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Polio Oz News

June 2024 - Winter Edition

My Polio Journey

By Michael Tu

My name is Michael Tu. I am a 48-year-old polio survivor. My encounter with this life-altering disease began when I was just one year old. In the aftermath of the Vietnam War, the North Vietnamese army halted all polio vaccinations to the South in 1976. This decision had devastating consequences.

For many years, I grappled with the physical and emotional challenges of polio. It wasn't until 1978, when my family and I arrived in Australia as refugees, that I began to have functionality in my left leg. However, my struggle to understand why this had to happen to me was just beginning.

Growing up, I often found myself excluded from many activities due to post-polio syndrome. This exclusion, while painful, ignited a fierce determination within me. I was determined to challenge my body and engage in everyday activities, including sports, which were often seen as beyond my reach.

One of my proudest achievements was participating in the <u>Tour de Cure</u>, an endurance cycling event dedicated to raising funds for cancer research. This endeavour was deeply personal. I had promised a beloved family member, who was in the final stages of life battling cancer, that I would participate. It was one of the hardest things I have ever done, but completing it not only fulfilled my promise but also gave me a profound sense of purpose.

This sense of purpose has driven me to seek ways to give back and support others who have faced similar challenges. This is why I reached out to Polio Australia to explore how I could contribute and be part of their mission. In October we are looking to engage with STRYDE4 to participate in a walking [or wheeling] event to raise Polio Awareness. Being a young polio survivor, I encourage other young[er] survivors like me to get involved and participate.

Ed Note: Polio Australia is in the process of Registering for STRYDE4 Day, where 100% of money raised goes directly to a nominated charity.



STRYDE4 Day just happens to coincide with International Polio Day on 24th October 2024.

This is a great Team Building activity for corporate, community, and family groups. Thousands of "champion ambassadors" representing up to 30 charities will embark on a Bondi to Maroubra (10km) or iconic Bondi Beach to La Perouse (21km) walk. For those who are not in Sydney, is the option of a "DIY Walk".

We hope those who are connected to extended family/work/community groups will sign up to participate, either in Sydney or wherever you are. Start the conversation today!

More details will appear in the Spring edition of *Polio Oz News* in September.

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Representing polio survivors

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Winter is on my head, but eternal spring is in my heart 🦣 (

~ Victor Hugo ~

Polio Australia's Websites



Living with polio?

Breath Click To View Our own Womer Brand New Resources



My A Fact Sheets & Videos & Clinical Papers & and more! ations

Polio Australia

Representing polio survivors throughout Australia

Welcome to the Polio Australia website. Polio Australia is a notfor—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

11 Australian Polio Register 13 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

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President's Report



By Gillian Thomas OAM President

For the first time since 2019, the Polio Australia Board members had a face-to-face meeting in Sydney in early May. Representatives from every state network (except Queensland), as well as the three independent members

got together over 1 1/2 days to discuss the future of our respective state and national services.

It must be said that this meeting was a clear of of indication the dedication the are all representatives, considering we volunteers, and everyone paid their own way to be there, including flights, accommodation, and meeting costs. As you can appreciate, it was also both a logistical and physical challenge for many.

Key topics included: Ongoing Funding For The Health Worker Education Program; Where To From Here?; How To Keep The Board Functioning; Current Board Member Commitments; The Role Of A National Patron; and PA Legacy Resources Management.

Team members Michael Jackson (Clinical Educator) and Devalina Battacharjee (Community Development Worker), were also at the meeting to report on their respective program areas. This helped the Board members to better understand the role of Polio Australia's national approach to service provision which is designed to support, not take the place of, the state networks.

The government funding for the Health Worker Education Program was not renewed when the contract period ended in 2022. This has meant that Polio Australia has had ongoing financial challenges to keep this key program operating. Michael has agreed to transition to fewer hours and quarterly contract renewals, as Polio Australia continually assesses our core funds.

Devalina's program is funded by the Department of Health until the end of May 2025, after which time it will not be renewed.

Polio Australia is reliant on donations. This end of financial year (EOFY), more than ever, we are asking people to consider making a tax-deductable donation to Polio Australia so that the national programs run by our dedicated team can continue to support Australia's polio survivors for another year. (See page 6 for details.)

From The Editor



By Maryann Liethof Editor

I was delighted to have connected with the dynamic Michael Tu (P1) following his outreach to Polio Australia earlier this year. Michael was keen to do a ride similar to his *Tour de Cure* event with the aim of raising post-polio

the aim of raising post-polio awareness, as well as much needed funds for Polio Australia's programs. Even though this sounded fantastic, on a practical level, we lack the necessary (human) resources to organise such an activity. Michael has since introduced Polio Australia to Geoff Coombes OAM, the CEO of STRYDE4, who encouraged us to Register for the STRYDE4 Day on 24th October. Now we just need to raise the Registration Fee!

Using every second of his 3 day week, when he's not educating health professionals, Michael Jackson is actively involved in keeping post-polio research current. His latest 2024 Survey (P4), explores the use of post-polio-related terminology. Language is constantly evolving and it is important for advocacy organisations to stay ahead of the curve.

Devalina Battacharjee's Community Information Sessions have revealed a slowing down of people

attending face-to-face sessions in favour of Zoom meetings, which are very popular.

Do you have dietary restrictions that leave you struggling to get the necessary nutrients for optimal health? Nutritionist, Melinda Overall, has a few tips that might help (P9). If you would like more specific advice, Melinda can be booked for a telehealth consultation via her website.

The good folk at <u>Freedom2live</u> have published a tidy summary of the Federal government's 2024-25 Budget, and what it means for people living with a disability (P11). As many of our readers are over the age of 65 and, therefore, not eligible for NDIS, perhaps the <u>MyAgedCare</u> update might be more relevant.

In articles about polio from around the world, I was interested to read about Khizar, a 32 year old teacher in Pakistan, who has set himself a goal of planting 10 million trees! The language in the Pakistan-based article describes him as a 'victim' but it is clear that Khizar sees himself as anything but.

There are always numerous articles about the ongoing, and often heroic, efforts of polio eradication campaigns—some more positive than others. As Editor, I continually strive to select an assortment which will provide a balanced overview. Read on!

Maryann

2024 Survey



By Michael Jackson Polio Australia Clinical Health Educator

Terminology in Post-Polio Advocacy and Research

This article reports on some of the major findings of the survey Polio Australia ran in April 2024

exploring identity terminology used in the postpolio community. We sought to understand what the most effective and inclusive terms might be for those who had contracted and had lived an experience with polio. This was to help us better identify and advocate for all of those who experience polio's effects. Many thanks to our volunteer statistician Edwin Li, who helped tremendously with data handling and analysis for this survey.

The development of this survey stemmed from numerous observations:

- Outreach for those affected by polio seemed limited by looking for 'polio survivors', as opposed to those who had experienced polio;
- Conversations with those who had polio in our advocacy work revealed that a noticeable proportion did not see themselves as "survivors" or rejected the term;
- 3. A favouring of the term 'polio survivor' in published post-polio literature;
- 4. Other survivor groups (domestic violence, cancer, PTSD) contesting the term *survivor* in their identities;
- 5. A societal movement towards the use of accurate and person-centred identity terms;
- 6. Contests that alternative identity terminology was cumbersome or lengthy.

Our survey asked 23 questions in English about:

- Factors that may have influenced polioidentity;
- How one identifies with different words related to their polio experiences;
- Opinions on how such words should be used by different groups.

In this article we look at general aspects of the survey and the responses to the primary focus of the survey: post-polio identity. A PDF summary of the responses to each quantitative question from the survey has been created and includes a split of responses by four locations, and contrasts of other questions against identity. The PDF can be viewed at this link: https://bit.ly/PPS-identity. Further findings will be in a subsequent article of Polio Oz News this year.

GENERAL ASPECTS

Those on Polio Australia's contact list were the primary subjects informed of the survey, with further outreach encouraged and performed via individuals' and organisations' networks and social media. A total of 448 responses were submitted in the two weeks the online-only survey was open. We extend our thanks to those who took the time to participate.

The majority (74%) were from Australia, with the next largest national groups being the United States and the United Kingdom. The majority (80%) were aged between 70 and 84 years, and 60% of total responders were female. These responder demographics are reflective of the survey's methodology of the survey, with the major limitations to a broader sample being language, and internet access and literacy.

The mean age of contracting polio was 4.4 years, with 65% being Australian-born. 68% were hospitalised to some extent during their acute polio experience, and some adulthood visible level of impairment was claimed by 73% of the responders. Most (84%) found out or knew they had polio as a child, with few (3%) reporting finding out as an adult; the remaining 13% of these responses were unclear. For 64%, the topic of polio was freely or occasionally talked about in the family home when growing up. These historical features are central to the identity question we explore shortly, but one in particular informs a burning question: What percent of the polio-affected population are immigrants? (i.e. what portion had polio in their country of origin.) From the data we were able to discern the following:

	Australian	Non-Australian
Acute polio resident	282 (85%)	104 (89%)
Acute polio immigrant	49 (15%)	13 (11%)
Total:	331	117

For the Australian post-polio population, we knew the majority experienced their acute polio in Australia. This table gives us a data point for an answer, with the caveat being that non-English speaking and internet-limited people in this population were unlikely to have participated in this survey and are likely underrepresented. A comparable proportion is evident for the non-Australian responders despite vast location differences within that portion of responders.

Community Program 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 completed sessions throughout Tasmania, after a long while, with two sessions being conducted in Launceston and Hobart in late March. The sessions were successful in raising awareness about Late Effects of Polio among people affected who had hitherto not been aware and helped in increasing numbers for our Australian Polio Registry. The Launceston session provided an opportunity for those members who used to interact in-person pre-COVID, but had been unable to get in touch with each other since then, and as

such was a lovely occasion for everyone to reconnect.

We have successfully conducted community information sessions all throughout New South Wales and Canberra, earlier in May, in areas such as Riverwood, Blaxland, Lithgow, Bathurst, Young, Belconnen and Kambah. The sessions were successful in attracting new members to join our existing community and spread awareness about Late Effects of Polio, bringing survivors and their carers into the fold who had thus far been unaware of us and our efforts. It's very rewarding when attendees claim that they feel as if they finally have an explanation as to what they have been experiencing and feel empowered to be able to verbalise their issues which had previously been inexplicable.

In the next month, we are visiting the sunshine state, namely, Townsville, Rockhampton, Bundaberg, Ipswich and Acacia Ridge, in addition to Seymour and Coburg, in Victoria. For more information, please visit: www.polioaustralia.org.au/community-information-sessions/

Until then, keep safe and keep warm!

Ed Note: In the 2023-24 financial year, Devalina's Community Information Sessions have been run in all states and the ACT. Although Polio Australia considered visiting the NT, there were insufficient numbers to proceed.

The number of people who are able to physically attend these sessions has greatly diminished over the years. However, they still managed to attract the following:

ACT = 9 / NSW = 24 / VIC = 32 / TAS = 20 / SA = 60 / WA = 18QLD Sessions to be held from 2 to 7 June, 2024

For those who are unable to attend a session in person, Devalina also facilitates online Zoom sessions, which are generally very well attended.

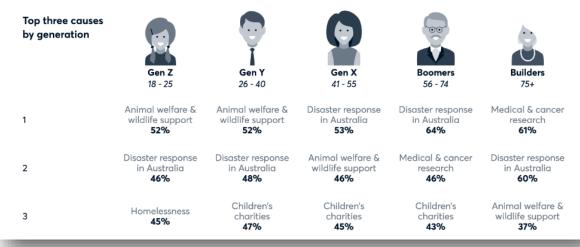
Check the website for details: www.polioaustralia.org.au/community-information-sessions/



End Of Financial Year Call Out



WHO DONATES TO SUPPORT PEOPLE WHO ARE AGEING WITH A DISABILITY?



Source: https://mccrindle.com.au/article/charitable-giving-behaviour-in-australia/

2024 Survey (Cont'd from p4)

While 70% openly speak about polio and their polio experiences as adults, 30% report some degree of aversion to the topic or discussing their experiences. 81% of the responders' note that those in their current social circles are aware of their history of polio. These are unique questions of this population. While they were included in context of exploring identity, the findings should also be of interest to those who work from a counselling or mental health perspective with those with post-polio conditions.

41% have received a diagnosis of Post-Polio Syndrome (PPS), but only 12% reported ever being an adult subject in polio or post-polio research. This is another topic of interest, and requiring further investigation: To what extent is post-polio research participation limited by a PPS diagnosis or by the identity terminology used in subject recruitment materials?

Overall, the responses to the first 16 questions give us a picture of the demographics of those who responded and highlight some of the factors that may influence their identity.

IDENTITY ASPECTS

The focal question in this survey was Question 17 – How would you DESCRIBE YOURSELF NOW in relation to your life experience with polio? The provided answers were the following, with an option to describe in Other:

- I am a polio survivor;
- I am a polio-affected person;
- I am a person who contracted polio;
- I am a person who was exposed to polio;
- I am a person with a post-polio condition;
- I am a post-polio affected person.

Surprisingly, these options were chosen by 98% of the responders; only 7 chose to nominate some other identity. A 'polio' orientation was chosen by 64%, and a 'post-polio' orientation was chosen by 34%. The *exposed to polio* (4th) option was chosen by one person, and is considered rarely preferred. The most selected term was *polio survivor*, but it represented less than a third of responses (31%). The remaining options were selected by between 15-18% of the responders. In other words, 69% of those who responded, and who have a polio experience, do not identify primarily as polio survivors.

Question 18 provided the same six options as in Question 17 (but with any combination being able to be chosen) and asked What terms are you comfortable with OTHERS USING to describe YOU? A larger amount (23) of responders chose the exposed to polio option, 12 provided an Other, 80 chose Any of the above, and 9 chose None of the above (showing some objection).

The remaining five provided options were favoured 23-33% of the time (when adding the 11% of the *Any of the above* responses to their totals). The option *A person who contracted polio* (33%) was slightly more favoured than *polio survivor* (31%). For this question, *polio survivor* maintained its percent favourability from Question 17, while the other options increased their favourability.

Looking deeper into how Question 17 and 18 interact: 64% of those who identified as a *polio survivor* were comfortable being described with a term including *survivor* by others. Hence, a third of those who identify as a survivor don't prefer to be addressed as such – this should be considered by post-polio organisations and advocates in how they describe those with a polio experience.

Questions 19 asked about objectionable polio terms (i.e. terms they disliked others using about them), and Question 20 about reserved polio terms (i.e. terms only for use by those who experienced polio). A text analysis was required to draw out term incidences.

The highest frequency objectionable terms reported were:

- 198 (44%) No objection/none;
- 57 (19%) Cripple, and variations of it;
- 25 (6%) Disabled;
- 22 (5%) Survivor, and variations of it;
- 19 (4%) Victim;
- 18 (4%) Handicapped;
- 18 (4%) Spastic.

The results for reserved terms were:

- 286 (64%) No reserved term;
- 49 (11%) Not applicable;
- 24 (5%) Polio, and variations of it.

These two questions showed that for these respondents there are numerous terms that are objectionable to some (some historically used but leaving an imprint; mostly cited without reasoning), and a majority (3/4) do not consider any specific identity terms to be solely for their population's use.

Question 21 asked about the terms researchers should use when describing this population in academic writing. In published research since 1985 on PubMed, polio survivor has been the dominant term, but on Googles Vgram viewer (published books) polio survivor only recently (2018) surpassed the long-reigning polio victim (since WWII) as the dominant term. While this is certainly progress within books and consistency within this century's research, what do our living experts prefer to be published as?

2024 Survey (Cont'd from p7)

The results were almost identical by percentage to the responses in Question 18 (terms others should use), showing some consistency or perhaps undifferentiated positions on what terms any other person uses. *Polio survivor* in this answer set however, was ranked third, behind people with post-polio conditions, and people who contracted polio. The primary options presented did not receive total rejection – no one chose *None of the above* as an answer, thus providing a soft endorsement for use of any of those listed. Researchers might have to consider their choices contextually with this apparent flexibility.

Looking at contrasts of other survey questions against the primary identity preference question: responses appeared to be clustered slightly toward hospitalisation duration (for months), and strongly for finding out (remember it, or was told), visible impairments (very visible), and public discourse on polio (talk freely on topic and self). These patterns may reflect commonalities within the population sample – people who know they had polio and have lived with a long knowledge of polio in their experience.

FIRST CONCLUSIONS

Is there a single 'best term' to use for this population? Should we lean on one term for convenience or for research consistency? It does not appear so. This population is too varied in their polio and post-polio experiences and health presentations for a single term to stand out or be preferred.

There are limitations to this survey already noted. However, a significant concern (and limitation) persists in that those who found out as an adult (or should have already, or will in the future) are as if not more under-represented than those who are immigrants. Although this survey has a colossal bias towards responders who are already aware of their polio history, it provide stimulus for reconsidering language use and how we phrase education and awareness about post-polio within our society to better identify those at risk for post-polio conditions.

It is apparent – as suspected – that *polio* survivor may not be as well received or identified with as assumed, despite it being the predominant term used in our own resources and documentation, and within research internationally.

What this survey has certainly revealed is that – regarding close-to-heart terminology related to identity – our own advocacy work and published materials should be guided by the populations' preferences, respecting the 'Nothing about us, without us' principle.

In the next issue of this newsletter we will look further into the results from the perspective of answering other specific questions. If you have a question that you are particularly interested in and think this survey's results may answer, please email michael@polioaustralia.org.au and we can take a look!

Q13 When the topic of polio is mentioned or is being discussed in a public social setting, how do you participate?	AUSTRA	LIAN		NON-AL	ISTRAL	IAN							
Count of What is your gender?2													
			Australia Total	UK		UK Total	USA		USA Total	Other Countries		Other Countries Total	Grand Total
Row Labels	Female	Male		Female	Male		Female	Male		Female	Male		
I talk freely about polio, and I talk about my polio experiences	128	99	227	20	15	35	23	10	33	13	6	19	314
I talk freely about polio, but do NOT talk about my polio experinces	12	1	13	1	1	2		1	1	2	2	4	20
I listen to what is being said, but I only participate if I feel it is important to do so	48	33	82	1	3	4	8	1	9	6	1	7	102
I listen to what is being said, but I do not participate	4	4	8		1	1		1	1	1		1	11
I change the subject or I remove myself from the discussion		1	1										1
Grand Total	192	138	331	22	20	42	31	13	44	22	9	31 Other =	448 0

Nutritional Balance With Dietary Restrictions

By Melinda Overall JP

Nutritionist / Counsellor www.overallnutrition.com.au

Maintaining a balanced diet that meets all of the nutritional requirements at every life stage can be difficult, and it can be even more difficult where dietary restrictions are present. Dietary restrictions can manifest for a number of reasons. These include food allergies and intolerances, medical issues, religious grounds, contraindications with medications and personal choices such as vegetarianism, veganism and dieting.

When we remove whole food groups or reduce our intake of foods we can reduce our overall intake of micronutrients (vitamins and minerals) and macronutrients (fats proteins and carbohydrates). This can mean that we don't meet all of the recommended dietary intakes nutrients for our age, gender and physical activity, putting us at risk of nutritional deficiency. As we age it's important to maintain a nutritionally replete diet for ongoing good health, muscle maintenance, a robust immune system, mental health and physical reserves.

If you have had to remove a food/s from your diet for any reason it is important to replace that food with another of similar nutritional value. Doing this helps to ensure nutritional adequacy throughout our lives. An example of this might

be that someone is lactose intolerant and friends might have indicated that they should avoid milk. Milk is a valuable source of calcium, the requirement for which increases as we age, and removing it means that it becomes more difficult to meet the recommended dietary intake of calcium. A better option here would be to switch to lactose-free milk which has the same calcium content but no lactose. Of course, it would be a different question if the person had an allergy to dairy proteins. In this case switching to a calcium fortified alternative/plant-based milk would be necessary.

There can be a tendency to choose foods that are more highly processed or convenient when a person lives with dietary restrictions. This offers greater risk of nutritional deficiencies and a greater risk of developing overweight or obesity. Dropping out grains can reduce fibre intake impacting bowel function and the microbiome.

If you have had to, or have chosen to, remove certain foods from your diet, it is important for you to learn about healthy replacement foods. Whether you're new to your dietary restrictions or even if you've had diet restrictions for some time, a review of your diet every year or so can help to keep you on track. If you have had dietary restrictions for some time you might find that you have either become a little complacent about your diet or you have might been sticking to the same safe foods overtime. This could have limited your nutritional intake.

Some examples of foods swaps:

Avoiding	Replace with
Lactose-containing dairy	Lactose-free dairy
Dairy protein	Soy milk and other plan based milks, cheeses and yoghurts
Sodium/salt	Herbs
Animal proteins	Tofu, tempeh, legumes, nuts and seeds
Grains	Fruit and vegetables

Dietary restrictions can be boring and can impact social interactions, so getting on top of them can improve quality of life. A qualified nutritionist or dietitian can be helpful in ensuring nutritional balance through sensible and sustainable foods substitutes.

Vale Paul Alexander

By Katherine Itoh

Paul Alexander, polio survivor in iron lung for over 70 years, dies at 78 after Covid diagnosis

Source: www.nbcnews.com - 14 March 2024

Paul Alexander, the man who lived inside an iron lung for over 70 years after contracting polio, died Monday after being hospitalized for Covid last month, his friends and family said. He was 78.

Alexander's death was announced on a GoFundMe set up to help him with finances.

"I am so gratitude to everybody who donated to my brother's fundraiser," Philip Alexander said on the GoFundMe. "It allowed him to live his last few years stress-free. It will also pay for his funeral during this difficult time. It is absolutely incredible to read all the comments and know that so many people were inspired by Paul. I am just so grateful."

"His story traveled wide and far, positively influencing people around the world. Paul was an incredible role model that will continue to be remembered," GoFundMe organizer Christopher Ulmer wrote on Tuesday.

The cause of his death was not mentioned. Alexander, who lived in Dallas, Texas, was rushed to the hospital in late February after testing positive for Covid, according to his social media manager. He was released from the hospital but was struggling to eat and drink.

Alexander was declared the longest surviving iron lung patient last March by the <u>Guinness World Records</u>. He contracted polio during an epidemic of the debilitating disease in the 1950s as a child living in Texas.

Despite his condition, Alexander graduated from college with a law degree and ran his own legal practice. He also became a published author with the book "Three Minutes for a Dog" detailing his life.

A Champion Of Polio Eradication Dies

Source: polioeradication.org/ - 13 May 2024

John Sever, an infectious disease specialist and champion of Rotary's polio eradication program, died on 25 April. He was 92.



John Sever (center)
Photo by Monika Lozinska/Rotary International

A Rotary member since 1964, the Chicago, Illinois-born Sever worked for almost three decades as chief of the Infectious Diseases Branch at the National Institutes of Health. Later he served as a professor of pediatrics, obstetrics and gynecology, microbiology, immunology and tropical medicine at the George Washington University School of Medicine and Health Sciences. He published over 600 scientific papers in these fields.

On Sever's recommendation in 1979, Rotary would embark on its decades-long effort to eradicate polio globally, expanding what began as a vaccination campaign in the Philippines. Because of his expertise and advocacy, Sever served on the International PolioPlus Committee (IPPC) from its inception in 1994 and was a member and vice chair. His tireless efforts were instrumental in driving the global campaign to eradicate polio.

Read more on the Rotary website.

Where Budget 2024 Delivers For People With Disability

Budget 2024–25

Source: www.freedom2live.com.au/ - 15 May 2024

Disability employment outcomes and strengthened evidence-based approaches to disability support were key highlights from the 2024-2025 Budget.

A new specialist disability employment program commences on July 1, 2025. It replaces the current Disability **Employment** Services program and will people help with disability, injury or illness find and maintain sustainable employment and includes a flexible service tailored to individual circumstances.

The program is also intended to benefit employers with access to improved supports to hire people with disability. Employers will receive a new wage subsidy that will pay up to \$10,000 for each participant to ensure they are well-supported in the workplace.

Providers will also be able to assist more people with disability with their employment and career goals, with eligibility expanded to an estimated additional 15,000 people a year, including those with less than eight hours a week work capacity and volunteers not receiving income support.

A Disability Employment Centre of Excellence will also be established to develop best practice evidence-based information and training to help providers deliver effective employment services. The National Disability Abuse and Neglect Hotline and Complaints Resolution and Referral Service will receive funding to ensure service continuity and support people with disability to

access fair, impartial and independent advice and to voice their concerns regarding the delivery of supports.

Responding to the Budget, People with Disability Australia president Marayke Jonkers said the income support payment was a step in the right direction, but more is needed.

"We tentatively welcome the NDIS establishment of а Evidence Advisory provide Committee to government advice to about what works for participants, but this will only be successful if it's people led by with disability who are NDIS participants. And while \$20 million has been pledged commence designing the new navigator

role, we will be watching closely to see that the design process is done right," she said.

However, there was disappointment the government has failed to prioritise people with disability in the housing measures announced.

National Disability Services CEO Laurie Leigh welcomed some measures in the budget, but expressed disappointment at the lack of targeted action to ensure disability service providers can continue to support people with disability.

"Inadequate pricing and spiralling costs have already seen many good quality providers closing their disability services in the past 12 months. With ongoing uncertainty surrounding key elements of the NDIS and disability sector reform, clear signals are needed from government to boost the confidence of the sector," he said.

Nurse Falsified Vaccine Records

By ABC News

Source: www.abcnews.go.com — 10 May 2024

(WEBSTER, N.Y.) — An upstate New York nurse has been accused of falsifying vaccine records for more than 100 children across the state.

The New York State Department of Health (NYSDOH) issued a \$55,000 penalty against Sandra Miceli, a licensed nurse practitioner and registered professional nurse at Surviving Naturally in Monroe County.

Miceli is accused of falsifying immunization records for 116 school-aged children for nearly

550 different scheduled vaccinations.

Health professionals say that by lying about the vaccination status of dozens of children, Miceli left them exposed to numerous communicable diseases including measles, chickenpox and polio.

"Falsifying school-aged children's vaccine records endangers both the child and their peers, as vaccination is the best protection against preventable disease," NYSDOH Health Commissioner Dr. James McDonald said in a statement this week.

"Furthermore, this is an example of how the spread of vaccine misinformation undermines the entire system that exists to protect the

Nurse Falsified Vaccine Records (cont'd from P11)

public's health. The New York State Department of Health will continue to investigate those who falsify vaccine records and use all available enforcement tools against those who have been found to have committed such violations," the statement continued.

Both Miceli and an attorney representing her declined an ABC News request to comment.

Miceli is the owner and operator of Surviving Naturally, a so-called "natural wellness center" in Webster, a suburb of Rochester, according to an investigation by the NYSDOH Bureau of Investigations.

From July 2019 through February 2021, Miceli provided false information to the New York State Immunization Information System (NYSIIS) about 546 vaccinations that never occurred and children who were never vaccinated, according to the health department.

The majority of children that Miceli falsely claimed had been vaccinated live and attend schools in Monroe County and Western New York, but some lived as far away as New York City, according to the NYSDOH.

All of the unvaccinated and under-vaccinated children Miceli claimed were immunized must be fully up-to-date on their required vaccinations or be in the process of receiving the missing vaccinations before returning to school or day care, the NYSDOH said.

In its investigation, the NYSDOH says they learned that Miceli would purchase a small supply of vaccines and pretend to administer doses to children. For one vaccine, she reported that she had administered 30 times the number of doses than she had purchased, according to the NYSDOH.

Miceli allegedly was a long-time opponent of vaccines and vaccine mandates, which she made clear on social media, according to the NYSDOH. On Surviving Naturally's Facebook page, officials say, she posted material claiming vaccines have "unidentified contaminants" that lead to autism, pregnancy miscarriage, cancer, and death.

"In posting anti-vaccination propaganda on social media, Miceli spread dangerous publichealth falsehoods and sowed fear about vaccines at the same time that she claimed, as a licensed nurse, to be protecting public health by administering immunizations required for enrolment in schools and day cares," the NYSDOH said in a press release.

Miceli also allegedly expressed her opposition to a New York state bill that eliminated nonmedical exemptions from the state's school and day care vaccine requirements. The bill was passed by the state legislature and became law in June 2019.

Miceli was fined \$55,000 by the New York State Department of Health for her alleged actions, \$30,000 of which she was ordered to pay within 10 days of the stipulation and order going into effect. The remainder of the penalty will be suspended as long as Miceli is compliant with the terms set forth in the order, according to the NYSDOH. Those terms include refraining from facilitating, aiding, abetting, advising, recommending, or conspiring in any scheme to misrepresent vaccination status, the NYSDOH says.

Additionally, Miceli and other staff of Surviving Naturally are "permanently excluded" from the NYSIIS, and are barred from administering any vaccine that is required to be reported to the NYSIIS, the NYSDOH says.



Fight Against Climate Change

By NNPS Desk

Polio victim contributing in fight against climate change, plans to travel 400 cities to plant saplings

Source: www.app.com.pk/ - 13 April 2024

PESHAWAR, Apr 13 (APP): A young polio victim performing as role model for countrymen in ongoing fight against increasing threats of climatic changes has decided to embark on a countrywide travel by visiting 400 cities with the objective of planting saplings and spreading awareness about importance of increasing green cover.

"The objective of countrywide visit is to convey message about pressing need of planting trees to reduce the impacts of climate changes in shape of devastating floods, erratic rains, global warming, heat wave," said Khizar Wali Chisti, a young teacher of 32 years age who is a polio victim and walks with the support of crutches with a mission of planting 10 million trees in the country with his hands.

"I have set the target of planting 10 million trees in the country and so far succeeded in planting more than 150,000 saplings," said Khizar whose left leg is paralyzed due to polio. Talking to APP from his hometown, Pak-Patan, Khizar Wali Chisti informs that he is arranging funds to purchase a heavy vehicle for carrying of sapling in different parts of the country.

The countrywide journey is tentatively scheduled to start in June 2024 during which Khizar Wali will visit different cities and meet with public to inform them about growing threats posed by climatic changes.

Pakistan is ranked among top ten in the list of most vulnerable countries due to climate induced disasters and the disastrous flood of 2022 is an eye opener for all the countrymen, Khizar opined.

Khizar also spent recently passed holy month of Ramzan and religious festival of Eid in plantation of trees in different cities of Punjab. During Razman, I visited Lahore and besides planting different trees also planted a Miyawaki forest in the city, he told APP.

Around a couple of months earlier, Khizar Wali organized Fourth Annual National Tree Festival in Pak-Patan wherein experts from across the country were invited who apprised visitors about importance of planting indigenous trees and tips about kitchen gardening.

Being a teacher, Khizar Wali Chisti also tries to create awareness among people about importance of increase in green cover. If heat wave continues to increase with the same pace and temperature kept on around or more than 50 degree Celsius in major parts of the country, how people will bear it and there will be crisis of very serious level for mitigation of which we have to work jointly by creating awareness and taking practical measures, he added.

There is a need for creating awareness among all sections of society because people from top to bottom and of all ages are getting affected from climatic changes, Khizar stressed. Khizer has formed a group in name of `Green Oasis' on social media platform for creating awareness about importance of increasing green cover.

He upload all his activities regarding planting of trees at different locations on social media with the objective of awareness of his followers spreading in different parts of the world. Apart from environment friendly services, Khizar also concentrates on welfare oriented activities by arranging free health camps, collecting funds for education of poor children and feeding of birds and animals.

Being a victim of polio, Khizar Wali Chisti also spreads message regarding importance of vaccination of children against the crippling disease. He said he understands harshness of disability and don't want to see any other facing the same problems being faced by him and in this connection inform people about importance of immunization of children against polio disease.

In response to a question, Khizar said disability caused by polio cannot hinder him from continuing his mission of increasing green cover of the country broiling due the impacts of global warming.



34 Countries At Risk For Polio Outbreaks

By Karen McClorey Hackett

Source: www.precisionvaccinations.com – 3 May 2024

US CDC polio travel health advisory April 2024

According to an updated Travel Health Advisory, there are now 34 destinations that may have circulating poliovirus.

As of May 3, 2024, the Global Polio Eradication Initiative confirmed various countries reported WPV1, cVDPV2, and cVDPV1 polio cases this year.

On April 26, 2024, the U.S. Centers for Disease Control and Prevention (CDC) reissued its Level 2 – Practice Enhanced Precautions notice regarding recent polio outbreaks.

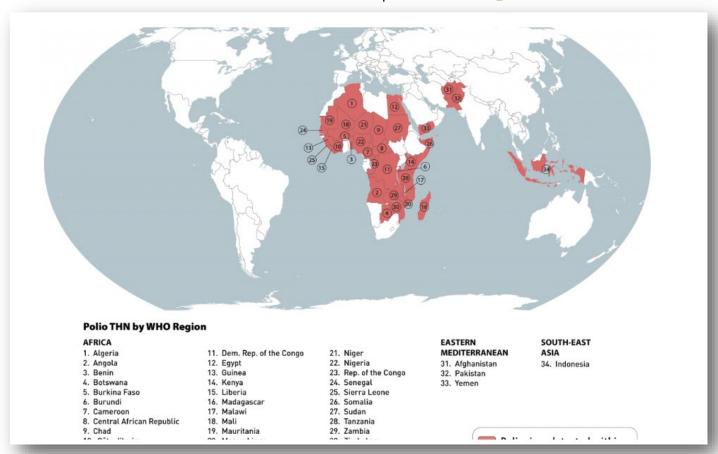
The CDC says that adults who previously

completed the full, routine polio vaccine series may receive a single, lifetime booster dose of polio vaccine before traveling to any destination listed. And to ensure that anyone who is unvaccinated or incompletely vaccinated completes the routine polio vaccine series before departing abroad.

In the U.S., polio vaccination services are generally available at health clinics and community pharmacies.

Previously, the World Health Organization (WHO) confirmed during the 38th meeting of the IHR Emergency Committee for Polio that the spread of the poliovirus remained a Public Health Emergency of International Concern and recommended its extension for a further three months to July 2024 to reduce the risk of the international spread of poliovirus.

Unfortunately, the U.S. is included in the WHO April 2024 notice. ●



Polio Eradication Is Within Reach

By Cynthia Tully

Source: www.forbes.com - 25 April 2024

We're in the last mile in the fight to eradicate polio, but progress is fragile. As long as the disease is a threat anywhere, it remains a threat everywhere. A look at how UNICEF and partners are working to reach every child with lifesaving polio vaccines.



Photo: In Kwango Province, Democratic Republic of the Congo (DRC), 5-year-olds Makiese, left, and Madinu brandish red cards after receiving their polio vaccinations. In August 2023, the Ministry of Health, with support from UNICEF and partners, launched the "Red Card Against Polio" campaign using the popularity of soccer to garner widespread community support for childhood vaccination, with the aim to "Kick polio out of DRC" and protect children from other vaccine-preventable diseases.

Since the introduction of the first **polio** vaccine in the 1950s, fully vaccinated children have been protected from the dangerous viral illness that attacks the nervous system, causing paralysis and sometimes death.

Today, polio is on the brink of eradication, but conflict, climate disasters, displacement and vaccine misinformation are hindering efforts to reach some of the world's most marginalized children with lifesaving vaccines.

In 1988, a public-private partnership was formed to reach every child in every country with the polio vaccine. Led by national governments and supported by six core partners — UNICEF, the World Health Organization (WHO), Rotary International, the U.S. Centers for Disease Control and Prevention (CDC), the Bill & Melinda Gates Foundation and Gavi, the Vaccine Alliance — the Global Polio Eradication Initiative (GPEI) vaccinates over 400 million each year, maintaining 99 percent eradication in global polio.

After almost four decades of close collaboration, more than 3 billion children have been vaccinated. The wild poliovirus has been wiped out in much of the world — today, it's confined to a few districts in Afghanistan and Pakistan.

Smallpox was eradicated in 1980 — polio could be next

Thanks to the commitment of community health workers (CHWs), government leadership and GPEI partners, polio is poised to become the second disease to be declared eradicated, after smallpox. UNICEF and partners and will not rest until every child is protected.

What does reaching the final mile look like?

The poliovirus is transmitted from person to person or, less frequently, through contaminated food or water. To eliminate polio, every child in every household must receive multiple doses of the vaccine. Millions of "zero dose" children, those who have not received a single dose of the polio vaccine series, remain vulnerable.

In significantly under-immunized populations, a strain of polio related to the weakened live strain found in the oral vaccine can arise. The lower the population's immunity, the longer variants can survive, replicate and exchange genetic material to become more dangerous strains. Most of the recent cases have been recorded in eastern Democratic Republic of the Congo, northern Nigeria, south central Somalia and northern Yemen. A fully immunized population will be protected against both wild and vaccine poliovirus strains.

Battling misinformation by building trust

One of the greatest impediments to polio immunization is widespread mistrust of vaccines. Trained CHWs, the majority of whom are women, are the front line in reaching every child with lifesaving vaccines. In addition to administering vaccines to children ages 0 to 59 months, they dispel misconceptions and fears around vaccine efficacy.

Many female health workers are mothers themselves; they build trust by sharing their experience vaccinating their own children. Women vaccinators can also enter households that may prohibit unrelated males from entering due to religious or cultural norms.

Engaged leaders boost vaccine acceptance and embrace sustainable health systems

UNICEF and partners engage with governments and community leaders to enlist them as immunization advocates. Visible leadership participation in campaign launches and household visits reassures communities of vaccine safety.

From donkeys to drones — vaccines stay cold every step of the way, no matter how far the journey

Ensuring every child under 5 receives multiple rounds of vaccines requires supply chain management and procurement and distribution

Polio Eradication Is Within Reach (cont'd from P15)

capability that only UNICEF offers. UNICEF leverages its unrivalled supply chain and cold storage capability to procure and distribute more than 1 billion doses annually.

Once vaccines are procured and designated for specific clinics and communities, health workers use any conveyance necessary to cover the terrain between vulnerable children and vaccine administration. With diligence and determination, they reach the most remote areas and large populations of people traveling within countries and across borders.

The legacy of GPEI and polio's eradication

Beyond the elimination of the poliovirus, in many areas, GPEI has developed an infrastructure that strengthens local health systems and provides a blueprint for other disease outbreaks and public health crises. Without vaccination campaigns, the under-5 mortality target for SDG 3: Ensuring good health and well-being for all at all ages cannot be met.

Many public health systems now have a highly skilled workforce that can break down cultural barriers and build trust in immunization and routine health activities. Resources previously spent on polio activities can be invested in other critical health and nutrition interventions for children.

Angola Becomes Another Polio Hot-Spot

Fact checked by Holly Lutmer PharmD

Source: <u>www.precisionvaccinations.com</u> – 25 May 2024

Polio vaccinations scheduled for over 5 million children in Angola

The World Health Organization (WHO) Africa recently confirmed that the African country of Angola had been free of wild poliovirus since July 2011 and declared the interruption of polio transmission in November 2015.

Unfortunately, Angola recently reported a concerning development in early 2024.

Four cases of Poliovirus Type 2 have been detected in environmental samples of sewage water collected in two provinces. Additionally, two cases of Acute Flaccid Paralysis (AFP) have been reported in early May 2024.

These AFP cases are the first in Angola since the 2019-2020 outbreak, which recorded 124 cases.

Furthermore, 36 potential AFP cases are awaiting classification by the National Committee of Polio Experts, which may or may not be related to the polio virus.

On May 17, 2024, the WHO indicated that this polio outbreak is not just a concern; it's a call to action. These AFP cases underscore the urgency of the national polio vaccination campaign and the danger of continued poliovirus transmission among children.

Nationwide, the government has identified 5,549,140 children under the age of five in need of polio vaccination. The next-generation nOPV2 vaccine, administered over 1 billion times, is now being offered in Africa.

"Vaccinating our children is not just a public health measure but, more than that, it is a commitment to the progress and prosperity of our country," said the Secretary of State for Public Health, Dr. Carlos Alberto Pinto de Sousa, said in a press release.

"This is a crucial step in maintaining our poliofree status and ensuring the health and future of our children."

The risk of outbreak spread is high in Angola, with less than 60% of children having immunity to poliovirus types 1, 2, and 3.

The Government of Angola has classified three out of 18 provinces as high-risk. This population group includes children under five years old, unvaccinated individuals, or those who have received fewer doses of polio vaccines, particularly in urban areas and areas with poor water and sanitation infrastructure.

According to the WHO and other organizations, polio remains endemic in two countries, Afghanistan and Pakistan. Until poliovirus transmission is interrupted in these countries, all countries, including the United States, remain at risk of polio importation.

On May 23, 2024, the U.S. CDC confirmed that 34 countries pose polio risks to international travellers. Before any international travel, make sure you are up to date on your polio vaccines, says the CDC.

In the U.S., polio vaccines are offered at health clinics and pharmacies. ●

Polio This Week

Global Circulating Vaccine-derived Poliovirus (cVDPV) as of 28th of May 2024

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