

# **Polio Perspectives**

# polio network victoria

Chair report Bev Watson

elcome to the Summer, 2024 edition of Polio Perspectives. I hope the beginning of the New Year has been kind to all. Given the range of recent weather events I do hope you are all safe and well.

This year I would like to have a focus on our Support Groups. The convenors, who are so good at maintaining contact and support for their members provide a valuable link to the wider Polio community. For example: Lilydale & Yarra Ranges

Jan Green from the Lilydale & Yarra Ranges Group reports that her group meets socially in Lilydale on the second Wednesday of each month for brunch. There are eight regular members and few who attend occasionally. This is a very friendly and supportive group, always open to welcoming new members. Jan reports that "this group has morphed into a "family", supporting each other in difficult times – it's amazing." Contact Jan on 0423 214 930 or email: jan@jgreen.id.au for more information.

Given the success of 2023 Polio Day held at Hastings, we have settled on Seaview at Williamstown for Polio Day October 23, 2024. The program is being drawn up, focussing on issues to help us manage the ongoing tricks played by the virus.

As we head into this year, I know committee members will be working to ensure we are able to continue to provide the best information and support in all areas we can.



Summer 2024

Helen and Leon Farrell who joined the committee in 2021 have retired. We are most grateful for their contribution and welcome new members – Vicky Goodwin, Deanhna Culshaw and Graham Picone. For the committee's continued support of Polio Network Victoria, I say a huge thank you as the combined effort is greatly appreciated.

I wish all good things for this coming year and encourage you to let us know of any topics you would like covered in *Polio Perspectives* or matters you would like the PNV committee to highlight.

Bev Watson Chair – Polio Network Victoria

In this edition: P2-5: Polio Day 2023 coverage P6: PPS explained for those who don't understand! P7-8: Internal shivering and benefits of Valium P8-9: Vale PDQ Bach and Margo Ashton; Who's who? P10-11: useful lists.



Hastings venue: Sanctuary Inn, Western Port

Summer 2024



**Polio Perspectives** 

# Polio Day 2023 at Hastings

The theme selected by the PNV committee for Polio Day 2023 at Hastings, was 'Stayin' Alive'. With current changes to Aged Care and NDIS, cost of living, challenging weather conditions, lack of focus on our rights to move around the community, needed clarification. The speaker on that topic was, Dr Natasha Layton, with her presentation "What have human rights to do with assistive technology?'

More than 60 attendees, plus a generous army of Rotary Internationals from the Calder Cluster and helpers from the 100 year old Uniting Church across the road, were welcomed by PNV chair Bev Watson. The event was opened by the MP for Hastings, Paul Mercurio. He was across the topic thanks to prior provision of research by the host support group - Mornington Peninsula.

Dr Natasha Layton has a formidable range of experience – as an occupational therapist and senior research fellow is local, state, national and international. "The disabled individual's life experience and rights experience is much more complex and interactional than that of persons without disabilities. Persons with disabilities have been particularly prone to fall between the cracks," she quoted from a convention in 2008.

Denial of needed supports is discrimination, as is reasonable accommodation, also access to work, health and recreation facilities. "I do not expect to get access to the Pyramids or Uluru but I do want to get into all of the library and all of the community centre" – quote from Shut Out report, 2009. Australia signed up to the United Nations Convention of the Rights of People with Disabilities in 2008. There have been various reports and fact sheets since, Natasha's display showed. And there have been a number of reports of violations to the Convention since. These can be followed up at: *https://www.ag.gov.au/rights-and-protections/human-rights-and-anti-discrimination/united-nations-human-rights-reporting/treaty-body-reporting* 

If making submissions appears hard, help is available. Most of the time when basic life, like getting in and out of supermarkets, is beyond us, make a list for discussion and follow up with authorities. As Bev Watson says "why does it have to be so hard!". Email *polionetworkvichelp@gmail.com* and we'll contact the people or organisation responsible.

Next speaker was Dion Abel from Services Australia, aka Centrelink etc. He worked through the application processes for Aged Care Packages. His message was that in this time of change for the department, they were trying to work with clients rather than focus on providers as in the past. There were robust questions about costs, timings, waiting lists. One required his assistant to answer – can you be on NDIS and My Aged Care simultaneously? Took phone call to office, not sure if a clear answer emerged. Afterwards, it was suggested next year we invite front line troops from SA to speak.

After a heady morning, we cut the Polio Day Cake 2023. It was as light a cake as last year's 36th anniversary (pictured P2).

After lunch we heard from Ryan Smith, access consultant and avid traveller. He gave a thorough talk on the range of places we can go with latest assistive equipment, and the need to demand accessible travel, accommodation. He said Egypt was surprisingly accessible, also Norway from where he took an accessible cruise. Locally Point Nepean had the best accessible toilet and bathroom seen anywhere, he said, showing pictures. Glamping at Mansfield also was pleasant, while Tidal River accommodation had power points and clothes hangers within reach.

Equipment wise, he plugs an e-bike onto his wheelchair for faster travel. And uses trail riders for which Bev said she'd been a guinea pig. This is from Parks Victoria website: "TrailRider all-terrain wheelchairs are now available in a number of Victoria's parks. Allows visitors to access rugged walking trails not accessible with conventional wheelchairs. Local staff provide expert advice on the best routes for chairs. A minimum of two chair operators are required to operate the chair. TrailRiders have adjustable seating and supports, making them suitable for adults and children with varying abilities. Motorised chairs are available at some locations allowing visitors to explore steeper and longer trails. TrailRiders are free to use, book in advance. Users are required to bring a helmet and undertake a chair induction. The chairs easily disassemble and fit in the back of most medium sized SUVs". Ryan is currently assessing Gold Coast hotels for accessibility. Hugh task.

'A Miracle Baby' was the title of Dawn Baudinette's talk. Dawn came across from Portland on the western edge of Victoria. She had Polio in 1937 and spent six years in Sale Hospital where everything was taken away, her doll and even her name. She talked for the first time about bullying received at school, attended in a body brace. One day, she revealed, boys threw her to the ground and stripped off her clothes to see if she was flesh and blood underneath the metal. Being Dawn, that made her even more determined to succeed. She applied for a teaching scholarship, but was refused on grounds of the Polio. So her grandfather, Sir Albert Lind, then Victorian Premier, encouraged her to come up to Parliament House and sign a document stating she would never accept superannuation from the State of Victoria.

Dawn, christened Rose Mary, but dubbed Dawnie by her grandfather (causing passport and other identity problems) went on to be the State's first female principal and school inspector, winning a Fulbright Scholarship to America. Her husband had a serious farm accident, so she resigned from teaching to care for him, which involved looking after the farm, learning to shear and getting a truck licence. She decided the farm was better suited to growing lavender. For this she learned distillery, about essential oils, awarded a Churchill Fellowship looking into planting, pruning, harvesting, distilling and drying. Dawn never mentioned having Polio until realising she had late effects, reduced the scale of the lavender farm, and applied for a job at Portland Smelter which involved an extensive medical. She had to confess, got the job. But still unable to access all the superannuation she was due.

When the Warrnambool Support Group was formed, Dawn was drawn in, finding the support and information she needed, while still not wanting to be seen as a polio. So, for her to reveal to us the treatment she received as a child was a huge act of trust.

Hard to follow that, but Bron Roberts came on with her Laughter Workshop, most people took part in the fun, relaxing.

Then it was time for afternoon tea and raffles. Prizes were super handmade goodies including a beautiful rug made by JoanTie (pic P2). Cash raised goes of course to staging next year's Polio Day. The buzz in the room at Polio Days is always warm and

friendly. It 's about old pals coming together to share experiences, information and hugs. Polio Day 2023 was very much like that.

Presenters offered us information on moving forward where we need help and justice to avoid drowning. Not everyone can be feisty enough to take on authorities, but we now know better whose and what buttons to press. Polio Network Victoria is there for us.

Very grateful to our 'boots on the ground' helpers and venue staff. The day ran smoothly, food appreciated. Polio Day 2024 is due to be held in a metropolitan area, and the PD committee has settled on a delightful venue at Williamstown. Details of the program and bookings will follow in the next edition of PP.



The Stayin Alive logo and poster was designed by Dr Zoe Thomas and Dennis Veal, who was a tremendous support collecting donated items for raffles and gifts for guest speakers. Including specially made condiments from Benton's Rise farm.





Services Australia team, so helpful. Top Natasha Layton's graphic illustrating our dilemmas.



Polio Day committee: Max Keystone, Bev Watson Fran Henke, & Georgie Stayches, Fetching Events.

# The Basics of Post Polio Syndrome

Mumbai Live explored Post-Polio Syndrome, shedding light on symptoms, challenges, and the potential of regenerative medicine in offering hope for those living with PPS. May be a useful summary to explain to friends, family, and yes, health professionals.

IN the mid-20th century, the world faced an epidemic of a crippling disease called polio. Thanks to widespread vaccination efforts, polio was virtually eradicated by the turn of the millennium. However, the story did not end there for many survivors of the virus. Post-polio syndrome (PPS), a condition that can emerge decades after the initial infection, continues to affect millions of people worldwide. This article by Dr Pradeep Mahajan, Regenerative Medicine Researcher and Founder of StemRx BioScience Solutions India, explores Post-Polio Syndrome, shedding light on its symptoms, challenges, and the potential promise of regenerative medicine in offering new hope for those living with PPS.

#### What is Post-Polio Syndrome?

Post-polio syndrome is a condition that typically strikes polio survivors 15 to 40 years after their initial recovery. The precise cause of PPS remains elusive, but experts believe it may be related to the excessive stress that polio places on motor neurons. Over time, these overworked neurons may start to deteriorate, leading to the characteristic symptoms of PPS.

**Symptoms of PPS can** vary widely among individuals but commonly include muscle weakness, fatigue, muscle and joint pain, and difficulties with breathing or swallowing. Many PPS patients also report a heightened sensitivity to cold temperatures, which can exacerbate their symptoms. These physical challenges can result in a significantly reduced quality of life, as patients struggle with daily activities that were once manageable. Due to nerve involvement and infection, the patient develops lower limb weakness with foot drop and muscular atrophy of the lower limb.

#### Regenerative Medicine is a promising option:

While there is no cure for Post-Polio Syndrome, researchers are increasingly turning to regenerative medicine as a potential source of hope for patients. Regenerative medicine harnesses the body's own ability to repair and regenerate damaged tissues, offering a novel approach to treating a wide range of diseases and injuries.

One promising avenue involves mesenchymal cell therapy. These cells have the unique ability to differentiate into various cell types, making them a potential solution for replenishing damaged motor neurons. By introducing healthy mesenchymal cells into the affected areas, researchers hope to stimulate the regeneration of damaged neurons, thereby improving muscle function and reducing pain.

Additionally, advances in regenerative medicine have led to the development of innovative therapies like tissue engineering and gene therapy, which hold potential in treating PPS. Tissue engineering can create artificial muscle tissues that could potentially replace damaged muscle, while gene therapy aims to correct the underlying genetic and molecular factors contributing to PPS.

**The take-away:** Post-polio syndrome continues to affect a significant number of polio survivors worldwide, robbing them of their physical abilities and quality of life. While there is no cure at present, regenerative medicine offers a glimmer of hope. Cell therapy, tissue engineering, and gene therapy are among the avenues that researchers are exploring, with the potential to alleviate the symptoms and improve the lives of those suffering from PPS.

# **INTERNAL SHIVERING**

Question to Dr Bruno: I have been experiencing a lot of internal shivering. It used to wake me up at night but now is coming and going throughout the day as well. The problem seems to stem from my spine between and just below my shoulder blades, could this be something to do with my weakened respiratory and diaphragm muscles.

A: The first rule is to make sure nothing other than PPS is causing the shivering, like an infection, thyroid abnormality.

That said I have heard over the years from a number of polio survivors reporting "internal shivering". Your experience is probably not related to respiratory or diaphragm muscles. And it makes sense that you feel the shivering below your shoulder blades since it is your core muscles, especially lower chest, and also leg muscles that are the primary shivering muscles.

Remember the form and function of shivering: rhythmic contraction of muscles to generate heat to help you stay warm. Polio survivors should shiver more easily because poliovirus damage opens skin blood vessels, allowing hot blood to flow to the skin surface, dump heat into the environment and drop your core body temperature.

There may also be a brain reason for polio survivors to shiver more easily. The "shivering center" in the brain (the posterior hypothalamus) was consistently damaged by the poliovirus, possibly making polio survivors more sensitive to being even slightly cold (for example not being thoroughly covered in bed) and therefore shivering more easily.

For more information about temperature regulation in polio survivors, go to <u>polionetwork.org/encyclopedia</u>, click on the INDEX/CATEGORIES BAR and look for your topic of interest in the ENCYCLOPEDIA of POLIO & PPS.

## Valium and Polio Survivors

#### By Richard L. Bruno, HD, PhD

VALIUM is the great grandfather of the benzodiazepine ("benzo") family of antianxiety drugs. Valium © (diazepam) has been on the market for 60 years. After its FDA approval in 1963, Valium became the best-selling medication from 1968 to 1982, with more than 2 billion tablets prescribed in 1978 alone. Valium was nick-named "Mother's Little Helper" after The Rolling Stones 60's song about women becoming dependent on drugs to deal with the "drudgery and anxiety" of suburban living.

But Valium and its offspring do not necessarily cause dependence. In 2016, benzodiazepine misuse (i.e.use "any way a doctor did not direct") was reported in 2% of the 31 million benzo users, with adults 65 or older reporting the lowest (<1%) misuse. So, with the less than 1% misuse potential in the back of our minds, let's look at the benzos that help treat polio survivors' symptoms.

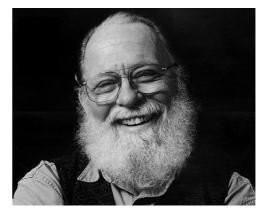
<u>VALIUM</u> © (diazepam) Benzodiazepines not only effectively treat anxiety, but also treat muscle spasms, seizures and used to provide sedation for medical procedures. Benzos work by stimulating receptors for the neurochemical GABA that "calms" neurons. For polio survivors, Valium's usefulness is in treating muscle spasms. Polio survivors, with their muscle imbalances, muscle overuse, leg length differences, unusual spinal curves and muscle overuse, are prone to develop painful muscle spasms, often in the back and neck. At The Post-Polio Institute we found that a week or two of low dose (2.5 mg to 5 mg two or three times a day) could break the cycle of pain and spasm and then Valium could be stopped. We never had a patient abuse the drug. When patients got rid of the spasm and pain they also got rid of the Valium.

One important feature of Valium is its half-life (the time it takes for half the dose you've taken to leave your body) of between 20 and 50 hours. This can be a good thing since you don't have to keep taking the drug frequently during the day. But it can also be a problem because Valium is sedating and can keep you too "relaxed" for too long. So you have to be aware of how Valium and all benzos affect your attention and coordination before, as the package insert warns, you "drive or operate heavy equipment". But Dr Bruno added: "did not appear associated with subsequent dementia"

# RIP Peter Schickele aka PDQ Bach, Polio Survivor

MUSICIAN, comedian and satirist Peter Schickele died in January at his home in Bearsville, New York.

Schickele was born in 1935, studied music at Swarthmore College, Pennsylvania, then composition at Juilliard. In New York he began exploring musical comedy, and in 1965, debuted his comic alter-ego P.D.Q. Bach. Named as a play on the vast family of Baroque composer Johann Sebastian Bach, P.D.Q. was, according to Schickele, "the youngest and oddest of Johann Sebastian's 20-odd children", and entirely fictional. Schickele's ambitions as a pianist were cut short when he contracted



Peter Schekiele aka PDQ Bach

polio at 19. He ended up with limited use of his left hand and a left foot that flopped, which made his physical exploits more remarkable. As late effects of Polio kicked in, he used a wheelchair.

When the Woodstock Chamber Orchestra performed at the Woodstock Playhouse, Peter Schickele then 77, put in a rare appearance and even walked up to the microphone to address the crowd (eschewing the wheelchair). "I'm very pleased to talk with you, but I didn't know I was going to talk with you or I would have worn my other pair of jeans." Another notable performance was with fellow polio survivor, violinist Itzhak Perlman. They brought the house down in 1994 at a Boston Pops Concert. The pair played 'Konzertschitcke for two violins mit orchestra' by P.D.Q. Bach - "the 21st of Bach's 20 children". The great composer John Williams conducted - for star wattage.

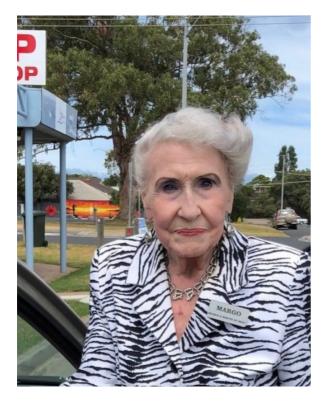
#### Who's who in our Polio world

**Polio Australia** is the national organisation representing Australia's 400,000 polio survivors since 2008. Provides information, education and support services to polio survivors, families, carers, and health professionals. Has received Federal Government funding to provide educational services for GPs. Polio Australia continues to apply for project and operational funding through philanthropic sources while establishing a relationship with Rotary Clubs and Districts.

**Post Polio Victoria** since 2012, advocates for Polio survivors to have access to information and services to live actively and independently. Has received some government funding; but relies on donations and volunteers to help achieve goals. Recently won Focus on Ability Film Festival 2023, Nova Employment Choice Award.

**Polio Network Victoria** since 1987 initially auspiced by ParaQuad Victoria, now independent, has supported polio survivors, carers and families through state-wide support groups and the quarterly newsletter *Polio Perspectives*. Funded by memberships, grants and bequests, managed by a representative committee.

**Polio Services Victoria** (PSV) established by the Victorian Government in 1998 to provide ongoing expertise and support for people with a history of polio. PSV consists of a core allied health team available to provide consultations to clients. A rehabilitation medicine consultant is also available to consult on polio-related medical needs. It is based at St Vincent's Hospital, also conducting regular regional clinics.



Margo Ashton outside the Op Shop at Rye she served as co-ordinator for so many years.

### **RIP Margo Ashton**

Long standing member of Mornington Peninsula Post Polio Survivors Group Margo Ashton has died. Margo, nee Hester, had polio in 1944, aged seven, at Port Melbourne. She and much loved late husband Seaton Ashton, were journalists with the Herald Sun and Leader, living at Rye on retirement. After his death, she moved into supported accommodation. Daughter Barbara Smith who brought Margo to the PSV clinic at Hastings, 2021, advised of her death on January 24.

She was much loved member of Southern Peninsula Rescue. In 2017 to mark the 20th anniversary of the Search and Rescue Op Shop at Blairgowrie, which raised \$785,821 to support the squad, coordinator Margo Ashton was recognised.

While unable to attend group meetings, Margo corresponded regularly, updating her polio and health issues, which now provide a picture of ageing faced by us all. *-Fran Henke* 

**Late news:** Paul Alexander who has spent 70 years in an iron lung in Texas, has been rushed to hospital after contracting coronavirus. Mr Alexander, 77, has lived in the 7ft ventilator since he was six years old. The Dallas, Texas, resident was left paralysed by the Polio virus and is the last person living in an iron lung. Fears about his condition were announced on his social media page. After surviving one deadly outbreak, he did not expect to be affected by another. He sadly died on March 11, 2024.



Polio Day, PP, and our support groups exist for us to keep in touch with fellow survivors. We have special relationships going back to childhood. We may not have known each other then, but that friendship today runs deep. Was there a pal from childhood polio days at Fairfield, Lady Dugan, Mt Eliza, Mt Macedon Golf House, Hampton, the various base hospitals, you'd like to talk to again? Let us know and we'll try to help that happen. *polionetworkvichelp@gmail.com* 

"Sometimes I fall without anyone pushing me", Nigerian Busayo Olaitan, entrant and polio survivor in an Of Course online challenge.

Readers of *Polio Perspectives* have indicated willingness to pay \$10 annually to receive the quarterly newsletter. No longer supported by an auspicing body, Polio Network Victoria relies on funding to print and email this newsletter, undertake other activities, so Dear Readers now is the time to send your \$10. Address to The Treasurer, PO Box 205, Woodend, 3442, or by direct deposit to: BSB 633 000 a/c 169 887320. A/c name Polio Victoria Inc. Be sure to put your name in

the reference field and **provide email address** to save postage and paper. Thank you!

#### Vol6 No1

# Useful ínfo

## **Contact PNV:**

PO Box 205, Woodend, Vic. 3442 Phone: 0407 227 055 polionetworkvichelp@gmail.com Contact Bev for any questions, venues of meetings, PP content.

#### PNV meeting: Sept 20.

#### Polio Services Victoria (PSV) 9231 3900

St Vincent's Hospital, ground floor, Bolte Wing, Fitzroy, 3065. Team of allied health professionals offers: access to a rehabilitation consultant (referral required); specialist assessment; referral to & collaboration with mainstream health providers to develop client service plans; information & education service to health providers, clients who had polio, & the wider community. **PSV** online: www.psv.svhm.org.au

#### **Mobility Aids Australia**

offers electric scooters, lift chairs, wheelchairs, walkers, electric beds, bathroom and toilet aids and much more. 1/820 Princes Hwy, Springvale Ph: 9546 7700

#### **Travellers Aid service**

www.travellersaid.org.au/ bookings

- Southern Cross station 9670 2072
- Flinders St Station: 9068 8187
- Seymour 5793 6210

#### Home & Community

#### My Aged Care

Australian Government website and phone line on aged care services available. Ph: 1800 200 422

#### NDIS

If aged under 65 with a disability - requires assessment. Contact 1800 800 110

### Equipment funding

State Wide Equipment Funding – SWEP Ph: 1300 747 937. Aids and equipment to enhance independence at home. Arrange through SWEP's physio or OT.

Leef Independent Living Centre 652 Glenhuntly Rd, Caulfield South, Ph: 1300 005 333. Stocks scooters, walkers, assistive technology, shoes and clothing.

#### **Disabled Motorists Australia**, 2A Station St, Coburg, Vic.

Ph: 9386 0413 Assists motorists with disabilities to gain independence through motoring. Referrals & support.

#### Neuromuscular Orthotics NB: new address

Phone:1300 411 666 25 Glendale Cres, Mulgrave, 3170. Darren Pereira - Principal Orthotist. *www.neuromuscularorthotics.com.au* 

#### Regional clinics for Polio Services Victoria 2023

currently accepting expressions of interest for this clinic: **Shepparton**: Oct 11-12 **Traralgon**: Nov 22-23

Contact PSV on 9231 3900 or 1800 030 324

# Polio Support and Advocacy Groups

For all contact details: Bev Watson: 0407 227 055 polionetworkvichelp@gmail.com

Ballarat meets socially Bayside first Tuesday Bendigo third Saturday bimonth Bairnsdale, Echuca & Eastern Region groups in recess, contacts available. Geelong in recess Hume second Saturdays Lilydale/ Yarra Ranges meets second Wednesday, monthly social group.

Mornington Peninsula: second Saturdays, 11am @ Mornington Community House. Also luncheons, third Tuesdays. Northern region in recess.

Shepparton quarterly first

Tuesday.

South Eastern Region second Saturday

**Traralgon** Contact Elaine Smythe **Warrnambool** fourth Tuesday.

# Bookshelf

#### Life Skills for Polios – a lighthearted handbook

Everything you wanted to know about post-polio but were too afraid to ask? The ideal book for health professionals, friends, family and polios wanting to know how to manage not only post-polio symptoms, but how gracefully to:

- go shopping when supermarkets are too big;
- downsize home and life:
- demand the right chair:
- avoid falls and worse;
- manage the big four painful body parts:
- exercise without overdoing it:
- and find much needed sleep.

#### Cost \$15 plus \$9 postage and packaging.

As an e-book \$US5: www.postpolioinfo.com/ lifeskills.php

#### Iron Wills – Victorian Polio Survivors' Stories

Stories from schooling to later life, plus a Polio Network Satchels - \$15 Strong with strap for shoulder or scooter/ wheelchair back. Also drawstring bags \$5

#### The Polio Day Cookbook

- fine food for the fatigued \$15 plus \$9 postage packaging

#### to purchase: polionetworkvichelp@gmail.com

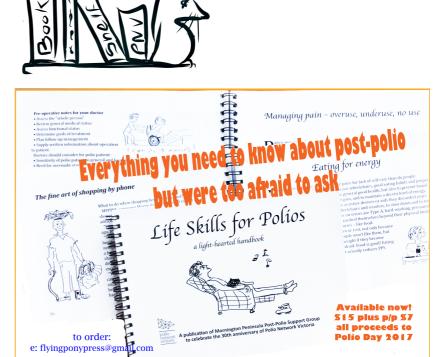
**Polio Perspectives is edited Fran Henke** 

info@postpoliovictoria.org.au 0431 702 137 Ross House Association 247-251 Flinders Lane. Melbourne VIC 3000.

Polio Australia/Polio Health National information/advocacy: https://www.poliohealth.org.au (03) 9016 7678

Opinions expressed in this newsletter may be those of the writers only. 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.

Post Polio Victoria Information and advocacy



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