



Polio Oz News

September 2018—Spring Edition

Paris Rehabilitation Congress

**By Paul Cavendish,
Clinical Health Educator**

The International Society of Physical and Medical Rehabilitation held a Congress in Paris during early July.

There were a range of topic areas covering all areas of rehabilitation and an array of products that sparked plenty of interest among attendees. Of particular note, and my reason for attending, was a focus session on polio specifically featured in the program. You can read about each presentation from this session [here](#).

It was really positive to hear the chairs introduce this session, calling for greater medical support and services for people with a history of polio despite the number of poliomyelitis cases have, thankfully, diminished. This message was well received from the large number of attendees interested in hearing more research on the Late Effects of Polio.

A particular highlight of this program was the inclusion of research conducted in Australia by Polio Services Victoria, a service of St Vincent's Hospital Melbourne. The presentation was delivered by one of the key researchers and Physiotherapist from St Vincent's, Claire Formby, discussing physical activity patterns of younger polio survivors. This again highlighted the need for accurate statistics on the number of people across Australia who have a history of polio. Without this, there will



continue to be difficulty in adequately planning and providing services to meet the challenges of a complex condition, especially as a polio history interrelates with ageing and other health conditions.

Professor Kristian Borg (Karolinska Institute, Sweden) presented an overview of Post-Polio Syndrome (PPS), why he is so interested in the condition, and treatment options for inflammation within the body of those with a history of polio. There remains hope with this work but still a number of significant hurdles to overcome before there is a specific product on the market to deal with the symptoms of fatigue that polio survivors experience.

It was great to see a number of young French Rehabilitation Specialists who undertook PPS as a focus with their work, and continue to investigate improving symptom

management. In fact, I was pleasantly surprised to hear how the French Post-Polio organisation—who had been given a booth free of charge by the organising committee in order to meet more medical and health professionals — spoke so appreciatively for their medical professionals.

There was plenty of interest in technology throughout the Congress. This is an area moving so fast and the potential for enabling greater support to people with a range of physical limitations is quite impressive.

A consistent theme from this Congress was on the potential of brain stimulation to improve, or regenerate, movement patterns in conditions. A presentation from Japan investigated this in regards to Post-Polio Syndrome.

(cont'd P5)

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throughout Australia

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“**Spring is a season of the
soul to regain its strength.**”

~ Lailah Gifty Akita ~

President's Report

Gillian Thomas

I don't know about you but I'm always pleased when winter's chill becomes less severe and the sun gets strong enough to start warming my bones. The older I'm getting, the longer the winters seem to be! I confess to being quite jealous of Maryann as she jets off to warmer climes for a well-deserved holiday.

Apart from being President of Polio Australia, I am also the Business Manager (volunteer), and I am delighted to advise that our Financial Report reveals we are in the strongest financial position we've been in since we were incorporated in 2008. Of course, this is all thanks to a three year Federal government grant which pays for the Clinical Health Workshops Program; a two year sponsorship donation from Spinal Life Australia; and another incredibly generous personal donation from Jill Pickering, which pays for our Community Development Worker, Steph Cantrill. We also received an unexpected but very welcome donation from St George Association for People with Physical Disabilities for \$10,000, being the balance at the cessation of their operations. With the increased funding enabling the Polio Australia team to be greatly expanded, our programs in support of polio survivors across Australia have likewise been greatly extended.

Now that we have seven staff members, Polio Australia has recently had a review of its governance functions and has established two Board Sub-Committees for:

1. Governance and Risk Management; and
 2. Finance.
- These Sub-Committees have

prepared three new Policies covering these areas, and will now be working on related Procedures.

We have also recruited a new Independent Board Member, Noel Will, who, prior to retirement, was a teacher for 16 years, and in the financial services industry for 22 years, primarily as a financial planner.

Other changes to the Board structure have seen Brett Howard move from Treasurer to the position of Vice President, which has been vacant since the 2017 AGM. Alan Cameron has become the new Treasurer, a role he also fulfills for Polio NSW. We believe these changes will assist Polio Australia in strengthening its Governance role and ensuring the charity continues to comply with relevant legislation. You can read more about all the Board Members [here](#).

This year, our Annual General Meeting will be combined with both our *Walk With Me* event, and the Health and Wellness Retreat being held in Glenelg, South Australia in October. As our Board members come together from across Australia, we have decided that it is both more economical and less tiring for those living with the Late Effects of Polio! This combination of meetings also gives everyone the opportunity to participate in two of Polio Australia's key activities, and enables the State Polio Networks to generate funding themselves, with 50% of all *Walk With Me* donations going to the states. Have a look at the participating 'Teams' [here](#). We encourage you to support both Polio Australia and your State Network by donating to your local team.

As the above shows, and as reported elsewhere in this issue, what a difference 10 years of effort and a growing funding base can make. ●

Gillian

From the Editor



Maryann Liethof
Editor

Hooray! Spring has just about sprung, and I'm just about to go on holiday for the month of September!! It's the first time I'm leaving the office in the very capable hands of my amazing 'Team'. I feel supremely confident that Polio Australia's programs will happily chug along whilst I'm having my break. It's a fantastic feeling, I can assure you.

So completing this edition of *Polio Oz News* is my final task before I pack up my desk. I will certainly have to be alert when I return in October, because we have a lot scheduled for Polio Awareness Month, including the Polio Health and Wellness Retreat. The reason there is no further promotion of the Retreat in this edition is because all the places have now been filled! If you would still like to read more about the Retreat, click [here](#).

Paul Cavendish, our Clinical Health Educator, has also been travelling recently, although he assures me that his trip to Paris was *purely* to find out what's being done in the area of post-polio and rehabilitation and share it with you. Apparently, he didn't even take time to sip wine on the banks of the Seine! He really does take

his work very seriously . . .

We are currently seeking feedback on 'orthotics use', and also requesting people's experience of any difficulty you may have had accessing assistive technology such as mobility aids, orthotics, and home modifications through MyAgedCare. On page 4, you will find more information on how to contribute your stories which we can then share with health professionals, and provide 'case studies' to the government. Please help if you can.

Another program area Polio Australia is starting to develop further is reaching out to "The Next Generation" of polio survivors. We have been Skype-meeting with a small focus group of polio survivors born from 1975 onwards, who have given us some excellent advice on the type of information they are seeking at this stage of their lives, and how they would like to receive it. Read more on Page 7.

Other offerings include *The Saga Of Billy The Kid (ney)* by Dr John Tierney on Page 8, and information on My Health Record on Page 11, where you will also see the rather disturbing news of a polio outbreak in nearby PNG. This is topped off by a couple of fascinating articles from the USA on Mona Randolph, one of their last iron lung users, and FDR.

Take your time and smell those roses! 🌹

Maryann

Polio Australia Celebrates 10 Years!



"So much information to re-read, and new treatment techniques and strategies to implement in my clinical work. The biggest thing I got from the session was that polio survivors are strong, determined, capable people, and are not to be underestimated!"

"Thank you so much for this informative presentation. It was greatly appreciated. To hear that my symptoms are 'normal', and that I'm not alone, was wonderful."

August 2018 marked Polio Australia's 10 year anniversary. To celebrate this achievement, we asked "How has Polio Australia helped you in your experience with post-polio?" You can read some responses above. Take a look at our 10 year timeline featuring highlights of our achievements over a memorable ten year period [here](#). 🌟

Orthotics Use and Satisfaction Survey

Polio Australia is seeking feedback of polio survivors on orthotic devices and your satisfaction levels with these to provide this information to health professionals who work with orthotic prescription. This includes presenting this information to those who make customised footwear at their annual conference later this year.

Your contribution to this survey will help us continue to reach our vision that all polio survivors in Australia have access to appropriate health care and the support required to maintain independence and make informed lifestyle choices.

Please find link to orthotics questionnaire [here](#).



Survey - Orthotics Use and Satisfaction

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[Click to view survey](#)

Assistive Technology For Older People—Case Studies

As a member of the Assistive Technology for Older People (ATOP) Alliance, Polio Australia is seeking real-life stories from people over the age of 65 who are experiencing challenges with funding for assistive technology (home modifications, adaptive equipment, orthotics, etc).

The ATOP Alliance recognises that ageing with a disability is different from ageing in the general population, and that those with disability, such as those living with Late Effects of Polio or Post-Polio Syndrome, often have greater and more specific needs. We therefore need stories like yours to strengthen our voice and let the government know that you need more than what's currently on offer!

Particularly, we are wanting to hear from people who are linked in with MyAgedCare and finding that you still need to self-fund equipment. You may, for example, have an aged care package, but find that the allocated funding is only just enough to cover the services you need and doesn't allow any additional funding for equipment.

If you're able to help, please get in touch with Steph Cantrill, Polio Community Officer, on 0466 719 613 or steph@polioaustralia.org.au. Ideally, we'd love to be able to use your name and include a photo. If that's beyond what you're willing to offer, even anonymous stories would be helpful – the more stories we have, the stronger the voice! 🌈



Paris Rehabilitation Congress (cont'd from P1)



The case study he presented of improved hand function after trans-cranial direct stimulation was amazing. It will be interesting to see if these improvements from this technology will continue given the issues of long-term loss of motor neurons and the demand placed on the existing/fatigued giant motor neurons in the spinal cord. We are, however, still learning of the potential our bodies have and, without trying, we can never be certain of anything.

A huge array of rehabilitation devices and equipment was available with the adjoining trade display. A novel product with great potential was foot orthotic assessment. With a simple insole, professionals are able to gather a picture of how a polio survivors walk in their own environment

(accounting for the stairs, slopes, activities) rather than a quick clinical assessment. They claim their pressure mapping information that is obtained from this insole is accurate and can lead to better prescription. A concern for both parties with orthotic assessment is *"did they get the right information?"* Providing an Orthotist with feedback on how someone puts pressure through their foot at home with and without various devices has great potential to get the prescription right.

The area of robotics is also fascinating and offers plenty for rehabilitation and home assistance. Although much of this potential has yet to result in a commercial product at an accessible price point, the funding and concepts that are emerging in this field is nothing short of amazing. From robots that can perform food preparation and other household tasks with intuitive features to recall recipes or scan and reach for items, e.g. *"where did I put those keys/phone/wallet"*, was incredible. There were a number of studies also looking at how to address social isolation, often with a combined approach of features that act similar to Skype but enable a 'home tour' for family and health professionals, along with simple platforms to enable photo slides of past experiences, family, as well as playing favourite music all from a single device. These concepts can mean a paradigm shift for most of us, but it was interesting the researchers were well aware of the need to make sure their developments really assisted people and not create an environment where a product replaces human interaction, a vital element for everyone's health and wellbeing. 🌈

Upcoming Clinical Practice Workshops

UPCOMING CLINICAL PRACTICE WORKSHOPS

BRISBANE	13TH SEPTEMBER 18
BUNDABERG	15TH SEPTEMBER 18
LITHGOW	24TH SEPTEMBER 18
ORANGE	25TH SEPTEMBER 18
BROKEN HILL	28TH SEPTEMBER 18
PORT PIRIE	2ND OCTOBER 18
ADELAIDE	4TH OCTOBER 18

CLICK HERE TO VIEW MORE DETAILS & TO REGISTER



Quality Education

Workshops offered by Polio Australia are developed and driven by best-practice research emerging from Europe and the USA. Paul Cavendish, Accredited Exercise Physiologist with a neurological background, delivers the workshop with vital contributions from 'lived experience expert' polio survivors.

Who Should Attend?

Allied and other health practitioners such as: physiotherapists, occupational therapists, orthotists, exercise physiologists, nurses, podiatrists, speech pathologists, dietitians, social workers, case managers, and anyone else who is interested in knowing more about the post-polio body. 🌈

Supporting Polio Australia

Polio Australia would like to thank the following individuals and organisations for their generous support from 1 May to 31 July 2018. Without you, we could not pay our rent, core operating expenses, or management staff!

Hall of Fame

St George Association for People with Physical Disabilities—\$10,000
 Anonymous—\$10,000
 Jenny Jones—\$2,000
 Michael and Rachel Evans—\$1,000
 Margery Kennett—\$1,000

Total—\$24,000

General and Regular Donations

Anonymous	Elizabeth Brooker	Jill Burn	Scott Cantrill	Walter Liddelow
Wilf MacBeth	Dorothy Robinson	Liz Telford	Gillian Thomas	
Joyce Thompson	Helen Tracey			

Total—\$1,795

Rotary Club Donations

Rotary Club of Mackay (Qld)—\$2,000
 Rotary Club of Geelong Central (Vic)—\$1,000
 Rotary Club of Albany Creek (Qld)—\$500
 Rotary Club of Kerang (Vic)—\$300
 Rotary Club of Geelong East (Vic)—\$250
 Rotary Club of Ivanhoe (Vic)—\$250
 Herman Vorster (Qld)—\$200
 Karin Kolenko (Qld)—\$100



Total—\$4,600

Grand Total—30,395

Walk With Me

Glenelg, South Australia

11th October 2018

Polio Australia's annual fundraising event

[Click here for details](#)

Polio Australia's annual "Walk With Me" event aims to raise awareness about the Late Effects of Polio.

Funds raised allow us to continue to support polio survivors and provide education to health professionals.



WHEN:
ASSEMBLE:
WALK:

DONATIONS:

Thursday, 11th October 2018
 3:00pm Between Moseley Square and Glenelg Pier
 3.30pm – A relaxed 1km walk or wheel in the sunshine, along the beautiful Glenelg beach esplanade
 Whether or not you are 'walking' on the day, please [donate](#) to 'Team Polio Australia' or support your own State Polio Network

Donations for this event will be accepted until 31 December 2018.

The Next Generation

Polio Australia commenced 10 years ago to provide a national focus, and represents the state-based Polio Networks which were all established in Australia in the late 1980's. As such, most of the information on the Late Effects of Polio (LEoP) has been developed with older Australian or European polio survivors in mind.

However, Australia has also become home to younger, migrant polio survivors. We have found that younger polio survivors are currently not connecting with either Polio Australia or the state Polio Networks, so are not accessing our information on the LEoP, and how best to manage the condition into the future.

Polio Australia is committed to supporting younger polio survivors, and we are eager to build a community of 'Next Generation' Polio Survivors. Throughout August, we conducted a focus group, inviting polio survivors born in 1975 onwards to contribute. We discussed the issues that they are currently facing, and what Polio Australia can do to help this demographic.

Some of the main themes were:

- National Disability Insurance Scheme (NDIS)
- What precautionary measures should younger polio survivors be taking to avoid a worsening condition;
- What support and resources are available for polio survivors;
- Desire to connect with other polio survivors around the same age;
- All survivors expressed that they were simply "busy with everyday life stuff", and this wasn't a major "focus";
- They want to access clear, succinct information – a forum would be useful;
- Tips on building self-esteem; and
- Maintaining independence.

Meet Vilas

Born in India in 1982, Vilas contracted polio at the age of 2. He first came to Australia in 2013, and is now a permanent resident living in NSW with his wife and infant son. Vilas works at an educational institution and enjoys water sports swimming.



You can read more about our Next Generation Focus Group [here](#).

Moving forward, Polio Australia will be producing a series of updated resources which more effectively target the Next Generation, and allow them easier access to the information they desire.

To help us create some fresh design ideas, as well as explore information delivery options, Polio Australia has established a partnership with Swinburne University in two project areas:

- Professional Intern (Charlotte), will be developing video content featuring Next Generation polio survivors; and
- 'The Bureau', a group of graphic design students, are working on developing some fact sheet designs.

More details on the progress of these exciting projects will be provided in the Summer edition of *Polio Oz News*! 🌟

Polio Awareness Month—October

October is Polio Awareness Month!

In 2018, Polio Australia will work with the theme: ***The life stages of post-polio.***

As we have identified with our *Next Generation* polio survivors, there are a range of post-polio issues that affect people across all stages of their lives.

We will be focusing on how Polio Australia's programs can support people in their 20's, right through to their 90's—and beyond!

If you'd like to tell your story, contact Rachel on rachel@polioaustralia.org.au.

To check for information updates, please go to: www.polioaustralia.org.au/polio-awareness-month/

Other things happening in October:

2018 Polio Health and Wellness Retreat
in Glenelg, South Australia
on Thursday 11 to Sunday 14 October
[Now Full!](#)

Walk With Me Annual Fundraising Event
also in Glenelg, South Australia
on Thursday 11 October
[Donate Now!](#)

Polio Network Victoria's Polio Day
"We're still here!"
at the Hawthorn Arts Centre, Victoria
on Saturday 20 October
www.polioday2018.eventbrite.com.au
Ph: 1300 704 456

The Saga Of Billy The Kid(ney)

By Dr John Tierney

From time to time, I would muse about how I might depart this life. In the miracle world of modern medicines and operations with highly sophisticated technologies, the life exit options are rapidly narrowing. Once at a Sydney Art Gallery lecture on the enlightenment period, the lecturer cast his gaze across his flock of 300 greying heads in the audience and told us, "if this was the 18th century, most of us would not be here, we would be residing in the local cemetery."

For many of our forebears, in their short and often brutal life, making it past 60 was quite an achievement. Widespread old age is a very modern phenomenon. As to the manner of their departure from this life, our ancestors were spoilt for choice. There were so many dangers that could snuff out human existence, particularly for the young.

Now, in 21st century Australia, death is most likely to come to us via a much narrower range of options including heart failure, stroke, cancer, accident, or dementia. A good guide to our likely final fate usually lies in our family history. The men in my family are heart people. As my very fit and healthy dear father was approaching his seventieth birthday, he suddenly died from a massive heart attack, which came without any warning.

Just after I reached my seventieth birthday, as if on cue, I received a warning. As I chatted to a colleague in a coffee shop, suddenly it seemed as though I was talking from another room with a glass panel between us. I found out later that the cause of this strange sensation was likely to have been a lack of oxygen getting through to my brain, brought on by Arterial Fibrillation (AF) of the heart.

The effect of AF is that the four chambers of the heart beat very inefficiently and in an uncoordinated way. In my case, the bottom two chambers were playing Mozart and the top two, heavy metal. When my pulse rate was checked, instead of a steady 75, mine was beating at a rate of 70, then 92, then 38, then 84, etc.

Untreated, the likely outcomes of AF are either a stroke, a coronary or death. My heart came back to a regular beat of 75 after a massive electric shock was administered to it. That was three years ago and my pulse rate has stayed around 75 ever since. But just like my father and the men in the family before him, it seemed that I was on the death by heart failure track.

So, imagine my great surprise when I suddenly switched to a completely different and unexpected life-ending track. Early in 2018, I had my regular bi-annual *Late Effects of Polio*



MRI scan of the lumbar region of my spine. The radiologist carefully examined the MRI of my increasingly misshapen spine and ongoing degeneration, all caused by contracting polio at birth 72 years earlier because the delivering GP didn't wash his hands properly.

One MRI lumbar spinal scan clearly show my kidneys, which looked like two fried eggs [pictured above]. "That left kidney is a funny shape", he said. "What shape should it be?", I enquired. Deadpan, the radiologist replied, "kidney shaped". Within a week, my wife Pam and I sat in the urologist's office where, on the wall, a new CAT scan showed that my left kidney had developed a large 'complex cyst'. Peering at the image, the crusty old Scottish urologist said, "Humph!" No further diagnosis was needed because I knew exactly what he meant. As I suspected, it was a cancerous tumour. "Well, that left kidney will have to come out pronto", we were told.

In my fifty years of marriage to Pam, during which time we raised six children, life threw quite a lot at us. Whenever we were ever confronted by really bad news, we would go out to a restaurant for a nice dinner. It was our "Up yours!" to the world and 'the slings and arrows of outrageous misfortune'.

At our celebratory dinner the night following our visit to the urologist, Pam decided to cheer me up with a new nickname. My middle name is William, so the moniker that she came up with was 'Billy the Kid(ney)'. Singular, because I would only have one in the future. I have always been a 'glass half full' kind of a guy, and there actually was something to celebrate. The CAT scan was of the whole body trunk and it revealed that the cancer had not metastasized (spread) to any other body organ.

(cont'd P9)

The Saga Of Billy The Kid(ney) *(cont'd from P8)*

I am 72, and if the cancer had stayed undetected, I probably wouldn't have seen my 75th birthday.

Over dinner, I said to Pam, *"I think that I have dodged another bullet"*. *"What do you mean?"* she asked. *"Well, polio tried to take me out at birth; more recently, heart AF; and now kidney cancer. What else could possibly do me in?"* I mused. She replied sweetly, *"Me"*.

The operation was scheduled for five days later. I was on a very necessary fast track to head off the cancer escaping from the kidney, which could occur at any moment. But a series of unrelated events took place, which put in danger the good fortune of the early accidental discovery. It could have even restored the original trajectory of death from cancer. Had my destiny been always written in the stars? Was my number up and death back on track to happen in my early seventies?

A frustrating string of time delays occurred, set in train from unrelated sources. Finally, as the new delayed date approached, and now in the dead of winter, for the first time in my life I developed severe bronchitis. One night at 4:00 am I thought that I saw blood in my urine, but I wasn't sure. Had the kidney cancer metastasized already? The surgical team picked up on the growing sense of urgency and there was no further delay, even though my lungs had not fully recovered from bronchitis. Continuous breathing can be helpful during a four hour operation.

Pam kept a lonely hospital vigil for the entire day of the operation, but when I came to, I was so out of it on morphine, I really can't remember any of our conversation, or even that she had been there. I didn't even care, when I became conscious, that the nurse was changing over my penile catheter. In the disorientation and pain caused by major surgery, concerns about modesty and dignity just seem to disappear.

The comfort and affection of a large family really comes into its own during such times. Our six adult children have an ongoing light hearted competition as to which one of them is 'pet'. My eldest son, James, was the clear winner on this occasion, when he offered to donate one of his kidneys to me. I thanked him but declined his kind offer. It was lucky that I already had a spare one.

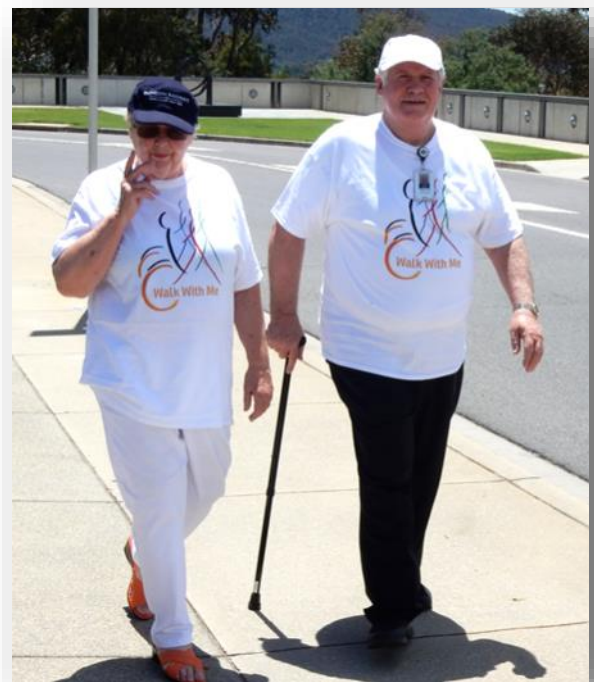
A week following the operation, I received a phone call from the medical research people. A biopsy of 'Billy the Kidney's' cancer cells revealed that they were dividing and multiplying very rapidly and in an unusual way. Fifteen medical research people wanted permission to research this and it was provided. As with Henrietta Lacks HeLa cell line (1951 USA), which was

instrumental in the development of Salk's polio vaccine, 'Billy the Kidney' had been removed in the nick of time, but now had a big chance to make something of himself, and possibly leave a mark on the world of medical research.

A week in a hospital bed gives you a lot of time to reflect. What if I hadn't made it through the operation and that was the end for me? Given the heart complications there was probably about a 30 per cent chance that it would have suddenly been all over for me, as it was for my father, exactly 40 years earlier. But I have been given another chance at life, so what should I do differently?

It is said that on their death bed, no one ever regrets not spending more time at the office. So now fully retired, with a large family, the way forward seemed clear to me. But what else? In the end days, life can be full of regret for many people. *"Regrets, I've had a few . . ."* crooned old blue eyes. In hospital, I reflected on what should I try to do to make some things right in my remaining time. That guide to living, *The Lord's Prayer*, provides some hints. In only 62 words, 12 words in that iconic prayer are devoted to one thing, forgiveness.

How easily it rolls off the tongue, *"forgive us our sins as we forgive those who sin against us"*. The last part is the kicker! Easy to say but so hard to do. In our shared half a century of life, Pam would sometimes say to me, *"When are you ever going to forgive 'X'?"* I would reply, *"About ten years after hell freezes over!"* I now believe that, if ignored, we internalise hatred and it then literally eats at us, possibly triggering cancer. Now for the hard part, forgiving that bastard of a doctor who gave me polio! 🌈



Dr John and Pam Tierney at the 2017 Walk With Me event

Universal Design 2018



Now in its third year, the Australian Universal Design Conference will take place at the Brisbane Convention and Exhibition Centre on Tuesday 4 September and Wednesday 5 September.


Under the theme of 'Home and Away', the two-day conference features **THREE** keynote speakers covering the economics of inclusion, future of transportation, and a UK perspective on inclusive tourism.

Universal design is a process of thinking and designing inclusively, whether it is a house, website, product, service, or a learning program. Universal design is itself explained in a diversity of ways across the world: 'design-for-all' and 'inclusive design' are other terms used. Designing universally means being inclusive of a diverse population.

Universal design is an international movement recognised by the World Health Organisation, and the United Nations through the Convention on the Rights of Persons with Disability. They both cite universal design as a way to create greater social and economic inclusion for everyone. Australian state and federal policy documents also recognise universal design as the way forward in the National Disability Strategy. With the roll-out of the National Disability Insurance Scheme and policy changes planned for older people, everyone needs to be ready to embrace the principles of universal design in their daily work.


Why Attend


- Increase your knowledge in this expanding area of expertise
- Help shape the future of universal design in Australia
- Reflect on your own practice and research and learn from others
- Make valuable connections
- Discover the progress being made in Australia and overseas



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Polio Outbreak In Papua New Guinea

PNG provinces getting second round of polio vaccine

Source: www.radionz.co.nz—20 August 2018

Morobe, Madang and Eastern Highlands provinces of Papua New Guinea are receiving a second round of the polio vaccination campaign from today through to September 2.

This comes after four recent cases of polio and dozens of suspected cases.

The PNG secretary of health, Pascoe Kase, said parents were being reminded to bring children under five years of age to the vaccination point.

It was important to get the vaccine in every round of the campaign to ensure full protection, he said.

From next week Enga, Chimbu, Southern Highlands, Western Highlands, Jiwaka and Hela will have their first round of vaccinations.

The campaign in the nine provinces aims to reach over 700,000 children under five.

A nationwide polio vaccination campaign is

planned for September and October targeting over one million children under the same age.

The World Health Organisation's representative in PNG, Luo Dapeng, said polio was a very dangerous disease with no cure and that vaccines were the only weapon to protect children in PNG.

The polio vaccine was safe, effective and free, he said.🌐



The WHO's Regional Director for the Pacific, Dr Shin Young-soo provides oral polio vaccine in Lae in Morobe

My Health Record

My Health Record changes positive step for consumers

Source: Consumers Health Forum (CHF) [Media Release](#) – 1 August 2018

The Consumers Health Forum welcomes the Government's announcement that it will amend the My Health Record Act to strengthen safeguards to protect security and certainty of personal medical records.

"The announcement last night by Health Minister Greg Hunt of legislative changes states that no MHR record can be released to police or government agencies, for any purpose, without a court order," the CEO of the Consumers Health Forum, Leanne Wells, said.

"The Minister has also said that the legislation would be amended to ensure that if any Australian wished to cancel their record, they could do so permanently, with their record deleted from the system."

"The legislative tightening on access to MHR files would "remove any ambiguity on this matter", Mr Hunt says.

"Although the Digital Health Agency's policy is clear and categorical that no documents have been released in more than six years and no documents will be released without a court order,

enshrining this provision in legislation adds clarity and certainty to MHR safeguards.

"MHR will only succeed in reaching critical mass in terms of its reach and effectiveness if Australians – both consumers and clinicians – can trust that patient information is secure and is seen only by those authorised to see it.

"These changes are important. The MHR system is in place and the more it is used the more it should evolve and improve over time based on consumer and clinician experience with it.

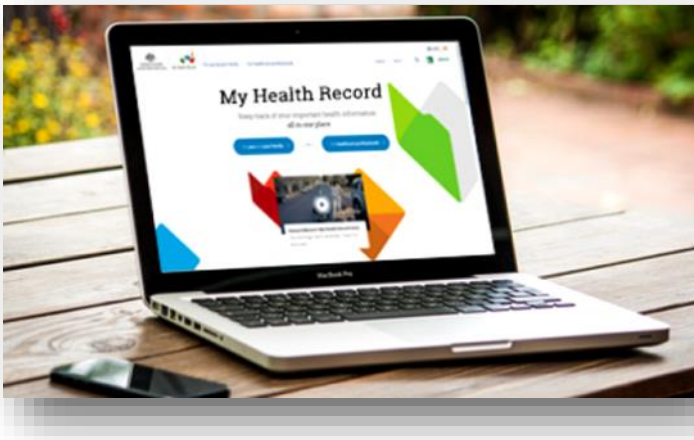
"The power of MHR to reduce safety risks and clinical harms that arise from doctors not having the right information at their fingertips is a major advance and must be kept in mind in balancing the actual benefits versus the possible risk of a potential privacy breach.

"We welcome the Government's commitment to an extended education campaign and the prospect of more time for consumers to consider whether to opt out, a move which the minister has flagged he will be discussing with other Health Ministers today.

"The Government is proposing more support for doctors to participate in MHR as there is a need for much more active involvement by the medical profession if they and their patients are to gain full benefit.

(cont'd P12)

My Health Record *(cont'd from P11)*



"Likewise, the first fortnight of the opt-out period has indicated there needs to be a more comprehensive and active information and education effort for consumers."

"We have previously proposed that the Government distribute explanatory letters to all households providing factual details about MHR."

"The latest changes make such a public information initiative even more worthwhile."

"The Consumers Health Forum next week launches a series of webinars on MHR for the benefit of health consumers because we believe a well-informed public is a key to the success of MHR," Ms Wells said.

Register here: <https://chf.org.au/register-follow-my-health-record-webinar-series> 🌐

Health Insurance

Health insurance needs in-depth scrutiny in the public interest

Source: Consumer Health Forum (CHF)
[Media Release](#) – 7 August 2018

Discounts on health insurance premiums for young people under 30 would erode the community-sharing principles of private cover, further entrenching a two-tiered system, the Consumers Health Forum said today.

In its submission to the Senate Community Affairs Community inquiry into health insurance legislation, the Consumers Health Forum said a Government proposal to allow health funds to introduce age-based discounts would undermine community rating, a fundamental principle of health insurance aimed at ensuring equal premiums regardless of age or health status.

"Such changes to health insurance rules seem designed largely in the health funds' interests to shore up declining member numbers but go nowhere far enough to respond to the frustration and concerns many consumers have about their health cover," the CEO of the Consumers Health Forum, Leanne Wells, said.

"The latest statistics showing a significant year-on-year overall fall in health insurance members, particularly the 5.3 per cent drop among those in their 20s, highlights the need for a searching examination of Government assistance and regulation of health insurance."

"While we can understand health funds' need to recruit younger, healthier members, the discount plan seems destined to be taken up by the minority of young adults who have the means, while the majority who struggle with high costs

on modest wages will see little reason to take up insurance."

"It is also likely that those who do join will take out minimum cover and tend to rely on public hospital care if they need it, defeating the objective of taking pressure off public hospitals."

"There are a number of other problems with the proposed amendments to health insurance rules, including the provision that funds are not required to make discounts available for all ages between 18 and 29, or to maintain offering those discounts throughout the life of the policy."

"Consumers will have no assurance as to whether they will continue to have access to a discount as these can be cancelled."

"The lack of certainty for consumers in these and other proposed rule changes that tend to favour the health funds seems to contravene the aim of improving transparency and making insurance simpler for consumers. That is after all meant to be the aim of this reform package."

"If there is a desire to move away from the community rating principle then there should be a full and transparent discussion about that rather than the proposed approach to chip away at the edges."

"Because of this and the complexity of the issues impacting on health fund consumers, the Consumers Health Forum has been calling for a Productivity Commission inquiry into private insurance for some years," Ms Wells said. 🌐

Meet One Of America's Last Iron Lung Users

By **Mary Kekatos**

Source: www.dailymail.co.uk – 21 August 2018

Missouri woman, 82, is still using the decades-old machine after she was paralyzed by polio at 20



- Mona Randolph, 82, from Kansas City, Missouri, contracted polio in 1956 when she was 20 years old
- She became paralyzed from the disease but was able to breathe on her own
- In the 1980s, she came down with post-polio syndrome and was forced to use the iron lung to sleep at night
- The machine has a motor and a pump that changes pressure inside the airtight chamber, which forces the lungs to expand and contract
- Randolph is one of three known people using the iron lung in the US because they are not made any more and most have switched to more modern aids

Six nights a week for the last 36 years, Mona Randolph has been put in the decades-old machine that helps her breathe. The 82-year-old's head sticks out on one side as her body sits in an airtight chamber where a motorized lever creates negative pressure and forces her lungs to expand. The contraption is known as an iron lung machine and Randolph, of Kansas City, Missouri, is only one of three people in the US to have survived polio that still uses it.

But the devices are no longer covered by insurance companies or serviced by manufacturers, which means that the owners like Randolph are completely responsible for their maintenance, she said in an interview with the [Kansas City Star](#).

Randolph came down with polio in 1956 when she was just 20 years old. The disease paralyzed her, but she was able to get away without using a respirator for years. Randolph told the newspaper that she contracted polio when she was age 20 and that the first sign was an intense headache as she was waiting for a bus to go

home. The headache turned into an extreme sensitivity to light and sound.

"Everything was off-key," she said. "I couldn't stand to hear people talking in the kitchen. They'd whisper and it would hurt my ears. I couldn't stand any light. Mom put blankets over the windows." On the third day after her headache began, she couldn't breathe and she was taken to St Luke's Hospital in Kansas City, where she was diagnosed with polio.

Polio, short for poliomyelitis, is a viral infection that is highly contagious and spread through person-to-person contact. About one in four people infected the virus have flu-like symptoms including a headache, sore throat, fever and nausea, according to the CDC. In most cases, the symptoms will last between two to five days before disappearing.

However, polio can result in serious conditions including meningitis - an inflammation of the membranes covering the brain and spinal cord - and paralysis. The CDC says that anywhere between two and 10 out of 100 people who become paralyzed from polio die when their breathing muscles also become immobilized.

A SHORT HISTORY OF THE IRON LUNG

An iron lung is a non-invasive negative-pressure ventilator, used to artificially maintain respiration during an acute polio infection. They were first used in the 1920s and work by producing pressure on the lungs that causes them to expand and contract so that patients can breathe.

In most cases it would only be used for one or two weeks, until the patient could breathe independently, but some polio survivors with permanent respiratory paralysis rely on them daily. They are now all but obsolete, replaced by positive-pressure ventilators such as modern day respirators.

Randolph's diagnosis was in 1956, just a year after the US government had approved the polio vaccine. However, it was widely marketed as being for children. Adults like Randolph were not considered to be at risk, the Star reported.

According to the National Institute of Neurological Disorders and Stroke, around 35,000 people were stricken with polio every year between the late 1940s and early 1950s. But after the nationwide campaign to get children immunized began, the numbers began falling drastically and, in 1979, polio was declared to be eradicated in the US.

At St Luke's Hospital, an iron lung sat in the basement, which had already fallen out of use at the time, and staffers brought it up and put Randolph inside.

(cont'd P14)

America's Last Iron Lung Users *(cont'd from P13)*

The respirators were created in 1927 by two scientists at Harvard University. The machine has a motor and a pump that changes pressure inside the airtight chamber, which forces the lungs to expand and contract.

The iron lung was meant to be used until a person could regain the ability to breathe, about one to two weeks after infection. But some people, whose breathing muscles had become paralyzed, permanently relied on them.

Randolph was in the machine for three months and it took her eight months after she first fell ill to become well enough to sleep without a breathing machine, reported [KSHB](#).

Currently, Randolph is unable to move her left arm and has limited movement in her right arm, but she was able to get by without the iron lung for years. But, in the 1980s, she began to suffer from post-polio syndrome, which affects polio survivors years after their recovery.

In the 1980s, she [developed] post-polio syndrome, which affects polio survivors years after their recovery and she began having trouble breathing. This forced her to use the iron lung at night.

[People with post-polio syndrome] begin suffering from muscular weakness and fatigue, pain as their joints deteriorate and being unable to breathe or swallow properly.

Randolph was forced to use the iron lung at night, and is currently one of three known people in the US still using the machine. During the day, Randolph uses a CPAP machine, which increases air pressure in the throat so that the airway does not collapse when you inhale, according to Kaiser Permanente.

But at night, Randolph's husband Mark, and one of her good friends, put her into the six-foot-long tube which Randolph calls her 'yellow submarine', the Star reported. It takes about an hour as a sling transfers Randolph from her bed to the 700-pound behemoth. Randolph's head and neck are adjusted and blankets are placed over her so she doesn't get too cold. The couple lives in constant fear that of maintaining machine's condition.

The company that made the machines, JH Emerson, stopped doing so in 1970 and insurance companies do not cover the mainly obsolete machines. After a series of mergers, medical supply company Respironics inherited responsibility of the machines.

In 2004, Respironics gave iron lung users three



choices: choose another ventilator device, keep using the iron lung with the knowledge that Respironics may not be able to repair it, or accept full ownership and responsibility, reported [Gizmodo](#). The news outlet reported that if the machine breaks down, Mark, a software engineer, or Randolph's cousin who is former aircraft mechanic repair it. Mark told Gizmodo that the cost of keeping the machine working is equivalent to buying a new car every year.

The respirators were created in 1927 by two scientists at Harvard University [pictured above]. The machine has a motor and a pump that changes pressure inside the airtight chamber, which forces the lungs to expand and contract.

Brian Tiburzi, the executive director of Post-Polio Health International (PPHI), told [Daily Mail Online](#) last year that there is a bit of reluctance from iron lung users to let go of the machine.

"Part of it is just habit," he said when asked why they might be hesitant to use more modern breathing aids. *"That's sort of what they have been used to all their life. Some people also use them because they have trouble with the masks, some leak, some people get sores, or find them uncomfortable to wear. The vast majority have switched."* He also said that the announcement by Respironics in 2004 meant *"they were sort of told they were on their own."*

Randolph said she is a big advocate of people undergoing vaccinations to prevent themselves from ending up in a situation similar to hers. *"I believe getting vaccinated is the thing to do, but I also believe people ought to act according to their faiths,"* she said. *"It's a personal decision. But something like vaccinations that you can see the proof of with epidemics just seems more logical."*

Read the full story [here](#). 🌟

Franklin D Roosevelt Walking—Video



A newly discovered film shows Franklin D. Roosevelt, who had polio, walking

By **Michael E. Ruane**

Source: www.washingtonpost.com.au
—27 June 2018

On April 22, 1935, a tourist from New York named Fred Hill waded through the crowd at the White House Easter Egg Roll, pointed his movie camera at the South Portico and captured seven seconds of history.

As Hill filmed, President Franklin D. Roosevelt, who had been disabled by polio 14 years before, emerged and — with the help of a cane and his bodyguard — walked unsteadily to wave to the crowd.

Walking was something Roosevelt did with great difficulty. He looked awkward and vulnerable, and he was rarely filmed doing so.

On Wednesday, the Franklin D. Roosevelt Presidential Library and Museum unveiled the newly acquired Hill footage, which it says offers a fresh, remarkably clear glimpse into one of the great secrets of FDR's public life.

"When I saw [it] . . . I gasped," Paul Sparrow, the director of the library in Hyde Park, N.Y., said last week. "I had never seen this footage before, and we had a sense that no one had ever seen this footage before," he said.

Sparrow said newsreel cameramen were warned against filming FDR while he was walking, lest his disability be shown. The president could walk

only with heavy leg braces and assistance, and only for short distances. And even then he walked with a stiff, unnatural gait. "Mr. Hill . . . didn't know the rules so he just" ran his camera, Sparrow said.

The film of Roosevelt continues for another 30 seconds as the president's bodyguard, former New York City policeman Gus Gennerich, steps into the background. The president, then 53, wears a double-breasted coat and pocket handkerchief. He strides into the sun, hooks the cane over the balcony railing and greets the crowd. He smiles and waves, always keeping one hand on the railing. First lady Eleanor Roosevelt stands beside him, along with two of her nieces, Diane Roosevelt, 8, and Amy Roosevelt, 6, according to Roosevelt biographer Geoffrey C. Ward. With a final wave, Roosevelt slips the cane off the railing with his right hand. Gennerich reappears at his left side, and the group walks back across the portico.

"I was dazzled," Ward said of the new footage. "It's by far the clearest image I've ever seen of something that's obsessed me for 20 years."

The silent 16mm film, in black and white, was donated to the library, which is a part of the National Archives, in December by Richard Hill. He is a lawyer in Reno, Nev., and Fred Hill's grandson. The film was digitized for the library at a private laboratory in Rockville, Md.

Richard Hill said his grandfather was the bookkeeper for the family business — Hill and Sons, in Brooklyn, which had been founded as a horse wholesaler in New York — and later got into real estate in Nevada.

(cont'd P16)

Franklin D Roosevelt Walking—Video *(cont'd from P15)*

The family wound up running a dude ranch in Reno, where his grandfather made dozens of home movies. He said he discovered the Roosevelt clip in the 1980s by accident when a local TV station was seeking historical footage of old Reno.

Hill, 66, said in a telephone interview that he had offered the clip to the library in the 1980s, but he lost interest and didn't follow up. He said he made the donation last year because he is getting older and it seemed like the right time.

"I've kind of jealously guarded this stuff," he said. Now, it *"needs to go where it belongs . . . It's an important part of history that almost got away."*

Roosevelt was a rising figure in Democratic Party politics in 1921. He was 39 and had been assistant secretary of the Navy and a candidate for vice president. But that summer he was stricken with polio and lost most of the use of his legs. His courageous recovery, and efforts to conceal the extent of his disability, are rich chapters in American history.

He mostly used a wheelchair to get around, although he often had to be carried by aides and sometimes crawled from one room to another on the floor, according to biographer Ward, who also was stricken with polio. Roosevelt fought to be able to walk.

"I must give principal consideration for at least 2 years more to getting back the use of my legs," he wrote a friend in 1926 about his political future. *"Up to now I have been able to walk only with great diff. with steel braces and crutches, having to be carried up steps, in and out of cars, etc. etc. Such a situation is, of course, impossible in a candidate,"* he wrote.

"No movies of me getting out of the machine, boys," he told waiting cameramen as he was about to get out of a car the day he was elected governor of New York in 1928, according to Ward. The cameramen obliged.

"People didn't want him to be handicapped," Ward said. *"We were in the middle of a depression. They wanted their president to be a vigorous, able person, and he wanted to fulfill that role."* Of the hundreds of photographs taken of him, only a handful show him in his wheelchair, Ward said.

And footage of him "walking" is just as rare. *"There are a number of very short, very blurry shots,"* Ward said in a telephone interview last week.

Four years ago, seven seconds of amateur film surfaced of FDR making his way up a ramp at Washington's old Griffith Stadium for the 1937 baseball All-Star Game. In August 1933, a doctor filmed him walking, again holding Gennerich's

arm and using a cane, at a public event in Poughkeepsie, N.Y. The clip lasts six seconds.

Brief, partially obscured footage exists of him walking at Mount Vernon in 1939, at his third inauguration in 1941, getting off a train in Boise, Idaho, in 1937, and at other public appearances in New York, according to the FDR library.

The known clips appear to total less than a minute. In Fred Hill's, *"you really get to see . . . [FDR's] gallantry and also you get a pretty good glimpse of the way it's orchestrated,"* Ward said.

Gennerich, as well as being FDR's bodyguard, was *"his enabler, that allowed him to walk,"* Ward said. *"Roosevelt sometimes used his sons, who were also big guys, to do that. But Gennerich was the daily guy."*

"It's like choreography," Ward said. *"You watch him bring Roosevelt up to the railing. The minute he gets to the railing, he steps way back and then he goes back behind [a] pillar. And he doesn't come out again until Roosevelt is ready to leave,"* Ward said.

The president had *"this amazing ability to look as if absolutely nothing was wrong,"* he said. *"When you look at him, he looks like the most carefree man in the world."*

But sometimes, the choreography didn't work. In June 1936, Roosevelt almost fell at the Democratic National Convention in Philadelphia at the University of Pennsylvania's football stadium, Franklin Field. There were 105,000 people present, according to news reports.

"Spotlights followed him as he made his halting way toward the microphones . . . to accept his renomination for the presidency," Ward wrote in his 1989 book about Roosevelt, *"A First-Class Temperament."* Holding a cane with his right hand and the arm of his son, James, with his left, he stopped to greet someone in the crowd. He lost his balance, the brace on his left leg gave way and he started to go down.

But Gennerich was near and caught the president under the arm just in time. (Five months later, Gennerich would die of a heart attack on a trip with Roosevelt to Argentina.)

"There I was, hanging in the air, like a goose about to be plucked," Roosevelt told reporters later. *"But I kept on waving and smiling, smiling and waving."* There is no known film of the mishap. And the speech he gave minutes later *"was one of the most memorable addresses of his life,"* Ward wrote.

"There is a mysterious cycle in human events," Roosevelt said. *"To some generations much is given. Of others much is expected. This generation of Americans has a rendezvous with destiny."* 🟡

Can Polio Workers Overcome Complacency

By Carol Pearson

Source: www.voanews.com—18 July 2018

The move to end polio started in 1985 with Rotary International. At that time, polio paralyzed hundreds of thousands of children every year. There is still no cure, but two scientists developed vaccines against the virus in the 1950's.

Dr Jonas Salk produced one with an inactivated virus that could protect against polio without spreading the disease. Later, Dr Albert Sabin developed an oral vaccine with weakened strains of the virus.

In 1988, public and private groups joined the effort in the Global Polio Eradication Program. Members included governments, the World Health Organization, the United Nations Children's Fund (UNICEF), Rotary International, the U.S. Centers for Disease Control and Prevention (CDC) and the Bill and Melinda Gates Foundation.

Since then, the number of polio cases has dropped by 99.9 percent. Last year, 22 children were crippled by this disease. The wild polio virus exists in only three countries: Pakistan, Afghanistan and Nigeria, but it's still a global threat.

Dr John Vertefeuille, from the CDC said, *"This last mile is a complicated mile."* It's not just because of conflict or terrorism. *"It's extreme remoteness. It's very fragile health systems."* And in these remote conflict prone areas gaining access to children can be a major problem.

If polio exists anywhere, it can once again spread everywhere. Vertefeuille and other experts discussed strategies to realize a polio-free world July 10 at the Center for Strategic and International Studies in Washington.

Widespread unrest in Afghanistan has kept thousands of children from receiving polio vaccines this year. Conflict in northern Nigeria does the same.

What's more, the border between Afghanistan and Pakistan stretches for more than 2,000 kilometers. Thousands of people who cross this very porous border can easily transmit the virus in both countries.

While the funding and technical support has to come from large, private-public partnerships, immunization teams succeed best if they are local. Approaches have to take culture and customs into consideration.

In many places the vaccinators are women because women can go into the homes, talk to other women and gain access to the children.

Elsewhere, soldiers vaccinate children when they take over an area run by anti-government forces. Vaccination teams have to be prepared to move quickly when there is a lull in the fighting and to deliver multiple doses of vaccine in a short period of time.

Surveillance is just as critical. To end polio, you have to know where the outbreaks are. Community volunteers are a great resource. Some get cell phones so they can alert health officials if a child becomes paralyzed.

Another challenge is getting children in migrant groups vaccinated. Vertefeuille says this is where technology helps. The CDC uses satellites to see where people have moved and what areas are abandoned. Clues are where structures have been repaired, where the grass grows on roads, indicating abandoned areas, and where it doesn't, indicating where people are living.

Dr Andrew Etsana from the International Federation of Red Cross and Red Crescent Societies said these groups present a particular challenge because *"you have people moving with a virus and it is difficult to track them and vaccinate the vulnerable children in this mobile population."*

Another issue is the nature of viruses themselves. Viruses mutate. So far, the polio vaccines have been effective, but if not enough children get vaccinated, the virus can change, and perhaps make the vaccine less effective. That's why every child needs to be vaccinated.

Outbreaks can be avoided by vaccinating the whole population so that there are no gaps for the mutated virus to slip through. International experts are working with local leaders to close this gap.

Another issue is complacency. Etsana said, *"People are getting tired. The program has been going on. They thought it would have ended."*

Rotary has pledged to continue its support, other groups as well. International support and funding is critical to ending polio, but after three decades, many people have never seen polio. Etsana says he sees complacency creeping into all areas of the program. *"The funders of the program are also getting tired. The fund is drying up and if the fund dries up and the job is not done, we're going to have a major problem. We may have reinfection."*

But, if people recognize the program's value—it has united communities, established vaccine centers, created partnerships never before imagined—the world can not only end polio, but tackle other diseases as well. The polio program is widely credited with stopping the spread of Ebola in Nigeria while the disease ravaged other west African countries. 🌍

Polio This Week

Source: [Polio Global Eradication Initiative](#) — as of Wednesday 23 August 2018

Take a look at how the Papua New Guinea Government, the World Health Organization, and partners of the Global Polio Eradication Initiative are [responding](#) to the country's recent outbreak of circulating vaccine-derived poliovirus.

Pictured: At Malahang health clinic near Lae in Morobe Province, a health worker administers the oral polio vaccine (OPV) at a supplementary vaccination activity targeting children under five years. As part of the health ministry's response to Papua New Guinea's recent polio outbreak, four additional rounds of OPV vaccination are planned in Morobe, Madang and Eastern Highlands provinces.



Photo: Gavi/2018/Brendan Esposito

Wild poliovirus type 1 and Circulating vaccine-derived poliovirus cases

Total cases	Year-to-date 2018		Year-to-date 2017		Total in 2017	
	WPV	cVDPV	WPV	cVDPV	WPV	cVDPV
Globally	14	25	9	41	22	96
—In Endemic Countries	14	5	9	0	22	0
—In Non-Endemic Countries	0	20	0	41	0	96

Case breakdown by country

Countries	Year-to-date 2018		Year-to-date 2017		Total in 2017		Onset of paralysis of most recent case	
	WPV	cVDPV	WPV	cVDPV	WPV	cVDPV	WPV	cVDPV
Afghanistan	11	0	6	0	14	0	17 Jul 2018	N/A
Democratic Republic Of The Congo	0	11	0	8	0	22	N/A	24 Jun 2018
Nigeria	0	5	0	0	0	0	N/A	15 Jul 2018
Pakistan	3	0	3	0	8	0	18 May 2018	N/A
Papua New Guinea	0	4	0	0	0	0	N/A	8 Jul 2018
Somalia	0	5	0	0	0	0	N/A	26 May 2018
Syrian Arab Republic	0	0	0	33	0	74	N/A	21 Sep 2017