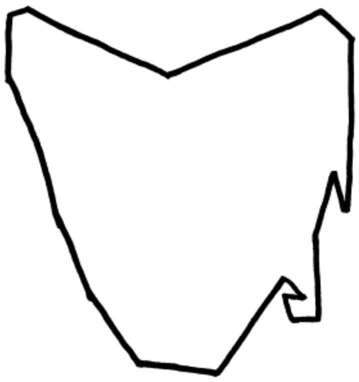
Arthur's
TAS POLIO NEWS



Issue No. 38 **October 2021** **FINAL ISSUE**

INCORPORATING

Volume 11, Issue 3

Polio Oz News

September 2021 — Spring Edition

Inside this issue:

SUPPORT GROUP INFORMATION

The **EASTERN SHORE** Post Polio Support Group of predominately residents of Hobart's Eastern Shore is currently not meeting due to the Covid 19 virus.

Contact **David Shirley** on 62287462 further information.

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Please Note The **GLENORCHY** Post Polio Support Group no longer meets on a regular basis but its members still keep in contact with each other. **Peggy Garland** is still the contact on 62491014.

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PLEASE NOTE

The **WEST TAMAR** Post Polio Support Group meets at the **Riverside Hotel, 407 West Tamar Highway, Riverside** at 12 noon on the 3rd Monday each month over a light luncheon. Anyone is welcome to join us

Contact **Ron & Jan Storay** on 63265523 for further information.

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These groups do provide an excellent opportunity to meet with other polio survivors and share ideas and hints on making life easier for us. **The old saying "A problem shared is a problem halved" is very relevant for polio survivors.**

Why not join a support group near you? If there is not one, why not start one? It only takes a phone call to someone you know who has also had polio and it can grow from there.

Kindly printed by the office of **Senator Wendy Askew** (Liberal, Tasmania) whose support is greatly appreciated.

Thank you

This newsletter has been compiled as a service to Tasmania's Polio Community by Arthur L. Dobson following the demise of the Post Polio Network—Tasmanian Inc.

This is the final issue I will be compiling as the Late Effects of Polio (LEoP) are making it just too difficult to carry on.
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From the Editor

Welcome to the **final issue** of my newsletter.

Until relatively recently I hadn't envisaged that this would happen quite so soon but I now realise that I have been suffering from most of the things that were mentioned in the leading articles in the July issue (Breaking The Silence etc.) and these are just making it too difficult and stressful to try and continue. The loss of fine motor skills (which adversely effect my typing) and concentration have turned what was an enjoyable learning experience into dreaded, frustrating chore.

I had hoped that someone would take up the challenge and continue compiling this information that so many people have found so useful in living with the Late Effects of Polio but so far no one has indicated a willingness to do so.

In gathering articles for this issue I have been going through the store of older material that I have collected over the years and found articles from 20 odd years ago that are still just as valid today as when they were first published so while the information has not greatly changed the methods of making it available have certainly became much more diversified. One such article appears on page 8.

I wish to sincerely thank all those kind people who have sent me their good wishes and support since I made the decision to retire from this role. A special thank you to those people (particularly the editors of other newsletters) who have provided the articles and information that I have used over the years. As I have often said it is this sharing of information between fellow polio survivors that has provided us the ability to survive one of the most debilitating health problems the world has ever experienced.

(With the current COVID-19 pandemic causing so much unrest in the community I can't help but wonder what would have happened if the same selfish, narrow minded attitude on the same scale had occurred during the polio epidemics of the 1930s,40s and 50s. Polio would probably still be with us with millions of crippled people living in poverty all around the world and millions others dead.)

A big thank you especially to all those people who have generously provided the finance for me to undertake this task.

I hope to be able to continue to represent Tasmania's polio survivors at a national level on the Board of Polio Australia, along with Billie, for a while yet and to also continue providing information and support on request.

If however there is anyone out there who would like to take over this role, I will gladly step aside. The Polio Australia Board Meetings are held on the computer conferencing medium, Zoom, four times a year with most other communication via email.

Polio Australia has achieved much more in its first decade of existence than the individual states were able to simply by joining forces and all pulling together. I'm proud to be part of it and to be able to contribute to its success. Obtaining acknowledgement of our condition and finance to relieve the pressure on volunteers by employing staff has made life a lot easier for us.

You can all contact Polio Australia by

Mail at

P O Box 2799, North Parramatta, NSW 1750

Telephone on +61 3 9016 7678

Email contact@polioaustralia.org.au

Website www.polioaustralia.org.au

DON'T FORGET, I still have supplies of the following information to help you cope with the Late Effects of Polio/Post Polio Syndrome that are available from me at no cost you. **You only have to ask.**

- **The Polio Library** (The contents of which were included in the October issue of this newsletter.) There are still a number of DVDs on living with the Late Effects of Polio on my shelf looking for new homes.
- **The Polio Australia Factsheets** (Which have been mentioned a number of times in this newsletter.) I have an abundant supply of these and I can bind them into a booklet form if you wish.
- **The Late effects of polio** (A guide to management for medical professionals produced by Spinal Life Australia and recognised by the Royal College of General Practitioners as an Accepted Clinical Resource.) It is a useful source of information for anyone wanting to know more about us and our health and disability issues.

I am also able to reprint many articles on subjects related to polio and its late effects and supply them to you.

In the July issue of this newsletter Paulette Jackson (Administration Office with Polio Australia) mentioned the Polio Australia Blog. I decided to check this out and found the following article which I'm sure many of you will find very useful. If I had followed these tips earlier I may not be in the position I find now myself in. *Arthur*

Five Tips for Managing Post-Polio Fatigue at Social Events

By: Steph Cantrill

Large family or social gatherings can be times of great fun and laughter. People come together to celebrate milestones, to coo over new grandchildren, to feast, and to make memories that last a lifetime.

But, for someone with post-polio fatigue, these gatherings can also be absolutely exhausting. So how do you take part in events without spending the next three days in bed? Here are some ideas – we'd love to hear yours too!

Tip 1: Plan

A big part of managing fatigue is planning. If you really want to prioritise this event, make sure you've got a quiet day before and after. It might seem obvious, but if you've got a party on tonight then today might not be the day for vacuuming the house!

Remember to be kind to yourself – if you want to go to the event, it doesn't have to completely wipe you out. It may still be tiring, but you can plan your week so that it's as manageable as it can be.

Tip 2: Say "yes" to help

Once upon a time, you might have spent the week leading up to an event in full preparation mode: cooking enough for a hundred more people than you need to, cleaning every inch of your house (or someone else's house!), polishing the deck, mowing the lawn, planning the music, arranging the table decorations…

How many times has someone offered to help, and you've automatically responded with, "No, no – I can do it!" Maybe it's time to let them take over? It may not be exactly what you would have done – why did they choose *that* music? I would never have cooked that! And is that *dust* on the shelf? – but you might find you're able to enjoy yourself more if you're not completely wiped out from getting the event ready.

Is someone offering to take the work off your hands? Time to say yes!

Tip 3: Say "no" to overdoing it

In the same vein, perhaps it's time to start saying no… Just because you've always done something – provide the meal, pass out the drinks, write the thank-you cards, or whatever it may be – doesn't mean you have to keep doing it! What can you delegate? What can you downsize? What can you let go of altogether?

Saying no, especially when you're used to saying yes and being available to those around you, can be difficult. Give yourself time to respond – try something like: "Can I get back to you on that?" And, if you need to, practise saying no – rehearse what you're going to say with a partner or trusted friend (or even in the mirror!).

If you feel uncomfortable saying no, try to remind yourself that it's sometimes an important part of caring for yourself. And if you can care for yourself well, you'll have more capacity to be there for others in the way that you want to.

Tip 4: Know your limits

Sometimes we can fall into an "all or nothing" trap. If we can't go for the whole event because of fatigue, we feel like we may as well not go at all.

Being aware of your own limits can help you find a middle ground. For example, can you limit the time you spend at the function? Can you skip dinner and just meet your friends for dessert?

Also, think about the seating at the event. If it's the kind of event where people are standing around, balancing a drink in one hand and a plate of nibbles in the other, that can be very difficult for people with post-polio issues. Remember that you don't want to overwork polio-affected muscles, and prolonged standing can be problematic. Perhaps you could ask the host to ensure you're able to sit down in a comfortable, supportive chair. That way you can chat to those around you without having to "work the room."

Tip 5: Communicate

Speaking of talking to the host, communication can be a big part of managing your fatigue. Remember, people don't know what you don't tell them. Your friend or family member may not be aware that a standing-only event is too physically demanding for you. Or, they might see how well you walk up and down steps and think it's fine to hold an event upstairs, but not know how much it contributes to your fatigue or pain. It can be difficult, but letting others know your concerns can make a big difference.

If you're not comfortable telling all the people at your gathering that you have limitations due to fatigue, muscle weakness or other issues, perhaps you could choose just a few people to share with. The Spoon Theory can be a good tool for communicating your capacity.

So… Let's party!

The following article is from the Winter Warmer edition of the Mornington Peninsular Post-Polio Support Group Newsletter which has supplied so many useful articles that I have used over the years thanks to its Editor, Fran Henke. I felt it was a fitting article for my final newsletter.

It comes courtesy Medscape Medical News and it references polios and doctors well known to us, covers basic information, but the references may provide light bulb moments for those of us still puzzled by what we're going through. Particularly the quote: "Doctors have observed that post polio syndrome is more pronounced in patients who had severe cases of acute polio and then made the most complete recoveries. They say this is very consistent with a very small number of surviving neurones doing a large share of the work".

Warning for COVID Long Haulers from Polio Survivors

By Sarah DeWeerdt, Medscape. *October 22, 2020*

WHEN working as a family doctor in Denver, Marny Eulberg, MD, (pictured here) noticed that she had begun to feel weaker and more tired than usual and was having trouble lifting the front part of her foot off the ground when she walked. One day, doing rounds at a local hospital, she fell and landed hard on her outstretched wrists.

"I probably ought to pay attention to this," Eulberg recalls thinking. The year was 1985. She was in a solo private practice and knew that if she were to fall and injure herself, she could be out of commission long enough to destroy her livelihood. She sought advice from a physical therapist at the hospital, who suggested that she wear a brace to stabilise her leg. Eulberg was aghast: The idea of wearing a brace "felt like failure," she said. When Eulberg was four years old, in the fall of 1950, she had contracted polio, which partially paralysed her left leg. After six months in the hospital, extensive rehabilitation, and seven orthopaedic surgeries, she gradually progressed from using crutches and a long-leg brace to a short-leg brace. When she was in junior high school, she was finally able to leave these reminders of her illness behind.

During her rehabilitation, Eulberg had been exhorted to "just do one more, work a little harder," as had many children who contracted polio during the epidemics that swept the United States in the 1940s and 1950s. She was told, she explained, that "if you work hard enough, you can get rid of your braces, crutches, whatever." From the experience, she emerged with a kind of matter-of-fact grit common among polio survivors of her generation. So she devised an experiment to prove the physical therapist wrong. First, she counted how many times a day she tripped and almost fell while going about her daily routine: 14. Then she borrowed a short-leg brace and wore it for a few days, again counting how many times she tripped: 0. "So much for the experiment," Eulberg said.

Polio is considered a disease of the past. A vaccine for the virus that causes it was developed in the 1950s, and the disease was eradicated in the United States by 1979. But there are still up to half a million polio survivors in the country. And, like Eulberg, many of them have developed new pain and disability that can be traced to the disease they thought they had recovered from decades before — a condition that has become known as postpolio syndrome. It is still an under-researched and poorly understood syndrome.

There's no definitive way to diagnose it, its cause remains unclear, and no treatment is known to slow or halt its progression. Yet there are effective ways to manage symptoms, say physicians who treat post polio patients. The syndrome is thought to affect between 20% and 85% of those who have recovered from the disease, meaning the condition likely affects tens of thousands of people in the United States and many more around the world. Their experience is a timely reminder that epidemics can ripple through the decades, sometimes in unexpected ways, even after the pathogens that cause them are eradicated.

Trouble Years Later

According to diagnostic criteria developed by the March of Dimes, post polio syndrome is new muscle weakness or decreased endurance that occurs in people with a history of paralytic polio, after partial or complete recovery from the infection and a long interval — typically 15 to 30 years — of stable functioning. The weakness comes on gradually, persists for at least a year, progresses slowly, and can be accompanied by fatigue, muscle wasting, and muscle and joint pain. Some patients also develop breathing problems and difficulty swallowing.

French neurologist Jean-Martin Charcot first described symptoms similar to post polio syndrome in 1975, but the condition only became widely recognised in the 1980s. That's likely because polio was a sporadic disease until the 20th century, so post polio syndrome would have been sporadic too, and its symptoms difficult to ascribe to a specific cause. It was only when a critical mass of survivors of the epidemics in the 1940s and 1950s, Eulberg among them, entered middle age and began to develop these problems that the medical community recognised the pattern as a distinct syndrome.

But early on, some patients faced skepticism and misdiagnosis from medical professionals. "I ended up going to several different doctors and they

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all told me something completely different," said Sunny Roller, who contracted polio at the age of 4, in 1952, and developed post-polio syndrome three decades later. Roller, a former high-school teacher, was a hall director in a college dorm and, in her mid-30s, working on a master's degree when pain and weakness from the condition forced her to move back home with her parents. One doctor said she needed spinal surgery, another advised her to lose weight, and yet another told her it was all in her head, she explained. In fact, what she needed was rehabilitation and eventually a scooter to help her get around.

A Tricky Diagnosis

Even today, post polio syndrome can be difficult to diagnose. There's no biomarker for the condition and no specific test that can identify it with certainty. Often it is a diagnosis that emerges over time, after laboratory and clinical tests have ruled out other common causes of fatigue, such as thyroid problems, and once it's clear that a patient's symptoms are persistent.

Many clinicians perform electromyography, which records electrical activity in muscles and the nerves that control them, as part of post polio syndrome diagnosis. The test can't distinguish between a patient with post polio syndrome and one who has a history of polio but whose condition is stable. But electromyography can confirm that a muscle has been affected by polio — sometimes one that was not thought to be involved at the time of the initial illness — and can help assess a patient's prognosis, said Jan Lexell, MD, PhD, a rehabilitation physician and researcher who runs a post polio clinic at Lund University Hospital in Sweden.

Researchers are also unsure of what brings on post polio syndrome. For a while, it looked like reactivation of the poliovirus might be to blame, but studies haven't consistently been able to identify viral genetic material or evidence of a poliovirus-specific immune response in patients with the syndrome. Other researchers, building on evidence of elevated inflammatory markers in some patients, have suggested an inflammatory or autoimmune process, but again, these changes aren't present in all patients and their relation with the progression of symptoms is not clear.

The Search for a Cause

Although these theories haven't been definitively ruled out, the scientific consensus has coalesced around the idea that the cause of post polio syndrome is a straightforward one, involving degeneration of motor neurons and the consequent weakening of muscle fibres they control. Still, the details of this process remain somewhat murky.

The poliovirus causes paralysis by infecting and killing motor neurons that innervate muscle fibres in the legs, arms, or other parts of the body. During recovery from acute polio, neighbouring motor neurons that remain sprout new projections and reinnervate* muscle fibres that had lost their connections. A motor neuron can innervate up to seven times as many muscle fibres as normal in polio survivors. With time, this extra stress on the remaining motor neurons can cause them to wear out, leading to the characteristic weakness of post polio syndrome.

In support of this scenario is the fact that doctors have observed that post polio syndrome is more pronounced in patients who had severe cases of acute polio and then made the most complete recoveries. They say this is consistent with a very small number of surviving neurons doing a large share of extra work.

Normal ageing processes likely contribute, too. "We all get weaker as we get older," losing muscle mass at a rate of about 1% per year after age 30, said Carol Vandenakker-Albanese, MD, a rehabilitation physician who runs a post polio clinic at the University of California, Davis. In a patient whose muscles are already weakened by polio, this seemingly minor loss is "making a much bigger impact on the strength and functionality of a muscle." The slowly progressive nature of post polio syndrome and the fact that those who suffered milder cases of acute polio typically develop post polio syndrome later in life lend heft to this theory.

Altered body mechanics in polio survivors might also contribute to pain, fatigue, and weakness. Weakness of a polio-affected limb can cause deformities in bones and joints, leading to excess wear and tear, said Vandenakker-Albanese. "Often then their good limb will develop arthritis as well because they're so dependent on that," she added. "I'm a lot more disabled now than I was immediately after my acute attack," said Daniel Wilson, PhD, a retired history professor who taught at Muhlenberg College in Allentown, Pennsylvania and has written several books about the history of polio epidemics in the United States. Wilson had polio in 1955, when he was 5 years old. The virus affected the right side of his body and resulted in scoliosis, which was corrected with spinal fusion surgery when he was 10. Over time, the spinal curvature returned above and below the fusion, causing him severe breathing difficulties.

Technically, such problems are termed "late effects of polio," whereas post polio syndrome is restricted to neuromuscular problems. Wilson also developed weakness in his right leg in the mid-1980s, roughly three decades after his bout of acute polio. But some researchers use one term or the other — or use them interchangeably — to refer to the complete suite of problems that polio survivors can experience in their later years.

Hit-and-Miss Treatments

Despite a variety of studies since the 1980s, "we still have no medical treatment proven to have any benefit for post polio syndrome," said Fred Maynard, MD, a retired rehabilitation physician

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who was active in early efforts to define post polio syndrome in the 1980s and who treated patients at the University of Michigan post polio clinic in Ann Arbor. Maynard was the physician who finally prescribed the correct course of management for Roller's post polio symptoms, and the two later collaborated on studies of the condition.

Trials have shown that drugs — such as pyridostigmine, a medication used to treat myasthenia gravis; amantadine, which is beneficial in patients with Parkinson's disease; and the steroid prednisone — have little effect on patients with post polio syndrome. Similarly, studies of supplements such as coenzyme Q10 and creatinine have been a wash. Non-pharmaceutical treatments, such as transcranial direct current stimulation and whole-body vibration, haven't panned out either. Still, some researchers remain optimistic about intravenous immunoglobulin therapy in post polio syndrome. A randomised controlled trial is now underway to clarify its benefits, whether it will only help a subgroup of patients, and the most effective dose.

The mainstay of treatment is rehabilitation and exercise therapy, usually involving a multidisciplinary team of medical professionals. But it has been difficult to establish an evidence base for even this. For example, researchers in the Netherlands conducted a randomised trial to see whether physical training or cognitive behavioural therapy were effective for patients with post polio syndrome. Neither intervention helped patients preserve muscle strength or functioning.

The nature of post polio syndrome makes it a difficult subject of treatment trials, said Frans Nollet, MD, PhD, a researcher at the University of Amsterdam who led the study. The condition progresses slowly, so it's difficult to see an effect of treatment — let alone differences between treatments — unless a study is very long (and therefore very expensive). "The second big problem is that it's not a uniform disease," he added. The muscles affected, the degree to which they are damaged, and the compensations patients have made since their acute illness all vary widely from one patient to the next.

After the disappointing results of their study, Nollet and his colleagues took a closer look at the patients in the physical-training group. "We saw that we did not have the right intensity of training for each patient," he acknowledged. "So for some it was too intense and for others it was not intense enough." The team is now conducting a randomised trial of individually prescribed exercise, he reported.

Lessons for COVID Long Haulers

Despite underwhelming results from studies of treatment for post-polio syndrome, many clinicians who treat these patients are upbeat about their ability to make a difference in patients' lives, precisely because an individualised approach is possible in the clinic. "It's a really careful assessment of what exactly their activity level is, what they are doing, what muscles they are stressing, what muscles are overstressed, and whether those muscles need rest or protection," said Vandenakker-Albanese. "So sometimes using exercise to strengthen is the solution and sometimes doing less exercise is the solution."

The problem is that this kind of expertise is becoming rare. After addressing her own symptoms, Eulberg started a clinic in Denver for polio survivors in collaboration with the physical therapist who had helped her. Today, she is retired but continues to see a small number of post polio patients on a volunteer basis. "I keep thinking I'm going to have seen everybody in Colorado," she said. But every year, new patients come.

Vandenakker-Albanese sees several hundred patients each year at her post-polio clinic. As other clinics have closed, the geographic area she serves has expanded beyond California. She now sees patients from Arizona, Hawaii, Nevada, and Oregon, and even from outside the United States (around the world, there are an estimated 15 to 20 million polio survivors).

Moreover, as the generation of American polio survivors who first brought attention to post polio syndrome passes into history, the younger generations behind them will be at risk of developing post-polio syndrome. An increasing proportion of patients seen at American and European polio clinics are immigrants who acquired their polio overseas. Many of the millions of patients with polio around the world are just now entering adulthood. As a result, post-polio syndrome will remain a significant public health problem for decades. The understanding of post-polio syndrome that rehabilitation doctors in North America and Europe have developed since the 1980s needs to be maintained and shared in other parts of the world, Lexell said.

Post polio experts also see a resonance between polio and the coronavirus currently affecting the world, particularly in the experience of so-called long-haul COVID-19 patients who have lingering symptoms for many months, or longer. These patients should be followed in a uniform way, Nollet argued. "You really have to take it serious," he said. "Start looking at what interventions are effective" and believe patients when they say they have new limitations.

The memories of polio survivors can provide a guide, and perhaps also a cautionary tale. "When I had polio, our culture kind of wrapped us up and gave us a big hug in so many ways," Roller said. From the network of rehabilitation centres throughout the country, to assistance with medical expenses from the March of Dimes, to the inspiring example of President Franklin D. Roosevelt, himself a polio survivor, "it was like our whole culture wanted to help."

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But that help has to remain for as long as survivors need it, and it has to encompass new difficulties that emerge over time. Today, with the gradual erosion of expertise and a drop off in research on post-polio syndrome, many people with the condition feel left behind. "I think that researchers aren't interested in polio because it's just seen as a disease of the past," Roller said. "People don't realise that we're still here."

Medscape Medical News © 2020

**Reinnervate: supply (an organ or other body part) with nerves.*

Sunny Roller

Specific Recommendations for Post-Polios

Do's and Don'ts, General Therapies and things to avoid

This information was handed to me by a now deceased polio survivor who had been involved in Tasmania's original TAS POLIO Support.

What follows is a general, practical guide for post-polios to use and that summarises in outline form the current thinking about post-polio. It is not a substitute for individual medical evaluation or therapy. It will be most valuable if it stimulates you to seek further and more specific information.

- Take time to rest: nap if possible during the day. work fewer hours, take longer vacations.
- If you are experiencing increasing muscle weakness, exercise only under the supervision of a knowledgeable physician.
- Make sure you get adequate nutrition.
- Be alert to (not obsessed with) changes in your body, and heed your body's signals.
- Take note of any new symptoms plus clear or gradual changes.
- Get enough exercise to prevent disuse atrophy, but not enough to produce overuse damage.
- Learn how to pace yourself.
- Prevent the secondary complications of weakness, particularly falls; this might entail the use of crutches or a cane or a wheelchair for extended travel, or braces or other adaptive equipment.
- Avoid weight gain; too much weight only aggravates stress on joints and muscles.
- Consider possible adaptations to your life style; even minor adjustments, changes in hobbies or modes of transportation, can help.
- Do not assume every physician fully understands post-polio problems; and never hesitate io ask questions.
- Minimize alcohol use, particularly at bedtime:-alcohol inhibits swallowing, interferes with nutrition and causes falls and other accidents.
- Try to maintain a positive attitude toward your health; accept change, adapt, and never equate your self-worth with physical disabilities.
- Post-polios with respiratory insufficiency should take common colds very seriously.
- Get enough bulk-producing fibre in your diet. Avoid stimulant laxatives.
- Medical evaluation of post-polios should include a complete history, physical examination, and appropriate lab studies.
- Muscle strength evaluation should be done by a registered physical therapist or someone familiar with neuromuscular diseases. Repeat muscle testing is now advised every year, even if there is no obvious change in strength.
- The current recommendation is that all post-polios have a complete medical - evaluation covering the three major areas affected by polio: neuromuscular, circulatory and respiratory.
- Problems with extremities or joint function may require special consultation from physiatrists, orthopaedists and/or neurologists familiar with skeletal deformities and muscle weakness.
- Experienced physical or occupational therapists can help determine functional losses and how best two adapt.
- Muscle stretching and joint range-of-motion exercises are important where there is muscle weakness.

These recommendations are just as valid today as when written in the early days of post polio support. *Arthur*

So far in Tasmania (as of September we have avoided the dreaded Covid-19 Delta variant which has caused so much stress and havoc in the other Eastern States but can this situation continue? We certainly hope so but we must prepare ourselves for the likelihood of an outbreak here as it only takes one thoughtless, selfish person to do the wrong thing and everything will change. The following article is taken from the Mornington Peninsular Post-Polio Support Group Newsletter and I thank the Editor, Fran Henke, for letting me reprint it here. We all might find it useful if the worst happens and we face lockdowns here.

COVID-19: A psychological pandemic

The CSIRO's behavioural scientists are studying the psychological impact of COVID-19 on Australia since the pandemic began in 2020. Millions of people in NSW and Victoria are bunkering down for another long lockdown. Other states have introduced snap restrictions to control the virus. Behavioural scientist Dr Jillian Ryan shares her research and lockdown tips for remaining resilient. In early 2020, as Australia's first lockdown began, Jillian and our research team mobilised quickly. They wanted to get a snapshot of how living with COVID-19 containment measures impacted Australians' wellbeing. They've recently published the findings in a report. It examines the impact of COVID-19 on social and professional roles and identity, emotion, behavioural regulation, and social influences. Jillian said the survey found that interruptions to our social, health, and fitness routines (aspects within our behavioural regulation domain) were felt to have the most negative impact. "Our health, fitness and social routines keep us healthy and happy. But closures to pools, gyms, sports centres and social distancing measures disrupt them. It can be challenging to bounce back from those disruptions," Jillian said. "Additionally, people commonly shared that changes to their usual healthy eating patterns and an increase in their alcohol consumption was a negative consequence of life in lockdown."

Some silver linings

Broadly across the survey, 20 per cent of respondents could find a silver lining in at least some of the changes pandemic lockdowns bring to our lives. Many other respondents shared that they enjoyed the slower pace of life as the obligations of life faded, and a greater sense of cohesion in their neighbourhood emerged. "The survey responses speak to all of us really and it helps to know what you're feeling is a common reaction," Jillian said. "It's important to acknowledge, while the lockdown may be lengthy, it's a temporary disruption. So, if your children have too much screen time on a rainy day, or you struggle to get in your normal amount of fruit and veggies, it's okay. It's something you will be able to correct when restrictions ease.

″Survival tips: livin' la vida lockdown

Overall, there is only one rule for living well in lockdown – be kind to yourself. Don't stress if you're not acing it. And, if you have any energy leftover, try some of the lockdown tips below. The main things we can do to protect our wellbeing during times of uncertainty is to take steps towards controlling what we can control. Maintaining a regular routine, staying active, and avoiding too much alcohol will help to protect our physical and mental health including sleep quality.

Here are some ideas on how to achieve this.

1. Set specific, daily goals related to health and physical activity

Think 10,000 steps per day, five alcohol-free days per week, six takeaway-free days, two litres of water, or five serves of vegetables each day. Write your goals down and tick them off each day. Maintaining healthy habits is enormously helpful for ensuring that we get a good night's sleep and have positive mental health.

2. Use technology to stay connected

While normally too much screen time is not recommended, recent evidence shows that staying connected to loved ones via digital means can help to combat lockdown loneliness. Technology can be used to have video chats and meetings, messaging, and playing social games to maintain connection.

3. Maintain a daily routine

Sticking to a routine is important for staving off stress and boredom, and the start-of-day events are critical. When you wake up, make sure you shower straight away and get dressed in clean clothes (trackies are A-OK!). And make your bed immediately to remove the temptation to fall back into it. A daily routine will help you to feel in control of your environment and reduce stress throughout the day.

4. Set clear boundaries while working from home

You might be noticing that work-from-home creep: work hours can get increasingly longer or weirder, and this lack of separation can be bad for our mental health. Spend some time configuring your work computer and smartphone to mute all work-related alerts and notifications on software that you use for work between 5pm and 9am each day. This includes programs like Teams, email, or Slack, for example. If possible, use your work office or desk only for work – don't mix uses so that you can physically turn off the computer and step away from the desk when the workday is over.

5. Start a new project

Starting a new project can help us to remain positive while in lockdown. While you don't need

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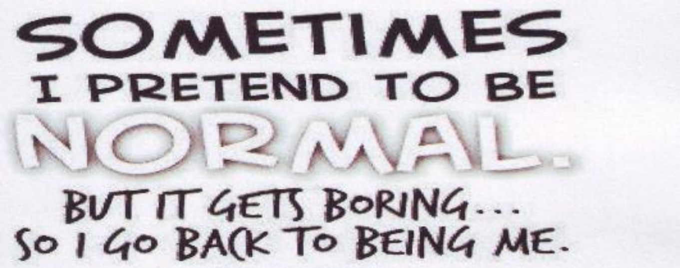
to take on a major home renovation, try to start a simple project. This could be a new puzzle, reading a book, enrolling in an online class, or cooking a few new recipes each week. Share your successes and failures with friends and family.

Seek support if you need it from your GP or psychologist. Alternatively, you call always call Beyond Blue on 1300 22 46 36 or Lifeline on 13 11 14 for support.

MEDICAL TERMINOLOGY FOR THE LAYPERSON

ARTERY...The study of fine paintings
BARIUM...What you do when CPR fails
CAESARIAN SECTION... A district in Rome
COMA...A punctuation mark
CONGENITAL...Friendly
DILATE...To live longer
FESTER...Quicker
MEDICAL STAFF...A Doctors cane
MINOR OPERATION...Coal digging
MORBID...A higher offer
NITRATE...Lower than day rate
ORGANIC...Musical
OUT PATIENT...A person who fainted
POST-OPERATIVE...A letter carrier
PROTEIN...In favour of young people
SECRETION...Hiding anything
SEROLOGY...Study of English Knighthood
TABLET...A small table
URINE...Opposite of you're out
VARICOSE VEINS...Veins which are very close together



Supply shortages, anti-vaxxers, infighting: What can go wrong in vaccine rollouts By Tim Barlass, SMH March 19, 2021

'Vaccine product of long, costly fight.' 'Vaccine has been shown to be from 80 to 90 per cent effective.' 'In a year and a half, they had produced two potent vaccines.

'THESE claims relate to the rollout of a vaccine in the mid-1950s to combat every parent's worst nightmare, infant paralysis, better known as polio.

Much like the difficulties in distributing the COVID-19 vaccines, the polio rollout was plagued with state and federal government infighting, supply shortages, vaccine-related deaths, the objections of anti-vaxxers and unexpected outbreaks.

The initial plan in 1956 had been to immunise all children under the age of 11 within a year, but by mid-1957, only 1 million out of a population of 7.5 million had been vaccinated.

Polio displayed symptoms that could be mistaken for the common cold. There were three variants and victims were left with paralysis in limbs and some required leg callipers. Deaths caused by polio peaked in 1951 at 357.

Medical historian Kerry Highley described the rollout in her paper *A Perfect Storm, Shortages of Salk Polio Vaccine in Australia in 1961* given to a post-polio conference. "The similarities between the coronavirus epidemic and polio epidemic are huge which makes me very philosophical about the whole thing, having seen it all before. There are so many things that can go wrong," she said.

There were two main contenders in the United States to be the first to develop a vaccine. A fierce battle took place between Jonas Salk in Pittsburgh and Albert Sabin in Cincinnati. The two men loathed each other.

In April 1955, in what is known as the Cutter Incident, 200,000 children were given a faulty batch of Salk vaccine. Some 40,000 developed

(Continued on page 11)

(Continued from page 10)

polio, 200 suffered paralysis and 10 died. Trials of Salk's vaccine were announced as a success in mid-1955 but its introduction didn't mark the end of polio in Australia.

Highley, author of *Dancing in my Dreams*: *Confronting the Spectre of Polio*, said shortages of the vaccine in Australia occurred by July 1956, immunisation campaigns were cancelled at short notice and furious parents were turned away. The states and the federal government blamed each other.

From January to the end of June 1961, some 1,700,000 units of the vaccine were withheld for failing the safety screening. Some anti-vaccinationists objected on religious grounds.

In May 1961, an outbreak began in Berkeley, Wollongong with almost two hundred patients admitted to Prince Henry hospital in Sydney. By 1964 immunisation levels were still way below the level of 95 per cent needed to maintain herd immunity.

Sabin's pink-coloured oral syrup given on a spoon or sugar lump took over as vaccine of choice in the '60s after trials and was used through the '70s and '80s. Later on, the Salk injection was reintroduced following cases of polio resultant from Sabin's vaccine.

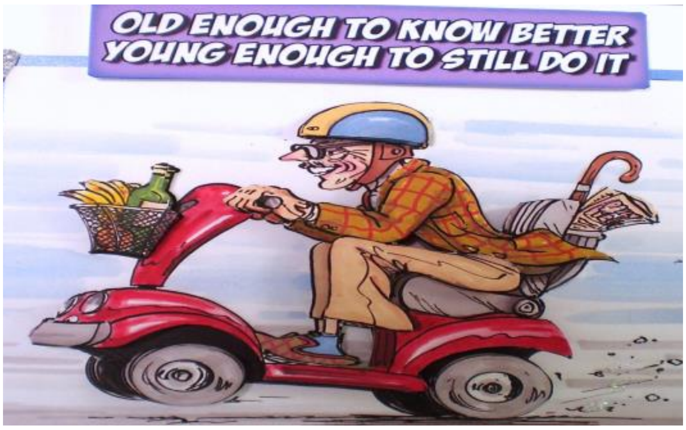
President of Polio Australia Gillian Thomas was living in Wollongong and developed the disease at the age of 10 months in 1950 along with her sister. She ended up with paralysis in both legs and one arm and has worn callipers all her life.

"As we age the muscles that didn't really think they were weak become more so, there is a whole range of symptoms," she said.

"It is certainly the forgotten disease, not only by the public at large but also by the doctors who treat us, they haven't seen an acute case of polio and don't necessarily recognise it."

Australia was declared polio-free in 2000, although there has been no known local transmission here since 1972. The risk of importing polio from overseas means vaccination of Australian children remains critical.

This article was taken from the Mornington Peninsular Post-Polio Support Group Newsletter.



As my own body gets weaker I am continually looking for ways to improve my mobility. I have been using a large mobility scooter for some years for local shopping as my suburb has all the venues I need within a block or two of my home. I had originally intended to simply run it up ramps into the back of my Caddy Van for trips further afield but this became too difficult so I recently invested in a smaller model that I can easily lift into the van and this works well.

While this means I can negotiate larger stores like K-Mart and Bunnings, the down side is lack of carrying space for the articles you purchase. I am experimenting with different ideas and am quite happy with my current set up.

I see a lot of people struggling with their shopping and comment on how they wish they had a similar set up but express concern about the likely cost.

The larger scooter was purchased from an ad in the newspaper and I paid $1,000 for it. The smaller one cost $2,200 from a specialist disability aids provider and are both quite satisfactory for my needs.

So whilst you can spend a lot of money you don't necessarily have to. The following article may help you find what you need. Arthur

Wheel Chair? Power Chair? Scooter?

Reprinted from Pa. Polio Survivors Network June, 2019 www.papolionetwork.org via Polio NSW Network News December 2019.

Your body is hinting that you need one. Your doctor has been hinting that you need one.

Where do you buy it? What's the right one for me? How do you buy it? Will Medicare cover it? Will your medical insurance pay for it? How can you get it in your car? All of these questions can be answered. Be thorough.

Your doctor along with your physical/occupational therapist will be very specific in terms of your needs. If your doctor is a physiatrist (a rehabilitation doc that does a medical residency learning to help people thrive with their disabilities) who is educated in the area of PPS you are one step ahead of the game.

(Continued on page 12)

(Continued from page 11)

<u>First</u> Think through, very carefully, what you think you need and ***why*** you think you need it.

- Will you be using it only in the house?
- Will you want to be outside in it? How often will you need to use it?
- Does your house have a ramp?
- Do you want it to be portable?
- Do you have limitations to be able to break down your new 'wheels' to put it in the car? If you are not able to break it down, can your car 'handle' a lift? Do you have a spouse/caregiver that can help with the lifting?
- Do you have one side more affected by your PPS than the other? Keep this in mind. This equipment is available with the controls (steering and seat) on either side.
- If you are thinking you might put a lift in/on your car, research them at the same time (for compatibility as to your car, power chair /scooter and YOUR needs).
- Many power chairs/scooters are marketed as "light weight". Know your limitations.

<u>Second</u> Let your doctor/physical therapist help you decide if your goals are realistic.

- They must conduct a "face to face" examination prior to writing a prescription.
- You may like the scooter you saw, and think it's great. Your doctor/PT will help you understand if that scooter works or if a power chair "fits the bill" for you in a better way.
- Be honest to yourself and to your physician as to how you want to use it.
- Be open minded.

<u>Third</u> Hopefully you can find a recommended dealer in your area that has inventory on hand, and who will let you try different products. Ask them about their return policy.

- Talk to the dealer about what you've discovered in the process to determine what you need.
- Realize that your body has certain requirements because of your physical limitations. Don't let them convince you to purchase something that your physician/PT hasn't recommended.

<u>Fourth</u> When you get your new piece of equipment, make sure it's right.

- If it's not right, contact your supplier immediately. If they do not respond, contact your physician for help.
- If you are purchasing your equipment online, verify you are purchasing from a credible company. Know their return policy and get it in writing.

Things are changing rapidly in the world of this equipment. Careful planning is not the key to getting what you want, but for getting what you really NEED. The result? FREEDOM

**www.papolionetwork.org/uploads/9/9/7/0/99704804/power_mobility_equipment_-_making_the_right_purchase. pdf

Editor's Note: Advice regarding any mobility product can be found at the Independent Living Centre where a large range of products are on display to try. Phone for an appointment with the Occupational Therapist on site who can help you choose the most suitable product for you. They do not sell any product but will provide you with the details of a supplier nearest to you for purchasing of the product.

In Tasmania the Independent Living Centre can be found at 275 Wellington Street, South Launceston. Phone 1300 885886

ilc@ilctas.asn.au *www.ilctas.asn.au*

"I HAVEN'T FOUND A BARRIER YET THAT STOPS ME!"

From the Polio Australia Blog Page

Lingering COVID-19 Effects: Some familiar barriers

1 September 2021

By: Michael Jackson

In my role educating health professionals about post-polio conditions it is important to compare and contrast aspects of other health conditions with Late Effects of Polio (LEoP). Doing so helps professionals to connect the features of different health conditions in their knowledge schema (internal map of information).

The current pandemic has provided numerous pathways by which to relate polio epidemics and viral health consequences to the lived pandemic experience of health professionals. A pathway of particular interest is long COVID – the lingering or re-emerging symptoms that occur months after recovery from the initial coronavirus infection.

In a TIME article published in late August 2021 about recent findings for those experiencing long COVID, the closing paragraph was particularly striking. The point being made was not about specific features of long COVID, but about a broader view of clinician-patient interaction. The statement by David Putrino, Director of Rehabilitation Innovation at Mount Sinai Health Systems, was:

> ***"It's the tip of the iceberg of enormous potential inequity and disparities in health. Most persistent symptoms are invisible symptoms, and walking into a doctor's office and saying you have extreme fatigue [only] gets treated seriously when you're not a member of a historically excluded group. And when you are, in many cases you don't bother to even go to the doctor's office because who is going to believe you?."***

While the statement is about long COVID, it contains some clear parallels that those who experience Late Effects of Polio will recognise.

The statement highlights some persistent problems that polio survivors continue to experience and report:

- Having, and reporting on, persistent invisible symptoms
- Health professionals not fully grasping the impact of symptoms
- Health professionals making assumptions (i.e. expecting paralysis)
- Being in a recently excluded (or ill-recognised) group
- The frustrations of not being heard and becoming disenfranchised with health care

It is important for those who are health professionals to understand and recognise prevalent conditions – including their essential facts, figures, patterns, protocols, interventions and outcomes. It is also important to understand the aspects of a condition which are not easily seen, and which are not within their lived experience.

It will be years if not decades before we come to fully understand what we currently describe as long COVID. In the meantime, those who have experienced LEoP are well positioned to provide perspective on the lived experiences facing long haulers.

SOURCE: **https://time.com/6093164/long-covid-19-largest-study/**

Longevity expert says snacks weaken our health

A leading researcher says eating too often can lower our resistance to chronic diseases.

Will Brodie, journalist 28.5.21

A leading longevity researcher says eating too often can lower our resistance to chronic diseases.

"It's not just about what we eat that matters to our health – it's also how often we eat and when," Professor Luigi Fontana said. "Our ancestors didn't have the luxury of three meals a day and snacks. The way we eat has changed and our eating frequency has increased without any physiological reason. People snack even if they're not hungry.

"Prof. Fontana says our bodies aren't designed to eat too many times a day."

Each time we eat, we produce insulin to control our blood glucose – and one effect of turning insulin on too often is that it inhibits the processes that help repair damage to the body's cells.

"We know that when cells accumulate damage, they're more vulnerable to diseases, including cancer and dementia."

He recommends putting gaps between meals without snacks, so insulin isn't "prodded" into action. This will "kick off molecular processes that enhance DNA repair and clean up cells".

If you eat an early dinner and don't snack before bedtime, you give insulin activation a good break. Prof. Fontana says proper meals will keep you from getting hungry enough to feel you need a snack.

"My meal portions are huge, but they include a lot of different vegetables, legumes, nuts and minimally processed whole grains, so there's always lots of fibre. This creates so much bulk in your stomach that you feel super full for longer.

"If you do need a snack, eat something like an apple, a handful of blueberries or a couple of carrots – food that's slowly absorbed and leads to less activation of insulin.

Prof. Fontana, author of *The Path to Longevity*, says if he has a snack in the afternoon, it's just a piece of fruit. He says his house does not contain sweets or biscuits.

He says it's time to get over our obsession with eating for weight loss and focus more on eating to maximise our health.

"The real question we should ask is not 'How can I drop some kilos?', but 'How can I avoid developing chronic diseases as I age, and live a longer, healthier and fulfilling life?'"

Dr Edward Bitok, assistant professor, nutrition and dietetics, at Loma Linda University, told insider.com that the wait time between meals should be between three and five hours because that is "the average time it takes for the stomach's contents to be emptied into the small intestine after a standard meal".

Nutritional expert Dr Priya Khorana agrees that waiting three to five hours between meals ensures a true appetite has returned to sustain the body "instead of just eating out of habit or as an emotional response". Waiting any longer can cause "lack of focus, acidity, irritation (hangry), shakiness, low energy, low blood sugar levels and eventually, overeating".

Nutritionist Kate Freeman told the healthyeatinghub.com that snacking is considered useful for weight loss because digesting food boosts metabolism. But this 'thermic effect' makes up only 8 per cent of overall energy expenditure.

She says lifting weights and exercising regularly boost metabolism much more.

"It's always better to have an eating plan that is easier to stick to than worry about whether or not your eating habits are 'boosting' your metabolism. You will lose weight if you are controlling your energy intake to be less than your energy expenditure regardless of how often you eat."

That's because "weight loss is not dependent on how often you eat or how large or small your meals are; it's dependent on your energy intake being less than your energy expenditure over a prolonged period of time".

"You will not lose weight if you do not maintain a negative energy balance over the long term," she says.

Merely skipping meals won't help you lose weight either because it sets you up to overeat.

One trick for weight loss is to eat foods high in fibre or protein as they tend to be more filling, says medicalnewstoday.com.

"This means a person will feel satiated faster and may eat less at each snack time or meal."

10 nutritious snacks (*eatingwell.com*): **almonds, grapefruit, chickpeas, grapes, dark chocolate, popcorn, yoghurt, hummus, oatmeal and dried fruit.**

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And a reminder on health eating for polio survivors:

Dr Lauro S. Halstead, professor, physician, author and polio survivor, has been on this journey. He put himself on what he thought was a sensible diet but was still exhausted. He went to a nutritionist. As it turned out, every he was doing was wrong.

Writing for Post Polio Health (Winter edition 1998) he said: 'The bananas and orange juice were 'empty' calories, the soft drinks were a sugar fix, and my lunch was skimpy at best. My biggest sin was the small amount of protein I was eating (about 5-6 ounces per day).

Dr Halstead started investigating the role of pro-

(Continued on page 15)
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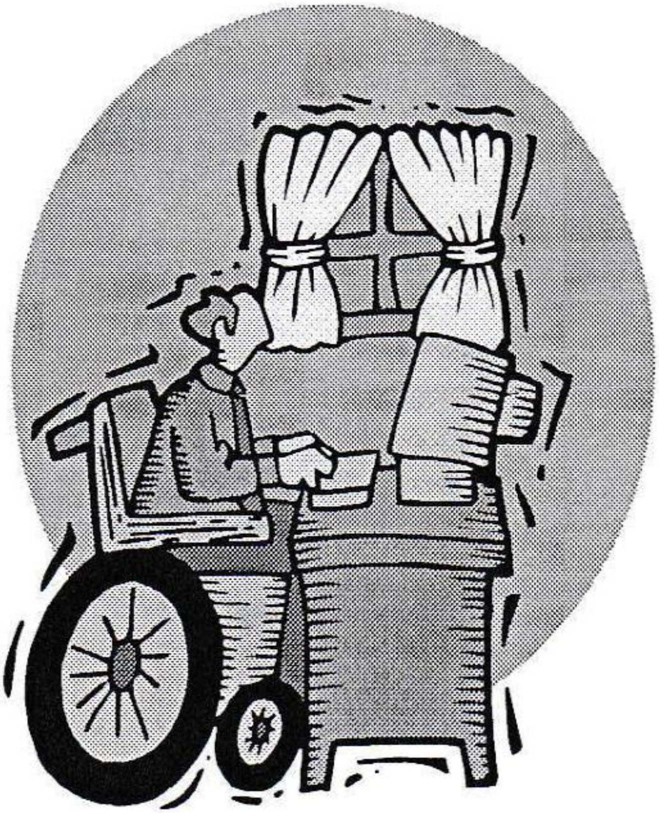
teins.'…Proteins are in all human cells. In fact, they form the basic building blocks for each cell, its metabolism, and life itself… Most important for persons with post-polio syndrome, the largest "consumer" of protein in the body is muscle.

'For the muscles to have a fighting chance to maintain or increase their strength, there has to be a generous amount of protein in the diet. We are not carnivores by chance,' he wrote, then he went on a "nutritional makeover."

Dr Halstead chose to eat lean meat regularly, with nuts, fish, eggs, oatmeal, anything else with protein. He ate less fruit for snacks. The results? His daily intake of protein more than doubled to at least 12 ounces per day, his total calories went to between 1800-2000 per day. His weight was unchanged.

"The best part is that my "good" arm, which used to be tired all the time, feels stronger, gets less fatigued at the end of the day, and seems to recover faster when it gets overworked,' Dr Halstead concluded.

Our Polio Day Cookbook filled with useful recipes and nutritional details is still available from the Polio Network Victoria.



Important Note

Please read before proceeding.

The following pages comprise the Spring 2021 Issue of **Polio Oz News**, the newsletter of Polio Australia. In these pages you will find many words underlined and/or advising you to click here or something similar. These messages only apply to the original version of **Polio Oz News** which is only available online. It can be found by just typing Polio Oz News into your browser.

I reproduce this newsletter in a printed format so that those people who don't have access to an online computer can have access to the valuable information that it contains. The links mentioned above are unavailable in this version.

The only other body producing a printed version of **Polio Oz News** as part of their newsletter is **Polio NSW** and as this is the final issue of **TAS POLIO NEWS** that I produce, I suggest you contact **Polio NSW** at **PO Box 2799, North Parramatta, NSW, Australia. 1750** (Phone 02 9890 0946) and ask if you can go on their mailing list. They have indicated that they are willing to accept Tasmanians as members

An increasing amount of information is only becoming available on-line so perhaps it is time you considered asking a family member or friends who are into computers and on-line if they can access information for you and you can then supply them with a suitable printer to print copies out for you. I personally have trouble reading from a computer screen so routinely print out most of the information that I receive.

Kind regards, *Arthur*

Polio Australia
Representing polio survivors throughout Australia

Volume 11, Issue 3

Polio Oz News

September 2021—Spring Edition

Lockdown Impact On Polio Survivors Survey

By Michael Jackson

Polio Australia Clinical Educator

On August 3rd a research article out of Turkey (Sahin et al.) was published in the journal European Neurology titled *"The Impact of the COVID-19 Lockdown on the Quality of Life in Chronic Neurological Diseases: The Results of a COVQoL-CND Study"* (source link). Much to my dismay, but not surprise, the neurological conditions included in the study did not include post-polio conditions.

The study was a multicentre, cross-sectional study of 577 patients who had a chronic neuromuscular diseases (CND). It included Parkinson's disease (PD), cerebrovascular disease (CVD), headache, multiple sclerosis, epilepsy, and polyneuropathy. The study looked at demographics, a quality of life form, and the Impact of Event Scale-Revised (IES-R) information. They concluded that lockdown causes variable posttraumatic stress and deterioration in the quality of life in those with CND.

Of most interest were their findings related to post-traumatic stress disorder (PTSD) in these populations in response to lockdowns, as measured by the IES-R.

In our 2020 and 2021 Zoom discussions with Australian polio survivors, mental health topics were brought up and discussed, including coping with the pandemic, access to care, unwanted changes in routine and exercise, and traumatic experiences within a personal history of polio. Additionally, in our late 2020 survey we had asked about impact of the pandemic (at large in 2020), and we found that 35% had negative experiences. These negatives were a mix of limited access to services, isolation and travel limitations, coping difficulty and changes in physical condition.

As we had not asked Australian polio survivors specifically about their responses to lockdown experiences, and the Turkish study had both posed this question and excluded polio survivors, we were prompted to investigate.

In Australia at the start of August, numerous states were in or had just been in a COVID lockdown. The timing was ideal to gather some data from our polio survivors. It was necessary to 'strike while the iron's hot' because the instrument of interest the Turkish article used (IES-R) has a 7-day window of validity. Essentially, the IES-R needs to be filled out while the experience is relatively fresh in survey responders' minds. *(See Demographics Chart on page 8)*

Those polio survivors who were younger than 65 or who lived in a rural area were quite few in responding, and so it is unreasonable to draw conclusions from their minimal data points. QLD and NSW residents made up the majority (77%) of those who had recently experienced lockdowns and so had the greatest eligible respondents.

The non-PD conditions in the study by Sahin et al. had mean IES-R scores between 37 to 53 and were in the 'HIGH Group' – they all had considerably and statistically higher mean scores. PS mean scores were comparable to the 'LOW Group' of PD scores, and only slightly higher (mean scores of 27 vs 25).

While there is a low and high split between all these NMD conditions, they all had large percentages of respondents showing probable PTSD.

Sahin et al. used 30 as a cut off value for PTSD, as this had been suggested for the Turkish population from an earlier study. Higher scores (over 30) were deemed a *"probable PTSD case"* in their study of those with CND, and were therefore la-

(Continued on page 4)

Polio Australia
Representing polio survivors

PO Box 2799
North Parramatta 1750
Phone: +61 3 9016 7678
contact@polioaustralia. org.au

President—Gillian Thomas OAM
gillian@polioaustralia.org.au

Vice President—Gary Newton
gary@polioaustralia.org.au

Secretary—Maryann Liethof
maryann@polioaustralia.org.au

Treasurer—Alan Cameron
alan@polioaustralia.org.au

Editor—Maryann Liethof
editor@polioaustralia.org.au

Inside This Issue

> **" An Optimist is the human personification of Spring "**
>
> **~ Susan J Bissonette ~**

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

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

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

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

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President's Report

By Gillian Thomas OAM

President

I am happy to advise that I have now joined the ranks of the fully vaccinated against Covid-19. I live in Sydney, and with the number of Covid cases in NSW being so high, it was not a difficult decision to make.

However, life goes on, and we are currently gearing up for *Polio Awareness Month* in October. The Team has been doing a great job operating in this difficult climate. Whilst it is hard to make any travel-related commitments to mark the occasion, Steph Cantrill, Polio Australia's Community Programs Manager, has devised a plan which encourages people to contact their local councils, asking them to 'light up' as many significant places as possible in 'post-polio orange' to help raise awareness of the Late Effects of Polio. She is also getting *"We're Still Here!"* face masks produced. Both practical and awareness-raising! Read more about these activities on page 5.

Polio Australia's Clinical Health Educator, Michael Jackson, has also been busy conducting the survey on page 1, as well as slipping in and out of states to facilitate education sessions between lockdowns—see page 4. All this has made for trying times, and challenges in meeting Polio Australia's Strategic Plan. However, the Team's dedication, flexibility, and ingenuity has been laudable.

Paradoxically, for the first time since incorporation, Polio Australia's funding is looking secure for the next couple of years—with grants coming from both the philanthropic and Federal Government sectors—see page 7. Mark Coulton MP, one of Polio Australia's Parliamentary Patrons, was instrumental in helping to secure the Federal Government grant. Although Mark has since lost his *Regional Health, Regional Communications and Local Government* portfolio following a front bench reshuffle earlier this year, his strong support of polio survivors remains.

Another Parliamentary Patron, Senator Rachel Siewert, is leaving parliament this month and we will be sad to see her go. Amongst other social justice campaigns and advocacy for the charities sector, Rachel strongly advocated that there be no age limit for the NDIS. We wish her well.

Polio Australia's Board Members have been in the news lately as well—see pages 11 to 13. In typical polio style, this virus won't stop us!

Gillian

From the Editor

By Maryann Liethof

Editor

Despite being in what seems like a never-ending lockdown in Melbourne, Spring has burst out all over to help make the world just that little bit brighter.

As with the last few issues of *Polio Oz News*, I have included a variety of articles on Covid-19 from a range of angles. Not surprisingly, there is no shortage of support for vaccination amongst our post-polio community. As you will read on pages 12, 13 and 14, there are people who have been doing their utmost to encourage others to get immunised. This will help lift us all out of, what will soon become, the pandemic of the unvaccinated.

The inequity of the National Disability Insurance Scheme (NDIS) age 65 cut off has resulted in hardship for many older Australians, many of whom are polio survivors. Page 11 outlines the ongoing campaign to end the age discrimination.

If you're looking for a good story to read during lockdown—or just out of interest—then the two polio-related books profiled on page 10 might be worth a look.

As Australia's polio survivors are predominantly in the older demographic, it can be interesting to see what is happening around the world. Like the participation of younger athletes in the Paralympics in Tokyo (page 17), and body building/gym trainer, Birbal, in India (page 16). The Late Effects of Polio may be something to deal with in future, but it is hard not to celebrate their tenacity and positivity.

Two studies piqued my interest for this edition: one discussing the possibility of the polio vaccine being used to induce an immune response to SARS-CoV-2 (page 17); and how it may be more feasible to eradicate Covid-19 than polio (page 19). Special mention was made in relation to the second study regarding the "added impact of public health measures" such as the mandatory wearing of masks, etc.

Then there's Afghanistan (page 20). It has been impossible to avoid seeing the shocking scenes of devastation on the news, following the withdrawal of US and allied troops. However, as a country that has never eradicated polio, the 'new' regime poses an added challenge to achieving the global polio eradication quest.

Back in Melbourne, Australia, I am looking forward to warmer days ahead, and a time I can travel further than 5 kms from home!

Maryann

2021 Program Update: Clinical Practice Workshops

By Michael Jackson

Polio Australia Clinical Educator

In 2021 to date, 13 in-person workshops were able to be delivered across several states (QLD, NSW/ACT and VIC) in the presence of shifting border restrictions and COVID outbreaks. Nine of the locations visited were hospitals, while the other four locations were private clinics.

Ten Zoom/online workshops were also completed in this period, being a mix of monthly Zoom workshops, two university workshops for pre-professionals, and one regional health district. In the last few months there has been increased interest from hosts of in-person workshops to simply switch to a Zoom workshop when an outbreak occurs, rather than reschedule.

In these 8 months we have reached 189 professionals through workshops. If we include the 35 GPs and 5 nurses from the May GPCE conference, our total reach is 129 professionals.

	CPW In-Person (total)	**CPW Attendees (total)**	**CPW Attendees (average)**	**ONLINE Zoom CPW (total)**	**ONLINE Attendees (total)**	**ONLINE Attendees (average)**
2020 End	3	19	6	2	8	4
2021 YTD	13	114	9	11	83	8

Our program benchmarks are to deliver 55 workshops per year, reaching 800 health professionals across Australia. While we are some distance to those targets, there has been a positive trend towards increased interest, scheduling, and participation in workshops this year. We have not yet been able to visit SA, WA or TAS yet this year, but do have 3 upcoming SA workshops on our schedule.

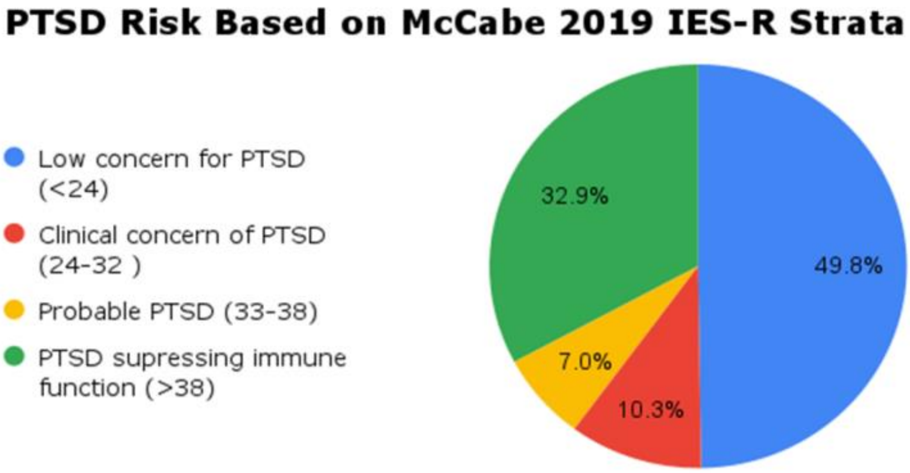
The majority of our attendees in 2021 have been physiotherapists (35%), occupational therapists (24%), allied health assistants (8%), and exercise physiologists (4%).

The RSMANZ Virtual Conference was held on 31st July and I presented the recently published research paper on Polio Survivors and Exercise to the mixed rehabilitation professionals audience. The AAG conference being held at the Gold Coast in-person, and scheduled in early November, remains on the calendar. We are also scheduled to present the paper at that event.

belled PTSD (+).

Lockdown Impact On Polio Survivors Survey *(Continued from page 1)*

A Rory Meyers College of Nursing (New York University) review of the IES-R by McCabe in 2019 offered interpretations based on PTSD thresholds identified in other's work. Using those thresholds and definitions, polio survivors responding to our survey were as follows:



(Continued on page 8)

Community Programs Update

By Steph Cantrill

Community Programs Manager

As I sit here in Melbourne, which is under lockdown orders once again, I reflect on the all the challenges that have presented themselves over the past 18 months. It's been great to see the way that many people in our community have been able to adapt in spite of all the difficulties, but I know it hasn't been easy. My thoughts are with those who are isolated, concerned about potential exposures to COVID-19, or restricted from their usual activities or services.

Community Information Sessions

As you may expect, we remain unable to conduct in-person information sessions, so we are still meeting on Zoom. We know it's not everyone's cup of tea, and we do apologise for that. However, for some it's been a blessing as there's no need to travel and you can connect with people all over the country.

Monthly Zoom sessions: we continue to meet monthly on Zoom. Join us any time – it's a great way to connect and learn from others! Our recent chat about people's favourite gadgets really got people talking, but really the conversation is interesting each time. First Monday of every month at 11.00am Australian Eastern Standard Time (AEST).

NDIS Zoom chats: these have been really valuable for shared learning and support. Our next chat for polio survivors who are either on the NDIS or believe they meet the eligibility criteria will be on Wednesday 1st September at 11.00am AEST.

My Aged Care: Home Care Packages chats: following the success of NDIS chats, we've decided to trial a similar theme for those who have a Home Care Package, those who have applied and are waiting, and those who are thinking about it. Polio Australia is facilitating these chats – but you will be each other's experts, based on your own experience. Our first chat will be Wednesday 8th September at 2.00pm AEST.

Webinars: we have two confirmed upcoming webinars/other chats:

- Staying clear and strong when communicating with healthcare providers and other services, with Liz Telford OAM – October *(exact date TBA).*
- Information and resources for carers with a representative from National Carer Gateway – Monday 27th September at 11.00am (AEST).
- Others not yet confirmed include demonstrations of smart home tech and creative equipment solutions.

Register for all Zoom chats, webinars and information sessions at:

www.polioaustralia.org.au/community-information-sessions

Resources

NDIS factsheets: these are being redeveloped. The first two, titled *"What is the NDIS?"* and *"How to Apply for the NDIS"* will be available soon at:

www.polioaustralia.org.au/services-ndis

Blog: we now have a blog! The latest posts include a Clinical Practice Workshop update and a summary of an assistive technology expo.

Advocacy/Awareness-Raising And Lobbying

Access to in-person health services: due to Covid lockdowns and restrictions, many people have been unable to access their usual services. For some with progressive post-polio conditions, this has meant a significant decline in mobility and movement. We are working on a position paper calling for access to in-person services, where required, for those with progressive conditions.

NDIS exclusion: we support Spinal Life Australia's *Disability Doesn't Discriminate* campaign, and congratulate them on reaching almost 19,000 signatories to the petition (at the time of writing). We absolutely agree that all people with disability should have access to the care and support they need, no matter what their age.

Assistive Technology for All: a range of campaign materials are nearing completion with the ATFA Alliance. We will keep you informed about how you can get involved in advocating for fairer access to assistive technology for those outside the NDIS. This is concurrent with our support of the *Disability Doesn't Discriminate* campaign.

NDIS Independent Assessments: Polio Australia contributed to submissions with two of our networks – the Neurological Alliance of Australia and the Australian Federation of Disability Organisations. Both of these submissions can be viewed here. We are very pleased to hear that, without a transparent and collaborative plan in place, these assessments have been scrapped for now. Advocacy in action!

Accessible housing: speaking of successful lobbying, we are happy to hear that the campaign to ensure mandatory minimum accessibility

(Continued on page 6)

Community Programs Update *(Continued from page 5)*

standards was successful! However, there are still some states who have not yet committed to implementing the new National Construction Code. Polio Australia has joined the *Building Better Homes* campaign – visit their website to see how you can get involved.

Polio Awareness Month 2021: with the help of a small committee, we're finalising plans for Polio Awareness Month. Activities will include *"We're Still Here!"* masks, a Facebook awareness campaign, and orange lighting in various landmarks around the country. See our lighting template to get involved – and you might even go into the draw to win a prize!

Don't forget – if you're on social media, stay connected! We regularly update our Facebook page with news and information. And our Polio Australia group is a platform for you to share news and ask questions. We also have the NDIS Hub Facebook group for the younger ones. Come and join us!

And, if that just isn't enough social media for you, you can always view our videos on our YouTube channel, and follow us on Twitter.

Help us raise awareness of polio and its late effects by contacting your local council or a landmark in your city or town. We can't say for sure just yet, but you just *MIGHT* go into a draw to win a prize!

To help raise the "*We're Still Here!*" message – that tens of thousands of polio survivors are still here and living with polio's late effects – we're lighting as many landmarks as we can in orange during the second week of October.

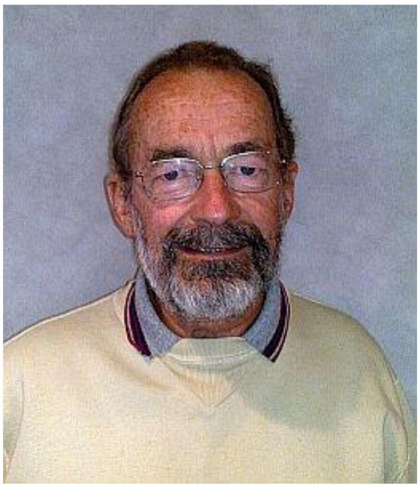
If you'd like to write a letter or email to your local council or other relevant authority, we have provided a template on page 23 which can be copied and pasted, with your relevant details in the highlighted sections. Some councils or buildings will also have an online form. If so, you can just copy and paste the relevant text.

Please let us know who you've contacted, so we know just how orange Australia is going to be. And, hypothetically, so we know who goes into the prize draw!

Treasurer's Report

Polio Australia would like to thank both individuals and organisations for their generous support of **$20,485** during the third quarter of 2021. Be assured that 100% of these tax-deductable donations are used to support Australia's post-polio community.

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/ or contact the Polio Australia office on Ph: 03 9016 7678 or Email: contact@polioaustralia.org.au.



By Alan Cameron

Treasurer

Since we have passed financial year end it is timely to give a quick summation of our position on both revenue and expenses. Please note that my comments relate to the unaudited figures so I'll be dealing only in the rough numbers that may yet need more work. A full report on the Audited results will be provided with the Annual Report.

The result for the year has been very much complicated, and supported, by the receipt of Job Keeper and Cash Boost contributions from the Federal Government, which hopefully will not need to be repeated. As suggested likely in the previous report, we did indeed reach year end showing a surplus, which is encouraging and, furthermore, there is an expectation that it will be sustainable in the short to medium term.

During the twelve months, during which work was largely performed on a 'work from home' basis, it became clear that with staff in four states, it was unnecessary to maintain a physical office located in Kew, Victoria. The office closure has resulted in ongoing cost savings.

We look forward to further stabilising and growing the organisation over the next 12 months.

Ministers

Department of Health

Continuing support for Australia's polio survivors

More than $400,000 has been invested by the Federal Government to continue support for polio survivors who have life-long impacts from the disease.

Tens of thousands of Australians survived the infection and now endure the debilitating neurological condition Late Effects of Polio (LEoP) / Post Polio Syndrome (PPS).

Regional Health Minister and co-chair of the Parliamentary Friends of Polio Survivors, Mark Coulton said Australia had been declared free from new polio infections since 2000.

'Most polio survivors are now aged over 30, and LEoP or PPS can have significant and debilitating on their lives' Minister Coulton said.

'Australians are fortunate that the successful polio vaccine was incorporated into our Australian National Immunisation Program in 1975. Within 25 years we had eradicated the deadly and disabling disease from our shores.'

'We want to ensure the Australian survivors are supported to live fulfilling and healthy lives, so we have provided more than $400,000 to continue Polio Australia's Community Information Program'.

Minister Coulton said the program helps polio survivors to identify and better understand their condition and the strategies available to manage that condition.

Gillian Thomas, National President of Polio Australia and a polio survivor herself said after a successful trial of community programs on a smaller scale, Polio Australia is thrilled to have the opportunity to increase its reach to the polio community across the country.

Many people who had polio are unaware that symptoms they are now experiencing relate directly to that childhood infection. And they don't know who to see or what they can do to manage their ow condition' Ms Thomas said.

'Our Community Information Sessions printable resources and online engagement can help to bridge that gap'.

Funding Boost!

Thank you for your Application for funding through Perpetual's 2021 IMPACT Philanthropy Application Program.

We are pleased to inform you that Polio Australia has been successful in receiving funding of **$91,485** for Polio Australia Community Programs: Facilitating connection and shared learning among the post-polio community in Australia.

Funding has been provided on behalf of the Lionel & Yvonne Spencer Trust.

Congratulations on receiving this grant. Perpetual is honoured to assist our clients in providing funding to the areas they wish to support through their philanthropy

Lockdown Impact On Polio Survivors Survey

(Continued from page 4)

Applying Sahin et al. and McCabe's interpretations to our survey would suggest that 40-45% of those polio survivors who completed the IES-R are likely to have PTSD symptoms related to their lockdown experiences. While this appears high, it is considerably lower than other CNDs studied, and comparable to those with PD.

It is important to note that the IES-R thresholds used apply to different health condition populations, from different cultures than Australian polio survivors. In addition, our respondents were not oriented to the scale by their neurologist (like those in Sahin et al.).

In our Zoom discussions, a number of polio survivors talked about difficulty coping with some aspect of their life. They used a range of strategies to manage this including delegating tasks to ease the load, or seeking professional help such as counselling or psychology. Difficulty coping is a mental health issue, and this lockdown survey highlights the challenges that many people face. It's important to seek appropriate support.

If you were a respondent to this survey and you recall choosing greater than 2 on most of your answers, and you recognise lingering difficulties related to being in lockdown, it is recommended that you follow up with your GP.

It is important for you to mention any concerns to your GP about coping with lockdown. *"At-risk patients may not readily report PTSD symptoms, making it important for GPs to ask probing questions, use screening tools and raise the possibility of PTSD."* (Source)

In a future *Polio Oz News* I will return to this survey to examine aspects such as the IES-R subscale results, and other comparisons with the Sahin et al. study.

Demographics Chart *(from Page 1)*

Below are the demographics and preliminary results from our polio survivors

(respondents = 213, as of 24-8-21)

IES-R Polio Survivor (PS) respondents	Females 58% Males 42%
Age of respondents	<65 years 7% >64 years 93%
Metropolitan resident	62%
Regional town or city resident	32%
Rural resident	6%
State of residence where they experienced the lockdown	NSW 32% QLD 45% SA 11%
HIGH group = CVD (IES-R mean 53)	PS are much lower (mean 27)
LOW group = PD (IES-R mean 25)	Comparable to PS (mean 27)
PTSD (+) [Sahin et al. rated as >29]	45% of PS
PTSD (-) [Sahin et al. rated as <30]	55% of PS

Questions And Answers—New Feature!

This new Q & A page is the first in what we hope to be a regular feature in *Polio Oz News*.

Please send in your polio-related questions to team@polioaustralia.org.au and we will do our best to source the most validated answers for you from the Team and/or other Late Effects of Polio experts.

Note: whilst your Q & A request will be responded to promptly by one of the Team, a maximum of two questions will appear in each edition of *Polio Oz News*. Additional Q & A responses may be included on Polio Australia's Facebook and/or groups pages.

Question:

Did Sister Kenny cure polio?

– from Wen (international)

Answer:

Thanks to Wen for submitting this interesting question. The short answer is, well, no. But let's look at this fascinating person in a bit more detail.

– by Steph Cantrill, Community Programs Manager

Who was Sister Kenny?

Elizabeth (Lisa) Kenny (1880-1952) was born in New South Wales and grew up in the town of Nobby, Queensland. When Lisa was 17, she fell off a horse and broke her wrist. Her treatment and rehabilitation led to a keen interest in anatomy, especially in learning how muscles worked. The doctor in charge of her care became her mentor, and Lisa even made her own model skeleton to learn from.

Instead of jumping straight into nursing though, Lisa was certified as a teacher of religious instruction, then listed herself as a piano teacher as well. She moved back to NSW and worked as a broker of agricultural sales, and then got a job in the kitchen at a cottage hospital. With what she learned at the hospital, combined with her earlier training and a recommendation from the cottage hospital doctor, Lisa returned to Nobby and became a 'bush nurse'.

Nursing career – beginnings

Nurse Kenny, as she was then known, started her nursing career in Nobby and then opened a cottage hospital in Clifton, near Toowoomba, in 1911. It was during this time that she believed she saw her first cases of "infantile paralysis" – now known as polio.

In 1915, she volunteered as a nurse in the First World War, despite not having an official nursing qualification. It was during her service that she earned the title 'Sister' by which she is now famously known. In 1918, Sister Kenny returned to Nobby to look after patients infected with the Spanish flu. She also became the first president of the Nobby branch of the Country Women's Association. She later returned to NSW to care for the daughter of a childhood friend, who had Cerebral Palsy.

Developing a new polio treatment

In 1931, Sister Kenny stayed with other friends for 18 months to nurse their niece, who had contracted polio. When the girl was able to walk, local newspapers began calling it a "cure". Over the next few years she worked with more and more children paralysed by polio, and set up various "Kenny Clinics" around the country.

Sister Kenny's treatment regime promoted passive muscle movement and heat. Her 'method' was quite different from the usual treatment of the period, which mostly involved immobilising affected limbs using casts and splints.

The Sister Kenny method wasn't universally accepted, with many doctors and the British Medical Association questioning her practices. She started to make enemies as well as friends in the medical field. However, it was in the United States that she found most support. Kenny Treatment Centres were established throughout America and her 'method' was used with hundreds of children recovering from polio. While some of her theories remained controversial, her principles for rehabilitation became the foundation for modern physiotherapy.

No cure – but the vaccine has helped

Despite the significant recovery that many children experienced, the treatment was not a cure, as anyone who experiences Late Effects of Polio could tell you. To this day, polio does not have a cure. But it does have a powerful enemy: the vaccine. With both the Salk and Sabin vaccines in common use today, polio cases have reduced by 99% since 1988. With one last effort to ensure universal access to the vaccine, we could see polio eradicated from the globe.

Sources

https://en.wikipedia.org/wiki/Elizabeth_Kenny

https://adb.anu.edu.au/biography/kenny-elizabeth-6934

https://www.who.int/news-room/fact-sheets/detail/poliomyelitis

Books

"No Spring Chicken: Stories and Advice from a Wild Handicapper on Aging and Disability" — www.amazon.com

Francine Falk-Allen feels for people as they age. Most will develop some kind of disability, maybe several, or an impairment that will interfere with life as they've known it, even if just temporarily. To go from being abled to disabled isn't always an easy transition.

Not to say that it's been easy for Falk-Allen, but being disabled is all she remembers. The San Rafael resident contracted polio when she was barely 3 years old, and emerged from six months in a rehab hospital with a permanently paralyzed foot and a partially paralyzed leg.

It did not stop her from much, and she doesn't want disabilities to stop others, which is why she wrote *"No Spring Chicken: Stories and Advice from a Wild Handicapper on Aging and Disability"*. Filled with stories of her numerous travels across the country and world, as well as advice for the newly and future disabled, and the people who love them, her book taps into the resiliency of "crips" — a cheeky term many in the disabled community have embraced — to help others.

"It can be harder on a person who suddenly has physical difficulties when you've had a lifetime of able-bodiedness. For those of us who have had handicaps or disabilities most of our lives, we've had a lot of time to adapt to it. We have more tricks and tips so I thought I have all this information, let me see if I can put it in a book and make it appealing", says Falk-Allen.

It's a companion to her award-winning first book, *"Not a Poster Child: Living Well with a Disability, a Memoir,"* published in 2018, and written with the same sass, practicality and boldness.

Read full article here.

Opportunities

by Alexander Neilson — www.amazon.com.au

Asha is one of India's many polio victims, with nothing better than a pole to hop around his native Nagpur.

Fate takes a hand in the form of Robert, [Australian] businessman and philanthropist. Father of a disabled child, Robert is motivated to help – with polio uppermost in his mind. Robert offers to fund an operation that could change Asha's life in ways he cannot imagine.

For a new life brings new challenges. Able to attend university in a foreign land, will Asha land on his feet now he can walk, or will he stumble in his studies, slip up when socialising, fall flat in wheelchair sports and be wrong-footed by racial prejudice?

To see how far a handicapped person can go in life, and how near and yet how far life with a disability compares to that of the able-bodied, *Opportunities* will open eyes as well as hearts.

Pain Awareness Month

www.painaustralia.org.au

September marks Pain Awareness Month hosted by the International Association for the Study of Pain (IASP). Ideally, this month will spark more conversations and understanding about pain between health professionals, people living with pain, policy makers and the wider community.

To mark Pain Awareness Month, Painaustralia will release a series of educational materials, including factsheets, blogs, online videos, and host a webinar to raise awareness of the reality of living with chronic pain.

FREE Registration for ATSA Canberra 2021

Admission to the shows is free to therapists, the general public, end users and ATSA members. Those who pre-register can reserve seats at the seminar sessions that take place throughout each day of the show.

REGISTER FOR CANBERRA NOW

Campaign To End NDIS Age Discrimination

‘Morally wrong and unfair’: Campaign to end NDIS ‘age discrimination’

By Jewel Topsfield

Source: www.smh.com.au—17 July 2021

Peter Freckleton contracted polio during Australia’s last polio epidemic in the 1950s.

Dr Freckleton, 74, said he grew up feeling like a freak. *“If I did go out at times, kids would burst into laughter behind me as I passed: ‘That man walks funny!’*

“First of all I was totally paralysed and then I got my upper body strength back but I had to wear callipers and crutches all my life and then a wheelchair later on.”

When the federal government introduced the National Disability Insurance Scheme in 2013, he hoped he would finally receive the support and equipment he needed to have a fully active life.

But to his dismay he discovered he was not eligible because he had already turned 65.

In Victoria, where the NDIS was rolled out from 2016, anyone born after 1952 was eligible for the scheme, whereas someone with the same disability born before 1952 was not.

“It’s so arbitrary – you are banned because you happened to have your birthday at the wrong time,” Dr Freckleton said. *“It’s not only morally wrong and unfair but it’s a breach of the UN Convention on the Rights of Persons with Disabilities, which prohibits discrimination against people with disabilities on all grounds.”*

Also excluded from the NDIS are people who become disabled after they turn 65. They, like Dr Freckleton, are forced to rely on the aged care system, which provides much less funding and access to specialised care, aids, equipment and therapy.

Spinal Life Australia – backed by other disability groups including Polio Australia and Muscular Dystrophy Foundation Australia – has launched a TV advertising campaign calling on the federal government to stop age discrimination against people with a disability over the age of 65.

It says a person over 65 who has a spinal cord injury receives $52,000 a year under My Aged Care compared with $165,600 under the NDIS.

The campaign comes amid warnings from NDIS Minister Linda Reynolds that the scheme faces serious sustainability issues, with expenditure forecast to grow to $40.7 billion in 2024-25, $8.8 billion above estimates.

Senator Reynolds said the design of the scheme reflected the Productivity Commission’s recommendation that a person needed to have acquired their disability and requested access to the scheme before the age of 65 in order to become an NDIS participant.

Photo: Dr Peter Freckleton and Post Polio Victoria president Shirley Glance

Credit: Eddie Jim

“The legislation put forward by the Gillard government in 2012 to establish the NDIS, with bipartisan support, reflects the Productivity Commission’s recommendation,” she told *The Age* and *The Sydney Morning Herald*.

“The government supports these longstanding policy settings. The NDIS is not intended to replace services already provided through the health or aged care systems.”

The Productivity Commission also recommended the establishment of a separate National Injury Insurance Scheme, to be funded by the states, which would cover people who had been catastrophically injured. This would reduce the cost to the NDIS, but has not been fully implemented.

Senator Reynolds did not respond to a question on whether the government had done any costing on removing the 65 age limit.

Last year Richard Colbeck, the Minister for Senior Australians and Aged Care Services, told ABC TV’s *7.30* it was not a piece of research he had seen.

However, given 1.9 million Australians over 65 have a disability, according to the Australian Bureau of Statistics, and the average payment to NDIS participants was $53,200 in 2020-2021, removing the age cap would cost the scheme billions.

(The 1.9 million figure includes people with a disability who were NDIS participants before they turned 65 and can remain on the scheme.)

Elizabeth Kendall, a professor of disability at Griffith University, said the cost of removing the age cap needs to be offset against the cost of aged care.

“As people age, the consequences of disability can become more profound and the impact of

(Continued on page 12)

Campaign To End NDIS Age Discrimination

inadequate or insufficient care can mean more frequent costly hospital admissions caused by urinary tract infections, skin problems, respiratory problems and so forth," she said.

"It may also mean earlier transition to residential aged care, which is far more costly."

Last year's royal commission into aged care recommended that by July 1, 2024, every person receiving aged care who is living with disability – regardless of when it occurs – should receive the same level of support they would be entitled to under the NDIS.

"It is a matter of equity," the royal commission report said.

In its response in May, the federal government said the recommendation was subject to further consideration, with work to develop a new support-at-home program to be completed by the end of next year.

The government said it would take into consideration the level of support available to people in aged care, including those who would otherwise be eligible for the NDIS but for the age criteria.

The Disability Doesn't Discriminate campaign calls on people to write to their federal MP asking them to remove the age limit for the NDIS or adopt the royal commission recommendation.

Spinal Life chief executive Mark Townend said in a few months the campaign would ask all MPs where they stand.

In 2019 independent MP Zali Steggall presented Parliament with a petition with almost 20,000 signatures calling on the government to extend the NDIS beyond 65 or improve the aged care system.

Opposition NDIS spokesman Bill Shorten said when the NDIS was being set up the aged care system offered much greater support, so the NDIS filled the gap for people with disability under 65.

"But, after eight years of the Coalition's neglect of aged care, the NDIS – even though it has its problems – is now superior when compared with aged care packages," he said.

"Labor believes people should get the care they need no matter how old they are."

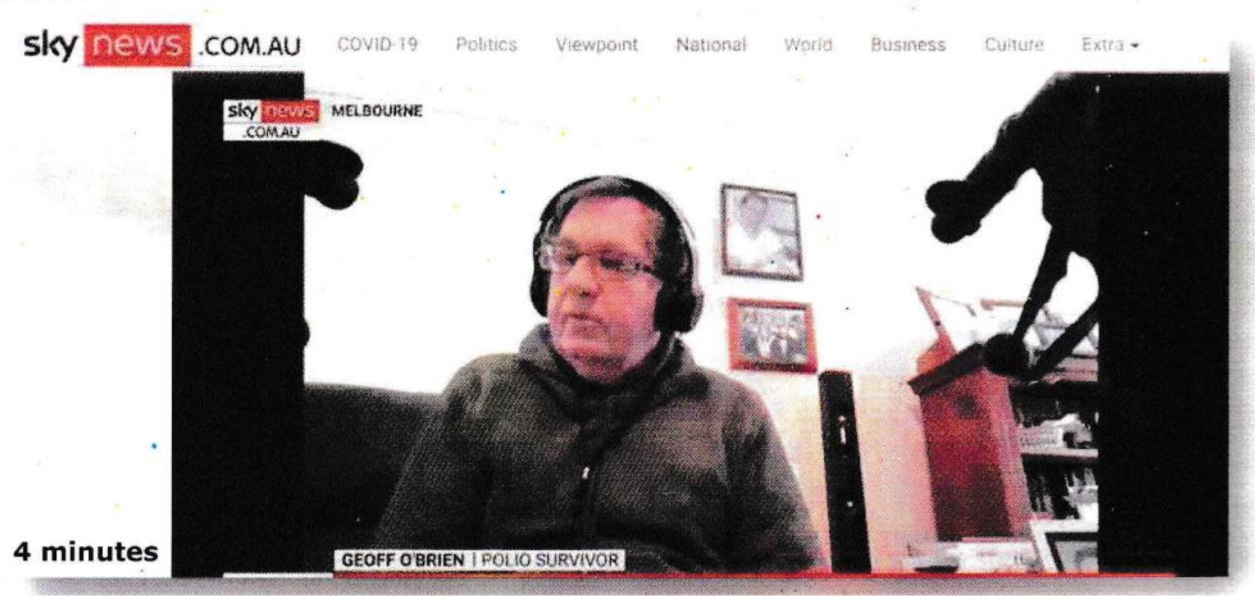
Editor's Note: *Peter Freckleton is Post Polio Victoria's representative on the Board of Polio Australia.*

What Happens Without Vaccination

Polio survivor: 'I know from experience' what happens without vaccination

Source: www.skynews.com.au—23 June 2021

A Melbourne polio survivor is furious many people are hesitant about having the COVID-19 vaccine after he contracted the disease at just two years old in 1953, three years before the Salk vaccine was made available.



The Polio Survivors Encouraging Vaccination

Meet the polio survivors urging Australians to get vaccinated against COVID-19

By Jacquelin Robson and Pip Christmass

Source: 7news—8 July 2021

Polio survivors have told of the terrifying years when the highly contagious virus was crippling children and spreading across the globe. They have shared their story as a cautionary tale, hoping to inspire more people to get vaccinated against COVID.

For survivors of polio, the coronavirus pandemic brings back unsettling memories. From 1944 to 1955, polio killed more than 1,000 people in Australia, while hundreds of thousands survived.

Like COVID-19, poliomyelitis also a highly infectious viral disease. Polio typically spread through dirty water, invading the nervous system – mainly of children.

Jenny Jones was five years old when she contracted the disease. She'd missed out on getting the polio vaccine by five weeks. *"I was a very active, healthy strong girl,"* she said. *"I ended up in hospital for eight weeks, I couldn't walk when I came out, I missed most of year one (at school)."*

Polio outbreaks came in waves, usually in the summer. Ian Holding caught the virus as a toddler, leaving his father terrified.

"He was sitting in a waiting room with a child of two that couldn't stand up," Ian said. *"It upset him a lot. We weren't allowed to visit anyone, but dad was still allowed to go to work."*

The first polio vaccine was developed in 1955. As it began to make its way around the globe, polio was eradicated.

"A van went around the schools and you all lined up," Jenny Jones recalled.

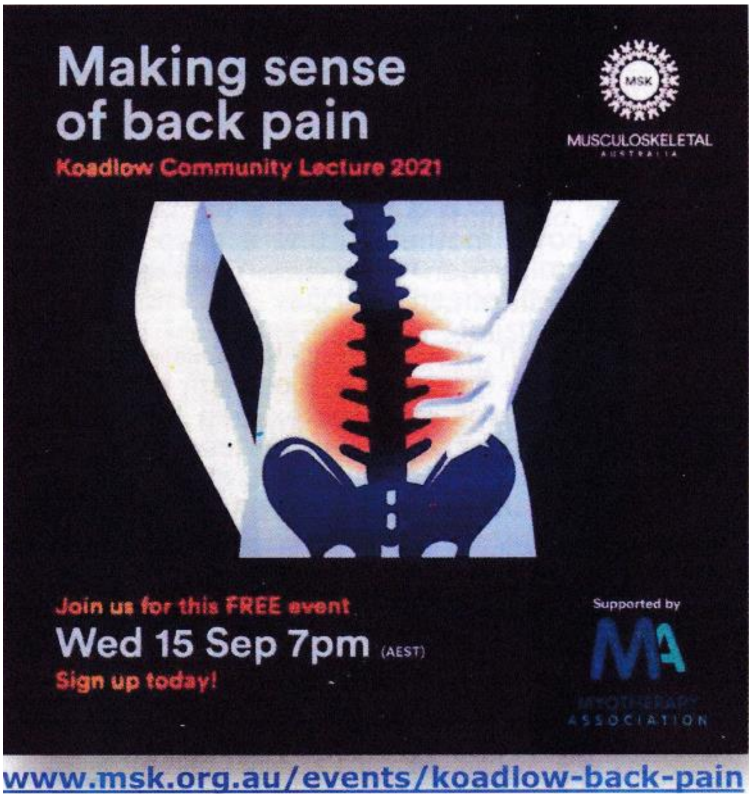
"It went from 399 cases a year to two a year, so the impact of that vaccination was enormous," Ian Holding added.

But even then people needed convincing – as they do now.

Full article here: https://7news.com.au/lifestyle/health-wellbeing/meet-the-polio-survivors-urging-australians-to-get-vaccinated-against-covid-19-c-3346597

Editor's Note: *Both Jenny Jones and Ian Holding are Polio WA's representatives on the Board of Polio Australia.*

Photo: Jenny Jones and Ian Holding both had polio as children. Credit: 7NEWS



No Concept Of How Awful It Was

‘No concept of how awful it was’:

the forgotten world of pre-vaccine childhood in Australia

By Meg Keneally

Source: www.theguardian.com

—15 August 2021

Until relatively recently, lethal infectious diseases stalked the lives of Australian children – including my father, Tom Keneally. Vaccines have saved millions.

It’s 1940, and a five-year-old boy lies in an oxygen tent. He struggles for breath and hallucinates that his leaden toy soldiers are alive and marching around the room, monstering him with their bayonets.

He has diphtheria, a disease also known as *The Strangling Angel*. There is a vaccine, but not every child has been inoculated. The bacterial infection creates a membrane across the back of the throat, cutting off air supply.

The little boy’s mother, sitting a desperate vigil next to the oxygen tent, has seen diphtheria take other children.

It will not, in the end, take her son. The membrane will fail to fully close off his airway, and he will emerge from the oxygen tent. He will attend the funerals of classmates who die of diphtheria and polio. He will, in time, run alongside his friend, a fine athlete born blind after his mother contracted rubella during pregnancy. He will rattle a stone in a can to guide his friend to the finish line.

Throughout his schooling, children he knows will die from disease. He will, through luck, survive. He is still alive now, at the age of 85. He’s my father, and his name is Tom Keneally.

“One of the brothers (the Christian Brothers of St Patrick’s College in Sydney’s Strathfield) would come into the classroom from time to time and tell us someone had died,” Keneally said. *“We would say a decade of the Rosary for them, and the brother would say that God takes the best children, and I would be relieved I wasn’t one of those. It didn’t feel like an ever-present threat as kids because we were just living our lives, although I think for our parents it was always there, that possibility.”*

Shortly after birth, Australian children are vaccinated against hepatitis B. Between six weeks and 18 months of age, they receive vaccines against a range of diseases including diphtheria, tetanus, pertussis (whooping cough), pneumococcal disease, meningococcal disease, measles, mumps, rubella, polio, *Haemophilus influenzae* type b (Hib), rotavirus and varicella (chickenpox).

Some vaccines can also protect against certain cancers later in life. As Prof Raina MacIntyre, head of the Biosecurity Research Program at the Kirby Institute and professor of global biosecurity at the University of NSW points out, the hepatitis B vaccine protects against liver cancer, while human papillomavirus vaccine guards against cervical and penile cancer.

“People don’t remember the gains we’ve made,” McIntyre says. *“In the 19th century, the leading cause of death in children was infectious disease. People would have 10 children and might lose five of them. We lived with high rates of infant mortality,”* she says.

As well as two world wars, Australians in the first half of the 20th century had a Spanish flu pandemic and a bubonic plague outbreak to contend with, along with numerous spot-fires of disease.

The lethal diseases that routinely beset the population – such as the choking diphtheria, the crippling polio, the wracking tetanus – made childhood precarious.

One in 30 children died from gastroenteritis, diphtheria, scarlet fever, whooping cough and measles in 1911. In 1907, infectious diseases killed more than 300 people in every 100,000, according to data from the Australian Institute of Health and Welfare. By 2019, that number had dropped to around 10.

To modern parents, disease names like polio and smallpox and diphtheria have been relegated by vaccination to arcane words with no practical relevance. But while these cruel diseases no longer kill Australian children, experts say there may be a risk of lapsing into complacency.

“The visibility of the ravages of polio, and the fact that most people knew someone who’d had a child die were really powerful drivers, people were desperate for vaccines,” says David Isaacs, clinical professor in paediatric infectious diseases at the University of Sydney, and author of *Defeating the Ministers of Death – The Compelling History of Vaccination*. *“Many younger people have no concept now of how awful it was.”*

Tom Keneally’s diphtheria infection was not to be his last childhood spell in hospital. In 1944 he lay recovering from pneumonia near a boy in an iron lung, suffering from polio. The boy was studying for the Leaving Certificate, the forerunner of the HSC.

“He had a bracket above his head that textbooks could be slid into, and I remember him studying Hamlet,” Keneally says. *“His mother was always there, turning pages and changing books, and that’s how he studied.”*

Sometime later, he learned the boy had died when a power cut rendered his iron lung useless.

Dr Peter Hobbins, a medical historian at the Aus-

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No Concept Of How Awful It Was

(Continued from page 14)

tralian National Maritime Museum, says polio was still killing children into the 1950s.

"It was a reality of life in Australia. A lot of people don't realise how many diseases were rampant until relatively recently. There's a reduced visibility of the consequences of these diseases, people don't appreciate the fear parents felt of sending a child to school and possibly having them not come back into the family," he says. *"Thankfully we are not seeing new cases of polio, but there are still people living with the consequences of the disease, and they feel forgotten."*

Not that there weren't triumphs, notably the eradication of smallpox, which Isaacs says killed up to one in three babies in the London of the 18th and early 19th centuries. A campaign by the World Health Organization, starting in 1967, saw it wiped out by 1980.

The first smallpox vaccinations in Australia were given in the early 1800s. That was no good to the people of the Eora nation. In 1789, a disease believed to be smallpox was introduced by the colonists. It tore through the Aboriginal population of Sydney, killing up to 70%.

While smallpox is no longer a threat, MacIntyre warns that diseases we have almost forgotten can easily return if vaccination rates slip.

"One example is the fall of the Soviet Union," she says. "There were good vaccination programs, and then when the Soviet Union fell, many stopped being conducted."

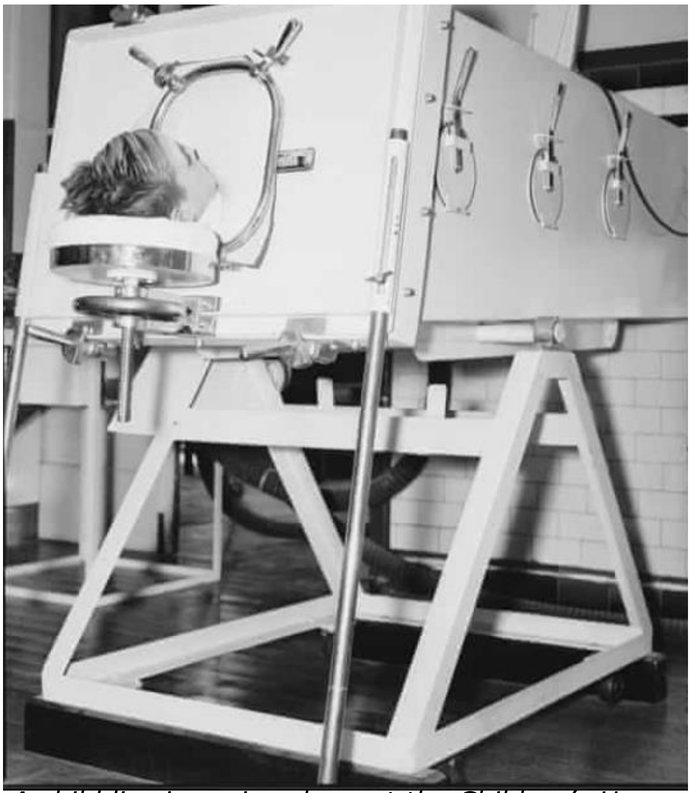
As a result, cases of diphtheria, which had been almost unheard of due to vaccination, reached 140,000, and the disease killed 4,000 children and young adults.

"If we stopped vaccinating against diphtheria here, we would see the same," MacIntyre says.

Despite their life-saving properties, vaccines have often been greeted with suspicion. Hobbins says a tragedy in 1928 had an impact on diphtheria vaccination rates – but it may also have ultimately increased vaccine safety.

"It became known as the Bundaberg Tragedy, or the Serum Tragedy. A batch of diphtheria vaccine contaminated with Staphylococcus aureus was injected in high doses into 20 children, and 12 died," he says.

"An outbreak of diphtheria could potentially kill 12 children in 20, but that event set the course of vaccination back several years. But one consequence of the tragedy was a rise in manufacturing and quality testing standards, which drastically reduced the risk of that vaccines might become contaminated."



A child lies in an iron lung at the Children's Hospital 20 May 1938.
Photograph: Olson/State Library of NSW

While vaccine mandates are sometimes raised as a counter to vaccine hesitancy, they can backfire. In Defeating the Ministers of Death, Isaacs writes of 80,000-strong protests in the UK city of Leicester in the late 19th century, in response to a smallpox vaccine mandate.

"I truly believe in negotiation and respecting people's intelligence, because vaccine hesitancy is not about intelligence. A lot of hesitancy is based on fear and misunderstanding, and we don't want to alienate people," he says. *"Then you can sometimes bring people around if you've developed a close relationship, which is why I'm a firm believer in using GPs to get those messages out."*

Still, Australians are very supportive of childhood immunisation, he says. *"Our uptake of routine childhood immunisations is about 95%. That's enough to give you herd immunity, so that there's no endemic spread of measles at all."*

MacIntyre agrees. *"Australia has had high rates of vaccination. Anti-vaxxers are around 2%, which is not that much,"* she says. *"It's not so much vaccine hesitancy as vaccine confusion [with Covid-19 vaccines]. I believe we can achieve good rates of vaccination [against Covid-19] in Australia."*

As for committed anti-vaxxers, Tom Keneally knows what he would like to do to try to shift their perspective. *"I'd like to take anti-vaxxers back in time to my childhood. There would be a story on every street which could change their minds."*

Dr Anthony Fauci Interview With CNN

Fauci says U.S. 'probably would still have polio' if there had been as much misinformation as with covid vaccines now

By Joe Walsh, Forbes Staff

Source: www.forbes.com—17 July 2021

Amid sagging Covid-19 vaccination rates and stubborn levels of vaccine hesitancy, Dr. Anthony Fauci [Chief Medical Adviser to President Biden] told CNN the United States' successful campaigns to eradicate smallpox and polio in the last century wouldn't have succeeded if those vaccines were subject to the same level of misinformation that currently surrounds coronavirus vaccines.

KEY FACTS

- In an interview with CNN, Fauci warned that some unvaccinated adults have been exposed to false information, are often sceptical of objective Covid-19 data and frequently justify their decision not to get vaccinated with *"things that are really just not true."*
- After anchor Jim Acosta compared the situation to polio, the government's top infectious disease expert offered a dire warning: Fauci said efforts to eliminate smallpox (which was eradicated worldwide over 40 years ago) and polio (which has been eliminated in almost every country) would have faltered under the current climate of misinformation.

Polio No More A Crippling Fear For Him

A gym trainer, Birbal is now teaching dynamics of fitness to others

By Ajay Joshi

Source: Tribune News Service—16 July 2021

Birbal was diagnosed with polio at the age of five due to lack of proper medical facilities in his village. The unavailability of proper treatment crippled him for his entire life. He suffered a major setback early in his life but was always keen on moving on and complete his education despite his disability. However, constant slurs from peers forced him to drop out of the school. What remained constant throughout his growing years was his zeal to become independent and support his family.

Now, 31, Birbal took to body building in 2004 to shape up his career and body. *"I had just entered my teens when I started working on my physique. The idea initially was to have an enviable body despite my inability to use legs. I didn't want this to be any kind of hurdle in my dreams. With time, bodybuilding became my passion and within a few years, I started participating in several body-building championships. I believe, it is easy to give up and blame circumstances for one's shortcomings, but the joy of achieving something is only felt when you persevere through life to overcome difficulties. This joy comes with hardwork and sacrifice,"* said, Birbal, a resident of Lidhran village, near Suranussi.

Being the eldest among his siblings, he says, his parents started worrying when he was diagnosed with polio. Wrong medication by doctors further made him miserable and he couldn't grow normally. Apart from following his passion, he used to do odd jobs to earn a living for himself. In the absence of any tricycle, he even had to crawl to move from one place to another.

"To shed extra fat from my upper body, I used to crawl faster using my hands. The encouragement came from observing others. I made my mind stronger and thought, why not make optimum use of two hands gifted to me by God. When I turned 18, I participated in my first body-building competition and the journey forwarded from district to state level competitions," shares Birbal.

Now, standing tall with his list of achievements, Birbal is popular among budding fitness freaks as Billu Paji. It has been over five years, since he became a gym trainer and now rides an Activa [Honda scooter].

Polio At The Paralympics

Source: www.polioeradication.org

With the largest audience the Games have ever garnered, polio-affected athletes have joined the fight to end the disease which paralyzed them.

Footballer Dennis Ogbe of Nigeria is just one of some 25 athletes living with polio participating in events from wheelchair basketball to powerlifting at the Games. They come from countries as different and far-flung as the Great Britain, US, Nigeria, India and South Africa. Paralympians living with polio know well the full impact of the disease. Their own personal paths to reach the top of their sport at the global level is a powerful metaphor for the global fight to eradicate the disease.

Paralympic athletes at the garden party sponsored by Rotary International, in association with UNICEF, the Bill & Melinda Gates Foundation, the British Pakistan Foundation, and the Global Poverty Project.

Three such athletes were the stars at a garden party in London sponsored by Rotary International, in association with UNICEF, the Bill & Melinda Gates Foundation, the British Pakistan Foundation, and the Global Poverty Project. The party capitalized on the excitement surrounding the opening day of the 2012 Paralympic Games on 30 August to rally government dignitaries from the United Kingdom and Pakistan to raise funds for Paralympic athletes and Rotary's PolioPlus program.

"We wanted to celebrate the achievements of these amazing athletes and Rotary's hard work towards polio eradication," says Judith A. Diment, PolioPlus national advocacy adviser for the UK and a member of the Rotary Club of Windsor St. George, England. *"Both groups have persevered through great odds to be where we're at today."*

The event raised thousands of dollars for PolioPlus and the Pakistani Paralympic Committee and advocated for a polio-free world. Wajid Shamsul Hasan, the High Commissioner of Pakistan to the United Kingdom, praised Rotary's efforts to eradicate polio in Pakistan and spoke about his government's commitment to step up resources to rid his country of the disease.

Could Polio Vaccines Help Target SARS-CoV-2?

Could polio vaccines induce cross-reactive antibodies that target SARS-CoV-2?

By Dr. Liji Thomas, MD

Source: www.news-medical.net—24 June 2021

Among the intriguing aspects of the current pandemic of coronavirus disease 2019 (COVID-19), caused by the severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2), is the apparent selectivity of its pathogenicity. Young children are typically spared the severe or life-threatening features of infection, compared to adults over 60 years.

A new study led by researchers at Johns Hopkins University, USA, explores a link between immunity to SARS-CoV-2, the earlier SARS-CoV, and childhood poliovirus vaccination. Almost 90% of the world's people have received this vaccine, but antibodies elicited by it reduce over time and are almost absent at the end of adolescence.

Study: *Poliovirus Vaccination Induces a Humoral Immune Response that Cross Reacts with SARS-CoV-2.* A preprint version of the study is available on the *medRxiv** server, while the article undergoes peer review.

Background

Some earlier studies have shown that certain vaccines have cross-protective efficacy against not just the specific viruses based on which they were created, but on structurally similar viruses too. This is true of the poliovirus vaccine and the mumps vaccine, with one report indicating that the susceptibility to SARS-CoV-2, and COVID-19 severity, are inversely correlated with the titers of mumps antibodies.

Both the poliovirus and SARS-CoV-2 contain a single-stranded ribonucleic acid (RNA) molecule as their genetic material, and all proteins are directly translated off this template strand. During viral replication in both, the genome is replicated off this strand, using RNA-dependent-RNA-polymerase (RdRp) protein synthesized.

The RdRp enzyme is fundamental in viral replication, and multiple screening attempts have been made to inhibit its activity and thus cripple the

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Could Polio Vaccines Help Target SARS-CoV-2?

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virus.

The researchers in this study explain, "*The structural similarities in the RdRp of all single-stranded, positive sense RNA viruses may explain the cross-reactivity of polio-immune serum with SARS-CoV-2 antigens*."

Two types of polio vaccines have been used worldwide, one being the oral polio vaccine (OPV) which is a live attenuated vaccine, and the other an inactivated poliovirus vaccine (IPV). Concerns about the potential for reversion to wild-type paralytic poliovirus have led to the cessation of OPV in the USA, where IPV is universally administered. Not only is the latter associated with high efficacy, but it cannot lead to the escape of vaccine-derived-poliovirus (VDPV) into the environment and has few side effects.

Image Credit: Numstocker / Shutterstock

What were the findings?

The researchers intended to test their theory that the age-dependent morbidity and mortality from COVID-19 is mediated by immunity to the virus, which is partly contributed by poliovirus vaccination. Using data from the top 100 countries to be hit by the virus, they found that the higher the median age, the higher the prevalence of the virus was in that country, and the higher the mortality rate from COVID-19.

Secondly, they found that the RdRp from SARS-CoV-2 and poliovirus had similar molecular weights of approximately 130 kD, with similar tertiary and quaternary structures. Both were bound at one site, at least, by the mouse anti-RdRp monoclonal antibody 4E6.

The researchers found anti-RdRp antibodies in a sample of both adults and children, which were able to recognize the RdRp of both viruses. Higher titers were seen in those who had received IPV. Immune serum from these individuals inhibited viral replication in Vero cells, with stronger effects being observed when the antisera were added to the cells before viral challenge.

The strongest inhibition was seen with antisera from fully immunized young children and from young adults.

If poliovirus immunization builds immunity to the novel coronavirus, these results are expected since, by one year of age, the child would have been fully immunized but not at four months. The same effect is seen when an adult is immunized with two doses of IPV, inducing stronger inhibition of SARS-CoV-2-induced cytopathic effects (CPE) in the cell culture.

Protection from either polio or SARS-CoV-2 declines with age, but inhibition of CPE improves by over a third with a single IPV booster dose. Lower immunity in adults aged 60-65 years may be partially compensated for by IPV, raising the immunity above that of an adolescent who was not recently immunized.

In vitro inhibition of RdRp activity was observed with poliovirus antisera randomly selected from immunized adults and children, with 13 of 17 samples showing effective inhibition of RdRp enzymatic activity.

What are the implications?

The study shows that "*poliovirus vaccination raises antibodies that cross-react with SARS-CoV-2, with the primary target of these antibodies being the RdRp of poliovirus and coronavirus*." Antisera from immunized individuals prevent SARS-CoV-2 CPE in cell cultures. The antisera successfully reduced RNA replication by inhibiting RdRp activity.

These findings may imply that childhood vaccinations elicited antibodies to SARS-CoV-2 in younger individuals and thus reduced their susceptibility to the virus. This harmonizes with studies that indicate a possible role for the anti-tuberculosis BCG, MMR (targeting measles, mumps and rubella) and poliovirus vaccines in protecting against SARS-CoV-2 infection.

The study also draws attention to the potential importance of RdRp as a therapeutic target. Anti-RdRp antibodies apparently inhibit SARS-CoV-2 CPE by preventing its adsorption or internalization into the host cell, mediated by viral genome-RdRp interactions. Thus, other SARS-CoV-2 protein antigens than the immunodominant spike may be suitable for vaccine development.

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Could Polio Vaccines Help Target SARS-CoV-2?

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"*We suggest IPV immunization may induce adaptive, generally long-term, and specific immunity to poliovirus and SARS-CoV-2 infection*." The authors are continuing their investigation via a larger clinical trial to test the usefulness of this vaccine in the prevention of COVID-19.

The possibilities are bright, as the poliovirus vaccine is a decades-old vaccine with abundant safety data, and established pharmacological standards. Manufacturing and toxicity data are also readily available. In the light of significant vaccine hesitancy directed at the newly developed COVID-19 vaccines and the shortfall in vaccine supplies, the researchers suggest that the utility of the poliovirus vaccine be re-examined in this light.

***Important notice**

medRxiv publishes preliminary scientific reports that are not peer-reviewed and, therefore, should not be regarded as conclusive, guide clinical practice/health-related behaviour, or treated as established information.

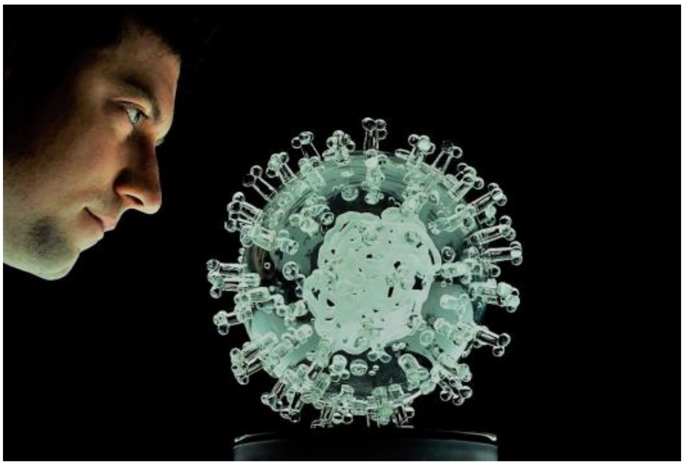
Journal reference:

Comunale, B. A. et al. (2021). Poliovirus Vaccination Induces a Humoral Immune Response that Cross Reacts with SARS-CoV-2. *medRxiv* preprint. doi:

https://doi.org/10.1101/2021.06.19.21257191,

https://www.medrxiv.org/content/10.1101/2021.06.19.21257191v1.

Global COVID-19 Eradication More Feasible Than Polio



Global COVID-19 eradication more feasible than polio: Study

By Abigail Anderson

Source: www.socialpost.news—15 August 2021

According to an analysis published Tuesday in BMJ Global Health, global eradication of COVID-19 is more feasible than polio, but much less so than smallpox.

Public health experts from the University of Otago Wellington in New Zealand note that vaccines, public health interventions, and global interest in achieving this goal have eradicated COVID-19. However, the main challenges are ensuring sufficiently high vaccination coverage and responding quickly enough to SARS-CoV-2 variants that escape the immune system, the virus that causes COVID-19.

The authors evaluated the feasibility of eliminating COVID-19, which is defined as *"the permanent reduction to zero in the global frequency of infection caused by a specific pathogen as a result of conscious effort."*

They compared it to two other viral pests for which vaccines have been made – smallpox and polio – using a number of technical, social, political, and economic factors likely to help achieve this goal.

The authors used a three-point scoring system for each of the 17 variables, including availability of a safe and effective vaccine, lifelong immunity, impact of public health measures, and effective government management of infection control messages.

They said the average score in the analysis was 2.7 for smallpox, 1.6 for COVID-19 and 1.5 for polio. Smallpox was declared eradicated in 1980, and two of the three serotypes of poliovirus have been eradicated worldwide.

"Our analysis with different subjective components appears to bring the possibility of COVID-19 eradication into the realm of the possible, especially in terms of technical feasibility," the authors wrote in the study.

They acknowledge that technical challenges in eliminating COVID-19 versus smallpox and polio include weak vaccine adoption and the emergence of more transmissible variants that bypass immunity and possibly bypass global vaccination programmes.

"However, the evolution of the virus is of course limited, so we can assume that the virus will eventually reach its peak and that new vaccines can be formulated," the authors explained. *"Other challenges we face will be the high cost of vaccination and the modernization of health systems,"* they added.

The researchers also suggest that persistence of the virus in animal reservoirs could also thwart eradication efforts, but they add that this does not appear to be a serious problem. On the other hand, they realized that there was a universal

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Global COVID-19 Eradication More Feasible Than Polio

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will to fight infection.

The massive health, social, and economic impact of COVID-19 in most parts of the world has sparked *"unprecedented global interest in disease control and massive investments in pandemic vaccination,"* according to the authors.

I put my trust in smallpox. And polio, COVID-19 is also benefiting from the added impact of public health measures such as border control, social distancing, contact tracing and wearing masks, which can be very effective with good use.

Taken together, the authors added, *"Take these factors together, they may mean that an 'expected value' analysis can ultimately estimate that the benefits outweigh the costs, even if eradication takes many years and has a high risk of failure."*

U.S. Departure From Afghanistan

U.S. departure from Afghanistan imperils global quest to eradicate polio

By Leslie Roberts

Source: www.sciencemag.org—4 August 2021

The U.S. troop withdrawal from Afghanistan—along with the surge of the Taliban there—is imperilling the 3-decade global quest to eradicate polio. The Taliban has blocked house-to-house polio vaccination in areas under its reign for the past 3 years, putting up to 3 million children out of reach of the campaign and leaving Afghanistan one of only two countries, along with Pakistan, where the wild polio virus survives. Since the United States began to pull out troops, the Taliban has made rapid military gains and now controls much of the country. Some fear it may wrest complete control from the Afghan government—which supports the eradication campaign—after U.S. forces are gone in September.

That's a frightening prospect to many polio watchers. But some inside and outside the Global Polio Eradication Initiative (GPEI) say a clear resolution to the conflict, regardless of who prevails, may actually aid eradication efforts. They hope the campaign will be able to work with the Taliban to keep vaccinations going. Until the conflict subsides, though, chaos is likely to interfere with vaccination drives.

The U.S. withdrawal comes at a time when the program is making strides against the wild virus after several years of setbacks. Cases in Afghanistan almost tripled to 56 between 2018 and 2020, and the country also saw explosive outbreaks of polio virus derived from the live vaccine, which paralyzed more than 300 children in 2020. Roughly 85% of all cases occur in areas inaccessible because of Taliban control, says Aidan O'Leary, who in January took over as head of GPEI, headquartered at the World Health Organization in Geneva. The COVID-19 pandemic initially made things worse.

But so far this year, there has only been one case caused by the wild virus. That may be partly due to reduced population movement during the pandemic and more hand washing, says GPEI's Hamid Jafari, who directs eradication efforts in the region. Even so, *"The trend is very real."*

Afghanistan's fate is closely tied to that of Pakistan, with which it shares a porous, 2670-kilometer border. That country has also reported just one wild virus case in this year, after a similar upsurge from 12 in 2018 to 84 last year. (The spike there was largely because of vaccine refusals driven by rumors and a virulent disinformation campaign, along with a sometimes-inefficient eradication program.)

Some optimism about Afghanistan stems from the belief that the Taliban is not opposed to polio vaccination per se—in fact, it has collaborated with the program in the past. "It was purely for security reasons in specific areas where it imposed the ban," Jafari says. The insurgents accused polio vaccinators of passing along information to help the United States target airstrikes that killed Taliban leadership. *"Whether right or wrong, if that is the perception, that is reality,"* O'Leary says. *"You have to admit, the airstrikes have been brutal"* for the Taliban and civilians, adds Stephen Morrison, senior vice president and director of the global health policy centre at the Centre for Strategic and International Studies in Washington, D.C.

The hope is that if the Taliban continues to consolidate power, its suspicions may ease and GPEI may be able to operate unimpeded. Following years of negotiations, the Taliban recently gave GPEI the green light to conduct vaccination in mosques in the provinces where it has imposed the house-to-house ban. The program is awaiting *"a more formal statement"* to proceed this month, O'Leary says—if the security situation allows. The Taliban will select people it trusts to be trained as vaccinators by GPEI, Jafari says.

Mosque campaigns are usually not as effective as going house to house, O'Leary says, reaching perhaps 40% to 50% of the target population,

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U.S. Departure From Afghanistan

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"but we can hope to build on that."

Given this opening, Jafari thinks it unlikely the Taliban will issue new bans on polio vaccination. *"We are on a very different trajectory in negotiations with them,"* he says. Others decline to speculate. *"The Taliban's endgame remains to be determined. There are more dire and more benevolent views," O'Leary says. And Morrison cautions that "U.S. aerial campaigns won't necessarily end with the withdrawal."*

Although fighting between the Taliban and the government is a major obstacle, *"the program is not at a standstill,"* Jafari says. But it has had to cease activities where there is active fighting, says Godwin Mindra, UNICEF's polio team lead in Kabul. And districts that are accessible today might not be tomorrow, Mindra adds. A nationwide polio vaccination campaign is scheduled for September—if it can be conducted safely—with smaller campaigns scheduled for November and December. *"We will look very carefully at how the situation is evolving,"* O'Leary says.

The worst-case scenario is a descent into full civil war, with escalating violence, large numbers of refugees, and a broader public health crisis. Even then, GPEI leaders point out that the program has lots of experience operating during conflict, in Syria and many other countries.

GPEI's new strategic plan for 2022–26 aims to interrupt all polio transmission in Afghanistan and Pakistan by the end of 2023. *"If we can continue to vaccinate through this year, we can make good progress"* toward that goal, Jafari says. But success also depends on stopping the virus in Pakistan, as the virus has often jumped back into Afghanistan just as the country was making gains. Although the polio program is *"very resilient, very innovative,"* Morrison thinks the 2023 time frame may be *"a bit delusional."* For now, O'Leary says, *"We are hostage to events on the security side."*

GPEI Statement On Afghanistan

Source: www.polioeradication.org—19 August 2021

The Global Polio Eradication Initiative (GPEI) is closely monitoring developments in Afghanistan. GPEI partners and staff are currently assessing immediate disruptions to polio eradication efforts and the delivery of other essential health services, to ensure continuity of surveillance and immunization activities while prioritizing the safety and security of staff and frontline health workers in the country.

The polio programme in Afghanistan has operated for many years amid insecurity and conflict, and will continue working with all actors, agencies and organizations who enable delivery of immunization as well as deliver humanitarian assistance to populations in need across the country. The GPEI remains steadfastly committed to protecting all children from polio and supporting the provision of other essential immunizations and health services.

We strongly believe that the delivery of health care – including polio vaccination – is essential to prevent diseases and safeguard communities. Together with our partners, the people of Afghanistan, national and provincial authorities, we will do everything in our power to continue this critical work.

Polio This Week

Global Circulating Vaccine-derived Poliovirus (cVDPV) as of 24 August 2021

Summary of new WPV and cVDPV viruses this week (AFP cases and ES positives):

- Nigeria: six cVDPV2 cases and five cVDPV2 positive environmental samples
- Tajikistan: eight cVDPV2 cases

(See table next page)

Low levels of immunity and surveillance leave countries at risk of polio returning. To ensure that every country stays free from polio, it is essential to reach every child with polio vaccines and to strengthen disease surveillance.

2 ENDEMIC COUNTRIES

26 OUTBREAK COUNTRIES

5 KEY AT-RISK COUNTRIES

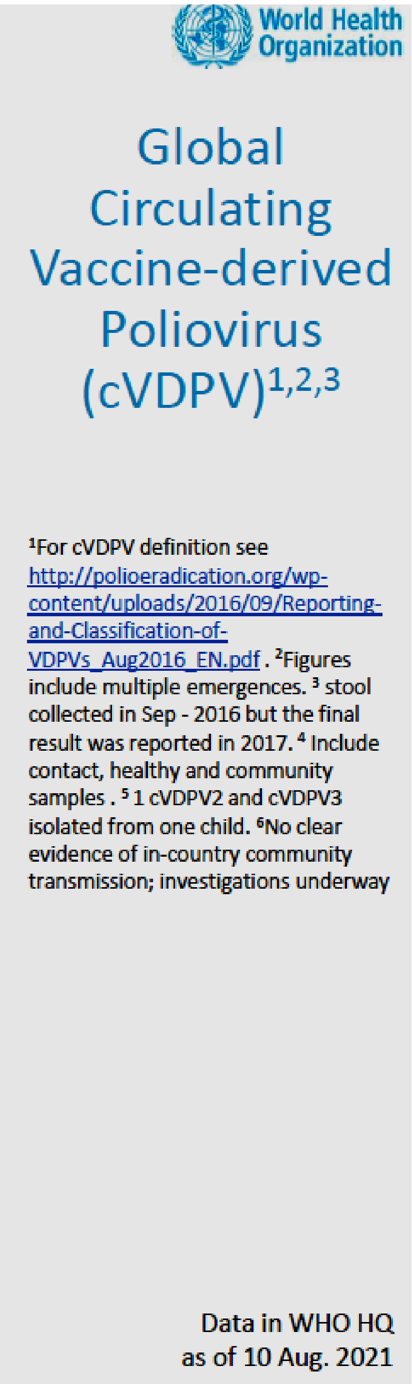
Indonesia

Mozambique

Myanmar

Papua New Guinea

Philippines



World Health Organization

Global Circulating Vaccine-derived Poliovirus (cVDPV)[1,2,3]

[1]For cVDPV definition see http://polioeradication.org/wp-content/uploads/2016/09/Reporting-and-Classification-of-VDPVs_Aug2016_EN.pdf . [2]Figures include multiple emergences. [3] stool collected in Sep - 2016 but the final result was reported in 2017. [4] Include contact, healthy and community samples . [5] 1 cVDPV2 and cVDPV3 isolated from one child. [6]No clear evidence of in-country community transmission; investigations underway

Data in WHO HQ
as of 10 Aug. 2021

POLIO GLOBAL ERADICATION INITIATIVE every last child

	Country	AFP cases (Paralysis onset between 2016-2021)							Other sources (Human)[4] (Collection between 2016-2021)							Other sources (Environment) (Collection between 2016-2021)						
		2016	2017	2018	2019	2020	2021	Onset of most recent case	2016	2017	2018	2019	2020	2021	most recent collection date	2016	2017	2018	2019	2020	2021	most recent collection date
cVDPV1[1]	Madagascar					2	6	11-Jun-21						13	6-May-21						12	7-Jun-21
	Yemen				1	31	3	27-Mar-21				1			7-Jul-19							
	Malaysia				3	1		14-Jan-20											12	9		13-Mar-20
	Philippines				2			28-Oct-19				1			31-Oct-19				14			28-Nov-19
	Myanmar				6			9-Aug-19				6			21-Aug-19							
	Indonesia			1				27-Nov-18				2			13-Feb-19							
	PNG			26				18-Oct-18			7				20-Sep-18			7				6-Nov-18
	Laos	3						11-Jan-16	5						9-Feb-16							
	Total type 1	3	0	27	12	34	9		5	0	7	10	0	13		0	0	7	26	9	12	
cVDPV2[1]	Afghanistan					308	43	9-Jul-21					36	2	3-May-21					175	40	23-Jun-21
	Nigeria	1		34	18	8	68	29-Jun-21	2[2]		53	18	8	17	30-Jun-21	1		44	64	5	37	29-Jun-21
	Tajikistan					1	23	26-Jun-21						20	16-May-21						13	20-May-21
	Ethiopia				14	36	7	24-Jun-21				9	7		13-Oct-20				3	4		28-Dec-20
	Senegal						13	14-Jun-21						26	12-Jun-21					1	4	6-May-21
	Gambia																				2	9-Jun-21
	Burkina Faso				1	65	2	9-Jun-21					12		19-Sep-20							
	Egypt																			1	10	8-Jun-21
	Sierra Leone					10	4	28-Feb-21					5	6	19-Mar-21						9	1-Jun-21
	Uganda																				2	1-Jun-21
	Liberia						3	28-May-21					2	5	21-Jan-21					6	12	20-Apr-21
	Somalia			6[5]	3	14		25-Oct-20				2	12		10-Nov-20		2	19	5	26	1	23-May-21
	Pakistan	1			22	135	8	23-Apr-21				14	2		11-Nov-20	4			40	135	32	18-May-21
	Benin				8	3	2	2-Apr-21						1	14-May-21					5	1	22-Mar-21
	DR Congo		22	20	88	81	10	30-Apr-21		19	15	29	88	2	21-Feb-21					1		29-Apr-20
	Congo					2	2	10-Feb-21					2		12-Oct-20					1	1	14-Apr-21
	South Sudan					50	9	10-Apr-21					18	5	25-Feb-21					6		1-Dec-20
	Guinea					44	6	1-Apr-21					1		5-Sep-20					1		30-Dec-20
	Iran																			3	1	20-Feb-21
	Kenya												1	2	25-Jan-21			1		1	1	13-Jan-21
	Côte d'Ivoire					61		18-Oct-20					24		1-Nov-20				7	93		23-Dec-20
	Mali					50		23-Dec-20					3		15-Aug-20					4		29-Aug-20
	Sudan					58		18-Dec-20					10		1-Oct-20					14		9-Nov-20
	Niger			10	1	10		25-Aug-20			4	6	2		13-Oct-20					8		8-Dec-20
	Chad				11	99		28-Nov-20				6	17		15-Oct-20				10	3		13-Mar-20
	Central African Republic				21	4		29-Oct-20				43	1		5-Oct-20				9	2		5-Feb-20
	Cameroon					7		11-Sep-20					4		29-Mar-20				4	9		29-Sep-20
	Ghana				18	12		9-Mar-20				16	10		22-Feb-20				17	20		17-Sep-20
	Togo				8	9		3-May-20				1	9		9-Jul-20							
	Angola				138	3		9-Feb-20				22			31-Oct-19				17			2-Dec-19
	Malaysia																		3	5		4-Feb-20
	Philippines				12	1		15-Jan-20				6			23-Nov-19				19	4		16-Jan-20
	Zambia				2			25-Nov-19				2			25-Sep-19							
	China				1			25-Apr-19				3			18-Aug-19			1				18-Apr-18
	Mozambique			1				21-Oct-18			2				17-Dec-18							
	Syria		74					21-Sep-17	1[3]	66					12-Sep-17							
	Total type 2	2	96	71	366	1071	200		3	85	74	177	274	86		5	2	65	198	533	166	
cVDPV3[1]	China												1		22-Jul-20						1	25-Jan-21
	Somalia			7[5]				7-Sep-18			2				29-Jun-18			11				23-Aug-18
	Total type 3	0	0	7	0	0	0		0	0	2	0	1	0		0	0	11	0	0	1	
Gender	Female (all sero type)	3	54	34	151	489	78															
	Male (all sero type)	2	42	70	215	606	130															
	Gender Unknown				12	10	1															

🟩 Environmental surveillance for poliovirus in selected sewage sites established and working **Changes from previous week**

★ Due to backlog reporting of viruses from member states, numbers in this table may increase without being notified as new case/specimen in the current week

"We're Still Here!" letter template from Page 6.

Date

Building or council name
Building or council address (if applicable)

Dear name of person or building,

My name is (your name), and (brief statement about your connection to this town, building or council, e.g. I am a resident of your council/I live in (name of this city)/I love to attend events in your building etc.)

Lighting to raise awareness of polio's late effects – 11th to 17th October

Polio Australia exists to represent survivors of polio and to raise awareness of the ongoing issues they face due to Late Effects of Polio. Our catchphrase is ***"We're Still Here!"*** – a reminder that polio has not been around in Australia for decades, but thousands of Australians (whether born here or overseas) still live with its effects.

October is National Polio Awareness Month and we particularly focus our activities in the second week of the month. Our theme colour is **orange**, and we are aiming to get as many significant places as possible across Australia lit up to help raise awareness of the Late Effects of Polio.

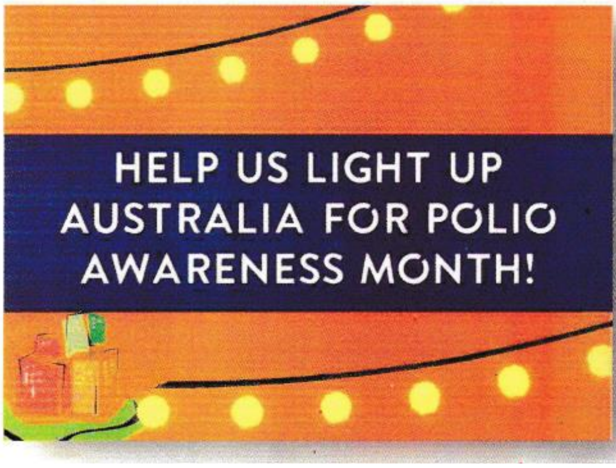
We already have several landmarks on board, and we would love your help and participation as well!

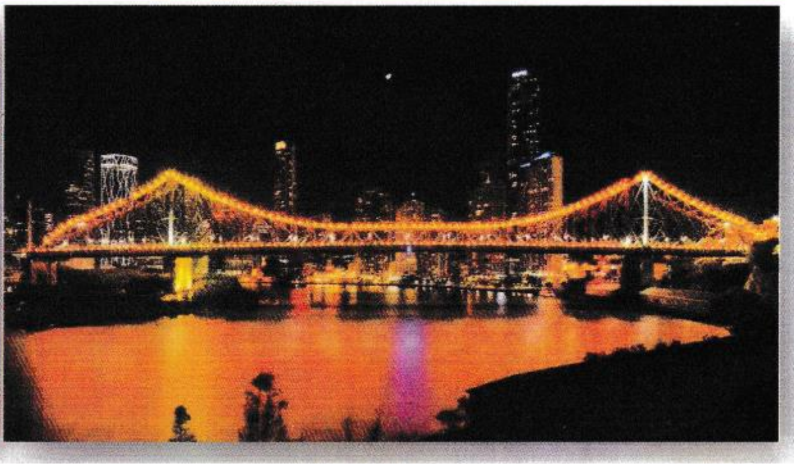
Will you support our campaign by **lighting (building/city/town) orange for the week of 11-17 October 2021**, or on any specific day during that week?

For more information, please contact Stephanie Cantrill, Community Programs Manager at Polio Australia, on 03 9016 7678 or steph@polioaustralia.org.au. We look forward to hearing from you.

Kind regards,

Your name





Arthur's TAS POLIO NEWS has been compiled by Arthur L. Dobson, former Secretary of the Post Polio Network—Tasmania Inc. (no longer operating), as a service to Tasmania's polio survivors to provide them with the latest information available to assist them living with the Late Effects of Polio (LEoP), sometimes referred to as Post Polio Syndrome (PPS).

Did you enjoy reading it?

Did you find the information it contained useful?

Do you know anyone who could take over the role of compiling each issue?

It doesn't have to be the same format that I have been using as this has developed over the years as circumstances have changed.

This is the last issue I will be compiling due to declining health but I will be happy to assist anyone willing to take on the role. Please read important note on page 15.

I can be contacted as follows:

Mr A L Dobson
P O Box 36
MOWBRAY 7248
Phone — (03) 63269340
Email — arthur_dobson@bigpond.com

That's All Folks,

Cheers, Arthur