



**POLIO NSW**

*formerly Post-Polio Network (NSW)*

# NETWORK NEWS

*Incorporating – Polio Oz News*

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## Editor's Report:

In our March newsletter we were reeling after months of bushfires and the hardships and trauma they caused to so many. Since then we have been dealing with the Covid-19 pandemic and the isolation restrictions that followed. It has been a challenge but I'm sure we have been adapting to all the changes these times have brought to us. Technology has opened up our options to keep in touch with our friends and loved ones and it has given us time to be more creative in keeping ourselves occupied and stimulated. Something we have had lots of practice doing!

This edition has an update on Anaesthesia from Dr Selma Calmes, a useful article to give to our doctors when surgery or procedures requiring sedation are contemplated.

I first read Dr Bruno's Ten Commandments 30 years ago and found it clarified how I should be managing PPS (instead of pushing myself to exhaustion). It is a reminder to us to "conserve to preserve" and to "work smarter, not harder". A further article by Dr Bruno "The Psychology of Treating PPS" is on page 11 and on page 18 an article on techniques for "getting a better night's sleep".

During the pandemic new interest in the polio epidemics has been aroused and an article by journalist Amanda Hooton appeared in the Sydney Morning Herald, Good Weekend on 11<sup>th</sup> April, 2020. Amanda interviewed polio survivors Joan Ford, Gillian Thomas, John Tierney and Michael Lynch. Read more on page 13 of the attached issue of Polio Oz.

Merle Thompson, OAM, Polio NSW Secretary, has also contemplated the Covid-19 virus and how it compares to the polio virus. She has written a very thoughtful article on page 6.

Historical articles on Sister Elizabeth Kenny and Dr Jean Macnamara are on pages 15-17.

A one-day seminar in Brisbane is planned by Polio Australia in conjunction with Spinal Life Australia and the Rotary Foundation for 23<sup>rd</sup> October, 2020. If any of our members, especially our northern members, would be interested in attending this seminar please contact Steph Cantrill by email – [steph@polioaustralia.org.au](mailto:steph@polioaustralia.org.au).

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# VALE - Jill Chauncy OAM



Jill Chauncy (nee Throsby) sadly passed away on 23<sup>rd</sup> February, 2020. Her daughter said her mother enjoyed receiving Network News and attending our seminars and Polio Australia's retreat.

Jill was awarded the Medal of the Order of Australia in the Queen's Birthday 2016 Honours List for her service to people with disabilities, and to the community of Moss Vale.

As part of Jill's rehabilitation after contracting polio she did horse riding to help strengthen her body. As a result she held a lifelong passion for horses and for helping people with a disability. In 1975 Jill founded the Riding for Disabled (RDA) Moss Vale group. She was director of the RDA NSW branch from 1985-88. Jill was foundation member of the Bowral Hospital Shop. She also volunteered for several other community organisations, including Legacy, Red Cross and the Quota Club.

## Dorothy Robinson - Wollongong Support Group



Dorothy (far right) at Polio NSW 25<sup>th</sup> Anniversary lunch

Dorothy is a foundation member of the Network (1989) and has been the Wollongong Support Group convenor for 20+ years. You could guarantee that Dorothy would be seen at our many seminars, conferences, AGMs and Polio Australia's Retreats. This required significant travelling time for Dorothy.

Dorothy trained as a nurse and as such was appointed by Nola Buck to be the first aid officer at our Merroo Conference in 1996. Dorothy spread the word about post-polio syndrome by giving interviews to local newspapers which drew new members to her support group.

In addition to Dorothy's many skills, nursing, Guiding and Support Group Co-ordinator, and probably others of which I am unaware, she has been a very efficient Quartermaster. Each year Dorothy and her husband, Lloyd, would set out to visit a remote national park in Northern Australia, along with a group of Speleologists, for a period of two weeks. For this expedition, Dorothy would order all the food from a supermarket in Katherine and collect it on their way to their destination. It is always amazing how talented and versatile so many of our Polio members are.

Sadly, Dorothy has decided to 'ease out' as convenor of the support group and we would like to thank her for all her hard work promoting Polio NSW, for her dedication and for her support of our functions.

## Prince Henry Hospital Museum



An exhibition presented by Prince Henry Trained Nurses Assn, '**Bravery, Bandages and Bedpans**', has been dedicated to the International Year of the Nurse and was launched on 12<sup>th</sup> May, 2020 - it is open for viewing on Sundays from 10am – 3pm. The exhibition can also be viewed online at [princehenryhospitalmuseum.org](http://princehenryhospitalmuseum.org). Leonie Dunn, President of PHTNA spoke at the launch - "as I put together this Exhibition I am reminded of the tireless work and sacrifice of the Nurses at the Coast and Prince Henry Hospital at Little Bay. They should never be forgotten; our nurses pioneered responses to epidemics and infectious diseases in NSW."

Prince Henry Hospital played a significant role in Polio treatment during the outbreaks of 40's, 50s and 60's. In the museum there is an iron lung on display along with an account of the experience of Gaby Hannemann (Gaby passed away in July 2012). Her story has been updated for this new display. The online link: [princehenryhospitalmuseum.org/gabrielle-hannemann-a-true-survivor](http://princehenryhospitalmuseum.org/gabrielle-hannemann-a-true-survivor).

# Summary of Anesthesia Issues for the Post-Polio Patient

By Dr Selma H. Calmes, MD, Chairman and Professor, (retired) Dept of Anesthesiology, Olive View-UCLA Medical Center, Sylmar, California.

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## From the American Society of Anesthesiologists: “Safe, Successful Surgery Starts with Anesthesia Care”.

Polio results in widespread neural changes, not just destruction of the spinal cord anterior horn (motor nerve) cells, and these changes get worse as patients age. These anatomic changes affect many aspects of anesthesia care. No study of polio patients having anesthesia has been done. These recommendations are based on extensive review of the current literature and clinical experience with these patients. They may need to be adjusted for a particular patient.

1. Post-polio patients are nearly always very sensitive to sedative meds, and emergence can be prolonged. This is probably due to central neuronal changes, especially in the Reticular Activating System, from the original disease.
2. Non-depolarizing muscle relaxants cause a greater degree of block for a longer period of time in post-polio patients. The current recommendation is to start with half the usual dose of whatever you're using, adding more as needed. This is because the poliovirus actually lived at the neuromuscular junctions during the original disease, and there are extensive anatomic changes there, even in seemingly normal muscles, which make for greater sensitivity to relaxants. Also, many patients have a significant decrease in total muscle mass. Neuromuscular monitoring intraop helps prevent overdose of muscle relaxants. Overdose has been a frequent problem.
3. Succinylcholine often causes severe, generalized muscle pain postop. It's useful if this can be avoided, if possible.
4. Postop pain is often a significant issue. The anatomic changes from the original disease can affect pain pathways due to "spill-over" of the inflammatory response. Spinal cord "wind-up" of pain signals seems to occur. Proactive, multi-modal post-op pain control (local anesthesia at the incision plus PCA, etc.) helps.
5. The autonomic nervous system is often dysfunctional, again due to anatomic changes from the original disease (the inflammation and scarring in the anterior horn "spills over" to the intermediolateral column, where sympathetic nerves travel). This can cause gastro-esophageal reflux, tachyarrhythmias and, sometimes, difficulty maintaining BP when anesthetics are given.
6. Patients who use ventilators often have worsening of ventilatory function postop, and some patients who did not need ventilation have had to go onto a ventilator (including long-term use) postop. It's useful to get at least a VC preop, and full pulmonary function studies may be helpful. One group that should all have preop PFTs is those who were in iron lungs. The marker for real difficulty is thought to be a VC <1.0 liter. Such a patient needs good pulmonary preparation preop and a plan for postop ventilatory support. Another ventilation risk is obstructive sleep apnea in the postop period. Many post-polios are turning out to have significant sleep apnea due to new weakness in their upper airway muscles as they age.

7. Laryngeal and swallowing problems due to muscle weakness are being recognized more often. Many patients have at least one paralyzed cord, and several cases of bilateral cord paralysis have occurred postop, after intubation or upper extremity blocks. ENT evaluation of the upper airway in suspicious patients would be useful.

8. Positioning can be difficult due to body asymmetry. Affected limbs are osteopenic and can be easily fractured during positioning for surgery. There seems to be greater risk for peripheral nerve damage (includes brachial plexus) during long cases, probably because nerves are not normal and also because peripheral nerves may be unprotected by the usual muscle mass or tendons.

**For more info:** Review "Postpolio Syndrome and Anesthesia" by David A. Lambert, MD; Elenis Giannouli, MD; & Brian J. Schmidt, MD, The University of Manitoba, Winnipeg, Canada, in the September 2005 issue of *Anesthesiology* (Vol. 103, No. 3, pp 638-644). This article reviews polio, post-polio syndrome and anesthetic considerations for this patient population.



## The Ten Commandments of Post-Polio Sequelae

By

**Dr Richard L Bruno** Chairperson, International Post-Polio Task Force, and Director, The Post-Polio Institute, Englewood Hospital and Medical Center, Englewood, New Jersey USA  
**Dr Nancy M Frick** Executive Director, Harvest Center Inc, and Director of Education, International Post-Polio Task Force

### 1. Listen to Yourself!

Polio survivors often turned themselves off from the neck down after they got polio. The first step in treating PPS is to listen to yourself: to what you feel, physically and emotionally, when you feel it and why. Our most powerful tool in treating PPS is the daily logs our patients keep that relate activities to their symptoms. However, polio survivors sometimes listen too much: to vitamin salesmen saying some herb or spice will "cure" PPS, to other polio survivors who warn that you will eventually have every possible PPS symptom, and to friends and family members (and the voices in your own head) saying you're lazy and that you must "use it or lose it". Polio survivors need to listen to their own bodies, not to busybodies.

### 2. Activity is Not Exercise!

Polio survivors believe that if they walk around the block five times a day, spend an hour on the exercise bike and take extra trips up and down stairs, their muscle weakness will go away. The opposite is true: the more you overuse your muscles the more strength you lose. Muscles affected by polio lost at least 60% of their motor neurons; even limbs you thought were not affected by polio lost about 40%. Most disturbing is that polio survivors with new muscle weakness lose on average 7% of their motor neurons per year, while survivors with severe weakness can lose up to 50% per year! You need to substitute a "conserve it to preserve it" lifestyle for the "use it or lose it" philosophy. Stretching may help pain and non-fatiguing exercise for specific muscles can prevent you from losing the strength you have after you get a brace. But polio survivors need to work smarter, not harder.

### 3. Brake, Don't Break

The follow-up study of our patients showed that taking two 15 minutes rest breaks per day - that's doing absolutely nothing for 15 minutes - was the single most effective treatment for

PPS symptoms. Another study showed that polio survivors who paced activity -- that is worked and then rested for an equal amount of time -- could do 240 per cent more work than if they pushed straight through. Our patients who took rest breaks, paced activities and conserved energy had up to 22% less pain, weakness and fatigue. But polio survivors who quit or refused therapy had 21% more fatigue and 76% more weakness. For polio survivors, slow and steady wins the race.

#### **4. A Crutch is Not a Crutch ...**

... and a brace is not a sign of failure or of "giving up". You use three times less energy (and look better walking) using a short leg brace on a weakened leg. Overworked muscles and joints hurt and nerves die after decades of doing too much work with too few motor neurons. So why not use a brace, cane, crutches (dare we say a wheelchair or a scooter) if they decrease your symptoms and make it possible to finally take that trip to Disney World? We know, you'll slow down and take care of yourself "when you're ready". And you'll use a wheelchair "when there's no other choice". Well, you don't drive your car until it's out of gas. Why drive your body until it's out of neurons?

#### **5. Just Say "No" to drugs, unless ...**

Five studies have failed to find any drug that treats PPS. And there have been no studies showing that herbal remedies or magnets reduce symptoms. Polio survivors shouldn't think that they can run themselves ragged, apply a magnet or pop a pill, and their PPS will disappear. Pain, weakness and fatigue are not-so-subtle messages from your body telling you that damage is being done! Masking symptoms -- with magnets or morphine -- will not cure PPS. However, two studies have shown that polio survivors are twice as sensitive to pain as everyone else and usually need more pain medication for a longer time after surgery or an injury (see 10 below).

#### **6. Sleep Right, All Night**

The majority of polio survivors have disturbed sleep due to pain, anxiety or sleep disorders, such as sleep apnoea (not breathing) or muscles twitching and jumping all over your body during the night. However, polio survivors are usually not aware that they stop breathing or twitch! You need a sleep study if you awaken at night with your heart pounding, anxiety, shortness of breath, choking, twitching, or awaken in the morning with a headache or not feeling rested. "Post-polio fatigue" may be due to a treatable sleep disorder.

#### **7. Some Polio Survivors Like it Hot**

Polio survivors have cold and purple "polio feet" because the nerves that control the size of blood vessels were killed by the poliovirus. Actually, polio survivors' nerves and muscles function as if it's 20 degrees colder than the actual outside temperature! Cold is the second most commonly reported cause of muscle weakness and is the easiest to treat. Dress in layers and wear socks made of the silk-like plastic fibre polypropylene (sold as GORTEX or THINSULATE) that holds in your body heat.

#### **8. Breakfast Is the Most Important Meal of the Day**

For once Mom was right. Many polio survivors eat a Type A diet: no breakfast, coffee for lunch and cold pizza for dinner. A recent study shows that the less protein polio survivors have at breakfast the more severe their fatigue and muscle weakness during the day. When our patients follow a hypoglycaemia diet (have 16 grams of low-fat protein at breakfast and small, non-carbohydrate snacks throughout the day) they have a remarkable reduction in fatigue. Protein in the morning does stop your mid-day yawning.

#### **9. Do Unto Yourself as You Have Been Doing For Others**

Many polio survivors were verbally abused, slapped or even beaten by therapists or family

members when they had polio to "motivate" them to get up and walk. So polio survivors took control, becoming Type A super-achievers, "the best and the brightest", doing everything for everyone except themselves. Many polio survivors do for others and don't ask for help because they are afraid of being abused again. Isn't it time that you got something back for all you've done for others? Accepting assistance is not the same as being dependent. Accepting assistance can keep you independent. But appearing "disabled", by not doing for others, asking for help or using a scooter, will be frightening. Remember: If you don't feel guilty or anxious you are not taking care of yourself and managing your PPS.

### **10. Make Doctors Cooperate Before They Operate**

Polio survivors are easily anesthetised because the part of the brain that keeps them awake was damaged by the poliovirus. Polio survivors also stay anesthetized longer and can have breathing trouble with anesthesia. Even nerve blocks using local anesthetics can cause problems. All polio survivors should have lung function tests before having a general anesthetic. Your complete polio history and any new problems with breathing, sleeping and swallowing should be brought to the attention of your surgeon or dentist - and especially your anesthesiologist - long before you go under the knife. Polio survivors should NEVER have same-day surgery or outpatient tests (like an endoscopy) that require an anesthetic.

**[Editor's Comment: As an overnight stay may be necessary to recover from anaesthetics, a hospital admission rather than a day-surgery-only facility may be more suitable for polio patients.]**

#### **The Golden Rule for Polio Survivors**

*If anything causes fatigue, weakness, or pain, Don't Do It!  
(or do a lot less of it)*

#### **The Golden Rule for Polio Survivors' Friends and Family**

*See no evil, hear no evil . . . and help only when asked*

Polio survivors have spent their lives trying to look and act "normal". Using a brace they discarded 30 years ago and reducing their super-active daily schedule is both frightening and difficult for them. So, friends and family need to be supportive of life-style changes and accept survivors' physical limitations and new assistive devices. Most important, friends and family need to be willing to do the physical tasks a polio survivor should not do, but only when the polio survivor asks. Friends and family need to know everything about PPS but say nothing: neither gentle reminders nor well-meaning nagging will force survivors to use a new brace, sit while preparing dinner or rest between activities. Polio survivors must take responsibility for taking care of themselves and asking for help when they need it.

(This article can be viewed at <https://www.youtube.com/watch?v=fykVp0ryy3U>)

## **A Tale of Two Viruses**

**By Merle Thompson OAM**

**17 May 2020**

While other people are focussing on, and writing about, their experiences with COVID-19 lockdowns and restrictions, I have had some rather different thoughts and have decided to record them.

**2020:** At New Year the world was initially only aware of the idea of a new virus causing major problems in specific areas of China. Progressively the situation worsened and we all became gripped by the horror of the numbers of infections and deaths as the virus rapidly spread around the world. At the time of writing there have been about 4 million infections recorded and about 300,000 deaths, and that is recorded numbers and not necessarily the total numbers.

**1946:** Anzac Day, the first one after the end of World War II. Emotions were high in Australia with mixed grief for the men and women killed or injured and relief and celebrations that the war had at last ended. My father took my sisters to the local events. My mother stayed home with me. I was 15 months old and desperately ill. Next morning I was put onto the floor to walk across the room. I had been walking since 11 months but I got down and crawled. One leg was sticking out sideways. Later that day I was diagnosed with polio which was then known as infantile paralysis.

I had contracted the poliomyelitis virus which has in its own way caused as much havoc in the world as COVID-19.

During the current pandemic my mind has been exploring ideas of the similarities and differences between polio and COVID-19 and, of course, of the impact of each of them on me personally and my family.

**History of the viruses:** COVID-19 was only identified late in 2019 and formally named during the early months of 2020. In contrast we believe the polio virus has been known for perhaps 4,000 years. At least we believe that its effects have been experienced for this long even though it did not have the name. Hippocrates described it 2,000 years ago. There is an engraving in a tomb in Egypt which dates back to over 3,000 years and depicts a young man whose withered leg looks very like a polio-caused disability. An even earlier record is that of “Lesley”, the name given to a young woman of 18-20, whose skeleton was found in 1993 in a grave used in around 2,000 BC in the UAE. It is thought that she must have had polio because the skeleton shows classic symptoms of polio. The painting in the Tokali Church, Cappadocia, Turkey from about 10<sup>th</sup> Century showing Christ healing a lame man also looks very like a polio person and ties in with my own, maybe fanciful, idea that all the lame and crippled people in the Gospels were polio survivors. The artist must have thought the same way. Polio was first clinically described in the early nineteenth century.



**The virus and its spread:** The polio virus was identified in 1908. A poliomyelitis virus particle is symmetric, like a soccer ball, constructed from five-sided segments (pentagons). On each pentagonal face of the virus particle there is a symmetric “hill”. The outer layer of the poliomyelitis virus is a thin shell constructed from proteins. The shell protects a molecule of ribonucleic acid (RNA) which resides at the centre of the particle. The virus particle readily reproduces itself and so a single virus particle is infectious. It is colourfully represented by this diagram which is used as a logo by Polio Australia and Polio NSW. If the logos used on television to depict the COVID-19 virus is anything to go by, this virus is a much looser shaped particle with hairs or “arms”.



COVID-19 is a respiratory illness and spread by droplets. Polio is initially an illness of the gut and spread by faecal matter. The spread of both can be curtailed by good hygiene.

COVID-19 is regarded as a pandemic, that is, cases are occurring world-wide. Epidemics of polio tend to be more localised, sometimes within a small geographic area and sometimes across the nation. While other countries may have epidemics at the same time, the spread is not such as to be labelled pandemic. The early 1950s was a time when cases occurred across a very wide area – Australia, UK, Europe and USA at least.

To date COVID-19 has only been experienced in Australia in Summer. What difference will it make when we move into Winter? With influenza the incidence is higher in colder

weather whereas other illnesses, such as rubella, peak in Spring to Summer. Polio may be more like the latter, but I have not seen statistics on this and only asked for the year, not month, of initial illness when I conducted my own research projects. However, in the USA polio has been called “the Summer Plague” indicating the experience in that country.

That expression, “the Summer Plague”, also represents the fear which the prospect of a polio outbreak engendered in the population. So, as with COVID-19, there was widespread anxiety regarding the possibility of contracting the illness. Government responses in some countries to COVID-19 have been proactive with restrictions on movement and social gatherings being introduced to reduce the spread. With polio there were also some restrictions on movement and activity but they were more reactive, that is, introduced after the epidemic had taken hold. In the 1937-38 epidemic in Australia schools were closed and some borders were closed with movement between NSW and Victoria banned for anyone who had been near a school.

**Age factors:** While with both viruses people of all ages can contract the virus, there are major differences in incidence, severity of illness and death rates at different ages. It is not yet known whether a lot of children have had COVID-19 without apparent symptoms but they are under-represented in case statistics. And from what I understand from news reports, young adults and perhaps middle aged adults tend to have milder symptoms but this is not universal as there have been deaths of younger people. The greatest loss of life is among those aged over 60 and even more so, over 70.

Polio on the other hand was predominantly known with children. In my own second research report, which analysed information from nearly 500 polio survivors in NSW, just over 70% were aged 10 or under and only around 9% aged 21 and over.

This means that for people now aged 60 and over, they have had a “double whammy” of vulnerability and potential impact. We were children in the era when polio was rife and are more vulnerable to severe illness with COVID-19. Having been hit by one, I have to do all I can to avoid the second.

**Incidence of major illness and death:** There are some similarities between the two illnesses. Many people who contracted the polio virus were totally asymptomatic or had fairly minor symptoms, perhaps similar to a gastric flu. It appears that there are also people with COVID-19 who have been asymptomatic and, for a significant proportion, the symptoms are relatively mild. In both illnesses, however, a proportion develops an extremely severe illness with a high fever common to both. The death rate in COVID-19 may overall be around 1- 2% but much higher if only older age groups are considered. In polio it is thought that in around 1 – 2% of cases the virus passes from the gut to the blood stream and into the nervous system causing inflammation particularly in the lower brain and in the anterior horn cells of the spinal cord. This results in the death of motor neurones and hence paralysis and muscle weakness. The death rate within this small proportion was probably about 10%.

It is estimated that there were between 20,000 and 40,000 cases of paralytic polio in Australia in the 1930s to 1960s. This represents only around ½ to 1% of those who were affected by the virus. Or, as Sir Gustav Nossal expressed it, “*with polio there are approximately 200 invisible cases for every visible case*”. As Australia’s population was only 6 million in 1930 and did not reach 10 million until 1960, the overall proportion of the population who could have been concerned is extremely high. Fortunately the numbers of COVID-19 cases has not reached these proportions but the situation experienced in specific clusters illustrates the potential.

**Hospitalisation and treatment:** We have seen and agonised over film of families peering through windows at family members in isolation and staff in protective gear. It must be so hard to not be able to comfort each other, or even worse, say goodbye to someone who is dying. With COVID-19 many of the people concerned were elderly. With polio the majority were babies and little children, many even pre-language or too young to understand. Parents could only look through a window. To make matters so much worse, hospital stays were not just a matter of weeks, as is the case with some COVID-19 patients, but were sometimes as long as 3-4 years with most being at least several months. Visiting times were very regulated, limited and strict with once a week for 1-2 hours or even once every few weeks as common practices. Many patients were tied down or placed in a “double Thomas splint” with limbs in plaster or braces. Treatments could include very painful hot

packs and physiotherapy.

In this regard I was very fortunate. I was cared for by an orthopaedic specialist who was working as a GP because of post-war restrictions. He had worked with polio children in London and Sydney and he was also the father of young children. He wanted to avoid my being sent away to hospital with such limited visiting and my parents did not own a car. Nor did he want to see me strapped down, so he said that if my parents were prepared to cope they could keep me at home. I think he also was not in favour of immobilisation as a treatment. I suspect in order to achieve this I might never have been registered otherwise he might have been forced to send me to isolation.

**Long-term effects:** It might be too early to say whether there are longer-term implications for those who have recovered from COVID-19. We don't know whether there are post-viral issues or recurrences as experienced with some illnesses. For a number of people in the short-term they seem to recover well and relatively quickly.

Unfortunately with polio this is not the case and people are impacted in two ways. Firstly, a significant proportion of those who experienced the paralytic form of the disease have life-long disabilities. A small number lived most of their lives in iron lungs, the then equivalent of a ventilator. Some were left quadriplegic, many have significant disabilities, particularly relating to mobility, but also upper limb weakness, scoliosis, breathing difficulties, and no two are the same. The image of the "polio kid" with little ones in callipers and orthopaedic boots was known to everyone in that era.

Then, anything from 25 to 40 years later, the Late Effects of Polio and the sub-set of this known as Post-Polio Syndrome can "kick in". These problems result from a range of factors including the initial effect on the brain, the loss of motor neurones which were weakened in the initial illness or were "re-growth" ones and also from over-use and unusual use of muscles. Polio is regarded as one of only two or perhaps three diseases which have a secondary phase, the others being syphilis and perhaps tuberculosis.

**History, Services and Attitudes:** How will history record COVID-19? We can only conjecture. Obviously it must feature in historical records and there will be analyses of the origin, management and treatment from a global perspective and also within each nation and jurisdiction.

But what of the patients? Much will depend on what happens from now, both in terms of the virus itself and of the impact on individuals. If the virus is eradicated, as with smallpox, the situation would be very different from one where there has to be ongoing prevention and management of outbreaks and individual cases.

Were it to become a "thing of the past" and there not be new cases, either globally or in more limited areas, would it be a situation similar to polio where we have people saying: "polio – didn't we get rid of that years ago?" Should there be no long-term effects on individuals this might not matter. But if, as with polio, people who contracted the virus have life-long problems then will COVID-19 patients face this kind of attitude? This is why Polio Australia's community education and lobbying for assistance with information programs and services is called "We're Still Here" to try and get recognition that the disease might not be rife in our country now but the survivors are still here and need services.

In NSW we have no government-funded clinic, assessment or treatment services specifically for polio and in any services where there is the specialised knowledge it is based on the interest and willingness to learn by individual practitioners. Most polio survivors are not eligible for the NDIS as they were 65 or older when it was introduced in their area. They are expected to get assistance from aged care services which are not appropriate. Or, unless they are able to self-fund, they have to rely on limited state-funded services for assistive technology such as wheelchairs, callipers and orthopaedic boots. How many people in the general community are limited to one pair of shoes every couple of years? And often on a waiting list to get them.

It might be regarded as cynical, but there are times when we feel governments and service providers are just waiting for the last survivors to die so they don't have to be concerned about the issues. After all, it is more than 60 years since the last major epidemic. But what about the younger migrants coming in from countries where polio hasn't been eradicated?

**Vaccines:** Developing a vaccine for COVID-19 is regarded as the "holy grail" and what will enable

us to return to life as normal. There is hope that one will be produced and readily available within 18 months. The development of the polio vaccine took decades. The first one was introduced to Australia in 1956 and is universally available in this country. That cannot be said for a number of countries in the world. In fact, even in the last couple of years there have even been murders of aid workers delivering the vaccine.

An unfortunate side-effect of the COVID-19 pandemic could be that the World Health Organisation has to put aside its work on polio eradication to work with those countries without good health services in order to deal with the pandemic. Polio eradication has been a primary focus of the WHO in recent years.

At least there is some level of cooperation between institutions working on a COVID-19 vaccine. There was not that cooperation in developing the polio vaccine but rather intense rivalry. Shall we just say Salk and Sabin, who were the two who successfully produced vaccines, were not close friends.

**Restrictions and lockdowns:** Is there any special concern for polio survivors in the COVID-19 pandemic or effects of restrictions? On a community level probably not, as it would not seem that being a polio survivor makes one more vulnerable, other than the fact that most are in the vulnerable age group. On an individual basis there may well have been specific issues with dealing with the emotional aspects of anxiety about contracting COVID-19 and the physical difficulties of dealing with one's disability within the restrictions.

From a personal point of view I live alone and can often go several days without face to face or telephone conversation, so such limitations were not new to me. I acknowledge I am sensitive, prone to be despondent and anxious on health issues which combined with dealing with a minor non-COVID-19 respiratory infection did make me anxious, even to the level of counting days since contact with people in case I could have infected them or them me. I had a COVID-19 test for this reason but was still anxious after the result came back negative. I also had to cancel appointments related to dealing with my disability including a 2-day therapy program and my on-going exercise physiology appointments which are aimed at keeping me as mobile as possible. I had a 10 week instead of 6 week gap with podiatry which led to an increase in severity of a major on-going issue and I cannot yet have an assessment related to another problem with my feet until my GP is happy to make referrals again.

Perhaps ironically, the other impact of the restrictions on me personally has been the cancellation of my trip to Spain to attend the 3<sup>rd</sup> European Polio Congress. A conference to consider the latest ideas in treatment and services for the survivors of one terrible virus had to be cancelled because of another terrible virus. Even if it is re-scheduled will our travel restrictions allow for attendance or might my own anxiety mean I am hesitant to go?

The issues which result from polio infection are more personal with the economic impacts being on the person and family and, in the past, organisations which supported survivors. On the other hand, the impact of COVID-19 is massive disruptions to the community and the economy at local, state, national and global levels.

**Positive outcomes:** Can there be any positive outcomes from the horror of the COVID-19 pandemic? A significant positive that came out of polio epidemics was the development of Intensive Care Units. And it is the availability of ICUs and associated equipment such as respirators that has been a major concern in preparedness for dealing with COVID-19 cases.

We don't know yet about such matters with COVID-19 but it has been positive to see more bipartisanship and cooperation politically and between commonwealth and state/territory jurisdictions. There have also been some wonderful examples of manufacturers quickly developing or adapting processes to produce medical supplies.

And, of course, there has been, on the whole, community support for individuals and willingness to undergo restrictions for the greater good.

**Concluding ideas:** In the media we have seen comparisons drawn between the COVID-19 pandemic and AIDS which is, of course, a valid comparison, especially in relation to fear and anxiety in the community and tragic loss of life. In both cases there have been important

community awareness campaigns. My personal comparison has been with poliomyelitis and I sincerely hope that those infected with COVID-19 do not have on-going medical and disability issues to affect their later lives as has been the situation for many polio survivors.

## From the Polio Australia Team

Steph Cantrill, Community Programs Manager, attended a meeting via Zoom with the ATFA (Assistive Technology for All) Alliance in April. ATFA would like more people to sign their petition calling for equitable access to assistive technology for people outside the NDIS. There is also an opportunity on the same page for people to share their own stories.

“Older Australians who are ineligible for the NDIS and younger people with a disability or acquired injury who are not NDIS participants have limited access to assistive technologies. This includes devices such as wheelchairs, prosthetic aids, screen-reading software and rails in the bathroom to help them remain independent at home.

We understand it's a shared problem for all levels of Government, but we're calling on the Australian Government to stop people falling through policy and program cracks by establishing a **National Assistive Technology Program** so that everyone has equitable access to life altering technology.” - ATFA

To sign the PETITION go to: <https://assistivetechforall.org.au/take-action/>

## The Psychology of Treating PPS

Taken from PA Polio Survivors Network April 2020 [www.papolionetwork.org](http://www.papolionetwork.org)



### A Bruno Byte

From Dr. Richard L. Bruno, HD, PhD  
Director, International Centre for Polio Education

There is no question that the biggest obstacle to treating PPS is polio survivors' fear of change. From our 1995 International Post-Polio Survey we know that polio survivors experienced 34% more physical abuse and 94% more emotional abuse as kids just because they looked disabled. As so many patients have said to me, “Why would I want to (insert any change in activity or use of any assistive device) look disabled and be abused and rejected *again?*”

So, the challenge in managing PPS is dealing with what's going on from the neck up, more even than the neck down. After 36+ years and treating thousands of people with disabilities, I've found some tips and techniques to help patients deal with their powerful feelings that can prevent a physical disability from becoming an emotional one.

"Irritability Is Not An Emotion." When something life changing happens, like becoming disabled, people often have trouble knowing what they feel, let alone being able to express their emotions. Sometimes folk know what they feel but believe they are burdening their families and friends by talking about feelings. But, strong emotions don't go away or remain hidden. Feelings make themselves known whether or not you're aware of them or you want them to, often as irritability. If you are irritable - nasty as a rattlesnake, sniping at your spouse, and kicking the cat - there is a powerful emotion inside of you that's trying to get

out. Better to tell someone what you feel, or even say that you don't know what you feel, than to be irritable.

Looking for feelings underneath the irritability and talking about them not only helps you feel better, by bringing the feelings into the light where you can deal with them, but also helps your family, friends and pets feel less like they're living near Mount Vesuvius.

"The Stages Have Left Town." Once you get beyond being irritable and know what you're feeling, what do you do? Do you remember the "stages of acceptance" of dying: denial, anger, bargaining, depression and acceptance? These stages have been applied to losses other than dying, including having a disability. The problem is that there is no sequence of "stages of acceptance" for dying or for disability. People don't neatly move from denial through to acceptance. Some folk can go from a rehab hospital bed to acceptance, while others flip from acceptance to denial and can experience everything in between in any order. What's important is that we're not forced to fit emotional stages but are free to feel what we feel, when we feel it.

We also shouldn't accept labels for our emotions. Sadness, fear, helplessness and hopelessness are often all labelled as "depression" by doctors. Too often patients are given an antidepressant and sent on their way. It's far better to work with a psychotherapist to deal with your specific feelings than to accept a label, take a pill and hope the "bad" feelings disappear. Depression is a medical illness and can be treated with antidepressants. But, when depression is gone, your feelings remain and will still have to be dealt with.

"It is Better to Curse the Darkness Than to Light A Thousand Candles." Back in the early 1970s, Richard Pryor (who later contracted Multiple Sclerosis) was pilloried for using profanity in his comedy. "Why does he have to use 'four letter words'," whined mothers across America?

Pryor used "four letter words" because he was describing 300 years of abuse. What was he supposed to say, "Oh darn, my great-great-grandfather was kidnapped and stuck in the hold of a slave ship and, shoot, he and his family were forced to pick cotton for generations, and heck, they were beaten and hanged asking for basic civil rights?"

Darn, shoot, and heck didn't do it for Pryor and they don't do it for most people with disabilities. Having a disability stinks. If you're lucky, you'll learn from the experience and grow. But, I think people with disabilities, and especially their shrinks, should acknowledge that disability bites and say so.

I have found that one good "damn" is worth a thousand "darns." Profanity vividly communicates pain and sadness while releasing frustration and anger. So, if my patients curse, I curse right along with them. I sometime curse on my own to make a point or to help break a patient's feelings loose. A well-placed "damn" or "hell" lets patients know that they can feel and express anything they feel.

### **The Encyclopedia of Polio and Post-Polio Sequelae**

contains all of Dr. Bruno's articles, monographs, commentaries and "Bruno Bytes"

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



# Media release - Patients feeling better with Telehealth

Taken from Consumers Health Forum (CHF) 26<sup>th</sup> May 2020 [www.chf.org.au](http://www.chf.org.au)

**By Mark Metherell**, Communications Director, CHF

*“I was more relaxed in my consultation. I was in my familiar environment and the specialist and I were both at ease. I didn’t have the stress of getting the two people I care for sorted before the 90-minute drive to the city hospital for this appointment. I saved money on fuel and parking fees. I didn’t have to sit in a full waiting room. I didn’t have to turn down work for that entire day because of the travel time and waiting room time blowouts. The benefits of telehealth are immense.” – **Australia’s Health Panel respondent.***

The introduction of the expanded Telehealth Medicare benefit has drawn strong support from respondents to an Australia’s Health Panel survey, an initiative of the Consumers Health Forum.

The [Telehealth services survey](#) found that more than 80 per cent of those who were offered telehealth services used it. Of these a similar proportion viewed the service as excellent or good quality.

“This response gives us any early indication of the value of telehealth particularly at a time of health anxiety as we are experiencing at present with COVID-19,” the CEO of Consumers Health Forum, Leanne Wells, said.

“As the respondent’s comments quoted above show, telehealth offers considerable medical and social benefits for the many patients who may need to consult a doctor but do not require physical examination.

“CHF has also recently completed a survey on a related issue of access to medical care --- [after hours services](#). This showed that while most people expect they should be able to get care after hours, many people encounter significant difficulties.

“While the telehealth survey was of modest size, the overwhelmingly favourable response indicates strong community support for the scheme to continue in the post-COVID era.

“An interesting result was that slightly more panellists said the telehealth consultations were better than face-to-face consultations compared to those who preferred face-to-face services.

“The survey found that key barriers to telehealth services were lack of access to required technology, unreliable internet access and non-awareness of the option.

“These sorts of issues will need to be resolved if telehealth services are available equally to all Australians. This initiative might have become imperative because of the necessities triggered by COVID, but telehealth and digital technology generally is becoming routine and the way of the future.

“The survey on after hours care found more than two thirds of respondents had used after hours primary care at least once in the previous five years, with 43 per cent accessing services between 8pm and 11 pm and 20 per cent between 11pm and 7am.

“There can be big differences from one region to another in availability of services, often with rural areas having meagre services. The great variation is shown by the survey results which found 24 per cent of respondents reported easy-to-access after-hours services, 18 per cent found it difficult and 25 per cent extremely difficult to get care outside of business hours.

“The results of these two surveys offer fresh impetus for the Government to exploit telehealth further in ways that bridge the gap in access to Medicare between city and country,” Ms Wells said.



# Electronic Prescribing

Taken from the National Prescribing Service newsletter NPS MedicineWise

Ahead of the introduction of electronic prescribing later in the year, please be aware **interim** arrangements are now in place for prescribing to make supply of medicine more convenient following a telehealth consultation.

Under the interim arrangements, a digital image (such a photo, scan or pdf) of a prescription can be sent electronically by the prescriber to the patient's pharmacy of choice. This electronic copy can be used by the pharmacy to supply the medicine and claim from the PBS in the same way as a paper prescription. The pharmacy may communicate directly with the patient to arrange payment and to organise collection or home delivery of the medicines.

Alternatively, the paper prescription can be sent by post to the patient. The prescription can then be taken to a pharmacy by a family member or friend. As part of the National Health Plan, electronic prescribing is being fast-tracked. Work to upgrade healthcare providers' clinical software is well underway and is expected to be ready by May 2020. The Australian Government has announced the interim arrangements for prescribing will remain in place until 30 September 2020, or until full electronic prescribing rollout is implemented.

Factsheets summarising these interim measures are available for prescribers, pharmacists and consumers. For more information, see the [Australian Government Department of Health website](#).

NPS MedicineWise understands that currently most states and territories have provided for the interim measure arrangements in their local legislation. Prescribers and pharmacists should check advice from their specific state or territory health department.

## MT WILGA LEO P CLINIC

Dr Mackie informed us late last year that she would be transitioning into retirement during this year. She has now advised us that she will not be taking new patients after June. She will, however, be continuing as a consultant at Mt Wilga and will be seeing outpatients and day patients via the hospital appointments system, mostly on a Tuesday in her old room. This will enable her current patients to continue to see her. She may also be available as a holiday locum for Dr Grace Leung. Dr Leung will look after Dr Mackie's patients who are admitted to Mt Wilga as inpatients and will eventually take over all of her work.

Kate Bradbury, the physiotherapist who has mostly worked with polio survivors in the last two to three years, will continue to work in Polio and members may see her as an out-patient on Mondays or Tuesdays.

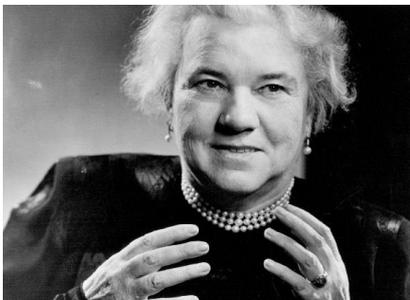
While the Late Effects of Polio Clinic will not operate as initially set up, Dr Mackie has assured us that Mt Wilga can undertake the full range of services including assessment, outpatient therapy, day rehabilitation for 2 to 10+ days (3 sessions/day e.g. a combination of Physiotherapy, hydrotherapy, occupational therapy or psychology etc) or inpatient program; all with a good understanding of post-polio syndrome and LEO P. You will, however, need to be covered by the NDIS or a private health fund or choose to self-fund your treatment.

To make an appointment or to discuss assessment options, or for more information, please contact **(02) 9847 5000**.

## Sister Elizabeth Kenny: a 'raging tiger, merciful angel' who challenged doctors on polio

By Curt Brown, Special to the Star Tribune

**Her methods largely rebuked in Australia and fell on deaf ears around the U.S., until she got to Minnesota.**



Yousuf Karsh caught Sister Kenny's expressive hands in a portrait. "They are full of healing," another nurse once said.

IN the spring of 1940, a Minneapolis lawyer carried his polio-ravaged 18-year-old son down the stairs of their home at 5210 Girard Av. S. Despite treatment at President Roosevelt's polio treatment centre in Georgia, Henry Haverstock Jr., was in rough shape. Both legs, an arm, his back and stomach were paralysed. His body was trapped in a stiff corset. Doctors said the steel braces would remain on his legs for the rest of his life.

"There is some woman here from Australia," Dr. John Pohl told Henry's parents. "I don't know if she has anything, but he won't walk again and it's worth a try."

Sister Elizabeth Kenny, a 59-year-old nurse who'd just arrived in the United States after a lifetime in Australia's outback, began examining Henry. She wasn't a nun; following military custom, she'd earned the "Sister" title as an Aussie head nurse during the First World War.

Kenny believed Henry's muscles weren't dead but in spasm, so the casts, splints and braces were "all wrong." Her so-called Kenny Method instead called for hot packs and gentle muscle manipulation. Henry returned to the hospital, where she urged him to concentrate as she retrained each of his muscles.

"The doctors and nurses almost fell out the windows when he came walking out of his room," said one person watching Henry using two short hand crutches Kenny had given him. Two years later he was climbing the stairs at college, according to Victor Cohn's 1975 book, "Sister Kenny: The Woman Who Challenged the Doctors."

"The average among us breathe youthful fires and cool as we age and harden. ... She never gave up," Cohn wrote of Kenny's late-in-life rise from bush nurse to polio pioneer and namesake of a 67-year-old rehabilitation institute in Minneapolis.

Australian nurse Elizabeth Kenny came to Minnesota in 1940 at the age of 59, with revolutionary ideas about polio treatment — using hot packs and muscle manipulation instead of the accepted practice of using braces, casts and immobilisation. She won awards from the Congress of Physical Therapy and the Minnesota Public Health Association, and honorary degrees from several universities despite little formal training as a nurse.

During the deadly 1946 polio epidemic in Minnesota, Kenny would wake at 5 a.m. and "never see my bed again until after midnight." She blamed her overexertion for the Parkinson's disease that led to a fatal stroke in 1952. "But I would do it all again if I had a life to live over again."

**CURT BROWN:** Cohn, who covered Kenny's revolutionary polio treatments as a Minneapolis Tribune reporter, asked in his book: "How can we explain this woman who was called both a fraud and a medical genius, a cheap quack and an unhappy martyr, a raging old tiger and a merciful angel?" The daughter of an Irish immigrant farmer, Kenny rode horses and then motorcycles to visit early patients. She had little time for romance after an early paramour in Australia offered her an ultimatum when she was asked to help a woman in childbirth. In her autobiography, she said a man named Dan asked her to decide between marrying him or her vocation. She picked nursing.

Most experts at the time thought polio killed nerve cells and yanked muscles out of place, requiring immobilising casts and splints. Kenny insisted the muscles were merely tight so "your splints and casts are illogical; throw them out."

Her methods largely rebuked in Australia, Kenny's hot packs approach to polio also fell on deaf ears when she first arrived in the United States 80 years ago. She went to New York and Chicago, where doctors thought her "a screwball." Cohn wrote that she was told she was wrong "politely, then impolitely, then brutally." But when she got to Minnesota, she found open doors and minds at the Mayo Clinic and University of Minnesota.

Kenny was unafraid to call doctors "dodos" to their faces, the Minneapolis Star wrote: "Many medical men saw red, but the stubborn woman with the powerful frame succeeded in throwing off the splints and casts that had bound polio victims."

Most crippling polio cases struck children. "The time was ripe for the dramatic appearance of an underdog who appealed to parents with the simple message: 'I can help your children.'" Emerging at a time when, in Cohn's words, "women held only a thin beachhead," Kenny said a surgeon once told her: "Doctors are not going to be taught by a nurse." Especially one with little formal training.

But Kenny found fame in the United States she could never have imagined back in Australia. For 10 years, pollster George Gallup found her ranked second to only Eleanor Roosevelt as the most admired woman in America. She was voted No. 1 just before her death in 1952.

Kenny drew a crowd of more than 1,000 parents of polio victims on a 1944 trip to Washington. "It's like watching a miracle," one policeman said. "You can't keep them back." When Hollywood released the film "Sister Kenny" in 1946, some 20,000 people reportedly jammed Times Square in Manhattan for its world premiere and nearly knocked Kenny over.

"She looked like an M-4 tank," said actress Rosalind Russell, who played Kenny in the movie and became her friend. "But her eyes were the loneliest and loveliest I have ever looked into."

Kenny spent only a decade in Minnesota before retiring in 1950 and returning to Australia, where she died at 72 in 1952 after a stroke. But she left her mark here like few others before or since. "That Sister Kenny found a place in Minneapolis to forward her work is and should be a source of pride to the city," a Star editorial said when she died. "To those who especially helped her here there is the unique satisfaction of having recognised greatness, and of having given it the chance it deserved."



# Polio Doctor Jean Macnamara's Work Reminds US That Viruses Can be Vanquished

By Patty Ramsmussen

**Dame Jean Macnamara worked tirelessly for her patients, but it was her research that helped lead to the polio vaccine for which she is most remembered.**

**Published for Google's recognition of Dame Jean's anniversary.**

LIVING through a global pandemic will have a wealth of unintended consequences positive and negative, but one will certainly be a greater appreciation for those in the medical professions — from those on the front lines treating patients to those researchers labouring behind the scenes, seeking to isolate viruses and to discover vaccines both now and in the past.

Dame Jean Macnamara was one such heroine. She witnessed and made remarkable contributions in her chosen profession — medicine — principally in the area of polio research, and her work with patients with partial or complete paralysis.

Macnamara was born in Victoria, Australia, April 1, 1899. She was born into a family that prized hard work and education, and she excelled at both. Macnamara attended Presbyterian Ladies College and became the editor of the school's magazine, winning the prize for general excellence. She distinguished herself at the University of Melbourne, graduating in 1922 with degrees in both surgery and anatomy. She went on to become a resident medical officer at the Royal Melbourne Hospital.

Macnamara was just 23 when she was appointed resident at the Royal Children's Hospital in May 1923, where she worked until 1925. It was a critical time as a horrifying disease — poliomyelitis, also known as polio — was sweeping the globe. After leaving the hospital, Macnamara worked as a clinical assistant at the Children's outpatients' physician and entered private practice to focus on poliomyelitis patients.

But it was in Macnamara's research where her light shone brightest. It was her conclusion that immune serum needed to be used in polio treatment during the pre-paralytic stage. She published and defended her results in both Australian and British journals, though it was a treatment that was never widely administered.

However, it was her discovery in 1931, along with Australian virologist Sir Frank Macfarlane Burnet, of more than one strain of the polio virus that made her reputation. Their finding is credited as one of the first steps toward the eventual discovery of the Salk vaccine. She traveled to England and North America on a Rockefeller Fellowship from September 1931 to October 1933, even meeting President Franklin D. Roosevelt, himself a polio survivor.

In addition to her keen interest in curing disease, Macnamara sought to alleviate the pain and suffering it left in its wake. She is credited with ordering the first artificial respirator (or ventilator) in Australia. She introduced novel approaches to rehabilitation and splinting damaged limbs, most developed in conjunction with conversation with patients and her own splint-maker. Macnamara proved to be a tireless advocate for people with disabilities long before it was in vogue. She married a fellow physician, dermatologist Joseph Connor in 1934, and in 1935, Macnamara was appointed Dame Commander of the Order of the British Empire (DBE) for her services to the welfare of children. She died in 1968 of heart disease.

AND: While visiting Princeton University, Macnamara also learned about the virus myxomatosis that infected and killed rabbits. It was at her urging that the Australian government held field trials using the virus to eradicate millions of Australia's rabbits — considered to be pests — that had overpopulated the country.

# 11 Sleep Hacks That Really Work

Taken from PA Polio Survivors Network March 2020 [www.papolionetwork.org](http://www.papolionetwork.org)  
Source: <https://blog.aarpmedicaresupplement.com/11-sleep-hacks-that-really-work>

## **NIGHT MAY BE THE MOST IMPORTANT PART OF YOUR DAY**

It's a fact. Most Americans of all ages don't get enough sleep. As young adults, sleep loses out to studying, working late or partying 'til the wee hours.

As we age, our sleep may be disrupted by anxiety, physical discomfort, or needing to use the bathroom more frequently.

The consequences of insufficient sleep are many. Poor sleep impacts our mood and mental health, our ability to learn, to do our jobs well, and may even put us in physical danger (think drowsy driving). Long term sleep deprivation also contributes to myriad health problems including increased risk for obesity, heart disease, diabetes and dementia. And it's not just under-sleeping that causes trouble. Studies have shown that people who regularly sleep more than nine hours each day are at increased risk for serious health issues, too.

## **Plan Ahead For A Better Night's Sleep**

Most sleep experts agree on the same basic principles that can help promote better sleep. If you find that you're sleeping less, or less well than you'd like, try some of these recommendations from the National Sleep Foundation, Mayo Clinic, and other healthcare organizations.

## **Create Your Own Personal Sleep Schedule**

The recommended amount of sleep for a healthy adult is at least seven hours, and no more than nine. Try to get to bed at the same time each night –even on weekends –and get up at the same time, too. If you need to make an adjustment on the weekend, try to vary your schedule by no more than an hour on either end.

## **Make Your Bedroom More Sleep-friendly**

Keep your bedroom at 60 to 67 degrees for the optimal sleeping temperature. Invest in a better pillow if yours is less supportive or comfortable than you'd like. Pay attention to noise, and use ear plugs or a white noise machine (or phone app) to block out noise from adjoining rooms or snoring.

## **Ease Your Way into Sleep with a Bedtime Routine**

Take a warm bath, lower the lights, massage your hands and feet, or listen to relaxing music. Setting the mood for sleep should help you fall asleep more quickly and sleep more soundly.

## **Avoid Napping, Especially Late In The Day**

If you must take a nap, limit your nap time to 30 minutes.

## **Get Some Exercise Every Day, Preferably Early In The Day**

And if you can get outside to walk or bike –even better. Our natural body clock or Circadian rhythm is influenced by bright light, and sunlight is a powerful signal to the brain that it's time to wake up. On the flip side, bright light and vigorous activity in the evening may make it difficult to wind down before bed. Easy stretching in low light is more conducive to sleep.

## **Turn Off The TV, Phone, Tablet, And Other Electronics**

As noted above, light is a wakeup call to the brain, and the light emitted by electronic devices is particularly bright and strong. Even e-readers can make it more difficult to fall asleep. If you like to read before bed, you may want to opt for a book instead.

## **Keep Track Of Your Sleep**

If you're accustomed to tracking your fitness and food intake and your fitness tracker has a sleep diary feature, be sure to use it to track the amount and quality of your sleep. If you notice a pattern of poor sleep, review the list above to see if there are any lifestyle changes you can make to help you sleep better.

## **Steer Clear Of Alcohol, Cigarettes, Caffeine and Big, Spicy Meals Near Bedtime**

All of these "sleep stealers" can negatively impact your ability to fall asleep and stay asleep.

- Alcohol may help you feel more relaxed, but once it's been processed by the body, it has the opposite effect, and can make you wake up again.
- Cigarettes and caffeine are stimulants and tend to wake us up, rather than calming us down. You should try to avoid any caffeinated drinks for a full eight hours before bedtime.
- Spicy foods and large portions can lead to heartburn, especially if you lie down after eating. Enjoy small portions at dinner, and if you're hungry before bed, have just a small snack.

## **Don't Carry Your Cares To Bed**

Got a lot on your mind? Most of us do, and some people have a very difficult time sleeping when they're particularly busy or worried. If you wake up at night, start thinking, and can't get back to sleep, get up and write down what's on your mind before heading back to bed. Better yet, be proactive! If you have a busy day coming up, make a list of tasks to get them out of your head. If you're worried about something in particular, write down a plan of action that you can deal with during daylight.

## **Aging Can Affect The Quality Of Your Sleep. Take Steps To Help You Sleep Better**

Our sleep patterns tend to change as we age, and there's not much we can do about it.

The video about Aging and Sleep ([www.papolionetwork.org/living-with-post-polio-syndrome](http://www.papolionetwork.org/living-with-post-polio-syndrome)) includes valuable information that may help.

Finally, these additional suggestions from the Mayo Clinic may also help improve your sleep quality.

- Review medications and supplements with your doctor to see if any could be affecting your sleep.
- Stop drinking fluids within two hours of bedtime to minimize trips to the bathroom.
- If pain keeps you awake at night, talk to your doctor about taking an over-the-counter pain medication before bed. Gentle stretching before bed may also ease joint pain that sometimes disrupts sleep.
- Try taking 1-2 milligrams of melatonin in sustained release tablet form about two hours before bed.

**\*\*Be sure to speak with your doctor before starting or stopping any medication or supplement.**

## **On the topic of "Exercise" as it refers to Polio Survivors**

\*Editor's Note: The above article refers to the importance of exercising each day. It also refers to "gentle stretching in low light" being conducive to sleep. All Polio Survivors have a different definition to the word "exercise". For some it is bike riding for others it is gentle stretching. Seek help from your health care professional to determine what the term "exercise" means for you. None of us wants to put additional wear and tear on our already tired neurons.

"Polio Survivors –you are all the same and you are all different"

Dr(s) Richard Bruno, PhD and William DeMayo, MD



# 2020 Polio Program Activities

<b>Wednesday 18th November 2020</b>	<b>Burwood RSL 96 Shaftesbury Road Burwood</b>	<b>Polio NSW AGM and Seminar Speaker to be confirmed</b>
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## Management Committee - Executive Members Contact Details

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Have you added your details to the Australian Polio Register?  
[www.australianpolioregister.org.au](http://www.australianpolioregister.org.au)



# Polio Oz News

June 2020 – Winter Edition

## My Reflections In The Time Of Coronavirus

By Joan Smith

It is too hard for me to adequately comprehend this world-wide pandemic of COVID-19. We are presented daily with tallies of infections and deaths and news film of countless destitute people around the world, social isolation, loss of employment and starvation. Such devastation. I feel so fortunate to live in Australia.

Personally, I have re-visited memories of my childhood days of the polio epidemic of 1952, to try to better understand other people's experiences of today.

Back then, my isolation as a three-year-old child meant no contact with my family for months on end, punishing physio, bandaged into splints and no ability to play as other children enjoyed.

Of course, there were no televisions, mobile phones or any of the communication technology we take for granted today.

In contrast, from my own perspective, I have actually appreciated some aspects of today's changes to everyday life in our personal lockdown.

While everyone must practise *Social Isolation* this time around, I have really enjoyed the guilt-free ability to slow down. I love the quiet days without structure and obligations.

The skies are so blue with reduced pollution, and our roads and neighbourhood are quiet. I have little need of large shopping centres, enjoying leisurely visits to local small businesses for the essentials.

Many younger ones are learning to home cook in their extra time. There is also so much technology to help us to shop and catch up with friends. I have even learned to use Zoom and Skype, surprising my family with video calls. Just a few weeks ago, I didn't even have such terms in my vocabulary.

I have read twelve books, made dozens of cards, and enjoyed the sunny days in our garden, shared only with so many happy birds and my husband.



As we cautiously move towards our 'normal' lifestyle, I hope that some of our adaptations will continue into the future. However, my greatest joy will be to hug my family and close friends again.

Just to wind up these reflections of mine, I say a big thankyou to my grand-daughter who has been working very long days in her nursing vocation – our own hero. Stay well and warm all my fellow polio survivors as we look to our new world. 🌟

**Polio Australia**

Representing polio survivors  
throughout Australia

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“Don't count the days;  
make the days count.”  
~ Muhammed Ali ~

**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

In 1966 Robert F Kennedy delivered a speech that included the following: *"Like it or not, we live in interesting times. They are times of danger and uncertainty; but they are also the most creative of any time in the history of mankind."* Those sentiments are just as true today, if the different ways of working that have developed across Australia, including telehealth

and widespread video conferencing, are anything to go by.

Polio Australia is no exception. Although all staff have been working from home, and both local and interstate travel has necessarily been on hold, this *Polio Oz News* shows that our team has certainly not been idle and has been very creative in finding ways to keep the communication lines open with polio survivors and health professionals alike.

To help support our staff as they work remotely, Treasurer Alan Cameron, Maryann and I are joining them in monthly video conferences. The Board and its Sub-Committees are now also holding video conferences for their meetings,

## From the Editor



Maryann Liethof  
Editor

Well, hasn't a lot changed since the last edition of *Polio Oz News*! Throughout this edition, you can read various articles on how COVID-19 has changed our lives and our world.

Joan's "Reflections" article (p1) is actually quite a positive take on how the pandemic has carved out some guilt free

down time for many — me included!

It seems I picked a good time to 'retire' from the office workspace, considering the Polio Australia team is currently working from home. However, as Steph reveals (p5), they have been highly productive in spite of the lockdown. In this age of technological wizardry, the staff have been able to keep busy with emails, social media, videos, virtual meetings, and more.

Michael reports on his project idea for a potential telehealth specialist clinic to support polio survivors across Australia (p4). He has also been hosting a professional webinar series that can be accessed through Polio Australia's Facebook page (p6).

rather than the usual teleconferences.

As well as its usual activities, the Board has been busy finalising a position statement on the inequity of the NDIS ban on those over the age of 65, with a media release and further advocacy on this issue in the pipeline. The Finance Sub-Committee is developing further strategies to raise funds to ensure Polio Australia's ongoing viability, while our Risk Management and Governance Sub-Committee is completing work on our risk management policy and procedures.

Finally, it is with great regret that the Board recently accepted the resignation due to ill health of Brett Howard, South Australian representative and past President of Polio SA. Brett has been a valued part of the Board since October 2010, and for the majority of the time he has been a member of the Executive, first as Treasurer and then as Vice President. In these roles he has performed vital services for Polio Australia, and has been a great support to me personally. Brett has always willingly taken on any task in support of our activities. I will miss sharing a bottle of Barossa Valley red with him when we met in person at Polio Australia AGMs. Peter Wierenga, South Australia's second representative, has since been elected as Acting Vice President until our AGM in October. ●

Gillian



Polio Australia recently welcomed Paulette Jackson to the team (p8); and readers can share their thoughts on the need for registering or screening aged care workers for a submission to the Department of Health (p8).

The link between polio epidemics and the COVID-19 pandemic is highlighted in a couple of excellent Australian articles: *Two Infectious Diseases That Changed The World* (p10), and *Past Polio Epidemics* (p12).

However, with US President, Donald Trump's, decision to withdraw funds from the World Health Organisation, the ongoing polio eradication program has been dealt a serious blow. Polio Australia wrote a letter of support for WHO to Australia's Prime Minister, Scott Morrison, which precedes a detailed article on the risks posed by cutting funding to this vital program (p16 and 17).

Thankfully, the "Silver Lining" (p19) and "Free Wheelchair Services" (p21) articles end this edition on a more uplifting note.

The start of winter in Melbourne has been a cliché of cold and wet. I'm enjoying my warm house, track pants, and access to hot beverages. Who needs to go out? Just sit back and read . . . ●

Maryann

## Potential Telehealth Specialist Clinic for LEOp



**By Michael Jackson**  
Clinical Health Educator

A grant opportunity that came to our attention in March 2020 was the Ideas Grant 2020 – a National Health and Medical Research Council (NHMRC) grant. The NHMRC is Australia's leading investor in health and medical research. This particular grant provides funding for projects and research on health topics of community concern.

This type of grant presents an opportunity to think big about the larger barriers we encounter in ensuring polio survivors across Australia are obtaining what they need. In this instance, the topic of *accessibility to specialist clinics for regional polio survivors* arose.

While there are traditional (in-hospital) specialised polio clinics in some capital cities, these clinics are not evenly distributed geographically nor reasonably accessible to regional polio survivors. The consistent utilisation of existing polio clinics, and the known barriers for polio survivors at the GP point of care, indicate a telehealth model polio clinic may be more cost effective in reaching regional polio survivors and their GPs. Further, regional survivors may experience less physical strain and symptom exacerbation by using telehealth.

Telehealth as a mode of healthcare delivery has been on the rise for several decades in Australia. It is already being utilised across regional Australia for a variety of health conditions. With the arrival of COVID-19, telehealth services have seen an uptick in utilisation and funding.

In consulting with the Polio Australia Board and Clinical Advisory Group in April, an outline was

developed and discussed for a telehealth project.

Our plain language summary of a project that would enable increased specialist clinic access to polio survivors nation-wide, is as follows:

*Australian polio survivors can get complex symptoms called Late Effects of Polio. These reduce survivors' quality of life and ability to function. Specialist clinics are an ideal way to manage such a condition. In Australia, the six city clinics are not practical to attend for many polio survivors.*

*We propose a telehealth clinic model that can assess a survivor living anywhere in Australia. The clinicians would consult via phone or video with the survivor, and then conference remotely to make their decisions. The team would provide the survivor's GP with an expert-informed care plan and educational materials.*

The existing post-polio clinics scattered across the country serving polio survivors are the ideal model of multidisciplinary care. Nothing can beat face-to-face interaction between a polio survivor and specialist clinicians. The proposed telehealth clinic would act as a supplement to these existing clinics. It would operate on a broader level to serve those who could not easily access traditional post-polio clinics.

While we were not able to secure the institutional backing or project leadership needed to apply for the Ideas Grant 2020, we did receive input and interest from potential contributors. The grant opportunity that presented enabled the idea to move forward. There is support for implementing a pilot telehealth clinic. We will pursue the idea on that scale.

If you would like to comment on this project please contact [michael@polioaustralia.org.au](mailto:michael@polioaustralia.org.au). If you feel you would be a candidate for using this model of clinic, please state such in an email to [advocacy@polioaustralia.org.au](mailto:advocacy@polioaustralia.org.au). 🇵🇹

### Looking for a support group?

In the recent survey of polio survivors' interactions with medical professionals, many people indicated that they were interested in joining a support group but weren't aware of one in their area.

If you're not yet a member of your state network, please visit:

[www.polioaustralia.org.au/support-and-services](http://www.polioaustralia.org.au/support-and-services)

and click on your state on the map. This will take you to the contact details of your state network. Give them a call to enquire about membership and find out if there's a support group near you.

And hey, if there isn't, why not consider starting one? Get in touch with your state network to find out how. 🇵🇹



## What Is Polio Australia Doing In These Isolated Times?



**By Steph Cantrill**

*Community Programs Manager*

Like many, many other people across the country (and the world), the staff of Polio Australia have been working from home. While this is just the standard mode of operation for some of us, others have had to make some adjustments. I

must say, I have adjusted quite well to wearing trackies and ugg boots to work ...

While the team is used to being spread across the country to some degree, things are definitely different. Community Information Sessions, Clinical Practice Workshops, face-to-face meetings – all are on hold at the moment, and we've had to get a bit creative!

So what on earth are we doing? Well, here's a summary of how we've been spending our time:

### Phone and Email

Answering enquiries that come in via email or phone is continuing as usual. It gives us great satisfaction to be able to provide information to people who have been desperately seeking answers to their post-polio questions.

### Printed Resources

Our 20 most-requested fact sheets have now been printed in bulk, with a share being distributed to each state. If you would like to access a particular fact sheet in printed form, please contact your state network or Polio Australia. (See p24 for link to Fact Sheets.)

### Social Media

We are trying to keep the community informed and (at times) entertained through our Facebook, Twitter and LinkedIn accounts. We're sharing videos, articles and stories on a range of topics. If you're not already connected with us through social media, please join us!

- To "like" our **Facebook page**, go to [www.facebook.com/PolioAustralia](http://www.facebook.com/PolioAustralia)
- To join our **Facebook group**, go to [www.facebook.com/groups/PolioAustralia/?source\\_id=315670380164](http://www.facebook.com/groups/PolioAustralia/?source_id=315670380164)
- If you're younger (say 50 years and under), come and join our **Next Generation group** [www.facebook.com/groups/NextGenPolioSurvivors/?source\\_id=315670380164](http://www.facebook.com/groups/NextGenPolioSurvivors/?source_id=315670380164)
- Our **Twitter** account is [twitter.com/PolioAustralia](https://twitter.com/PolioAustralia)

So you've got plenty of options to stay in touch in these times of social distance!

### Videos

If you already like us on Facebook, you will have seen some new videos floating around. We're trying to use this medium as an opportunity to share some self-management strategies for post-polio symptoms, as well a chance for the team to introduce themselves and share a bit about what we're up to. Over the coming weeks, we will also share some videos that have already been made but not previously shared. Topics include: assistive technology, sleep and breathing, pain, and managing emotions. Watch out for videos, new and old, on our Facebook page over the coming weeks.

### Virtual Meetings

We may not be able to meet face-to-face, but we can still gather! We're in the process of setting up some virtual community meetings via Zoom. We'll be using these meetings to connect people in a particular geographic area, and to allow people to share and learn about how they manage the Late Effects of Polio. Michael, our Clinical Educator, will also share a bit about his role in educating health professionals.

We're starting with a session for people in or near Port Macquarie, and we'll spread across the country as time goes on. Watch out for a session in your area! (See p6)

### Advocacy

We recently sent a letter to the Prime Minister, commending his decision to continue support for the WHO despite the US withdrawal of funds, and urging him to keep polio eradication on the radar. This letter has been shared as an image on our Facebook page.

The Assistive Technology for All (ATFA) Alliance, of which Polio Australia is a member, is continuing the campaign for fairer access to aids and equipment for those not eligible for NDIS funding. If you haven't already, we'd love you to sign the petition here:

<https://assistivetechforall.org.au/take-action/>

We are also involved in some other joint advocacy projects, including a statement of support for Telehealth and widening this service in the future.

### Planning

And, of course, we're planning for the future! When things get back to, well, whatever normal is going to look like, we'll be ready to hit the road again. Clinical Practice Workshops will continue when health services are ready. A conference in Brisbane for polio survivors and their families is being planned for the 23<sup>rd</sup> of October. And I will be heading to Northern NSW for Community Information Sessions in Ballina, Coffs Harbour and Port Macquarie in November. If and when it is safe for us to proceed, we will slowly return to gathering in person. Which means I'll need to get out of my ugg boots! 🐼

## Professional Webinar Series On Facebook

**By Michael Jackson**  
Clinical Health Educator

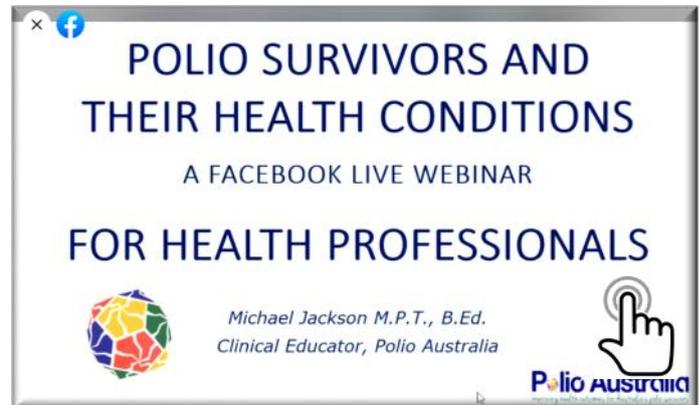
The COVID-19 Pandemic brought Polio Australia's clinical practice workshops to a halt in March this year. The restrictions placed to contain the spread of the virus limited the workshops in two ways: we were not able to travel to deliver the scheduled workshops, and most host facilities placed holds on facility access and their non-COVID-19 education programming.

One of our many interim projects was the development of a four-part webinar series directed at health professionals. While we could not deliver workshops in person, we could utilise other media platforms to deliver some of the information from the workshops.

The webinar series is titled "*Polio Survivors and their Health Conditions*", and it was delivered on Polio Australia's Facebook page via the LIVE feature over two weeks, starting in the last week of May. The four sessions were about 45 minutes in length and covered foundation information and concepts from our workshop information.

We utilised targeted advertising to health professionals on Facebook and LinkedIn before and during the series. The format for each webinar was a 10-slide presentation with Q&A time, with a learning reflection form linking the series together. The finished series will have subtitling and language translation added, and it will be added to our YouTube channel.

Each webinar topic was delivered five times on the scheduled day, and the 'best' version was then tidied up and saved on Polio Australia's



Facebook page. This frequency allowed for different time zones to tune in at a variety of times. Polio survivors are most welcome to view the series and we encourage you to direct your local healthcare practitioners to the recordings of the webinars.

Recordings can now be found on Facebook at: [Polio Australia/Videos/Playlists/Webinar Series](https://www.facebook.com/PolioAustralia/Videos/Playlists/Webinar-Series): Polio Survivors and Their Health.

These webinars are not a substitute for the clinical practice workshops, however, they do serve as another entry point to post-polio health conditions for health professionals and as an introduction to our polio survivor population.

Our workshops have the advantage of real-time flexibility in discussion, a focus on information pertinent to the audience's profession, an emphasis on assessment and treatment (this being limited in the webinars), and interaction with a local Lived Expert polio survivor. 🌟

## Zoom Meetings For Polio Survivors

**Join us for a virtual meeting! Includes:**

- Meet and greet with other polio survivors in your region (partners also very welcome!).
- Brief discussion and overview of the Late Effects of Polio.
- Learn about Polio Australia's health professional education.
- Numbers are capped at 20 per session, but don't worry if you miss out! We will certainly arrange more if we reach the maximum in your state or region.

Dates and regions for the sessions are:

- Monday 15<sup>th</sup> June, 10.30am – **North NSW and Queensland**
- Tuesday 16<sup>th</sup> June, 10.30am – **Victoria**
- Thursday 18<sup>th</sup> June, 10.00am – **SA and NT**
- Friday 19<sup>th</sup> June, 10.30am – **Tasmania**
- Monday 22<sup>nd</sup> June, 10.00am – **WA**
- Tuesday 23<sup>rd</sup> June, 10.30am – **NSW and ACT**

It's easiest to join a Zoom meeting with a smartphone, tablet or computer, and works best with the Zoom app. You can also call in from a phone – talk to me if you haven't done that before and want more info.

To register for a session, please contact me on [steph@polioaustralia.org.au](mailto:steph@polioaustralia.org.au), or call 0466 719 613. 🌟

# State of Residence Characteristics of Australian Polio Survivors in 2020

M.Jackson, M.P.T. B.Ed., Clinical Educator, Polio Australia, Kew, AUSTRALIA.



## INTRODUCTION

Those who survived polio in Australia display heterogenic levels of disability. Later in life, polio survivors can endure a spectrum of symptoms known as the Late Effects of Polio. Heterogeneity within the survivor population is also expected based on macro environment - state of residence.

This descriptive study serves to identify the similarities and differences between state populations of Australian polio survivors. Three categories were examined:

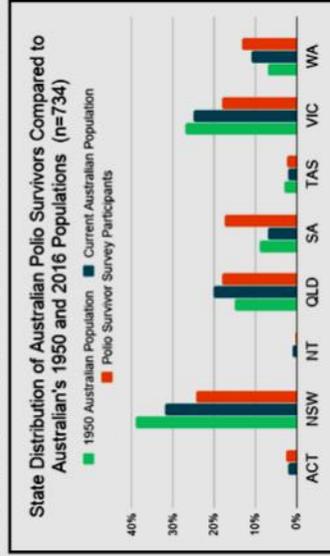
- population and representation
- aspects of health
- service impressions

## METHODS

An electronic survey was distributed to Polio Australia's contact list in December 2019, and was available for two months. 29 mandatory closed-ended questions and three optional open-ended questions were asked in the survey. Data was collated, filtered, and correlated to provide insight on how survivors are positioned as a state group.

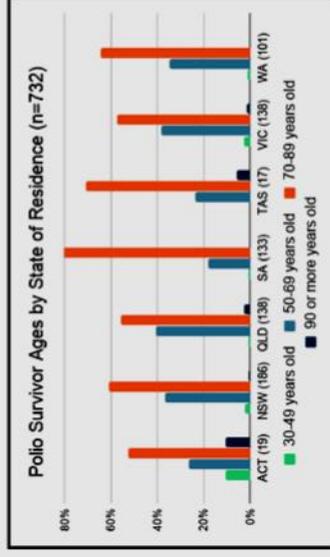
## RESULTS

**POPULATION AND REPRESENTATION:** 734 survivors responded to the survey. NSW, QLD, SA, VIC and WA were each represented by over 100 Late Effects of Polio symptomatic polio survivors. ACT and TAS had <20 responders each, NT had 2. SA was overrepresented (+10%) compared to Australian state population ratios, while NSW and VIC were underrepresented (-7% each). All states had distinctly

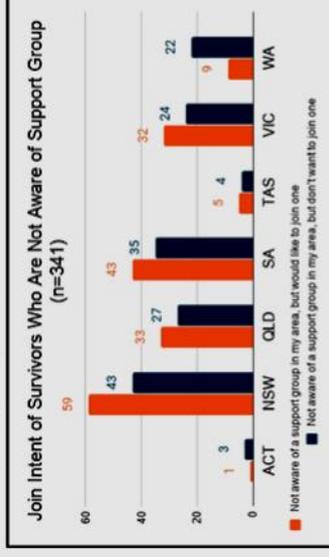


more (19-79%) metropolitan than regional respondents, except NSW and QLD (1-10%). SA had a larger proportion of older respondents, with 4 in 5

(81%) being in the 70 to 89 years age bracket. Other states had 3 in 5 in that age group (mean of 60%).

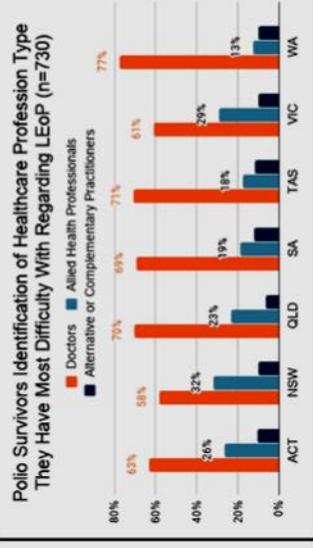


**ASPECTS OF HEALTH:** All states except QLD had 'no chronic diseases' as the most frequent chronic disease load. Compared to the Australian population, respondents to this survey had an almost inverse chronic disease profile. WA and the ACT were not biased towards interest in joining support groups, but all other states were. When

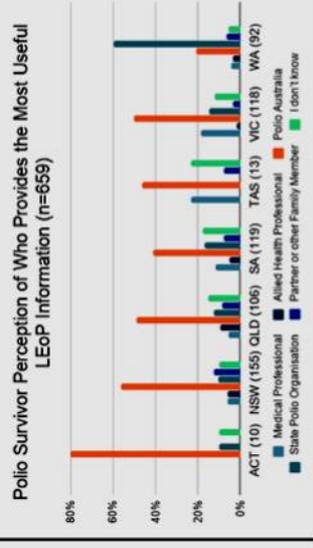


challenged to change Late Effects of Polio risk variables states shared consistent positions (mean variance  $\pm 3\%$ ), except for TAS which had a willing bias (mean +18%) and the ACT which had an aversion bias (mean -9%).

**SERVICE IMPRESSIONS:** WA had a 6:1 response ratio identifying doctors causing more care interaction difficulty with Late Effects of Polio care, than allied health professionals. NSW and VIC had the lowest ratio at 2:1 for the same care difficulty sources. TAS was considerably more satisfied (3.3/4 score) than other states (2.5-2.8/4) regarding GPs providing adequate appointment time to address LEOp concerns. Appropriate referrals were closely



tied to states' satisfaction with their GPs. TAS (2.9/4 score) had slightly higher satisfaction levels than other states (2.5-2.7/4). All states but one had a strong preference (41-80%) towards Polio Australia being the provider of the most useful Late Effects of Polio information. WA's preference was towards their state polio organization (60%).



## CONCLUSIONS

Group differences based on polio survivor state of residence are apparent from this survey. This information may be useful for Australian state polio organisations to address the contentions and/or needs of their polio survivors. Polio Australia can utilise this information to guide resources and education, and to support states.

## REFERENCES

1. Australian Bureau of Statistics - <https://www.abs.gov.au/>
2. Australian Institute of Health and Welfare - <https://www.aihw.gov.au/>
3. British Polio Fellowship General Practitioner Survey - <http://www.britishtopolio.org.uk>
4. Headley, J. (Fall 2014). Post-Polio Medical Care: Post-Polio Specialists and Primary Care Physicians
5. Westbrook, M. (January 1991). Findings of the Polio Survivors and Their Health Survey.

## Aged Care Registration Or Screening?

### Your thoughts: aged care registration or screening?

The Department of Health is currently seeking consultation from the community about the need for registration or screening of aged care workers.

One reason for this is to avoid having unsuitable aged care workers simply moving from one employer to another rather than being screened or required to meet a set of standards.

Another is the concern that abuse, neglect or poor quality care are allowed to continue without proper procedures in place.

### Polio Australia is working on a submission, and we would appreciate your help.

To respond to any or all of our questions below, please email [steph@polioaustralia.org.au](mailto:steph@polioaustralia.org.au). If you prefer, you can call Steph directly on 0466 719 613.

- Have you or a family member had assistance from aged care workers, either in residential aged care or in-home care?
- How confident do you feel that you are getting quality care from either residential or home-based aged care workers?
- What competencies do you think are required for people working in aged care?
- What do you think about either:
  - \* A registration system for aged care workers, including minimum qualifications and mandatory ongoing training; or



- \* A screening system for aged care workers, including screening for criminal history, complaints and disciplinary findings?
- Would you be happy to be quoted in our written submission? If yes, would you prefer your quote to be anonymous?

To view the consultation paper and submit your own response (either by completing a survey or as a written submission), go to the [Aged Care Worker Regulation Scheme Consultation](#) page on the Department of Health website. 📍



**Australian Government**  
**Department of Health**

## Welcome Paulette Jackson



My name is Paulette Jackson, and I am the part-time Administrative Officer for Polio Australia. Having joined the Polio Australia team 2 months ago, I wanted to say hello and introduce myself. My role includes supporting the Clinical Educator and assisting with the Clinical Practice Workshops for health professionals. My husband, Michael, is the Clinical Educator for Polio Australia, so work meetings are convenient.

Michael and I lived and worked in the United States for before relocating to Australia to be closer to his family. We arrived in June of last year, and it has been an adventure. One of the biggest challenges for me has been learning how to drive on the left side of the road!

While in the United States, I worked primarily as an exercise physiologist and registered nurse. Early on in my education I became interested in the cardiac population and spent the majority of my career working in the cardiac rehabilitation setting. I find it rewarding to help others achieve their health goals.

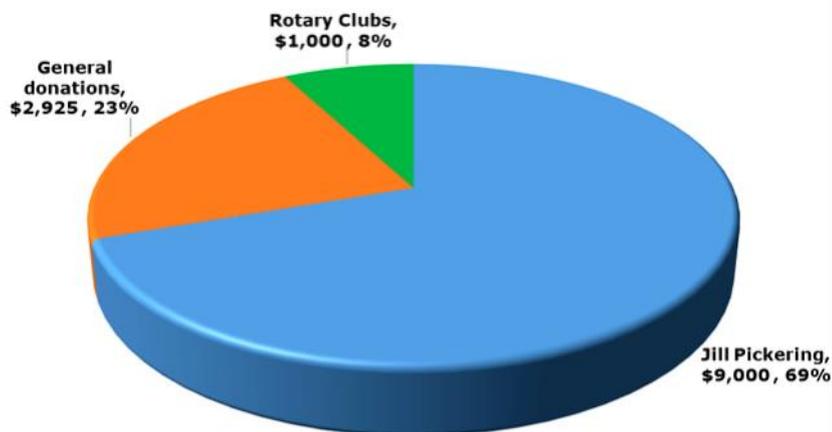
Joining the Polio Australia team has already been rewarding. This is a phenomenal organisation with a highly motivated team. I have especially enjoyed learning more about polio, the late effects of polio, and how Polio Australia assists in reducing the gaps in healthcare services for this population. I look forward to meeting you should we cross paths at a conference or polio event in your area. 📍

## Supporting Polio Australia

Polio Australia would like to thank the following individuals and organisations for their generous support from 1 March 2020 to 31 May 2020. Without you, we could not pay our rent, core operating expenses, or management staff!

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).

**Donations - March to May 2020**



### Comments

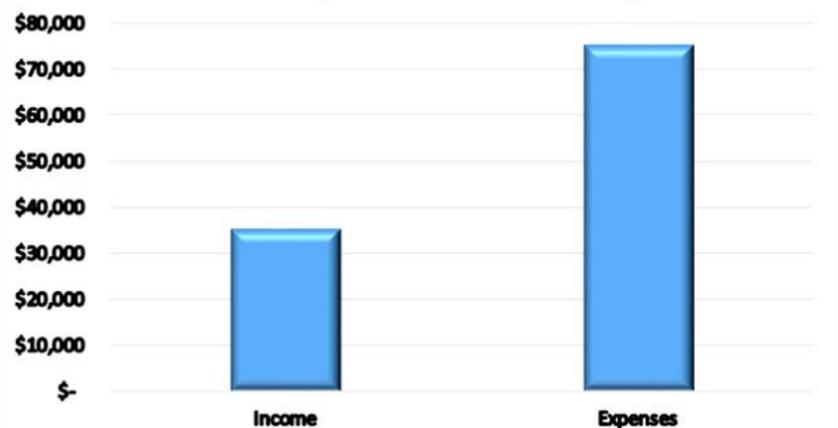
Total income for the quarter March to May 2020 was \$35,458. The two main components of this income were:

- Donations \$12,925 (see graph above)
- Government support during COVID-19 \$22,000

The government support comprised:

- Job Keeper \$12,000 (this is \$1,500 per fortnight x four staff)
- Cash Boost \$10,000. Two further payments of \$5,000 each will be received in each of the next two quarters.

**Income and Expenses - March to May 2020**



Total expenses for the quarter were \$75,376. These were three main components to these expenses:

1. Expenditure for the DOH (Department of Health) grant \$29,352. This includes salaries for two staff (1 x FTE and 1 x 0.5 FTE).
2. Expenditure for the community outreach to polio survivors \$21,235. This includes salary for one staff (1 x 0.9 FTE).
3. Expenditure for overhead expenses for running the main office as well as two part-time office staff \$15,914. Staff comprise 1 x 0.52 FTE and 1 x 0.24 FTE. Rent for the quarter was \$2,604 (excluding GST).

Donations and Bequests to Polio Australia help ensure that all polio survivors in Australia have access to appropriate health care and the support required to maintain independence and make informed life choices. Polio Australia is endorsed by the Australian Taxation Office as a Health Promotion Charity and a Deductible Gift Recipient making all Australian donations over \$2 tax deductible. Polio Australia will issue an official receipt for all donations received.



## Two Infectious Diseases That Changed The World

By Larissa Romensky

Source: [www.abc.net.au](http://www.abc.net.au)

— 4 April 2020

**Polio survivors see in coronavirus era levels of fear not seen since poliomyelitis epidemics**  
— ABC Central Victoria

**Polio survivors have noted striking similarities between the series of 20th-century epidemics and today's coronavirus — two very infectious diseases that changed the world.**

Key points:

- Groups supporting those affected by polio 1911-1988 say the coronavirus is bringing back memories for many survivors
- Of the several polio epidemics that occurred in Australia the most notable happened in the late 1930s and early 1950s with about four million infected with the virus
- Survivors have written to governments pleading "not be subject to enforced euthanasia through failure to provide best-practice treatment" during COVID-19's spread
- During the height of the polio epidemic in parts of Australia, state borders, schools, pools, and theatres closed, and travel restrictions and quarantine measures were introduced.
- Newspapers published daily case numbers and deaths.
- Sound familiar?

Gillian Thomas, president of Polio Australia, said the coronavirus crisis brought back memories for many survivors of poliomyelitis.

Known as 'the silent epidemic', the highly infectious viral disease struck people out of nowhere and moved silently throughout the community.

"The population was really scared of it because they didn't know how they were getting it," Ms Thomas said. "You just didn't know who it was going to strike next."

Those infected were left isolated from the community and often stigmatised. "People would cross the streets to get away from someone because they were scared to go near them," Ms Thomas said.

She said today polio has "totally passed out of the consciousness of Australians" because of the success of its vaccination program in the mid-1950s. "I think people get a little bit blasé about this and I think Australians have been ill-prepared for this coronavirus pandemic," Ms Thomas said.

### Watching From Behind The Glass

Polio was first recognised as a notifiable disease in Tasmania in 1911, with the rest of Australia following in 1922.

Of the several polio epidemics that occurred in Australia the most notable ones happened in the late 1930s and early 1950s.

It was a disease that mainly affected children under five years of age.

The virus attacked the motor neurons that relayed messages from the spinal cord to muscles, often leading to muscular degeneration and in some cases paralysis.

Ms Thomas contracted polio in 1950 when she was 10 months old and was put in isolation. Her mother would stand outside the ward and watch her two daughters from behind the glass. The next few years were spent in hospital, away from her family.

"I was left with both legs paralysed along with one arm and wore callipers," Ms Thomas said, who now uses a wheelchair.

But she was one of the lucky ones as some of those severely affected were placed in an iron lung, an artificial respirator, some for the rest of their lives.

According to the World Health Organisation 1 in 200 infections led to irreversible paralysis. Among those paralysed about 5 to 10 per cent died when their breathing muscles become immobilised.

It has been estimated that about four million Australians were infected with the virus, with about 20,000 to 40,000 developing paralytic polio between 1930 to 1988.

### Royal Handwashing Breakthrough

Medical historian and author Kerry Highley said when her book *Dancing in my Dreams: Confronting the Spectre of Polio* came out five years ago, she was hard pressed to think of another time in history when Australians have felt that level of fear — until now.

Polio was a disease feared worldwide but was more prevalent in affluent countries with the highest incidence recorded in Denmark, Sweden, Switzerland, Canada, Australia, and the United States.

With no idea as to what caused polio, or how it was transmitted, there was no shortage of theories about transmission — including one theory the virus entered the body through the nose which prompted many people to wear camphor balls around their neck.

Dr Highley said one of the breakthroughs came when the Queen visited Western Australia in

## Two Infectious Diseases *(cont'd from p10)*

1954 as concern of excessive handshaking prompted a public health message.

*"Somebody came up with the bright idea of issuing every child with a bar of soap and a towel, so they were told to wash their hands frequently throughout the day as they lined up to see the Queen go past," she said.*

*"They saw there was this marked drop [in the incidence of polio] and they realised there was this possible connection between this handwashing and the fact that the numbers were dropping in WA."*

Eventually, it was discovered that polio was contracted through infected faecal matter entering the mouth, usually via someone's hands or an object.

An effective vaccine became available in Australia in 1956, developed by American medical researcher and virologist Jonas Salk and his team in 1954.

Dr Highley said it changed the course of the world. *"I'm sure it will be exactly the same feeling when a vaccine is developed for the coronavirus, which it will be," she said.*

### Post-polio Survivors More At Risk

With [tens of thousands of] polio survivors in Australia the pain and fear continues today, according to Post Polio Victoria (PPV) President Shirley Glance OAM. Especially now in light of this coronavirus.

Many of those afflicted with polio in the 1950s

are now experiencing a range of symptoms recognised as post-polio syndrome (PPS).

The symptoms can include muscle weakness, pain and fatigue, with some people developing severe neurological symptoms.

With the elderly already more vulnerable to coronavirus, there is also an additional fear felt by many polio survivors.

*"We've battled through this far, and we want to stay alive,"* said PPV member, Peter Freckleton.

In a letter to the Prime Minister and Federal and state health ministers on behalf of polio survivors from PPV, polio survivors insist on being given full treatment if infected with COVID-19, including the use of ventilators.

*"Moreover, PPV insists that polio survivors not be subject to enforced euthanasia through failure to provide best-practice treatment, or other way,"* the statement said.

A senior rehabilitation physician and perhaps one of Australia's best PPS specialists, Stephen de Graaff, said if post-polio survivors were to contract COVID-19 they were at more risk of serious illness.

He said about 40 to 50 per cent have restrictive lung disease causing a respiratory compromise.

*"Their lung capacity isn't as great so they can't move the air as well as an unaffected individual,"* Dr de Graaff said.

Read full article [here](#).



**PHOTO:** The polio ward at Ballarat Base Hospital in regional Victoria. (Image Supplied: Dr Kerry Highley)

## Past Polio Epidemics

### What Australia Can Learn From Its Past Polio Epidemics

*Excerpts from Good Weekend*

**By Amanda Hooton**

**Source:** www.smh.com.au—11 April 2020



Joan Ford [pictured above], 77, is a fragile-looking woman with blue eyes, fine features, and an air of hidden steel. Gathering lunch things in her big, light-filled house on Sydney's eastern beaches, she's quietly competent. But she limps noticeably, and she needs both hands to lift her glass of water.

Both these physical details – and perhaps the steel, too – are the results of the events of May 7, 1949. Six-year-old Ford was on the bus on her way home from school in Garden City in Port Melbourne when her legs stopped working. When she tried to get off, she collapsed. She'd caught polio in one of the last great epidemics of the disease in Australian history. That year, about 750 people were paralysed in Victoria, and more than 1600 across Australia.

In Australia between the 1930s and 1960s, some 2000 people were killed by successive polio epidemics, and more than 40,000 were paralysed. Until recently, figures like these have been impossible to connect to our own lives: if we think of polio at all, it's only as a kind of distant horror story from medical history.

But now, caught in our own global pandemic, many of the details of polio feel eerily similar to those of COVID-19. Both illnesses are highly infectious; those stricken with polio, like COVID-

19, often present with fever and flu-like symptoms that are hard to define.

The most important health advice offered by governments during polio outbreaks was to avoid others and wash your hands frequently; people were told to stop shaking hands or touching each other. Schools were closed for months on end, as were beaches, swimming pools, shops, cinemas, churches. Economies of towns and states shrank during polio outbreaks, though polio was more local than COVID-19 in its effects: because people travelled so much less, outbreaks tended to occur in isolated clusters.

As with COVID-19, polio rumours were rife: who caught it, how to cure it, what treatment worked best. But, just like COVID-19, no rumour could compete with the truth: that anyone could catch it, and nothing could cure it – for better or worse, the disease had to run its course.

Polio was treated with equipment that sounded more suited to a gothic dungeon than a 20th-century hospital – iron lungs, metal braces, wooden crosses, ratcheted splints, steel screws – but ironically, the world's first ICU units and ventilators, now the last and most significant redoubt of COVID-19 treatment, were [invented to ventilate polio patients in the 1950s](#).

Of course, polio and COVID-19 are very different diseases. But perhaps the most significant difference, from a human perspective, is this. As far as the science so far can tell, the novel coronavirus hits older people particularly hard. Polio, conversely, most often hurt the youngest. The victims of polio were overwhelmingly children, and overwhelmingly under 10.

Just as we hope for in the case of COVID-19, the defeat of polio came via a vaccine. Mass vaccination of children began in Australia in 1956, and within a handful of years the disease had all but vanished. Or so we believed. But the seminal lesson of horror stories is that the monster never really dies.

Australia, you might think, is a good place to get these kinds of support, because unlike almost all other countries, we have a specialised disability service, the [National Disability Insurance Scheme](#) (NDIS), established in 2013. After all, polio is arguably the most notoriously disabling disease of the 20th century: the NDIS might have been designed for it.

But as it turns out, this is not the case. When it comes to the NDIS, virtually nobody who suffered and survived polio in Australia, and is still alive today, is even eligible to apply.

[John] Tierney saw first-hand the way polio survivors were excluded from the NDIS.

## Past Polio Epidemics *(cont'd from p12)*

And not just polio survivors. In fact, not a single person in Australia aged 65 and over can apply for the NDIS. This is blatant age discrimination, as even the government recognised: Australia's [Age Discrimination Act](#) had to be amended to allow the passage of the NDIS legislation. But as Tierney points out, *"other disabled groups are spread across different ages. With polio, since we're almost all over 65, or only recognised we had these late symptoms after 65, the entire cohort is ineligible!"*

At the time, the justification for this discrimination was that the over-65s didn't need the NDIS, because they would be supported through the aged-care system. As government documents from the time put it, older people with disabilities would be simply incorporated as part of a *"seamless transition through the different phases of life"*.

Greens Senator Rachel Siewert, whose portfolios include ageing and community services, and who fought in vain for polio survivors' inclusion in the NDIS, says this isn't true. *"What a joke,"* she laughs. *"No. Not now, no. Absolutely not."*

Aged care, in this context, refers to Home Care packages: fixed amounts of money (starting at about \$8000) given to eligible over-65s to help them remain living at home. They are typically used for assistance with the likes of meals, domestic chores and personal hygiene. But the very highest level of payment in a package is about \$51,000 annually. Amounts are capped, and often require the recipient to make means-tested contributions. The NDIS, by comparison, is not means-tested, has no cap, and if you join

before 65 and remain, pays people an average of \$99,000 per year.

There are other schemes, like the federal "continuity of support" system, and the [Commonwealth Home Support Program](#). But the most serious needs of many polio survivors – aids like electric wheelchairs and motor scooters – are not funded by these schemes, which are often means-tested and capped. Such aids are also too expensive for most Home Care packages.

Take John Tierney. He has scoliosis; his legs are different lengths, his feet are different sizes; he's had five knee operations on his polio-affected leg including a knee replacement. He currently gets by with a stick and thrice-weekly hydrotherapy, but he knows he'll need a motorised scooter at some point; he may eventually require special equipment to shower, get out of bed and move around his own home.

*"There's no way that stuff would be covered by Aged Care,"* he laughs. *"An electric wheelchair might cost \$10,000, and that might be your entire package for the year. Then what are you supposed to do?"*

Both Helen Nugent, chair of the NDIS board, and Stuart Robert, minister for the NDIS within the Department of Health and Social Services, which administers aged-care programs, declined to be interviewed by *Good Weekend*. According to a spokesperson: *"The NDIS is not intended to replace services provided through the health or aged-care systems."*

Read full article [here](#).

### Polio epidemics provide lessons for "new normal" during coronavirus pandemic

By Alexandra Beech on PM

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National Cabinet is preparing to make some big decisions tomorrow on easing Australia's COVID-19 social distancing rules. It's already clear there'll be inconsistencies between how those restrictions are rolled back in different states. But experts say no matter where you live, life will look very different moving forward, with some comparing it to life in Australia during the polio epidemics.

**Duration:** 3min 55sec

**Broadcast:** Thu 7 May 2020, 5:20pm

#### More Information

Featured:

Professor Joan McMeeken, University of Melbourne faculty of medicine, dentistry and health sciences professorial fellow

<https://www.abc.net.au/radio/programs/pm/polio-epidemics-provide-lessons-for-new-normal/12225772>

<https://pursuit.unimelb.edu.au/articles/remembering-australia-s-polio-scurge>

## Fleeing Polio On Wings Like An Eagle

**Barbara Ker-Mann** is the author of *Fleeing Polio on Wings like the Eagle*.

Barbara had polio at the age of three and was the first in the Wairarapa (New Zealand) 1936 epidemic to catch polio so has lived her life dealing with the effects. Her memoir reveals how she drew inspiration from Isaiah 40, Verses 30,31 which she heard read in church at age 4.

As a long term survivor of polio, there is a life filled with many and various activities from learning violin at age 10 to visiting the Kitami Institute for Solar Research, Hokkaido, Japan, alone, in an endeavour to learn more about useful solar technology for New Zealand. Between times, Barbara has published novels and poetry, done a Master of Music degree, and been an AAUW International Fellow studying with Shinichi Suzuki in Matsumoto.

Her husband died in 1995 but their 4 children and grandchildren live fulfilled lives in various countries.



Barbara's memoir, *Fleeing Polio on Wings like the Eagle*, was published by Balboa Press AU— [www.balboapress.com.au](http://www.balboapress.com.au) — where it is available for purchase online.

In New Zealand, the memoir is available by emailing the author directly: [kermannb@gmail.com](mailto:kermannb@gmail.com)  
Please include 'Memoir' in the subject line, along with your name and address for post.  
Pay: \$24.00 NZ into BNZ 02-0152-0241620-083

## TWiV 604: Oral Poliovaccine

### TWiV 604: Oral poliovaccine to prevent SARS-CoV-2 infection?

**Source:** [www.microbe.tv/twiv/twiv-604/](http://www.microbe.tv/twiv/twiv-604/) — 21 April 2020

Kostya Chumakov discusses the hypothesis that oral poliovirus vaccine can provide non-specific protection against many other viruses, and might prevent infection with SARS-CoV-2.

Host: Vincent Racaniello

Guest: Kostya Chumakov

Click below to download: TWiV 604 (39 MB .mp3, 64 min)



ATSA Independent Living Expos postponed until October 2020

Due to the escalation of COVID-19 and the Federal Government announcing a ban on gatherings of more than 500 people, ATSA has postponed the Perth and Melbourne expos, previously to be held in May, until October 2020. The new dates are Melbourne – October 13-14; and Perth – October 28-29, 2020.

Given the exceptional circumstances faced, and in line with the developing government health guidelines around COVID-19, ATSA believes postponing the event is a responsible decision to ensure a health and safe experience for all.

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

## PHI's New Website Is Finally Here!



PHI's completely rebuilt website is now online. The new site can be found at the same URL as the old, [www.post-polio.org](http://www.post-polio.org). We've listened to many of your suggestions as to how we could improve the old site and hope the new site will provide a more user-friendly experience and aid your search for post-polio information and resources.

### The Post-Polio Directory

One of the biggest changes to the new site will be the [Post-Polio Directory](#). The printable PDF will remain available, but we believe the new interactive version will make it easier to quickly find health professionals, support groups and financial resources in your area. The new online tool actually combines the traditional *Post-Polio Directory* and PHI's newest resource, *A Polio Survivor's Guide: Funding Resources for Medical & Adaptive Equipment*.

When you navigate to the [page](#), enter your city in the location search box (or hit the button at the end of the search box to have it automatically detect your location) and the map will display a list of nearby results within a customizable range. Map markers will differentiate between health professionals, support groups and funding resources. Or if you prefer, click directly on the map to find resources in other parts of the country or around the globe.

### ... And Much More

All of the same trusted information from the old site is still there. Take a look around and discover resources you perhaps had overlooked before. Let us know your thoughts. Send any comments or suggestions to [info@post-polio.org](mailto:info@post-polio.org).

### Post-Polio Health International

50 Crestwood Executive Ctr, Ste 440  
St. Louis, MO 63126-1916

[www.post-polio.org](http://www.post-polio.org) / [www.polioplace.org](http://www.polioplace.org)

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## Polio Australia Supporting WHO



The Hon Scott Morrison, MP  
Prime Minister of Australia  
Parliament House  
CANBERRA ACT 2600

Dear Prime Minister

Polio Australia commends the Australian Government on its ongoing commitment to support for the World Health Organization. We were very disappointed by the US decision to suspend funding to this vital international organisation, and would like to emphasise WHO's importance in helping the international community to address the scourge of the current COVID-19 pandemic.

As the national peak body representing survivors of polio, we also acknowledge the crucial role of WHO and the Global Polio Eradication Initiative in bringing polio vaccination and awareness to countries across the globe. We implore the Australian Government to continue its support, in order to make the dream of global eradication of polio a reality.

Yours faithfully

Gillian Thomas OAM  
President

4 May 2020

## Polio Was Almost Eradicated

**Polio was almost eradicated. Then came the coronavirus. Then came a threat from President Trump.**

**By Emily Rauhala, Danielle Paquette and Susannah George**

**Source:** [www.washingtonpost.com](http://www.washingtonpost.com)  
— 16 May 2020

For decades, the United States has worked with the World Health Organization and others to quash polio, beating back to near extinction a merciless disease that once paralyzed hundreds of thousands of children each year.

That progress is in danger as the pandemic forces health-care providers to suspend door-to-door vaccination campaigns that have slashed the number of infections.

New cases have emerged in Niger and Chad, and fears have mounted about a resurgence in Afghanistan and Pakistan. Although the number of new polio infections has been small — 155 confirmed cases since January — even blips are worrisome, public health experts say, because small increases can trigger explosive outbreaks, especially in poor countries without the resources to combat the virus alone.

"The polio virus is being let free," said Abdul Qadir, a health worker who has spent the past eight years delivering the vaccine in western Pakistan.

The polio program also risks becoming collateral damage in a political controversy that could hinder eradication efforts long after the pandemic subsides.

Last month, President Trump threatened to cut US funding for polio and every other WHO program over the UN agency's coronavirus response, which he called "China-centric." In the weeks since, the president and his aides have worked behind the scenes to sideline the WHO. They have also sought to deflect criticism of the United States' handling of the crisis by pointing to WHO's failure to demand more transparency and accountability from China in the earliest stages of the outbreak.

While many say the WHO legitimately warrants scrutiny, there is consensus in the public health community that stripping the agency of hundreds of millions of dollars earmarked to combat polio and other diseases could be devastating.

"Ultimately, the impact is not on the institution, it's on health," said Jen Kates, senior vice president and director of global health and HIV policy at the Kaiser Family Foundation.



*A Pakistani health worker administers polio drops to a child at a railway station in Lahore in November. (Arif Ali/AFP/Getty Images)*

Of the \$893 million the United States sent in the 2018 and 2019 funding period, \$237 million was an "assessed contribution" to the Geneva-based agency — a type of state membership due that may prove hard to cut without congressional approval.

At greater risk is the "voluntary contribution," money provided to US agencies for health efforts and then given to WHO programs. The largest share of this money goes to fight polio eradication, with large chunks to fight vaccine preventable disease, malaria, tuberculosis, HIV/AIDS and the provision of basic health care.

Pulling US money from polio could undercut a system of disease surveillance that could be central to combating this pandemic and those in the future.

The cuts are "certainly not a good idea," said Thomas J. Bollyky, director of the global health program at the Council on Foreign Relations. "Americans have a stake in the ability to control these viruses."

When Hamid Jafari, a doctor and infectious disease specialist who now leads one of the WHO's regional polio eradication programs, started his work in 1994, the disease paralyzed hundreds of thousands a year.

Over a nearly 30-year career at the Centers for Disease Control and Prevention — including 16 years seconded to the WHO — he and colleagues beat back the virus. "We made so much progress. We are 99 percent of the way," he said.

But the past few years have been tough. Conflict has made some children hard to reach. Disinformation about vaccines has fueled skepticism and attacks on health workers.

The outbreak of the novel coronavirus made

## Polio Was Almost Eradicated *(cont'd from p17)*

things worse. Afghanistan, Pakistan and more than a dozen African countries have halted or postponed vaccine deliveries, citing pandemic-driven travel restrictions, overburdened health-care workers and an inability to administer the drugs at a safe distance.

In Congo, at least 86,905 children did not receive the oral polio vaccine during the first two months of the year, according to the United Nations Children's Fund. The drop-off in doses could leave children particularly vulnerable as attention shifts to covid-19, the agency warned this week.

Misinformation on social media has marred progress in the eradication fight, said Kevin Bekolo, a public health doctor in western Cameroon. Posts about vaccines containing the coronavirus have gone viral.

*"This had already turned most of the population against the polio vaccination campaign,"* Bekolo said, *"even before it was postponed."*

Though it is hard to count cases during periods of lockdown, at least 155 cases have emerged worldwide since January, according to the Global Polio Eradication Initiative — a 182 percent jump from this time last year.

Sylvester Maleghemi, a Nigerian doctor who leads the WHO's polio immunization team in South Sudan, said his job has transformed since the respiratory threat reached the East African country. *"It's now 80 percent coronavirus, 20 percent polio,"* he said.

His team didn't want to spread the coronavirus, so after consulting with South Sudan's health officials, it suspended the door-to-door vaccine program. The nation hasn't seen a case since 2014, but Maleghemi fears a resurgence. *"I don't sleep at night sometimes,"* he said. *"I just ask myself: Where next might I have an outbreak?"*

Public health professionals say suspending vaccination will have grave consequences because much of the developing world relies on an oral vaccine that contains live virus.

The oral droplets are roughly ten times cheaper than the injectables used in the United States and Europe, which employ an inactivated virus and do not carry the same threat.

Vaccine-derived infections spread after children who have received the droplets use the restroom in areas without water filtration plants. A mutated strain of polio grows in the water supply and can infect those who drink from the tap before they have immunity. (Naturally occurring polio, known as wild polio, also spreads through feces-contaminated food and water.)

*"As soon as you let off, you get cases,"* said Andrew Noymer, an associate professor of population health at the University of California at Irvine.

Such was the case in the West African nation of Niger, which reported two new cases of polio in April. Doctors blamed the stalled vaccine campaigns. Workers who administer the droplets are not allowed to travel because of the pandemic, said Anya Blanche, the WHO's representative in Niger. *"The challenges are daunting,"* she said. Cutting funding to the WHO adds another challenge.

The White House wants to divert money from the WHO to other organizations. The State Department is already advising employees to start finding new partners. In a limited number of cases, that could work, experts said. But the agency's expertise and deep networks in the world's most hard-to-reach places will be tough to replace, especially for polio.

*"There is no substitute for WHO in this instance,"* said J. Stephen Morrison, director of the Global Health Policy Center at the Center for Strategic and International Studies. Health experts are worried about explosive outbreaks, he said. *"Having the US throw this wrench into the works doesn't help matters."*

For those on the front lines the hope is that Trump, having got the organization's attention, will retreat from the funding threat. In interviews, Secretary of State Mike Pompeo has suggested that the United States might continue to support WHO work on polio and other diseases. *"Let's see if there's a piece of this which we ought to continue to participate in,"* Pompeo told *The Jack Heath Radio Show* on May 7, *"because it's doing good work on polio or whatever it may be,"* he said. *"But then let's make sure that when the next risk arises,"* he continued, *"when the next risk from a pandemic arises, we need an institution that's going to deliver good outcomes for the American people."*

On the front line of the polio fight, health workers are waiting out lockdowns and worrying about the kids at risk. Qadir, the health worker in Pakistan, has worked through conflict and death threats — and will keep working. For now, he has been detailed to the coronavirus response. As soon as it is safe, he will be back in the polio fight, he said. *"The children we don't reach may become paralyzed for life."*

*George reported from Islamabad, Pakistan. Haq Nawaz Khan in Peshawar, Pakistan, contributed to this report.*

Read full article [here](#).

## There's A Silver Lining



Health worker administers a polio vaccine to a child, in Kabul, Afghanistan, on May 17, 2016.  
Credit: Haroon Sabawoon [Getty Images](#)

### Coronavirus Pandemic Threatens to Derail Polio Eradication —but There's a Silver Lining

By Peter Schwartzstein

Source: [www.scientificamerican.com](http://www.scientificamerican.com)  
—22 May 22 2020

COVID-19 has stifled the world's largest immunization program. Yet polio's vast workforce is also helping in the fight against the new disease.

The year 2020 was on track to be a good one for South Sudan's polio hunters. But now many of those working in the global polio eradication campaign are grappling with the potential reversal of much of their work. All house-to-house immunization efforts have been suspended because of the continuing coronavirus pandemic. Disease surveillance officers can scarcely travel at all. Polio samples awaiting testing are trapped in South Sudan because there are no flights to transport them to external laboratories, and local experts are bracing for the worst.

*"The fact is, we cannot even move around anymore. This limits our action time,"* says Sylvester Maleghemi, South Sudan polio team leader for the World Health Organization (WHO). *"And this could overturn our work. But this is the reality of where we are right now."*

The worldwide polio eradication effort was suspended in late March, bringing campaigning to a near halt. More than 20 million doctors, technicians, and other medical and community practitioners have put much of their work on hold, leaving at least 13.5 million children unvaccinated or undervaccinated for polio so far, according to estimates by the public-private

global health organization GAVI, the Vaccine Alliance. The WHO says that number could rise to at least 60 million by June in the eastern Mediterranean region alone (the area includes northern Africa, the Middle East and Central Asia).

Yet even those figures mask the full extent of a disruption that could stifle polio eradication efforts for years, a dozen doctors, senior scientists and public health officials say. Millions of stored polio vaccine doses will lose their effectiveness if the pandemic prevents immunization for much longer, and some countries that are proceeding with limited vaccinations might run out before they can be resupplied.

*"If the lockdowns are in place for too long, then vaccines will just expire in many places,"* says Thabani Maphosa, managing director of country programs at GAVI. *"And we're currently not able to get vaccines where we need to."*

Disease surveillance systems, which involve the collection and analysis of data on flare-ups so they can be suppressed, are a cornerstone of polio eradication. These systems are also wavering, in large part because of pandemic-related shutdowns and travel restrictions.

When it comes to having the data or observations from the ground needed to keep polio in check, *"you really don't want to go blind. But we are seeing this generally across the board,"* says Hamid Jafari, the WHO's director of polio eradication for the eastern Mediterranean region. *"Many health centers are closed. Patients are reluctant to seek help because they're scared. Frontline workers are scared. And the severe restrictions on movement within [each] country make life difficult."*

Afghanistan and Pakistan, the two countries where wild polio remains endemic, largely rely on a "tiered" system for identifying the disease's spread. This approach consists of community informers, frequent in-person visits to hospital pediatric wards and regular calls to local clinics to check for signs of acute flaccid paralysis—a rapid-onset weakening of respiratory muscles and other muscles that is associated with polio. But as the coronavirus pandemic advances and nations stall, these tiered networks are not functioning as they once did. In their reduced state, polio might gain a firmer footing.

And then there are the complications posed by the polio immunizations themselves, which must be administered in several doses at different intervals. If too many are skipped, Maphosa says, *"it's a question, then, if it's possible to catch up."*

## There's A Silver Lining *(cont'd from p19)*

With roads still locked down in dozens of countries and polio teams unable to distribute vaccine stocks from central warehouses, many children are already missing doses—even when they are close at hand—according to GAVI.

The oral polio vaccine contains a weakened version of the virus, which is excreted in human waste. In rare cases in populations that are underimmunized, the weakened virus can mutate and infect nonimmunized people. It is too soon to determine if Niger's recent outbreak of such "vaccine-derived polio" developed after the eradication campaign's suspension. In any case, doctors anticipate an uptick in cases there and elsewhere over the coming months.

But in spite of these setbacks, the global polio program's adaptability may actually have a silver lining for the current pandemic.

### Retooling To Fight Coronavirus

Many countries have been quick to realize the usefulness of the polio network — the largest immunization program of its kind in the world — in fighting the pandemic. Much of the network has been redeployed accordingly.

Polio contact tracers, who are accustomed to searching out telltale signs of the disease such as sudden leg weakness, are now pursuing reports of severe respiratory distress, fever and other symptoms of COVID-19.

*"It's a no-brainer, really,"* says Maleghemi, who estimates that 80 percent of South Sudan's polio personnel are now tracking coronavirus cases themselves or training new tracers to do so where they cannot. *"At a state level and county level, where we have the foot soldiers, everyone has been repurposed. If you go look for [acute flaccid paralysis], you can go look for [COVID-19]."*

The polio network's enormous infrastructure has been turned over to pandemic response in countries that have few other resources at their disposal. The WHO says Nigeria's and Pakistan's 24-hour emergency polio hotlines are now mostly dedicated to COVID-19, as are hundreds of labs and networks of country-wide cold freezer rooms and mobile units that normally store or transport polio vaccines. Once a vaccine is ultimately developed for COVID-19, the polio eradication teams are the ones most likely to support its distribution among the world's less accessible areas, Jafari says.

Above all, the polio program contains considerable relevant technical expertise, which government officials in Somalia and Mali say has

been instrumental in guiding their countries' pandemic responses. Even though the parallels that can be drawn between the two diseases are limited, the basic principles are similar: case investigation, personal hygiene and patient isolation are vital. Disease surveillance is key, and it will become even more important if scientists find that water and wastewater analysis can yield the same kind of information for COVID-19 tracking as it does for polio. The WHO and the Bill & Melinda Gates Foundation are among those following up on promising early results.

Ultimately, however, polio teams will have to revert to their core mission. And when they do, they will face a rash of challenges.

### Postpandemic Polio

Catching up on all those missed vaccine doses will be expensive—at a time when extra money is likely to be in short supply. The US is the largest public funder of polio eradication. But the Trump administration has frozen its contribution to the WHO, through which much of the world's polio aid is dispensed. Medical freight costs have already grown around 20 percent as a result of decreased air traffic, GAVI's Maphosa says.

And the consequences of previous, much smaller disruptions to eradication efforts suggest polio teams will have a massive amount of damage to contain: In 2003 a single Nigerian state stopped vaccinating against polio for a year. This change fueled a resurgence in more than 20 countries, the WHO says.

In the long run, however, the pandemic-enforced stoppage may enable polio campaigners to reevaluate their approach, according to scientists at almost all the major polio partner organizations. After several disappointing years, during which the number of reported wild cases rose from an all-time low of 22 in 2017 to 176 last year, the polio teams need to take stock of past failures — and to refocus accordingly. If nothing else, they will likely begin again in a world more conscious of the perils of allowing health crises to fester.

*"The polio program is sort of looking at this gap in our ability to actually implement [eradication efforts] to reexamine our strategies. And I think that, taking the long view, there's been progressive success,"* says Jay Wenger, head of polio eradication at the Gates Foundation. *"It's just been slow. And I think this gives us the opportunity to reevaluate what we really need to get done to finally finish the job."*

Read full story [here](#). ●

## Letters To The Editor

### Polio-era epidemiologist warns: Trump's 'warp speed' vaccine effort may be dangerous

By Lauri D. Thrupp, M.D., Santa Ana

Source: [news.yahoo.com](https://news.yahoo.com)  
Los Angeles Times Opinion – 21 May 2020

**To the editor:** Reporter Daniel Miller's [review of Dr. Jonas Salk's legacy](#) and your [editorial on the Trump administration's "warp speed" effort](#) to develop and distribute a coronavirus vaccine are *déjà vu* warnings from the polio era.

As a young Epidemic Intelligence Service Officer in 1956, I was the lead agent from the Center for Disease Control working with the Chicago Board of Health on its 1,500-case polio outbreak. As someone with 65 years' experience in infectious disease and epidemiology, I offer a warning from the errors and lack of oversight in the Salk vaccine saga that resulted in avoidable tragedy.

Salk's research actually implied that each lot of his killed-virus vaccine would require sophisticated testing to ensure that no live virus remained. But this caveat was not adequately conveyed to the several pharmaceutical companies rushing to produce vaccine. Importantly, federal law at the time did not require or permit direct involvement of US Food and Drug Administration scientists in confidential monitoring of the production process, which is required today.

Cutter Laboratories, inexperienced in viral research, failed to detect live virus in multiple lots. The resulting thousands of children infected and several deaths is called the Cutter Incident. Other companies' vaccines also caused infections. In fact, all companies had found live virus in numerous lots never distributed, but never disclosed to the FDA. The production issue was resolved, but it took a massive public re-education effort in order to resume the life-saving program.

In the "warp speed" push for a COVID-19 vaccine, the Trump administration's anti-science policies and budget cuts to key agencies, its silencing of scientists like Dr. Rick Bright, and its suppression of CDC's detailed safe opening guidelines are dangerous to the public's health not only in America, but worldwide. ●

## Free Wheelchair Services To People With Disabilities

By Shreya Pothula

**Ravindra Singh and Anil Pereira's social impact startup myUDAAN aims to provide accessibility, assistance, and mobility to people with disabilities.**

Source: [yourstory.com](https://yourstory.com) — 19 March 2020

Ravindra Singh was diagnosed with post-polio paralysis when he was just eight months old. He and his family dealt with the personal and societal struggle that comes along with being a person with disabilities.

*"One challenge I am always faced with is accessibility. Be it with buildings, elevators, public toilets, or ATMs. As a person with post-polio paralysis, this is a major concern. I started thinking about ways to change this",* Ravindra says. Recounting a pivotal moment in his life, he adds, *"I was on a tour to the Statue of Unity and the available wheelchair had been reserved for VIP use. There was no assistance either. That gave me the idea to start an on-demand assistance service."*

This led Ravindra to bring accessibility, assistance, and mobility to the PwD community

and establish myUDAAN, a social impact startup conceived to aid people with disabilities and the elderly.

### How It All Began

After founding a successful digital marketing company, Ravindra decided to work on a project that would create social impact and solve problems of the PwD community. He reached out to a close associate, Anil Pereira, who had worked with Askme and Medlife, to build a strong founding team for his myUDAAN.

*"MyUDAAN was born specifically from Ravindra's need to address the great challenges in mobility that a person with disability faces",* Anil tells SocialStory.

India's first free wheelchair service, myUDAAN, was made operational at Seawoods Mall in Navi Mumbai in July 2019. This service aims to provide a stress-free experience for people with disabilities and works to promote accessible mobility in an efficient way. When their idea and strategy was still in the nascent stage, the self-funded CIBA-incubated startup contemplated the best way to improve the access to mobility and transport that the elderly and the PwD community require.

## Free Wheelchair Services *(cont'd from p21)*

"The government transport system and private transportation are not up to the mark", says Anil, emphasising that very few transport options are disabled-accessible to begin with. More importantly, Ravindra and Anil wondered how to make their brainchild sustainable. They brainstormed a plan to make myUDAAN's social services function without a glitch.

Currently, the team comprises four members, with Ravindra overlooking Operations and Anil handling Marketing, Sales and Tech. As of today, they already have 650 customers who are using their services.

### App-Based Solutions

"With myUDAAN, anyone who demands instant assistant services (indoor and outdoor mobility) can be catered to. Our app has seen above 1,000 downloads", Anil says. On the app, the PwD community can go to the 'Book My Assistant' option, which provides the user with a specially-trained assistant as well as information on the location they wish to explore. Through this option, users can venture out to malls, multiplexes, and large stores, without taking intense physical or mental stress.

Besides the app, there are other ways in which senior citizens or people with disabilities can book the wheelchair assistant services. One can make a call to the service number, or drop a message on WhatsApp, sharing their need or request.

"After many years, my mother's desire to witness live dance performances was fulfilled

today! Huge thanks to myUDAAN for this great initiative of providing wonderful, complete, professional wheelchair assistance for two hours! On my one phone call and an app request, the assistant was ready with a comfortable wheelchair right at the car parking. He was careful and polite", shares Saraswati, a customer of myUDAAN's services at Seawoods Mall, Navi Mumbai.

One of the greatest recognition the startup got was when the team featured as one of three finalists on Meet The Drapers, a reality television show that encourages crowdfunding for startups. They also got to interact with American venture capital investor Tim Draper. Ravindra and Anil were also finalists at Social Alpha Birac Quest and Villgro's iPitch. The myUDAAN team was among the finalists at the BIRAC-Social Alpha Quest for Assistive Technologies.

### The Plan Ahead

When asked about what drew him to founding and working with myUDAAN, Anil says, "I always thought I'd be with mainstream startups. But with my third startup aiming for social impact, I am truly excited." Ravi and Anil plan to extend myUDAAN's services to 24 malls across locations in Mumbai, Navi Mumbai, and Thane. They hope to expand the scope of their project by the end of this year.

Read more at: [https://yourstory.com/story/2020/03/my-udaan-wheelchair-services-mumbai?utm\\_pageloadtype=scroll](https://yourstory.com/story/2020/03/my-udaan-wheelchair-services-mumbai?utm_pageloadtype=scroll)



myUDAAN Founders Ravindra Singh (seated) and Anil Pereira

## Polio This Week

Source: [Polio Global Eradication Initiative](#) — as of Wednesday 26 May 2020

### Wild poliovirus type 1 and Circulating vaccine-derived poliovirus cases

Total cases	Year-to-date 2020		Year-to-date 2019		Total in 2019	
	WPV	cVDPV	WPV	cVDPV	WPV	cVDPV
Globally	61	123	40	36	176	367
—In Endemic Countries	61	53	40	10	176	40
—In Non-Endemic Countries	0	70	0	26	0	327

### Case breakdown by country

Countries	Year-to-date 2020		Year-to-date 2019		Total in 2019		Onset of paralysis of most recent case	
	WPV	cVDPV	WPV	cVDPV	WPV	cVDPV	WPV	cVDPV
Afghanistan	12	7	12	0	29	0	22 Mar 2020	18 Apr 2020
Angola	0	2	0	4	0	130	N/A	9 Feb 2020
Benin	0	1	0	0	0	8	N/A	16 Jan 2020
Burkina Faso	0	2	0	0	0	1	N/A	11 Feb 2020
Cameroon	0	3	0	0	0	0	N/A	29 Feb 2020
Central African Republic	0	1	0	2	0	21	N/A	5 Feb 2020
Chad	0	13	0	0	0	10	N/A	11 Mar 2020
China	0	0	0	1	0	1	N/A	25 Apr 2019
Cote d' Ivoire	0	4	0	0	0	0	N/A	14 Mar 2020
Democratic Republic Of The Congo	0	5	0	12	0	88	N/A	8 Feb 2020
Ethiopia	0	14	0	1	0	12	N/A	16 Mar 2020
Ghana	0	11	0	0	0	18	N/A	9 Mar 2020
Myanmar	0	0	0	2	0	6	N/A	9 Aug 2019
Niger	0	4	0	1	0	1	N/A	15 Mar 2020
Nigeria	0	1	0	10	0	18	N/A	1 Jan 2020
Pakistan	49	45	28	0	147	22	4 May 2020	10 Apr 2020
Philippines	0	1	0	0	0	15	N/A	15 Jan 2020
Somalia	0	0	0	3	0	3	N/A	8 May 2019
Togo	0	7	0	0	0	8	N/A	11 Mar 2020
Zambia	0	0	0	0	0	2	N/A	25 Nov 2019

## Polio Australia Factsheets

Polio Australia has developed factsheets to assist with your understanding of living with polio. These factsheets, and others, are available on our Polio Australia website.

In 2020, the factsheets listed below were printed and distributed to the polio state networks across Australia. We printed the factsheets for the 20 most frequently requested topics.

### Health

- Anaesthesia and Surgery
- Bone Density & Health
- Continence
- Physical Activity and Exercise
- Fatigue
- Womens Health
- Footwear/Pedorthics
- Pain management
- Sleep and Breathing
- Cold and Heat Intolerance

### Lifestyle

- Aids & Equipment
- Falls - What to do if you have a fall
- Speech and swallowing
- Medication
- Driving & Vehicle Mods
- Orthoses

### Services

- Disability Services
- NDIS
- MyAgedCare

### Providers

- Types of Health Professionals