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victoria

Polio Perspectives

The e- newsletter for Victoria's polio survivors, families & friends



Warrnambool Support Group convenor Anne Clapham with Polio Network Victoria chair Bev Watson at Lady Bay Resort venue of Polio Day 2019

Growing to change in the west

Report from the Chair - Bev Watson

AS we hurtle towards the end of 2019, welcome to our Spring Edition of Polio Perspectives.

Our Polio Day was held on October 24 at the Lady Bay Resort in Warrnambool and feedback from those who attended indicate it was a great success. I believe it is vital that Polio Network continue to hold Polio Day, hopefully on an annual basis. This dedicated event provides Polio survivors the opportunity to come together to learn, share experiences and knowledge and renew friendships, many of which have existed for decades.

Such a day as Polio Day could not happen without the tireless effort of so many people. The extraordinary support from Anne Clapham and the Warrnambool Polio Support Group meant that we had a stunning venue, amazing guest speaker gifts and total commitment to ensuring a successful event.

So much assistance from individuals and support groups meant that our budget was not as hard hit as it could have been.

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Right: Guest speaker Professor Joan McMeeken on 'Telling our stories - lest they forget'



Bev Watson with PNV banner at Lady Bay resort.

Our theme for Polio Day was "Change to Grow" – and what changes the Network has seen this year.

As many will be aware, our auspice of more than 30 years, Independence Australia, has cut the apron strings due to changes in their funding from State Government. This has meant we have had to become an incorporated body in our own right. This process has now been completed and we have an ABN and are registered with all appropriate regulators. This huge challenge was most ably handled by a very experienced committee member and my heartfelt thanks for the amazing result.

It cannot go without acknowledgement, the support Polio Network Victoria has received over the decades from Independence Australia staff. For many years we have had a meeting place, administration support and a point of sale for our merchandise as well as wonderful staff backing up our requirements.

All this means we will need to find another "home" for our committee meetings which meets the requirements of those who attend. A number of committee members travel long distances to be available for meetings and we need to ensure this

change is not too big a burden for them.

You will be receiving/have received a letter regarding the transfer of information from the IA database to our new incorporation. This information is required by us to continue to deliver *Polio Perspectives*, either by email, as many of you have indicated you would prefer, or in hard copy. If you do not want your information transferred, you must "opt out" by returning the form to Independence Australia.

The network has been successful in receiving a State Government grant to help with the cost of producing and delivering *Polio Perspectives* and this will certainly assist with our finances. As indicated previously, we would welcome your willingness to pay a subscription fee of \$10 to help offset the cost of *Polio Perspectives* and other expenses we will incur.

As we enter a new era, I ask that you all continue to support your local group convenors and fellow group members. By staying united we can bring about the changes we all face and to continue to grow to live independent, valued lives as part of our community.

Many will know that Polio Australia's Program Manager, Maryann Liethof, is retiring after 10 years with that organisation. Maryann has been dedicated to raising the profile of matters affecting Polio survivors. My thanks go to Maryann along with very best wishes for a restful retirement. A job well done.

My sincere thanks to the wonderful committee members who have been so committed to ensuring our transition from dependent to independent.

May you all enjoy the holiday season, rest up and be prepared to come on this new journey with Polio Network Victoria well into the future.

Bev Watson Chair – Polio Network Victoria

Perceptions on our needs to change to grow



MC Dr Denis Napthine

Polio Day 2019Held at Lady Bay resort, Warrnambool, October 24, 2019 (Notes by Fran Henke) WE were welcomed by convenor of Warrnambool PPSG Anne Clapham, who suggested holding the event in her town because "Warrnambool can do it cheaper!" Thanks to support from the owner of Lady Bay Peter Walsh and his staff (one of whose father had polio, so she requested to work that day) and Warrnambool Cheese and Butter Factory, that was feasible. Anne said a regional polio day had been held there 11 years ago, and the guest speaker was former Premier and local MP Dr Denis Napthine. He returned this day as Master

Dr Napthine was of course a most accomplished MC, welcoming all guest speakers also doing fine promos for the raffle prizes, filling in between speakers with useful discussion about accessibility etc. He spoke at length about the attractions of his most liveable community in Australia, although the historic village nearby Port Fairy, was NoI in the world. He told about

Middle Island with the remarkable story of its penguins wiped out by foxes and feral others, to be reinstated thanks to the Maremma dogs, immortalised in the film 'Odd Ball'. He said while a vet by profession, he had undertaken a post doctoral degree in epidemiology, so was most interested and concerned by recent polio outbreaks in Philippines and New Guinea, and the impact of the anti-vax movement. Dr Napthine was keen to see those of us who had lived through the experience, to maintain vigilance on vaccination levels to produce a healthier place for the future.

of Ceremonies.

(It was on his watch in Government that Polio Services Victoria was established, celebrating this November, 21 years of service to the community).



Professor Joan McMeeken, AM, PhD

Dr Napthine introduced Professor Joan McMeeken, AM, PhD, who held for 15 years the chair of physiotherapy at the University of Melbourne, in her spare time undertaking a PhD in history and philosophy of science; also writing history about risk resilience and recovery of veterans and polio survivors. Joan's mother graduated in 1937 in physiotherapy so she has an intergenerational knowledge of physiotherapy and passionate about treatment of polio. Her topic was 'Telling our stories: lest they forget".

"Your stories have been told by you and others

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about you", she began, showing slides of books about and by polio survivors. She traced stories of early practitioners such as masseurs, electrologists, galvanists, manipulative and remedial gymnasts, medical professionals most of whom eventually came together as physiotherapists. Noting in the 19thc, 17 per cent of people admitted to hospital died. Joan told about founding practitioners in Victoria such as Alfred Peters and Teepoo Hall with Sir Colin MacKenzie, a pioneer in orthopaedics (His interest in orthopaedics , noted his biographers, was possibly connected with the severe epidemic of poliomyelitis which had broken out in Australia, beginning in Sydney in the summer of 1903-04 and spreading widely over four States.) He was the first to speak of muscle re-education and recovery, also inspired the founding of Healesville Sanctuary through his interest in native species.

Joan McMeeken's mother was the first itinerant physiotherapist, visiting patients in their own homes around the State, working with Dame Jean Macnamara, whom Joan described as a 'formidable lady' to nods around the room. Dame Jean, a down to earth scientist, put the onus on families to do the muscle training required to assist their children.

The self-styled 'Sister' Kenny on the other hand, arrived in a chauffeur driven car, would be wearing a picture hat and a corsage, to conduct her alternative rehabilitation, frowned on in Australia, but welcomed in the United States.

Joan showed pictures of the dreaded Double Thomas and standing frames, also Mt Eliza, where patients spent time on the verandah in the sun and got to go to the beach. Owing to the risk of bombing in WW2, many city patients were moved to Mt Macedon where trenches were dug, wide enough to take Double Thomases.

She mentioned the high number of cases of polio in Warrnambool where children were thought to be more susceptible to the virus, possibly brought from Melbourne, also by water supply from the river into which sewage inevitably was drained in those days. Warrnambool was also fortunate to have the services of aviator John Grace who survived WW2 to become a physiotherapist, working with Dame Jean on her visits. His two sons also studied physiotherapy and one has a practice in the city to this day.

The Iron Lung and development of 'frog breathing' in the 1940s, brought to Australia from US by Bea Burke. Other leading physics of that time were Betty Fussell, who spoke at Polio Day in 2005 (apologising for tough treatment they had to mete out) and Marjorie Farnbach



who was the physiotherapist in charge for the Victorian Department of Health.

Joan said her next task was to pull together the stories of polios and physiotherapy. "You are the experts. I need your help to tell those stories and I will travel anywhere to collect them. You need to tell these stories yourselves. Old people don't rate much. Young physios want to treat sports clients."

Questions: several about medical records, how and where to find them. Joan said many hospitals were getting rid of their archives. Another question: Are young physios being taught about polio? A: No.

Psychologist with Melbourne Health and in private practice, Anne Silbereisen spoke next on 'High Quality Self Care'. Anne accepted that we were a very resilient group but prone to anxiety and depressive conditions. Our title for the day

Anne Silbereisen speaking on Mindfulness.

Grow to Change, she said was fantastic. "Every day is a new day with changing circumstances and we have to grow with it. We grow in flexibility in the moment. The present moment is all we really have got, said Mindfulness expert Jon Kabat Zinn*.

That 'thought virus' is what makes us feel worst as in 'I cant handle this'. If we replay those thoughts we talk ourselves down, she said. "However, the same mind that gets panicky and anxious of course, can also be brilliant. We need to support the mind to support the whole system. Mindfulness allows us to be in the present to let go, not wishing we were somewhere else. Let go worries, critiques, judgements. Mindfulness allows us to be detached from our thoughts and be in the moment as fully as we can. Grow to change: you have to be aware to change, to be awake. Breathe, expand, observe your feelings. Feeling anxious – you can do anxiety or breathe, expand and cope.

"Endurance, willingness is called for. I know you've got it in you. Being awake is "turning up for ourselves".

Anne spoke about 13thc Persian poet Rumi's poem **The Guest House* in which he says every being is a guest house, with new people turning up every day.

"You are your own expert, decide what pace you can work with especially when going for medical interventions. Check in with yourself: breathe, check, stretch and relax, jaw, shoulders, arms, legs, ankles, feet".

She mentioned Kabat Zinn's advice on being in the present moment without judgement. "If the bad news radio comes on in the head, turn the volume down. Practise breathing involving the whole body. When stressed we tend to breathe shallowly. Deep breathing helps us let go. Be your own expert. Know your triggers, risk factors and use protective strategies. With festive season coming up, know your risk factors – stress, diet, sugar, caffeine, alcohol. Protective strategies include good diet, vegetables, exercise, protein, being in nature, reading in bed – pets are great therapy.

"If a stressful situation comes up, such as going to a physio which might have a traumatic history, if feeling panicky, scared, get grounded. Go in feeling neutral".

A questioner spoke up to say she had been doing that every day of her life, using her mind to take her somewhere else. If going for an appointment with her mum, she knew they would have an ice-cream afterwards. Anne agreed this was a good strategy, to have something pleasant to do afterwards, as someone else added after the experience of childbirth, she would have a lovely baby next day.

"Grounding yourself is also a physical grounding, if able to press your feet to the ground and press hands together. While doing this be aware of sight – note five things you can see; hear – four things you can hear (birds, traffic, conversations); three things you can sense (clothes on skin, chair); two things you can smell (coffee, perfume); one thing you can taste (in the mouth). Relax, enjoy being in the garden, listening to music, being in nature, seeing the stars; reading something inspiring helps.

"In the event of emotional crises, have a first aid plan. Sit down, breathe, drink water, contact medical team, phone a friend, phone a helpline. Phone a polio friend – groups like this are about support. Ensure your group has people willing to be contacted. Support and rescue resources. Ensure you trust your GP and other clinicians".

Discussion followed on the message of avoid over doing it. As Joan McMeeken pointed out, as she ages she loses three nerve fibres whereas polio survivors lose five.

After lunch Denis Napthine asked who had come the furthest: Horsham, Melbourne, Mansfield, Swan Hill, Koo-wee-rup, Hastings, Bendigo, Ballarat, Birchip, were noted.

Fran Henke editor and author of PNV's newsletter as well as Mornington Peninsula's monthly, and several polio books, next spoke about plans for *Polio Perspectives* without the physical and financial support of Independence Australia. She asked for email addresses to reduce cost of printing and posting and a list was circulated. A website is planned for the

network, that will provide immediate resources, as well as a new contact email address: *polionetvic@gmail.com*. (And she forgot to add that her essay on Growing up with Polio is being included in a new book *Growing up with Disabilities*, published by Black Inc, 2020).



Bev and Max in full flight on travel tips

Dr Napthine filled in while Bev Watson and Maxine Keystone prepared their travel talk, by discussing the need to make our communities aware of accessibility needs – starting with chairs of varying heights, with arms to assist seating; ramps instead of steps; automatically opening heavy glass doors; pavements suitable for mobility scooters and wheelchairs and so forth. We need to speak up about how to design homes and community buildings to better suit various needs, he said.

Bev and Max's topic was 'Change your Travel'. The two have travelled together many times, been friends for 15 years. "At first Max expected me to get better," Bev said. Over that time, they have changed the way they travel with Bev in a manual chair.

Firstly, the travel agent must understand needs of people with disabilities, they said.

You can't take anybody's word that something is accessible: "there's only a small step into the shower, you can manage that".

One change they have made is to spend longer in one location, three or four days, rather than move around so much, packing and unpacking. Ireland is popular for them, as there's always an accessible toilet. "How come Ireland can do it when other countries can't!" exclaimed Max.

Bev said her abilities had changed. It takes her 40 minutes to get out the door these days and "that's a big change I've had to accept mentally. It drives me nuts, but I've accepted finally that I will have to say 'I might need you to help me'."

Max: "We find locations we can wheel around. This takes a lot of research. Don't waste time when you're there, looking for something accessible".

Bev's great wish in France was to see Monet's Garden at Giverny, and that was a dream come true. They organised to go when there were no queues and Bev had a guide.

Bev said other changes needed for her included to equipment. She uses a manual chair and ensures parts of the chair go with her on the aircraft. She now uses a slide board for transfers to protect shoulders. They keep the chair parts in a special bag as hand luggage.

Max: "we do our bit to look after ourselves in order to do the things we want to do".

Dr Napthine asked if one airline was better than another.

Bev: "It's not necessarily the airline staff, often it is the on ground staff in some stop overs who look down on women with disabilities and are unhelpful. We go business class. I continue to work so we can do that. I turned 70 a while ago and realise I will not have many more trips in me".

Max: "we plan our trip with the same airline company so that you know they have the chair somewhere. Bev can't go to an aircraft toilet without some difficulty, so we can spend a long time waiting for a scissor lift, then spend ages in the terminal looking for an accessible toilet for Bev. Joking: "it's awful for me" (knowing how hard it is for Bev). Bev said in Abu Dhabi one time they gave her an airline wheelchair (wrong size) then walked away and left her.

Question/comment time, included a plug for Travellers Aid at Spencer Street, whose volunteers took Fran and Joan Tie, to the platform, picking Fran up just before knock off time on arrival in Melbourne.

Dawn Baudinette spoke about a recent trip she'd done, sharing with a lady who didn't know what she'd got into. Her companion had two hips and knees done and was grossly overweight. She was totally unprepared for the exertions of the trip, including dealing with a shower over the bath in all the hotels. "But don't be put off", advised Dawn.

Bev wound up the event saying how delighted they were to see so many new faces. "We are flying solo now and will do our best. If something goes wrong, we will fix it," she said.

Bev thanked Warrnambool group members for their work in arranging the fabulous venue, free. And thanked Independence Australia staff for their assistance over the past 23 years. It had been a great partnership. She acknowledged representatives from Polio Australia attending. Bev also thanked PNV committee members who travelled to meetings from Drouin, Warrnambool and Mansfield. Especial thanks went to Dr Denis Napthine "who did us proud".

The raffle with prizes donated by Joan Tie, Lyn Bates, Elaine Smythe, Fran Henke, Joan McMeeken and Maxine Keystone, raised \$242.85 for the Network.

*Jon Kabat-Zinn is an American professor emeritus of medicine and the creator of the Stress Reduction Clinic and the Centre for Mindfulness in Medicine, Health Care, and Society at the University of Massachusetts Medical School. He has written several books and narrated audio books.

*The Guest House

By Jalaluddin Rumi

(Translated by Coleman Barks)

This being human is a guest house. Every morning a new arrival.

A joy, a depression, a meanness, some momentary awareness comes as an unexpected visitor.

Welcome and entertain them all! Even if they're a crowd of sorrows, who violently sweep your house empty of its furniture, still, treat each guest honourably.

He may be clearing you out for some new delight.

The dark thought, the shame, the malice, meet them at the door laughing, and invite them in.

Be grateful for whoever comes, because each has been sent as a guide from beyond.



Listening intently



Listening too



Mindfulness session on 'grounding'

Try Anne's tips to better manage stress:

•Talk to someone you trust

•Learn to say "no"

Be active - get moving - whatever exercise you can do, chair exercises count - and boost your mood
Scale back your to-do list - prioritise what you need to get done now and what can wait
Learn to relax - try meditation, deep breathing, taking a walk, or yoga
Do things you enjoy - get involved in accessible sports, spas/massages, reading, dining out, spending time with friends & family
Eat a healthy balanced diet
Avoid unhealthy methods to cope with stress -

smoking, drinking, over/under eating, over/under sleeping

- •Get support
- •Visit beyond blue for more tips.

WE NEED YOU!

To continue to publish and post *Polio Perspectives*, we need your permission to access addresses from the list of 1200 recipients held by Independence Australia. We have received a grant to print the newsletter in order to reach those who do not use computers. If you agree that we may access your postal address, you do not have to do anything. However, a donation of \$10 annually will help cover postage. If you do NOT want us to have your address any longer please advise PNV chair Bev Watson. If you have an email address and are content to receive Polio Perspectives, email PNV on *polionetvic@gmail.com* NB: this list will not be used for anything but communications from PNV.

Useful ínfo

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

Independence Australia 1300 704 456

Not-for-profit organisation supporting people with a disability or other physical needs, providing services and products to regain and extend independence including attendant care, psychology, respite and accommodation services. This includes personal care, domestic assistance and overnight care.

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

<u>Home & Community</u> My Aged Care

Australian Government website and phone line on what aged care services may be available. Telephone 1800 200 422. **NDIS**

If aged under 65 with a disability, to participate in the NDIS, first be assessed against access requirements.

Contact 1800 800 110

Equipment funding State Wide Equipment Funding – SWEP Ph: 1300 747 937. Aids and equipment to enhance independence at home can be arranged 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.

Orthotics

Neuromuscular Orthotics Phone:1300

411 666. 1846 Dandenong Rd, Clayton. Darren Pereira -Principal Orthotist. Website: www.neuromuscularorthotics.com.au

Garth Talbot Orthotics,

20 Clarendon Street, Frankston. Ph: 9781 0400 www.gtorthotics.com.au

Travellers Aid

Buggy service at Southern Cross and Seymour stations; equipment hire, luggage storage, and companion services for medical appointments Phone: (03) 9068 8187 for assistance from Flinders St, and 03 9670 2072 – Spencer St station.

Regional clinics for Polio Services Victoria 2019

- Bairnsdale November 27-29
- Contact PSV on (03) 9231
 3900 or 1800 030 324

Make it a date

PNV meetings 2019:

November 29

Contact Bev: 0438 542 728 kyrama@westnet.com.au with any questions and for venues of meetings.

For any queries or ideas for content within PP contact editor Fran Henke <u>polionetvic@gmail.com</u>



For all contact details: Bev Watson: 0438 542 728 kyrama@westnet.com.au

Ballarat meets first Wednesday of the month **Bayside** first Tuesday **Bendigo** third Saturday bi monthly

Bairnsdale, Echuca & Eastern Region groups are in recess but local contacts available. Geelong first Monday Hume second Saturday Knox Yarra Ranges meets socially only

Mornington Peninsula: second Saturday of the month, outings third Tuesday (all welcome)

Northern region in recess.

Shepparton quarterly on first Tuesday.

South Eastern Region second Saturday

Traralgon Contact Elaine Smythe

bastian@dcsi.net.au **Warrnambool** fourth Tuesday.

Post Polio Victoria

Ph: 0431 702 137. www.postpoliovictoria.org.au PPV was established to advocate for people with Polio so access information and services needed to live actively and independently. info@postpoliovictoria.org.au



Life Skills for Polios - a light-hearted handbook

Everything you wanted to know about post-polio but were too afraid to ask? This is the ideal book for those 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.

Published by MPPPSG to benefit PNV and Polio Day Cost \$15 plus \$7 postage and packaging. As an e-book \$US5: www.postpolioinfo.com/lifeskills.php

Iron Wills – Victorian Polio Survivors' Stories Iron Wills includes a history of polio; how Polio Network Victoria was founded, plus survivors' own stories. Cost \$20 plus \$7 postage and packaging.

The Polio Day Cookbook – fine food for the fatigued - inc. recipes, nutritional advice. Cost: \$15 plus \$5 postage/packaging

Travel/takeaway mug – \$12.

Polio Network Bags -\$15

Strong with strap for shoulder or scooter/ wheelchair back. Also drawstring bags \$15



to purchase Polio books and merchandise email Fran Henke polionetvic@gmail.com or ph:03 5979 7274

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.

'I walk, but walk different' – Timaru Polio survivor

Esther Ashby-Coventry Oct 28 2019, The Timaru Herald

NEW Zealand polio survivor Reita-Anne Peebles is grateful she can walk, though it is with difficulty. When the oral polio vaccination program rolled out in Timaru in 1961 the Peebles' children were first in the queue. Now in her late 80s the paralytic poliomyelitis survivor still remembers the day when, as a 12-year-old, she began to feel ill.

World Polio Day was marked last month and it brought back memories for Peebles who says the condition – sparked by poliovirus, which destroys nerve cells in the spinal cord, causing possible paralysis – has a lasting impact on her life. In 1943 when she contracted the condition, she was one of 179 cases throughout the country,



Reita-Anne Peebles, polio survivor NZ

24 of whom died. A pupil at Geraldine Intermediate School, Pebbles said she felt ill, went home and collapsed. "I could not hold my weight," she said. Her father realised it was infantile paralysis immediately and called for the doctor and while the doctor wanted to keep her home to use his own methods of healing, her father wasn't having it.

He said: "If you don't take her to hospital, I'll take her in the back of the truck." The doctor complied and Peebles stayed in Timaru Hospital's isolation ward for six weeks. World War II was raging causing uncertainty for those at home whose loved ones were fighting abroad. "During the Japanese invasion (Pearl Harbour) I would sit in the sunporch and watch for Japanese planes coming in." Looking back she is unsure what she would have done if they had arrived in New Zealand skies.

While she doesn't remember being given medication she does remember the lumbar punctures she underwent and a boy in a bed beside her who died from the disease.

Once discharged, the pre-teen spent the next year at home and was forced to walk, with help, every day. Her school work went by the way and instead she concentrated on playing the piano. Eventually back at school she had to repeat her Standard 5 class. With her left leg particularly weak, school bullies would wait until she was on the old swing bridge across the Waihi River on her way home from school and push it so the swaying caused her to topple over. "Down I'd go . . . I had a lot of falls."

Determined not to have iron calipers to support her leg she swam regularly and only used a walking stick. Her parents bathed her legs in hot water twice a day and rubbed them with ascetic acid followed by olive oil. They did not mollycoddle her, she said. "They taught me to just get on with it." That mindset helped her cope with having four children, one dying at 36 hours of age. Her husband Tom was supportive and considerate as were the children, she said. Peebles, and a baby called Helen, were the only two in the district to get the disease in the same year. They had no connection despite how contagious the disease is, Peebles said.

Pain has been her constant companion and she has had two knees and two new hips due to the pressure on her body from the effects of polio. "I walk, but walk different."

Peebles is not bitter about what happened to her but thinks people who choose not to vaccinate are "foolish" to ignore something that could prevent life-long suffering and potential death.

Polio Day photo album





Dawn Baudinette

Right: IA's **Richard Burn** catches up with MC Denis Napthine. Below, conversations in the room









Maree Jongkryg,



Bev being interviewed by Warrnambool Standard



John van Delft

Polio Perspectives