

Mornington Peninsula Post-Polio Support Group



Next meeting: **Saturday, November 13**, at 11am at the Information office, Mornington, cnr Main and Elizabeth Sts, rear of the building. The December meeting will be on **December 4**, as the meeting room is required for our usual second Saturday of the month - this could be an early Christmas party? Contact social secretary Tricia Tagliabue 0475 455 248 **if you need a lift.**

In this Edition

WELL, what a time we've had - lockdowns, storms, power outages - but We're Still Here.

Polio Day 2021 passed without us being able to gather, so Post Polio Victoria and Polio Australia made our presence felt with strong articles in national newspapers.

In our 300th edition (**howzat!**) we have reprinted a selection of the Polio Day reports from The Guardian and Sydney Morning Herald, even the Winchelsea Star because we sometimes also need to be reminded We Are Not Alone.

The piece from Winch Star came about when a friend told Fran about a new book on the philanthropist Elizabeth Austin, who funded the Austin Hospital. She went in search of the author, ended up chatting to journalist Mick O'Mara, suggested it was Polio Awareness month he might talk to someone local. She sent him a pic of her old horse Prince which triggered his own memories of a polio friend. - see P3

Meanwhile, if anyone is still unable to get help, losing strength and mobility, or becoming chronically morose, please speak out. Call one of us (numbers right) or PNV on 0407 227 055.

Cheers Ed



One of the many articles published around Polio Day. Pictured is Gayle Kennedy, polio survivor, NSW, proud member of the Wongaibon Clan.

Contact details:

Convenor: Ian Bladon 0419 588 973

Treasurer: Martin Fisher 9789 2082

Secretary/editor Fran Henke 5979 7274

Social secretary: Tricia Tagliabue 0475 455 248

All correspondence: 48 Lyall St, Hastings, 3915

e: polionetworkvic@gmail.com

An Expert Explains:

How is poliovirus similar (or different) to a coronavirus

Poliovirus was first isolated in 1909 by Karl Landsteiner and Erwin Popper and the first human coronavirus was isolated in 1933 by Leland David Bushnell and Carl Alfred Brandley.

Written by Dr Pavithra Venkatagopalan

IN a world overwhelmed by the current Covid-19 pandemic, it is easy to forget about the existence of other viruses which can cause serious illness. One such virus that has affected our lives since the times of the Egyptian civilisation is the poliovirus. Every year, October 24 is marked as World Polio Day in celebration of the birth of Jonas Salk, the American researcher who developed the first polio vaccine in 1955.

The poliovirus is the simplest known human virus. It is very small at only 30 nanometers. In comparison, SARS-CoV-2 is a slightly larger virus at about 100 nanometers. Poliovirus was first isolated in 1909 by Karl Landsteiner and Erwin Popper and the first human coronavirus was isolated in 1933 by Leland David Bushnell and Carl Alfred Brandley.

Poliovirus causes a disabling and life-threatening disease called poliomyelitis. The virus spreads from person to person and can infect a person's spinal cord, causing paralysis. In about 25 per cent of all people infected with polio, it causes very mild flu-like symptoms including sore throat, fever, tiredness, nausea, headache, and stomach for about 2-5 days and they make a full recovery.

However, in a smaller portion, the infected individuals can develop other symptoms like 'pins and needles' or a sensation of tingling or prickling in their arms and legs, meningitis and paralysis of the arms and legs. Children under the age of five are highest at risk of developing serious poliovirus-related complications, which affects their quality of life. Poliovirus is highly contagious and can easily spread from person to person – the R-naught value, that is, the number of people one infected individual can infect for polio is 5-7. For Covid-19, the R-naught value is 1.4 to 3.9.

Poliovirus spreads by person-to-person contact, especially via the faecal-oral route. Poor hand hygiene, lack of access to clean water, improper sewage systems are the most common reasons for the incidence and transmission of polio. However, in the 1950s, the first polio vaccine was invented by Jonas Salk. This was a very safe and effective inactivated poliovirus vaccine, administered by injection.

While highly effective, in those times, the availability of disposable syringes was rare, and the speed of immunisation was low. Another polio vaccine, invented by Albert Sabin in 1961, was called the Oral Polio vaccine (OPV). This was more easily administered to large numbers of people with ease. A combination strategy was determined, and mass administration began. Polio eradication is one of the most ambitious global health initiatives in history, and polio will be only the second human disease in history to be eradicated (the first was smallpox).

Today, the only places in the world where wild polio exists are Pakistan and Afghanistan. The successful use of this vaccine reduced the number of polio cases from 3.5 lakh in 1988 to 33 in 2018.

Because polio is highly contagious, no one is safe until everyone is vaccinated. Since the introduction of the Global Polio Eradication Initiative (GEPI) in 1988, the rigorous efforts of the Ministry of Health and family welfare for surveillance of sewage samples for poliovirus and a robust vaccination program as a public-private partnership with Rotary International has made this vaccination program a resounding success. As of March 27, 2014, India has been declared polio-free.

The science of vaccine development and our understanding of our immune system has improved vastly since the development of the polio vaccine. In the field of vaccinology, researchers have been working on how to design and develop safer, effective, cheaper vaccines for decades.

Various safe and effective vaccines against Covid-19 have been developed across the globe using classical vaccine development technology as well as more modern state-of-the-art technology.

Designing a strategy, developing a vaccine, testing its safety and efficacy is a laborious, time-consuming and expensive process. However, in the times of Covid-19, vaccine developers had decades of data, abundant volunteers, and sufficient funding to study the effectiveness of the different vaccines. Collaboration between scientists, regulatory agencies, vaccine manufacturers has paved the way for us to have multiple vaccines against Covid-19 in such a short time.

Tuesday 19 October 2021

The Winchelsea Star

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Vaccines Have Been Around for a Long Time

The Winch Star's review of Barry Lamb's biography of Elizabeth Austin has gone far and wide. Many enquiries re the book have come in. One enquiry was from Fran who lives on the other side of Melbourne. Fran is a journalist and author. I put her in touch with Barry Lamb and I think there are further plans do more material on Elizabeth Austin.

I realised from her emails that Fran had been a polio sufferer as a child. When I was a kid polio caused similar lock-downs as covid is doing now. It was a dreaded disease that, if you survived, you could be crippled for the rest of your life. I remember at primary school if there was a case at school the school closed down for a considerable period. Then in 1950's a Doctor Salk came up with a vaccine. I am not sure if it was compulsory or not but every one had it.

Long time memories have it that the vaccine was delivered through a needle

type instrument that was dipped in the vaccine bottle and used to scratch a hole in your skin until a bit of blood appeared. The vaccine was introduced to your body through the scratch.

The instructions were that you protected the vaccination site from any knocks and bangs. At that stage I was a football fanatic who, one day, was going to play with Carlton so I continued on. The next game I played in I gave someone a hip and shoulder bump. My arm rapidly swelled and became very sore and stayed so for some weeks. However I never caught polio.

We had a family friend who did. You may remember Bernie's brother, Kevin Hinze, who used to run the ABC's gardening program. Bernie caught polio as a youngster and had to walk with the assistance of steel leg braces. At that time we had a horse called Mother who could best described as recalcitrant. She would do what she wanted to do with no regard to what her rider intended. She would plod along when we were heading away from home and be a race horse when turned towards home.

One day Bernie was around when we were saddling up Mother and he asked if he could have a ride? We sniggered and said, "Yeah" How could someone who had trouble walking control this horse? Bernie did have trouble climbing up into the saddle but, once there, went for a quiet canter up and down the paddock. The lesson for me. You be in control. Not the horse.!

Unfortunately Bernie died at a fairly young age as did many polio sufferers.

An email from Fran showed her on her pony. Fran found the same enjoyment as our friend Bernie in using horses to overcome their disability.

Now to the point of this article. Polio doesn't happen now days. The polio vaccine put it out of business. The same principle should apply to covid virus. If every one who can has the vaccine then covid virus will hopefully go the same way as polio virus.

Mick O'Mara

End in sight for a disease that closed borders, shut pools and theatres

By Julie Power

October 24, 2021

SIX years before polio vaccinations began in Australia, Dorothy Thomas recorded the news that parents feared. Her 10-month-old daughter, “darling Gillian had been stricken with the dread polio”.



Gillian Thomas, chair Polio Australia, pic SMH

Gillian Thomas, now 71 and the president of Polio Australia and Polio NSW, was paralysed in both legs and one arm. Her three-year-old sister had a mild case. When COVID-19 hit, Ms Thomas got vaccinated as soon as possible. “I know what it was like for me. Vaccines were unavailable.”

Nearly 70 years after the polio vaccine was invented, elimination is close. Two cases of the virus poliomyelitis have been reported worldwide so far this year compared to 140 last year, says the World Health Organisation. A case was reported in Afghanistan, where the Taliban has announced it will allow mass door-to-door vaccination of children next month, and the other in Pakistan.

Reported first by the ancient Egyptians about 4000 years ago, huge polio outbreaks in the first half of the 20th century terrorised families. Australia will celebrate being officially polio free for 21 years next week, and about 40,000 people live with some form of paralysis caused by polio.

Even today, there is no cure. Polio is spread through person-to-person contact, mainly by the transmission of faeces to the mouth, and sometimes by contaminated water. If eradicated, it will be the second disease to become history. Smallpox was the first. The Global Polio Eradication Initiative (GPEI) is calling for a last big push to eradicate the disease. Its members include the WHO, the Gates Foundation, Rotary International, Global Citizen, Gavi and Polio Australia. They are also asking the Australian government to increase funding, estimating a \$15 million annual contribution would help immunise 11.5 million children.

Sarah Meredith, regional director of Oceania with Global Citizen, a non-profit, said the news of two cases was “terribly exciting”. She said the polio program’s success in reaching people with vaccines had been a blueprint for how to end the COVID-19 pandemic.

“As Australia and the world begin to open up post-COVID, it is worth noting that neither smallpox nor polio has ever reached natural herd immunity,” Ms Meredith said. “Vaccines

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

are the solution. Like smallpox, it can only be eradicated once there are no cases. About 85 per cent of the population needs to have the polio vaccine for that to happen.”

The GPEI also reports on cases of circulating vaccine-derived poliovirus. If not enough children are immunised against polio, the weakened virus can pass between individuals and over time genetically revert to a form that can cause paralysis.

That’s why it was so important to reach every last child, said Ms Meredith. “Only once there are zero cases for two to three years, will the World Health Organisation start the certification that we are polio free,” she said.

To achieve total elimination by 2026, though, requires a multibillion-dollar effort to vaccinate 400 million children in 50 countries - an estimated 3.5 million in Afghanistan alone - and surveillance in 70 countries. Without eradication, polio could again surge to 200,000 new cases. While there are only two cases, traces of the virus were reported in 63 places, mostly in water, in Afghanistan and Pakistan.

Jonas Salk, who was an international hero when he invented the first polio vaccine, has opted not to patent his vaccine. When asked why he didn’t, he replied: “Well, the people, I would say. There is no patent. Could you patent the sun?”

For many polio survivors, the similarities with COVID-19 were hauntingly familiar. In the United States and Australia, borders between states were closed, and pools and theatres shut to prevent the spread. Houses were fumigated, people quarantined, and entire families ostracised, wrote the University of Melbourne’s Professor Joan McMeeken.

Compared to vaccination for COVID-19, Ms Thomas recalled there was less hesitancy about the polio vaccine, very likely because the effects of polio were highly visible. “What is similar is parents were so scared that their kids were going to get polio,” she said. “I remember in my baby book, my mother wrote ‘my darling Gillian has been stricken with the dread polio.’ It was such a poignant statement she made. It just shows the dread in the community, and early on they didn’t know how people contracted it, and there were all sorts of weird ideas.”

“For example, how did I get it? I was a baby. They didn’t know when it was going to strike. They were hanging out for a vaccine to become available.”

**About Dr Peter Freckleton, Board Member, Post Polio Victoria, see article p 8.
From his bio on the PPV website:**

“I commenced on the PPV Board in February 2018. At the age of 6, I was hit by a speeding taxi, resulting in a broken thigh bone and a lengthy spell in traction. I contracted polio while learning to stand again. Initially, I had almost total paralysis, being unable to move my limbs or lift my head. After being sprung from Fairfield Hospital, I regained upper body strength, but the legs remained paralysed, so since then I have needed two callipers and crutches to get around. I studied Law/Arts at Melbourne Uni and was a tutor at Monash and Melbourne. Subsequently I was granted a French government scholarship and obtained a doctorate from the University of Paris. On returning to Australia, I became a barrister at the Victorian Bar, which has been my main profession, later branching into French legal translation. I joined the Board of PostPolioVictoria (PPV) after meeting people involved in it, and, was impressed by its work for polio survivors, which is going from strength to strength.”

Australia's polio survivors: 'They've forgotten that we're still here'

For most, our previous pandemic is a distant memory. But for these polio survivors new health problems have just begun (This article featured five Australian polio survivors, we have chosen two Victorian stories for space reasons -Ed).

by Sophie Black

AUSTRALIA was officially declared polio-free in 2000. Two decades later, for many people the only time they've stopped to think about the disease was the moment the poliovirus vaccine certification was stamped into their medical records, or later, their children's. But for many polio survivors in this country, and there are approximately 40,000 of them, the last 18 months have served as a reminder of living with the last virus to shut down public places and spread fear through communities.

Of the several polio epidemics that occurred in Australia, the most notable ones occurred in the late 1930s and early 1950s. About four million Australians were infected (although many cases went under-reported), with about 20,000 to 40,000 developing paralytic polio between 1930 and 1988. Polio (poliomyelitis) is a disease that mainly affects children under five years of age. The highly infectious virus attacks the motor neurons that relay messages from the spinal cord to muscles, often leading to muscular degeneration. One in 200 infections leads to irreversible paralysis. Among those paralysed, 5% to 10% die when their breathing muscles become immobilised.

Gary Newton, Geelong

I'M the youngest of five kids. I was a healthy baby, learned to crawl and stand and walk by the age of nine months. Just after my first birthday, 15 months, in the summer of 1954, my older sister came home from school and went to get me out of my cot like she always did. But when she tried to lift me out I couldn't raise my arms ... I was kind of like a rag doll.

So that was the beginning of the journey. I had 32 days in complete isolation at Fairfield Infectious Diseases hospital. At that time, polio was a disease that came in waves, mostly during summer. Public places were closed down, like cinemas and pools, and there was a lot of fear. And there was a stigma associated with having a child with polio, I think that was probably part of the reason why my mum and dad never really spoke to me about it. It was a fairly traumatic time, for many parents, not just mine. Imagine putting your child into isolation for 32 days. No one to stop them crying. I was left with permanent paralysis in my legs. So I've worn callipers or braces every day of my life.

More recently, I've lost about 30% use of my arms. About five years ago, I started to read about people who were holding chickenpox parties [in order to deliberately infect



Imagine putting your child into isolation for 32 days. No one to stop them crying. - Gary Newton

children]. I thought, I don't think these people really know what preventable diseases can be like, I need to do something. Maybe I could use my voice to change people's perceptions of these diseases, which people have forgotten.

Polio survivors are now the forgotten generation because we've lived two generations of not having the virus in Australia. I don't dwell on what polio has taken away, I focus on what it has given me and the gratitude that I've got for all the things around me.

Gabe Mostafa, Melbourne

I WAS born in Egypt – Cairo – in 1958, and moved to Australia in 1967. I wasn't on a ventilator or anything like that, but my right side was affected. My sisters and brothers say that my body looks like Hercules on one side and the other half looks like Peewee. At the time I didn't go to hospital because mum thought they couldn't do anything for me. Mum kept me at home and basically looked after me and massaged my legs and arms – back then there was very little knowledge about polio.

I learned to live with it and was very active in adulthood, I used to run 10kms a day, did things like helped a friend build a house.

Now I'd be lucky to do any of that stuff because fatigue sets in and all I want to do is go to sleep. I started to get pain in my back, pain in my legs. But it wasn't until last year when I read an article about post polio or late effects of polio that I realised I ticked a lot of the boxes. They told me I'd need a back brace, and an arm splint. I'd been falling over a lot too. Earlier this year I bent over to pick up something at my office and I fell and really injured myself. My right side is very weak. My wife won't let me get my own dinner out of the oven. I can't carry it with both hands, and I could lose balance. They're the things that are challenging now. I'm glad I didn't know it was coming though, I would've wrapped myself up in cotton wool.

Back in Egypt and Gaza, all my siblings and cousins used to go to the beach, and they'd all go out swimming but I was left sitting on the shoreline because I was in callipers. So when I eventually came out of the callipers I was like a bull out of a gate.

I asked mum a while back about how I contracted polio. All my brothers and sisters got the vaccine, but I couldn't – she told me, "you always had a cold, so you couldn't get in to get the vaccine". And then I got it, I contracted polio. Mum used to sit for hours crying when I was a kid, one of my brothers told me recently.

My children went and got vaccinated [against Covid] recently. It wasn't an issue. Everybody in my family has been vaccinated.



Gabe Mostafa lives with the late effects of polio. Diagnosed in 2020, he wasn't vaccinated when in Egypt, his country of birth. Photograph: Christopher Hopkins/The Guardian

Peter is in a wheelchair after getting polio, but the NDIS says he's too old for funding

By Dana Daniel Oct 25, 2021

THE Australian Human Rights Commission has accepted a discrimination complaint against the National Disability Insurance Agency, challenging the age limit that restricts funding for service to those aged under 65.

Peter Freckleton, 74, lost the use of his legs after suffering polio as a child, but has been unable to access disability support services under the NDIS because legislation governing the scheme makes anyone aged 65 and over ineligible.

"This is a clear breach of the United Nations Convention on the Rights of Persons with Disabilities," Dr Freckleton told The Sydney Morning Herald and The Age.

It comes as the Morrison government attempts to reform the NDIS to rein in spending, after its controversial trial of independent assessments. NDIS Minister Linda Reynolds has warned that the NDIS faces serious sustainability issues, with expenditure forecast to grow to \$40.7 billion in 2024-25, \$8.8 billion above estimates.

Dr Freckleton is seeking for his NDIS eligibility to be assessed solely by reference to his disability, without regard to his age, for the NDIS Act to be amended so that all polio survivors are eligible, and for age restrictions to be removed for all Australians accessing the NDIS. The Public Interest Advocacy Centre has agreed to represent him at the UN if his matter is not resolved through the AHRC, which conciliates complaints and can make recommendations but does not make binding decisions. Dr Freckleton's argument relies on the UN convention because the NDIA is exempt from the Age Discrimination Act.

Dr Freckleton said removing the age limit for NDIS services would not result in cost blowouts, as only a minority of elderly Australians would meet the eligibility requirements.

NDIS independent assessments will be introduced this year despite concerns and mistrust. "It has to be a permanent and significant disability," he said.

The Disability Doesn't Discriminate campaign, which has collected signatures of more than 20,000 Australians, has the support of a number of crossbench MPs and senators, including Greens health and disability spokesman Jordon Steele-John.

"It is clear in speaking to the community that the aged care system is not providing enough supports for many disabled people," Senator Steele-John said.

A spokesperson for Minister Reynolds said the design of the NDIS was based on the Productivity Commission's recommendation that access be restricted to participants aged younger than 65, noting this was a bipartisan policy.

"The NDIS was designed to avoid replacing services already provided through the health or aged care systems," the spokesperson said.



Dr Peter Freckleton with Post Polio Victoria chair Shirley Glance. Pic: The Age and SMH