



Polio Oz News

June 2021 – Winter Edition

COVID-19 Vaccination And Polio Survivors

By the Polio Australia Team

Please note that information given here is general and not to be taken as individual advice. Please discuss your health conditions, symptoms and concerns with your doctor.

In the mid-20th century, polio was a very real threat in Australia. Now, it's mainly seen as a disease for the history books. This, of course, is thanks to the vaccine, which was first introduced here in 1956.

And now we have a new nasty virus, and a new protective vaccine. As with anything that's new, people understandably have questions.

Why do we need a vaccine for COVID-19?

COVID-19 is currently infecting hundreds of thousands of people each day across the world. However, the numbers of community cases here in Australia are very low. So do we need a vaccine here?

The short answer, of course, is yes. Just like polio, COVID-19 anywhere is a threat everywhere – it's only a plane ride, a canoe ride, or even a walk to the local café away. And, while we can be grateful that our current infection rates are very low, we really want to keep it that way.

COVID-19 is a mild illness for many people (as was polio, although we couldn't predict who might be more seriously affected). But some people are particularly vulnerable to serious illness or even death from COVID-19. We want to do what we can to protect them.

Many polio survivors, for example, are now older and therefore in a higher-risk category for serious illness from COVID-19. Those with breathing problems may also be at a higher risk.

Should I get the vaccine?

While a lot of polio survivors are eager to get their COVID-19 vaccine – or have already had it – we are getting quite a few questions about whether it's safe.

We'll start by saying we don't have all the answers yet, but we'll share what we know.

The vaccine is considered safe. Local redness and soreness for a couple of days is a common side-effect. Serious adverse events are very rare – for example, anaphylaxis after the Pfizer vaccine impacts around 1 in 100,000 cases, and dangerous clotting after the AstraZeneca vaccine is also about 1 in 100,000.

You can also read Polio Australia's Position Statement on this topic [here](#).

Which vaccine type would I get?

As you are no doubt aware, there are a number of versions of the COVID-19 vaccine. A [statement](#) from Paul Kelly, Australian Government Chief Medical Officer, contains the following information:

- The Pfizer vaccine is the preferred vaccine for adults under 50 years old, due to a slightly increased risk of blood clotting in this age group with the AstraZeneca vaccine.
- The AstraZeneca vaccine is now available to all adults aged 50 plus.
- There is no vaccine currently available for children.

I have post-polio symptoms. Am I at a higher risk for side-effects?

Please be aware that the COVID-19 vaccine is very new, and we don't have all the answers. It is important that you discuss your concerns,



Cont'd page 7

Polio Australia

Representing polio survivors

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“ **Laughter is the sun
that drives winter from
the human face.** ”
~ Victor Hugo ~

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**Polio Australia**Honouring Australia's polio survivors - "We're Still Here!" 

Polio Australia's "We're Still Here" website is a hub for sharing people's stories, polio survivors in the media, polio awareness raising campaigns, events of interest, Rotary talks, and so much more. It is constantly being updated, so check in often.

www.stillhere.org.au

President's Report



Gillian Thomas OAM

It is pleasing to again report that Polio Australia's programs are still being provided in spite of the difficulties that COVID-19 keeps throwing up (pages 4-7). Since the last *Polio Oz News*, Michael, our Clinical Educator, has managed a couple of interstate trips, while Steph, our Community Programs Manager, will hopefully be back on the road in July.

We received some wonderful news when the Federal Budget was delivered in May — included was funding to enable Steph's valuable community programs to continue (see further details on p 11)! The \$421,400 grant over 3 years from 1 July 2021 will go a long way towards helping us reach unconnected polio survivors and to continue to provide resources and information for the polio community across the country. Using stories and statistics from the community programs we have conducted over the last three years — information sessions, resource development and online engagement — we were able to clearly articulate the ongoing importance of this work. Without the generosity and vision of Jill Pickering, who has funded our community programs for the last three years, this grant would not have been possible. THANK YOU, JILL!

From The Editor



Maryann Liethof
Editor

As this edition of *Polio Oz News* is being prepared for publication, those of us living in Victoria are experiencing our fourth COVID-19 lockdown. This has become an unfortunate 'side effect' of not enough of our population being vaccinated. As my retirement plan at the end of 2019 was to travel (a lot), I was very keen to get my job as soon as possible. For anyone who is hesitant about being vaccinated, the *COVID-19 Vaccination And Polio Survivors* article on page 1 and 7 will, hopefully, provide some clarification. There is also an excellent reflection on *How [the] Polio Campaign Beat Vaccine Hesitancy* (p 18).

If you are one of the many polio survivors who are living with osteoporosis, Nutritionist Melinda Overall's article (p 8) provides comprehensive recommendations regarding dietary intake and other considerations. A timely reminder to us all as the weather cools down and we reach for more 'comfort food'.

How good are you at self-advocating when it comes to getting what you need from your health professionals? Maybe the *Self Advocacy*

At our recent Board meeting, members spoke of educating their GPs and also health professional students about the late effects of polio, and referring them to our [Polio Health](#) website. We can all do this — be sure to explore the site yourself so you can point out items which may be of particular interest to your health team.

Board members also regularly speak at Rotary Clubs — not only about the late effects of polio but also about Polio Australia's work in support of the polio community. We are deeply appreciative of any donations which result from these talks. In April, I was privileged to be invited to speak to members of the Lane Cove Rotary Club. I was made welcome by a very interested and engaged audience. This Club was one of those which had donated towards Rotary District 9685's funding of our first round of eight Clinical Practice Workshops in 2015/16. They were delighted to be updated on how their efforts had helped to kick start Michael's current program, and to learn that from that modest beginning we have recently passed 1,500 health professionals educated around Australia on the diagnosis and management of the late effects of polio.

For those living in a Retirement Village, why not follow Joan Smith's example (p 14) and share your story with other residents if similar opportunities exist. You might even find "hidden" polio survivors!

Until next time — keep warm! 🌟

Gillian

article on page 12 will help with some tips to develop more confidence in this area.

Updates on the ongoing issues around access to assistive technology and the NDIS can be found on pages 14, 15 and 16. There is actually a lot of work going on behind the scenes — both in the aged care and disability sectors. Hopefully, the boost to NDIS funding in the May 2021 budget will help achieve more positive outcomes.

Two research papers which may be of interest explore: 1) *Fear Of Falling* for people with physical disabilities being linked to lower physical activity (p 16); and 2) whether *Paracetamol* medications are more effective than a placebo (p 17).

It was shocking to read about the murder of three female medics in Afghanistan who were simply providing the polio vaccine to children. Sadly, this seems to be an all too familiar occurrence, and makes the goal of a polio-free world all the more difficult to achieve.

On a more positive note, the *Patient Zero: Back From The Brink* podcast (link on p 22) reveals how organisations working together averted a major polio outbreak on our own doorstep.

Keep safe out there! 🌟

Maryann

2021 Program Update: Clinical Practice Workshops



By Michael Jackson
Polio Australia Clinical Educator

The workshops program continues to feel the effects of the coronavirus pandemic, however there has been considerable movement over the last few months with workshops and other activities. This year to date I visited locations in QLD, VIC, and ACT, with several more workshops scheduled for June. Early in the new financial year there are visits to NSW, VIC and SA, however TAS and WA locations have been unresponsive to outreach over the last few months.

Workshops Delivered

Obviously, 2020 set a low bar for success in 2021 when it comes to the delivery of workshops – there were only three workshops in Cairns. With everyone getting used to 'how a pandemic worked' there was an increase in interest in our workshops over the last 4 months. That said, the Brisbane outbreak caused the cancellation of 4 workshops which fell in the 14-day period in which greater Brisbane was a hotspot (these have been rescheduled into July). Very recently I had to skip the Swan Hill workshop in late May in order to abruptly exit Victoria. Despite making some ground, we are well below the grant targets of 55 workshops across the continent per year and average of 14 attendees per workshop.

From what we have achieved in the last few months it is apparent that facilities are increasingly confident to host external educators. Facility education calendars are again active, or at least they are now accepting non-COVID related topics! However, a clinician participation problem persists at facilities – several hosts (Roma, Portland, Hamilton) noted clinician disengagement with education being provided in general (not our program/topic specifically). During the pandemic there has been a shift towards a preference for on-line education across the workforce, but also indicators of on-line education/meeting fatigue. (See chart below.)

Due to the pandemic, in December 2020 we started offering the standard 2-hour workshop monthly via Zoom. This is a try-test-learn project to determine if e-Learning/Webinars have greater uptake or have comparable participation. The Zoom sessions have slightly less attendance than the workshops this year on average, and a much lower conversion rate. It is a valid mode, as it enabled us to reach 18 professionals this year which we would not have otherwise. Those reached via Zoom have been from a wider number of professions and from further afield (states we did not reach in-person) – notable positives of this mode of delivery.

Our workshop has had its endorsements updated, these being 1-2 years' duration, and some including advertisements in organisation newsletters. Not all peak bodies endorse education activities. Our endorsements are from:

- Australian Primary Health Care Nurses Association
- Australian Nursing & Midwifery Foundation
- Exercise & Sports Science Australia
- Australian Orthotics Prosthetics Association

How do our attendees perform on the workshop quiz? The average of all 40 submitted quizzes to date is 96/100. Those taking the quiz receive professional development credit. Feedback from 19 of 58 participants indicates the qualities (organisation, communication, recommend) of the workshop are overall scored as 4.6/5, and their confidence and understanding of the content scored as 3.7/5. The feedback rate is reasonable (30%), and indicates the need to further adapt the content to improve participant confidence and understanding.

Our twice yearly outreach email to attendees will be sent out in late June and so this will provide further information on the actual impact of the workshop in the months after attending.

Increased Understanding of LEOp

GP friendly resources were developed over the last six months to make our information more accessible and directly practical for GPs and their staff.

2021 Workshops to date	Attendees	Workshops	Attend Average	Conversion (Registered and then attended)
In-Person	40	9	4.4	70%
Zoom	18	5	3.6	41%
OVERALL	58	14	4.1	60%

2021 Program Update *(cont'd from p4)*

This included a summary sheet for GP education and resources on LEOp, a LEOp exercise summary, and tips for an office to better engage polio survivors as patients.

Paulette has been adding many new research entries to our research database on the Polio Health website. It is worth noting that upon a lookback that the previous 12 months from March 2021 to March 2020, 17 LEOp/PPS-specific articles were published worldwide – a rate of almost 1.5 per month.

Recently HealthPathways Tasmania informed us that our request to have LEOp included as a pathway had not only been approved, but had been drafted out! This pathway needs review and feedback before it is released, and when published will bring the number of LEOp pathways to three in Australia (of 33 nationwide). COVID-19 remains a high priority for most HealthPathway portals.

Health Professional Outreach

Paulette has confirmed new entries onto the Professional Register, increasing the number of health professionals who can serve as clinical advocates and LEOp-informed referrals.

I attended the three day GPCE Conference in Sydney in mid-May, speaking directly with about 35 GPs (mostly from NSW), and five other NSW clinicians. Connections were also made with other organisations (hosting booths) related to our program. Although attending this type of event is expensive, a few minutes of face-face time with multiple GPs as captive audiences is nigh impossible in their work environment. We will also be at the Brisbane GPCE in September, applying some new strategies to get their attention! Further participation at these types of events in Victoria and WA will be considered.

In April I presented live on the Ramsay Health Network education platform to advise their nation-wide staff about, and provide sample content from, the workshops we provide. This was a half-hour session and is also available on-demand for internal employees.

At about the same time, I put together a non-Ramsay 14-minute [video](#) with a similar goal for facilities who are contacted regarding hosting a workshop. This video has been posted on PA's YouTube channel, and has been emailed out in recent waves of outreach to facilities.

The RMSANZ conference is virtual and in mid-June 2021 but it offers an opportunity to engage with rehabilitation professionals on both sides of the Tasman: rmsanz.net/index.php/calendar/isprm-2021-virtual-congress/ We have submitted our recent study abstract (see the next paragraph) for their consideration and if it is accepted I will present the paper and findings virtually.



Partnerships

The research project with UNE and UA academics has been published: *Effects of muscle strengthening and cardiovascular fitness activities for poliomyelitis survivors: A systematic review and meta-analysis.*

www.medicaljournals.se/jrm/content/abstract/10.2340/16501977-2832

A position statement reflecting the findings and an interpretation for clinicians and polio survivors will be created in due course and available on our website.

Two university partnerships have progressed in the past few months, with confirmation of a Zoom workshop for 3rd/4th year University of Queensland physio students on June 30th, and a lecture and lab styled workshop at the James Cook University 4th year physios in mid-September. Reaching pre-professionals is a strategy being pursued primarily to scattershot LEOp information with graduates as they enter a wide number of facilities upon entering the workforce.

Several research-oriented grants have been submitted with the target population being SA polio survivors' healthcare. The two topics are a census of polio survivors in large regional cities in SA, and a pilot telehealth post-polio clinic in SA. These topics have been slowly developed over the last year in context of the pandemic and other arms of research in the field, and aim to answer the questions:

- Are estimates of 1 polio survivor per 600-1000 residents accurate in Australia?
- Is a telehealth post-polio clinic a comparable alternative to an in-person post-polio clinic?

In conclusion, the delivery of workshops are trending towards recovery and our hand in related projects and new opportunities continues. In addition, the great news that our Community Programs have been funded for several years adds a great deal of stability and confidence to our education programming. 🌟

Community Programs Update



By Steph Cantrill
Community Programs
Manager

We are continuing to find ways to engage with the polio community across the country, especially focusing on online means for now. But please remember that we're also available for those who don't like online engagement. **Call us on**

03 9016 7678 if you would like information or resources on post-polio issues. We're only a phone call away!

The **very exciting news** is that community programs will continue to be funded for the next three years. The Department of Health has recognised what we do, and provided us with vital funding to allow us to continue and scale up our community activities. Yay!

Community Information Sessions

Monthly Zoom sessions: we continue to meet monthly on Zoom. Join us any time – it's a great way to connect and learn from others! First Monday of every month, 11.00am Australian Eastern Standard Time.

NDIS Zoom chats: these have been really valuable for shared learning and support. Our next chat for polio survivors who are either on the NDIS or believe they meet the eligibility criteria will be on Wednesday 16th June, 11.00am Australian Eastern Standard Time.

Webinars: we have also had webinars on Late Effects of Polio and Self-Advocacy. See our article on self-advocacy in this edition of Polio Oz News, based on the webinar.

Register for all Zoom chats, webinars and information sessions at:
www.polioaustralia.org.au/community-information-sessions.

Resources

Assistive Technology factsheets: OT students from Monash University worked on a range of fact sheets about aids and equipment for specific activities. The factsheets on Dressing and Eating & Drinking have been completed and uploaded, and the remainder will follow soon. See our new factsheets at:
www.polioaustralia.org.au/lifestyle-aids-and-equipment.

NDIS factsheets: these are being redeveloped. The first one, titled "What is the NDIS?" is provisionally complete pending a collaborative review at the next Zoom meeting.

Blog: we now have a [blog](#)! The first post is about managing post-polio fatigue at social events. We aim to add new posts a 3-4 times per month. Take a look – and please get in touch if there's a topic you'd like us to address.

Advocacy/Awareness-Raising and Lobbying

NDIS exclusion: we are writing to the Minister for NDIS in response to the recent opinion piece in The Age/Sydney Morning Herald about NDIS exclusion. We will post the letter to our [advocacy page](#) when it is completed and sent.

Assistive Technology for All: a range of campaign materials are nearing completion with the ATFA Alliance. We will keep you informed about how you can get involved in advocating for fairer access to assistive technology for those outside the NDIS. Also see the flyer on page 24.

NDIS Independent Assessments: Polio Australia contributed to submissions with two of our networks – the Neurological Alliance of Australia and the Australian Federation of Disability Organisations. Both of these submissions can be viewed [here](#).

Polio Awareness Month 2021: we have a small committee meeting bi-monthly in the hope of scaling up our awareness-raising activities for October. If you would like to join the committee, please contact advocacy@polioaustralia.org.au.

Don't forget – if you're on social media, stay connected! We regularly update our [Facebook page](#) with news and information. And our [Polio Australia group](#) is a platform for you to share news and ask questions. We also have the [NDIS Hub Facebook group](#) for the younger ones. Come and join us!

And, if that just isn't enough social media for you, you can always view our videos on our [YouTube channel](#), and follow us on [Twitter](#). 🌟

Polio Australia
Representing polio survivors throughout Australia

NDIS POLIO HUB

COVID-19 Vaccination And Polio Survivors *(cont'd from p1)*

individual medical history and current medications with your doctor.

According to the Australian Technical Advisory Group on Immunisation ([ATAGI](#)), people who have had a severe allergic (anaphylactic) reaction to a first dose of COVID vaccine should not receive a second. And those who have previously had an anaphylactic reaction to one of the vaccine's components should not be given the COVID vaccine at all.

Precaution should be used for people with certain other conditions, including:

- Mast cell disorders
- Bleeding disorders
- Prior anaphylactic reaction to another vaccine
- Non-anaphylactic allergic reactions to a component of the COVID-19 vaccine, or to the first dose

There are some [common side-effects](#) from both the Pfizer and AstraZeneca vaccines, including:

- Arm pain
- Fatigue
- Headache
- Muscle pain
- Fever and chills

We have spoken to some polio survivors who have had side-effects after their first dose, including arm pain, fever, fatigue, and joint pain with muscle weakness. We have also heard from others who had no reaction at all. We cannot find evidence of any precaution against the vaccine for specifically for people who have had polio.

What about blood clots or other serious side-effects?

Serious side-effects are rare. Thrombosis with Thrombocytopenia Syndrome (TTS) is a blood clotting disorder that has developed after the

AstraZeneca vaccine in very rare cases. There are no specific risk factors identified, according to information from the [Department of Health](#).

While some types of blood clots are more common for people who are not able to move around much, the blood clotting disease resulting from the COVID vaccine isn't related to how mobile you are. If you are taking anticoagulants, you may be at an even lower risk than the general population of developing clots.

If you have had a blood clotting disorder before, speak to your doctor before taking the vaccine – they may recommend taking a different type.

Who should I talk to?

If you have any concerns at all about the vaccine, you should start by speaking to your GP.

If you have specific issues or symptoms, you should speak to a specialist who deals with that area. For example, if you have chronic breathing problems, it may help to speak to your respiratory specialist.

For further information, see the [Australian Government Department of Health](#), the [CDC resources](#), and Polio Australia's [Position Statement](#) on COVID-19 vaccination. 🌐



Polio Australia's Team Blog



By Paulette Jackson
Administration Officer

Have you had a chance to check out Polio Australia's new Team Blog? In May, our team rolled out a new blog with the specific goal of addressing various topics and questions we receive from our post-polio community.

The blog can be found on the Polio Australia website at: www.polioaustralia.org.au/team-blog/.

In our first blog post, Steph presented five excellent tips for managing post-polio fatigue at social events. She discussed various strategies you can use to help to prepare yourself ahead of time allowing you to conserve energy for the event.

Do you have a specific question? Or is there a topic you would like to learn more about? Send us an email at office@polioaustralia.org.au. 🌐

Osteoporosis And Nutrition

By **Melinda Overall JP**

Nutritionist and Counsellor—[Overall Nutrition](#)



It is estimated that over one million Australians are living with osteoporosis, and that 66% of Australians over the age of 50 have osteoporosis or osteopaenia [1,2]. More women are likely to develop the disease than men, and slightly more Aboriginal and Torres Strait Islander people will develop osteoporosis or osteopaenia than non-Indigenous Australians [1].

Polio survivors are a high-risk group for developing osteoporosis. A study by Mohammad et al (2009) highlighted that 96% of the study cohort of polio survivors had osteoporosis or osteopaenia [3]. Nearly 40% of the study cohort had experienced a pathological fracture over a five-year period, and the majority of these fractures impacted the femoral neck (hip) on the side most affected by poliomyelitis [4].

What is osteoporosis?

Bones are being broken down and rebuilt throughout our lifetimes, and for some people the rebuilding of bones may not be as effective as it once was. Osteoporosis is a chronic, and often silent, condition that leads to poorer bone mineral density over time. This ultimately results in weak and brittle bones that can fracture with very little impact through minor incidents [2]. Such fractures are known as pathological, or minimal trauma, fractures. The risk of pathological fracture is particularly increased in the hip, spine and wrist, and this risk is increased further for polio survivors [2,4].

Osteopaenia is essentially the same condition but the bones are not as weak, or brittle, as seen in osteoporosis. Bones are therefore less likely to break but can still fracture more readily than healthy bones. A diagnosis of osteopaenia is an indication that you might need to take some dietary and lifestyle action to prevent or slow the progression of osteopaenia to osteoporosis [5].

Impact of osteoporosis

In Australia, in 2017-18, there were over 93,000 hospitalisations due to minimal trauma fractures in people aged 50 or older [1]. Other than the fractures themselves, osteoporosis has significant impact on the individual and the economy.



For the individual, impacts include: greater reliance on walking aids, greater risk of falls, increased risk of mortality and morbidity, loss of independence and mobility, and a decline in quality of life. Increased pain and increased psychological distress are also reported by people with osteoporosis [1]. People with osteoporosis who have experienced a hip fracture are more likely to experience urinary tract infections, bed sores and respiratory infections [6].

In 2017, the financial cost of osteoporosis and osteopaenia to Australia was estimated to be \$3.44 billion dollars. This figure doesn't include the cost of reduced quality of life, loss of productivity, or the increased impact on disability [7].

What are risk factors for osteoporosis?

There are a number of risk factors for the development of osteoporosis and osteopaenia.

Modifiable risk factors include: Poor diet and poor nutrient status (calcium, vitamins D and K, protein, magnesium and other bone building minerals), lack of weight-bearing exercise, smoking, alcohol consumption and body weight [2,8].

Non-modifiable risk factors include: family history, age, gender, digestive malabsorption issues such as coeliac disease, chronic kidney disease, rheumatoid arthritis, thyroid dysfunction, diabetes, and the use of some medications including corticosteroids [2,8].

How much calcium do you need?

The Australian Bureau of Statistics reported that in 2011-2013, 73% of females and 51% of males aged over two, did not meet their recommended dietary intake of calcium [9]. Recommended intakes are listed in Table 1 (see next page).

Osteoporosis And Nutrition *(cont'd from p8)*

Table 1: Recommended Dietary Intake of Calcium for Australian Adults [10]

Gender	Age	Recommended Dietary Intake (daily)
Male	19-70	1,000mg
Male	Older than 70	1,300mg
Female	19-50	1,000mg
Female	Older than 50	1,300mg

(modified from NHMRC, 2021)

What does that look like in food?

Table 2: Calcium Content of Common Foods

Food	Calcium (mg/serve)
1 cup (250ml) milk	300mg
1 cup (250ml) soy milk	300mg
1 tub (200g) yoghurt	386mg
1 slice (20g) cheddar cheese	160mg
2 tablespoons almond butter	110mg
6 dried figs	160mg
1 boiled egg	21mg
90g canned pink salmon (in water)	280mg
90g canned sardines (in water)	480mg
100g fillet snapper, grilled	163mg
1 cup firm tofu	832mg
1 cup green leafy vegetables	60-90mg
10 Brazil nuts	53mg
1 tablespoon unhulled tahini	66mg

We cannot absorb all of the calcium in foods, and this will depend on the individual and the health of their gut. Other factors can reduce our level of absorption too. These include: low vitamin D status, excess consumption of coffee and alcohol, certain diseases and medications, and high consumption oxalates and phytates [2].

Easy ways to increase calcium intake are:

- Add a little cheese to sandwiches.
- Add yoghurt or tofu to soups.
- Consume the bones from tinned fish (high calcium tuna is now available at supermarkets).
- Increase consumption of green leafy vegetables.
- Consume yoghurt or custard for dessert.
- Snack on nuts, dried figs or apricots.

Other considerations

- Get some sunshine. Human bodies can make vitamin D when skin is exposed to sunlight. Vitamin D is an important co-factor for the proper absorption of calcium. Very little vitamin D is available through food. Foods that include vitamin D are butter, full cream milk, oily fish, eggs, liver or fortified foods.
- Increase fruit and vegetable consumption.
- Reduce salt consumption.
- Include and/or increase exercise/movement as tolerated. Resistance and weight bearing are beneficial – but check with your physio or other health professional first when exercising polio-affected muscles.
- Maintain a good body weight – not too light, not too heavy.
- Eat a wide and varied diet – to get other bone building nutrients in (phosphorous, magnesium, manganese, boron, vitamin K, vitamin C, silica).

Osteoporosis And Nutrition *(cont'd from p9)*

- Eat adequate protein to maintain muscles — strong muscles help to build strong bones.
- Drink soft drinks only as a treat.
- Reduce alcohol and caffeine consumption.
- Quit smoking.

Supplements?

Calcium supplements can be an easy way to increase calcium status, although food is the preferred source of all nutrients [2]. It is preferential that calcium supplements contain some vitamin D3.

It is important to check your calcium supplement/s for any contraindications or cautions with any medications that you might be taking. If taking a medication for osteoporosis and a calcium supplement, take them two hours apart but check with your healthcare professional first.

Calcium supplementation dosing is considered safe and effective at 500-600mg per day (with vitamin D). There have been several studies that have shown an increased risk of adverse cardiovascular events with long-term calcium supplementation of 1,400mg and over, predominantly in women. Whilst the research is controversial it is reasonable to use food first, lower dose supplementation and to never self-prescribe any supplements including calcium but rather, talk to your health professional about your needs and medications.

Osteoporosis is really a silent disease of youth that manifests in later life. Polio survivors are particularly prone to the disease. It is important to remember that whilst there is no evidence to suggest that osteoporosis can be cured, there are a number of strategies that can reduce the risk of, and slow the progression of, osteopaenia and osteoporosis.

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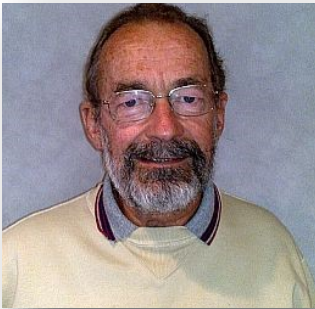
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Treasurer's Report

Polio Australia would like to thank both individuals and organisations for their generous support of \$3,630 during the second quarter of 2021. Without you, we could not pay our core operating expenses.

If you would like to see how your 'living bequest' can support polio survivors now, click on the following link: www.polioaustralia.org.au/donations-bequests/ or contact the Polio Australia office on Ph: 03 9016 7678 or Email: contact@polioaustralia.org.au.



Alan Cameron
Treasurer

The Profit and Loss report for April, and including Year to Date, shows a loss for the month of \$522.20 and a profit for the year to date of \$143,440.35, which by any measure is a most pleasing outcome and differs significantly from earlier budget estimates.

Unfortunately, and I say it with the unbridled pessimism inherently baked into a Treasurer's psyche, there are a considerable number of one-off revenue items to be considered before thinking we are really making a profit or are in any way financially stable. JobKeeper and Cash Boost payments in particular will not be repeated, and donations and grants of \$86,000 are not necessarily sustainable.

Nonetheless it does mean that for the full year we will end up recording a surplus which will certainly strengthen the Balance Sheet for future years.

Earlier this month we were advised of our success in receiving funding in the Federal budget for \$400K over 3 years starting on July 1st to support the Community Engagement Program Steph Cantrill is heading (*see below*). This provides some much needed stability for both individuals and the organisation when looking to the future. 🟡

Federal Government Funding Success!



THE HON MARK COULTON MP

Minister for Regional Health, Regional Communications and Local Government
Federal Member for Parkes

I would like to take this opportunity to thank you, and acknowledge your continued work and advocacy for Australians affected by polio. The success of your initial work has paved the way for this further expansion in to regional Australia - something I feel very strongly about.

Polio Australia's Community Program together with the Clinical Practice Workshop Program directly derive from our Mission and Vision. These complementary programs comprise both sides of the education coin, and both are required to help mitigate the ongoing impacts in Australia of polio and its late effects.

From a Government perspective, one of the great benefits of the Community Program is that by helping polio survivors to better understand their condition, and the available strategies to manage that condition, it significantly reduces the direct impacts on the health system. There is no doubt in our view that the costs of the program are vastly less than the benefits accruing to Government via reduced patient health care dependency.

To continue the valuable Community Program, Polio Australia's proposal provides for:

- Planning, promotion and conduct of at least 30 Community Information Sessions nationally per year, over 3 years, building on the successful pilot program.
- Continued digital engagement, with at least 15 virtual information sessions, community video conferences or webinars per year.
- Follow-up video conference sessions at 3 months with in-person session attendees, to monitor longer-term outcomes.
- Focus on regional engagement, with at least 80% of in-person sessions to be held in regional centres. 🟡



Self-Advocacy

By Steph Cantrill

Polio Australia Community Programs Manager

with

Liz Telford OAM

Polio Survivor and Advocate

As many people know all too well, navigating the health system and getting the right treatment isn't always easy. This is especially true if you have a complex condition that many health professionals know little about, such as Late Effects of Polio or Post-Polio Syndrome.

This is where advocacy comes in. We're going to share a bit about a particular type known as self-advocacy, based on information Liz Telford shared with us in a recent webinar.

What is Self-Advocacy?

As the name suggests, the term "self-advocacy" means speaking up for yourself. And it's not just about health – we can advocate for ourselves in any situation that involves dealing with other people.

With self-advocacy, we might be:

- speaking up about a particular situation in which we feel we've been misunderstood;
- asking for something to be changed; or
- seeking respect, dignity or a better service.

What We Need To Know To Be Our Own Advocates

Firstly, it helps to know *our rights*. To learn about your rights, you can go to a formal document such as the [Convention on the Rights of Persons with Disabilities](#). Liz referred to a number of rights in her webinar. For example, you have the right to:

- participate, and have the best health care
- feel good about your care
- ask questions
- make mistakes
- change your mind
- have an opinion, and disagree with someone else's opinion
- do less
- say no
- feel angry
- be happy

Another thing we need to know is *what we want* and *what we need*. We should keep in mind how we want to be treated in our healthcare interactions, and what we need to do to ensure that we get the treatment we deserve. Ask yourself: Is my health service helping me to achieve my own goals and working with my priorities? Am I being respected?



Next, we need to know *who to talk to*. When you're not happy with the treatment you're getting, sometimes the best person to talk to is the person in front of you – the one providing the treatment. Sometimes, it's better to talk to their supervisor or another person with influence over the situation.

In order to advocate for ourselves in this way, it's also important to *know ourselves*. Ask yourself: Am I good at speaking off-the-cuff, or is that stressful for me? Do I tend to feel anxious when I'm telling people how I feel? Does it help me to feel more confident if I take a deep breath and smile before I talk? What other strategies have worked to help me manage anxiety?

Remember that assertive communication can be learned, but it's still important to know yourself and how you work best.

Assertiveness and Self-Advocacy

Assertive communication is not aggressive. Being assertive is not about getting into a fight. Instead, it's about being respectful and positive towards the other person – and expecting and seeking respect from them as well. Rather than escalating a situation, assertiveness minimises conflict.

Of course, being assertive and communicating your needs isn't always easy. And some things can make it more difficult. For example, many people who had polio as children were taught to just cooperate and be a "good patient". You may have been told that the doctor is very busy and you mustn't put them out, or to just be grateful for what you're getting.

Even now, the way the health system is set up can be challenging. There can be an apparent hierarchy in the workforce, leading us to be hesitant about taking up "important" people's time. Or it might appear that everyone is very busy and won't have the time to listen to our concerns.

Self-Advocacy *(cont'd from p12)*

Here are some tips for assertive communication:

- Express yourself in a positive way and treat the other person with respect, despite the power system that might seem to put you at a disadvantage.
- Tell them how you see the situation.
- Use "I" statements ("I feel..." rather than "you are being...").
- Use direct language, so it is clear what you need.
- Remember – you can't control another person's behaviour, only your own. Keep in mind that every health professional you work with is human – they might be stressed and overworked, or they might be having a bad day because of something in their personal life.
- Try to work together with your health professional as a team, and discuss your priorities.
- Write your questions or concerns down in advance.
- Use resources to help explain your condition and what you need – but don't overload them with stacks of paperwork to read!

Other Advocacy

If you have tried to talk to the appropriate person but need to take your complaint further, you can go to the health ombudsman or complaints commission in your state. To find them, go to [this site](#) and search under "Health Complaints".

If you just don't think self-advocacy is going to be enough, or if you don't want to go it alone in advocating for your needs, there are some options:

Individual advocacy

- Having someone speak *for* you (not *about* you) can help to get your message across.
- An individual advocate can be a trusted friend or family member, or someone from an advocacy service.

- To find an advocate in your area, you can try the [Advocacy Finder](#).

Systemic advocacy

- This is advocacy on a larger scale, calling for long-term social or policy change.
- Your [state polio network](#), Polio Australia, and many other disability organisations are involved in systemic advocacy.
- Do nothing; this is an option! You don't always have to take issues on.

Examples

During the webinar, Liz gave us some great examples of speaking up for your needs and rights. Here are a few:

To an anaesthetist:

I know that you have a tight schedule but would appreciate it if you would take a few minutes to read this information from PA and give me your thoughts as to how it relates to my surgery.

To a medical specialist:

At our last consultation I left feeling very rushed and with unanswered questions, so I have written these down to discuss with you.

To an occupational therapist:

I am not clear on the reasons you are suggesting this equipment and how they fit with my priorities?

To the head nurse in a hospital:

I'd like to talk to you about my difficulty in getting assistance. I know you have many patients, but I cannot get out of bed unassisted, and I have been left for too long today. Can we talk about what is a reasonable expectation?

And remember – you have the right to ask for what you want and need. Communicate directly, clearly and respectfully. Where needed, use available resources to inform health professionals about your post-polio or other conditions. And let's all get the treatment we need and deserve! 🌈



Sharing Our Stories

By Joan Smith
Polio Survivor

We all remember those childhood days when the polio epidemics left some 40,000 Australians with crippling effects. It's past history for most, but for those of us who contracted the disabling condition prior to the Salk and Sabin vaccines, it rears its ugly head as we survivors age. It is known as post-polio syndrome (PPS) or late effects of polio (LEoP).

The Social Committee at Waterford Park Retirement Village invited me, as one of those affected, to tell my story of a childhood with polio, my full life after apparent recovery, and my current experience of PPS.

After years of rehab involving splints, callipers, painful daily exercises and long lonely hospital stays, I, along with other survivors, managed to rebuild damaged nerve endings and muscle power up to 50 – 60 %. To friends and observers everything was back to normal, but over-used and mis-used weakened muscles suddenly started breaking down again close to fifty years after the original polio. The old saying of 'use it or lose it' didn't work anymore.

To prevent rapid decline it became 'conserve to preserve' by once again using mobility aids and pacing activity with rest and change of lifestyle. There ended a full life of being a Mum, teaching, being Principal of a Special School, scouting, gardening, and living up in the hills.

I spoke of the role of Polio Australia in educating today's medicos as well as survivors. Lots of conversation and browsing of a display continued over Devonshire Teas.



My hand-made card sales, along with generous donations, raised \$690. Added to previous card sales this year, I was delighted to be able to donate a total of \$940 to Polio Australia.

Thank-you to the Waterford Park Retirement Village Social Committee for their wonderful support, and to all those who attended and purchased cards.

Perhaps there are other polio survivors out there who could also take up the challenge of speaking to a local group. The more who know about us, the better for us all. It may even positively influence people's decision about getting the vaccination for the current world-wide pandemic! 🌟

See page 19 for details on how you can purchase Joan's hand-made cards.

Royal Commission Recommendations

Source: www.cotavic.org.au – 15 March 2021

ATFA 
Assistive Technology for All

COTA Victoria coordinates a national collaboration of peak bodies and consumer advocates called the Assistive Technology For All (ATFA) Alliance. The Alliance has been advocating for improved access to [assistive technology](#) for the many older people with disability who are excluded from the National Disability Insurance Scheme (NDIS).

The Royal Commission into Aged Care Quality and Safety presented the Alliance with a unique opportunity to influence change. We made two [submissions](#) to the Royal Commission – one in December 2019, and the other in December 2020.

Our message wasn't complicated. We believe that all Australians, irrespective of age, should have equitable access to assistive technology. It shouldn't matter whether someone is accessing support under the NDIS or the aged care system – they should still have the same access to the assistive technology they need, when they need it. Right now, though, older Australians with disability who are ineligible for the NDIS do not have the same access to assistive technology as younger people with the same or similar conditions. This is discriminatory and inequitable, and it needs to change.

When the final report from the Royal Commission was released earlier this month, we were overjoyed to see that our concerns had been reflected in the Royal Commission's recommendations* and that the inequity experienced by older people with disability had finally been acknowledged.

*Read the recommendations in the full article [here](#). 🌟

ATSA Melbourne Breaks All Records

By **Kymerly Martin**

Source: www.freedom2live.com.au
– 26 May 2021

Despite Covid and a year filled with challenges the ATSA* Expo in Melbourne triumphed.

The sold-out two-day expo was the largest disability event to be held anywhere in the world this year, attracting 3,000 visitors and 160 exhibitors on May 18-19.



Shadow Minister for the NDIS, Bill Shorten, was a guest speaker. He called for more creative thinking when it comes to assistive technology (AT) and the disability sector. He posed this question to the audience, "where is the voice of AT in your industry?"

While acknowledging the AT presence at the expo he said the industry needs to think more boldly.

"The sum of the parts of AT is greater than the voice you currently have and as a sector you need to do it better. You are a sector with your own identity, making changes to many lives."

"Keep doing 99 per cent of what you are doing but change the one per cent. How do you create a domestic industry in Australia to manufacture more here and prioritise investment?"

"I always thought the NDIS would create new markets with AT innovations that would lead to thinking differently about disability. The industry needs to become more unified with a louder voice to make you bigger players in an economy where you are already prominent. You are at the exciting end of disability."

"A lot of people are doing very clever things based on technical knowledge and knowing someone they want to help. Some of the rehab I have seen with robotics and mechanical devices are incredible."

When it comes to the NDIS there are a lot of arguments on top of what he believes is too much red tape with some

of the processes to get approvals described as "mindboggling".

"Sometimes I think the government spends more money arguing with people about what they should be receiving than the cost of what they are trying to get. In the past year \$17 million was spent on lawyers employed by the National Disability Insurance Agency (NDIA) to argue with participants. The NDIS has become a system that protects itself and not the people in it."

And he is not buying the argument that there is a crisis in the NDIS on sustainability.

"I don't think people with disability are getting too much, or the way they receive an individual package should be made harder for people to get into the scheme. If the government wants to save money it should be sure that providers are not over-servicing invoices or bogged down in waiting times to change plans, get reviews and assessments."

"Being miserly at the front door does not necessarily save money and it comes down to individual choice which the government seems to be struggling with."

"Individual assessments should be standardised so everyone is part of the same decision making process. The problem is not to make it harder for people who are already in the scheme unless you have a cost-cutting agenda. There are legitimate issues of reform and it is always good to make decision making more transparent," he said.

A link to a video on the Melbourne expo is located on [this page](#).

Don't miss: ATSNZ – Auckland – July 6-7; and Canberra – October 27-28.

* Assistive Technology Suppliers Australia 🌐

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Budget Delivers A Funding Boost To The NDIS

By **KyMBERLY Martin**

Source: www.freedom2live.com.au
— 12 May 2021



The NDIS will receive an additional \$13.2 billion up until 2023-24 for disability supports, with \$17.9 million in early support funding going to young children with disability and developmental concerns. This is in addition to the \$3.9 billion included in the 2020-2021 Budget.

"As the scheme reaches maturity, our focus is on ensuring its sustainability and that it continues to deliver a high-quality essential service for those who need it," Treasurer Josh Frydenberg said.

NDIS funding is tipped to reach \$122 billion over the next four years with the scale and cost per participant now on a trajectory well ahead of what was anticipated by its original design, NDIS Minister Linda Reynolds said.

"Labor's original NDIS framework makes it inflexible and administratively burdensome to

make hundreds of individual decisions for hundreds of thousands of participants every year. The number of participants was also estimated well below the 530,000 Australians expected to access the scheme in coming years," she said. *"The Commonwealth will continue to discuss with the states and territories how we can work together to guarantee the affordability of the NDIS to ensure it endures for many generations of Australians to come."*

The minister said the NDIS will need around 83,000 new workers by 2024.

Physical Disability Council of NSW CEO, Serena Ovens, said while the budget provides much needed funds for both the NDIS and aged care, details on how these funds will be spent to target those with disability was not clear.

Ovens welcomed the funding to assist children, but specific funding to address the significant gaps in assistive technologies for those who are over 65 would have been appreciated. *"We can only hope that the additional 80,000 aged care packages will mean people with significant disability may finally get the Level 3 and 4 packages they need to be provided with appropriate care,"* she told F2L.

"We know there is still considerable reform taking place in the NDIS and the review of the NDIS ACT still leaves us concerned as to the government's long-term plan for the scheme, and individuals' choice and control over their lives."

There are currently 450,000 people receiving disability support with more than 100,000 joining the scheme in the past year. 🌐

Fear Of Falling Research

Fear of Falling May Be Linked to Lower Physical Activity for People with Physical Disabilities: *A study funded by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR).*

Source: National Rehabilitation Information Centre — 24 March 2021

A growing number of people are aging with physical disabilities acquired earlier in life, such as muscular dystrophy (MD), multiple sclerosis (MS), post-polio syndrome (PPS), or spinal cord injury (SCI). People with these long-term physical disabilities may have fears about falling while performing everyday activities. Regular physical activity or exercise that builds strength, endurance, and balance can help to prevent falls as well as promoting health more generally. However, people aging with physical disabilities may be reluctant to exercise regularly if they are worried about falling.

In a recent NIDILRR-funded study, researchers looked at physical activity level, fear of falling, actual fall history, and disability type in a sample of adults with either MD, MS, PPS, or SCI. They wanted to find out whether levels of physical activity differed by disability type and whether fear of falling or a history of falls were related to physical activity levels in this sample.

[Read the article.](#) 🌐

Paracetamol

Source: www.painaustralia.org.au — May 2021

You might have seen a recent study published in the *Medical Journal of Australia*, conducted by the University of Sydney, which found that the evidence is not clear that paracetamol medications are more effective than a placebo for the most common illnesses or injuries.

When it comes to pain relief, there are few medications that are as well-known and trusted as paracetamol. It is one of the most used medicines in the world and has been in Australia since the 1950s.

However, the findings indicate the most ineffective use of paracetamol is when it is taken for acute low back pain. In trialling paracetamol to treat almost 50 common pain conditions, it was discovered that only knee and hip osteoarthritis, craniotomy, tension headache and perineal pain after childbirth were better for managing pain than a placebo.



The prevailing issue is that paracetamol has become so ubiquitous in the treatment of chronic pain that it is difficult to know how these new findings will be accepted and adopted in Australia.

Following the restriction of opioid medication recently together with boxed warnings for medications containing pregabalin or gabapentin, the roll out of real time prescription monitoring and the exceptionally long wait times to see a pain specialist of at least a year, people living with chronic pain now appear to have even fewer medication options to help them manage their condition.

Further research is required to determine paracetamol's efficacy for managing pain. In the meantime, it seems the need to educate consumers and prescribers about alternative treatments and the importance of a multidisciplinary approach to pain management is becoming more important in light of diminishing medication options. 🌟

Splendid Solution

By Jeremy Kay

Source: www.screendaily.com
— 31 March 2021

Bron and 21 Laps have set Jeremy Strong to star in their adaptation of polio vaccine drama *Splendid Solution*.

The feature is based on Jeffrey Kluger's novel of the same name about Jonas Salk's quest to discover a vaccine as polio ravaged the United States in the early 1950s.

Gillian Weeks will write the screenplay. The producers did not announce a director on Tuesday (March 30).

Shawn Levy (*Free Guy*) and Dan Levine (*Arrival*) will produce on behalf of 21 Laps Entertainment, with Becca Edelman and Emily Feher managing the project.

Aaron L. Gilbert (*Those Who Wish Me Dead*) will produce for Bron.

Strong (pictured right in *Succession*) is an executive producer alongside Bron's Brady Fujikawa (*Good Boys*) and Ashley Levinson (*Pieces Of A Woman*).

Jared Kramer brought the project to Bron and will oversee on behalf of the company.

"We can't think of a more timely story to tell — of one man's journey to save the world from a devastating pandemic while overcoming misinformation from the media ... and how he believed so much in the vaccine that he tested it on himself and his children to prove to the world that it was safe," said Levy and Levine.

"This project is tailor-made for the time we're living in," said Gilbert. "I am confident that this true story of hope and perseverance in an era of uncertainty will resonate with viewers across the world and remind them of what humankind has overcome."

Strong's credits include *The Trial Of The Chicago 7*, *The Big Short*, *The Judge*, and *Zero Dark Thirty*. 🌟

(Release date not yet announced.)



Vale John Konrads

Australian Swimming Legend John Konrads Dies At Age 78

Source: www.abc.net.au — 26 April 2021

Key points:

- Born in Riga, Latvia, John emigrated with his family initially to Germany in 1944
- In 1949 their application to immigrate to the United States was refused and they were relocated to a camp in the Riverina region of NSW
- In 1958, John won three gold medals for Australia at the British Empire and Commonwealth Games in Cardiff

Konrads dominated world swimming as a teenager in the late 1950s and early 1960s, winning the 1500m freestyle at the 1960 Rome Olympics among a haul of three medals at the Games.

Across a decorated career, Konrads set 26 individual freestyle world records between the 200m and 1500m events before he turned 15.

Konrads, who died on Sunday [25 April] at the age of 78, was inducted into the Sport Australia Hall of Fame in 1985.

"He was a proud Sport Australia Hall of Fame member with an extravagant sense of humour who will leave a lasting legacy around the world," SAHOF chairman John Bertrand said.

Born in Riga, Latvia, John emigrated with his parents Janis and Elza, grandmother, and sisters Eve and Ilsa in August 1944, initially to Germany.

Living in Germany until 1949, their application to immigrate to the United States was refused on account of the large size of the family.

They were relocated to a camp at Uranquinty, 15km south of Wagga Wagga in the Riverina region of NSW.

Konrads suffered polio as a child and his father thought swimming would be of therapeutic benefit.



He first caught the attention of famed Australian swim mentor Don Talbot, who was working as an assistant coach while teaching at a Sydney primary school Konrads and his sister Ilsa attended.

The Konrads siblings were at their record-breaking best in 1958, the year John won three gold medals at the Empire and Commonwealth Games in Cardiff.

In 1959, John won every Australian freestyle title.

After retirement, Konrads entered the world of swim coaching before becoming the Australasian director of cosmetics giant L'Oreal.

He assisted with the bid for the 2000 Sydney Olympics, was a company director operating the Cook and Phillip Park Aquatic & Fitness Centre, as well as consulting in human resources. 🇦🇺

How Polio Campaign Beat Vaccine Hesitancy

By Susan Brink

Source: www.wyomingpublicmedia.org
— 3 May 2021

The mass inoculation of millions of American children against polio in 1955, like the vaccinations of millions of American adults against COVID-19 in 2021, was a triumph of science.

But the polio vaccine had overwhelming public acceptance, while stubborn pockets of vaccine hesitancy persist across the U.S. for the COVID-19 vaccine. Why the difference? One reason, historians say, is that in 1955, many Americans had an especially deep respect for science.

"If you had to pick a moment as the high point of respect for scientific discovery, it would have been then," says David M. Oshinsky, a medical

Polio Campaign Beat Vaccine Hesitancy *(cont'd from p18)*

historian at New York University and the author of *Polio: An American Story*. "After World War II, you had antibiotics rolling off the production line for the first time. People believed infectious disease was [being] conquered. And then this amazing vaccine is announced. People couldn't get it fast enough."

Today, the unprecedented speed of the COVID-19 vaccines' development, along with a flood of disinformation on the internet about all vaccines, has led to a lingering hesitancy among some Americans to receive the increasingly available COVID-19 shots.

"In hindsight, Operation Warp Speed wasn't the best name," says Oshinsky. *"It sounds like the project prioritized speed over everything else. They did roll it out quickly, but the FDA and CDC have done an amazing job of testing the vaccines and ensuring their safety and efficacy."*

During the late 1940s and early '50s, according to statistics from the Centers for Disease Control and Prevention, polio disabled an average of 35,000 people a year in the U.S., most of them children. As outbreaks popped up across the country in the hot summer months, people were terrified and voluntarily isolated. Many parents kept their children close to home and away from community gathering spots like movie theaters, roller rinks and beaches.

"Back then, it affected business and travel," says Stacey D. Stewart, current president and CEO of the March of Dimes. *"People didn't know how the virus was transmitted. They lived in a state of fear. Pools were closed. Businesses were affected because people didn't want to be out in public."*

President Franklin D. Roosevelt, who had himself essentially lost the use of his legs after a polio infection in 1921, when he was 39, launched the National Foundation for Infantile Paralysis, a charitable organization, in the late 1930s. Later renamed the March of Dimes, the foundation took the lead in efforts to fund research at a time when the National Institutes of Health was in its infancy.

"Roosevelt's passion for finding a solution — a cure, a vaccine — made polio a priority coming from the very top leader of this country," says Stewart. *"People across the country felt like they were called to duty. It was a call to action, like the war effort."*

An army of volunteers for the March of Dimes, largely mothers, went door to door, distributing the latest information about polio and the effort to stop it; they also asked for donations. As little as a dime would help, they said. And the dimes and dollars poured in, Oshinsky says, handed to the volunteers, or inserted into cardboard

displays at store checkout counters or placed in envelopes sent directly to the White House.

Cases of polio may have peaked in the U.S. in 1952 with nearly 60,000 children infected. More than 3,000 died. (By comparison, roughly a year's worth of comparable statistics for the COVID-19 pandemic reveal more than 32 million reported cases in the U.S. so far and more than 573,000 deaths.)

The years-long campaign of information and donations to the polio eradication effort made anxious Americans feel they were invested in a solution, Stewart says. So confident was the public in the research leading up to the polio vaccine that by the time the Salk vaccine was ready for experimental testing in 1954, the parents of 600,000 children volunteered their own offspring as research subjects.

When the results of those studies showed the vaccine to be safe and effective in 1955, church bells rang. Loudspeakers in stores, offices and factories blared the news. People crowded around radios. *"There was jubilation,"* says Stewart. People couldn't wait to sign their kids up for a shot.

Then tragedy struck. One of the six labs manufacturing the vaccine, Cutter Laboratories in Berkeley, Calif., made a terrible mistake. The correct list of ingredients for the Salk vaccine called for polio virus that had been inactivated, but in the Cutter facility, the process of killing the virus proved defective. As a result, batches of the company's vaccine went out that mistakenly contained active polio virus. Of the 200,000 children who received the defective vaccine, 40,000 got polio from it; 200 were left with varying degrees of paralysis, and 10 died.

In April, the U.S. campaign against COVID-19 suffered a blow too. Reports that an extremely rare but serious blood-clotting disorder might have resulted from Johnson & Johnson's vaccine — one of the three authorized for use against COVID-19 in the U.S. — once again raised the question of whether possible harms caused by a vaccine might derail people's confidence in a public health campaign at a crucial time.

On April 13, the CDC and the Food and Drug Administration jointly announced that among the 6.8 million doses of the Johnson & Johnson vaccine administered to date, six cases of a serious blood-clotting issue had been recorded, and one woman had died.

Ten days later, after a careful review of those cases and others, the pause was lifted and immunization with the vaccine resumed, with new guidance for recipients and doctors about what to look for in the way of symptoms and how to treat these extremely rare events.

Polio Campaign Beat Vaccine Hesitancy *(cont'd from p19)*

Polio vaccinations were temporarily halted in 1955 following the Cutter error as well. In both incidents, health officials followed the science. After Cutter's manufacturing error was pinpointed as the problem, vaccinations restarted within weeks, with renewed quality control efforts and minus any involvement from Cutter Laboratories.

In 1955, mothers and fathers jumped right back in following the Cutter tragedy, once again signing permission slips and lining their kids up to get their polio shot. It was widely understood and accepted that the risks of polio were a much greater threat than the risks of the vaccine.

"I think back then, people were so personally invested in the vaccine," Stewart says. "They listened to what happened in the Cutter case, and they understood. They continued to trust."

Because of that trust, the campaign to prevent polio with vaccines — first Jonas Salk's and then also Albert Sabin's — was successful, eventually nearly eliminating the disease from the planet. But that also means, says Oshinsky, that people born after the mass vaccination effort don't have memories of how bad the disease could be.

"Vaccines have been a job ... done so well they have obliterated evidence of what the disease can cause: kids on crutches, in wheelchairs, in iron lungs," Oshinsky says. "I remember seeing the occasional empty desk in school because a child had died. People had seen polio every summer, and they wanted kids vaccinated as soon as possible."

The polio vaccine effort offers some lessons for today, says Stewart. First, volunteers from local communities are trusted and invaluable in providing education on disease, research and vaccines. To get people's attention, add to that numerous high-profile advocates — individuals recognized and esteemed by various parts of the population. The March of Dimes recruited Judy Garland, Mickey Rooney and Marilyn Monroe to join the fundraising effort to educate people about polio and the value of the vaccine. And in 1956, Elvis Presley was vaccinated backstage at *The Ed Sullivan Show*.

Vaccine efforts at the time did have to contend with racism. Oshinsky writes, for example, about some areas in the Jim Crow South where Black children lined up for shots on the front lawns of white schools, while white children got their shots indoors. The Black children, he notes, weren't allowed inside those white schools, even to use the bathrooms. Very aware of the prejudices of the times, Stewart says, the March



Elvis Presley got his polio vaccination from Dr. Harold Fuerst and Dr. Leona Baumgartner at CBS' Studio 50 in New York City on Oct. 28, 1956. The chart-topping singer took part in a March of Dimes campaign to convince teens to get vaccinated.

Seymour Wally / NY Daily News Archive via Getty Images

of Dimes knew it would also need to recruit prominent and popular Black performers to promote the polio vaccine.

Sammy Davis Jr., Louis Armstrong and Ella Fitzgerald joined the campaign. *"There was a very early recognition that you couldn't just have white people talking about the vaccine," Stewart says. In addition to beloved Black celebrities, she says, "the March of Dimes had Black children on the posters to raise awareness in Black communities."*

It has now been several months since Sandra Lindsay, a nurse on Long Island, N.Y., became the first person in the U.S. to receive a COVID-19 vaccination. At least 30% of the country's total residents are now fully vaccinated, and more than 44% have received at least one dose.

"That's the low-hanging fruit," says Oshinsky. "After you vaccinate all the people champing at the bit to get it, that's when you have to think of strong marketing strategies for those who are hesitant."

The strong, consistent message during the polio years was *"We're all in this together."* The same message, says Stewart, must come across loud and clear today. 🟡

*Susan Brink is a freelance writer who covers health and medicine. She is the author of *The Fourth Trimester* and co-author of *Change of Heart*.*

Three Female Medics Killed In Afghanistan

By Ahmed Sultan, Orooj Hakimi

Source: www.reuters.com — 1 April 2021

JALALABAD/KABUL (Reuters) — The killing of three female polio vaccine providers in Afghanistan this week has forced aid agencies and the government to re-assess field postings for thousands of female medics at a time when nearly 10 million Afghan children need polio drops.

Officials at the United Nations Children's Fund (UNICEF), one of the agencies helping in the large-scale polio vaccination drive across Afghanistan that was launched this week, said they were reviewing the involvement of women in the role after unidentified gunmen killed three frontline workers in the eastern city of Jalalabad on Tuesday.

A UNICEF official said that steps were being taken to ensure that vaccinations continue but that the polio campaign in three districts, targeting an estimated 320,722 children under the age of five, will be delayed until after the Muslim holy month of Ramadan in May.

"We feel terrible that women who are selflessly offering services to children are killed senselessly in line of duty... It's crucial we maintain momentum to ensure every child is vaccinated against polio," said Godwin Mindra, an immunization specialist at UNICEF.

"We are considering providing a layer of security to female frontline workers but we are also aware that we cannot militarize any health campaign," Mindra told Reuters, adding that an estimated 9.9 million children need polio drops this year across the war-torn country.

About 70,000 staff, including vaccinators, are involved in implementing the polio campaign, of which about 40% are women.

Afghanistan's COVID-19 vaccination has not been affected since inoculations are being done at health centres and not door-to-door like the polio campaign, which exposes health workers to more danger, officials said.

They said scaling down the polio vaccinations would be catastrophic as the country this year reported about two dozen polio cases and about three million children were deprived of the vaccine in the past three years.

Female medics have been effective in implementing polio vaccine campaigns in conservative Afghan society as women in rural areas are reluctant to take their children to a male nurse due to cultural or religious issues.

Ghulam Dastagir Nazari, the head of the immunisation programme in the health ministry,



said the motive behind targeting frontline female health workers remains unclear and he was re-assessing not just door-to-door campaigns but also protection to all health centres, where the COVID-19 vaccines are being administered.

"Our female employees can enter houses directly and even raise awareness about other health issues ... they secure financial independence but such attacks could force many to leave the job," he said.

Shot In The Forehead ...

Afghanistan and neighbouring Pakistan, both Muslim-majority nations, are the only two countries of the world where polio remains endemic.

Last year, religious hard-liners in Pakistan's northwestern city of Peshawar spread rumours of children falling sick due to the vaccine, triggering backlash in the conservative Khyber Pakhtunkhwa province bordering Afghanistan, where most of Pakistan's polio cases have been detected.

"The attack serves as a warning and we should take serious precautions and actions to prevent them in future," Nazari said, adding more young men could be hired to run the polio vaccine drive.

No militant group, including the Taliban, has taken responsibility for the latest attack. In recent years, followers of the ultra-radical Islamic State group have been active in Nangarhar province, of which Jalalabad is the capital.

Families of the young medics killed said even women who step out of their homes for a noble cause are not safe in Nangarhar.

"The gunmen shot my cousin in her forehead and fled," said Faisal, a relative of 23-year-old Samina who was killed along with her colleagues this week.

"It was her second day as a vaccine provider and she has been killed in the line of duty," said Faisal, who uses a single name. 🌟

Patient Zero

07 | Patient Zero: Back From The Brink (Podcast)

Source: www.abc.net.au/radionational—21 May 2021

A six-year old boy in Papua New Guinea wakes up one day and is suddenly unable to stand up. Less than a year later, children in three other Asia Pacific nations are experiencing the same alarming symptoms.

A disease that was eradicated from this region is back — and it appears to be spreading. 🌐



20:49 / 40:30

Handmade Cards For All Occasions

If you are looking for that special card for the special people in your life, Melbourne-based polio survivor, Joan Smith, creates beautiful and unique handmade cards, which you can now purchase. Cards all come with individual envelopes and are protected by plastic sleeves.

Joan donates all proceeds from the sale of her cards to Polio Australia, for which we are very thankful!

These exquisite cards are sold in mixed packs of **5 for \$20** including postage and handling (within Australia only). There are also Christmas Cards, although we are unable to guarantee the postage times late in the year. Why not get in early and beat the rush!

Below is a sample of Joan's beautiful cards. Click through to Polio Australia's website to order yours today: www.polioaustralia.org.au/giving-opportunities/ 🌐



ATFA in Conversation with Graeme Innes

Improving access to assistive technology
for people outside the NDIS



We're hearing a lot about the shortcomings of the NDIS and the threat of independent assessments. While these are important issues, what about the 90% of Australians with disability who are not eligible for the NDIS at all?

The **Assistive Technology for All Alliance** is advocating for a universal assistive technology program to meet the needs of people with disability who are excluded from the NDIS.

Come along to our **free online forum** featuring former Disability Discrimination Commissioner, **Graeme Innes AM**, to find out more.

During this event, you will:

- Learn more about Australia's obligation to provide assistive technology to people who need it
- Hear from people with disability who are directly affected by the lack of access to assistive technology outside the NDIS
- Learn more about the Assistive Technology for All campaign and how you can get involved.

This event will be Auslan interpreted.

Get in touch: call COTA Victoria on 1300 13 50 90 if you have queries or need assistance with booking.

Date: Wednesday 9 June 2021
Time: 11 am - 12.30 pm | **Location:** Zoom

[Click Here to Book](#)

