



Polio Oz News

September 2019 – Spring Edition

My New Leg

By Jan Williams

I feel, in general, many polio survivors tend to have the attitude that if something works for you, don't change it. Each time we were provided with new equipment, it became a learning curve all over again. Understandably, by the time we became accustomed to a new way of walking or using our upper limbs yet again, the thought was, "well that's good, let's stay with it."

Such was my case, however, having used the same orthotic for 43 years, and now in my 60's, I wondered if, just maybe, with advancements in technology, there might be something better.

To this end, in April, my husband, Ray, and I met with Darren Pereira and his team at [NeuroMuscular Orthotics](#) in Clayton, Victoria to discuss whether there may be something they could offer me that might be more beneficial to my mobility than the below knee orthotic custom made for me at the Royal Children's Hospital, Melbourne in 1976. During almost 2 hours with Darren, he explained what they could offer me, how it would work, and what I would need to do to make it work. With the decision made to proceed, a cast of my right lower leg was made there and then.

We returned 5 days later to collect my new carbon fibre orthotic – very different, in all ways, to the old one. Following fitting and adjustments to suit my personal requirements, we headed for home in Queensland, with a recommendation from Darren that I would benefit from input from a neuro exercise physiologist to assist me in becoming accustomed to walking with my new 'leg'.

I was advised to initially use the new orthotic for a few hours at a time to become accustomed to it. Me being me, I decided to wear it all day! Hence, by day 5 I could barely walk as my gait had changed and my lower back was suffering. Alas, if all else fails, go back to doing what you are told to do. Hence, my back recovered and, over a two-week period, I built up to wearing it all day. At this point, I also began seeing an exercise physiologist, as suggested.

I am now:

- walking with a far more even gait; my right leg is actually 'walking';



- walking longer distances (albeit still with my two walking sticks) without the need to rest nearly as frequently as previously;
- standing straight;
- standing for longer periods of time without fatiguing; and
- on a known, level walking surface, I can now look around me while walking rather than constantly looking at the ground watching for 'hazards'.

My fatigue levels have greatly reduced and I believe this in part is due to the fact that now my right leg is doing a lot more of the work. It has taken some of the hard work off my stronger left leg which has, for my lifetime with polio, done most of the 'heavy lifting'.

I've been using my new 'leg' for just on 3 months now and have to say that I am both pleased and excited with the difference it is making. My walking is still a work in progress but, most noticeably, I have gradually been able to get around known areas (i.e. at home) with just one stick rather than 2 and negotiate steps and slopes far easier.

Am I pleased with my new 'leg'? A resounding "YES"!.

Polio Australia

Representing polio survivors
throughout Australia

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“**Spring is a true constructionist.**”

~ Henry Timrod ~

**Polio Australia's Websites**

Polio Australia

Representing polio survivors throughout Australia



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

www.polioaustralia.org.au

Polio Australia

Improving health outcomes for Australia's polio survivors



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

www.poliohealth.org.au

Australian Polio Register

Have you added your polio details?



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

www.australianpolioregister.org.au

Polio Australia

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



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

www.stillhere.org.au

President's Report



Gillian Thomas

As a polio survivor who's not getting any younger, I am really looking forward to some warmer weather. This winter has absolutely chilled me to the bone. I know many of you will understand.

We were delighted to learn that Dr John Tierney, our National Patron and past President, received a Queens Birthday Honour in June, and has now been made a Member of the Order of Australia for significant services to people with polio (p8). We certainly have a lot to thank John for, having led Polio Australia campaigners through the halls of Parliament on many a lobbying visit.

I can happily report that Polio Australia's financial situation has been boosted by the Department of Health grant for our Clinical Health Education program. This has become an integral service, ensuring more health professionals are better informed about working with the post-polio body. I have certainly benefitted from it and I'm sure others have too.

However, we also have many other programs that are important in providing information to polio survivors and the community in general, for

which we require ongoing financial support. Of course, we do receive project grants from time to time. We are very grateful to the Kirby Foundation, who recently funded a series of forums in NSW; The Marian and EH Flack Trust for subsidising the cost of our Retreat; and the Department of Social Services for supporting polio survivors/Board members to attend the conference in Sydney.

We have also received a couple of substantial donations, which can be used to pay our running costs. It's **these** we need more of! All our donations are gratefully acknowledged in the 'Supporting Polio Australia' piece on page 10.

I'd also like to take this opportunity to formally welcome our new staff member, Darlene. I know her skills will eventually lighten my load as Polio Australia's pro-bono Business Manager.

This year, we are unable to run our *Walk With Me* for a few logistical reasons. However, as this generates much-needed funding, we are trialing a different activity: the Polio Awareness Month Fundraising Challenge (p11). I have been thinking about what I might do for the 'challenge'. Considering I wear so many hats, maybe I'll take up the say "no" option! But then, who would do the work? . . . Maybe a daily meditation? Hmm, I might have to think a bit longer on that. ●

Gillian



From the Editor



Maryann Liethof
Editor

Well, spring may not *quite* have sprung yet, but it's certainly on its way! The days are longer and spirits are lifting in that "*glad to be alive*" way.

And "*being alive*" can also be both challenged and enhanced when we take chances, like Jan with her "*New Leg*" (p1).

Unfortunately, cost can be prohibitive for many people who are not eligible for the NDIS or an 'adequate' Aged Care Package. However, increased mobility and decreased fatigue both sound like a great result for Jan's efforts.

Polio Australia is delighted to welcome Darlene, our newest Team member (p4). Darlene works 3 days a week, and is learning the ropes before my departure in December. As Resource Manager, Darlene, together with Rachel (who will transition into the role of Program Operations Manager) will share the daily management functions of Polio Australia. I am anticipating progressive and positive changes to come.

Paul and Steph continue to educate/inform health professionals and polio survivors/community respectively, with upcoming workshops and information sessions listed on p5.

Have you been to a Retreat yet? This is your *last chance* to experience this highly informative, friendly and fun-filled self-management weekend. Don't miss out! More on p6.

If you are up for a *challenge*, Polio Australia would love to hear from you in relation to participating in our Polio Awareness Month Fundraiser (p11). Spreading the "*We're Still Here!*" message is as important today as it ever was.

Read the inspiring story about Paralympic Swimmer, Elizabeth Edmondson, and a new memoir from Nadina LaSpina, who contracted polio in Sicily.

I hope you enjoy these, and all the other offerings, in this Spring Edition of *Polio Oz News*. ●

Maryann

Community Engagement



By Steph Cantrill

Community Engagement Officer

Winter started out with a great combined information session at the Bayside Polio Group, with the always-popular Dr Stephen de Graaff and a guest speaker from Carers Victoria. This was followed by another collaborative session with

Carers Victoria at the Bendigo support group. Both sessions were well-attended and hopefully gave the groups some helpful information.

Later in June, I took a trip down to beautiful (but very cold!) Tasmania. While there, I met with various organisations working with migrant communities, to help build a network of support and awareness for polio survivors born overseas. I also met with aged care providers to discuss the particular needs of polio survivors when receiving in-home care. In Launceston, I was lucky enough (thanks to Tassie Board Member, Arthur Dobson) to attend an event at St Giles, an organisation that once played a key role in the childhood of many of Tassie's polio survivors.

It was great to meet a few people there and hear about what they're up to now.

Travelling down to Hobart, I presented at a Lions Club and a CWA meeting, informing them about the Late Effects of Polio and the message that survivors are "still here!", and ran a community information session together with the support group there. The session was attended by quite a few people who had not been connected with the polio survivor community before, and I hear that a few new members were in attendance at the next monthly meeting.

Since returning from Tasmania in early July I have been in full planning mode, and have organised an information session road trip in NSW to coincide with the World Polio Day event in Canberra and the Polio Health and Wellness Retreat in Sydney. Sessions have been arranged for Albury, Canberra, Central Coast and Wagga Wagga. There are many more sessions to come, with NSW being a particular focus at the moment thanks to a \$10,000 grant from the James Kirby Foundation.

But there may be more than just information sessions in the pipeline – watch this space! 🌟

Welcome Darlene!



Hi, my name is Darlene and I'm so happy to have been given the opportunity to work at Polio Australia as the Resources Manager.

I'm a Certified Practising Accountant by training, but have always loved roles that are broader than just accounting, so the role at Polio Australia is

perfect for me – with a mixture of responsibilities around finance, HR, policy, grants, admin, and generally helping out wherever needed.

I have two kids - both grown up now. My daughter, Stephanie, is 21 and in her second year at uni doing a double degree majoring in Chemistry and German. My son, Lachlan, is 19 and studying for a Diploma in Surveying at RMIT.

Lachy was born with a condition called Achondroplasia, which means that he is short-statured. When he was 4 years old, Lachy was getting terrible pain in his knees and elbows. When we went to the Children's Hospital, they said that his legs had bowed so much that they would not be able to hold his body weight up much longer and that he needed to undergo a pretty radical surgery called 'limb reconstruction'.



This surgery involved cutting right through both legs, inserting metal rods in several places, and encasing his legs in metal braces (see photo). For the next 6 months, 4 times a day, my husband had to use a spanner to slowly straighten his legs. Over this 6 month period, the bone was growing where they had cut it and at the end of 6 months, the bone had fully formed and his legs were straight. Then he had 6 weeks of plaster and after that, he had to learn to walk again. Lachy has such a fantastic attitude and has never let 'being different' hold him back.

I am told that this is a typical story for many polio survivors as well. I'm so looking forward to getting to know you all. Thank you for welcoming me to the Polio Australia community. 🌟

Clinical Practice Workshops: Winter Program Review



By Paul Cavendish
Clinical Health Educator

Clinical Practice Workshops:

The winter period can be one where people look to hibernate rather than attend professional development. However, many still braved the dark nights and cold weather for our education sessions!

With the birth of my second son, I was happy to deliver some sessions close to home at Tweed Heads and Gold Coast to aged care providers and health professionals. Our renewed Department of Health contract was signed during June which will allow us to deliver education to professionals in aged care and disability, as well as health.

This is an important area for us. Many of our polio survivors have just as much interaction with professionals in disability and aged care. Providing this information and understanding of the symptoms of the late effects of polio is vital and we will continue to develop opportunities in these areas.

I also delivered a session to medical professionals at Shepparton Hospital in Victoria, and presented on our fatigue and impact of impairments survey at the ATSA Independent Living Conference, Canberra. The results highlighted to me the importance of education. When we separated out the fatigue severity scores, the highest results were recorded for those who had not, or did not know if they had, a diagnosis of Post-Polio Syndrome (PPS). This was separate to those who had a diagnosis of PPS or the Late Effects of Polio (LEoP). Understanding the symptoms and management is going to make a difference.

We have more work to do to educate and liaise with health professionals on treatment and management. We also need to continue our efforts with providing [information](#) and links to [health professionals](#) who have the skills and knowledge on post-polio.

We have also entered into a partnership with Polio NZ to extend the reach and knowledge of our [Clinical Advisory Group](#). This is part of ensuring we have the most appropriate information for health professionals and polio survivors. Spring always brings more education sessions and gladly we have a number of sessions across all states to health and medical professionals to help treat and manage LEoP. 🌟

Upcoming Clinical Workshops And Community Information Sessions

UPCOMING CLINICAL PRACTICE WORKSHOPS

ADELAIDE, SA	9TH SEPTEMBER
WHYALLA, SA	16TH SEPTEMBER
ADELAIDE, SA	17TH SEPTEMBER
ADELAIDE, SA	20TH SEPTEMBER
LAUNCESTON, TAS	24TH SEPTEMBER
HOBART, TAS	26TH SEPTEMBER
COFFS HARBOUR, NSW	29TH OCTOBER
TOWNSVILLE, QLD	20TH NOVEMBER

MORE DETAILS AND TO REGISTER:
WWW.POLIOHEALTH.ORG.AU/WORKSHOPS



POLIO COMMUNITY INFORMATION SESSIONS

ALBURY	14th OCTOBER
CANBERRA	16th OCTOBER
CENTRAL COAST	22nd OCTOBER
WAGGA WAGGA	24th OCTOBER

THE INFORMATION SESSIONS WILL COVER:

Current information about the Late Effects of Polio	Self-management strategies
What to tell your health professional	Q&A
	Local connections

MORE INFO/REGISTER:

ONLINE: www.polioaustralia.org.au/community-information-sessions/
CONTACT STEPH: 0466 719 613 OR steph@polioaustralia.org.au



FINAL Polio Health And Wellness Retreat 2019

By Maryann Liethof, National Program Manager

In 2009, I was fortunate to have been one of 5 Australians who travelled to Roosevelt Warm Springs, Georgia, USA to attend Post-Polio Health International's Health and Wellness Retreat. For anyone who would like to read more about this wonderful adventure, click [here](#).

The Warm Springs Retreat self-management program provided the inspiration for Polio Australia to start its own annual Polio Health and Wellness Retreat. Polio Australia's Retreats have now been held every year since 2010 (apart from 2016 due to Polio Australia's international Conference) across New South Wales, Victoria, South Australia and Queensland (being the largest states by population).

We have identified numerous health—and other—professionals willing to donate their time, skills and knowledge to present on topics of interest to the post-polio community. No doubt, many have also taken away important lessons learned from the polio participants themselves!

Well over 500 polio survivors and their spouses/partners/carers have now gone through the program, with many returning year after year, and several firm friendships made. We have also had participants from New Zealand (*now running their own Retreats*) and Taiwan! We learned that most polio survivors have similar experiences, as well as great strategies to share. However, with many finding it increasingly difficult to travel, and with me retiring at the end of the year, we decided that 2019 is the right time to wind up the Retreat program.

Alternative educational forums will be presented in future, based on a one day format. We hope this will make it more affordable and accessible for even more people to attend.

We are ending where we started, in Baulkham Hills, NSW, from 17-20 Oct. **It's not too late to book** your place for this educational, fun, and interactive weekend. Click [here](#) for all the details. 🌟

Polio Health And Wellness Retreats—2010 to 2012



2010 NSW



2011 VIC



2012 QLD

Polio Health And Wellness Retreats—2013 to 2018

2013 SA



2014 NSW



2015 VIC



2017 QLD



2018 SA



John Tierney Received Queen's Birthday Honour



Picture: Simone De Peak

By Helen Gregory

Source: www.theherald.com.au
—10 June 2019

Honour: John Tierney pushes *"the case for survivors who have been woefully neglected by the government and the medical profession."*

John Tierney will never forget the reaction he received when he first started taking polio survivors to Parliament House in Canberra to press their case for assistance.

"We met the [health] minister and he said 'Polio? Didn't we get rid of that 60 years ago?'" he said.

"That was the level of knowledge in the parliament – zero – that there were 400,000 people in Australia that had been badly affected by the epidemics of the 20th century and that we're still here."

Dr Tierney has sat on both sides – as politician, having served as a federal senator for NSW, and polio survivor. He contracted the disease that attacks the central nervous system when he was born, after a doctor who had attended a polio case *"didn't wash his hands properly"* before delivering baby John.

He wore an iron caliper on his left leg to 12 and now lives with the late effects of polio, advocating for survivors with the hope of raising awareness and funds.

"All polio survivors are Type A personalities," Dr Tierney said.

"We're all driven, we won't let anything beat us. Polio tried to kill us and nothing else will. We just keep ploughing on."

Dr Tierney has been made a Member of the Order of Australia in this year's Queen's Birthday Honours, for significant services to people with polio and in his roles as Polio Australia's national patron and its president from 2012 to 2017. It follows him receiving a Medal of the Order of Australia in 2012, for service to the Parliament of Australia, to education and to the community. *"I'm quite honoured,"* he said from his Newcastle East home.

Dr Tierney's role has involved establishing the Parliamentary Friends of Polio Survivors group; appointing parliamentary patrons; bringing an event called *Walk With Me* to Parliament House, speaking to Rotary clubs and [supporting] an international conference. But he said the highlight was securing government funding to train doctors and allied health professionals about the bodies of people with polio. A three year package has recently been renewed for another three years.

"That was incredibly challenging – I spent seven years down there twice a year lobbying and it really annoyed me that we weren't making a lot of headway so I stayed with it until we actually got the funding... I look back on that with great pride. It was successful in the end just by sheer persistence."

He is still pushing for polio survivors – and everyone over 65 – to be included in the National Disability Insurance Scheme.

"We are the only disability, the only disease actually, that hits you when you're young... and then comes back to bite you again when you're old. The disease doesn't come back, but the damage it's done creates these late effects of polio."

Dr Tierney is mostly affected on his left side and the bottom half of his body.

While it would be easy to feel bitter towards the doctor who delivered him, *"I was born with a really optimistic outlook. If you're dealt a bad hand you look at what good cards you might have."* 🌟

Focus On Your Breath

By Paul Cavendish, Clinical Health Educator

It is often taken for granted that we can breathe well and that 'other demands' can make us tired. But this is not always the case.

We can have respiratory problems at rest, with exertion, and during sleep. Describing to your GP your symptoms (e.g. patterns at the beginning or end of the day) will help them to identify the best assessment and any other underlying factors to consider.

How can polio history affect breathing?

The poliovirus can weaken muscles that help us breathe in and out. The diaphragm sits at the top of the rib cage to push down and open space up for our airways to fill. Our abdominal, chest and neck muscles also assist to get air in and out of our body. Damage to the muscles may lead to restriction in breathing.

Our posture plays an important part in how we breathe. Muscle weakness may create curvature of the spine – either a hunch, or excessive bending to a side. This posture can impact lung function.

An unknown percentage of people had bulbar polio. This refers to damage, or lesions, at the brain stem. A common area that is affected is the message to take in a breath of air. This can reduce (rather than stop) our inhalation.

What are some signs we may need a review?

- Sleepiness

Feeling sleepy all the time, especially when you wake up. While this may be due to poor sleep practices, waking up throughout the night may be a sign of low oxygen levels.

- Headache at the end of the day

If you notice you seem to be short of breath, and develop a headache (regardless of activity levels), this may be a sign of fatigue.

- Shortness of breath

There are two parts to our breathing – getting air in and getting air out. There are many reasons why either the breath in or out can be difficult. If you had any problems with breathing during the initial polio infection/recovery, this puts you at increased risk for difficulties again later in life.

Common Tests for Breathing Function

A spirometer measures the amount of air you can breathe in and out, and also how quickly you are able to breathe out. This is performed several times. With polio survivors, it is recommended all results, rather than just the best, be recorded in case there is breathing muscle fatigue.

The diaphragm is an important muscle to check if it is functioning adequately. Sometimes when there is partial weakness or paralysis of the diaphragm, people do not have shortness of breath at rest (only during activities). A chest X-Ray is often used to identify a raised diaphragm position. Confirmation is often made by a subsequent 'sniff-test'; a fluoroscopy radiograph identifies the diaphragm raising rather than lower with a breath in. Ultrasound can also be used to detect this.

A sleep test is often required to check you are getting enough oxygen throughout the night. 🌙



Supporting Polio Australia

Polio Australia would like to thank the following individuals and organisations for their generous support from 1 May to 31 July 2019. Without you, we could not pay our rent, core operating expenses, or management staff!

Hall Of Fame

Anonymous x 2

Maureen Valerie Young Estate

Knox-Yarra Ranges Post-Polio Support Group Closing Balance

Total—\$24,221.35

General and Regular Donations

Jill Burn Scott Cantrill Information Session Donations Michael & Rachel Evans

Margery Kennett Dorothy Robinson Liz Telford Gillian Thomas RJ & JK Thomson

Total—\$4,167.00

Rotary Donations

Rotary Club of Nambour / Rotary Club of Mackay / Rotary Club of New Farm

Total—\$4,000.00

Grand Total—\$32,388.35



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2019|2020
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- Member-only priced cinema tickets, theme park tickets, flights, gift cards and more
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- Easy online search, mapping and reviews of participating businesses

Polio Awareness Month Fundraising Challenge!



What Is The Polio Awareness Month Fundraising Challenge?

This October, we are issuing a **Fundraising Challenge** to *anyone* who would like to participate in spreading the "We're Still Here!" message, and getting people to sponsor them to achieve their 'goal pledge'.

Your goal/s will be uploaded to Polio Australia's website, along with a brief story of why raising awareness is important to you. Family, friends, and other potential donors will then be able to click on your section to support your goal/s and raise much needed funds for Polio Australia.

Goal suggestions across October might be:

- Arrange to give one community talk a week (e.g. service club, social club, local school, etc);
- Drop (*X-number*) of notices into GP/medical clinics/pharmacies;
- Contact media outlets with your story (e.g. local papers, radio, social media);
- Arrange for (*X-number*) of meetings with Members of Parliament;
- Or you could challenge yourself to participate in specific health/wellness activities over the month (e.g. daily meditation, join weekly hydrotherapy classes, or even saying "no" to people/tasks that don't bring you joy!)

The options are endless! Information and various resources will be provided by Polio Australia. You will just need to provide a weekly update to Polio Australia in the form of a short report and photo for proof.

What Now?

Contact Polio Australia at:

office@polioaustralia.org.au or
Phone: 03 9016 7678

by the 30th of September and tell us your goal pledge!



October is National Polio Awareness Month. Many Australians who had polio in the last century are now living with [Late Effects of Polio](#).

Polio survivors may be unaware that progressive physical changes relate to their early polio infection. It can also be difficult to find GPs and other health professionals who know about the Late Effects of Polio.

"**We're Still Here!**" is the catch cry of Australia's polio survivors, and spreading the word is vital in ensuring people are informed, and that they receive the support needed to manage their condition.

Symptoms of the Late Effects of Polio vary from person to person and can generally be described as a neuromuscular condition.

Common 'new' symptoms can include:

- New muscle weakness and atrophy
- Increased fatigue
- Joint and muscle pain
- Breathing, sleep and swallowing problems

Common 'old' problems – relating to years of the body accommodating residual physical weakness – can include:

- Scoliosis and kyphosis
- Arthritis and osteoporosis
- Bursitis in hips and shoulders
- Carpal tunnel syndrome

Polio Australia is the peak national body supporting polio survivors living in Australia by providing a range of *FREE* programs, including:

- [Clinical Practice Workshops](#) for health professionals;
- [Information Sessions](#) for polio survivors, their families, and the community;
- [Fact Sheets](#) on more than 30 polio-related topics;
- [Health Professionals Register](#), where you can search for a practitioner in your area;
- [Australian Polio Register](#), where you can provide your polio details;
- [Polio Oz News](#), quarterly e-zine;
- [Social Media](#) links;
- [Systemic Advocacy](#);

And more . . .

As a not-for-profit charity, Polio Australia relies heavily on tax-deductible donations to fund these services.

Please help us to support the post-polio community because "We're Still Here!" 🇦🇺

Recognising Elizabeth Edmondson

Paralympic swimmer Elizabeth Edmondson's 1964 Tokyo Games record still stands 55 years on

By Tom Wildie

Source: www.abc.net.au – 25 August 2019



At just 14, Elizabeth Edmondson [pictured right wearing glasses] became the youngest Australian to claim an individual gold medal for swimming at either an Olympics or Paralympics.

It is a record that still stands today, but 55 years later she is only just starting to get recognition for her achievement.

"I was 14 and I expected to win, and I did," Edmondson recalled from her home in Perth's northern suburbs.

"There was only one race [for each event] and that was it, because there wasn't that many competitors."

Edmondson's medals from the 1964 Tokyo Paralympics are proudly displayed in her home, framed alongside pictures of her competing at various events.

But if not for a slice of luck, she may not have made it to the Games at all.

"I started swimming in January of 1964 with my sister. We trained at Tony Howson's pool at the Commonwealth Games village in City Beach," she said.

"I think he only had a 12.5-metre pool and after two weeks he said come and train with the squad at Beatty Park, which had opened for the Commonwealth Games in 1962."

A chance encounter

It was there that Edmondson, who had been diagnosed with polio when she was just 15 months old and spent a year in hospital, caught the eye of Howson's wife.

She was a physiotherapist who worked for Sir George Bedbrook, the founder of the Paralympic movement in Australia.

"That's how I found out about the Paralympics,

through Tony's wife," Edmondson said.

"When I had just turned 14, a couple of days later, Tony came up to me and said 'you've just broken a world record'."

"Before I knew it, I went to Adelaide [for trials] and I was selected for Tokyo."

A gold medal, then back to school

Edmondson can still recall travelling to Tokyo 55 years ago with her 14 teammates.

"The team all met up in Sydney, and that was the first time I had met the team," she said.

"We then flew to Hong Kong, to Manila and then to Tokyo, and that took nearly 24 hours."

But a lack of record keeping, combined with the limitations of technology at the time, meant she lost contact with most of her teammates from that Games.

"I got off the plane and went back to school the next day as if nothing had happened," she said.

"There was no reception. Government House generally gives a reception for the athletes, no ticker-tape parade. It was back to school and I sort of forgot about it."

Since 2000, the Australian Paralympic Committee has been writing the history of the Games on Wikipedia, something Edmondson has been involved with.

It was through this work that she understood what she had achieved in Tokyo all those years ago.

"I suddenly sort of realised, 'oh yes I am a Paralympian', and I'm sort of getting the recognition now," she said.

That recognition has grown in recent years, with Edmondson receiving several awards along with becoming the first person inducted into WA Swimming's Hall of Legends last year.

Raising the Paralympic profile

As someone who enjoyed success through the opportunities provided by the Paralympic movement, Edmondson said the value of the Games could not be overstated.

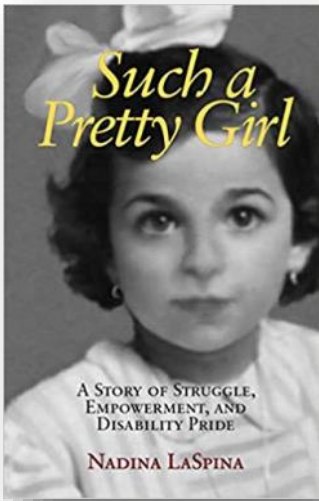
"It gives recognition to people with disability," she said.

"It's more on the television [these days], and people are much more interested and know about it, and I think there is much more awareness. It can only expand."

The Tokyo Paralympics begin on August 25, 2020.

Read full article [here](#). 🌐

Such A Pretty Girl—Book Review



By Grace Lapoint

Source: bookriot.com
— 24 July 2019

The title of Nadina LaSpina's new memoir, [Such a Pretty Girl](#), refers to her neighbors' comments in her hometown of Riposto, Sicily, around the 1950s. Neighbors say that it's "*such a shame*" that she's pretty and disabled. They view disability as tragic or a burden. Religious concepts of

charity, pity, fate, and suffering shape their attitudes. At her Catholic school, a nun tells her that she'll never be happy and suffering is her destiny. Despite her loving parents and grandparents, the ableism from others is traumatic. The memoir shows her journey from an inaccessible and ableist world to self-acceptance and political activism. Its subtitle is *A Story of Struggle, Empowerment, and Disability Pride*.

Born in 1948, LaSpina had polio as a baby. When she's around 13, her family immigrates to New York City. Her father believes that American doctors are the best in the world and might even cure her disability. At NYC's Hospital for Special Surgery, LaSpina has several procedures and uses a wheelchair for the first time. She's unsure whether wheelchairs were unavailable in Sicily or her father "*didn't want to see (her) in one*" (21). She feels unprecedented freedom and "*fell in love—with the wheelchair*" (22). Her father, though, wants her to be able to walk. As this section illustrates, even well-intentioned parents' feelings about their children's disabilities often differ from the children's feelings.

At the hospital, LaSpina meets other children of various races and disabilities for the first time. She learns English mostly from her best friend, Audrey. By their early 20s, Nadina and Audrey attend political protests for the Civil Rights Movement and against the Vietnam War. Both Audrey and Nadina have been told that their disabilities make them inferior and undesirable, but Audrey has internalized this message more. After several attempts, Audrey kills herself, believing she'll never have a happy life.

After Audrey's death, LaSpina becomes involved in several disability rights groups, including Disabled in Action and ADAPT. She gets arrested many times during protests. These groups are instrumental in helping to pass the Americans with Disabilities Act in 1990 and its precursor in the 1970s, Section 504 of the 1973

Rehabilitation Act. Her friends and fellow activists include Judith Heumann, the first wheelchair user to become a teacher in NYC. Disability pride and activism become important to LaSpina's life, and she wonders if they could have helped save Audrey's.

The author skillfully ties her personal experiences into a broader social and historical context. One example is the tension between the social and medical models of disability. The social model posits that inaccessibility disables individuals more than their conditions do. LaSpina's childhood in Riposto, where she relied on relatives and the nuns to carry her, seems to support the social model. In NYC, which is more accessible, she attends protests, works, and dates, all while using mobility devices. She also sees the merits of the medical model and accepting physical limits when she experiences painful symptoms of post-polio syndrome.

Such a Pretty Girl parses the author's complex, ambivalent feelings about her birth and adopted countries. While her parents are nostalgic for Italy, Nadina misses her grandparents and cousins, not the inaccessible environment. However, she returns to Italy to meet with Italian disability rights activists, who are horrified that the U.S. doesn't have a single-payer, universal healthcare system. LaSpina candidly writes about her career, sexual, and medical decisions. She teaches Italian and later designs and teaches an online disability studies course.

Content warning: this book describes multiple instances of ableist abuse and sexual assault, medical procedures, and Audrey's suicide after several attempts. I found these scenes disturbing but not gratuitous. LaSpina writes that after being conditioned to feel unattractive, she and Audrey often viewed even predatory sexual attention as positive. Ableism can be difficult to unlearn. Many non-disabled people are unaware that sexual predators frequently fetishize and target disabled people.

A disclaimer at the front of the book explains that some names have been changed to protect privacy and conversations reconstructed. LaSpina uses words often considered offensive today, like cripple or handicapped, depending on the era discussed in the book. This puts the changes in attitudes and language around disability in their historical, cultural context.

This is an empowering and feminist book. It shows an immigrant, writer, teacher, and activist's perspective on pivotal moments in history. In an intimate way, *Such a Pretty Girl* shows how far disability rights have come in the past 70 years and touches on inequalities that still exist.

Read full article [here](#).🌐

New Falls App

New app 'a game changer' in fight against falls

By **Natasha Egan**

Source: www.australianageingagenda.com.au
– 27 August 2019

An aged care provider in Sydney has teamed up with Australia's leading experts to trial an Australian invention that can predict falls among older people with 75 per cent accuracy.

The trial is part of a new partnership between Neuroscience Research Australia (NeuRA) and Mark Moran Group (MMG) to develop ground-breaking health and wellness innovations to support the aged care sector and older Australians.

The partnership includes the rollout of new app-based wellbeing assessment tool FallScreen+, which builds on more than 30 years of NeuRA's studies at the Falls Balance and Injury Research Centre.

In Australia one in three people aged 65 or over fall one or more times each year, and falls is a major cause of hospitalisation for this cohort.

The FallScreen+ app features nine tests, which are used to calculate the overall fall risk of a person over 60 and identify cognitive and physical impairments that can be treated.

Senior NeuRA researcher Associate Professor Kim Delbaere said the tool had significant implications for the aged care sector.

"FallScreen+ is unique because it screens issues early on, flags problem areas and makes recommendations for effective treatment strategies to address potential health problems," Associate Professor Delbaere said.

"This tool will help identify the specific needs of an individual and based on the data it collects, it will advise whether they need to be referred to clinicians or allied health professionals. For example, our trials have shown this tool can predict falls in older Australians with an accuracy of over 75 per cent," she said.

The tool is designed for use by aged care health professionals, such as physiotherapists, psychologists, fall prevention clinicians and researchers, to track an individual's likelihood of having a fall and select and monitor fall prevention treatments.

The tests assess wellbeing, weekly physical activity levels, concern about falling during daily

activities and executive function.

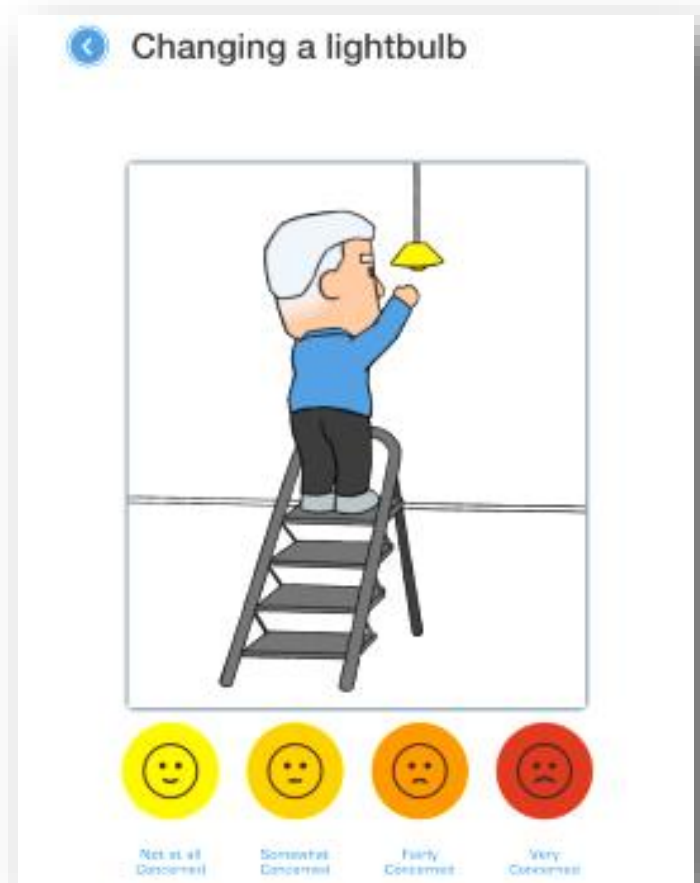
The tool also measures reaction time, ability to see edges under low contrast situations, lower limb strength, standing balance on foam, and coordinated leaning balance.

FallScreen+ is being trialled at Mark Moran Group, which has three aged care and retirement living facilities in Sydney, to measure the wellbeing and health status of residents.

"The FallsScreen+ app is a game changer," said MMG co-founder Mark Moran. *"One day we will look back and ask how older Australians could have aged safely without it. We're at a point where the technology is now available thanks to NeuRA. By working with NeuRA we're doing our bit to make sure it's available to older Australians. It's time for us all to step up and bring about change and work together to meet individual and collective aspirations,"* he said.

Following the trial, the tool will be made available via app stores for relevant aged care professionals.

Read full article [here](#).



Pic: NeuRA's FallScreen+ app to assess fall risk

Poor Diet Quality Tied To Frailty In Older Adults

By Lisa Rapaport

Source: Medscape – 25 Jul 2019

(Reuters Health) – When older people eat a poor-quality diet, they may be increasing their odds of becoming frail, a recent study suggests.

Researchers followed 2,154 older U.S. adults for four years. At the start, participants were between the ages of 70 and 81. They were either "robust" because they didn't appear to have any cognitive problems or issues with physical frailty, or "pre-frail" because they only had one or two symptoms of frailty.

Overall, 277 participants became frail. And among the 1,020 who started out in robust condition, 629 either became frail or developed pre-frailty.

People with poor quality diets were almost twice as likely as those with high-quality diets to become frail, and a medium-quality diet was associated with a 40% higher risk of frailty.

"A good-quality diet may reduce the risk of frailty," said Linda Milou Hengeveld, lead author of the study and a researcher at Vrije Universiteit Amsterdam in the Netherlands.

"It is hypothesized that protein intake may also be important to reduce frailty risk, because sufficient protein intake is important to slow down the loss of muscle mass and strength that occurs with aging," Hengeveld said by email.

But that's not what the study found. Lower vegetable protein intake was associated with a higher risk of "robust" people developing "pre-frailty" but it didn't appear to influence whether they developed full-blown frailty. There was no meaningful difference in frailty risk based on total protein intake, animal protein intake or total calories consumed.

"Possibly, it depends on the type of protein (which can be animal or vegetable) whether it is important for frailty prevention," Hengeveld said. "Even if it is not certain that higher protein intake prevents the development of frailty, sufficient protein intake is important for older persons to maintain their muscle mass and strength."

To be considered frail, participants had to have at least three of these five health issues: unintentional weight loss of more than 5% of their body weight in the past 12 months; weak hand grip strength or too much pain in joints to complete this assessment; regular daytime exhaustion; slow walking speed; and physical inactivity.

Diet quality was measured with food frequency questionnaires that assessed whether eating habits mirrored recommendations for a balanced



diet; total calories; and total protein intake.

Previous research has linked consuming animal protein to a lower risk of frailty, the researchers note in the *Journal of the American Geriatrics Society*, July 2. It's possible the current study got different results because it examined protein based on total grams consumed daily, versus other studies that looked at this as a proportion of total calories.

One limitation of the study is that it relied on elderly people to accurately recall and report on their eating habits over the previous year, and this might not provide a realistic picture of how they ate, the study team notes.

Another drawback is that it's impossible to know whether a poor diet might have caused frailty or if the reverse is true and people started eating poorly after they became frail.

Even so, following dietary recommendations may help older adults minimize their risk of severe frailty, said Kieran Reid, a scientist at the Jean Mayer USDA Human Nutrition Research Center on Aging at Tufts University in Boston.

U.S. dietary guidelines, known as MyPlate, emphasize eating whole fruits, fresh vegetables, whole grains, low-fat milk and dairy products, and protein from a variety of sources. These guidelines also advise against foods high in salt, saturated fat and sugar.

"Based on the evidence from this study among U.S. older adults, a lower quality diet increases the risk of becoming frail with advancing age," Reid, who wasn't involved in the study, said by email.

Study published here: [Journal of the American Geriatrics Society 2019](#)

Global Measles Cases Higher Than Last Year

Although this is not a 'polio' report, we thought the worrying increase in measles was an interesting example of what can happen when people stop vaccinating.—Ed

By Stephanie Nebehay

Source: Medscape – 29 August 2019



GENEVA (Reuters) – Every region in the world, except the Americas, is experiencing an increase in the number of cases of measles, a vaccine-preventable disease that can kill or disable children, the World Health Organization (WHO) said on Thursday.

The WHO's Kate O'Brien put the blame on weak health systems and misinformation about vaccines, and called on social media outlets and communities to make sure information about preventing the highly contagious disease was accurate.

"We are backsliding, we are on the wrong track", O'Brien, director of WHO's department of immunization, vaccines and biologicals, told a news briefing.

"We have a worrying trend that all regions are experiencing an increase in measles except for the region of the Americas, which has seen a small decline".

Nearly three times as many cases were reported from January to July this year than in the same period in 2018, the WHO said.

Nearly 365,000 cases have been reported globally this year, the highest figure since 2006, it said, noting that they represent only a fraction of the 6.7 million suspected cases. Measles caused an estimated 109,000 deaths in 2017, its most recent figures show.

The biggest outbreaks are raging in the Democratic Republic of Congo (155,460 cases), Madagascar (127,454) and Ukraine (54,246), it said.

Europe has also lost ground, with four countries stripped of their *"measles-free"* status in 2018 – Albania, Czech Republic, Greece and Britain, it said.

The WHO figures did not include a specific breakdown of numbers for the Americas region.

The United States has recorded 1,215 measles cases across 30 states in its worst outbreak since 1992, federal health officials said on Monday.

Health experts say the virus has spread among school-age children whose parents declined to give them the measles-mumps-rubella vaccine, which confers immunity to the disease.

Trust in vaccines – among the world's most effective and widely used medical products – is highest in poorer countries but weaker in wealthier ones where skepticism has allowed outbreaks of diseases such as measles to persist, a global study found in June.

"We do see misinformation as an increasing threat", O'Brien said. "We are calling on social media providers, communities, leaders, people who speak out, to be sure you are communicating accurate, valid, scientifically credible information".

In the 53 countries of Europe, 90,000 measles cases were recorded in the first half of this year, already more than that for all of 2018, said Siddhartha Datta, from the WHO's regional office for Europe.

Ukraine, which accounts for more than half of the cases, is implementing a robust response, he said. *"The ministry of health is doing targeted immunization campaigns ... They are also doing school-based vaccination, high-risk vaccination of military recruits and health care workers".* 🌐

Eradicating Polio

By Babar Bin Atta

Prime Minister's Focal Person on Polio

Source: www.thenews.com.pk 'Newspost'
– 10 August 2019

This refers to the letter 'Polio awareness' (Aug 9) by Sahir Ishaq. I would like to take this as an opportunity to inform you that the Pakistan Polio Eradication initiative is currently engaged in designing and implementing innovative strategies to bridge the gap between the programme and local health needs to address the concerns of Pakistani parents. Resistance by parents lies at the heart of the concerns you have pointed out. A Perception Management Campaign is being launched shortly to not only counter misinformation about the programme, but address the most pressing concerns people have about the vaccine, the vaccine's side effects, repeated campaigns, and the number of doses required. Instead of relying on our traditional advocacy methods, this campaign intends to bring the polio programme to the doorstep of the community in ways they are accustomed to, and in languages and actions they are familiar with. The programme is also set to launch a 24/7 call centre providing communities with uninterrupted access to credible and reliable information on polio eradication.

Our communication reviews show that the majority of anti-polio material is downloaded on phones from social media sites such as Facebook, Twitter and YouTube and then further disseminated through WhatsApp. The rapid spread of this content is unsurprising given that up to 55.4 million cell phone users have access to internet and social media on their phone in Pakistan. As such, the programme launched a social media cell earlier this year to monitor, evaluate and disseminate information based on facts in real-time so as to counter circulating misinformation and rumours. In the long term, the programme is focused on penetrating WhatsApp groups at the grassroots level, in even the most far-flung locations, in order to disseminate accurate, reliable, and trustworthy information. These innovative strategies extend well beyond the programme's traditional approach, and are anticipated to encourage increased knowledge of communities, build resilience to anti-polio rumours, and ultimately generate the demand seeking behaviour for vaccines that is key for polio eradication. We all agree that more has to be done to close the remaining gaps and turn the tide toward polio eradication in Pakistan. And, while challenges exist, the commitment to end polio in Pakistan remains very strong. 🌟

Propaganda Against Polio Vaccines

Source: www.asianage.com – 28 August 2019

Rumours swirled over social media that a one-year-old girl had died after she was administered with the polio vaccines.

Islamabad: Facebook has blocked at least 31 accounts which were reportedly involved in spreading "propaganda" against polio vaccination in Pakistan.

This comes after Imran Khan-led PTI government in Pakistan requested the social media giant to take action against the accounts.

On Monday, rumours swirled over social media that a one-year-old girl had died after she was administered with the polio vaccines.

"Print and electronic media showed responsibility and decided to wait till getting the autopsy report of the deceased. However, an organised campaign was launched on the social media that the girl had died because of the vaccine and people should not vaccinate their children", Prime Minister's Focal Person on Polio, Babar Bin Atta said.

However, the autopsy has cited suffocation to be



(Photo: AFP | Representational)

a cause of girl's death. Following this, the government approached Facebook with its demand.

"As per the autopsy report, the girl died due to suffocation as a peanut got stuck in her throat. Just after getting the report we contacted Facebook and officially launched a campaign against those accounts which were involved in propaganda against the vaccine", he said.

While 58 cases have been confirmed in the South Asian country until now, only 12 and eight cases were confirmed in 2018 and 2017, respectively.

Read full article [here](#). 🌟

Wild Polio Has Been Eradicated In Nigeria

... but infections will continue

By **Debora MacKenzie**

Source: www.newscientist.com
- 23 August 2019

Nigeria has officially wiped out wild polio. It is three years since it had a case caused by the natural polio virus, a heartening milestone for a country that nearly derailed the global drive to eradicate the disease after some regions banned vaccination in 2003.

But Faisal Shuaib, head of the country's public health agency, called only for "cautious euphoria". Nigeria has not wiped out polio.

As first revealed by *New Scientist* in 2000, the live, weakened virus used in the oral polio vaccine responsible for this week's victory is circulating and mutating back to its paralysing form. It has caused 15 cases in Nigeria so far this year. There are ways to stop this from happening, but they haven't been rolled out fast enough, says Michel Zaffran, head of polio at the World Health Organization.

Meanwhile there have been three times more cases of wild polio virus this year in Pakistan and Afghanistan, which are now the only countries where it still circulates, than at this time last year, due to a lull in vaccination after a change of government in Pakistan, and a ban on it by the Afghan Taliban.

Mutating virus

Pakistan is now back on track, says Zaffran. But "we are in a very critical and dangerous situation," he adds. Polio could roar back worse than ever if these resurgences are not contained.

The drive to eradicate polio was based on a cheap, effective oral vaccine containing three strains of live, weakened polio virus. The Type 2 strain replicated faster than the others, provoking the most immunity, and as a result, wild Type 2 polio has been eradicated since 1999.

But the Type 2 vaccine virus also tended to survive and circulate, sometimes reverting to the disease-causing form. So in 2016, the whole world shifted to a live vaccine containing only Types 1 and 3. Immunity to those improved, and cases fell.

At the same time, children were supposed to get an injected vaccine containing killed polio viruses, all three strains, making them immune to any vaccine-derived virus still circulating. In this way, India eradicated all polio in 2014.



PIUS UTOMI EKPEI/AFP/Getty Images

But too few children in poorer nations, including many African countries, get routine vaccination, so "there have been more outbreaks of Type 2 vaccine-derived virus than we expected," says Zaffran. The only way to stop such outbreaks spreading is to give people a live, oral vaccine containing only Type 2.

International outbreaks

This is because, while the injected vaccine will stop you getting infected, once you are infected only the live vaccine will create the right immunity in your gut to stop you spreading the virus. And in an outbreak, 95 per cent or more of people infected don't get sick, but spread the virus, so many must be vaccinated.

But the live, Type 2 vaccine also spawns yet more potentially dangerous vaccine-derived virus. And we could run out - only three companies make it. "We have enough to cope now, but there could be a crisis if the outbreaks don't improve," says Zaffran.

Yet there are ever more people susceptible to Type 2 polio, as children are born after the change in the oral vaccine, natural polio no longer circulates and immunises people, and too few get the injected vaccine.

All this is why the WHO has called the polio situation a Public Health Emergency of International Concern since 2014. Outbreaks have spread internationally: Nigeria sent neighbouring Benin its first case of vaccine-derived virus in July, and Iran detected wild polio from Pakistan in sewage, near the border, earlier this year.

It didn't get far: most Iranians are vaccinated. Zaffran worries about Iraq or Yemen with their demolished health systems. Yet the WHO lacks two-thirds of the \$5.2 billion it estimated is needed to finish polio. It plans to ask for funds in November.

Read more [here](#).

Polio This Week

Source: [Polio Global Eradication Initiative](#) — as of Wednesday 28 August 2019

- Technical Advisory Group on Polio Eradication in Afghanistan met on 25-26 August 2019 to discuss and propose recommendations on a range of thematic areas in combatting the ongoing wild poliovirus transmission in the region including: access issues, ban on house-to-house campaigns, optimizing community engagement, and geographic prioritization.
- Summary of new viruses this week: Pakistan — five wild poliovirus type 1 (WPV1) cases; Nigeria— one circulating vaccine-derived poliovirus type 2 (cVDPV2)-positive healthy contact sample; Democratic Republic of the Congo— six cVDPV2 cases; Ghana — one cVDPV2-positive environmental sample. See country sections below for more details. ●

Wild poliovirus type 1 and Circulating vaccine-derived poliovirus cases

Total cases	Year-to-date 2019		Year-to-date 2018		Total in 2018	
	WPV	cVDPV	WPV	cVDPV	WPV	cVDPV
Globally	71	55	21	65	33	104
—In Endemic Countries	71	15	21	14	33	34
—In Non-Endemic Countries	0	40	0	51	0	70

Case breakdown by country

Countries	Year-to-date 2019		Year-to-date 2018		Total in 2018		Onset of paralysis of most recent case	
	WPV	cVDPV	WPV	cVDPV	WPV	cVDPV	WPV	cVDPV
Afghanistan	13	0	16	0	21	0	16 Jul 2019	N/A
Angola	0	6	0	0	0	0	N/A	12 Jul 2019
China	0	1	0	0	0	0	N/A	25 Apr 2019
Democratic Republic Of The Congo	0	23	0	16	0	20	N/A	18 Jul 2019
Ethiopia	0	1	0	0	0	0	N/A	20 May 2019
Indonesia	0	0	0	0	0	1	N/A	27 Nov 2018
Mozambique	0	0	0	0	0	1	N/A	21 Oct 2018
Myanmar	0	3	0	0	0	0	N/A	14 Jun 2019
Niger	0	1	0	4	0	10	N/A	3 Apr 2019
Nigeria	0	15	0	14	0	34	N/A	20 Jun 2019
Pakistan	58	0	5	0	12	0	5 Aug 2019	N/A
Papua New Guinea	0	0	0	20	0	26	N/A	18 Oct 2018
Somalia	0	3	0	11	0	12	N/A	8 May 2019