were born with, neurons that were damaged and are also smaller, clogged, over sprouted and overworked.

**BOTTOM LINE:** “Save Your Sprouts!” <https://www.newswise.com/>

On the topic of the Diagnosis of “Post-Polio Syndrome”

**Question:** Is post-polio syndrome an accepted medical diagnosis or does every polio survivor of a certain age just automatically develop muscle weakness, fatigue and pain?

**Dr. Bruno’s Response:** Polio survivors can develop new symptoms -- overwhelming fatigue, muscle weakness, muscle and joint pain, sleep disorders, heightened sensitivity to anesthesia, cold intolerance, and difficulty swallowing and breathing – at any age. Not all polio survivors develop all of these symptoms and they don't automatically appear. But the presence of one or any number of symptoms in polio survivors, when other causes are ruled out, meet the criteria for accepted medical diagnosis.

The name for the diagnosis and your age don't matter. The symptoms and treatment do!

The Encyclopedia of Polio and Post-Polio Sequelae contains all of Dr. Richard Bruno’s articles, monographs, commentaries, “Bruno Bytes” (Questions & Answer articles) and his Video Library.  
The Encyclopedia of Polio and PPS is also available by a direct link from:  
[www.postpolioinfo.com](http://www.postpolioinfo.com)



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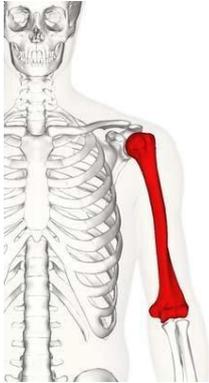
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# Post-Polio Osteoporosis

By Primary Care Physician **Dr. Marny Eulberg, MD**

Taken from PA Polio Survivors Network March 2021 [www.papolionetwork.org](http://www.papolionetwork.org)



I found this humerus. . . I've been told that I have a "weird" sense of humor, but I loved seeing a T-shirt that has this idea emblazoned on its front. For those of us who have studied anatomy it's probably a funnier joke! (Humerus. . . Humorous) Anyway . . .

All joking aside, while actively practicing primary care medicine and in the last few years since I have limited my practice to treating polio survivors, I have received many questions from polio survivors about osteoporosis/osteopenia and their treatments. Unfortunately, there has not been much written in medical journals about the issues that come with a diagnosis of osteoporosis in polio survivors.

The PA Polio Network recently forwarded an article to me that appeared in Science Direct in their Endocrine Practice section (1).

The article raised some new questions for me and re-enforced that, although much is known about osteoporosis in a "normal" population, not much is known about the specifics of bone health in polio survivors. We do know that many, many polio survivors are at risk of falling and breaking bones and many polio survivors have osteoporosis or osteopenia. I'd like to start at the beginning.

## Bone Formation

- Bones begin to form in utero around three months and bone formation continues into adolescence.
- Bone formation during childhood and adolescence depends on adequate nutrition including Vitamin D, calcium and normal weight bearing through that bone.
- After a person reaches their late 20s, the amount of mineral in that person's bones no longer increases and beginning in their 30s the amount of minerals (mostly calcium) begins to slowly decrease.
  - In women, these decrease more rapidly after menopause - either naturally occurring menopause (or) surgically induced by removal of both ovaries.
  - Men also experience bone loss - just a little later in life.
- Think about this like a bank account in which deposits are made regularly for the first thirty years of your life and then withdrawals are being made on a regular basis for the rest of your life.
- Just like a bank account, your bone mineral "balance" equals the total amount of bone mineral laid down in childhood/young adulthood minus the withdrawals. As *when* the "balance" approaches zero you are at risk of a broken bone/fracture because the bone structure has become weak.

## Early Effects of insufficient bone formation in Polio Survivors

What this means for polio survivors is that if you contracted polio at 2 years of age, you only had 2 years beyond the womb to build normal bone in those parts of your body that were affected by the polio.

- After that, how much bone mineral content your bones built up depended on how much weight bearing you were able to do through that part of your body plus background factors like nutrition (including Vitamin D intake).

- On the other hand, your unaffected limb(s) may have laid down denser bone because it was doing more than the usual share of weight bearing. Examples would be:
  - The arms of crutch users.
  - The stronger of your two legs.
  - If you walked using a brace the bones in that limb (or limbs) will experience less weight bearing than normal through those bones because the brace did some of the weight bearing.

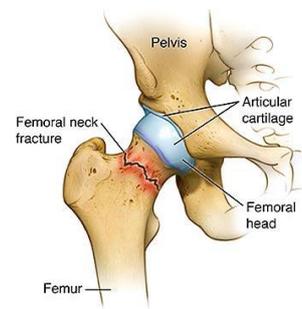
### Post-Polio Bone Loss

Decades later, we all find ourselves in the bone mineral loss phase. We probably started with less bone density, at least in some parts of our bodies, as we enter this phase, so it makes perfect sense that many aging polio survivors are being diagnosed with osteopenia and osteoporosis. This does make polio survivors more likely to suffer broken bones/fractures when they fall or incur another injury.

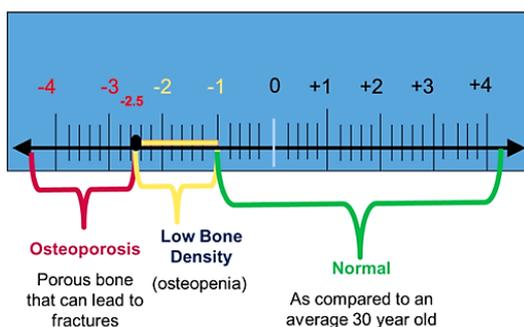
### Osteoporosis: The Test

Osteoporosis is diagnosed after a person has experienced a bone fracture with little or no significant trauma (or) after some sort of bone density imaging study has been done such as a DEXA (dual energy x-ray absorptiometry) test.

- The DEXA scan test, sometimes abbreviated as DXA, is similar to a normal x-ray with extra time given for additional measurements.
- The test normally looks at the bone density in your spine and/or the left and possibly right upper thigh bones at the location that hip fractures most often happen (the report refers to this is as hip and neck - meaning femoral neck).
- Some machines are set up to only look at the left hip, but it is important to ask that the technician also looks at your right hip if polio affected your left leg.
- Bone density can also be measured in your forearm.
- Any metal, such as surgical hardware, will prohibit the ability to take an accurate measurement of bone density in that particular bone, so bone density may need to be measured in other bones.



### Osteoporosis/Osteopenia –The Criteria for Diagnosis



Usually, the result that your physician will receive is the T-score, which compares the bone density of the patient with normal results for a 30-year-old person of the same sex.

- Osteopenia is a T-score of -1 to -2.5.
- Osteoporosis is diagnosed by a T-score of -2.5 or less.
- Severe Osteoporosis is indicated by a T-score of -3.0 or less.

Due to the way calculations are made, the actual bone density in a bone that is smaller than normal may be falsely low. This calculation uses a “normal” size for the bone(s) that was studied as part of the equation to yield a bone density result.

Note: This chart (²) is from American Bone Health

## Osteoporosis –What is my Risk for Fracture?

The important issue for anyone (both men and women) concerned about osteoporosis is not so much the score on a single test such as the DEXA, but the need to ask yourself the question “What is MY risk of fracture” ?

- There are some on-line bone fracture risk assessment tools available to health care professionals that include factors such as family history, smoking history, alcohol consumption, race, and history of taking certain medications or medical conditions that are associated with bone mineral loss in addition to a person’s T-score.
- Again, remember the final result showing fracture risk is based on “normal” people.
- The risks may be greater for persons with lower extremity weakness and/or increased risk of falls and less for people who primarily use wheelchairs for their mobility.

## Treatment for Osteoporosis (or) Osteopenia

You have been diagnosed with osteopenia or osteoporosis and your doctor is recommending treatment. What do you need to know?

### • Non-Drug Treatments:

If the recommended treatment is for one or a combination of the following things, you probably should do it!.

- fall prevention measures,
- balance training,
- stopping smoking,
- limiting alcohol consumption,
- increasing calcium\* via your diet or with supplements, or increasing intake of Vitamin D via diet, sunlight exposure, or supplements

\* There are a few medical conditions with which you probably should **not** increase calcium or Vitamin D. - Always, consult with a doctor who knows you and your entire history -

- History of chronic kidney disease (CKD),
- History of kidney stones,
- Certain endocrine problems such as hyperparathyroidism.

## Osteoporosis Medications

The guidance regarding whether polio survivors should take one of the various medications used to treat osteoporosis is less clear. Initially, studies of osteoporosis medications judged their effectiveness based on whether the DEXA scan showed improvement in people taking a particular medication. Later it was discovered that some medications improved the results on DEXA scans **but** did not decrease the number of fractures experienced by the users of those medications.

Obviously, the result that is most important to individuals considering taking an osteoporosis medication is whether it can decrease their risk of having a broken bone or compression fracture!

There are two broad classifications of medications used to treat osteoporosis -

- Antiresorptive medications include a class of drugs called bisphosphonates. These medications include:
  - Alendronate (Fosamax™, Fosamax™ Plus D)
  - Risedronate (Actonel™, Actonel™ with Calcium and Atelvia™)
  - Ibandronate (Boniva™)
  - Zoledronic acid (Reclast™)
  - Denosumab (Prolia™)
  - Estrogen therapy or hormone therapy (including estrogen, selective estrogen receptor modulators, and testosterone) that reduce bone resorption and subsequently bone formation.

Note: These medications preserve, but do not increase bone mineral density

- Anabolic agents that stimulate bone formation and subsequently bone resorption.
  - Abaloparatide (Tymlos™)
  - Romosozumab (Evenity™)
  - Teriparatide (Forteo™)

Note: These medications increase bone density.

### Medications That Have Been Shown To Decrease Fractures

- Oral Bisphosphonates
  - The “ronates” including (brand names):
    - Actonel, Boniva, Didronel, Fosamax
    - Aclasta, Reclast, Zometa(zolendronicacid)
- Intranasal Calcitonin (brand names):
  - Forticaland Miacalcin
- Estrogen and selective estrogen receptor stimulators (known as SERMs)
  - Estrogen - patch or ring forms.
  - Evistaand Osphena(SERMS)
- Anabolic Agents\* (brand names):

Note: These anabolic agent medications are not available in oral form, require injection and are expensive.

  - Synthetic Parathyroid Hormones
    - Forteo
    - Tymlos
  - Prolia

### Osteoporosis Medications – A Summary

No drug is without any adverse side effects and these drugs are no exception. Some of the known side effects of many of these drugs is a rare spontaneous fracture of the femur (thigh bone) or bony destruction of the jawbone (osteonecrosis). The estrogens and SERMs can increase the risk of blood clots in persons using them. The bisphosphonates can irritate the esophagus, so it is strongly recommended that persons taking these pills take them with a full glass of water at least 30 minutes before eating or drinking and sit/stand upright (don't bend over) for at least 30 minutes (60 minutes for Boniva). There are other less common or less serious side effects and any adverse side effects need to be brought to the attention of the prescriber.

The bottom line is that we don't have any research studies or data to predict how any of the osteoporosis medications will work in polio survivors. In the bones in limbs, or in the trunk, that were not affected by muscle weakness all these drugs will likely work as well as they do in the bones of “normal” people.

But we simply do not know how well these medications will work in bones that continue to do less than normal weight bearing and have begun the process of normal bone loss, with a lot less mineral in them.

(1) <https://www.sciencedirect.com/science/article/pii/S1530891X20481868>

(2) <https://americanbonehealth.org/bone-density/understanding-the-bone-density-t-score-and-z-score/>

**Dr. Eulberg's series of Articles and Videos are in the “Primary Care Perspective” section of our website: [www.papolionetwork.org/primary-care-and-pps](http://www.papolionetwork.org/primary-care-and-pps)**

**Do you have a question for Dr. Eulberg? Email us at: [info@papolionetwork.org](mailto:info@papolionetwork.org)**



# Post-Polio Osteoporosis Q&A

By Primary Care Physician **Dr. Marny Eulberg, MD**

Taken from PA Polio Survivors Network March 2021 [www.papolionetwork.org](http://www.papolionetwork.org)



**Question:** I am Class of '49, have lost the use of left arm and have a weakened right leg. I did walk and do stairs. I am 74 and I have osteoporosis. Last year I had a herniated disk which weakened my bad leg. I got a custom brace made. I am hoping to get better, but progress is slow. Any thoughts? I appreciate it.

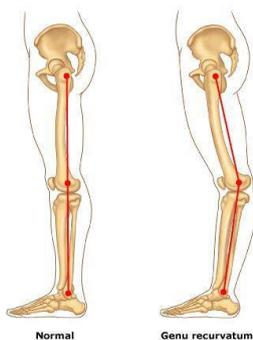
**Dr. Eulberg's Response:** I am going to make some assumptions (and you know what they say about "ass-uming"). First of all, it is not a surprise that as a 74 year old woman you have osteoporosis, which would not contribute to your weakness/slow recovery. Osteoporosis is a silent disease process and you wouldn't know you had it until you broke a bone or had a screening bone density test of some kind. But it is important for you, to know that you have osteoporosis, because of the need to actively prevent falling.

You did not mention what kind of treatment you had for the herniated disc. If it was surgery, then recovery in polio survivors can take up to 2-3 times as long as for a "normal" person. How long, or if, you will get recovery of nerve damage caused by the herniated disc depends on how long the disc had been exerting excessive pressure on the nerve. If the pressure on the nerve has been present for 6 months or longer before it is relieved, the function of that nerve may take up to 2 years or it may never come back. If the pressure on the nerve was present for less than 6 months, then recovery of nerve function may take up to 12-18 months.

Have you had any physical therapy? If so, what did that involve? Exactly what muscles in your leg are weak (or) if you don't know, what kind of movements/activities can you *not* do or are very hard? What kind of brace were you prescribed - a short leg brace (AFO) that goes under the foot and goes up to near your knee? A knee brace (KO) that goes from mid-thigh to mid-calf? A long leg brace (KAFO) that goes from foot/ankle up to mid to high thigh with some kind of knee joint? About how much does the brace weigh? And lastly, what other medical conditions do you have?

I'd be happy to respond in more detail when I receive more information to you.

**Survivor Response:** It is wonderful to have contact with a doctor who is also a polio survivor! I have found that younger doctors are puzzled by my issues. I do see a Rehabilitation Physician (physiatrist). I am being treated for osteoporosis with Prolia. I have been on it for 4+ years. I took Forteo before that. I am stable with some improvement. When I was diagnosed with the herniated disc, it was through an MRI.



I had PT for a long time; no surgery, no epidural. My affected leg was numb for a long time. I still get occasional numbness. My PT started with bed activities like heat, stimulation, massage and then progressed to gym work and exercise.

My weakness is in my quad muscles. I am unable to lift my leg from a sitting position, up to a full leg extension. I got my first brace (a KAFO) and have had it for 6 months. I developed recurvatum of the knee which made walking very difficult. I think I always had a tendency toward that problem and it was exacerbated by the herniated disc.

The brace is a big help. It allows me to walk more easily, though I still depend a lot on a cane. The brace is graphite and might weigh 2 lbs. The orthotist wanted it to be as light as possible. I am a healthy woman in other respects with good BP and no medication other than Vitamin D. [Editor: recurvatum of the knee is also known as knee hyperextension]

### **Dr. Eulberg's Response:**

Many people our age show herniated discs on an MRI but don't really have any ill effects from it. But it sounds like you had some sensory deficits.

Thanks for letting me know which muscle(s) are most affected. It is expected that if you have significant weakness of your quadriceps (and especially if you also have weakness of the calf muscles on that same leg) that you will develop recurvatum. It is simply a "normal" compensation to keep your knee from buckling. Slight hyperextension (recurvatum) allows you to stand balancing bone on bone and not need to have the quadriceps working during standing. But you can have too much of a good thing. If it goes much beyond 10 degrees then it can cause pain, problems walking and if left untreated keeps getting worse and worse as the ligaments in the back of the knee get stretched out. I suspect that the weakness of your quadriceps has been present for longer than you are aware because it usually takes several months to years to develop recurvatum that is bad enough to need to be braced.



Dr. Bruno has suggested that all people who use a KAFO should also use a cane (or two crutches). I am now wearing a KAFO on my left leg. I use a cane, when walking outside my home but unless I am really tired, I don't use the cane inside my home or in "safe" environments, thus reducing the stress on my shoulder.

It is impressive that your KAFO only weighs 2 pounds; often the knee joints alone weigh at least a pound. It does make sense to make a brace as light as possible while still strong enough to provide stability and not break too easily. I have one of my sister's braces from when she was about 8 years old (yes, she also had polio) and it weighs at least 5 pounds. I understand they did not have the same materials back then as we do now, but it never made any sense to me to recognize that a person had significant weakness of a leg and then add a heavy weight to it!



PPS is a slowly progressive disease process so as you are trying to "get your strength back" you are fighting a bit of an uphill battle. Sometimes "victory" is maintaining and not getting worse.

I do worry a bit about your statement that you do walk up stairs. I'd hate to have you fall going up or down the stairs. As you do future planning you might consider ways to limit doing stairs or, even better, completely eliminating the need to do stairs. Many people in their 80s no longer do stairs, whether they had polio or not. I am hoping that the stairs have a handrail, preferably on both sides of the stairs.

**Dr. Eulberg's series of Articles and Videos are in the "Primary Care Perspective" section of our website:**

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**Do you have a question for Dr. Eulberg, Dr. Bruno, or any of our thoughtful, professional contributors?**

Email us at: [info@papolionetwork.org](mailto:info@papolionetwork.org)

The following was distributed to by Stephanie Cantrill, Polio Australia's Community Programs Manager, to participants following a zoom chat meeting. These meetings take place at 11am on Mondays. If you are interested in participating in one of these chat sessions contact Stephanie via Polio Australia's website. [www.polioaustralia.org.au/community-information-sessions/](http://www.polioaustralia.org.au/community-information-sessions/)  
This fact sheet for GPs was put together by Michael Jackson, PAs Clinical Health Educator.  
For more fact sheets visit: [www.polioaustralia.org.au/living-with-polio/](http://www.polioaustralia.org.au/living-with-polio/)

## Exercising Muscle Groups with Giant Motor Units in the Presence of Partial Paralysis

### Specific guidelines for exercise in those with Late Effects of Polio:

- 🌈 Polio survivors should be encouraged to exercise to benefit their health.
- 🌈 Exercise in post-polio patients should be prescribed and monitored.
- 🌈 The expertise and guidance of LEOp-informed therapists should be used.
- 🌈 Avoid LEOp fatigue and pain rollercoasters by careful prescription.
- 🌈 When initiating exercise programs think: low-strain, slow, conservative.
- 🌈 Assess safety (fall, fracture, temperature) in each exercise mode choice.
- 🌈 LEOp weakness can be stabilised or slowed, but never normalised.
- 🌈 The goal to articulate, is to “stabilise function” NOT to “get stronger”.
- 🌈 Avoid unnecessary “extra” stress and strain on all muscle groups.
- 🌈 Educate survivors on moderate consistent exercise and risks of disuse.

### STRENGTHENING

- Any strength gains will emerge slowly; progress exercises gradually.
- Only exercise muscle groups that test as 3+ or greater out of 5.
- Fibre type, fibrosis, atrophy, and vasomotor tone affect muscle function.
- Low resistance (intensity), moderate repetitions, ensuring frequent rest.

### CARDIOVASCULAR

- With whole body modes, exert only to the capacity of the weakest limb.
- Modes that support weaker limbs should be prioritised (e.g. aquatics).
- Shorter moderate bouts with rest (intervals) may be tolerated best.
- Environment and clothing planning help reduce heat loss after exercise.

### JOINT RANGE AND MUSCLE LENGTH

- Stretching must appreciate surgical history and any limb bracing in use.
- Stretching can reduce pain, reduce asymmetry, and stabilise posture.
- Stretching intrinsically affects muscle control – this can present risks.

### BALANCE AND CONTROL

- Skill and balance activities should adhere to the above constraints.
- Reducing fall risk using a multifaceted approach should be a priority.



# Polio Pioneer Helps Survivors Hold On To Strength

By Joseph Shapiro

Reprinted with permission from Polio Perspective Newsletter, April 2021. Originally from National Public Radio (NPR), Washington DC **11/5/2009** To listen to this interview: <https://www.npr.org/templates/story/story.php?storyId=103892252>

Dr. Lauro Halstead is one of only a handful of doctors in the U.S. who specializes in polio — and he speaks to his patients with authority. He was one of the first doctors to publish evidence of a startling medical problem: Twenty-five years ago this month [editor: currently 36 years ago], he presented evidence that people who'd had polio as children were reporting a new weakening of their muscles as they got older. It became known as post-polio syndrome. But there's one more thing that gives him an understanding of his patients: Halstead is a polio survivor, too.

One challenge is that many doctors do not have experience treating patients with polio or post-polio syndrome, says Dr. Lauro S. Halstead in his book *Managing Post-Polio*. He recommends working with your primary care doctor to find a physician with expertise in post-polio care.

At the National Rehabilitation Hospital in Washington, D.C., Halstead comes down the hallway on an electric scooter. He is 73, and he would like to retire, but he can't. The number of aging patients who want to see him is growing. Post-polio patients — including many from around the country and even from other countries — come to his polio clinic here.

On a late April day, Edith Gerver sits in an exam room, with a bamboo cane at her side. The 83-year old explains that her daughter is moving to Florida, and she's thinking of going with her. But she's having a problem: Lately she's been losing her balance and falling, a few times a month. She has come to see Halstead, hoping he can come up with a solution.

The doctor asks her to take off her shoes. Her feet are strange: There are scars, but no ankles. Multiple childhood surgeries fused her bones so she could put weight on her feet and walk. Halstead uses his arms to press against her feet, testing the strength in her legs.

## Shared Experiences

He takes a medical history and gets a sense of her active life. They share their polio stories. He was 18, a college student touring Europe, when he got sick. She was an infant in Germany, and later, when her Jewish family fled to the United States, she wasn't at first allowed in because she had had polio.

Halstead tries to persuade Gerver that it's time to start wearing a leg brace. He rolls up his pant leg and shows the one he uses. She says she tried one before, but it was too uncomfortable. He tells her she should get a scooter, like his. She says it would be too hard to get around with it.

"What I want to do," he tells her, "is be able to make any modification that you are interested in that would help you have a more comfortable, enjoyable life."

But it's not easy for his patients to do things that look like they'd be giving in to their polio. People with polio worked hard to overcome their illness, so it goes against their nature — when post-polio syndrome kicks in — to slow down.

"So you may think, you think that maybe that's like giving in?" he asks her.

"I feel that as long as I can stand on my two legs, I'm ahead of the game," the woman says. "I know that doesn't make much sense."

"No, it doesn't," the doctor replies softly.

"But it's who I am," Gerver replies. "And I think polio made me that way."

"OK," says Halstead. "I will accept that."

## **Survivors**

But he doesn't give up. He keeps pushing her gently over the hour-long appointment. By the end, she agrees to let him call the hospital's orthotist. She'll try one more time to wear a leg brace.

Halstead can relate to patients like Gerver because he, too, is managing his post-polio syndrome. "I'm having a lot of the same issues that she is in terms of slow, progressive weakness in my legs," he explains. "So I can walk shorter and shorter distances. I continue to use a motorized scooter for longer distances, longer than 20, 30, 50 feet. I take afternoon naps to help get me through my afternoon fatigue."

There hasn't been a new case of polio in this country from the "wild" live virus since 1979. The use of the live-virus vaccine, which sometimes can cause infection, was discontinued nine years ago.

Still, there are hundreds of thousands of polio survivors alive in the United States. The National Center for Health Statistics estimates that there are more than 440,000. The leading polio survivors' group, Post-Polio Health International, puts the numbers at 775,000 or more. Many of these survivors are still paralyzed. But most aren't and, from looking at them, there's no way to know they had been infected. But all polio survivors face the threat that polio can come back as they get older — the post-polio syndrome first described in the mid-1980s by doctors like Halstead and Marinos Dalakas.

Another patient, Julie Lewis, waited six months for her appointment with Halstead. This is her first time to the clinic, so she spends two mornings seeing Halstead and his team, which includes physical and occupational therapists, and a social worker.

She has a busy and important job as a hospital administrator. She, too, finds it hard to accept all of Halstead's advice to slow down — including taking a nap at the office. After her long sessions with Halstead, she goes back to the office.

Lewis, at least until now, has always been able to hide her polio. But right away, Halstead spots the one visible tip-off. He holds his hand to hers. On both of them, the usually thick muscle at the base of the thumb has withered.

That looks familiar to me, your hand," Lewis tells the doctor. "I like your hand."

Halstead laughs and says, "But it's useless to me." There's no question that the atrophied hand muscle is a sign of polio, he says.

That comes as a relief to Lewis. She's 55 now. She remembers that when she was 9, she was so sick for weeks that her mother had to hold her up in bed and on the toilet. But she's had trouble finding a doctor to confirm that early memory. Her mother has since died, and her early health records are gone. "I'd been told all my life I had polio — by my family, my early doctor," she explains. "But as I got older and I had trouble finding doctors that could recognize and confirm that, I started doubting at times. Maybe I had an injury, maybe something else happened to me that I wasn't sure about."

### **Diminishing Resources**

Seeing a doctor who specializes in polio makes the difference. But that raises a question, says Joan Headley of Post-Polio Health International: "Who's going to replace these early champions and these early physicians?"

It was a member of her polio survivors' group that gets credit for first sounding the alarm about post-polio syndrome. In 1979, a man from Arizona wrote in the group's newsletter that, as he aged, he was having more difficulty with weak muscles and extreme fatigue. Other members wrote in to say they'd noticed the same thing. In 1982, Halstead was the first doctor to listen to the group's members, survey them, present his findings and then, with a handful of other polio doctors, spread knowledge about post-polio syndrome.

Last month, several hundred of Headley's members gathered at Warm Springs, Ga., the town whose warm mineral springs President Franklin D. Roosevelt and others with polio visited. At the recent meeting, a big topic of conversation was who would replace the generation of polio specialists like Halstead. Headley says many polio survivors say they still have difficulty finding doctors who understand polio. But there's also optimism that rehabilitation specialists — and even many family doctors — now have the expertise to treat them.

Headley says that's in no small part because of Halstead. "Dr. Halstead has certainly been the champion of the post-polio community over the last 30 some years," she says. And because Halstead spread the word about post-polio syndrome — with his research, writing, speeches and personal communication with doctors and survivors — there's reason to think, she says, that "most physicians now know about the late effects of polio and post-polio syndrome."

Halstead would like to retire. He's got a wife and teenage son, and he's got lots of interests: He travels to Italy a couple of times a year, in part because of his love of all things Italian, but also to help polio survivors there create the kinds of support groups and clinics found in the United States. And Halstead also plays music. He had been a trombone player before contracting polio, but stopped after his illness. (Although, while in the hospital, he taught himself to play piano with one hand.) But recently, he's taken up another brass instrument, the euphonium, with a special left-handed instrument made for him. But before he can retire, he's hoping his hospital can find and hire a young doctor — one he could mentor to take over his practice.



# Hello! It's Your Body Calling

By Millie Malone Lill, Editor of Polio Perspective

Reprinted with permission from Polio Perspective Newsletter, April 2021.  
A humorous letter from her body to her brain.

Hi there, you wonderful polio survivor you! This is your Body calling you. Pay attention. Remember when you got polio? How sick you were? You were just a little kid and all of a sudden you were whisked away to a strange environment, strange people, lots of poking and prodding, doctors and nurses in herds coming into your space.

You were scared, you wanted your Mommy and you wanted mostly to just go home. I remember that time, too. Legs refused to obey, Arms turned into overcooked noodles, Spine went limp. But do you remember the hot woollen wraps? Really hot, weren't they? They relaxed Muscles, though, and kept them from tightening up and staying that way. The exercise? Painful! Again, though, they eventually convinced Muscles to obey.

We worked really hard, you and I. You were stubborn, you did not give up. But neither did I. I and the rest of your Body all worked together with the doctors and nurses, the Physical Terrorists...I mean Therapists...to get you better. Brain went to work and convinced Neurons to shoot out sprouts to help the Muscles that had lost contact with Brain to function again. We made a great team, you and I.

Eventually, you got to go home. You learned to walk with crutches and braces. More therapy and more hard work got you to the point where you didn't need the crutches and finally you could also get rid of the braces. You were cured!

Or so we thought. You and I decided to put all of this behind us and get on with life. We played sports, we served in the armed forces, and we married and had families. Life was good. We were back to being Normal.

Life and time went on. We found we could not walk as easily as before, we tired quickly and we fell a lot. You started referring to parts of us, your Body, as Bad. My Bad Leg, my Bad Arm, my Bad Back. I want to tell you, we are insulted by this! We are not Bad! We worked hard with the equipment we were given, which was a dwindling supply of overworked neurons. Polio had left us with fewer tools to work with and even those tools were wearing out. We did the best we could, but we were rapidly running out of supplies.

Your doctor told you you had Post-Polio Syndrome. He said there were other tools you could use to compensate for the ones that your abused, polio-affected muscles had used up. Frankly, we, your Body, were elated by the thought of reinforcements. But no. You didn't want to "give in." You wanted to remain Normal, even though that was no longer working for you. The stubbornness that got you to that point was unwilling to relent.

So we fell more often. We ached. We did all we could to let you know that we wanted those new tools! And eventually, you gave in. What a surprise to find that a brace gave us more stability. We weren't falling nearly as often. We also found out that if we stopped pushing ourselves and allowed our Muscles to rest and revive, we could do more than if we just bulled on till we collapsed.

We discovered that using a power chair for distances saved us enough energy to actually enjoy life again. No longer were we focused on dragging ourselves from place to place. Life was good again. We were not exactly Normal, but we were actually better than that. Life is good, so please stop calling us Bad. We've worked too hard to help you maintain your life. We deserve your respect and dare I say even your admiration for all we've gone through.  
Sincerely, Your Body



# Polio Oz News

March 2021 – Autumn Edition

## Parenting After Polio

Polio in the Australian context is changing. While there has not been poliovirus transmission detected in Australia since the 1970s, transmission has continued beyond the 1970s in many nations.

A new generation of polio survivors is migrating to Australia from countries including but not limited to Afghanistan, India, Nigeria, Pakistan, Somalia, Vietnam and Russia. The Australian healthcare system is learning and adapting to meet the needs of parents and parents-to-be who have had polio.

Any new parent would know the challenges of dealing with baths, feeding, bedtime routines and so on, and the value of support at this exciting but overwhelming time. Many polio survivors have faced additional difficulties managing the tasks of being a new parent, and may not have known where to find the support they need.

Polio can have lifelong effects. We are mindful that cultural perspectives on the history of polio and the possible effects may vary. In the same way, we acknowledge that each person has a unique experience of polio and the responses of society and healthcare systems.

Knowing which health professionals can support you and connecting with them early in your pregnancy has been recommended by mothers



who have had polio. These mothers report that this has helped them to put NDIS funding plans in place, manage pain and fatigue, and prepare for baby's arrival, including feeding, bathing, and changing.

In late 2020, Polio Australia had the privilege of partnering with Polio Services Victoria and a member of Post-Polio Victoria's committee to supervise two occupational therapy students. Their project was to develop a resource for new parents.

After researching the issues, interviewing both parents and service providers, and examining the limited resources that already existed to support parents with disability, they decided it would be worthwhile to produce two

separate booklets. Thus, we now have access to a guidebook for new parents, and another for health professionals.

At present, the services and organisations listed in the booklets are Victorian-based. We aim to increase the reach of these resources by applying them to the other states as well. However, we hope that new parents or maternal health services anywhere will find benefit from these resources.

To download, go to Polio Australia's [home page](#) and click on the banner. 📄

*Featured image and some text taken from the Parenting After Polio booklet.*



## PARENTING AFTER POLIO

NEW RESOURCES FOR PARENTS AND HEALTH PROFESSIONALS

DOWNLOAD AT [WWW.POLIOAUSTRALIA.ORG.AU](http://WWW.POLIOAUSTRALIA.ORG.AU)



**Polio Australia**

Representing polio survivors

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“ **Autumn is the Season of change.**  
~ Taoist Proverb ~ ”

**Polio Australia's Websites****Polio Australia**Representing polio survivors throughout Australia 

Welcome to the Polio Australia website. Polio Australia is a not-for-profit organisation supporting polio survivors living in Australia. This website contains information about polio, the Late Effects of Polio, the work of Polio Australia and much more.

[www.polioaustralia.org.au](http://www.polioaustralia.org.au)**Polio Australia**Improving health outcomes for Australia's polio survivors 

The Polio Health website is a comprehensive resource for both health professionals and polio survivors. It contains clinically researched information on the Late Effects of Polio; the Health Professional Register; and where Polio Australia's Clinical Practice Workshops for Health Professionals are being held.

[www.poliohealth.org.au](http://www.poliohealth.org.au)**Australian Polio Register**Have you added your polio details? 

The Australian Polio Register was established by Polio Australia in October 2010 to gather information on the numbers of polio survivors living in Australia today, whether or not they contracted polio in this country. To make the Australian Polio Register truly reflective of the unmet need for polio services throughout Australia, we urge every Australian polio survivor to join the Polio Register. Our strength lies in our numbers—please help us to get you the services you need by adding your polio details to the Register. You can register online or by downloading and completing a [paper copy](#).

[www.australianpolioregister.org.au](http://www.australianpolioregister.org.au)**Polio Australia**Honouring Australia's polio survivors - "We're Still Here!" 

Polio Australia's "We're Still Here" website is a hub for sharing people's stories, polio survivors in the media, polio awareness raising campaigns, events of interest, Rotary talks, and so much more. It is constantly being updated, so check in often.

[www.stillhere.org.au](http://www.stillhere.org.au)

## President's Report



Gillian Thomas OAM

Despite some lock-down hiccoughs towards the end of 2020, we entered 2021 full of hope that the team could get back on the road. It is therefore pleasing to note that Michael reports the scheduling of 11 Clinical Practice workshops in QLD, VIC, and NSW. While the vaccine roll-out has started, forward planning continues to pose some challenges, and with borders snapping shut on a seeming moment's notice, the possibility of team members being trapped in, or out of, their home state is still very real. However, we are taking our usual "glass half-full" approach and look forward to a growing number of in-person workshops and community information sessions being held over the coming months, complementing the popular Zoom sessions.

At the end of 2020 we closed the Kew office which had been the workplace of our Victorian team for 11 years. With Maryann's retirement and Darlene's contract concluded, Steph is currently our only team member in Victoria. Since COVID turned the world upside-down in 2020, everyone has been enjoying the convenience of working from home, so it made sense to save the rent dollars and put them to better use in support of our programs.

## From The Editor



Maryann Liethof  
Editor

As I collate information over the 3 month period between *Polio Oz News*, I'm constantly surprised at how much is still being done in the 'polio world', where many people would consign polio to the annals of history long-gone. Not so!

Granted, a lot of polio survivors from the 'Western' epidemics are now well past child-bearing age. However, it is good to see that new resources are being developed for the next generation of polio survivors who still need information about "Parenting After Polio" (p1). I'm sure a lot of older polio survivors would have appreciated this type of support at the time they were raising their own families.

Polio Australia's Clinical Health Educator, Michael Jackson, presents survey findings in "Polio Survivors' Response To Pandemic Changes" (p11), some of which may (or may not) be surprising. Whilst there were clear problems relating to access to services and isolation, many people also reported feeling less stressed. There have to be *some* silver linings in all of this.

Our phone number 03 9016 7678 remains unchanged, as does our general email address [contact@polioaustralia.org.au](mailto:contact@polioaustralia.org.au). Calls and emails are handled promptly by team members, even though they are scattered around the country. The major change is that our postal address is now PO Box 2799, North Parramatta NSW 1750 (shared with Polio NSW). Our bookkeeper, Shylie, works part-time out of Polio NSW's Parramatta office and efficiently deals with incoming snail mail.

You have no doubt heard that the Aged Care Royal Commission released its final report in March. Steph has written a detailed article (p6) on how the report's recommendations apply to older people with disability. In particular, you will be hearing a lot about Recommendation 72 this year. As diverse as the disability sector is, organisations are united in advocating for full implementation of this recommendation which addresses equity for people with disability who are not eligible for the NDIS but instead receive aged care services. To find out how to add your voice, check out Steph's article.

In her Editorial below, Maryann reflects on how much polio is still in the news. You may also be surprised to learn that there have been at least 17 post-polio specific research papers published in the last 12 months. Michael and Paulette regularly add the details of such articles to our growing research database which you can search [here](#).

Gillian

Members of the post-polio community have also been quite active. Dr Margaret Peel OAM had an article published in *Microbiology Australia* titled "Epidemic Poliomyelitis, Post-Polio Sequelae And The Eradication Program". You can read the Abstract and link to the full article on page 13.

Spinal Life Australia, who represents Queensland on Polio Australia's Board, has provided an update on their polio-related campaigns (p14). And if you are thinking about a wheelchair accessible holiday in Cairns, you might like to check out the Spinal Life Healthy Living Centre.

An interesting article in *The Washington Post*—"Pandemic Parallels" (p17) covers an interview with polio survivor, James Hartt, and highlights the correlation between polio and COVID-19 and vaccine development.

Fran Henke, author, artist and polio survivor, has had her polio story published in the new Australian anthology "Growing Up Disabled In Australia" (p19).

And, did you know that the artist who created the iconic "Tumbling Dice" Rolling Stones cover is a polio survivor? Ruby Mazur recently completed "Rock n Roll Last Supper", which took him 3 years to complete (p19).

So, there's always something happening! 🌟

Maryann

## 2021 Program Update: Clinical Practice Workshops



**By Michael Jackson**  
Polio Australia Clinical Educator

**Clinical Practice Workshops**  
The clinical practice workshops (CPW) are on the return in 2021, with one in-person workshop (9 attendees) being delivered in Warwick QLD in February, and three monthly Zoom workshops (15 attendees) hosted over the last three months. Various occupations attended, and due to the broad reach of the Zoom workshops, we had attendees from all large states (but not TAS, NT, ACT).

Eleven in-person workshops are scheduled up until the end of this financial year in QLD, VIC, and NSW. The Zoom workshops will continue monthly this year for professionals as a means to test the mode of delivery, and to supplement the live workshop reach.

While travel barriers related to delivering workshops are reducing, securing a workshop still relies on facilities being confident hosting a workshop in their local and state health environments. Continued hesitancy in scheduling within each state, and amongst facilities, persists. Amongst those attending the Zoom workshops to date, COVID-19 continues to weigh on clinical education decisions at the individual level. The risk of an outbreak interrupting travel for both the educator and attendees is still substantial despite the vaccine rollout being underway.

### Academic Partnerships

Our current audience for the CPW consists primarily of licensed health and medical professionals. By educating health pre-graduates (still at university), LEOp knowledge can be taken into the workforce to clinics and facilities that Polio Australia may not otherwise physically reach. Educating emerging health professionals also serves to reduce the low confidence polio survivors have with new health professionals being able to appropriately and safely treat LEOp. Universities engaged with the clinical educator to

reach their pre-professional audience include: JCU, UQ, ACU Brisbane, USC, UTAS, UWA and Monash. The first audience will be 4<sup>th</sup> year physiotherapists at JCU in September this year.

### Health And Professional Use Survey

Our second survey of 2020 was open for three months (Oct-Dec 2020), and 185 respondents completed the survey. 35% had not participated in the early 2020 survey, and a further 42% were not sure if they had. This means at least 800 unique Australian polio survivors responded to our surveys last year – quite impressive participation. Thank you!

The topics of this end-of-year survey were:

- Support service use
- Prevalence of other health syndromes
- LEOp symptoms (current, worst, improved, impact)
- Mobility device use and falls frequency
- Age of functional change with common tasks
- Professional utilisation, responsiveness, and effect
- Anticipated (10 years) professional use
- COVID-19 impact in late 2020

You can read about the findings from one topic in this issue on page 11 – *Responses to the COVID Pandemic*. Other topics will be reported on in future *Polio OZ News* issues and used for education of both polio survivors and professionals within Polio Australia's programs.

### GP Resource – Podcast

In late December the Clinical Educator was recorded as the guest speaker on the Healthed podcast: *The Clinical Takeaway: Post-polio survivors – a forgotten group still in need of care*, and published on 22<sup>nd</sup> January 2021. The information discussed in this podcast episode was oriented to GPs as a focus audience. The Healthed network reaches up to 25,000 health professionals, and has at least 500-1000 podcast downloads. Tell your GP to listen to it on their commute next week! Podcast link to send to your GP office:

<https://www.healthed.com.au/podcasts/the-clinical-takeaway-postpolio-survivors-a-forgotten-group-still-in-need-of-care/> 🎧

### Would Your Healthcare Provider Benefit from LEOp Education?

Polio Australia's FREE Clinical Practice Workshop can help them get up to speed! 🎧

Our Clinical Health Educator visits your provider's office or facility at a time of their choosing to deliver education on the topic: **Polio Survivors and Their Health Conditions!**

The FREE workshop visit and FREE resources includes:

*A comprehensive presentation on LEOp  
Resources tailored to their discipline  
CPD hours credit including a certificate*

*Their specific questions answered in-person  
92-page E-Book on LEOp clinical management*

For more information, have your healthcare provider contact Michael on 0466 719 013 or email [michael@polioaustralia.org.au](mailto:michael@polioaustralia.org.au) to arrange a visit.

## Community Programs Update



**By Steph Cantrill**  
Community Programs  
Manager

Welcome to 2021! I hope everyone is doing well and settling into the year and the 'new normal'. Community programs remain a little restricted at the moment, due to the unexpected nature of, well, everything! But we're

ploughing on as best we can, and online methods of engaging the community are proving to be a real asset. We look forward to returning to face-to-face events when we can, but for now I hope to see you online soon!

Please remember that we're also available for those that don't like online engagement. Call us on 03 9016 7678 if you would like information or resources on post-polio issues. We're only a phone call away!

### Webinars

At one of our recent Zoom chats, we realised it would be worthwhile to do an online version of the Community Information Sessions we usually do in-person. We have also talked numerous times about the challenges of making yourself heard when talking to health professionals. With that in mind, our first two webinars will be:

#### 1. Late Effects of Polio – 15<sup>th</sup> March, 11am AEDT

In this webinar, we'll talk about common Late Effects of Polio symptoms, health professionals and how to work well with them, and some self-management strategies. As this will give an overview of post-polio issues, it would be a very good session to bring a family member along to, even if you've heard it all before.

#### 2. Self-Advocacy – 5<sup>th</sup> May, 11am AEST

Liz Telford OAM was the first president of Post Polio Victoria, an advocacy group that raises awareness of post-polio issues. She also has a background in Social Work and family therapy. Liz will be drawing on her wealth of experience to talk to us about self-advocacy, particularly relating to the way we interact with our health professionals and advocate for our needs.

To register for either session, please go to [www.polioaustralia.org.au/community-information-sessions](http://www.polioaustralia.org.au/community-information-sessions).

### Zoom Chats

As well as our webinars, we want to keep the conversation going with regular informal chats. Join us on the first Monday of each month\* at 11am Vic/Tas/NSW/ACT time as we have a discussion loosely based around the topic of the month. All welcome. Register at [www.polioaustralia.org.au/community-information-sessions](http://www.polioaustralia.org.au/community-information-sessions). You only need to register once to attend any or all of the sessions.

\*12<sup>th</sup> April instead of 5<sup>th</sup> due to the Easter Monday public holiday.

### Social Media

Our social media community continues to grow. The latest change is our NDIS Polio Hub, a Facebook group for people who had polio and are either in the NDIS or eligible to join (living in Australia, under 65, have some degree of disability or functional limitation). If that's you, we'd love you to join us so we can all share and learn together: [www.facebook.com/groups/ndispoliohub](https://www.facebook.com/groups/ndispoliohub).

For everyone, there's also our [Facebook page](#) and [Polio Australia group](#). Come and join us!

And don't forget you can always view our videos on our [YouTube channel](#), and follow us on [Twitter](#).



In 2021, the ATSA Independent Living Expo is set to have more than 100 exhibitors displaying a wide range of products and services in assistive technology, mobility solutions, pressure care, employment support, accessible recreation/holiday ideas, modified motor vehicles and a lot more.

ATSA Independent Living Expo is open to visitors of all ages, including those with a disability, seniors and their families, friends and carers.

Admission is free to therapists, the general public, end users & ATSA members.

**Melbourne: 18-19 May / Perth: 26-27 May / Canberra: 27-28 October**

[www.atsaindependentlivingexpo.com.au](http://www.atsaindependentlivingexpo.com.au)

## Royal Commission Into Aged Care Quality And Safety

**By Steph Cantrill**

Community Programs Manager

### Advocacy Update

On the 1<sup>st</sup> of March, the final report of the Royal Commission into Aged Care Quality and Safety was released. Many of you would have seen the list of recommendations already – if you would like to, you can view it [here](#). If you're interested in reading all 2,800 pages of the report, you can download it piece by piece [here](#).

### Why is this Royal Commission important?

Even before COVID-19 brought to light the many inadequacies in our provision of residential aged care services, problems such as long waiting lists for home care packages, insufficient funding for aids and equipment and an over-worked and under-supported workforce were emerging. As our population continues to age and the number of people requiring aged care services increases, the system needs significant improvements.

As many would agree, there is a lot of work to be done to ensure that aged care services are comprehensive and consistent, and that they uphold the rights and choices of the people at the centre of the care. The recommendations from the Royal Commission provide a helpful starting point.

### How does this apply to older people with disability?

Of particular interest to us at Polio Australia were the recommendations that focused on older people with disability. The exclusion of people over 65 from the National Disability Insurance Scheme (NDIS) has been a source of great disappointment to our community. We are pleased to see people with disabilities being specifically addressed in the recommendations.

Recommendations 30, 34, 72, 73, 109, 125 relate to people with disability and/or assistive technology (aids and equipment). But I'll draw your attention particularly to **Recommendation 72: Equity for people with disability receiving aged care:**

*"By 1 July 2024, every person receiving aged care who is living with disability, regardless of when acquired, should receive through the aged care program daily living supports and outcomes (including assistive technologies, aids and equipment) equivalent to those that would be available under the National Disability Insurance Scheme to a person under the age of 65 years with the same or substantially similar conditions."*

At Polio Australia, we have campaigned on two fronts. The first is aiming to remove the discrimination against people over 65 with disability by allowing them onto the NDIS. Failing that, or until it happens, we've been joining with the Assistive Technology for All (ATFA) Alliance to call for fair, equitable and nationally-consistent access to assistive technology for people with disability of any age. In light of both of these campaigns, it's heartening to see Recommendation 72 acknowledge the need for equitable support for older Australians with disability.

### What can we do?

So, what happens now? While there's an element of "wait and see", here are a few things you can do:

1. Sign on to the ATFA petition to call for equality of access to vital aids and equipment: <https://assistivetechforall.org.au/take-action/>
2. Write to your local MP to express your frustration with the ongoing discrimination against older people with disability, and your hope that these recommendations will be heeded (we're in the process of producing a letter template with ATFA)
3. Join ATFA's [Facebook page](#) to stay informed on the campaign

To view Polio Australia's submission to the Royal Commission into Aged Care Quality and Safety, submitted in 2019, see [here](#).

## CPW Receive Endorsements From Professional Orgs



**By Paulette Jackson**

Administration Officer

Historically, our Clinical Practice Workshops have been endorsed by various professional organisations as an accredited professional development activity. Over time, these endorsements expire. Recently Polio Australia submitted applications for endorsement to the Australian Nursing & Midwifery Federation (ANMF), Australian Primary Health Care Nurses Association (APNA), Australian Orthotic Prosthetic Association (AOPA), and Exercise and Sports Sciences Australia (ESSA). We are happy to announce the ANMF, AOPA, and ESSA applications have been approved. Decision is pending on the APNA application.

These endorsements demonstrate to health professionals that we have met certain educational standards as well as validate the quality our workshops.

## Nutrition, Food And Dining Experience In Aged Care

By **Melinda Overall JP**

Nutritionist and Counsellor—[Overall Nutrition](#)



On 18 March 2021, The Australian Department of Health partnered with the Maggie Beer Foundation to host the *National Congress on Nutrition, Food and the Dining Experience in Aged Care* at the ICC, Sydney. The Congress was an 'invitation only' event. I was honoured and privileged to have attended the Congress on behalf of Polio Australia. I was one of about 120 attendees. Most attended in person and some attended the live streaming of the event. Invitees included dentists, speech pathologists, dietitians and nutritionists, chefs/cooks, aged care workers and managers and food supply companies, to name a few.

The goals of the Congress were to bring a diverse group of stakeholders together to discuss best practice and key issues in the provision of nutrition, food and the dining experience in aged care homes. Michael Jackson, Polio Australia's Clinical Health Educator, and Steph Cantrill, Polio Australia's Community Programs Manager, and I met prior to the Congress to ensure that polio survivors had a voice in the aged care space.

The timing of this congress was significant given it took place just prior to the release of the findings of the Royal Commission into Aged Care Quality and Safety. Food and nutrition was identified in the Commission's report as one of four key areas requiring immediate attention<sup>1</sup>. Malnutrition is a complex beast, but a 2017 report found that a staggering '68% of people receiving residential aged care are malnourished or at risk of malnutrition'<sup>1,2</sup>. This puts aged care residents at greater risk of falls, poor immunity, mild cognitive impairment, slower healing times, cachexia and sarcopaenia, to name but a few health risks increased by malnutrition.

The Congress had three main components. The first was a number of presentations from professionals working across diverse areas relating to aged care, and this included several panel discussions. The second encompassed group activities to identify specific issues in aged care and possible solutions (some of the suggestions may have been a little ambitious but it highlighted just how much work was needed to

improve aged care). The final component was a meeting of the working group on the following day. The working group was comprised of the Maggie Beer Foundation, government agencies, peak bodies, university representatives, ethics specialists and aged care organisations. Polio Australia was not a member of the working group.

A number of issues were raised in our brainstorming group and across the Congress more generally. Many of these were consistent with some of the issues that Michael, Steph and I had discussed in relation to polio survivors living in aged care homes. Issues raised at the Congress that were specific to polio survivors included:

- **Late Effects of Polio** (Post-Polio Syndrome) — these signs and symptoms can return after 'recovery' from poliomyelitis (at least post-polio 15 years for diagnosis) and can include: muscle weakness and sarcopaenia, joint and muscle pain and fatigue, difficulty swallowing, loss of overall physical function and arthritic and degenerative decline.
- **Swallowing issues** — swallowing issues are common in the general population especially in their 90s. For polio survivors however, swallowing issues are more apparent in their 70s and this may be due to the late effects of polio. Polio survivors may require more support from speech therapists earlier than the general population.
- **Fatigue** is more apparent in late afternoon or early evening for polio survivors — therefore main/largest meals might be best served at lunch time. This is especially important for polio survivors as generally their swallowing capacity may decline over the day so larger meals are better suited to earlier in the day.
- **Polio Comorbidities** — due to general lack of mobility, polio survivors can be more at risk of developing other health issues such as overweight/obesity, type 2 diabetes, cardiovascular disease, sleep apnoea, dislipidaemia, osteopaenia/osteoporosis, sarcopaenia and arthritis. This needs to be considered in menu planning.
- Polio survivors have a greater need for high quality protein to help prevent sarcopaenia than the general population. This is generally above the Australian recommended dietary requirement of protein and needs to be considered in menu planning.
- Australia was declared polio free in 2000. Whilst there is a large number of Caucasian polio survivors in Australia who might enjoy similar meals, there are also a number of polio survivors who have immigrated to Australia from a vast array of nations.

## . . . Dining Experience In Aged Care *(cont'd from p7)*

As such polio survivors are a heterogeneous group with significantly different dietary preferences and requirements including those pertaining to their religion/faith. This would also likely be the case in the general aged population and so we believe there is a need for greater individualisation of meals within aged care settings.

Other more general issues/suggestions raised during the Congress included:

- The need for more staff in aged care homes.
- Staggered mealtimes to support residents who require more support with eating.
- Improving the quality of food.
- Improving the presentation and palatability of food generally but specifically regarding texture modified food.
- Improving socialisation around meals — including family members in mealtimes and improving the look and feel of dining areas in homes.
- Promotion of choice in the dining experience including seeking input from residents for menu planning.
- Reducing reliance on nutritional supplementation.
- Improving dental hygiene and care for residents.
- Allowing dietitians, nutritionists, dentists and speech pathologists into kitchens.

No doubt there's a long road ahead for aged care but let's hope that Royal Commission will shape a new way forward.



*PHOTO: Maggie Beer (left) attended the Congress. She was lovely, open and chatting to everyone. This photo is of Maggie and me. We were just heading back from lunch I had a mouthful of tofu, was trying to speak, smile, swallow and take a photo all at the same time. I realised I'm not great at multitasking!*

References:

1. Royal Commission into Aged Care Quality and Safety (March 2021). Final Report — Executive Summary. Retrieved March 8, 2021 from <https://agedcare.royalcommission.gov.au/publications/final-report-executive-summary>
2. Iuliano, S., Poon, S., Wang, X., Bui, M., & Seeman, E. (2017). Dairy food supplementation may reduce malnutrition risk in institutionalised elderly. *British Journal of Nutrition*, 117(1), 142-147. 🍌



## Aged Care And People With Progressive Neurodegenerative Conditions

**The Neurological Alliance Australia** is an alliance of not-for-profit peak organisations representing adults and children living with progressive neurological or muscular diseases in Australia. The Alliance was established to promote improved quality of life for people living with these conditions and funding to support research. Members of the Alliance include Dementia Australia, Brain Injury Australia, Huntington's Australia, Motor Neurone Disease (MND) Australia, MJD Foundation, MS Australia, Muscular Dystrophy Australia, Muscular Dystrophy Foundation Australia, Parkinson's Australia, Spinal Muscular Atrophy Australia, Leukodystrophy Australia and **Polio Australia**.

NAA believes that people diagnosed with progressive neurodegenerative conditions must have access to early intervention, specialised planning, ongoing expert assessment, complex support coordination, assistive technology and a range of services to meet their needs irrespective of where they live, their age or which sector funds the service.

Below is the introduction of the Position Statement NAA submitted to the Aged Care Royal Commission. Read the full Position Statement [here](#).

### NEUROLOGICAL ALLIANCE AUSTRALIA



## Position statement: Aged Care and People with Progressive Neurodegenerative Conditions

December 2020

### The Neurological Alliance Australia (NAA) believes:

- People diagnosed with neurodegenerative diseases must have access to a range of services to meet their care and disability needs irrespective of where they live, their age or which sector or sectors fund the required services.
- Access to reasonable and necessary government-funded disability supports based on the age of a person when they acquire, or are diagnosed with, a disability is discriminatory and contravenes [article 19 of the United Nations Convention on the Rights of Persons with Disabilities](#), that the Australian Government has ratified.
- Investment in Home Care Packages (HCPs) to reduce waiting list for home care, as recommended in the Royal Commission into Aged Care Quality and Safety Interim Report<sup>1</sup>, will improve the lives of thousands of people, reduce the need for residential Aged Care and boost home care sector employment opportunities during a time of rising unemployment.

**The NAA will continue to advocate for access to the NDIS for all people with a diagnosis of neurodegenerative diseases no matter their age when diagnosed.**

## The NDIS Age Loophole That Leaves Thousands Locked Out Of The System

By Dr John Tierney AM

Source: [newcastleherald.com.au](http://newcastleherald.com.au)  
- 22 December 2020

A few years ago, I spoke to the Port Stephens Rotary Club about my life journey with the little-known *Late Effects of Polio (LEoP)*. I mentioned that polio is the only disease that attacks the body when you are young, but then its late effects inflict further damage as you age. A doctor in the audience jumped up and exclaimed, "that's not true; syphilis also follows that pattern!" Great to know that we are in such good company.

As I explained to the Senate Inquiry into the NDIS Bill in 2012, this double-edged sword of the polio disease was the reason survivors should be included in the new disability support scheme. The 65-age cut off should be removed because all 40,000 of Australia's paralytic polio survivors are now past this age. With this barrier in place, they will miss out on any assistance along with every other person with a disability in this age cohort. It seems that one of the foundation stones of the NDIS is blatant age discrimination, almost amounting to criminal neglect.

Gillian Thomas, my successor as President of *Polio Australia*, and I argued before the NDIS Senate Committee that polio survivors should be "grandfathered" in the NDIS. Gillian was living proof. She contracted polio at the age of ten months in 1950. For the last twenty years, she has been a wheelchair user because of LEOp. In later life this completely disabled three of her four limbs. Gillian has partial use of her right arm and hand.

Being over 65 when the scheme was adopted makes her ineligible. When the NDIS legislation reached the parliament, Senator Rachel Siewert (The Greens) moved two amendments to allow polio survivors like Gillian to be included. Both amendments were voted down by Liberal and Labor, to their everlasting shame!

Why did they do this? Back in 2013, it was the age of budget 'debt and deficit.' There was a race between the two major parties to prove they were the most fiscally responsible. Had they included people with a disability over 65 in the NDIS, it would have blown out the cost of the scheme by billions. The government took the advice of the *Productivity Commission (PC)*, "this cohort could be looked after by Australia's aged care system." Really?

The findings of the current *Royal Commission for Aged Care* show that this advice was misguided.

It has revealed shocking gaps in care, particularly for those with a disability. This includes 120,000 people on the waiting list for aged care packages. According to ABC News (15/09/20), "thousands have also died waiting for already approved packages." Access to the NDIS for people over 65 with a disability would dramatically shorten this list. So how was it even possible for the adoption of the PC recommendation, to block access to the NDIS if you are over 65? Australia has an *Age Discrimination (AD) Act*, to prevent this – right?

When the enabling NDIS legislation went through the Parliament, there was a related bill which created a 'temporary suspension' of the AD Act, to enable the passing of the NDIS. This was never reviewed after two years, as promised. The department had hoodwinked the minister, the parliament and the *Parliamentary Joint Committee on Human Rights (PJCHR)*, which inquired into the initial legislation.

When the PJCHR examined the Bills in 2013, it found that the reasons for the suspension of provisions to cut out people over 65, "not compelling". This is polite parliamentary committee language for 'bullshit'. I contend that the Department of Family & Community Services was probably under marching orders from Treasury not to blow out the Federal Budget any further. Now, in 2020, this suspension is still in place. This allows blatant aged discrimination to continue in Australia in defiance of the *United Nations Convention of the Rights of Persons with Disabilities (2007)*.

How can this age discrimination in the NDIS be ended? If there is a will in the current government, it can be easily fixed. All that is needed is an amendment to reverse the suspension of the *AD Act*, as the government had initially promised in 2013. Prime Minister Morrison was asked about this last week. He replied, "the government doesn't plan to change the current NDIS arrangements."

If you are as outraged as I am about this blatant discrimination against the aged with a disability in Australia, write to the PM and copy in your local Federal MP and NSW Senators.

**Newcastle East's Dr John Tierney AM is the former President and National Patron of Polio Australia.**

**In 2019 he was awarded an AM 'for significant service' to Australia's polio survivors.** 🇦🇺

## Polio Survivors' Response To Pandemic Changes

**By Michael Jackson**

*Polio Australia Clinical Health Educator*

In late 2020, 183 Australian polio survivors responded to a survey through Polio Australia. On this survey we included a variety of questions related to the health of polio survivors and their use of health professionals. We asked the following pandemic-related question to capture how Australian resident survivors were coping with the pandemic: "COVID-19 has caused many changes in how Australian society has functioned in 2020. What have been the most notable aspects of these changes – for you as a polio survivor – living through this pandemic?"

The question was open-ended and so there were no cues for the content of the responses, and no cues to respond positively or negatively. Responses were coded by the most emphasised aspect submitted by an individual. The question was not mandatory on the survey: 56% of the respondents chose to not answer this question, 36% reported negative experiences, and 9% reported positive experiences.

The most common positive notable aspects reported by polio survivors experiencing the pandemic were:

- Fewer deadlines and commitments, and so less stress
- Less pressure to travel or to participate in events
- Availability of online ordering and home deliveries
- More time for home and hobbies
- Better coping and well being

Polio survivors experiencing the Late Effects of Polio often experience varying degrees of fatigue, and yet the term *fatigue* was included in only one response. We are unable to say that these positive responses were related to respondents' fatigue experiences, but the character of these responses in context of the group being asked hint at such. There appear to be mental health benefits experienced by some polio survivors during this pandemic – perhaps by those who are

less energised by or reliant on social engagement.

The most common negative notable aspects reported by polio survivors experiencing the pandemic are shown in the pie chart. Reduced or difficulty with access to services was the most reported negative aspect, and this is easy to appreciate in context of how healthcare changed during the pandemic. Isolation, coping, or a change in social aspects was difficult for half of those reporting negative experiences; this may reflect those survivors who lean on social engagement for support, care, and mental health. Negative effects on physical condition was reported by 15%, this being annotated with concerns about losing strength, endurance and general fitness that was being maintained through regular exercise. A direct example of pandemic exercise disruption was the closure of

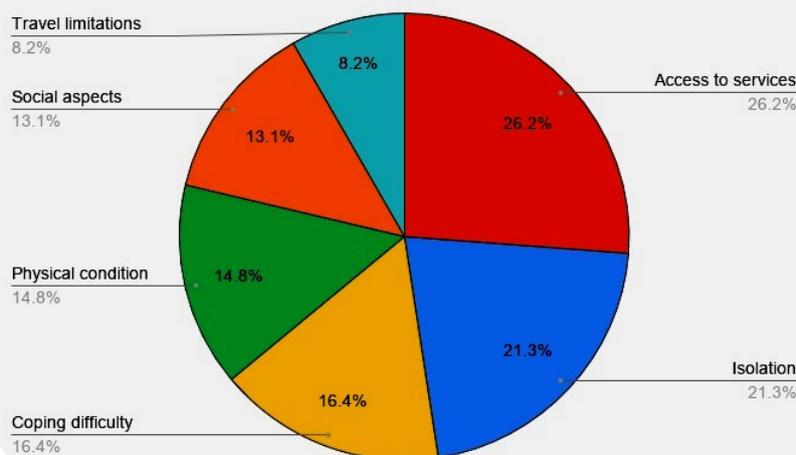
public pools, eliminating a known well-tolerated mode of exercise that could not be replicated in other environments.

It is worth comparing the positive and negative aspects reported. Themes around social preferences and needs presented strongly in both types of response. Removal from participation in

social events, ability to cope, and ability to travel were reported both positively and negatively. In contrasting the response types, positives included increased convenience of instrumental tasks of living and individual home activity, while negatives included accessing needed services and maintaining physical condition.

As is often the case with survey questions, and what we see here, is that asking a particular question can lead to other questions needing to be asked in order to gain a fuller understanding of a topic. It is unknown how these responses might compare to what may be observed in the general Australian population, in those with disabilities, or in the polio survivor population at large. The national pandemic strategies utilised in different countries, and the nuances of survivorship in each country, may additionally have an influence on the responses provided compared to this cohort. 🌐

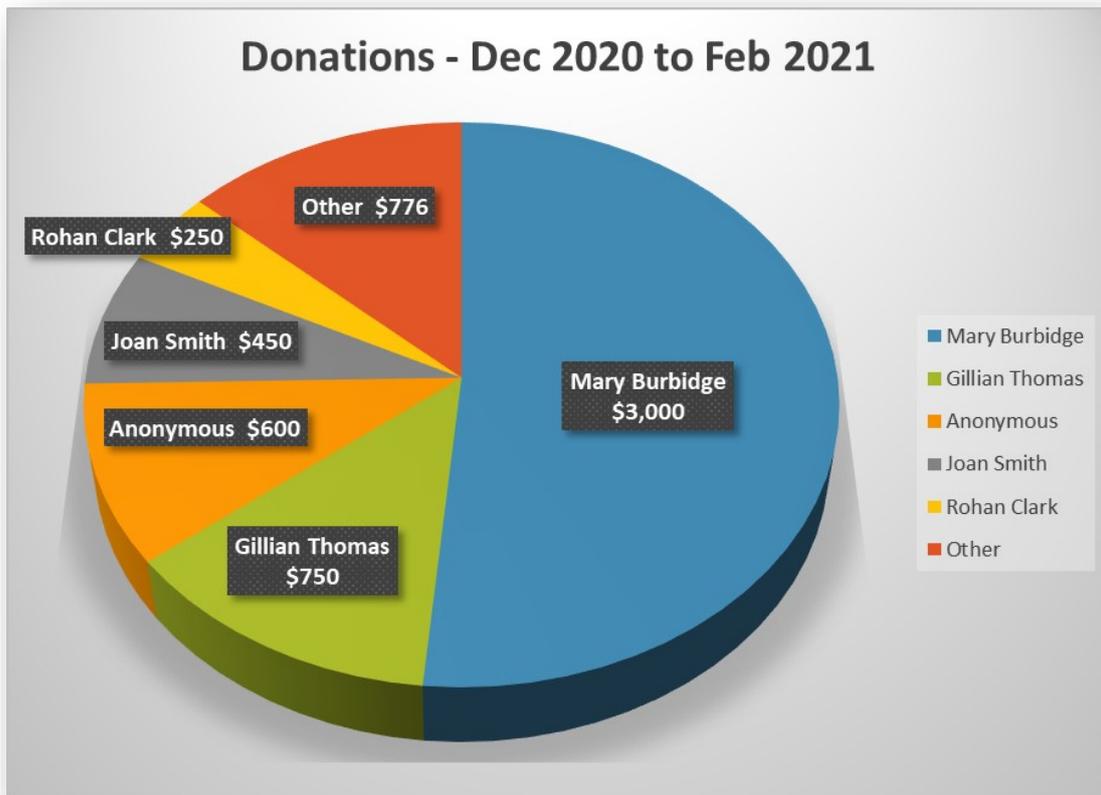
Negative Aspects of Pandemic on Australian Polio Survivors (n=64)



## Supporting Polio Australia

Polio Australia would like to thank the following individuals and organisations for their generous support from December 2020 to February 2021. Without you, we could not pay for our core operating expenses or for the staff to keep the wheels turning!

If you would like to see how your 'living bequest' can support polio survivors now, click on the following link: [www.polioaustralia.org.au/donations-bequests/](http://www.polioaustralia.org.au/donations-bequests/) or contact the Polio Australia office on Ph: 03 9016 7678 or Email: [contact@polioaustralia.org.au](mailto:contact@polioaustralia.org.au).



Although income increased and expenses decreased during this quarter, these outcomes were both the result of non-recurring events.

One-off subsidies and larger donations were gratefully received, while spending on travel in particular was curtailed due to COVID restrictions.

Efforts are continuing in 2021 to establish recurrent funding streams to support our education programs.



## Epidemic Poliomyelitis, Post-Polio Sequelae And The Eradication Program

By Dr Margaret Peel OAM

**Ref:** Peel, M.M. (2020) Epidemic poliomyelitis, post-poliomyelitis sequelae and the eradication program. *Microbiology Australia* 41(4), 196-200, 223. doi: 10.1071/MA20053  
Published: 20 October 2020

The full article relating to the Abstract below can be read [here](#).

### Abstract



Epidemics of paralytic poliomyelitis (polio) first emerged in the late 19th and early 20th centuries in the United States and the Scandinavian countries. They continued through the first half of the 20th century becoming global. A major epidemic occurred in Australia in 1951 but significant outbreaks were reported from the late 1930s to 1954. The poliovirus is an enterovirus that is usually transmitted by the faecal-oral route but only one in about 150 infections results in paralysis when the central nervous system is invaded. The Salk inactivated polio vaccine (IPV) became available in Australia in 1956 and the Sabin live attenuated oral polio vaccine (OPV) was introduced in 1966. After decades of stability, many survivors of the earlier epidemics experience late-onset sequelae including post-polio syndrome. The World Health Organization launched the global polio eradication initiative (GPEI) in 1988 based on the easily administered OPV. The GPEI has resulted in a dramatic decrease in cases of wild polio so that only Pakistan and Afghanistan report such cases in 2020. However, a major challenge to eradication is the reversion of OPV to neurovirulent mutants resulting in circulating vaccine-derived poliovirus (cVDPV). A novel, genetically stabilised OPV has been developed recently to stop the emergence and spread of cVDPV and OPV is being replaced by IPV in immunisation programs worldwide. Eradication of poliomyelitis is near to achievement and the expectation is that poliomyelitis will join smallpox as dreaded epidemic diseases of the past that will be consigned to history. 🌟

On the 10th of January 2021, Drs Margaret Peel and Pat Blackall were interviewed about polio by Jenny Davis on "Live Transmission", an episode aired on community radio RRR / 102.7 FM (Melbourne). To listen to this episode, click on the graphic below.

"Pandemic", "quarantine", "isolation" – all the words of 2020. But they're not new words and we're not the first to use them. Join Jenny Davis and guests exploring the microbes and diseases in Australia's past. From plague to polio, rabbits to rinderpest – learn it all on "Live Transmission" this summer. 🌟



Listen to Live Transmission

-



01:00:00 · 10 January  
2021

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## Spinal Life Healthy Living Centre

### Looking for a wheelchair accessible holiday in Cairns?



Located on the iconic and accessible Cairns Esplanade, the Spinal Life Healthy Living Centre is dedicated to supporting the health and wellbeing of people with spinal cord damage and other physical disabilities.

Everything about the Centre has been built to be fully accessible for wheelchair and mobility device users, from the accommodation to

the Active Gym, Café and Community Rooms.

SLA has drawn upon 60 years of experience in supporting people with spinal cord damage and physical disability to inform the construction and delivery of our flagship Healthy Living Centre and are proud to provide important services for residents and visitors of Far North Queensland.

Click the following link to the website: [www.spinalhealthyliving.com.au](http://www.spinalhealthyliving.com.au)

## Spinal Life Australia Update

**By Ross Duncan**

*Executive Manager, Member Services*



Over the past three years, Spinal Life Australia has been collaborating with Polio Australia, working to address some of the key issues affecting the lives of polio survivors, informed by personal feedback and experiences obtained from polio survivors.

We have achieved many of the goals we set out to reach, as detailed below, and we are now seeking input from people experiencing the late effects of polio as we plan the future activities of Spinal Life Australia in support of polio survivors.

[Click here](#) to take a short survey to share your thoughts.

Much of our previous campaign was aimed at raising awareness about the late effects of polio among health professionals, to increase their knowledge on supporting polio survivors as they age.

Our achievements so far include:

- creating an [information booklet for medical professionals](#), which was the first of its kind to be approved as an

accepted clinical resource by the Royal Australian College of General Practitioners (RACGP)

- working closely with leading experts in Queensland to develop Australia's first comprehensive [online education module for GPs about the late effects of polio](#), which was also accredited by the RACGP
- Participating actively on the Board of Polio Australia and assisting them to promote educational sessions to polio survivors and health professionals.
- Joining the [Assistive Technology for All Alliance](#) and advocating for more funding to be made available to polio survivors and other people over the age of 65 years.

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## Easing The Way For Drivers With Chronic Pain

By Sue Hewitt

Source: [www.racv.com.au](http://www.racv.com.au)  
—15 January 2021

### RACV launches new survey to address driving with chronic pain.

Many drivers can feel their muscles twinge after a long stint behind the wheel but for people with chronic pain, the challenge of driving for prolonged periods can impact their everyday lives. Experts say 14 per cent of Australians – 3.5 million people – suffer chronic pain, but many want to continue to drive.

*"Sometimes people find it difficult just getting in or out of a vehicle but want to adapt because they see driving as their independence",* says chief executive officer of Pain Australia, Carol Bennett.

She says there are many strategies and devices drivers with chronic pain can use to keep themselves safe and comfortable behind the wheel, including talking to health professionals.

However, [new RACV research](#) into Australian drivers suffering chronic pain has found health professionals need clearer guidelines on treating the issue to help motorists manage their pain.

Researchers interviewed 17 Australian health professionals and found they wanted specific training to better assess the subjective nature of pain and its effect on driving ability.

Researchers also conducted an online survey of 90 motorists, half suffering chronic pain and the rest being pain free, to assess the impact of pain on driving. They interviewed 23 drivers about their experience with chronic pain.

RACV's senior policy adviser on safety, Elvira Lazar, says this study is the first in Australia to seek strategies to improve safe driving among individuals with chronic pain.

She says the research shows motorists with chronic pain have difficulty with prolonged driving which can impact their daily lives.

*"The pain is often exacerbated after prolonged driving and there is an urgent need for better guidance to take the guesswork out of the best way to manage chronic pain in relation to driving",* she says.

Sometimes people find it difficult just getting in or out of a vehicle but want to adapt because they see driving as their independence.

The RACV research will form part of RACV's submission to the National Transport Commission (NTC) review into its national [Assessing Fitness to Drive guidelines](#).



The guidelines, which are used by state authorities including VicRoads to assess a person's ability to drive, do not currently address chronic pain.

The NTC is seeking input from the medical community, patient representative bodies, industry, public health and transport agencies on its review.

Pain Australia says chronic pain comes in many forms. It can be persistent migraines, arthritis or back pain, or debilitating pain after surgery. Sufferers may have multiple other health issues.

*"Chronic pain is often an invisible condition",* says Carol Bennett. *"But although the disability can't be seen in the form of a broken limb, the condition is so common that one in five GP consultations deal with some form of chronic pain."*

She says sufferers can help themselves through such self-management techniques as exercise and using driving aids like reversing cameras or lane-assist technology to minimise the need to turn their head.

*"Be practical; if you have back pain, use a lumbar support cushion, sit forward to reach the pedals and hold the steering wheel so it's comfortable."*

### Pain Australia's tips for driving with chronic pain

#### Talk to a medical professional

Your GP may suggest a range of strategies to help you deal with pain, including exercise, pain-management techniques, aids and devices. A physiotherapist can help with increasing and maintaining your movement and muscle strength through a tailored exercise program and pain-relief techniques. Staying active is key to continuing to drive.

#### Adjust your driving position

Sometimes simply adjusting your seat and mirrors can ease pain, but do it before you set out on a drive.

## . . . Drivers With Chronic Pain *(cont'd from p15)*

If you're suffering ankle or foot pain move your seat forward to ensure you're pushing pedals with your entire foot, not just the toes, and adjust the seat height so you can reach the pedals easily. Once the seat is adjusted ensure you have good visibility using your mirrors and windows.

### Know your medications

Check with your medical professionals and understand that medications can affect a driver's concentration, reaction time and coordination, or make them drowsy. People with multiple health problems may have different medications that adversely react with each other so check with your GP. Avoid drinking alcohol which can aggravate medication side-effects.

### Take a break

Long trips often aggravate pain and drivers should stop at least once an hour, get out and stretch or massage tight muscles. Build short breaks into a long journey and use the time to check out local sights. Pain is tiring and can lead to fatigue which will affect driving ability. Never drive if you're feeling fatigued or 'foggy'.

### Consider aids and devices

An occupational therapist can help advise on aids and devices to make driving more comfortable. They include:

- A swivel-seat cushion placed on top of your car seat. You sit down on the cushion with your body facing out and then swivel your body and legs around to face the dashboard.
- A lumbar back support pillow or a rolled-up a towel to support your lower back.
- A steering-wheel cover to make the steering wheel easier to grip if you have stiff, sore hands.
- A petrol-cap turner to twist the petrol cap on or off will also help those with bad hands.
- Grab handles and bars can be added to your car to make getting in and out easier.
- Reversing cameras and parking sensors are standard in many new cars and can be added to older ones. They make parking and reversing easier if you have problems twisting, turning your neck or looking over your shoulder. 🟡

## While We're Still Wearing Masks

This factsheet was prepared by the Australasian College of Dermatologists and the Occupational Dermatology Research and Education Centre, based at the Skin Health Institute in Melbourne. The factsheet will help you avoid skin problems so you can keep wearing a mask to reduce the risk of transmission of COVID-19. Click [here](#) to download this resource. 🟡



THE AUSTRALASIAN COLLEGE  
OF DERMATOLOGISTS



# Keep your face healthy during COVID-19

## Tips to avoid skin problems and allow you to keep wearing a mask

The COVID-19 pandemic has led to an increased use of face masks, not only amongst healthcare workers but also now the general public. Prolonged wearing of masks and goggles can cause adverse skin reactions such as acne, contact dermatitis and pressure effects, as well as exacerbating any underlying skin conditions.

Here are some tips from the Australasian College of Dermatologists and the Occupational Dermatology Research and Education Centre, based at the Skin Health Institute in Melbourne, that will help you avoid skin problems and allow you to keep wearing a mask.

## Pandemic Parallels

### Older adults remember polio vaccines

By Kathleen Shaw

Source: [www.washingtonpost.com](http://www.washingtonpost.com)

— 21 February 2021

HARRISONBURG, Va. — Like many kids his age, James Hartt as a teen in the '60s enjoyed passing the time with a bit of naive, reckless abandonment. One way Hartt found to amuse himself was leaping from a nearby bridge and sticking the landing on the other side, until one day, Hartt woke up unable to move his legs. Immediately, fear set in that it could be poliomyelitis — every parent's waking fear in the late 1940s and early 1950s.

Fortunately, a doctor deduced Hartt's diagnosis was two sprained legs as a result of his airborne adventures, but many children around the world were not as fortunate. When it became available, Hartt got his vaccine. Nearly 70 years later, Hartt senses a stark parallel to the excitement he felt then as he prepares to receive his second COVID-19 vaccine this weekend.

*"If you look back, polio and this thing is almost the same type of thing,"* Hartt said. *"Polio, they used iron lungs back then. Now they're using ... those air things that they run out of all the time. The symptoms are very close. The way they treated it was very close."*

Poliomyelitis — better known as polio — is an infectious disease that most commonly affects children, causing paralysis. Summer of 1894, the U.S. experienced its first polio epidemic, but it wasn't until 1955 that Dr. Jonas Salk's polio vaccine was approved for nationwide inoculation. Shortly after, a second vaccine option was approved for manufacturing with easier admission at a cheaper cost by Dr. Albert Bruce Sabin in 1961.

After cases peaked in 1952, with roughly 58,000 people diagnosed with polio in the U.S., the final case of wild-virus polio in the U.S. was reported in 1979.

With a tight-fisted grip around the nation, polio impacted thousands of children annually into the late 1950s, mercilessly attacking the nervous system. It was typically identified by paralyzed limbs, most frequently the legs. By 1957, there were less than 6,000 cases, and it had dropped to 120 cases by 1964, thanks to vaccines.

Today's pandemic of the novel coronavirus is harder to identify physically and largely plagues the lungs, which can lead to pneumonia, respiratory failure, septic shock or death, in severe cases.



Now those same children who were most vulnerable to the polio epidemic are grown and at greater risk for severe illness from COVID-19, but the fastest vaccine ever created is steadily being distributed in phases following the authorization of Pfizer's vaccine on Dec. 12 and Moderna's version six days later.

According to the Centers for Disease Control and Prevention, two doses of Salk's polio vaccine are 90% effective or more and three doses boosts the effectiveness to 99-100%. Both Pfizer and Moderna report their vaccines show approximately 95% efficacy at preventing both mild and severe symptoms of COVID-19.

*"I believe in these shots, and I believe they're doing the best thing they can,"* Hartt said.

According to the March of Dimes, the leading global agency fighting polio, up to 95% of people infected with polio were asymptomatic and less than 1% of infected persons experienced the virus attacking their nervous systems within the spine to result in partial or complete paralysis.

Salem-based Rotarian William 'Bill' Long is locally known as a polio expert. His father-in-law contracted polio in his youth, which stunted the growth of one leg. The connection inspired Long, who owns three iron lungs — a clunking beast of machinery that contracted lungs for those who could not breathe on their own — to allow the machinery to travel between Rotary clubs for educational purposes.

Long said the demand for hospital care was overwhelming, much like today's limitation of ventilators, and Memorial and Crippled Children's Hospital in Roanoke was the primary care facility for sick children in the southern Valley.

*"A whole floor with nothing but iron lungs on it,"* he said. *"Space between each iron lung, just wide enough for people to get through to work."*

## Pandemic Parallels *(cont'd from p17)*

In the Jan. 25, 1946, edition of James Madison University's newspaper, *The Breeze*, W. L. Baldwin, state chairman for the polio fundraiser, is quoted as saying, *"It is believed that over the last two-year period, Virginia has been hit harder by poliomyelitis than any other state in the nation."*

Following data reports Virginia's county and city goals that year were set more than 25% higher due to the cost of caring for over 1,100 polio victims over the span of 19 months. Infantile paralysis struck down children of every income bracket in 94 of the 100 counties of Virginia over the previous two years.

According to the CDC, there are 27 million total cases of COVID-19 in the U.S. and 486,466 total deaths, as of Wednesday.

Belmont resident Nancy O'Hare is scheduled to receive her second vaccine by the end of February, and she vividly remembers the fear that haunted her days and nights mothering a 5-year-old son and 2-year-old daughter while polio raged on.

*"I remember when Salk developed the vaccine. I remember when my children, who are now in their 60s, got the vaccine. ... It took them years to develop the one to defeat polio, so I'm thrilled we're able to do it so quickly now, develop this vaccine,"* O'Hare said.

Back then, O'Hare remembers going to doctor's offices to receive the polio vaccine while children received sugar cubes topped with Sabin's oral vaccine from schools or pediatrician offices.

*"We did not go to hospital, we did not go to vaccination stations. ... When it was released to be able to be consumed, it was fast. It was all over the country,"* she said.

Verona native Donn Meyer said he can remember his parents taking him to Fort Defiance High School at a very young age to receive the polio vaccine on a sugar cube in the '60s.

Back then, images of iron lungs were plastered on every screen, and harrowing stories of sick children written in papers. A nationwide vaccine campaign even featured Elvis Presley publicly receiving his vaccination.

*"We'd seen the pictures, we'd heard TV reports, we'd seen movies about it. And it was scary and that's why I think the world was so happy, or at least the United States was so happy, when the polio vaccine came out,"* O'Hare said.

An archived Associated Press article published in *Daily News-Record* on Aug. 13, 1955, reported that Southern states pioneered public programs to distribute the Salk vaccine shots to schoolchildren and tentative survey results showed a 46% drop in polio deaths compared to the previous year. By the time of publication, 191 deaths were recorded, compared to 355 within the same time the previous year.

While polio seems a thing of the past within the U.S., there is no cure for the disease and two countries remain endemic. Rotary International remains a leading agency in funding the end of polio, and members have contributed more than \$2.1 billion to eliminate the paralyzing disease since 1979.

With polio a shadow of a memory for most Americans today, those who endured the polio epidemic remember the clear parallels of quarantines, school closures and the dread.

*"Same things happened,"* Hartt said. *"I think they've come across something that's going to work, and I think everyone should get it."* 🌟

**2021 INSPIRED INSIGHTS FOR  
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23-25 JUNE 2021 VIRTUAL CONFERENCE AND ENGAGEMENT HUBS

Occupational  
Therapy AUSTRALIA



29TH NATIONAL CONFERENCE AND EXHIBITION 2021

### OTAUS 2021 NOW FULLY VIRTUAL WITH ENGAGEMENT HUBS

As we navigate the year ahead, your safety and quality of learning continue to remain our top priorities. With this in mind, allowing our association to move forward with confidence and purpose, the 29th National Conference and Exhibition 2021 will proceed as a fully virtual event taking place online 23-25 June 2021. While the conference will be virtual, we are also coordinating in-person engagement hubs in Adelaide, Brisbane, Melbourne, Perth and Sydney.

*For more information on the engagement hub locations [click here](#)*

## Author's Poignant Polio Story In New Anthology

By Mike Hast

Source: [www.mpnews.com.au](http://www.mpnews.com.au)—1 March 2021



HASTINGS author and artist Fran Henke (pictured above) has a chapter in the new Australian anthology *Growing Up Disabled in Australia*.

The 320-page paperback has been published by Melbourne publisher Morry Schwartz's Black Inc and is the fifth in a series of "Growing Up..." titles.

Released in early February, it has already been reprinted after attracting wide-spread interest and praise including for its editor Carly Findlay OAM, a Melbourne writer and disability activist who has a rare genetic disorder that affects her skin and hair.

Mrs Henke is an activist too – for polio survivors

who in later life experience post-polio syndrome and a wide range of symptoms that include new weakening of muscles including respiratory muscles, fatigue, joint degeneration and more.

She has advocated for polio survivors for more than 20 years both privately and publicly, and has written extensively on the subject.

Mrs Henke's essay is a matter of fact but also poignant story charting her life from when she contracted polio at age three when living in Gippsland to now aged in her 70s.

The condition has not stopped her having a varied career as a journalist in the United Kingdom and Australia as well as writing 23 books, gaining a visual arts diploma in her late 60s, and volunteering for many community groups. She is also an accomplished photographer.

*Growing Up...* contains contributions from 48 people, whittled down from more than 360 submissions.

Carly Findlay states in her introduction that *"the people in this book are disabled, chronically ill, mentally ill and neurodiverse, and inhabit the city, regional and rural regions and Aboriginal communities. They span generations – some are elders and some are still growing up – and genders, cultures and sexualities. I hope the book creates a sense of identity, pride and belonging to a community – for the contributors and for readers."*

The book includes interviews with high-profile Australians Senator Jordon Steele-John and Paralympian Isis Holt, both of whom are affected by cerebral palsy, as well as poetry, graphic art and more than 40 original pieces by writers with a disability or chronic illness.

RRP: [\\$29.99 \(book\)](#), [\\$12.99 \(ebook\)](#).

## Pop Artist Ruby Mazur Creates Rock's 'Last Supper'

By Ian Mohr

Source: [pagesix.com](http://pagesix.com)—15 February 2021

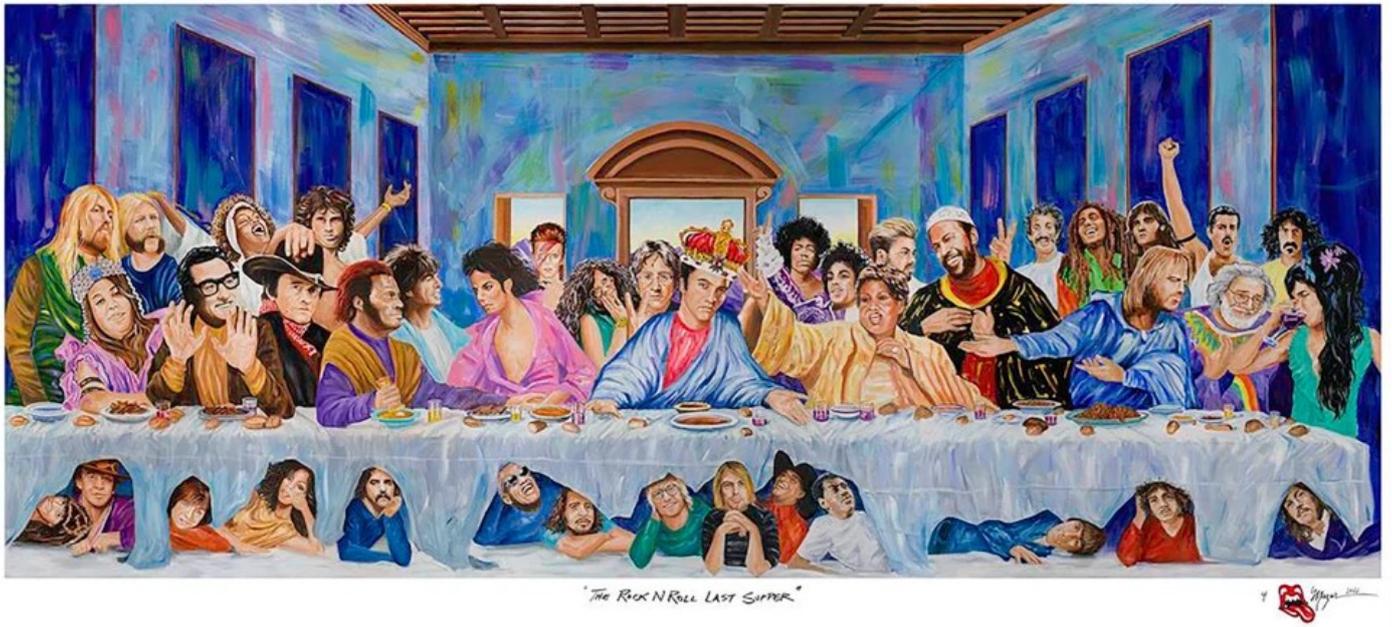
Pop artist Ruby Mazur (pictured right in 1993) is set to show his new work at Hawaii's Holle Fine Art Gallery this month. Getty Images

Pop artist Ruby Mazur — who created the Rolling Stones' famous mouth and tongue logo for the "Tumbling Dice" single — will show off his most recent work, "Rock n Roll Last Supper", as part of a new show at Hawaii's [Holle Fine Art Gallery](#) this month.



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## . . .Rock's 'Last Supper' (cont'd from p19)



**Ruby Mazur's "Rock n Roll Last Supper"**

The painting, which took three years to create, features 41 music icons from Elvis Presley, Jimi Hendrix and Jim Morrison to Johnny Cash, Freddie Mercury and Michael Jackson.

New York native Mazur has been living in Maui for the past 15 years. Decades after a **childhood bout with polio**, we hear that he was **recently diagnosed with post-polio syndrome**. A source said that the artist's daughter, actress Monet Mazur "has been very supportive of her dad, along with physical therapy and determination, as he continues to paint and create, with no intention of stopping anytime soon."

Also in the gallery show will be a new Mazur painting of the Stones' lips and tongue, plus new paintings of Keith Richards, Willie Nelson, Cher, Paul McCartney, Elton John, Billy Joel, Bruce Springsteen and others.

Mazur [notoriously feuded with Mick Jagger](#) over trademark rights to the iconic Stones image. He went on to design art for thousands of covers. 🎨

## Handmade Cards For All Occasions

If you are looking for that special card for the special people in your life, Melbourne-based polio survivor, Joan Smith, creates beautiful and unique handmade cards, which you can now purchase. Cards all come with individual envelopes and are protected by plastic sleeves.

Joan donates all proceeds from the sale of her cards to Polio Australia, for which we are very thankful!

These exquisite cards are sold in mixed packs of **5 for \$20** including postage and handling (within Australia only). There are also Christmas Cards.

Below is a sample of Joan's beautiful cards. Click through to Polio Australia's website to order yours today: [www.polioaustralia.org.au/giving-opportunities/](http://www.polioaustralia.org.au/giving-opportunities/) 🎨



# Polio This Week

## Global Circulating Vaccine-derived Poliovirus (cVDPV) as of 02 March 2021

	Country	AFP cases (Paralysis onset between 2016-2021)						Onset of most recent case	Other sources (Human) <sup>4</sup> (Collection between 2016-2021)						most recent collection date	Other sources (Environment) (Collection between 2016-2021)						most recent collection date		
		2016	2017	2018	2019	2020	2021		2016	2017	2018	2019	2020	2021		2016	2017	2018	2019	2020	2021			
cVDPV1 <sup>1</sup>	Yemen				1	29	25-Sep-20					1		07-Jul-19										
	Malaysia				3	1	14-Jan-20					1						12	8				13-Mar-20	
	Philippines				2		28-Oct-19							31-Oct-19				14					28-Nov-19	
	Myanmar				6		09-Aug-19					6		21-Aug-19										
	Indonesia				1		27-Nov-18							13-Feb-19										
	PNG			26			18-Oct-18			7		2		20-Sep-18			7						06-Nov-18	
	Laos	3					11-Jan-16							09-Feb-16										
<b>Total type 1</b>	<b>3</b>	<b>0</b>	<b>27</b>	<b>12</b>	<b>30</b>	<b>0</b>		<b>5</b>	<b>0</b>	<b>7</b>	<b>10</b>	<b>0</b>	<b>0</b>	<b>0</b>	<b>0</b>	<b>7</b>	<b>26</b>	<b>8</b>	<b>0</b>	<b>0</b>	<b>0</b>			
cVDPV2 <sup>1</sup>	Pakistan	1			22	135	6	14-Jan-21					15	2	11-Nov-20	4			40	135	10		15-Feb-21	
	Tajikistan					1	1	17-Jan-21							29-Jan-21						1		14-Feb-21	
	Egypt																			1	6	09-Feb-21		
	Kenya							22-Dec-20					1		20-Nov-20			1		1	1	13-Jan-21		
	Afghanistan					305	6	12-Jan-21					36		15-Dec-20					174	9		05-Jan-21	
	Iran																			3 <sup>5</sup>			25-Dec-20	
	DR Congo		22	20	88	78		24-Dec-20		19	15	29	88		28-Oct-20					1			29-Apr-20	
	Liberia												2		21-Dec-20					5			01-Dec-20	
	Sudan					57		18-Dec-20					10		01-Oct-20					14			09-Nov-20	
	Congo					2		14-Nov-20												1			16-Dec-20	
	Chad				11	99		15-Dec-20					6	17	15-Oct-20					10	3		13-Mar-20	
	Nigeria	1		34	18	8		10-Dec-20	2 <sup>2</sup>		53	18	8		16-Nov-20	1		44	64	5			13-Nov-20	
	Benin				8	3		30-Nov-20												5			04-Dec-20	
	South Sudan					47		30-Nov-20					18		04-Dec-20						3		03-Nov-20	
	Guinea					45		20-Nov-20					1		05-Sep-20									
	Sierra Leone					3		19-Nov-20																
	Burkina Faso				1	59		14-Nov-20						11	15-Jun-20									
	Mali					38		14-Nov-20					3		15-Aug-20					4			29-Aug-20	
	Somalia			6 <sup>5</sup>	3	14		25-Oct-20					2	12	10-Nov-20		2	19	5	26			24-Oct-20	
	Côte d'Ivoire					72		09-Nov-20						24	01-Nov-20					7	47		14-May-20	
	Central African Republic				21	4		29-Oct-20				39	1		05-Oct-20					9	2		05-Feb-20	
	Niger			10	1	9		25-Aug-20				4	6	2	13-Oct-20									
	Ethiopia				14	26		12-Oct-20					9	6	25-Feb-20					3	1		21-Sep-20	
	Cameroon					7		11-Sep-20						4	29-Mar-20					4	8		29-Sep-20	
	Ghana				18	12		09-Mar-20					16	10	22-Feb-20					17	20		17-Sep-20	
	Togo				8	9		03-May-20					1	9	09-Jul-20									
	Angola				138	3		09-Feb-20					22		31-Oct-19					17			02-Dec-19	
	Malaysia																			3	5		04-Feb-20	
	Philippines				12	1		15-Jan-20					5		23-Nov-19					19	4		16-Jan-20	
	Zambia				2			25-Nov-19					2		25-Sep-19									
	China				1			25-Apr-19					3		18-Aug-19			1					18-Apr-18	
Mozambique			1				21-Oct-18				2			17-Dec-18										
Syria		74					21-Sep-17	1 <sup>4</sup>	66					12-Sep-17										
Myanmar							05-Oct-15																	
<b>Total type 2</b>	<b>2</b>	<b>96</b>	<b>71</b>	<b>366</b>	<b>1037</b>	<b>13</b>		<b>3</b>	<b>85</b>	<b>74</b>	<b>173</b>	<b>265</b>	<b>3</b>	<b>5</b>	<b>2</b>	<b>65</b>	<b>198</b>	<b>468</b>	<b>27</b>	<b>0</b>	<b>0</b>			
cVDPV3 <sup>1</sup>	Somalia			7 <sup>5</sup>			07-Sep-18				2			29-Jun-18			11					23-Aug-18		
<b>Total type 3</b>	<b>0</b>	<b>0</b>	<b>7</b>	<b>0</b>	<b>0</b>	<b>0</b>		<b>0</b>	<b>0</b>	<b>2</b>	<b>0</b>	<b>0</b>	<b>0</b>	<b>0</b>	<b>0</b>	<b>11</b>	<b>0</b>	<b>0</b>	<b>0</b>	<b>0</b>	<b>0</b>			
Gender	Female (all sero type)	3	54	34	151	467																		
	Male (all sero type)	2	42	70	215	590	13																	
	Gender Unknown				12	10																		

■ Environmental surveillance for poliovirus in selected sewage sites established and working
 ★ Changes from previous week
   
★ Due to backlog reporting of viruses from member states, numbers in this table may increase without being notified as new case/specimen in the current week



### Polio Gender Champions

The GPEI gender workstream is supported by [Polio Gender Champions](#), who work to raise the voices of those engaged in the programme.

Champions include Senator Hon Marise Payne, Australian Minister for Foreign Affairs and Minister for Women; Wendy Morton, Minister of European Neighbourhood and the Americas at the Foreign, Commonwealth & Development Office in the United Kingdom; and Arancha González Laya, who is the Spanish Minister for Foreign Affairs, European Union and Cooperation.