Polio Australia
Representing polio survivors throughout Australia

Volume 11, Issue 4

# Polio Oz News

December 2023—Summer Edition

## Festive Feasting

***By Melinda Overall JP***
*Nutritionist / Counsellor*
www.overallnutrition.com.au

Well, here it is – the 'Silly Season'! It arrived quickly again this year.

I'm always intrigued that just before Christmas I seem to get a run of nutrition appointment bookings. I expect the New Year appointments – New Year resolutions and getting back on track after all the festivities. But *before* the celebrations (not that there's anything wrong with that)? What could it be? Is it the concern of being confronted with so much food and, for many, alcohol, over that time? Is it the search for *the* magic strategy that will ward off feared festive weight? Is it trying to gain a sense of control when everything else seems rushed and chaotic? Who knows? (Picture this nutritionist shrugging here.)

So, to help you out just a little, here are some ideas for the Silly Season:

- Ensure you have a good breakfast with protein.
- Don't try to under-eat early to make room for bigger meals in the day as this can lead to over-eating later.
- Don't skip meals.
- Fill up on vegetables.
- Keep hydrated – that means with water – as this will help to keep you fuller and likely to eat less.
- Take your time when eating. Can you be the last to finish?
- Share your edible gifts of biscuits and chocolates with neighbours, colleagues, friends, support-workers.
- If drinking alcohol, stick to the same type of drink and insert a glass of water between alcoholic drinks.
- Try non-alcoholic versions of your favourite bevvy.
- Don't drink and drive – we want you reading *Polio Oz News* in 2024!
- Send leftovers home with guests, or if you're a guest, politely decline leftovers.
- Remember, it's ok to say "no".
- Be mindful of food safety to avoid food poisoning. Here's a great link: https://www.foodsafety.edu.au/fsic-christmas-message/

And to help keep you focussed, here are a couple of easy recipes:

**Pineapple Orange Frappe** *(serves 2)*
Instead of sticking to alcohol or soft drinks, why not try a refreshing frappe?

- 1 frozen orange
- 1 cup frozen fresh pineapple *(cut all fruit into chunks before freezing)*
- 1 cup coconut water
- Small handful of mint

Whizz it all up in your blender and serve immediately.

**Two Ingredient Ice Cream** *(serves 1)*
For a light dessert or treat.

- 125g frozen mixed berries *or* frozen banana *or* frozen mango
- 2 tbs yoghurt

Blitz it in the blender and serve.

**Christmas Eve Cherry Smoothie** *(serves 1)*
Great for breakfast.

- ½ cup coconut milk
- 1½ tsp cacao powder
- 2 tbs dairy or coconut yoghurt
- 1 tbs shredded or desiccated coconut
- Big handful of fresh cherries … take the pips out!

Put your blender to work again – serve immediately.

Most importantly, ENJOY!

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*Representing polio survivors*

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## Inside this issue:



*"Keep your face always toward the sunshine—and shadows will fall behind you."*
~ Walt Whitman ~

## Polio Australia's Websites



**Polio Australia**

*Representing polio survivors throughout Australia*

Welcome to the Polio Australia website. Polio Australia is a not—for—profit organisation supporting polio survivors living in Australia. This website contains information about polio, the Late Effects of Polio, the work of Polio Australia and much more.

**www.polioaustralia.org.au**

**Polio Australia**

*Improving health outcomes for Australia's polio survivors*

The Polio Health website is a comprehensive resource for both health professionals and polio survivors. It contains clinically researched information on the Late Effects of Polio; the Health Professional Register; and where Polio Australia's Clinical Practice Workshops for Health Professionals are being held.

**www.poliohealth.org.au**

**Australian Polio Register**

*Have you added your polio details?*

The Australian Polio Register was established by Polio Australia in October 2010 to gather information on the numbers of polio survivors living in Australia today, whether or not they contracted polio in this country. To make the Australian Polio Register truly reflective of the unmet need for polio services throughout Australia, we urge every Australian polio survivor to join the Polio Register. Our strength lies in our numbers—please help us to get you the services you need by adding your polio details to the Register. You can register online or by downloading and completing a paper copy.

**www.australianpolioregister.org.au**

# President's Report

***By Gillian Thomas OAM***
*President*

At this time of year I reflect on what has been achieved over the previous twelve months, and the challenges we faced.

In 2023, we have continued to pursue funding to keep our keystone Clinical Education Program operating. We are currently not receiving any government or philanthropic support for this program, although we continue putting in funding submission after funding submission. Our reserves are severely depleted, but we are loathe to simply cease the program because it has proven to be so successful in educating the health professionals who work with polio survivors. What better way is there to support our demographic? However, hard decisions have had to be made and our phenomenal and dedicated Clinical Educator, Michael Jackson, has agreed to work part-time in 2024, until we can no longer sustain his position, or are successful in obtaining one of the many grants we are applying for.

Thankfully, we do have funding for the other members of our small team, Devalina Battacharjee (Community Information), Paulette Jackson (Administration), and Shylie Little (Finance). For a comprehensive look at Polio Australia's functions, our Annual Report can now be viewed online and/or downloaded.

In September, we were very sad to learn that South Australian Rehabilitation Specialist, Dr Nigel Quadros, passed away from cancer. Dr Quadros had been a great support to many of South Australia's polio survivors, and was a valued member of Polio Australia's Clinical Advisory Group. He was also always willing to contribute his time and expertise to us through consultations and speaking presentations. He will be missed.

Michael, Maryann, and myself recently had a Zoom meeting with some of the Directors of the European Polio Union to discuss four points relating to *"What is the current state of post-polio education worldwide?"* It was great to get an international perspective, and interesting to note that Polio Australia's Clinical Education model is seen as being at the forefront of these activities. If only the funding bodies could have been there!

Wishing you all a safe and happy Festive Season.

Gillian

# From The Editor


***By Maryann Liethof***
*Editor*

As another year draws to a close and I have been preparing my last *Polio Oz News* for 2023, I have been reflecting on all the high's and low's that this year has brought us.

We have seen fighting in Israel, Ukraine is still under siege, extreme weather conditions affecting countries around the world, earthquakes, floods, fires … Of course, all of these things can impact on the reintroduction and/or emergence of various diseases. This makes the vital work being done by health workers so much more difficult and urgent. I would take this opportunity to commend all these professionals, and I sincerely hope that the new year will see some respite.

In this edition, we have a number of articles *(from p14 onwards)* revealing how polio is still proving to be problematic in various countries. However, the determination of the health workers on the front line is both formidable and inspirational.

The high's are more reflective of the tenacity and endurance of the post-polio community.

For example, Polio Awareness Month activities (p7 & 8) showed us that: polio stories can still be interesting and relevant enough to win prizes — see *"Lives Well Lived"*; peer support groups continue to provide information and fellowship after 35 years — see *"Stayin' Alive"* event; and polio survivors are engaging with Rotary International to provide a context for why Rotarians are still running their epic *"End Polio Now"* campaign.

Additional post-polio accounts can be read in: *"Disease Is A Gift"* (p9) and *"Day Of People With Disability"* (p11).

Polio survivor and advocate, Peter Freckleton, has taken up the fight on behalf of everyone over the age of 65 who has a disability, with a complaint to the United Nations on the National Disability Insurance Scheme's age cap discrimination (p10).

We are also reminded of how polio epidemics of the 20th century, whilst devastating, were instrumental in revolutionising modern medical care (p13).

Finally, *"Festive Feasting"* (p1) might prompt some of us to consider a few new options if we are prone to over indulging. I know I am!

I am signing off with warm Seasons Greetings to all our readers.

Maryann

# Clinical Education Update

***By Michael Jackson***
*Polio Australia Clinical Educator*

## Professional Education Program Update

In the last edition of Polio Oz News I reported that this program had just visited Tasmania for a week. Since then we have reached the following audiences across several eastern states:

- Two neurophysio clinics and two rehab hospitals (75) east of Melbourne, in-person
- Wellington health district's physios (30) in NZ, via Zoom
- Brighton Probus Club members in Vic, in-person
- Peninsula Private Hospital's allied health staff (12) in Redcliffe Qld, in-person
- Baringa Private Hospital nurses (9) in Coffs Harbour, in-person
- A very engaged OAPL orthotist staff (8) in Alexandria NSW, in-person,
- A recorded hour-long workshop for the ARCademy members, and
- One neurophysio from the Sunshine Coast in Qld, via our monthly Zoom sessions

A total of 135 clinicians of mixed disciplines were reached over ten workshops in the recent 'between Polio Oz News quarter'. This financial year to date we have reached 206 clinicians over 16 workshops at an average of about 13 attendees per workshop. These were strong numbers considering our outreach for workshops was less than usual while we sought program funding and worked to bring in-motion projects nearer to completion.

Looking back at the three previous financial years' workshop data has revealed temporal trends. We reach 60% of our attendees in the first half of the financial year (July-November) and the remaining 40% in the latter half (February to June). In addition, we have delivered 58% of our workshops in the first half financial year (July-November) for the last two years. Both attendee numbers and workshop numbers tend to be healthier in the July to November period.

Decembers and Januarys for this program have historically had very few workshops able to be scheduled, due mostly to societal and health facilities' staffing factors. This is unlikely to change and is beneficial as it enables staff to strategise for the ten months which follow and to review existing processes and resources.

## Funding Snapshots

We continue our efforts to secure mid-term and long-term funding for this professional education program from a variety of sources.

Through their community grant support program, GlaxoSmithKline Australia will be supporting Polio Australia with $10,000 to restock our printed materials which are nearly depleted. In our education and advocacy work we provide and send a wide array of clinical manuals, fact sheets, information sheets and medic alert cards and so are grateful to GSK Australia for this assistance.

We have submitted two grant requests to Perpetual for the funding of two projects which would take place in the new financial year. This first is an advocacy advertising campaign – a multiple media national campaign to raise public awareness of those affected by polio and the post-polio conditions, and to improve screening and identification of those at risk for developing the conditions. The second request is for developing eLearning modules for six health disciplines that would be available on-demand and provide professional development credit. On -demand clinical discipline-specific post-polio education experiences do not exist – this project serves to fill that void.

## Project Snapshots

In Polio Australia's 2022-2023 Annual Report the potential for this program to serve as a blueprint and model for other countries, or as an international program, was outlined. We then developed a program synopsis to educate stakeholders about our program and its potential. Since then we have had conversations directly with representatives from Rotary, WHO – Western Pacific, The Bill and Melinda Gates Foundation, and the European Polio Union, and have surveyed post-polio organisations and support groups worldwide on their education models and practices. *(See p22 to 25)*

The hospitalisation of those with LEoP/PPS diagnoses in Australia manuscript has been completed by our research team and is about to enter the formal review process pre-publication. This will be reviewed in a future edition of PON once it has been published.

The research working group is also planning a Delphi Method study to be carried out in 2024. This involves specialists and researchers worldwide who can speak to post-polio conditions and exercise, who provide their impressions and opinions on exercise statements. Several rounds of clarification occur and a consensus statement is then formed. This will help both clinicians and their post-polio affected clients more effectively understand and plan exercise.

***Cont'd p5***

## Clinical Education Update *(cont'd from p4)*

HealthPathways Central Sydney has been developing a pathway on post-polio conditions for their region, and it is anticipated it will eventually be shared across NSW regions once fully developed. We accessed and viewed the draft this week, and looks to be listed as *Polio – Late Effects*. Once completed, it will inform services and clinicians in the Central Sydney area which including the RPA, Canterbury, Balmain and Concord Hospitals.

Our ten-part educational video series is currently being released, as described in another article in this issue.

A project which may come to fruition next year is an education tour of NZ cities to support their post-polio community through the education of local clinicians and train the trainer activities. We are seeking funding options that cover trans-Tasman activities for this project.

In the new year I will be working on a part time basis (0.6) unless or until program funding is secured. Our priorities and activities within this program will be reviewed early in the new year to enable us to continue to best serve our mission.

## Video Education Series

If you have been keeping an eye on our social media channels you would have seen posts regarding a weekly release of five educational videos throughout late November and December. An additional five will be released in the new year to complete the ten-part series.

The videos are 3 to 7 minutes in length and address the following ten fundamental questions that someone in your community might want answers to, but which also serve to introduce clinicians to the polio-affected population:

1 - Who gets post-polio conditions, and what are they?
2 - How would someone know if a person was exposed to polio?
3 - Do people exposed to polio live in my community?
4 - What does a person experiencing post-polio look like?
5 - How would a clinician identify who is at risk for post-polio?
6 - How is post-polio diagnosed and by who?
7 - What are the main symptoms of post-polio?
8 - Do those exposed to polio face health risks?
9 - What is most difficult for people who have post-polio conditions?
10 - Who helps people experiencing post-polio conditions?


These videos have their own playlist on Polio Australia's YouTube channel, found via this link. Like and subscribe to the playlist!

## Vale Dr Nigel Quadros

On Father's Day Dr Nigel Quadros passed away. Those living in South Australia are most familiar with his work and expertise as the primary post-polio specialist in SA who ran the state's only post-polio clinic. Nigel's family has encouraged those wishing to give tribute to donate to the Mary Potter Hospice.

Nigel was a Fellow of the Australasian Faculty of Rehabilitation Medicine (RACP) and worked for many years as the Senior Rehabilitation Medicine Physician in Central Adelaide Local Health Network, affiliated with the Queen Elizabeth Hospital, the Royal Adelaide Hospital and Hampstead Rehabilitation Centre. He was also a Senior Clinical Lecturer in the Faculty of Health and Medical Sciences at the University of Adelaide where he was involved in both undergraduate and post graduate medical teaching.

His clinical interests were in stroke and general neurological rehabilitation. His special interest in the assessment and management of people with late effects of polio was a topic on which he engaged with Polio Australia regularly. He had conducted a medical post-polio clinic at Queen Elizabeth Hospital since 2005, serving many people affected by polio in PolioSA's support network.

Dr Quadros had been central to the activity of our post-polio research working group – with our current study on the hospitalisation of polio survivors and through his own study on sarcopenia and functional decline in ageing polio survivors. He was also a long-serving and active member of our Australasian Clinical Advisory Group.

Nigel was proactive and made valuable contributions through his genuine and helpful approach in the post-polio scene in SA and in Australia. We already miss his expertise, insights and good humour – he will surely be missed by those who knew him.

# Community Programs Update

***By Devalina Battacharjee***
*Community Development Worker*

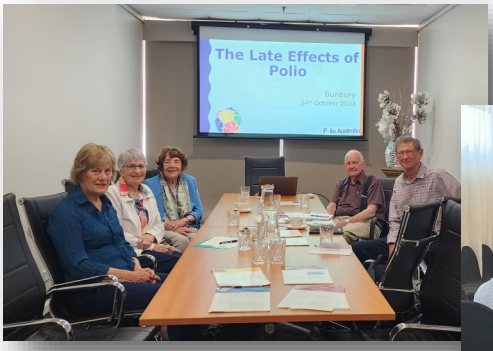
A lot has gone on in the Community Development department since we last touched base.

We have successfully conducted community information sessions all throughout South Australia, earlier in November, in areas including Adelaide, Mount Gambier, Port Lincoln and Murray Bridge. While the aim of the Mount Gambier, Port Lincoln and Murray Bridge sessions were to attract new members to join our existing community and spread awareness about Late Effects of Polio, bringing survivors and their carers into the fold that had hitherto been unaware of us and our efforts. The Adelaide session, however, was conducted for the pre-existing members of Polio SA, and was conducted to coincide with their Annual General Meeting.

We have also completed sessions throughout Western Australia, with two sessions being conducted in late October in Mosman Park, and one each in Armadale and Bunbury, respectively. The sessions were successful in raising awareness about Late Effects of Polio among people affected who had previously been unaware of the condition. It also helped in increasing numbers for our Australian Polio Register.

In the coming year, we hope to visit Tasmania, Canberra, New South Wales, Queensland, and Victoria. More details to follow soon and will be found here: www.polioaustralia.org.au/community-information-sessions/

Until then, have a Wonderful Holiday Season!




*Polio WA, Bunbury*

*Polio SA, Adelaide*


## Zoom Sessions Held In 2023

We are holding a series of Zoom chats throughout the year. The sessions will have a maximum of 100 live participants.

Some of the topics covered include: mental health and wellness, helpful aids and equipment, managing fatigue and pain, speech and swallowing problems, and experts presenting on various manifestations of the Late Effects of Polio.

**2023 MONTHLY ZOOM CHATS FOR AUSTRALIA'S POST-POLIO COMMUNITY**

**WHEN:** The first Monday of each month – join us for one or all of the sessions (No session in January)

**TIME**: 11:00am NSW/VIC/TAS time*

***NOTE** – This is 11am AEST or AEDT (depending on the month!)*

**Please check the right time in your area so you don't miss it!**

**WHERE:** Online Zoom Meeting

**Register**

**2023 NDIS ZOOM CHATS FOR POLIO SURVIVORS AND CARERS**

**WHEN:**
11th April
11th July
10th October

**TIME**: 11:00am NSW/VIC/TAS time*

***NOTE** – This is 11am AEST or AEDT (depending on the month!)*

**Please check the right time in your area so you don't miss it!**

**WHERE:** Online Zoom Meeting

**Register**

**2023 MY AGED CARE ZOOM CHATS FOR POLIO SURVIVORS AND CARERS**

**WHEN:**
18th April
18th July
17th October

**TIME**: 11:00am NSW/VIC/TAS time*

***NOTE** – This is 11am AEST or AEDT (depending on the month!)*

**Please check the right time in your area so you don't miss it!**

**WHERE:** Online Zoom Meeting

**Register**

# Polio Awareness Month

***By Paulette Jackson***
*Administration Officer*


Every October, Polio Awareness Month (PAM) brings attention to the tens of thousands of Australian people affected by polio who are living with Late Effects of Polio (LEoP). The theme, "*We're Still Here!*" reminds us of the ongoing impact of those affected. Although polio has been eradicated in Australia for decades, many Australians now experience LEoP.

During PAM, Polio Australia strives to increase health literacy around LEoP by promoting educational resources for both polio survivors and health professionals. Our campaign prompts people across Australia to consider *"Was I exposed to the poliovirus?"* and *"Who in my family was exposed to the poliovirus?"* We also encourage health professionals to consistently screen for exposure to polio in their clients. Recently, we published a video series addressing these questions. You can view the videos here: Answers to Ten Post-Polio Questions. Videos will continue to be published through the new year.

We were thrilled to see the country light up **orange** again for PAM. This activity draws community attention to the thousands of polio survivors living in Australia. A total of 80 landmarks and 13 tram stations illuminated orange! To see the complete list of participating landmarks, visit www.polioaustralia.org.au/light-up-your-city-orange-2023/. We also enjoyed seeing many of you wearing orange for our monthly Zoom chat.


Lastly, we held a Puzzle Competition on our social media sites. Four winners solved the puzzle and received prizes generously donated by **Bunnings**. Congratulations!

We look forward to another successful Polio Awareness Month next year. If you have any ideas on how we can bring awareness to this campaign, email us at office@polioaustralia.org.au.

# Polio Awareness Month *(cont'd from p7)*

## Other events during Polio Awareness Month 2023 included ...

**Post Polio Victoria** *(right)* submitted their film *"Lives Well Lived"* to the Focus on Ability Short Film Festival and they WON! The film features three polio survivors and can be viewed here: youtu.be/aToqAEdzuYs.


*PPV's Robyn Abrahams (2nd from left) and Shirley Glance OAM (centre) receiving the prize of a new Toyota*

**Polio Network Victoria** *(below)* hosted a "Stayin' Alive" event which presented on assistive technology, aged care, travel, and a polio survivor sharing her story.

*From left*

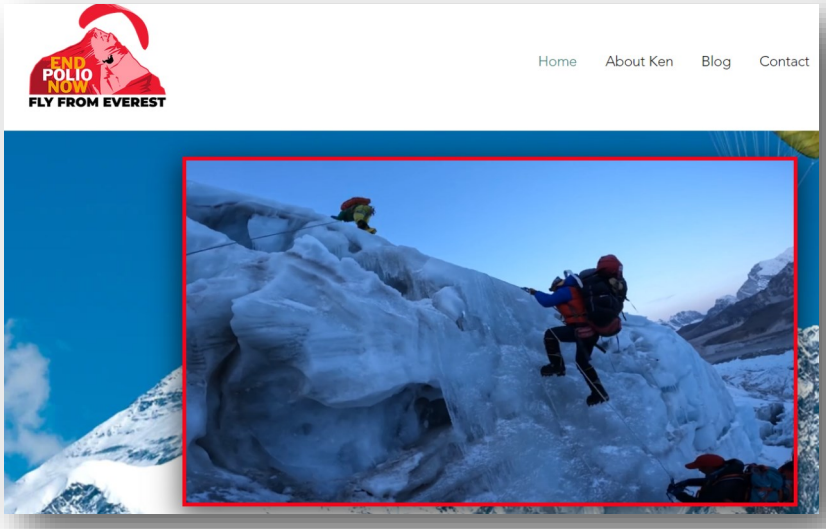
*PNV's Fran Henke, Maxine Keystone and Bev Williams, celebrating 35 years*


*Photo by PNV*

**Rotary Tasmania** hosted a World Polio Day Cocktail Party. Polio Australia's Vice President, Gary Newton was an honoured guest along with Dr Murray Verso, End Polio Coordinator Rotary International Zone 8.

**Perth Rotary** hosted a World Polio Day Dinner Event where Cambodian polio survivor, Addehka, presented on 'Surviving Polio and the Khmer Rouge'.

**The Rotary Club of Geelong East** hosted a movie screening of *"Fly from Everest"* documenting Ken Hutt's attempt to paraglide from Mt Everest to raise awareness and funds for the *End Polio Now* campaign. The Polio Australia logo was displayed on his paraglider.




*www.flyfromeverest.org/*

# Disease Is A Gift

***By Devalina Battacharjee***
*Community Development Worker*

In November, our guest speaker for Polio Australia's Monthly Zoom Chat was Susan L. Shoenbeck, who happens to be a polio survivor, author, nurse and educator. She shared her presentation on, *"Disease Can Be A Gift"*. Susan contracted polio at 7 months and was in an iron lung. She is the author of *"Polio Girl: It Only Takes One"*.

Susan discussed her Seven Principles, which were:

Principle 1: Patients and People are NOT a disease.

Principle 2: Every person with illness needs care specific to:

- who they are
- their unique symptoms
- what they want to do
- what type of support they need, e.g. financial, physical, etc.

Principle 3: Polio is not a disease of the past.

Principle 4: Polio affects family dynamics.

Principle 5: Kindness and goodness can go a long way in helping someone else.

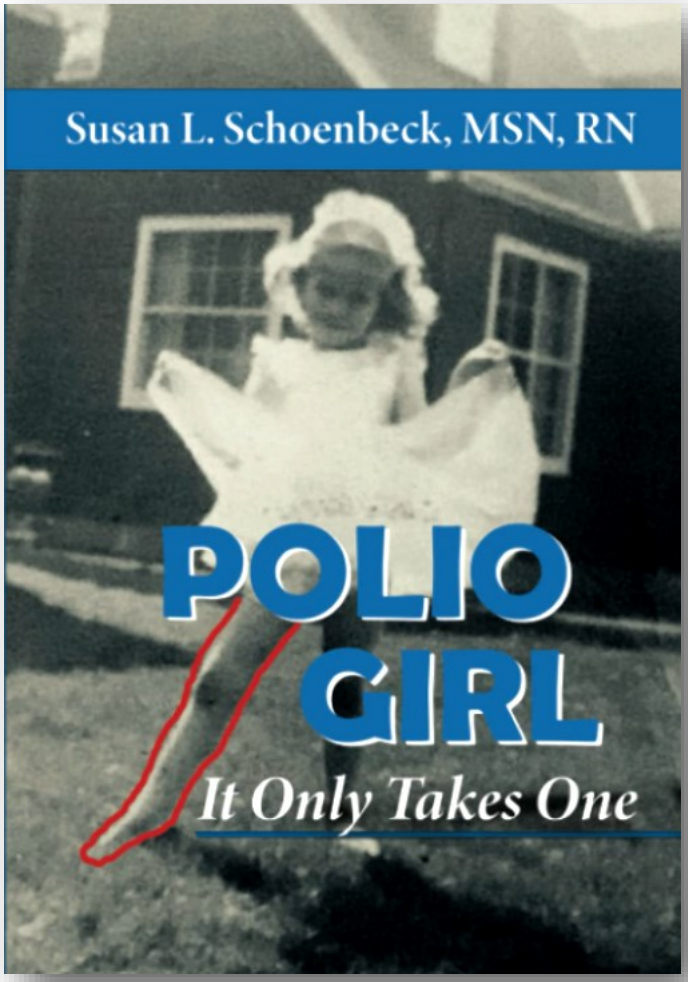
Principle 6: Play to your strengths.

Principle 7: Keep adapting.

Susan touched upon various testing procedures, i.e. Electromyogram (EMG) and Pulmonary Function Testing (PFT). She also presented an overview of Post-Polio Syndrome discussing hitting the polio wall, breathing problems, thermoregulation issues, digestive issues arising as a result of low gut motility, choking hazards, gastro oesophageal reflux disease (GORD aka GERD), and speech and swallowing issues.

Susan also discussed how to communicate with your doctors regarding pain, a resource that can be found here, https:/tinyurl.com/47cmdz4d/. Furthermore, she also discussed carpal tunnel and restless leg syndrome, as well as the grief over losing physical strength and the anxiety over future wellbeing.

She mentioned the Voices of Polio Survivors Virtual Museum (VPSVM), where polio survivors share their stories. If you would like more information or would like to contribute your story, email here monaarsenault@gmail.com.




*It only takes one. What we've learned from polio resonates today.*

*"Polio Girl" presents the history of polio, vaccine development, widespread vaccination campaigns, and the acute and long-haul symptoms polio survivors deal with every single day. The stigma for families of polio children and the guilt of those who may have transmitted the disease are told through people's stories. The book also contains advice for doctors, nurses, and other healthcare professionals who may come across one of the remaining 300,000 polio survivors.*

Available online here:

- www.amazon.com.au/Polio-Girl-Only-Takes-One-ebook/dp/B0B9LN5FLZ
- www.goodreads.com/en/book/show/62345921

# NDIS Age Discrimination Complaints Taken To The UN

***By the Specialist Reporting Team's Celina Edmonds and Alison Branley***

**Source:** www.abc.net.au/news
— 31 October 2023

When the National Disability Insurance Scheme (NDIS) rolled out 10 years ago, Peter Freckleton had hopes it would change his life for the better.

**Key points:**

- A Victorian man with a lifelong disability is lodging a complaint with the UN over the NDIS age cap
- Those aged over 65 are locked out of the NDIS and must rely on other services for support
- It's the latest step in a long-running campaign for older Australians with disability to be allowed into the scheme

Mr Freckleton has had a life-long disability, which began after contracting polio when he was just six.

*"I was paralysed totally. I finished up with two both legs paralysed and for the rest of my life, I had to wear leg braces and use calipers and use a wheelchair,"* he said.

But he was rejected for the scheme, because he was over the age limit. The day someone turns 65, they immediately become ineligible to lodge an NDIS application.

*"They didn't query my disability. It was just straight out 'no' because of the age requirement,"* he said. *"That's totally wrong."*

Mr Freckleton is now taking his fight to be included in the scheme to the United Nations, claiming the cut off is age discrimination and a breach of the Convention on the Rights of Persons with Disabilities.

*"I feel obliged to take it as far as I can on behalf of a number of people who are being really cruelly and unfairly treated,"* Mr Freckleton said. *"We're just asking to be treated like everybody else."*

Before going to the UN, Mr Freckleton had to close off all legal avenues in Australia. He made a complaint to the Australian Human Rights Commission, but it did not have the power to remove the NDIS age cap.

Peter Freckleton's lawyer Sheetal Balakrishnan, from the Public Interest Advocacy Centre, said the only way to fix the problem was to remove the age cap written in NDIS legislation.

*"That power is only held by parliament, so Peter doesn't have any legal remedy within Australia, which is why he's complaining to the UN,"* she said.

Peter Freckleton was paralysed by polio at age six and has lived with disability ever since. *(ABC News: Patrick Stone)*

Once the UN committee receives Mr Freckleton's complaint, the Australian government will be asked to respond, and its position will be considered by the committee.

*"The UN committee will provide a written decision about whether the Australian government has discriminated against Peter and whether [it] has breached Peter's human rights under the convention,"* Ms Balakrishnan said.

## 'Blatant age discrimination'

The campaign to remove the age cap on the NDIS is not new. In 2020, independent MP Andrew Wilkie described it as *"blatant age discrimination"* in a speech to parliament.

Last year, a proposed class action alleged excluding over-65s because of their age was unlawful.

Earlier this year, then Age Discrimination Commissioner Kay Patterson said it was *"odd"* that if you developed a disability the day before you were 65 that you could get the NDIS, but two days afterwards you could not.

Almost 25,000 people have signed a petition, launched by Spinal Life Australia (SLA), to have the age cap removed.

SLA chief executive Mark Townend said under the existing system, people with disability over age 65 were forced to rely on the aged care system, which was not structured to deal with their unique needs.

For example, there were caps on the amount of at-home support they could receive and less help for items like mobility aids.

*"You get services to get you out of bed one day a week compared to seven,"* he said. *"[Under the] NDIS, there's hundreds of thousands of dollars available for care all the time up to 24 hours if you need it."*

In Mr Freckleton's case, funding caps mean he is not able to make necessary modifications to his house.

***Cont'd p11***

## NDIS Age Discrimination Complaints Taken To The UN *(cont'd from p10)*

*"If he had access to the NDIS, it would make a real difference to his life,"* Ms Balakrishnan said.

Mr Townend said the action would force the government to justify its decision-making in writing.

*"It's really important that this government actually listens and realises it's serious and the population of Australia over 65 deserves better care."*

### What does the government say?

NDIS Minister Bill Shorten has publicly acknowledged the current situation is unfair. Governments have previously voiced concern that admitting older people would be too expensive as they become incapacitated by diseases of ageing.

Mr Freckleton said the National Disability Insurance Agency, which runs the NDIS, has not done any modelling on the cost of admitting older people to the scheme, particularly those who acquired their disability before age 65.

The government has previously suggested removing the age cap would see an extra 2.25 million people try to access the scheme. However, campaigners believe that is based on a liberal definition of disability, and using the more stringent one in the NDIS, the number would be significantly lower, closer to 25,000.

In a statement, a government spokesperson said it was considering reforms to in-home aged care to be introduced from July 2025.

*"The new Support at Home program is being designed to improve access to assistive technology and home modifications, including for older people with a disability who are not eligible for the NDIS,"* they said.

The spokesperson said the government had also commissioned research exploring *"opportunities to deliver higher levels of in-home aged care under the Support at Home program"* that also considers *"cost-effectiveness and safety considerations for people with complex care needs".*

## Day Of People With Disability

***By Rowan Cowley***

**Source:** www.thesenior.com.au – 2 December 2023

Having lived with polio for more than 70 years, Ann-Mason Furmage knows all too well how challenging it can be living with disability – especially for seniors.

As the world marks International Day of People With Disability on December 3, the 85-year-old has a simple message for seniors living with their own disabilities – while society may treat you differently, it's important to fight for your right to respect and the best available treatment.

### A torturous road

Ann-Mason was diagnosed with polio at the age of 12. While she was diagnosed early, her left hand, arm and shoulder became paralysed very quickly.

She was living in the USA at the time, and subjected to a gruelling and at times torturous treatment regimen of having hot woollen packs placed on the muscles, a method devised by Australian nurse Elizabeth Kenny.

She also had to undergo intensive physiotherapy sessions in warm water, all in the searing heat of a non-airconditioned hospital in summer.

Exercises were often agonising, calling on her to do things like touch her nose with her knees, there was plenty of incentive to complete the exercises, it was the only way to get the packs removed.

*"Polio would tighten all the muscles so that you couldn't move, even if you weren't paralysed. All the muscles tightened, so they just wouldn't work at all,"* she said. *"We had the hot woollen packs and also the physiotherapy to help to loosen up the muscles."*

While the treatment was agonising, it did produce results – while she is now wheelchair bound due to post polio syndrome, she was able to walk for many years.

### Hard to diagnose

Ann-Mason said she was luckier than some due to the fact she was diagnosed early.

*"One of the things about polio was that it was very difficult to diagnose. It presented in a number of ways – sometimes the doctors said it was kidney disease, sometimes they thought it was a chest infection, there were all sorts of problems doctors thought it might be. The only way they could know for sure was to take a spinal tap."*

### The good fight

Ann-Mason was forced to retire early from her work as an accountant due to the late effects of polio, but she found renewed purpose through a life of advocacy.

*"I looked around for something useful to do, and*

***Cont'd p12***

# Day Of People With Disability *(cont'd from p11)*

*I thought there's a lot that's happening to people that had polio, so I joined something called the Post Polio Network,"* she said.

Through that role, she learned there was a great need for disability advocacy for people living with all types of disabilities, so she joined the Physical Disability Council of NSW. She would go on to serve as a board member, and then the organisation's president for eight years.

In her role – which she served prior to the introduction of the NDIS, she travelled all over Australia, lobbying politicians for more support, spreading the message on available support services, and emphasising the importance of "self-advocacy".

## The *I* in independence

This need to self-advocate is something she sees as especially important for seniors.

*"The fact is more than half of the people who have disability are over the age of 65, but unfortunately we don't always get the same care and equipment that younger people do because of the way funding is structured, and also because of the attitudes of people, and that includes the medical community,"* she said. *"When something's happened to me medically, I always make it clear I intend to be as independent as possible for as long as possible, and I'm offered more physio than someone else in a similar position. "If you wish to remain independent, advocate for that. If your independence is not important to you, then I have no advice for you."*

## The road forward

Ann-Mason said it benefits the whole of society when things are done to improve the lives of people with disability.

By way of example, she points to lifts at stations, which were introduced for people living with disability, but now make life easier for people of all walks of life, including travellers and mothers who would previously have been forced to haul their suitcases or prams up the stairs.

While a lot of improvements have been made in terms of amenities, Ann-Mason believes we still have a long way to go in terms of respect.

*"I would be interested in seeing people having different attitudes towards people with a disability – that is something that is changing but it's changing very slowly,"* she said. *"I would hope people would treat us like they treat their own nanas, with a bit of respect."*

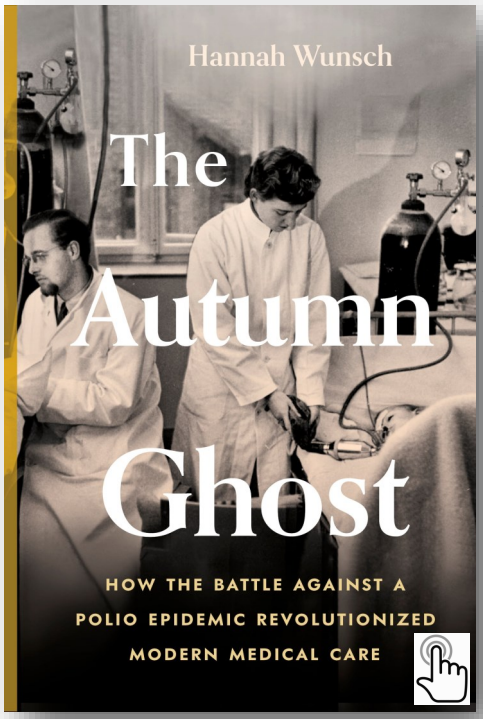
# How The Modern ICU Was Galvanized By A Polio Epidemic

**The following is an excerpt of a much longer** *(restricted access)* **interview between Eric J. Topol, MD and Hannah Wunsch, MD, MSc.—Ed**

**Source:** www.medscape.com — 15 August 2023

Eric J. Topol, MD: Hello. This is Eric Topol for the Medscape *Medicine and the Machine* podcast. We have a phenomenal guest today: Professor Hannah Wunsch from the University of Toronto, who authored a book called *The Autumn Ghost*. I had the chance to review her book in the June 6 issue of *Nature*.

Topol: We're going to talk a bit more about the parallels between COVID and polio, but before we do that, what I didn't know was the world of the intensive care unit (ICU) and how it was basically born because of polio. I had no idea.




As you portrayed it, it was remarkable what they discovered about positive pressure ventilation. Back then, all these medical and dental students were hand-ventilating the patients around the clock because there was no such thing as a mechanical ventilator. Something like 50 of these students would be breathing for the patients, basically, with an early Ambu bag or whatever.

I had no clue about all this. Or that it was thanks to polio that we have such a thing as an ICU, an appreciation for blood gases, mechanical ventilators, the interdisciplinary team, the respect for anesthesiologists. Can you take us through that? I don't think a lot of people really know how this all came together.

Wunsch: Even in my own specialty, which is critical care medicine, a lot of people didn't know this story, which is the origin story for the specialty. To put it into context, other people and factors at play were also pushing things in this direction. It's important to recognize that although I tell sort of a single story, it's never quite that simple.

But in the early 1950s, one of the things I had to appreciate and understand was just how little there was to do for people who were critically ill. There were iron lungs for people who had polio with respiratory failure. But with bulbar polio — difficulty swallowing, all of that — it was 90% mortality for those patients.

I stumbled on this story in a book called *The Rise and Fall of Modern Medicine* 20 years ago. It tells this story as an important pivotal moment in medical history when there's a major epidemic of polio in Copenhagen. They've seen a lot of polio over the years, but nothing like this. It was a particularly virulent strain, and it was just hitting an enormous number of people. By the time the epidemic was over, 1 in 200 boys aged 1 to 4 had been paralyzed by polio. The hospital had one iron lung, but they also recognized that iron lungs were not the solution because so many patients had bulbar polio.

The book is about early innovation, but it's also about modern innovation and the important factors involved for something to occur, like this major leap in figuring out how to keep people alive. In this case, it was bringing in an anesthesiologist by the name of Bjørn Ibsen.

At that point in time, anesthesiology was barely a specialty in Denmark. Anesthesiologists had been recognized only a year or two earlier, and they certainly were not involved in the care of polio patients. That was the domain of infectious disease doctors, maybe neurologists, but certainly not anesthesiologists.

Ibsen was the one who came in and suggested, *Let's do a tracheostomy on your patients. I think carbon dioxide retention is killing them. If we take the techniques of the operating room, where we keep people alive with ventilation, and apply them to patients with polio, I think I can save many of your patients.*

So, the crux of the story is what it took for them to let him try this. You alluded to the involvement of ultimately 1200 medical and dental students when they realized they had a technique that worked — positive pressure ventilation — but they didn't have ventilators yet. It still gives me shivers every time I imagine being one of those students sitting at the bedside. They did it in 6- to 8-hour shifts, 24 hours a day, for months. At one point, they kept 70 patients alive this way. It's a great story, but it's also an important story for people to understand how recently we didn't have these basic interventions that we consider part and parcel of modern medicine.

# Nobody Expected Polio To Be Back

**Polio is on the brink of eradication. Here's how to keep it from coming back.**

**The campaign to eradicate polio could succeed in the next few years. But that's just the beginning of a new challenge — keeping it away.**

**Source:** www.nature.com — 21 November 2023

*Photo: A child in Tanzania has his finger marked to show that he has received a polio vaccine during a door-to-door campaign in 2022. Credit: Ericky Boniphace/AFP via Getty*

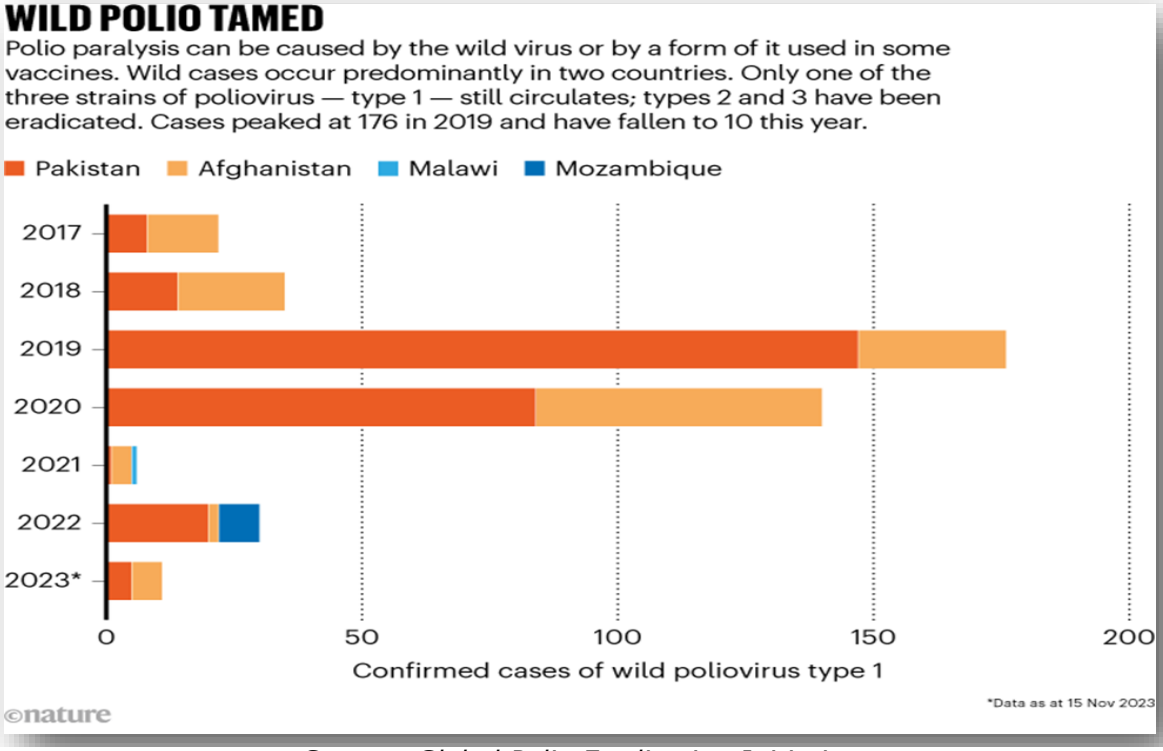
Nobody expected polio to be back.

It's 2040, a decade since the disease was eradicated. The global health campaign that vanquished the virus has disbanded; immunization efforts have slackened. Then, one day, a sick child in a conflict-wracked country develops paralysis; the cause turns out to be polio. Scientists trace the origin of the virus to a laboratory on the other side of the world. A technician at the lab had handled a forgotten batch of polio-infected material — and then visited their family abroad.

As cases multiply, the World Health Organization (WHO) appeals for help to conduct emergency immunization campaigns, but stocks of vaccines are low and few members of staff have direct experience of polio outbreaks. Soon there are tens of thousands of cases: millions more people around the world who haven't had the vaccine are at risk.

This is just one of many possible scenarios that could follow polio eradication. Although the world has not yet eliminated poliovirus, many observers think it could be gone within three years. The polio-eradication campaign has increased its intensity and funding in the past year in the hope of finally meeting a deadline that's been postponed many times since efforts were launched in 1988.

The front lines are Afghanistan and Pakistan, where pockets of wild polio persist but are shrinking (see 'Wild polio tamed'), and a swathe of Africa, where a polio vaccine that includes live virus has itself seeded outbreaks. There are signs that health campaigns are now bringing these vaccine-derived episodes under control.




*Source: Global Polio Eradication Initiative*

***Cont'd p15***

# Nobody Expected Polio To Be Back (cont'd from p14)

The final steps towards eradication are formidable, and it's not clear when — or whether — nations will reach this goal. Nonetheless, with the demise of the virus in sight, health authorities are planning what happens next.

That's because eradication is not extinction. Polio could lurk in testing labs and manufacturing facilities — from which it has leaked in the past — and even in some people. Mistakes years after eradication could let polio into an unprotected population where it could *"wreak havoc",* says virologist Konstantin Chumakov, former associate director of vaccine research at the FDA Office of Vaccines Research and Review in Silver Spring, Maryland.

The end of polio is only the beginning of another effort: developing the resilience to keep it away, says Liam Donaldson, a public-health specialist at the London School of Hygiene & Tropical Medicine, UK, and the lead author of a series of independent reports on the campaign's progress (see go.nature.com/49hho4a). *"People have signed up to polio eradication, but they've not signed up to the longer journey."*

## Stamping it out

Only one human disease has so far been declared eradicated: smallpox, in 1980. Polio has been more complex, says David Heymann, who heads the WHO's Containment Advisory Group. That's because of a key difference: every smallpox infection produces symptoms, but polio can silently infect up to 1,000 people before causing a case of paralysis. The other snag is that polio can be caused not only by the wild virus, but also, in very rare cases, by the vaccines deployed to prevent it. Eradication means getting rid of both forms for good.

The main tool is vaccination. Industrialized, polio-free countries use an inactivated poliovirus vaccine (IPV), which doesn't prevent the virus infecting the body and being shed in stools, but does protect against paralysis. Provided that immunization levels with IPV remain high and sanitation is good, a rogue poliovirus will probably peter out, according to Concepcion Estivariz, a polio researcher at the Centers for Disease Control and Prevention (CDC) in Atlanta, Georgia.

But because the inactivated vaccine can't block transmission, children in at-risk countries still receive another type: an oral poliovirus vaccine (OPV) that contains an attenuated form of the live virus, and can stop polio's spread — which is crucial for eradication. It's also cheaper and easier to deliver than IPV, which is administered by injection. The oral campaign has been hugely successful. Since 1988, the Global Polio Eradication Initiative (GPEI) estimates it has prevented 20 million cases of polio paralysis.

But OPV has some important downsides. There is a low risk that the vaccine itself can cause paralysis. And, on rare occasions, the weakened virus used in the vaccine can mutate sufficiently to regain virulence. This can lead to outbreaks of cases known as vaccine-derived polio among people who have not been vaccinated fully or at all. *"If we continue OPV,"* says Estivariz, *"we never stop the circle."* Most countries are now using IPV in their routine immunization programmes alongside OPV, and the WHO recommends that IPV administration should continue for a decade after disease transmission has been stopped, to protect against any accidental releases or hidden pockets of the virus.

Polio will be certified as eradicated when no case has been observed for three years, and when there is no sign of it in environmental surveillance data — that is, in samples of waste water. A year after that, OPV must be withdrawn to prevent vaccine-derived polio. The problem, however, is that removing it will be an extraordinarily delicate manoeuvre. Done messily, this process could trigger the return of the virus.

In 2016, for instance, the withdrawal of an OPV across 150 countries went disastrously wrong. *"The results were sobering",* says Kimberly Thompson, an epidemiologist at the research non-profit organization Kid Risk, in Orlando, Florida.

There are three strains of wild polio — types 1, 2 and 3. Type 2 was declared eradicated in 2015, and type 3 followed in 2019. The oral vaccine contained attenuated versions of all three strains, but after type 2 was eradicated, the aim was to withdraw vaccines containing that strain to minimize the risk of seeding vaccine-derived type 2 polio. So the GPEI orchestrated a two-week period in April 2016 in which all three-strain oral vaccines were switched for versions containing just types 1 and 3.

Swiftly, however, cases of vaccine-derived type 2 polio began to build — in two countries in 2016, spreading to 24 countries by 2020, with countries in Africa worst affected. A case popped up in the United States in 2022, and the United Kingdom found the virus in wastewater samples. The cumulative number of paralysis cases so far is just over 3,200; the yearly total peaked at more than 1,000 in 2020 and now seems to be declining, with 238 recorded so far this year (see 'Rare and receding: vaccine-derived polio'). African countries are still running multiple emergency campaigns delivering oral type 2 vaccines to stamp these outbreaks out.

*Read full article here.*

# The World Has The Tools To End Polio

**... but eradication remains elusive.**

***By the Editorial Board***

**Source:** www.washingtonpost.com — 28 September 2023

A variety of new hurdles has emerged in the long, difficult struggle to eradicate polio, a disabling and life-threatening disease caused by the poliovirus that can infect the spinal cord and cause paralysis. World health authorities have the tools to fight back. But the effort will require sustained attention — and funding.

In 1988, when the World Health Assembly created the Global Polio Eradication Initiative, there were 350,000 cases of wild polio across 125 countries, with more than 1,000 children per day becoming paralyzed. The battle against the disease in recent decades has reduced the cases of wild poliovirus by 99 percent and prevented more than 20 million cases of paralysis. Three poliovirus strains have existed: wild types 1, 2 and 3. The wild types 2 and 3 have been eradicated; type 1 remains endemic in Afghanistan and Pakistan. This isn't victory, but it is close.

What makes the polio campaign so tantalizing and yet exasperating is that it has often appeared to be on the cusp of eradication, only to see the goal slip away. A new status report from the eradication initiative's Independent Monitoring Board says the fight against polio is once again at a critical point.

A concerning problem now is the spread of variant poliovirus, or vaccine-derived poliovirus. One of the polio vaccines (not used in the United States since 2000) uses a live, weakened version of the wild strains to trigger an immune response by the human body. Sometimes, if not enough people in a community have been immunized, that strain can genetically revert in the environment to a form that causes paralysis. Cases of the variant polioviruses are especially common in Africa. The type 1 vaccine-derived strain, according to the report, *"has an incredible capacity to transmit. It is said to have 10 times greater capacity to paralyse than type 2 vaccine-derived poliovirus."*

Worryingly, the report found *"vaccine-derived polioviruses are paralysing nearly 50 times more children than wild polioviruses."* Of the 674 confirmed cases of paralytic poliomyelitis reported during the 12 months up to July 31, just 16 were caused by type 1 wild poliovirus, 217 by circulating type 1 vaccine-derived poliovirus, 436 by circulating type 2 vaccine-derived poliovirus and five by both types of vaccine-derived poliovirus. These cases were reported from 28 countries, 21 of them in Africa.

Children line up for polio vaccine drops given by health workers in Kandahar on Monday. (Sanaullah Seiam/AFP/Getty Images)

If the type 1 vaccine-derived poliovirus infects a vulnerable population — where immunization is low — it could easily set off a *"chain reaction"* and take hold, *"a very serious problem that risks destabilizing the whole Polio Programme,"* the report warns. It urges polio fighters to press harder against these variant polioviruses.

On top of that worry, lingering barriers to progress remain in Pakistan and Afghanistan. Late last year, there was a surge of wild poliovirus cases in south Khyber Pakhtunkhwa province, in Pakistan's northwest. The virus has a *"stubborn hold"* in the region, the report says. One reason: boycotts, in which local populations seek redress for their complaints — job-related, or grievances about lack of basic necessities — and boycott the polio vaccination campaigns. Without immunization coverage, the population remains vulnerable. In Afghanistan, now under the Taliban's strict Islamist rule, efforts to fight polio with vaccination campaigns face immense obstacles, not the least of which is a severe humanitarian crisis.

The good news is that a new oral polio vaccine that has significantly less risk of seeding new cases is being rolled out; as of this month, 700 million does have been administered across 33 countries.

The report says the goal to [introduce] a new oral polio vaccine that has significantly less risk of seeding new cases is being rolled out; as of this month, 700 million doses have been administered across 33 countries. But at this point, with so much invested and so much achieved, the world need not treat failure as inevitable, particularly with a safe new vaccine available. Sustained financial and political support for the battle against polio is essential. So are realistic expectations. As the report notes of the stubborn poliovirus, *"once transmission gets established, it takes a long time to get rid of it."*

# New Way To Boost Polio Vaccination

## Pakistan officials consider a new way to boost polio vaccination: prison

***By Adil Jawad and Maria Cheng | AP***

**Source:** www.washingtonpost.com
— 1 October 2023

KARACHI, Pakistan — Authorities in one Pakistan province are turning to a controversial new tactic in the decades-long initiative to wipe out polio: prison.

(Fareed Khan/AP)

Last month, the government in Sindh introduced a bill that would imprison parents for up to one month if they fail to get their children immunized against polio or eight other common diseases.

Experts at the World Health Organization and elsewhere worry the unusual strategy could further undermine trust in the polio vaccines, particularly in a country where many believe false conspiracies about them and where dozens of vaccinators have been shot and killed.

Adding to the problems faced by experts trying to persuade people of the vaccines' safety: The oral vaccines themselves now cause most polio cases worldwide.

WHO's polio director in the Eastern Mediterranean warned the new law could backfire. *"Coercion is counterproductive,"* said Dr. Hamid Jafari.

He said health workers have typically succeeded in raising immunization rates in vaccine-hesitant areas by figuring out the reasons for people's refusal and addressing those concerns, like bringing in a trusted political or religious leader to talk with people.

*"My own sense is that Pakistan wants to have this legislation in their back pocket in case they need it,"* Jafari said. *"I would be surprised if there's a willingness to actually enforce these coercive measures."*

Pakistan and neighboring Afghanistan are the only countries where the spread of polio has never been stopped. The potentially fatal, paralyzing disease mostly strikes children up to age 5 and typically spreads in contaminated water.

WHO and its partners have administered billions of vaccine doses since they first began trying to eradicate the disease in 1988. The effort costs nearly $1 billion a year and is largely funded by donor countries and private organizations including the Bill & Melinda Gates Foundation.

The immunizations, given to children as drops in the mouth, have reduced polio cases by more than 99%. But in very rare cases, the live virus in the vaccine can cause polio or mutate into a strain that triggers a new outbreak.

So far this year, there have been seven cases of polio caused by the wild virus — all in Pakistan and Afghanistan. Meanwhile, more than 270 cases have been caused by a virus linked to the vaccine in 21 countries across three continents.

In January, roughly 62,000 parents, mostly in Pakistan's Sindh province, refused polio vaccinations for their children, prompting authorities there to propose the new law with penalties.

The bill is in the final stages of becoming law after the provincial assembly approved it in August. It would punish parents with up to a month in prison for failing to vaccinate their children against certain diseases; they could also be fined up to 50,000 rupees ($168). Officials said their primary aim was to boost polio immunization rates, though diseases including measles, pneumonia and pertussis are also in the legislation.

Rukhsana Bibi, a health worker in Karachi, hopes the new law will reduce vaccine refusal rates and protect health workers. Karachi is considered at high risk for a polio resurgence.

Bibi noted that in the past, abusive or threatening parents have been detained by police. They were released on the condition that they have their children immunized, and that they help the polio team with outreach efforts.

There are multiple factors fuelling vaccine hesitation in Pakistan.

Many people are suspicious of the outside entities funding the vaccines and of the Pakistan government itself.

Some *"fringe elements"* believe in a false conspiracy theory — that the vaccines are part of a plot by Western outsiders to sterilize people, Bibi acknowledged. But many parents would prefer that the government provide better health care, food or financial assistance.

***Cont'd p18***

## New Way To Boost Polio Vaccination *(cont'd from p17)*

*"Parents believe that's because the government gets grants and donations for such vaccines, so it keeps focusing on (the polio vaccines) instead of providing basic health care,"* Bibi said. *"It makes parents suspicious."*

The public's already-shaken confidence in vaccine drives also took a dive in 2011, when the U.S. Central Intelligence Agency set up a fake hepatitis vaccination program in an attempt to gather intel on former al-Qaida chief Osama bin Laden. Militants have also gunned down health workers distributing vaccines and sent suicide bombers to blow up the police vehicles protecting them.

Heidi Larson, director of the Vaccine Confidence Project at the London School of Hygiene and Tropical Medicine, said it was disheartening that people were so mistrustful of the government that they didn't believe the polio vaccine was in their children's best interests.

*"I don't think in this kind of situation that throwing parents in jail is going to help,"* she said. *"Not only does it not work, but it's likely to ramp up the anger."*

Larson drew a comparison to COVID-19 vaccine mandates implemented in countries including Australia, Britain, France and the U.S.

*"It's a challenge because when you're talking about a (vaccine) that comes with a risk, even if it's a very small one, can you force this and make people take it?"* Larson asked.

In some parts of Sindh province, the refusal rate for the polio vaccine is as high as 15%, according to a government official who was not authorized to comment publicly and spoke to The Associated Press on condition of anonymity. To eradicate polio, more than 95% of the population needs to be immunized.

The Sindh official said parents would be penalized for refusing the vaccine, but doses wouldn't be administered to their children without their consent.

Dr. Paul Offit, director of the Vaccine Education Center at the Children's Hospital of Philadelphia, said it would be extremely challenging to rebuild trust with punitive measures.

*"The oral polio vaccine is not the best vaccine, but it's still much better than not getting the vaccine at all,"* Offit said. *"It's ultimately the job of governments to stand up for children and we know that if we don't vaccinate a certain percentage of children, that polio will always come back."* Last year, the virus was detected in rich countries including Britain, Israel and the U.S. for the first time in nearly a decade.

Muhammad Akhtar, the father of three children in Karachi, said he believes in the importance of polio vaccination because his cousin was sickened by the disease. But Akhtar disagrees with the idea of punishing people, saying parents should be able to choose which vaccines their children receive.

Another father, Khan Muhammad, of Benaras Town near Karachi, is among those who believe in the false conspiracy theories. He has seven children and argues that polio is just like any other debilitating disease.

*"Allah blessed us with these children and he alone will protect them,"* Muhammad said. *"At the end of the day, it's God's will."*

## For Yemen's children, the path to a polio diagnosis starts with a remarkable road trip

***By Hanan Eshaq & Kevin Cook, WHO***

**Source:** polioeradication.org – 8 November 2023

Stopping any polio outbreak starts with vaccine procurement, transport by airplanes and trucks, distribution involving complex logistics, and eventually the oral administration of the vaccine by drops in the mouths of every eligible child.

However, there is another, lesser known but equally important process that must also take place to halt transmission of the poliovirus. It begins with a humble stool sample – a thumb-sized smudge of poop – taken from a child with acute flaccid paralysis (AFP), then delivered to the nearest laboratory that can test the sample specifically for poliovirus.

But nowhere in Yemen is there any such lab. So the long and arduous journey of any stool sample from a Yemeni child to a receiving lab can take up to several days – following an easterly route, to the neighboring country of Oman.

*Read the full story here.*

# Pakistan Boycotts Polio Immunisation

## Districts of Pakistan boycott polio immunisation until economic and health demands are met

**Source:** www.bmj.com – 6 December 2023

Tribal elders in the last remaining areas of Pakistan to have endemic wild polio are boycotting immunisation campaigns until the country's government meets demands on infrastructure, livelihoods, and health.

Various tribal jirga (assemblies) in the south of Khyber Pakhtunkhwa province in the country's north west have staged 677 boycotts so far this year, with demands ranging from electricity provision to refuse collection. Without the boycotts, *"I would have finished polio by the end of last year,"* said Shahzad Baig, coordinator of Pakistan's National Emergency Operations Centre for Polio Eradication.

The growth of district-wide, large scale boycotts was highlighted at a 28 November press conference hosted by the Global Polio Eradication Initiative, which is led by the World Health Organization. In Bannu, one of the endemic districts, several union councils (elected local government bodies) have imposed a boycott, with more than 17 000 people missing vaccination. The councils' demands relate to electricity supply, roads, and bridges, as well as the release of prisoners arrested for anti-state activities, Baig told *The BMJ*.

Meanwhile, in the district of North Waziristan, leaders of the Utmanzai tribe prevented the vaccination of 140 000 children for three months. Negotiations with tribal elders have now improved access, said Baig.

*"The boycotts are not at the same place every round,"* he added. *"If I miss, say, 20 000 children because of boycotts, then at the next round, because of the efforts of our communication teams, we may reach 90% of those children—but then there is a boycott in another place. The result is enough to create a core part where transmission can be sustained."*

### Unprecedented support

WHO's Global Polio Eradication Campaign has eliminated most of the world's wild polio, but it remains in pockets of Afghanistan and Pakistan, which between them have recorded 12 cases in 2023. The international campaign has intensified its focus on these countries in recent years with high profile visits, such as one by the philanthropist and polio funding donor Bill Gates to Pakistan in early 2022.

Baig said, *"I have unprecedented support from the government and opposition, from the partners both at the national and international levels and donors; and I have an unprecedented technical team . . . so all the ingredients required to make it happen are there."* But he added, *"The people in the communities know that the only programme that the government takes very, very seriously is the polio programme, so that means they think this is now a bargaining chip."*

Baig oversees three to four national campaigns a year targeting Pakistan's 44 million-plus children aged under 5, and he has overseen seven emergency campaigns in the endemic districts in 2023.

Jai Das runs a project to develop new ways of incentivising communities at the Institute for Global Health and Development, Aga Khan University in Pakistan. He said that he saw *"a lot of backlash"* to the current programme. *"People are saying, 'We don't have food, we don't have hygiene—why is the government after polio only?'"*

Zulfiqar Bhutta, the institute's director, added, *"People are now very openly saying that this is principally a disease eradication strategy for the rest of the world and that polio is not their priority."*

Sheeba Afghani, senior manager of social and behaviour change at the UN children's agency Unicef, said that most boycotts are successfully resolved, with only 16 outstanding this year. Her team gathers *"social intelligence,"* charts the networks of influencers, and maps hotspots of likely resistance.

What follows is painstaking work with leaders, listening to grievances, resolving some of them, and urging leaders to delink others from safeguarding their children against polio. Afghani said, *"We don't have a choice. We have to act as a link between the community and the district administration—we become a facilitator."*

Read full article here.

# Taliban Declares War On Polio

**After long banning polio campaigns, Taliban declares war on the disease**

***By Rick Noack***

**Source:** www.washingtonpost.com — 5 December 2023

ACHIN, Afghanistan — During its 20-year armed campaign, the Taliban repeatedly banned door-to-door immunization campaigns, helping to make Afghanistan one of only two countries where naturally acquired poliovirus is still endemic.

Two years after the Taliban took power, however, it has done an about-face, and its unexpected efforts may now represent the best shot in two decades at eradicating the highly transmissible, crippling children's disease in Afghanistan.

Vaccinators in the country's northeast, the center of the poliovirus outbreak, search cars for unvaccinated children at roadside checkpoints manned by Taliban soldiers. With no deadly attacks on public health campaigners reported in Afghanistan this year, they also feel increasingly comfortable venturing into remote virus hot spots that were previously far beyond their reach.

*"We now have access all over the country,"* said Hamid Jafari, director of the WHO's regional polio eradication program.

After years of disrupting public health campaigns and amplifying vaccine scepticism, the Taliban now faces challenges of its own making. But the Taliban-run government says it is committed to the effort, and the unlikely alliance between officials and internationally funded health workers — if still at times uneasy — reflects the considerable shift in the priority the government puts on vaccinating Afghans against polio and other infectious diseases.

*"It's a priority for us,"* Zabihullah Mujahid, the Taliban spokesman, who for many years was tasked with announcing the group's bans, said in an interview.

The Taliban's resistance to door-to-door campaigns, he insisted, was never ideological. Much of its opposition arose after the CIA, seeking to hunt down Osama bin Laden, ran a fake hepatitis vaccination program in neighboring Pakistan aimed at collecting DNA that matched that of the al-Qaeda leader. While U.S. officials say the program never succeeded in collecting DNA from residents of the Abbottabad compound where bin Laden was later killed by U.S. Navy SEALs in 2011, the intelligence effort fostered distrust of vaccinators across the region and exposed them to a wave of deadly attacks after the ploy was revealed.

*"We didn't dare to go to villages for funerals of relatives out of fear that we'd be shot there,"* said Abdul Rahman Ahmadi Shinwari, a vaccinator.

On a recent day, Shinwari was at work at the Afghan border crossing of Torkham, accompanied by Taliban soldiers. *"It's a relief to be able to just stand here today with these men,"* he said.

Read full article here.

*A polio vaccinator vaccinates a boy among a group of returnees deported from Pakistan at the Torkham border crossing in eastern Afghanistan on Nov. 11. Two years after their return to power, the Taliban have been actively trying to fight polio, with awareness-raising and immunization campaigns across the country.*

*(Elise Blanchard for The Washington Post)*

# Polio This Week

## Global Circulating Vaccine-derived Poliovirus (cVDPV) as of 28 November 2023

| | Country | AFP cases (Paralysis onset between 2020-2023) | | | | | Other sources (Human)[2] (Collection between 2020-2023) | | | | | Other sources (Environment) (Collection between 2020-2023) | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | 2020 | 2021 | 2022 | 2023 | Onset of most recent case | 2020 | 2021 | 2022 | 2023 | most recent collection date | 2020 | 2021 | 2022 | 2023 | most recent collection date |
| cVDPV1[1] | DR Congo | | | 148[3] | 83[3] | 29-Aug-23 | | | 6 | | 09-Oct-22 | | | | | |
| | Madagascar | 2 | 13 | 16 | 23 | 26-Aug-23 | | 25 | 11 | 7 | 20-Jun-23 | | 31 | 147 | 90 | 31-Jul-23 |
| | Mozambique | 1 | | 22 | 3 | 27-Feb-23 | | | 1 | | 25-Oct-22 | | | | | |
| | Malawi | | | 4 | | 01-Dec-22 | | | 1 | | 19-Sep-22 | | | | | |
| | Congo | | | 1 | | 15-Oct-22 | | | | | | | | | | |
| | Yemen | 31 | 3 | | | 27-Mar-21 | | | | | 07-Jul-19 | | | | | |
| | Malaysia | 1 | | | | 14-Jan-20 | | | | | | 9 | | | | 13-Mar-20 |
| | Total type 1 | 35 | 16 | 191 | 109 | | 0 | 25 | 19 | 7 | | 9 | 31 | 147 | 90 | |
| cVDPV2[1] | Côte d'Ivoire | 64 | | | 5 | 05-Sep-23 | 25 | | | 14 | 05-Oct-23 | 95 | | 3 | 15 | 12-Oct-23 |
| | Central African Republic | 4 | | 6 | 14 | 07-Oct-23 | 1 | | | 15 | 14-Jun-23 | 2 | 1 | 8 | 1 | 19-May-23 |
| | DR Congo | 81 | 28 | 372[3] | 108[3] | 01-Sep-23 | 95 | 6 | 30 | 8 | 16-Sep-23 | 1 | 3 | 10 | 33 | 05-Oct-23 |
| | Nigeria | 8 | 418 | 48 | 43 | 08-Sep-23 | 8 | 204 | 28 | 19 | 12-Sep-23 | 5 | 303 | 82 | 54 | 04-Oct-23 |
| | Algeria | | | 3 | | 13-Dec-22 | | | 2 | 3 | 05-Jan-23 | | | 18 | 21 | 02-Oct-23 |
| | Mali | 52 | | 2 | 9 | 23-Aug-23 | 3 | | | | 15-Aug-20 | 4 | | | 3 | 29-Sep-23 |
| | Zimbabwe | | | | | | | | | | | | | | 7 | 26-Sep-23 |
| | Guinea | 44 | 6 | | 13 | 22-Sep-23 | 1 | | | 3 | 17-Jul-23 | 1 | 2 | | 2 | 06-Sep-23 |
| | Tanzania | | | | 2 | 14-Jul-23 | | | | 6 | 12-Aug-23 | | | | 3 | 18-Sep-23 |
| | Somalia | 14 | 1 | 5 | 5 | 16-Sep-23 | 13 | | 4 | 3 | 03-Aug-23 | 26 | 1 | 4 | 6 | 07-Sep-23 |
| | Kenya | | | | 8 | 21-Aug-23 | 1 | 2 | | 5 | 22-Aug-23 | 1 | 1 | | 6 | 15-Sep-23 |
| | Cameroon | 7 | 3 | 3 | | 22-Dec-22 | 4 | 3 | | | 29-Oct-21 | 9 | 1 | | 12 | 14-Sep-23 |
| | Egypt | | | | | | | | | | | 1 | 12 | 6 | 6 | 13-Sep-23 |
| | Chad | 101 | | 44 | 44 | 12-Sep-23 | 17 | | 4 | 6 | 21-Jun-23 | 3 | 1 | 7 | 3 | 10-Aug-23 |
| | Niger | 10 | 18 | 16 | | 25-Dec-22 | 2 | 1 | 3 | | 19-May-22 | 9 | | 14 | 2 | 04-Sep-23 |
| | Yemen | | 66 | 162 | 3 | 28-Aug-23 | | 17 | 33 | 1 | 11-Jun-23 | | 13 | 27 | 3 | 29-May-23 |
| | Botswana | | | | | | | | | | | | | 5 | 5 | 25-Jul-23 |
| | Burundi | | | 1 | 1 | 15-Jun-23 | | | 2 | | 24-Nov-22 | | | 7 | 13 | 13-Jun-23 |
| | Zambia | | | | 1 | 03-Apr-23 | | | | 4 | 25-May-23 | | | 3 | 2 | 06-Jun-23 |
| | Burkina Faso | 68 | 2 | | 2 | 04-Jun-23 | 12 | | | | 19-Sep-20 | | 1 | | | 28-Dec-21 |
| | Congo | 2 | 2 | | | 10-Feb-21 | 2 | | | | 12-Oct-20 | 1 | 3 | | 1 | 11-Apr-23 |
| | Benin | 3 | 3 | 13 | 3 | 15-Mar-23 | | 2 | 1 | | 01-Jun-22 | 5 | 1 | 9 | 3 | 21-Feb-23 |
| | Indonesia | | | 1 | 3 | 20-Feb-23 | | | 3 | 7 | 01-Jan-23 | | | | | |
| | Israel | | | | 1 | 13-Feb-23 | | | | | | | | 55 | | 24-Oct-22 |
| | Malawi | | | | | | | | | | | | | | 1 | 02-Jan-23 |
| | Sudan | 58 | | 1 | | 31-Oct-22 | 11 | | | | 01-Oct-20 | 14 | | 1 | | 28-Nov-22 |
| | United Kingdom | | | | | | | | | | | | | 6 | | 08-Nov-22 |
| | United States of America | | | 1 | | 20-Jun-22 | | | | | | | | 30 | | 20-Oct-22 |
| | Ghana | 12 | | 3 | | 14-Sep-22 | 10 | | 4 | | 01-Jun-22 | 20 | | 19 | | 04-Oct-22 |
| | Togo | 9 | | 2 | | 30-Sep-22 | 9 | | | | 09-Jul-20 | | | 2 | | 06-Sep-22 |
| | Canada | | | | | | | | | | | | | 2 | | 08-Sep-22 |
| | Djibouti | | | | | | | | | | | | 7 | 11 | | 22-May-22 |
| | Ethiopia | 37 | 10 | 1 | | 01-Apr-22 | 7 | | | | 13-Oct-20 | 4 | | | | 28-Dec-20 |
| | Mozambique | | 2 | 4 | | 26-Mar-22 | | | | | 17-Dec-18 | | | | | |
| | Eritrea | | 1 | 1 | | 02-Mar-22 | | | | | | | | | | |
| | Senegal | | 17 | | | 27-Oct-21 | | 34 | | | 17-Nov-21 | 1 | 14 | 1 | | 17-Jan-22 |
| | Ukraine | | 2 | | | 24-Dec-21 | | 18 | | | 09-Oct-21 | | | | | |
| | Mauritania | | | | | | | 4 | | | 19-Jul-21 | | 7 | | | 15-Dec-21 |
| | Uganda | | | | | | | | | | | | 2 | | | 02-Nov-21 |
| | Gambia | | | | | | | | | | | | 9 | | | 09-Sep-21 |
| | Pakistan | 135 | 8 | | | 23-Apr-21 | 2 | | | | 11-Nov-20 | 135 | 35 | | | 13-Aug-21 |
| | Guinea-Bissau | | 3 | | | 15-Jul-21 | | 1 | | | 26-Jul-21 | | | | | |
| | Tajikistan | 1 | 35 | | | 25-Jul-21 | | 22 | | | 24-May-21 | | 17 | | | 22-Mar-21 |
| | Afghanistan | 308 | 43 | | | 09-Jul-21 | 36 | 2 | | | 03-May-21 | 175 | 40 | | | 23-Jun-21 |
| | Sierra Leone | 10 | 5 | | | 28-Feb-21 | 6 | 8 | | | 19-Mar-21 | | 9 | | | 01-Jun-21 |
| | Liberia | | 3 | | | 28-May-21 | 2 | 5 | | | 21-Jan-21 | 7 | 14 | | | 20-Apr-21 |
| | South Sudan | 50 | 9 | | | 10-Apr-21 | 19 | 5 | | | 25-Feb-21 | 6 | | | | 01-Dec-20 |
| | Iran | | | | | | | | | | | 3 | 1 | | | 20-Feb-21 |
| | Angola | 3 | | | | 09-Feb-20 | | | | | 31-Oct-19 | | | | | |
| | Malaysia | | | | | | | | | | | 5 | | | | 04-Feb-20 |
| | Philippines | 1 | | | | 15-Jan-20 | | | | | 23-Nov-19 | 4 | | | | 16-Jan-20 |
| | Total type 2 | 1082 | 685 | 689 | 265 | | 286 | 334 | 114 | 94 | | 537 | 498 | 330 | 202 | |
| cVDPV3[1] | Israel | | | 1 | | 12-Feb-22 | | | 3 | | 24-Mar-22 | 1 | 5 | 25 | | 15-Mar-22 |
| | Occupied Palestinian Terr. | | | | | | | | | | | | 7 | 9 | | 12-Mar-22 |
| | China | | | | | | 1 | | | | 22-Jul-20 | | 1 | | | 25-Jan-21 |
| | Total type 3 | 0 | 0 | 1 | 0 | | 1 | 0 | 3 | 0 | | 1 | 13 | 34 | 0 | |
| Gender | Female (all sero type) | 493 | 296 | 376 | 157 | | | | | | | | | | | |
| | Male (all sero type) | 610 | 400 | 497 | 214 | | | | | | | | | | | |
| | Gender Unknown | 10 | 3 | 4 | 2 | | | | | | | | | | | |

Environmental surveillance for poliovirus in selected sewage sites established and working

Changes from previous week

***Data in WHO HQ as of 28 November 2023***

Polio Australia
Representing polio survivors throughout Australia

# Post-Polio Health Literacy and Clinical Education

*Project Synopsis*

> *"Due to efficient vaccination programs, acute poliomyelitis is no longer common. Nevertheless, polio survivors are still common worldwide. As post-polio syndrome is prevalent in these survivors, it is prudent to raise the awareness for this condition. Ignoring this significant morbidity can lead to unnecessary tests, delayed diagnosis and mistreatment with potential harm."*
>
> (Enghelberg et al., 2020)

## *BACKGROUND*

As polio eradication approaches successful completion, those who were not beneficiaries of the 45-year global vaccine rollout - those who were clinically and sub-clinically affected by polio infection globally - are experiencing a lower than typical quality of life and function due to the chronic and progressive health conditions known as:

- Late Effects of Polio (LEoP), and
- Post-Polio Syndrome (PPS)

*"For this population, therapeutic education is essential and the development of specific education tools is highly necessary"* (Laffont et al., 2010). Polio Australia has developed and tested a post-polio education program that addresses this problem and can serve as a template for broad international implementation.

## *PROJECT AIM*

To enable all people experiencing post-polio conditions to understand and manage their condition via improved health literacy, while concurrently improving clinicians' post-polio screening and intervention competency to accurately identify and safely help these people on their post-polio health journey.

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## *PRIMARY OBJECTIVES OF THE PROJECT*

- **Community Development Arm** – *Ensuring health literacy for persons with post-polio conditions and for those who co-exist with them* (is funded to June 2025)
  - People affected by polio infection are accurately identified
  - They are well informed about their risk for post-polio conditions
  - They demonstrate health literacy and report successful ageing
- **Clinician Education Arm** – *Ensuring post-polio clinical competency development for clinicians and health workers* (requires 14 months funding to June 2025)
  - Clinicians in medicine and allied health are aware of post-polio conditions
  - They have the knowledge and skills to screen for polio exposure
  - They reliably educate and care for people with post-polio conditions

## *COMPLEMENTARY NATURE OF THE TWO PROJECT ARMS*

The table below outlines the ideal structure and implementation of the two arms in a national program, presented side by side for contrast, and the investment required.

| | **COMMUNITY DEVELOPMENT ARM (CD)** | **CLINICAL EDUCATION ARM (CE)** |
|---|---|---|
| AUDIENCE | • People exposed to polio, unidentified<br>• Identified polio-affected people<br>• Partners, families, carers of polio-affected people<br>• Culturally and linguistically diverse (CALD), and disadvantaged populations' support organisations | • Clinicians who provide direct interventions to clients<br>• Hospital and surgical clinic administrators<br>• Workers employed to care for the elderly<br>• State, national government bodies |
| OPERATIONS PERSONNEL | Roles supporting both arms:<br>National Administrator, Communications Officer, Learning Design Officer | |
| DELIVERY PERSONNEL | CD Program Manager (CD-PM)<br>CD Outreach & Delivery Officer (CD-ODO) | CE Program Manager (CE-PM)<br>CE Outreach & Delivery Officer (CE-ODO) |
| NETWORK AND PARTNERSHIPS | • International CD programs' personnel<br>• State/regional post-polio support group leaders<br>• Community organisations<br>• Traditional media outlets<br>• Disability support alliance organisations | • International CE programs' personnel<br>• Public and private health networks<br>• State/regional governments<br>• Clinical Advisory Group personnel<br>• Post-polio researchers<br>• Neurological condition alliance organisations |
| PROJECT COMPONENTS | • See page 5 | • See page 6 |
| | • Web portal to these arms: https://www.poliohealth.org.au/post-polio-education-navigator/ | |

| | | |
|---|---|---|
| CURRENT AUSTRALIAN PROJECT EXAMPLE METRICS | • Delivered 28 in-person and 26 tele-conference community education sessions over the last 2 years<br>• Directly educated 1778 people affected by polio and their caregivers or partners during the last 4 years<br>• Hosted three one-day post-polio education conferences | • Delivered 220 clinical education sessions over the last 6 years<br>• Directly educated 2369 clinicians of 14 professional types and numerous support staff and clinical students<br>• Hosted booths at medical conferences; presented at local and international conferences |
| NATIONAL PROGRAM OPERATIONS | Resource Development:<br>• Print, publish, postage, office supplies, marketing, subscriptions, consulting. | |
| | Education delivery:<br>For transport, transfers, accommodation, meals, luggage, travel insurances.<br>• CD Arm - 45 in-person education activities<br>• CE Arm - 45 in-person education activities<br>• Sector Participation – 8 in-person attendances | |
| | Budget:<br>Annual program cost for a country of <30 million population: USD 0.6 million. | |
| CURRENT STATUS OF AUSTRALIAN MODEL | The Community Development Arm is currently funded by the Australian Department of Health until June 30th 2025. | The Clinical Education Arm requires funding up to June 30th 2025 to continue the refinement of the program to prepare the product for international implementation. |

## *GLOBAL POTENTIAL OF THE PROJECT*

Our vision for this program is to enable those people experiencing post-polio conditions globally to understand their health, and to receive higher quality care at lower risk from well-informed health teams.

The existing Australian program is unique worldwide, having been developed to serve Polio Australia's mission to *standardise quality polio information and service provision across Australia for polio survivors*. In serving only one population, it's reach and impact are limited. Globally, about three people in every thousand (Jones et al., 2017) would benefit from post-polio education. A similar number of healthcare workers would additionally be reached, based on WHO's Skilled Health Professionals data.

Internationally-based post-polio organisations and people affected by polio who come into contact with the Australian program see it as a desirable solution to challenges faced within their own populations. The fundamental shared frustrations expressed by these parties are both health literacy specific - *we have to find out about and decipher our condition ourselves and there is no one to guide us*, and healthcare intervention specific -

*clinicians are unaware of post-polio conditions and so they make assumptions in care plans which worsen post-polio symptoms and amplify risks.*

For implementation, propagating the Australian post-polio education program within an existing global or regional education infrastructure presents as a rational approach, however, instigating a novel approach may be required.

To achieve this vision - *advancing post-polio education* - we seek consultation with global health stakeholders.

## *PROGRAM CONTACT*

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*"Elimination of new polio cases should not also signal an end to worldwide engagement with polio. As many as 20 million continue to live with the disabling consequences of the disease."*

*"Given the number and diversity of health concerns among the millions disabled by polio and the existence or emergence of PPS, these issues realistically will be something many clinicians will regularly encounter during their professional careers."*

*(Groce et al., 2013)*

*Version: November 2023*


# We are switching off for the holidays

**Closed** 25th December 2023

**Reopening** 8th January 2024

Polio Australia

Representing polio survivors throughout Australia