



Polio Oz News

September 2022—Spring Edition

Knee Replacements And The Polio Survivor

Article Review By Michael Jackson
Polio Australia Clinical Educator

Knee replacements using rotating hinge implants



An article on knee replacements with polio survivors was published in August 2022, written by a group of Italian orthopaedic researchers. The article was oriented to rotating hinge implants on the most polio-affected side leg. These implants are designed to allow normal motion of the knee joint, yet offer more stability through limiting hyperextension of the knee (locking it back) in particular.

An orthopaedic intervention such as joint replacement is a means by which to regain or stabilise large joint motion which is essential to functional mobility (walking, using stairs, sitting, standing etc.). There are numerous hardware pieces, types and brands used for knee replacements – rotating hinge implants are one type of hardware. Many factors influence the decisions about what hardware is chosen for each knee for every individual.

For those with a history of polio weakness and paralysis in the lower limb, there is commonly some combination of quad weakness paired with a tendency to lock the weaker knee when standing or walking. This occurs as a way to compensate for the weakness, and a way to buy stability with less effort and risk when moving. Hyperextension postures and chronic posterior strain of the knee is the result.

These postures may be controlled or reduced by callipers, orthotics, shoe modifications or assistive device use. Over the long term, a most-affected side knee can become vulnerable to injury and joint degeneration from chronic atypical movements. Knee replacements on the stronger (or least affected side) leg are often a result of lifetime biases in weightbearing and function over the lifetime causing joint degeneration.

This article looked retrospectively at 14 polio survivor patient cases who had rotating hinge implants and a follow up of several years.

Of significant concern is that revision rates for knee replacements are higher for polio survivors than in other populations, mostly due to the complexity of the anatomical presentation of polio survivors' lower limbs and their functional movements. The authors suggested that the more constrained design of the rotating hinge implants is a good alternative to non-hinged implants – particularly where quad weakness is significant and there is a risk of ongoing instability in the joint after knee replacement. They also recommended polio survivors having knee replacements to do so in facilities where a high number of complex knee replacements are performed.

Source: Digennaro, V., Manzetti, M., Bulzacki Bogucki, B.D. *et al.* Total knee replacements using rotating hinge implants in polio patients: clinical and functional outcomes. *Musculoskelet Surg* (2022). <https://doi.org/10.1007/s12306-022-00755-w>

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Representing polio survivors

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**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

“ **An optimist is the human personification of Spring**
 ~ Susan J Bissonette ~ ”

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President's Report



By Gillian Thomas OAM
President

So far this 'spring', I'm still waiting for it to warm up and stop raining! Those of us on the east coast of Australia are experiencing "wetter than average" weather conditions, and La Niña looks like it will be with us for a while longer. For people like me who use a wheelchair for mobility, I'm keen to see how the new DASH service (P11) will transport people through the rain. Of course, this is particularly relevant to NDIS participants, which I am not eligible for.

As such, I'm even more interested in seeing how NDIS will be 'fixed' (P10), and if the over 65 year old's will finally get a look in. This age cap has been a major impediment to people who have lived for years with a disability, and are now reliant on the aged care system, which is both overwhelmed and underwhelming.

As (mis)fortune would have it, I have been living in an aged care facility since December last year when my partner and carer had an accident, leaving him with a lingering injury, and unable to care for me. It has been a frustrating time, not

least of which is training the staff how to work with my post-polio body.

Michael Jackson's work with the Aged Care Sector is not only important to me, but to any polio survivor who needs the services of a Personal Care Worker (PCW). Because of the tens of thousands ageing polio survivors living in Australia, Michael developed our [Working with Polio Survivors: A Professional Development Course for Aged Care Workers](#) which is provided as a free online course to help PCW's: a) improve knowledge about polio and post-polio conditions; b) help understand the lives of Australian polio survivors, and; c) improve ability to effectively help polio survivor clients.

In spite of the Clinical Education program being such a success, the cessation of federal government funding in June this year means we now face the very real risk of losing Michael's vital contribution as Clinical Educator for the post-polio community. In fact, as our Administration Officer, Paulette Jackson, was funded within the same program, our resources and, consequently, capacity to support polio survivors and their health practitioners, would be significantly reduced.

Treasurer, Alan Cameron, is calling for our readers to help prevent this loss (P4). Please help us to continue helping you. 🌟

Gillian

From The Editor



By Maryann Liethof
Editor

Another month, another outbreak! Since my last edition of *Polio Oz News*, a plethora of articles have been printed regarding polio found in London's waste water, as well as the story of a young man in New York contracting the polio virus.

My modus operandi is to collect and collate articles over the 3 months between editions, and then sort through them all to see how the news has progressed, and whether the stories have become more refined. As a result, a couple of the articles I have included in this edition tend to overlap. However, I believe the combination provides the most comprehensive and considered responses to the outbreak.

We start this Spring edition with an Article Review by Polio Australia's Clinical Educator, Michael Jackson. Over the past few years, Michael has been an enormous contributor to the post-polio information now available to both health practitioners and polio survivors.

Devalina Battacharjee has also been busy hosting the *Living Well After Polio* conference in Cairns in June, and a very lively video information session where participants shared



their tips on living with polio on a day to day basis (P5-6). It never ceases to amaze me how positive and generous people are with sharing their experience.

This is also played out with Polio Australia's very own 'Rotary Polio Champions' (P7), Sue Mackenzie (Queensland) and Gary Newton (Victoria). Sue and Gary are both on the Board and started out as volunteer speakers at Rotary Clubs, sharing their stories, and raising funds, where possible. Over time, they were invited to join Rotary and, this year, both have become Presidents of their respective Rotary Clubs! They are more involved than ever in raising awareness about all things polio.

October is fast approaching—which also means **Polio Awareness Month** (P8). Paulette Jackson is looking for polio-stories and help with lighting up your local landmarks in orange.

If you are considering a new diet plan, Nutritionist, Melinda Overall, has options which just might work for you (P9).

Finally, I was sad to learn that one of the great pioneers in post-polio research, Dr Lauro Halstead, passed away earlier this year. I met and interviewed Dr Halstead in 2008, which I have linked to the Obituary (P12).

Always take time to smell the roses! 🌟 *Maryann*

Clinical Practice Workshops Update



By Michael Jackson
Polio Australia Clinical Educator

In the last financial year, we delivered the greatest number of workshops (38) over the life of the program, and attendee numbers (total and average) continue to rise.

Our workshops are clearly impactful to those clinicians taking the opportunity to attend them, this being described by a host earlier this year as follows:

"Our team has a much more clear understanding of the impacts of LEOp and how to support those impacted. The presentation was clear, concise, informative and well presented. It has certainly increased the awareness of our clinicians and will ensure better care is provided across our region." (Coffs Harbour, NSW)

Our program will continue to deliver workshops at least until the end of December this year – a priority until then is to obtain program funding.

Are there philanthropists in your network who are in a position to support this program for several years?

Besides getting face to face with clinicians, it is important to get post-polio resources in their hands. In July we mailed out 100 Hospital Kits nationwide to get hard copies of our resources into the hands of front-line clinicians. These 100 hospitals collectively represent 32,436 beds – one third of those available in Australia. We are in the process of assembling and mailing out the second batch of 100 currently.

With this in mind – when you utilise hospital-based care (admitted or on an outpatient basis) please enquire about post-polio resources so that your care can be appropriately informed. (A map of the facilities where a kit has been or will be delivered can be found here:

<https://bit.ly/sentkits>)

Our online Aged Care course has now had 30 learners complete the course, more than double the number mentioned in the June Issue of PON. A long-term project for this program is to build and have available similar courses, specific to key clinical disciplines such as physiotherapy, nursing, occupational therapy, exercise physiology, orthotists and pedorthists, surgical teams, and care managers.

The Clinical Practice Workshop program is integral to Polio Australia's Mission, and there is much work to be done to further reduce the widely reported differences in the quality of care between LEOp informed and uninformed clinicians. 🌐

January-June 2022 WORKSHOPS	In-Person	Remote	Monthly Online	Total
Number CPWs	11	0	4	15
Attendees	115	0	16	131
Hospitals and community-based clinic audiences	11	0	4	15
States Delivered	NSW, VIC, QLD, SA	NA	NSW, VIC, QLD, TAS, WA	5 of 8 regions

Funding For Clinical Practice Workshops—Can You Help?



Immediately before the last election, the Federal Government announced that funding for the program would not be renewed. Since then, approaches to the new Government have, so far, been unsuccessful. Without a new commitment of **\$180,000 p.a.**, this wonderfully successful program will fold, which would be a mighty blow to the polio community.

The Board of Polio Australia is appealing to anyone who has ideas or contacts who may be able to help with philanthropic, industry, or community support, to make contact and put forward their ideas.

Your help is needed urgently!

Alan Cameron
Treasurer, Polio Australia

**HELP US
HELP OTHERS** ↩

Community Programs Update



By Devalina Battacharjee
Community Development Worker

As many of you may know, Polio Australia's *Living Well After Polio* conference had been in the works for a while and had been rescheduled three times over the past couple of years due to COVID, but this year after triumphing over many trials and tribulations, we were successful in hosting it on the 10th of June, in Cairns at the Healthy Living Centre, courtesy of Spinal Life Australia.

The conference was extremely well attended and we had many distinguished speakers and survivors who were generous enough to share their experiences with the attendees (thanks Maree and Margo!).

The speakers included Drs Peter Nolan, Timothy Nolan, and Natasha Layton, who presented on Anaesthesia, Sleep and Bone Mineral Density, and Living Well, respectively. We also had our

very own Clinical Educator, Michael Jackson, present a segment on Exercise, and had a demonstration by Aida Care on newly available assistive technology.

Furthermore, we have recently concluded Victorian community information sessions in Melton and Wandin on the 10th and 15th of August, respectively (thanks Maree and Joan!). These sessions were promoted in collaboration with Post-Polio Victoria and the aim was to attract new members to join our existing community and spread awareness about LEOp, bringing survivors and their carers into the fold that had hitherto been unaware of us and our efforts.

To that end, we were successful. In promoting our sessions through the well-established network of support groups and placing ads in Network Classifieds, we were able to attract some survivors and carers that had not been privy to any information regarding LEOp and PPS. The information being given out in the sessions was deemed informative and helpful, leaving the attendees feeling content.

Until next time, may spring quickly be sprung upon us! 🌈



July Video Session Summary

By Devalina Battacharjee

Community Development Worker



We had a very robust video discussion on the 22nd of July, with many people chiming in and sharing their thoughts on resources and tools that have helped them through their survivor journey. For those who couldn't join us, I hope this summary is useful for you.

Summary of chat

- A lot of survivors have found smart watches and pendants to be very helpful, particularly when it comes to planning for falls prevention and care.
- Luggies (see below), pull-along trolleys, ankle straps, induction cookers, wonder sheets, bed ladders and massage boards have all helped immeasurably in improving the quality of life for a lot of survivors.

- Delegation of chores, in the form of availing services such as supermarket deliveries and online shopping have gone a long way towards easy management of time and energy.
- Socialising with friends and inculcating a belief in spirituality have helped many survivors take care of their emotional health and wellbeing.

Resources

- Link to a list of books our website that can be helpful: www.polioaustralia.org.au/polio-books-overview/. Clicking on the individual tabs will bring up a list of book names.
- Polio Australia's "Living With Polio" Factsheets are full of useful information: www.polioaustralia.org.au/living-with-polio/.
- Rosalie of Polio NSW has come up with the wonderful idea of starting a Human Library and is looking for people who are interested in volunteering. Here is a page that talks more about the concept of Human Libraries for those who want more information: www.humanlibraryaus.org/.
- Link to Aida Care's website, a Queensland based organisation specialising in assistive devices: www.aidacare.com.au/

A few last things

- Remember that your state network has local advice and resources. If you are not a member of your state, go to www.polioaustralia.org.au/support-and-services click on your state on the map, and get in touch!
- If you haven't already done so, we'd love you to add your name to the Australian Polio Register. The higher the number of people registered, the stronger our advocacy can be. www.australianpolioregister.org.au
- And don't forget to join us on Facebook, if you're a Facebook person! 'Like' our page, join our general group, and join our NDIS-specific group if that applies to you: www.facebook.com/PolioAustralia

If you would like to join us for any future community information sessions, check here for details:

www.polioaustralia.org.au/community-information-sessions/

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Financial Update

Polio Australia would like to thank both individuals and organisations for their generous support, raising an EOFY-boosted **\$30,085** for the second quarter of 2022! This included a very much appreciated \$10,000 bequest. 100% of these tax-deductible donations are used to support Australia's post-polio community.

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.

Rotary Polio Champions



Sue Mackenzie (*pictured left*) is a Polio Australia Board Member, polio survivor, and current President of the Rotary Club of New Farm, in Brisbane, Queensland. The following two activities highlight the issues for both polio eradication and post-polio.

At a Rotary District Foundation dinner held on the 23rd of August, past International Rotary President, Ian Risley spoke on present situation of polio in the world today, especially the recent infection in New York, and the virus found in London's sewage system.

Ian spoke about the great work of the late Sir Clem Renouf from Queensland. During his role as International Rotary President, Sir Clem initiated – with WHO – the 'End Polio Now' campaign, the Mission being to have every child in the world vaccinated against polio.

Excerpt from the [Rotary Club of Alexandra Headland's website](#)

Sunday the 14th of August saw The Rotary Club of Alexandra Headland engage in a successful **Walk For Polio** at La Balsa Park, at Point Cartwright. It was a brilliant day with representatives from The Rotary Club of Maleny; The Rotary Club of Caloundra Pacific; The Rotary Club of Brisbane; and the Rotary Club of Alexandra Headland join together with members of the local community groups, with the purpose of raising awareness about the effects of polio, and the need

to raise some funds to eliminate this devastating disease that targets children under the age of five. Our thanks also to the Rotary Club of Nambour who gave a most generous donation in support of the Rotary Club of Alexandra Headland's **Walk for Polio**.

It was a bonus to have at our walk the District Chair of Rotary Foundation for Polio, Bruce McNaught, himself a survivor of polio. Also thanks to Sue Mackenzie, president of the Rotary Club of New Farm.

Polio Australia's Vice President, Gary Newman, (*pictured right-centre*) has also recently become President of the Rotary Club of Geelong East in Victoria.

Gary has accepted an invitation to MC the Rotary Zone 8 Conference in Canberra in October from 28th to 31st. The conference will see a large number of high profile decision-making Rotarians attending from Australia, New Zealand and the South Pacific. This will provide him with further opportunities to increase awareness of Polio Australia and the needs of polio survivors

Gary and Sue are champions for both polio eradication and polio survivors, raising awareness and vital funds for both causes. 🌟



Polio Australia is a non-profit organisation and is endorsed by the Australian Taxation Office as a Health Promotion Charity and a Deductible Gift Recipient, making all Australian donations over \$2 to Polio Australia tax deductible.

Please [click here](#) for a copy of Polio Australia's Constitution. You can also [click here](#) for Polio Australia's brochure, or [here](#) for Polio Australia's 2020-2022 Strategic Plan.

Polio Awareness Month—October 2022



By Paulette Jackson
Administration Officer

October is quickly approaching, which means Polio Awareness Month is right around the corner. This year's theme revolves around the strength and resilience of polio survivors:

Polio Survivors – Still Here, Resilient and Fighting On

hoping for more!

We are looking forward to seeing the country light up **orange** again to bring awareness to the thousands of polio survivors living here in Australia. Last year, twenty different landmarks were illuminated orange. This year, we are

If you would like to raise awareness and see landmarks/buildings lit up **orange in your area, ask your local council to illuminate landmarks the week of 24th October.**

If that week isn't available, ask if they can be illuminated any time during the month of October. Don't forget to email us if you were successful! This way we can promote it!

Also, any polio survivor wishing to share their story (either by writing about it or by being interviewed by media) can email us at office@polioaustralia.org.au.

We are looking forward to sharing your stories on our social media pages and our blog. Polio survivors, we celebrate you and we recognise your resilience!

See activities and photos from 2021 Polio Awareness Month [here](#).



polio
network
victoria

Polio Network Victoria's Polio Day 2022

"Navigating the System"

Guest Speakers:

Tanya Paynter – Clinical Services Manager
Libby Callaway – Rehab & Assistive Technology Specialist
Anne Silbereisen – Psychologist - Mindfulness

Wednesday 26 October 2022

No. 1 Events, Malvern Valley Golf Course
1 Golfers Drive Malvern East Victoria

10.00am – 3.00pm

\$40.00 = Early Bird (until 14/10) / **\$45.00 = Regular**
Lunch and refreshments included

Bookings: [Trybooking Polio Day 2022](#)

Enquiries: Maxine Keystone – mkeystone@westnet.com.au / Ph: 0423 020 407

Intermittent Fasting And Time Restricted Eating

By Melinda Overall JP

Nutritionist / Counsellor

www.overallnutrition.com.au

Intermittent fasting (IF) has been around for a long time in its various forms. It can be seen in the historical and current day practices of many religions including Christianity, Islam, Buddhism and Judaism, to name a few. There have been many recorded instances of political fasting, used as a non-violent statement of resistance, for example Gandhi and Bobby Sands. Medical fasting has also been used, since at least the time of Hippocrates (c.460BCE-C.370BCE), and was popularised by Edward Hooker Dewey in his book *The True Science of Living: The New Gospel of Health, Practical and Physiological; Story of an Evolution of Natural Law in the Cure of Disease, for Physicians and Laymen* (1894). [1]

Dr Michael Mosely and co-author Mimi Spencer, rejuvenated the popularity of intermittent fasting in their book *The FastDiet: Lose Weight, Stay Healthy, and Live Longer with the Simple Secret of Intermittent Fasting* (2013). In the book, the authors offered up the 5:2 diet as the foundation to improved health and weight loss. The dietary protocol is to eat normally for 5 days each week and restrict caloric intake to 500 calories (women) and 600 calories (men) on 2 days of the week, either consecutively or on separate days. As an aside, eating 'normally' means eating a healthy diet that meets your estimated energy requirements.

Restricted time eating (RTE) is another form of intermittent fasting but here the protocol is followed daily and the available time for consuming food is restricted. For example, you might choose to fast for 16 hours per day (eg 3pm-7am) and only consume foods during an 8 hour period (7am and 3pm). [2,3] This limits the available time for eating in a time where many people tend to eat from breakfast until they go to bed. RTE also often includes energy restriction.

Research suggests that RTE and IF both provide numerous health benefits through adherence. These can include lowered blood pressure, improved blood sugar regulation and reduced risk of other metabolic diseases, reduced risk of systemic inflammation, lowered cholesterol, reduced risk of some cancers and cardiovascular disease, and well as assisting with weight loss and weight management. [1-4]

These types of protocols could be better described as *protein-sparing modified fasting*, whereby the body is encouraged to utilise ketone bodies (the result of the breakdown of fat in order for it to be used as an energy-source), rather than protein once the blood glucose and



glycogen (the storage form of glucose) stores have been significantly reduced.

Whilst there is certainly evidence to suggest that there are a number of health benefits to be gained through the use of these dietary protocols, they may not suit everybody. Many of the studies for both IF and RTE were undertaken on animal models, and study results may not represent the impact of these protocols in humans. Additionally, these types of protocols have differences across the sexes in terms of their benefits and disadvantages.[5] So, as with all dietary modification, IF and RTE should be undertaken under the care of a nutritionist or dietitian to ensure that it is suitable for the individual and is appropriately tailored. [6]

Care should be taken in the approach of these protocols. They could change your metabolism and disrupt the efficacy of medications. They can be difficult to adhere to and may impact social interactions, especially around meals. They can also impact your ability to meet the recommended dietary intakes of vitamins and minerals, leading to nutrient deficiencies. They can lead to reduced protein consumption, which is already a challenge for polio survivors given your/their need for increased protein intake.

IF and RTE should not be perceived as a cure-all or quick fix. If your diet is already poor then fasting may not be helpful. This is especially so if you are eating energy-dense, nutrient-poor foods. Best results for IF and RTE will be seen if you eat good-quality nutrient-dense wholefoods and ditching highly-refined energy-dense foods.

Many people see IF and RTE as great weight loss tools, and they can be, although they seem to work slightly better for men than women and there is no singular diet that fits every person. [7] The underlying principle (simplified version and there may be other factors at play for some people) for weight loss, is to move into energy deficit or negative energy balance (calories in versus calories out). At the end of the day, any protocol that promises weight loss as a positive outcome is based on that principle, and this includes IF and RTE.[7]

IF And TRE (cont'd from P9)

So, are IF and RTE right for you? Perhaps – but talk to a professional so that you don't develop nutritional deficiencies, and consider the reasons that you want to follow such a protocol. If weight loss is the key reason, are there other things you can change in the meantime?

Eat well, stay well.

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NDIS Needs 'The Big Fix'

By Kymberly Martin

Source: www.freedom2live.com.au
– 17 August 2022



"The NDIS needs fixing." These opening words from NDIS Minister Bill Shorten in his address to the National Disability Summit, summed up what has been tumultuous few days for the scheme which he said has become a "bureaucratic nightmare".

"As a minister, I want to hear what the bad scenario is and prepare for the worst case, not the best case. In my experience, the best case looks after itself, it's the worst case that needs attention."

When it comes to tackling some of the hard issues he has requested the National Disability Insurance Agency fast-track NDIS plans to reduce the hospital bed block where people with disability who are NDIS eligible, can wait hundreds of days in hospital.

The housing shortage is another with Shorten calling for planners who are empowered, to make decisions on the spot. And resolving the long waiting lists in courts for participants

trying to reverse a package cut.

He also made it clear time is running out for NDIS "fraudsters" and wants government agencies, from tax, police to the NDIA, working together to identify the widespread illegal activities, with estimates of NDIS fraud said to be as high as \$6 billion.

There will be a review of the NDIS to be carried out by the Productivity Commission, that will start in the next few weeks, and people with disability will be involved at every level.

The appointment of a new NDIA CEO is imminent and there is also a search for a new NDIA chair and new directors, with Shorten declaring there will be "more people with disability in leadership positions."

In other news, Social Services Minister Amanda Rishworth will host a Disability Employment Roundtable on August 22, with a focus on three topics: Discrimination and attitudinal barriers to employment; the roles of government, employers, businesses and the community in programs to prepare and support people with disability into employment and employers to hire them; and building employment skills, experience and confidence of young people with disability.

"Hiring someone with disability should not be seen as an optional or charitable act," the minister said. ●

Cab Fleet Takes Off With New NDIS Service

By Kymberly Martin

Source: www.freedom2live.com.au

– 31 August 2022

Black & White Cabs has launched a new platform, DASH (Disability – Accessibility – Support – Hub), to help Australians with disabilities travel independently.

The platform provides services to NDIS participants including a dedicated support manager, a credit account, the ability to monitor trips, check NDIS plan spending and receive alerts when an account is reaching a low balance and nominating their preferred driver.

Participants, and their support coordinators or plan managers receive full access to the dashboard, enabling them to track participants' trips and spending, granting them access to travel patterns to ensure they are armed with knowledge when it's time to reapply for funding.

The DASH platform operates in QLD, NSW, VIC and WA.

Black & White Cabs managing director Greg Webb said DASH gives NDIS participants the tools to be independent when they travel with the fleet.

Once the limit has been reached or the agreement expires, the account is placed on hold to ensure there is no accidental spending outside the NDIS funding agreement, he said.

"The platform also provides an average trip spending amount, so if allocated funds are running low this feature will provide guidance on how many trips they have left."

For DASH user Olivia Rowsell, who averages 98 trips per month according to her DASH platform, it's the independence, flexibility and drivers that make Black & White Cabs an easy choice.

"The team were prompt and knowledgeable with all our questions at the beginning of my first plan and my mum worked closely with the NDIS coordinator and it gives me a safe way to get my destination and the independence to book and schedule trips. I have used the services across Queensland as well as interstate and the flexibility is a huge benefit".

Black & White Cabs were the first to put 'I love NDIS' stickers on the fleets. 🇦🇺



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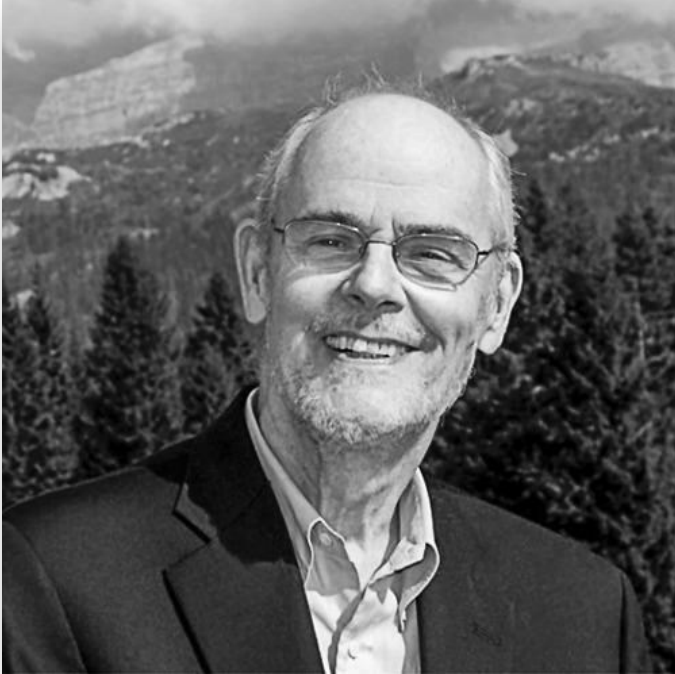
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Lauro Halstead Obituary

Source: Published by *The Washington Post* – 4 September 2022.



Dr. Lauro deBosis Storm Halstead

A Celebration of Life was recently held for Dr. Lauro deBosis Storm Halstead in Peru, Vermont. Dr. Halstead, a nationally known physician in identifying and treating post-polio syndrome, died at his home in Washington, DC on January 5, 2022. He was born in Bronxville, NY on February 27, 1936 and was the son of Gordon B. and Helen H. Halstead. He received a BA degree from Haverford College, his MD degree from the University of Rochester Medical School and an MPH from Harvard University School of Public Health.

Recovering from polio in his early 20's inspired Dr. Halstead to pursue a career in medicine, but a recurrence of symptoms and progressive disability in his 50's led to him identifying post-polio syndrome. His research, informed by his personal experience, contributed significantly to the basic understanding of this syndrome and to treatment approaches.

In conjunction with his colleague, Dr. Steven Seager, Dr. Halstead explored reproduction and function in spinal cord injury and was able to develop a technique for facilitating fertility and conception in spinal cord injured patients. Dr. Seager has estimated that 30-40,000 babies a year are born using the techniques developed by him and Dr. Halstead.

Dr. Halstead was the Director of the Spinal Cord Injury Program and the Director of the Post-Polio Clinic at the National Rehabilitation Hospital from 1986 until his retirement. He was also the

Medical Director for the Male Spinal Cord Injury Fertility Program at NRH where he was recruited from the Texas Institute of Rehabilitation. He was a Professor in the Department of Rehabilitation Medicine at Georgetown University School of Medicine, and previously was a Senior Instructor in the Department of Preventive Medicine and Community Health at the University of Rochester School of Medicine.

He received many honors and recognition for his work. Among these were the John Stanley Coulter Award and the Edward Lowman Award from the American Congress of Rehabilitation Medicine, The John W. Goldschmidt Award for Excellence in Rehabilitation from NRH and the Outstanding Alumnus Award, Haverford College.

He was the author of extensive peer reviewed publications, many articles and presentations. He wrote several books dealing with polio: [Managing Post-Polio: A Guide to Living and Aging Well With Post-Polio Syndrome](#), [Post-Polio Syndrome: Late Effects of Poliomyelitis](#), and [Research and Clinical Aspects of the Late Effects of Poliomyelitis](#). He also wrote a memoir: [An Unexpected Journey: A Physician's Life in the Shadow of Polio](#).

Dr. Halstead was a lover of all things Italian. His namesake, Lauro de Bosis, was his mother's first cousin and was a renowned Italian poet and anti-fascist during the rise of Mussolini. Dr. Halstead spoke fluent Italian and travelled to Italy as long as his health and strength permitted. He also wrote a book in Italian: *Racconti Fatti en Casa*, and, at the time of his death, was working on a book of short stories in Italian.

Dr. Halstead was also a musician. As a high school student, he played the trombone, won many awards in musical competitions and played in a swing band until his right arm was severely affected by polio. However, in his late 60's, when the swing band reformed briefly, a friend encouraged him to try playing the euphonium, which he was able to do with his limited mobility. He even played at the Kennedy Center Tuba Christmas. His weekly sessions with a brass group were a highlight of his week for many years.

Dr. Halstead is survived by his wife, Jessica Scheer; his children, Alexander Halstead, Larissa Royal and Christina Martinez; his brother, Dr. Scott Halstead; and his sister, Welthy Soni Myers; as well as former wife, Margaret (Kris) Halstead, two grandchildren and two step grandchildren and an extended family of nephews, nieces and cousins. 🌈

Ed – watch a 2008 video recording of Dr Halstead explaining PPS diagnosis here:
www.poliohealth.org.au/pps-shades-of-grey-diagnosis/

My Mother's Walk Through Life With Polio

By Andrea Kane, CNN

Source: edition.cnn.com — 20 August 2022

My mother never got to buy shoes. At least not in that obsessive, stereotypically female way we see in shows like *Sex and the City*.

She contracted polio in her native Argentina in 1941 when she was two years old, more than a decade before the polio vaccine was invented by Jonas Salk. As her body grew, so did her affected leg, but it never quite caught up. Polio left her with a foot that was smaller than the other, on a leg that was shorter than the other. Moreover, that leg did not work well; it didn't really work at all, acting instead more like a kickstand. That's because the virus damaged the motor neurons in part of her spine, leaving the related muscle fibers too weak to move the leg independently.

Not everyone who gets infected with polio experiences paralysis. Only an estimated 5% get any symptoms at all, and only 1% of that group (1 in every 200 cases) goes on to develop paralytic polio. People are affected to varying degrees. Some people who experience symptoms recover. Others don't.

There was no cure back then and there still is no cure today. The only thing that helps is prevention—with a vaccine.

Almost 93% of children in the United States are fully vaccinated against polio by the age of two, according to the US Center for Disease Control and Prevention. But there are communities where residents have been more reluctant to do so. It might be due to the success of the vaccine, which has resulted in collective amnesia about the panic polio outbreaks used to create, or because of an anti-vax sentiment.

When we think about polio today, it is often in one of two ways: with an historical eye to the time before vaccines, when terrified parents would keep kids away from public places during outbreaks, or in talking about acute cases, the number of people sick in this the moment. (Answer: Currently one — a man in Rockland county, NY — but public health experts fear that's just the tip of the iceberg as the poliovirus has been found, through wastewater testing, in Rockland County, neighboring Orange County and New York City).

But we almost never think about what it is like living with the consequences of polio, year after year, decade after decade. Polio has lasting repercussions that ripple outward over a lifetime, touching on everything that person experiences from the moment they get sick through the end of their lives. Up to 20 million people worldwide are polio survivors.



Shoes, shoes everywhere

I don't really know anything about the acute phase of my mother's illness: how sick she got or for how long she was hospitalized. I don't know anything about the course of her disease or all the things her anguished parents did to make sure she had the best outcome possible. All I know is that she got infected when she was a toddler and over the next twenty-plus years she endured many summer surgeries (so as not to miss school) and spent many months in a cast, recovering.

In addition to being smaller, her affected leg was full of scars. In photographs, she'd try to position herself to obscure it as much as possible. She also had a long scar on her good leg, from where they removed a piece of her thigh bone in an attempt to make her legs more even.

The shoes my mother had to wear were custom made to fit her uneven feet. The left shoe was smaller, and it had a lift. But it was not enough of a lift to prevent her from having a pronounced limp. This unevenness in the length of her legs eventually led to scoliosis, a curvature of her spine.

My mother had a distinct way of walking — she'd step forward placing all her body weight on her good leg then send her bad leg forward by swinging her hip, then she'd momentarily shift her weight onto the bad leg and step quickly forward again with her good leg. Her bad leg acted a bit like a wooden peg leg. This created a distinct clip-CLOP when she walked; my sister and I could hear her coming a mile away. We would, of course, make full use of that warning system to drop whatever forbidden activity we were engaged in and pretend to be doing our

My Mother's Walk Through Life *(cont'd from P13)*

homework or sleeping soundly, when we heard her in the hallway. She only ran — a skip-and-hop gallop — in real emergencies.

You'd think that some of it — the surgeries, the recoveries, the scoliosis, the fact that one leg had to do all of the work — would have been painful, but she never complained of anything, except how messy our rooms were. My sister and I never heard her dwell on her situation or her inability to participate in an activity; she never seemed frustrated. She was stoic — a trait shared by many polio survivors; she just marched forward, limp and all.

My mother ordered her shoes from Argentina, where an orthopedic shoemaker had an exact mold of her feet. She wore shoes in one of two styles: Mary Janes and T-Strap. At any given time, she might have two or three pairs in a very small variety of colors (black, brown, white or blue). When they completely wore out and fell apart, she would order one or two more. I recall they were very expensive.

She never got to wear dainty ballet flats, casual espadrilles, ugly-but-comfortable Birkenstocks, elegant riding boots — not even sneakers. Even if she had gotten regular shoes in two different sizes, it just would not have been comfortable — or maybe even possible — for her to walk. That meant she never got to own a pair of whimsical pink shoes "just because," or chunky Doc Martens that made her feel like a badass walking down the street, or sexy pumps that made her feel like a movie star.

My sister and I never got to play dress-up with her shoes; we did not dream of one day borrowing them to go out dancing or on a date. And that was ok; we never even knew it was something that little girls (and some little boys) did.

Silver lining

Although my mother avoided the worst outcomes of polio — death or needing an iron lung — I always wonder what her life would have been like if she hadn't gotten infected. Would she still have married my dad — or would there have been a more dashing, perhaps taller suitor? Would she have chosen a more exciting job than her secretarial position at the United Nations? Would she have been too busy leading the glamorous life of a jet-setter to want to bear children? Who among us ever knows what could have been?

But I could also flip that: what did polio push her to accomplish? I like to think that being "different" motivated her — gave her the impetus to settle thousands of miles away in New York City, far from Buenos Aires and what surely would have shaped up to be a more

traditional life. Would she have chosen to leave the warm and safe embrace of her family and friends if she had not felt the need to prove, if only to herself, she could make it on her own? Again, there's no way of knowing.

Still, I think it's pretty safe to say polio had a profound and lasting effect on her life choices and her personality. Like many people with a visible disability, she loathed being the center of any kind of attention (she'd probably be mortified to know that she was the subject of this article). Also, she always vehemently refused special privileges, especially if she perceived them to be out of pity. A classic example: it was only after decades of living and driving in New York City — where parking is both a blood sport and a strategic game of chess — that she even applied for a handicapped parking permit, and that was only because my father insisted.

She also had a lifelong fear of doctors, hospitals, the medical establishment. Even though she was probably too young to remember her earliest experiences with polio, the body remembers and holds on to these early terrifying, bewildering events. And despite her being a very dutiful and compliant patient, this underlying fear manifested in white-coat hypertension and a racing heart so severe that one doctor even had her wear a monitor for two weeks just to make sure there were no underlying heart issues.

But polio also made her strong. It sharpened her sense of what is right and wrong, acceptable or not. It crystallized her goals, and, once in her crosshairs, she went after them methodically and with a single-minded focus. It also made her able to endure hardships and disappointments large and small through sheer will. My sister and I never saw her feathers ruffled — she was always cool and composed.

Polio also had subtle effects on us, her family. The unspoken rule was: *protect her*. When walking along the sidewalks of the city, my father would always position himself in a way that would shield her from unintended bumps of passersby. On the rare occasions when she would take the subway, one of us would always stand behind her as she went up the stairs, one step at a time. A common admonishment from my father to us was, "*Don't wear your mother out.*" We always tried not to — but it's hard when you are young to rein in your childish wants.

Her limp meant she couldn't really run or chase us around the playground, but I don't think my sister or I ever noticed. As a family, we never did athletic or outdoorsy activities; we never went camping, hiking, bike riding or skiing. We did not even take long family walks through

My Mother's Walk Through Life *(cont'd from P14)*

Central Park. But we did other family things, like play board games and cards, and we went to the theater or traveling, when money wasn't tight.

The final insult: post-polio syndrome

While I don't think that polio cheated my mother of having a full and happy life, packed with friends, family and fulfillment, I do think it did rob her in her final years.

After working hard for decades to lead a "normal" life, polio caused her body to betray her again when she developed post-polio syndrome, a condition experienced by an estimated 40% of polio survivors. The March of Dimes, an organization founded by Franklin Delano Roosevelt after his struggle with polio, estimates up to 250,000 people in the US may have it.

Like others who get PPS, she started experiencing muscle weakness and fatigue. Her leg would suddenly collapse and she'd go down — in the apartment, on the street, wherever. While terrifying, we were lucky she never broke a bone or cracked her head, but there were many close calls and lots of ugly bruises. Eventually she started wearing a brace.

Researchers aren't sure what causes PPS, but the best guess is that after the initial infection, where patients can lose up to 70 percent of their motor nerve cells, the surviving muscle fibers attach to still-working motor nerves, allowing the patient to function. But eventually those motor nerves — which have been working twice as hard over the course of decades — get tired and wear out. People with PPS can go from being quite independent to needing a lot more assistance.

My father was right about not wanting us to wear her out. We didn't know it at the time, but her strength and mobility had an expiration date.

My mother also developed Parkinson's Disease, so in essence she had a movement disorder on top of movement issues. It made her incredibly unstable and she fell more and more frequently. Eventually she went from using a cane, to a walker, to a wheelchair.

While exercise is important for delaying the progress of Parkinson's Disease, it is pretty much a no—no for people with PPS. In fact, the motto with PPS is "conserve to preserve" — that is, conserve your energy to preserve your function. PPS requires polio survivors to avoid chronic overuse of their muscles — something their bodies had done by necessity every single day of their lives — in order to stay operational.

It turns out exercise is also good for staving off dementia, as study after study has shown. Was polio, which prevented my mother from exercising in the traditional sense of the word, a contributing factor to her dementia? Was Parkinson's? Was it an unfortunate combination of the two? Again, the answer is unknowable. (The one saving grace polio bestowed on the situation is that my mother was unable to wander off on her own — a frequent occurrence among dementia patients.)

In the last six months of her life, my mother no longer had any need for the specially made shoes that allowed her to literally and figuratively move through life. When she died, my sister and I each carefully picked out a pair to keep as a reminder. The shoes represent her strength, her accomplishments, her life. The shoes are her.

My mother died in 2019, at the age of 80. For more information on post-polio syndrome, visit [Post-Polio Health International](#). 🌟

Ed – also check Polio Australia's "Living With Polio" Fact Sheets

Was I Vaccinated Against Polio?

By Remy Tumin

Source: www.nytimes.com — 17 August 2022

Did you text Mom recently asking if you had been vaccinated against polio? So did we.

Michelle Tynan, 32, texted her mother a question last week that had never crossed her mind before: Had she received the polio vaccine?

"Yes you did!" her mother wrote back, sending a picture of her polio vaccination records and another, less pressing reminder: "Also, you got mail."

After health officials reported a case of polio in a New York suburb in July — the first detected in the United States in nearly a decade — and traces of the poliovirus circulating in New York City wastewater, some Americans felt the urge to take stock of their immunization history. If you, like Ms. Tynan — or this reporter for that matter — found yourself reaching out to parents and guardians inquiring about polio for the first time, you were not alone.

The conversation was one played out across the United States.

In Chicago, Tyler Edwards, 33, texted his mother a few times recently about his vaccine status.

Was I Vaccinated Against Polio? *(cont'd from P15)*

First it was to see if Mr. Edwards, who is gay, had received the smallpox vaccine, which has shown to provide some protection against monkeypox. (He had not.) He reached out again after the possible polio outbreaks, and she confirmed he had received that vaccine and sent him his old vaccine card as proof.

"It went through my head like, I knew I had some vaccines but didn't know for sure," said Mr. Edwards, who has also received his monkeypox vaccine. *"It was definitely a relief."*

For Ms. Tynan, the confirmation came as a relief as well amid coronavirus worries. She had recently tested positive for the coronavirus and had to quarantine in her parents' basement during a visit home two weeks ago to Olympia, Wash.

For younger generations on edge after they thought they had figured out how to fend off one virus, the threat of more — like polio and monkeypox — has caught many off guard. Polio may be seared into the memories of many older Americans as a disease with devastating consequences like paralysis and death, but a successful vaccination campaign beginning in the 1950s largely eradicated polio in the United States, and with it, the virus retreated from the public consciousness.

"Polio was once so feared here in the United States, but there's a reason we don't fear it anymore, and that's because of vaccines," said Dr. William Moss, director of the International Vaccine Access Center at Johns Hopkins University. *"This is one of the challenges of vaccines — you prevent a disease and it goes away, and people kind of forget about the disease or why it went away."*

The first polio epidemic in the United States began in Vermont in 1894, an outbreak that killed 18 people and left at least 58 paralyzed. Waves of outbreaks tore through the country over the next half-century, and peaked in 1952, when nearly 60,000 children were infected and more than 3,000 died. Many were paralyzed, including Franklin D. Roosevelt, who went on to start the National Foundation for Infantile Paralysis, later renamed March of Dimes. The organization sponsored vaccine trials and later, vaccination clinics across the country.

In 1953, Dr. Jonas Salk introduced the first polio vaccine, a multiple-shot regimen spread out over the school year. By 1955, after the vaccine was licensed, images of Americans with polio in leg braces and wheelchairs were replaced with mass vaccination sites in school gyms. Even Elvis Presley posed for a photograph while getting the vaccine in New York City in 1956.

From the 1960s to the 1990s, the United States

pivoted to an oral polio vaccine, which was more easily administered through drops. The oral vaccine contained weakened live poliovirus. It is still considered safe and effective, but in very rare instances, the weakened virus from the vaccine can revert to a form that is transmissible to other people who are not vaccinated and can cause paralysis. As a result of the rare side effect, the United States pivoted back to the highly effective shot, which does not contain live virus.

If you grew up in the United States, chances are you are vaccinated. According to the Centers for Disease Control and Prevention, all 50 states and the District of Columbia have state laws that require children entering child care or public schools to have certain vaccinations, including polio, diphtheria and tetanus. The C.D.C. now recommends a four-dose regimen for children.

Still, after three years of managing their coronavirus status and taking precautions, many young people found themselves whispering aloud their unknown status on social media.

Dr. Moss said adults who received vaccines decades ago should not be concerned that their vaccine is wearing off. The C.D.C. is considering whether or not to recommend a booster shot to high-risk individuals, Dr. Moss said, but for the time being, that applies only to people who come into regular contact with polio patients either in the United States or abroad.

"In general, people should not worry," he said. *"People who have been fully vaccinated or received at least three doses of a polio vaccine are in general going to be protected and should not worry."*

Dr. Moss's children, who are in their 20s, have not reached out to check on their vaccination status, he said. But he has heard from family members who live near the New York suburb where the polio case in an unvaccinated person was found. His message to them was simple: No extra vaccinations are necessary, but they *"shouldn't drink the wastewater."* 🌈



*Elvis Presley receiving a Salk polio vaccine shot in New York City on Oct. 28, 1956.
Credit: AP Photo/File*

Polio Outbreaks Put Scientists On Alert

Source: www.nature.com — 22 August 2022

Cases of paralysis in the United States and Israel suggest vaccine-derived poliovirus has infected many people.



The virus in widely used live oral vaccine for polio can on rare occasions mutate into a dangerous form capable of infecting the nervous system. Credit: Ezra Acayan/Getty

The discovery of poliovirus in New York state, London and Jerusalem this year has taken many by surprise — but public-health researchers fighting to eradicate the disease say it was only a matter of time.

"No country in the world is immune to the effects of polio," says Zulfiqar Bhutta, a global-health researcher at the Aga Khan University in Karachi, Pakistan. *"It's all interconnected."*

The virus found in these regions is derived from an oral polio vaccine used in some countries. So far, only two cases of polio-related paralysis have been reported, in Jerusalem in February and New York in June¹; the New York infection was the first such US case in nearly a decade. But wastewater samples in all three areas suggest that the virus is circulating more widely.

Polio causes irreversible paralysis in less than one in 200 of the susceptible people it infects, so the cases of paralysis suggest that many other people there have been infected, says Walter Orenstein, who studies infectious diseases at Emory University in Atlanta, Georgia. *"Cases like that are just the tip of the iceberg,"* he says. *"It's very concerning."*

Nature talked to researchers about the scale of the outbreak, and what can be done to stop it.

Why are these outbreaks happening?

Wild poliovirus circulates in only two countries — Afghanistan and Pakistan — where this year nine cases had been reported by June.

But vaccine-derived poliovirus appears periodically elsewhere, particularly in Africa and Asia. These cases come from a widely used oral vaccine that contains live, weakened virus that sometimes mutates to a dangerous form capable of infecting the nervous system.

Neither the United States nor the United Kingdom use that vaccine, opting instead for an injectable vaccine containing inactivated virus. This vaccine can keep the virus from infecting the nervous system, but it is not as effective as the oral virus at reducing viral shedding and halting transmission, says Raul Andino-Pavlovsky, a microbiologist at the University of California, San Francisco.

High polio vaccination rates in the United Kingdom, Israel and the United States mean that most children will be spared the virus's worst effects (about 94% of US 5- and 6-year-olds are vaccinated). But unvaccinated people are vulnerable to the illness.

"This virus is very, very good at finding unvaccinated individuals," says Orenstein. In the 1990s, a poliovirus outbreak in the Netherlands established a foothold in a community with a relatively low vaccination rate, despite the country's overall vaccination coverage of more than 90%, says Oliver Rosenbauer, a spokesperson for the Global Polio Eradication Initiative of the World Health Organization (WHO) in Geneva, Switzerland. The outbreak resulted in 2 deaths and 59 cases of paralysis, and occurred 14 years after the country's last endemic case of polio.

Has poliovirus spread beyond the regions where it was first identified?

Wastewater surveillance for polio is rare in rich countries; the United Kingdom routinely monitors sewage for the disease only in London and Glasgow. And New York began testing waste water in July, after officials learnt about the case of polio-related paralysis.

So it's unclear how far the virus might have spread. But there is reason to hope that it hasn't gone far: in London, [which has been detecting poliovirus in sewage since February](#), the virus seems to have remained concentrated in the city's north and east, and there have been no reports of polio-related paralysis. *"It appears to be fairly localized, even within London,"* says infectious-disease epidemiologist Nicholas Grassly at Imperial College London.

In New York, the virus has been detected in two counties as well as New York City, a geographical spread that is "very concerning", says Orenstein. *"It suggests we have had substantial transmission."*

Polio Outbreaks Puts Scientists On Alert *(cont'd from P17)*

The US Centers for Disease Control and Prevention (CDC) will prioritize wastewater surveillance for polio in under-vaccinated communities linked to the paralysis case. "Poliovirus testing from wastewater samples is very labour- and resource-intensive," a CDC spokesperson told *Nature*. But surveillance systems set up to monitor the coronavirus SARS-CoV-2 are working to provide support, she added.

Can the outbreaks be contained?

The United States, Israel and the United Kingdom are all boosting vaccination efforts, which should fill gaps created during the COVID-19 pandemic. This includes an ambitious effort to vaccinate all one-to-nine-year-olds in London.

This strategy should nip the outbreaks in the bud, says Grassly. But the campaigns in London and New York will use injectable vaccine, so they will not stop virus transmission.

If, in six months or so, wastewater testing suggests that poliovirus has continued to spread, it might be necessary to look at other options, he says. For example, in 2020, the WHO [listed a new oral polio vaccine](#) for emergency use.

This vaccine contains weakened poliovirus. But researchers used knowledge of the virus's genome — including how an error-prone enzyme involved in replicating the genome can generate genetic changes — to create a suite of mutations that keep the virus from regaining its ability to infect the nervous system.

"It's like putting the virus in an evolutionary cage," says Andino-Pavlovsky, who helped to design the vaccine.

That vaccine has not yet undergone large-scale human testing, and has not been approved by UK or US regulators. But more than 100 million people have received it, says Andino-Pavlovsky, with no signs of vaccine-derived poliovirus emerging.

What is the status of polio outbreaks elsewhere?

Outbreaks in wealthy countries get lots of attention, says Rosenbauer. "But over the past 20 years, we've had many, many serious outbreaks around the world in developing countries."

Rosenbauer says there are encouraging signs that the battle to eradicate polio is making progress, despite the disruption caused by COVID-19. Outbreaks in Yemen and a few countries in Africa are still active, he says, but their range is shrinking.

In places where there is armed conflict, such as areas of Afghanistan and Yemen, vaccination is difficult. "We need the political will to implement a plan to reach all the children in challenging areas," he says. Otherwise, "the disease will come back globally".

Reference

1. Link-Gelles, R. et al. *Morb. Mortal. Wkly Rep.* 71, 1065–1068 (2022). 🌐

How Polio Returned To The US



A child plays in the town of Monsey in Rockland county, which has one of the largest populations of ultra-Orthodox Jews in the country.

Photograph: Timothy A Clary/AFP/Getty Images

A Mutated Virus, Anti-Vaxxers And A Vulnerable Population

By Dana Smith

Source: www.theguardian.com
– 29 August 2022

This June, a young man from Rockland county, New York, went to the emergency room. He'd been feverish for five days and was suffering from a stiff neck, pain in his back and abdomen, and constipation. Even more concerning, for two days his legs had been abnormally weak. Doctors suspected the man had acute flaccid myelitis – muscle weakness caused by inflammation of the spinal cord, typically stemming from a viral infection. Lab tests revealed a shocking diagnosis: the culprit was the poliovirus.

Throughout the first half of the 20th century, thousands of children died or were paralyzed

How Polio Returned To The US *(cont'd from P18)*

due to polio; there were 20,000 cases of polio-induced paralysis in 1952 alone. Polio's eradication from the US in 1979 thanks to vaccines is one of the greatest achievements of modern medicine. In the 21st century, there had been just three known instances of polio in the US – all thought to be imported – affecting a total of 10 people, with only one involving community spread.

Alerted to the man's diagnosis, public health experts from the CDC, the New York health department and Rockland county sprang into action. Through wastewater testing, they discovered that the poliovirus had been circulating in Rockland county since May. They also found it in wastewater from neighboring Orange county and New York City. By mid-August, it became clear that not only was this the second case of polio from community transmission since 1979, it was probably a "silent outbreak" that had infected hundreds.

How did this happen?

Polio's return to the US resulted from the confluence of a complicated set of scientific and societal factors that allowed a mutated version of the virus to start circulating in a susceptible community. This is the story of a life-saving vaccine with an unfortunate loophole that produced that version of the virus, and a calculated anti-vaccine campaign that created a vulnerable population.

The virus

The poliovirus found in New York is not the same virus that once ripped through urban communities. Thanks to vaccination, that original, "wild" poliovirus has been eliminated from all but two countries: Pakistan and

Afghanistan. But paradoxically, most polio cases that emerge nowadays – including the one infecting the man from Rockland – are derived from the vaccine itself.

There are two types of polio vaccine, both developed during the 1950s. The oral polio vaccine, created by Albert Sabin, uses a live, weakened form of the virus to induce immunity. It is not dangerous to the person who receives it; the virus cannot pass from the patient's gut to their spinal cord, where it could cause paralysis.

But the weakened vaccine virus can acquire mutations that turn it into a live virus. As a result, for a few weeks after someone receives the vaccine, they excrete infectious, vaccine-derived poliovirus. Vaccine-derived poliovirus poses no threat to vaccinated people. But anyone unvaccinated is at risk.

Since the Covid pandemic, the pool of unvaccinated, vulnerable people has grown. The oral polio vaccine is typically used in developing countries because it is easier to administer and can be stored at room temperature. But just like everything else during the pandemic, campaigns using the oral polio vaccine were disrupted. So far this year, there have been an estimated 20 outbreaks occurring around the world, all from vaccine-derived poliovirus.

The other type of polio vaccine, developed by Jonas Salk, uses an inactivated version of the virus. While that vaccine is safer – a dead virus can't mutate and come back to life – it doesn't provide as robust protection. Because the oral vaccine travels through the gut, it offers local immunity there and prevents the vaccinated person from becoming reinfected.

Parents and children outside the Riverside public school in Elmira, New York, in July 1953, wait to get the polio vaccine. Polio's return is the result of a complicated set of scientific and societal factors.

Photograph: Paul E Thomson/AP



Cont'd P20

How Polio Returned To The US *(cont'd from P19)*

The inactivated vaccine, which is delivered via injection, stimulates an immune response that stops the virus from damaging neurons and causing symptoms but doesn't actually prevent infection.

Since 2000, the inactivated polio vaccine has been used exclusively in the US. That means the current outbreak originated somewhere the oral polio vaccine is used, and was unwittingly brought into the US by a person who didn't know they were infected. (Experts don't yet know where from.) It also means that much of the vaccine detected in the wastewater in New York is probably from vaccinated people infected with vaccine-derived virus but who don't have any symptoms and aren't at risk of paralysis.

"A virus that reverted from the vaccine emerged from a kid that was vaccinated, and because other humans that were around were not vaccinated or resistant to the virus, the virus has started to take hold in the human population," explains Raul Andino, a professor of microbiology and immunology at the University of California, San Francisco. *"This case of imported virus came into New York and took hold in the whole population because everybody's susceptible to infection ... Basically, we have a silent epidemic, and that doesn't cause a problem until somebody is not vaccinated."*

The community

Just up the Hudson River from New York City lies Rockland county, where a handful of villages and small towns are notable for two things: having one of the largest populations of ultra-Orthodox Jews in the country, and extraordinarily low vaccination rates. Those low rates – only 37% in one zip code – created precisely the kind of host community that Andino said the poliovirus could exploit.

They're also not an accident. Low vaccination rates in Orthodox communities across New York are the result of an organized campaign waged by national anti-vaccine groups for years. Vaccine hesitancy is not characteristic of Orthodox Judaism. The vast majority of rabbis and Jewish scholars interpret several passages in the Torah and other Jewish texts as being supportive of vaccines.

"This is not an Orthodox Jewish problem. In most Orthodox Jewish neighborhoods, it's 100% vaccination," says Aaron Glatt, chief of infectious diseases at Mount Sinai South Nassau and an Orthodox rabbi. *"The Jewish religion mandates you to get vaccinated, as far as I'm concerned. That's my official opinion as a rabbi. I tell my congregation, you have to get vaccinated. That's the Jewish way of protecting lives."*

Orthodox mothers in Israel who choose not to

vaccinate their children acknowledge that they are doing so against the advice of their rabbis, according to a 2021 paper published in the Journal of Religion and Health. Their motivations resemble those of other vaccine-hesitant parents, often rooted in standard anti-vaccine messaging, such as being *"more afraid of the vaccines than of the diseases"*.

"I think that there are people that may not be fully well connected to accurate information, and they are preyed upon by individuals that know exactly how to take advantage of these populations," says Glatt. *"And it's across all ethnic groups; it's across all religions."*

Indeed, anti-vaccine pockets have sprouted up across the US – some organic, others seeded by national groups – including in wealthy, liberal enclaves in Marin county, California; Portland, Oregon; and Clark county, Washington, as well as in an Amish community in Ohio and among Somali refugees in Minnesota.

Questions about vaccines started to emerge in the early 2000s with a new generation of parents who had no first-hand knowledge of vaccine-controlled diseases such as measles and polio, says Saad Omer, director of the Yale Institute for Global Health. *"In the minds of successive cohorts of parents, the salience of real or perceived side effects go up compared to the salience of actual disease,"* Omer says. *"That happened over several decades because vaccines were so successful in controlling polio in the US."*

Seizing this opportunity, national anti-vaccine groups became aggressive evangelizers, and their messaging has taken hold in communities that Omer says share several common traits, such as having strong values of purity (either secular or religious) and liberty – a combination of *"my body is a temple"* and *"you can't tell me what to do"*.

An outbreak becomes likely when these groups – which are often tight knit and insular – have frequent outside exposures, particularly through travel. For example, a measles outbreak occurred among the Ohio Amish community when two unvaccinated members contracted the virus while visiting the Philippines (reports conflict as to whether the trip was for charitable or missionary purposes).

Experts interviewed for this article weren't sure when vaccine hesitancy initially emerged in the Rockland Orthodox community. The first organized action appears to have been a phone hotline through which anti-vaccine activists *"would promote a lot of misinformation"* to parents with questions about vaccination, says Dorit Reiss, a professor at the University of California Hastings College of Law.

How Polio Returned To The US (cont'd from P20)

The movement gained traction in the mid-2010s with the publication of the Vaccine Safety Handbook, put out by an anti-vaccine group called Parents Educating and Advocating for Children's Health. Commonly known as the Peach pamphlet, the material was distributed to Jewish communities throughout New York and into Pittsburgh.

The handbook promotes standard anti-vaccine messaging, but *"everything has a Jewish flavor to it,"* says Miriam Knoll, co-founder and chief executive of the Jewish Orthodox Women's Medical Association (Jowma). *"It used a lot of Jewish wording and ideas to make things up about [vaccines]."*

No one knows who funded the effort or why, although Reiss says Barbara Loe Fisher, head of the National Vaccine Information Center (the country's oldest anti-vaccine organization), and Moishe Kahan, a member of the local Orthodox community who sells supplements, were among the names credited with writing the handbook. *"This is a collaboration between local anti-vaccine activists and the National Vaccine Information Center, and it's a very misleading pamphlet,"* says Reiss.

The consequences of the campaign became clear in 2018 when an unvaccinated child contracted the virus on a trip to Israel and triggered a measles outbreak in New York. Israel has a high national vaccination rate (upwards of 97%), but some Orthodox communities in the country have also absorbed anti-vaccine messaging. Measles and polio outbreaks – including the current one – have occurred simultaneously in both countries.

The New York measles outbreak ultimately affected 649 people, 93% of whom were Orthodox Jews. The situation attracted national attention and intensified campaigns from both sides of the issue. Rallies held in Rockland and Brooklyn in 2019 featured Andrew Wakefield, the disgraced British scientist who started the fraudulent claim that vaccines cause autism, and former Hollywood producer Del Bigtree, who directed the documentary Vaxxed: From Cover-Up To Catastrophe and is now chief executive of the anti-vaccination group Informed Consent Action Network.

In response, a group of Orthodox Jewish nurses formed Emes, which stands for Engaging in Medical Education with Sensitivity, and also means "truth" in Yiddish. They put out a rebuttal to the Peach handbook entitled *"A Slice of Pie: Parents Informed and Educated"*. A local Orthodox businessman also funded a pamphlet, printed in English and Yiddish, that quoted prominent Orthodox rabbis explaining how the



Torah supports vaccination. The state of New York stepped in too, officially removing the religious exemption to school vaccine mandates in 2019.

Thanks to these types of efforts, public health groups started *"making progress"* in counteracting anti-vaccine sentiments across the country, Omer says. But then the Covid pandemic hit.

Recent data revealed that childhood vaccination rates have declined worldwide since 2020 – the biggest backslide in 30 years. The reason is probably twofold: first, reduced access to routine pediatric appointments disrupted vaccination schedules, particularly in east Asian and Pacific nations. Second, at least in the US, growing distrust of government public health agencies and the spread of anti-vaccine talking points has taken a toll.

Knoll says that, anecdotally, physicians who serve the Orthodox Jewish community are seeing parents who *"were never anti-vax, always vaccinated their kids with all routine pediatric vaccines, but now with their younger kids, they're very hesitant to vaccinate. Why? Because of distrust sowed through the pandemic."*

However, she also says that the paralyzed young man in Rockland appears to have served as a wake-up call for many parents. A Jowma colleague of Knoll's who works in Rockland county reported that in the past week, *"half of her patients were people who came in for a polio vaccine"*.

Knoll says that when asked why they didn't come in sooner, the parents' most common response was: *"It just wasn't a priority."* But once they heard about the case, *"they got scared, so they came in."* 🟡

Polio This Week

Global Circulating Vaccine-derived Poliovirus (cVDPV) as of 30th of August 2022

Country	AFP cases (Paralysis onset between 2016-2022)								Other sources (Human) ⁴ (Collection between 2016-2022)								Other sources (Environment) (Collection between 2016-2022)							
	2016	2017	2018	2019	2020	2021	2022	Onset of most recent case	2016	2017	2018	2019	2020	2021	2022	most recent collection date	2016	2017	2018	2019	2020	2021	2022	most recent collection date
Mozambique					1		2	4-Jul-22																
Madagascar					2	13	8	30-May-22							25	6	28-Apr-22					31	63	20-Jun-22
Yemen				1	31	3		27-Mar-21				1												
Malaysia				3	1			14-Jan-20												12	9			13-Mar-20
Philippines				2				28-Oct-19				1								14				28-Nov-19
Myanmar				6				9-Aug-19				6												
Indonesia				1				27-Nov-18				2												
PNG				26				18-Oct-18			7								7					6-Nov-18
Laos	3							11-Jan-16	5															
Total type 1	3	0	27	12	35	16	10		5	0	7	10	0	25	6		0	0	7	26	9	31	63	
Ghana				18	12		1	4-Jun-22				16	10			1	31-May-22			17	20		14	2-Aug-22
Benin				8	3	3	4	5-Jul-22						2	1		1-Jun-22				5	1	4	12-Jul-22
Niger				10	1	10	18	10	3-Jul-22			4	6	2	1		13-Aug-21				9		5	27-Jun-22
Nigeria	1			34	18	8	415	33	9-Jun-22	2 ²		53	18	8	204	24	25-Jun-22	1		44	64	5	303	55
Chad				11	101		18	22-Jun-22				6	17		2		3-Mar-22				10	3	1	10-Nov-21
Algeria							1	11-Apr-22							1		16-Jun-22						3	21-Jun-22
DR Congo		22	20	88	81	28	75	14-Jun-22		19	15	29	95	6	10		16-Jun-22				1	3	2	7-Jun-22
Yemen						66	110	3-Jun-22						15	29		21-May-22					13	3	31-Jan-22
Central African Republic				21	4			29-Oct-20				43	1				5-Oct-20			9	2	1	3	29-May-22
Djibouti																						7	10	22-May-22
Somalia			6 ⁵	3	14	1	3	14-May-22				2	13		1		22-Feb-22		2	19	5	26	1	3
Egypt																						1	12	3
Mozambique				1			2	4	26-Mar-22			2					17-Dec-18							
Togo				8	9		1	21-Jan-22				1	9				9-Jul-20						1	22-Mar-22
Eritrea						1	1	2-Mar-22																
Côte d'Ivoire					64			18-Oct-20					25				1-Nov-20			7	95		2	9-Feb-22
Burkina Faso				1	68	2		9-Jun-21					12				19-Sep-20					1		28-Dec-21
Ukraine						2		24-Dec-21						18			9-Oct-21							
Mauritania														4			19-Jul-21					7		15-Dec-21
Senegal						17		27-Oct-21						34			17-Nov-21				1	14		18-Nov-21
Uganda																						2		2-Nov-21
Cameroon					7	3		11-Oct-21					4	3			29-Oct-21			4	9	1		25-Oct-21
Ethiopia				14	36	10		16-Sep-21				9	7				13-Oct-20			3	4			28-Dec-20
Gambia																						9		9-Sep-21
Pakistan	1			22	135	8		23-Apr-21				14	2				11-Nov-20	4		40	135	35		13-Aug-21
Guinea					44	6		1-Apr-21					1				5-Sep-20				1	2		11-Aug-21
Guinea-Bissau						3		15-Jul-21						1			26-Jul-21							3-Aug-21
Tajikistan					1	35		25-Jul-21						22			24-May-21					17		22-Mar-21
Afghanistan					308	43		9-Jul-21				36	2				3-May-21				175	40		23-Jun-21
Sierra Leone					10	5		28-Feb-21				6	8				19-Mar-21					9		1-Jun-21
Congo					2	2		10-Feb-21					2				12-Oct-20				1	3		1-Jun-21
Liberia						3		28-May-21					2	5			21-Jan-21				7	14		20-Apr-21
South Sudan					50	9		10-Apr-21				19	5				25-Feb-21				6			1-Dec-20
Iran																					3	1		20-Feb-21
Kenya													1	2			25-Jan-21			1		1	1	13-Jan-21
Mali					52			23-Dec-20					3				15-Aug-20					4		29-Aug-20
Sudan					58			18-Dec-20					11				1-Oct-20							9-Nov-20
Angola				138	3			9-Feb-20				22					31-Oct-19				17			2-Dec-19
Malaysia																				3	5			4-Feb-20
Philippines				12	1			15-Jan-20				6					23-Nov-19				19	4		16-Jan-20
Zambia				2				25-Nov-19				2					25-Sep-19							
China				1				25-Apr-19				3					18-Aug-19			1				18-Apr-18
Syria		74						21-Sep-17	1 ¹	66							12-Sep-17							
Total type 2	2	96	71	366	1081	682	261		3	85	74	177	286	332	69		5	2	65	198	537	498	108	
Israel							1								3		24-Mar-22				1	5	25	15-Mar-22
Occupied Palestinian Terr.																					7	9		12-Mar-22
China													1				22-Jul-20					1		25-Jan-21
Somalia				7 ⁵				7-Sep-18			2						29-Jun-18			11				23-Aug-18
Total type 3	0	0	7	0	0	0	1		0	0	2	0	1	0	3		0	0	11	0	1	13	34	
Female (all sero type)	3	54	34	151	493	396	110																	
Male (all sero type)	2	42	70	215	610	292	161																	
Gender Unknown				13	10	3	1																	

If a population is seriously under-immunized, there are enough susceptible children for the excreted vaccine-derived polioviruses to begin circulating in the community. If the vaccine-virus is able to circulate for a prolonged period of time uninterrupted, it can mutate and, over the course of 12-18 months, reacquire neurovirulence. These viruses are called circulating vaccine-derived polioviruses (cVDPV). ●