

Polio Perspectives

polio network victoria

STAYIN LIVE Informing and supporting polio survivors, carers and families

Chair report Bev Watson

ow wonderful to be heading into Spring and the prospect of some warmer and drier weather. I always look forward to this time of the year, except for the hay fever it inevitably brings.

It is with much delight I am able to advise that our Polio Day for 2023 - Stayin' Alive is to be held in Hastings at the Sancturary Inn on Western Port. The venue is light and bright with good floor space for all our "accessories". There is also accom - modation available on site. More information about accommodation options will be included with the Stayin' Alive flyer and booking details.

The guest speaker lineup includes: Dr. Natasha Layton who will provide valuable insight into the great advances of Assistive Technology, a representative from Services Australia to build on previous information relating to the My Aged Care program. A special session with an amazing Polio survivor Dawn Baudinette, relaying her life and

Polio Day 2023

October 25, 10.30am ~ 3pm



Principal guest speaker:

Dr Natasha Layton on assistive technology

Bookings: Trybooking Venue: Sanctuary Inn on Western Port, Hastings

Trybooking link is: www.trybooking.com/CLBIL

achievements. Travel information with Ryan Smith for those of us who sometimes baulk at the thought of organising or even taking the opportunity to travel with our individual needs. And to end the day a laughter session with Bron Roberts to ensure we all leave in the right frame of mind to keep on Stayin' Alive!

As we come out of our winter I hope those able to, have taken the opportunity to ease back into the community. I am fully aware that it may be

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What to do when - Polio Day 2023

10.35am Opening 36th Polio Day: Paul Mercurio, MLA, Hastings

10.45am **Presentation**s:

What have human rights to do with assistive technology plus Q&A – Prof Natasha Layton, PhD



Paul Mercurio MLA

11.15am

The Aged Care System & Accessing Aged Care – plus Q&A

– Dion Abel, A/Director, Dept Health & Aged Care (SE Region team)

12.15-1.15pm Lunch & cutting Polio Day Cake – Bev Watson, PNV chair

1.15pm Welcome back & Polio Story: Dawn Baudinette, Portland.

1.35pm Travel talk Ryan Smith, access consultant, avid traveller

2pm Laughter Workshop Bronwyn Roberts

2.30pm Afternoon tea and networking platters served to tables

3pm Home time!

Trybooking link for Polio Day is - www.trybooking.com/CLBIL
Contact details for assistance: Mobile: 0423 020 407 Email: mkeystone@westnet.com.au



Prof Natasha Layton



Bronwyn Roberts



Dawn Baudinette



Ryan Smith

From P.1

difficult for some to reconnect with their regular activities but do encourage you to have a go and ask for assistance if that makes getting out easier. I know it is not something we Polios do well but can be to our advantage and it's time we started thinking about ourselves and what we want for our own wellbeing.

Polio Network Victoria has been the recipient of a funding through the generosity of Mornington Peninsula Post Polio Support Group. Their late member Graeme Johnson, left the group a significant bequest (Tribute P6). My thanks are heartfelt for this as it means we are able to continue with our Polio Days and distribution of Polio Perspectives.



For some time I have been keen to have a section in

Polio Perspectives where we put former "mates" in touch with each other. Sometimes it is years since we have heard a name that is familiar and wonder how and where that person is now. So if you would like to reach out to someone, consider letting us know who you would like to contact and we will see if we can make it happen. See P9.

As always, I thank our Group Convenors for their continuing work in supporting the members in their local groups and the Committee members who are always ready and willing to assist with the function of the Committee.

Enjoy all the time ahead and I look forward to seeing many of you for Polio Day in Hastings. -Bev Watson, chair, Polio Network Victoria

Dawn Baudinette's story

Dawn, guest speaker at Polio Day, had polio in 1937, aged 18 months, spending six years in Sale hospital in an iron lung, unable to see her family. When 'strangers' arrived to take her home, owing to the depression, they, her family, had lost everything, but were dedicated to her recovery. After school, she trained as a teacher and to build up confidence joined a debating club. Dawn became Victoria's first woman school principal and won a Fulbright Scholarship to America. She has always believed fitness was her responsibility and aged 78 walked the Camino, 1000kms from Spain to France, to thank God for her life.



Her husband had 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 suited to growing lavender. For this she learned distillery, about essential oils, awarded a Churchill Fellowship looking into planting, pruning, harvesting, distilling and drying. As well, she took up breeding red kelpies after a vet insisted she take a crate of unwanted puppies.

Dawn never mentioned having Polio until realising she had late effects of polio, reduced the scale of the lavender farm, and applied for a job at Portland Smelter which involved an extensive medical. She had to confess. When the Warrnambool Support Group was formed, she was drawn in, finding the support and information she needed, while still not wanting to be seen as a polio.

Life was not done with her however, an explosion at the distillery damaged one of her eyes, already affected by two strokes. Being Dawn, she worked hard at rehab...

We look forward to hearing her story in person.

MEET OUR SPEAKERS

Our principal guest speaker, **Dr Natasha Layton** is an occupational therapist practicing, researching and teaching in the areas of assistive technology (AT), disability, and outcomes. She has been a member of the Clinical Advisory Panel for Polio Australia, and consultant to the World Health Organisation. She specialises in co-productive research, and in targeting research and dissemination to a range of stakeholders in order to generate change.

This Q&A with her was done for the United Nations Day of Women and Girls in Science



What is your background?

My degree in applied science is in occupational therapy. I was looking for a profession that would give me both technical skills and a worldview about humans as occupational beings.

Why did you become a scientist?

Health professions such as occupational therapists, physiotherapists and speech pathologists, are 'scientist practitioners'. We get to use therapeutic interventions with a huge diversity of people who have impairments or functional challenges, including people living with TBI. These are great professions with huge potential.

What does your research focus on?

My current research focusses on assistive technology, that is, products that can enable people to lead the lives of their choosing. This might be a powered wheelchair to get around a university campus for someone with physical disability, a smartphone and refreshable Braille device for someone living with deaf blindness who wants to check the footy scores, or an environmental control system for someone living with TBI wanting prompts and reminders to support their cognition.

What do you hope your research will help achieve?

Research into the effectiveness of these technologies will ensure they are well designed, fit for purpose, and available to people who need them.

What would you say to young girls and women who aspire to have a career in science? Science can take you to many, many places – from research and development through to application in the real world.

Dr Layton is also steering the Sock Project at Monash University, Frankston, looking at new sock materials to help maintain lower limb perfusion or circulation for those of us with cold legs and arms. Mornington Peninsula Post Polio Support Group has donated to the study to help cover costs of volunteers. Pictured are trial socks.



Learning to Laugh

About Let's Laugh Presenter Bronwyn Roberts: In the 1970's Bronwyn was the office administrator in a high-care rehabilitation centre. Her ability to inspire, motivate and bring a sense of joy to anxious clients caught the attention of management, and she was trained to run the new meditation and mindfulness program. Her version of the program included a connection and compassion component that filled the room with laughter. Many of her clients called her their accidental joy coach.



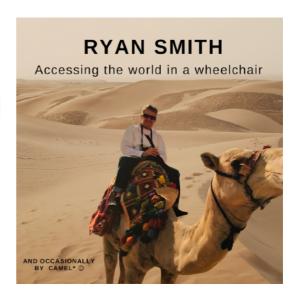
After caring for her mother, she was driven to support other carers so they wouldn't have to experience the burnout that plagued her journey. In 2002 Bron trained as one of the world's first fully certified Laughter Yoga Leaders and Teachers with Laughter Yoga International. She updates her meditation and mindfulness training qualifications on a regular basis and has trained as a Laughter Boss through the Humour Foundation.

To support all the fun, Bron has a Bachelor of Psychological Sciences through Swinburne University, is Australia's only Certified Humour Professional, having completed the three-year post-graduate diploma in humour as therapy through the University of Oregon (USA) and the Association for Applied and Therpautic Humor. In her spare time she's mother of two daughters, married to an avid cyclist, is a passionate traveller, supporting facilitator for a number of wellbeing studies, contributing author to wellbeing publications, and the Laughter expert of choice for a number of media outlets.

Ryan Smith - accessible traveller

Ryan is a creative director, an avid traveller, an Access Consultant and wheelchair user. He started travelling in a wheelchair in 2010 and began writing about access in tourism in 2017 through his blog <u>Freewheel Weekends</u>. He's visited New York, Texas, Tokyo, Berlin, Paris, London, Dublin, Amsterdam, Leiden, Helsinki, Copenhagen, Stockholm, Dusseldorf, Auckland, Tel Aviv, Jerusalem, Cairo, Alexandria and a few other places.

His creative career has spanned 25 years, working in London and Melbourne as a designer, marketer and communication consultant for the likes of Qantas, STA



Travel, TFE Hotels, Jetstar, Visit Ballarat, and Virgin Australia. As a qualified Access Consultant, he understands and advocates for universal design and as a creative he loves to work with teams to innovative and deliver elegant solutions to customer problems. He makes a mean café latte, is learning Spanish and has growing more and more fond of his local magpies.

Dion Abel is an Assistant Director at the Department of Health and Aged Care, working in the South East Regional Team which encompasses the South Metro Melbourne and Gippsland regions. Dion has worked in the APS for over 16 years with Services Australia, and the Department of Health and Aged Care and currently has a focus on First Nations, and In-home Aged Care. With significant national reform underway in the aged care sector, Dion works closely with local service providers to identify the unique needs and challenges facing the ageing & first nations populations within our geographically diverse region. He is committed to ensuring that all people within our regions receive the highest level of aged care services, through working with a range of local service providers, ACCOs & PHNs, and older Australians in a collaborative way to develop sustainable local solutions across the regions.





Graeme Johnson at home



At Polio Australia Conference, Mt Eliza 2011

VALE Graeme Johnson

A founding member of Mornington Peninsula Post Polio Support Group from March 1998 was Graeme Johnson, who had a holiday home at Rosebud (group formed in May 1996). Graeme, a builder, started attending the group as a visitor from the Western Polio Group, then moved to live full-time at Rosebud.

About 15 years ago, he bought a unit in a retirement village on the Gold Coast, going there regularly for the warmth, deciding to stay. He joined the Gold Coast Support Group, but always remained close to peninsula pals. His aim was to develop the unit into accessible living for himself. That didn't quite work out his chair wheel caught a door and one morning he ended up flat on his back with the chair on top. Front door was open, Postie arrived: "Parcel for you mate"! handed over without offering to help him up. Fortunately Graeme had a fabulous sense of humour.

Graeme Johnson died following a heart attack on April 16, 2022, aged 80. Had been admitted to hospital by a friend, worried about his condition, but left him in the ward with a smile on his face (as ever). A year later MPPPSG was advised by a friend of Graeme's to say he had died and made a bequest to the group. It was a significant amount, half of which has been donated to the network for Polio Day and production of this newsletter.

We have been stunned by the gesture and aim to make the very best use of it for Polio survivors as he would have wanted. - *Fran Henke*.

Why we can thank a polio emergency for the birth of intensive care

An outbreak of polio in 1950s Denmark led one hospital to pioneer mechanical ventilation, constant monitoring of vital signs and other innovations that are saving lives to this day - <u>Eric Topol</u>

The Autumn Ghost: How the Battle Against a Polio Epidemic Revolutionised Modern Medical Care *Hannah Wunsch* Greystone Books (2023)

The COVID-19 pandemic has brought home the central role of intensive care units (ICUs) in saving the lives of those in critical condition in hospitals today. Yet if you asked most people where the ICU concept came from, few would know that it was an outgrowth of a polio epidemic in Denmark. In her new book, Hannah Wunsch, an anaesthesiologist and critical-care-medicine specialist at the University of Toronto, Canada, traces the origins of the modern ICU to 1952 and the Blegdam hospital in Copenhagen — something she has written about before in *Nature*. There, a series of innovations arose out of dire need, including positive-pressure ventilation (the precursor to mechanical ventilators), blood-gas measurements for pH and carbon-dioxide levels and close monitoring by an interdisciplinary team of nurses, doctors (notably anaesthesiologists), pharmacists and others.

The treatment of one patient, a 12-year-old girl named Vivi Ebert who presented with bulbar paralytic poliomyelitis — in which poliovirus infects the brainstem — forms the centrepiece of Wunsch's book. Of the first 31 people to be admitted to the Blegdam in the summer of 1952 with paralytic or respiratory polio symptoms, 87% died, 70% within three days. Thanks to interventions including manual ventilation, supervised by anaesthesiologist Bjørn Ibsen, Ebert survived another twenty years, eventually succumbing to pneumonia at the age of 32.

The outbreak that invented intensive care

In those early days it took 50 people to provide the muscle power required for round-the-clock ventilation for 6–8 people with paralytic polio. The hospital's initial success led to more than 1,500 medical and dental students being employed as manual ventilators for patients admitted in the summer and autumn of 1952. Eventually, 'iron lungs' — mechanical ventilator machines — took the place of humans, and the ICU concept was built, focusing on the sickest patients, who required a breathing machine and constant monitoring. Over the next few years, the use of ICUs expanded to the treatment of people with major trauma, shock, tetanus and a variety of other acute, life-threatening conditions.

The treatment of polio, the main story of *The Autumn Ghost*, has rich parallels to the COVID-19 pandemic. In the 1950s, the prevailing hypothesis about the spread of polio was that the virus was inhaled into the body's upper airways. It took decades for the gastrointestinal transmission route — oral contact with the faeces of an infected person — to become accepted. Similarly, for COVID-19, there was an initial fixation on liquid droplets on surfaces and in the air as the main means of transmission, whereas it was determined later it was spread predominantly within tiny droplets or aerosols in the air.

Furthermore, a substantial proportion of both poliovirus and SARS-CoV-2 infections were asymptomatic. And both viruses have long-term consequences: for polio, not only

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potential paralysis, but also the debilitating neuromuscular syndrome that can occur decades later. Long COVID affects 10–12% of infected individuals, with a variety of enduring symptoms that can be incapacitating with potentially more longer-term effects that are yet unknown.

Polio taught us about the efficacy of positive-pressure ventilation for those having

difficulty with breathing. With COVID-19, we learnt that ventilating patients while they were lying face down was crucial to good outcomes. For poliovirus, large, randomised trials of γ-globulin — a substance derived from bone marrow and lymph gland cells containing antibodies thought to help fight the virus — had some success in the years before a vaccine became available. For COVID-19, large observational studies were undertaken of treatment with blood plasma from those who had recovered, although a lack of randomised studies makes it hard to assess the treatment's effectiveness.



Mechanical ventilators have been at the fore in the COVID-19 pandemic.
Credit: Yasuyoshi Chiba/AFP via Getty

Perhaps the most striking difference between the two viruses is how long it was before a vaccine was developed.

For SARS-CoV-2, it was 10 months from sequencing the virus to producing results from large, randomised trials demonstrating high levels of vaccine efficacy. Large-scale distribution quickly followed. Poliovirus was identified as the pathogen for polio in 1908, but it wasn't until 1955 that US virologist Jonas Salk developed the first effective vaccine to be delivered by means of an injection, followed quickly by an oral vaccine developed by US physician and microbiologist Albert Sabin in 1961.

Wunsch provides a detailed history of polio, the iron lung, the rise of the field of anaesthesiology, the development of the Salk and Sabin vaccines and the work at Denmark's Statens Serum Institute, a medical laboratory in Copenhagen, in manufacturing and rolling out the Salk vaccine ten days after it was announced. But she really hits her stride when she describes those whose lives were saved. Another early patient treated by tracheostomy and hand ventilation at the Blegdam hospital was 26-year-old Rosa Abrahamsen. She was a poet, and her beautiful poems, translated into English for the book, begin several chapters.

The Autumn Ghost might have been improved with a timeline, given that it bounces back and forth at many points. Although the extraordinary progress and innovations made in Denmark were central to the development of ICUs, the contribution of parallel efforts from around the world might not have been adequately highlighted.

When I was at the University of Virginia in Charlottesville in the 1970s, I worked as a respiratory technician on the night shift, maintaining Engström ventilators (alluded to in the book as the "Rolls Royce of artificial respiration") for patients in the ICU. I had no idea how those ventilators, or indeed ICUs, came to be. But seeing many patients 'come back to life' inspired me to go to medical school. Only five decades later, thanks to reading this book, have I learned the remarkable background to these profound innovations — and how the poliovirus radically transformed the future of medicine.

TREATMENT OF RESPIRATORY POLIOMYELITIS PATIENTS, WITH SOME NOTES ON CHEST RESPIRATORS

-Beatrice E Burke, Physiotherapist, Department of Health, Victoria, at Fairfield Hospital, Melbourne.

MOST of the information on glosso-pharyngeal breathing was brought back to Melbourne by Dr. Peter L. Colville, Poliomyelitis Officer, Department of Health, Victoria*, who spent six months in the United States of America studying the respiratory aspects of poliomyelitis. He went abroad aided by a grant from the National Health and Medical Research Council and a Fulbright travelling scholarship, and it is due to his efforts that we have made the progress herein reported.

Mrs. Margaret Usher, physiotherapist, also of the Department of Health, Victoria, was in the United States of America at the same time, and Dr. Colville requested her to spend a week in Boston to have a look at what was going on. This she did, and upon her return to Melbourne gathered together much of the original literature on the subject. She wrote the first "frog" breathing notes, and taught it to our first patients. I had at the same time been doing the chest respirator side of things, and since Mrs. Usher's retirement in February, 1956, have been carrying on both projects.

Definition.

Glossopharyngeal breathing (G.P.B.) is a substitute method of breathing that can be used to produce adequate ventilation when there is paralysis of the respiratory muscles. It makes use of the ability of the mouth and throat to act as a pump to force air into the lungs. The muscles of the tongue, soft palate, fauces, pharynx, and larynx must be functionat This method is also known as "frog breathing" because it is the method of forcing air into the lungs used by frogs.

Glossopharyngeal breathing was primarily discovered by a patient. It was noticed that a patient at Rancho Los Amigos in California, who had a vital capacity of 200 cubic centimetres (c.c.), was able to stay out of his respiratory apparatus for long periods, and during this time he was observed to be indulging in a peculiar gulping action. After he had gulped some air down, the amount was measured on a spirometer, and there was no doubt at all that he was getting air into his lungs, since the volume then recorded was considerably greater than previously.

Since one patient was deriving some measure of independence by this method, it was realized that it could be of very great value in helping other patients with complete or partial paralysis of the respiratory muscles. It was decided to analyse what he was doing and to attempt to teach it to other patients.

* Dr Colville was also a polio survivor, more into TAT (Tired All the Time) than PPS. Ed.



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. 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, who you'd like to talk to again?

Let us know and we'll try to help that happen.

polionetworkvichelp@gmail.com

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!

Useful info

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:

Mobility Aids Australia

www.psv.svhm.org.au

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

orthotics.com.au

Phone:1300 411 666 25 Glendale Cres, Mulgrave, 3170. Darren Pereira - Principal Orthotist. www.neuromuscular-

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.

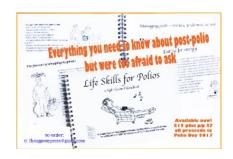
Mornington Peninsula: second Saturdays, 11am @ Mornington Community House. Also luncheons, third Tuesdays.

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 light-hearted handbook

Everything you wanted to know about postpolio 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 history of polio and founding of Polio Network Victoria.Cost \$20 plus \$9 postage and packaging.

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

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

Best wishes to our mates 'next door'

Polio SA Board has had to face one problem after another. Began with the loss of Peter Wierenga, treasurer and long term member of the Board.

The committee reported they were almost on top of accounts issues, then the Community Development Officer had to retire through illness. Replacement Lauren Russell, has joined staff.

Then the Board was informed that the building they rent is to be knocked down for the new road development, so Lauren started packing, also getting a new postal address for membership renewals. She had to buy a new phone as the old one gave up the ghost, and update the web site!

POLIO SA is now concentrating on developing an information and resource agency, Also it hopes to target local rural radios and newspapers as funds become available. Pleased to note that contact from members of the public have already occurred.

Andrew Kyprianou, President Polio SA

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.

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