

POLIO NSW

formerly Post-Polio Network (NSW)

NETWORK NEWS

Incorporating – Polio Oz News

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Patrons: **Michael Lynch AO CBE** **Professor Emeritus Sir Gustav Nossal AC CBE FAA FRSc**

President's Corner

Gillian Thomas

As shown below, this year there will be a number of learning opportunities about the Late Effects of Polio, for both polio survivors, our families, and the health professionals who treat us. There is also a cause for celebration ...

Polio NSW Turns 30 in 2019!

Polio NSW (*then known as Post-Polio Network (NSW)*) was incorporated in 1989 and so this year we are 30 years old. Over the years we have held a number of celebrations as milestones were reached. Videos and photos from our 25th Anniversary Lunch can be viewed here www.polionsw.org.au/25th-anniversary/. Recognising that members are finding it more difficult to travel, and wanting to broaden the celebration of our 30th Anniversary, the Management Committee decided to take a different approach this year to enable more people to take part. Accordingly, all members are invited to send in a photo of yourself (and/or of your Support Group). You could even make a short video on your phone! We will assemble everyone's contributions into a slide show, together with historic Polio NSW photos, for display at the year-end Annual General Meeting. We ask that you give permission for us to display your name, polio year and where you live (town/suburb), and it would be great if you could include how Polio NSW has helped you over the years. The final slide show will be available on our website, and disc copies can be posted to members without internet access. **We want everyone to be included in our 30th Anniversary so look forward to receiving your entries by the end of September – please email photos/videos to office@polionsw.org.au or post (marked "do not bend") to our PO Box above.**

Upcoming NSW Clinical Practice Workshops

Thursday, 9 May 2019 – 4 pm to 6 pm	Royal North Shore Hospital - Pacific Highway, St Leonards
Friday, 10 May 2019 – 3 pm to 5 pm	The Northcott Building - 1 Fennell Street, North Parramatta

In you live in either of these areas, please encourage your treating health professionals to attend, and ask them to visit www.poliohealth.org.au/workshops/ to register or for more information – the sessions are conducted by Polio Australia's Clinical Health Educator, Paul Cavendish. More workshops across Australia are being regularly scheduled.

Upcoming NSW Community Information Session

Thursday, 16 May 2019 – 2:30 pm to 4 pm	Broken Hill GP Super Clinic – 235 Thomas Street, Broken Hill
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If you live in or near Broken Hill, we encourage you to attend this session, presented by Polio Australia's Community Engagement Officer, Steph Cantrill, to learn current information about the Late Effects of Polio (LEoP), self-management strategies, local connections, and how to get more out of your health professional. To register, phone Steph on 0466 719 613, or visit www.polioaustralia.org.au/community-information-sessions/. There will be further NSW sessions announced in coming months. For our interstate members, Steph is also conducting sessions in Victoria and South Australia during May – visit the above web page for details.

Polio Health and Wellness Retreat Returns to NSW

Polio Australia's *Polio Health and Wellness Retreat* returns to NSW in 2019, from 17th to 20th October, at St Josephs, Baukhams Hills (same venue as the 2010 and 2014 Retreats). Polio Australia has announced that this will be the last Retreat, with future comprehensive LEoP management education continuing in the form of twice-yearly one-day conferences around the country. If you haven't yet been to a Retreat, you owe it to yourself to attend this final one – to see what they are all about, check out this page: www.polioaustralia.org.au/retreats/. **Registration will soon be open, so put in your expression of interest NOW!** You can do this online (www.polioaustralia.org.au/retreat-2019/), by email (office@polioaustralia.org.au), or by phone (03 9016 7678).

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CONGRATULATIONS

Merle Thompson, Life Member and current Secretary of Polio NSW, has been awarded an OAM in this year's Australia Day Honours List. Well done, Merle – a just reward for your many years of community service.



MEDAL (OAM) OF THE ORDER OF AUSTRALIA IN THE GENERAL DIVISION

Miss Merle Kay THOMPSON, South Bowenfels NSW 2790

For service to the community through a range of organisations

Australian Federation of Graduate Women

- National Delegate, Educational Conferences in Istanbul, Fiji and Cape Town.
- Served as Honorary Treasurer, Honorary Business Manager, Honorary Registrar.
- Past Committee Member, Blue Mountains Branch.

New South Wales Branch:

- Past Honorary Registrar
- Past Honorary Newsletter Editor.
- Member, since the 1960s.

Polio NSW

- Member, Joint Steering Committee, current (*NSW Health and Polio NSW*)
- Member, Management Committee, since approximately 1995.
- Secretary, 2012.
- Vice President, 1997-2011.
- Member, since approximately 1995.
- Life Member, 2009.

Australian Plants Society NSW (APS NSW)

- Board Member, current.
- Membership Officer, since 2009.
- Treasurer, 2007-2009.
- Co-editor, 'Australian Plants Journal', since 2008.
- Delegate to the Federal Council, for many years.
- Secretary, 1993-1995.
- Life Member, 2011.
- Member, since the 1970s.

Central West Group:

- Delegate to the State Council, since 2009.

Blue Mountains:

- Newsletter Editor, since 2002.
- Delegate to the State Council, 1987-2008.
- President, 1997-1999.
- Secretary, 1986-1996.



Vale - Gary Buchanan

By Nola Buck

On Wednesday, 2nd January 2019, a member of Polio NSW, Gary Buchanan, died. Although Gary did not attend Network functions, he was well known to members of the Polio NSW Management Committee through his wife, Anne, who has been an active member of the Committee for many years.

In 2003 Gary's polio story, "*I Used to Jump Puddles*", was published in our newsletter, *Network News* (reprinted on page 3). Despite the residual effects Gary experienced from contracting bulbar polio in 1951, he led a full and successful life. He had a successful career, rising to the position Group Sales Administrator of a Printing Group, before having to retire due to the late effects of polio.

He was a keen follower of cricket, this interest having developed when he played cricket at school with the assistance of a runner. He also enjoyed swimming in his pool. He had a pleasant tenor voice and loved to sing around the house and at family gatherings, particularly arias sung by his hero, Mario Lanza.

With the arrival of the desk top computer, Gary's world expanded, and he became an enthusiastic member of the Mario Lanza Fan Club. Listening to classical music was one of Gary's loves. Anne and Gary have always had a dog which although "their" dog, was in fact, Gary's dog.

Gary's input into Polio NSW, via Anne, will be missed and we extend sincere condolences to Anne on her loss and to Daisy, their little dog, who is missing Gary.



REMINDER: MT WILGA LEOP CLINIC

For an assessment under the direction of Mt Wilga's Rehabilitation Physician, Dr Helen Mackie, you will need to obtain a referral from your GP or specialist. We encourage those that have already been assessed at the Clinic to return annually for follow up treatment.

To make an appointment and to discuss assessment options, or for more information, please contact Dr Mackie's office on **(02) 9847 5085**. You can fax your referral on **(02) 9847 5013**.

Where does the Assessment take place?

Mt Wilga Private Hospital is a specialist dedicated rehabilitation hospital and day therapy centre.



66 Rosamond Street
Hornsby NSW 2077
<www.mtwilgaprivate.com.au>



I Used to Jump Puddles

A Polio Story by Gary Buchanan OAM – 2003

Reprinted with permission from his wife, Anne Buchanan

My polio story all began way back in 1951 when my life was changed forever.

I was an ordinary mischievous seven year old boy with the world as my oyster.

My family moved to a great place called Yowie Bay which was an outlying area of Miranda NSW in 1948 and it was a kid's paradise.

We were surrounded by dirt tracks, bush and swimming holes, our road itself being no more than a dirt track which ably served horses and carts though.

Yowie Bay had no shops except a general store on the waterfront that also doubled as a bank, post office, bottle shop and also sold petrol from a bowser out the front.

Our visitors to home were endless, there was the milkman, the iceman, the baker, the clothes prop man, the toilet man, the Rawleigh's man, the library man and the fruit and veg man, all who had stories to tell.

We lived next door to a paddock where there was a horse, goat and a cow that would come up to our makeshift wire fence and talk to us. Yes life could not have been much better in those days, until

Three years later

I remember the day I was on the school bus going home from Miranda Primary School to Yowie Bay and because the bus was packed I was standing at the top of the stairs when a big boy who had just realised the bus had gone past his stop jumped off and took me with him.

The next thing I remember is lying by the side of the road and being cared for by my mum, a policeman and two ambulance drivers who suggested to mum that as there appeared to be no broken bones that it would be best for them to take me home and for mum to phone the local doctor to come and check me out.

I had suffered apparently, along with a nasty gash to my head, concussion as well, to which the doctor advised mum I was to rest in darkness for at least three days and to be kept very quiet.

When I returned to school the next week I was treated like a hero as the boy who flew from the bus.

Sadly though, for the next two weeks I had lost all energy, felt lethargic and completely out of sorts and little did I know due to partly I suppose to my loss of stamina that when the enemy came a week later I had no resistance to fight it.

A week later in February 1951 ... It was a hot summer's afternoon after school and I was playing catchings with a tennis ball with my two mates Peter Sorensen and John Stewart

and I remember they made fun of me because I kept dropping the ball which was something I rarely did.

I remember also feeling sick and developing a bad headache and reluctantly giving up the game and going inside to mum.

The moment mum checked me out she sent me straight to bed and she told me I had a very high temperature and if I was no better in the morning she would have the doctor come.

I ate very little if anything that night and the next thing I knew mum was coming in the next morning to see how I was.

I told her I wasn't really feeling well at all so she suggested she would help me to the bathroom so I could freshen up a bit.

Then the world fell in I tried to sit up but couldn't move and with even the slightest movement felt agonising pain.

I still see the look on mum's face as she said as mums do ... "*Don't move*" ... as if ... "*and I'll get help*".

She bolted down the road to our nearest neighbour, Mrs Kentwell, and asked her if she could mind my two young sisters while she ran to the nearest phone to call for the doctor. At the time of these last few weeks dad was in Concord Hospital and had just had major surgery so mum was on her own with us.

The rest of the day was a bit of a blur ... I remember Dr Kellow coming and checking me painfully over and then he went and later came back with Dr Boxhall who both then left and came back about 5 pm with two more doctors who they told mum came from Macquarie Street.

I was told much later that our dining room was just like King Arthur's Court with all these people seated around the round table deciding on my fate. It's a pity nobody said, "*Hang him*".

The next thing I remember was lying in the back of an ambulance being taken to Prince Henry Hospital and asking mum if she could ask the man to put the siren on.

The siren was the last thing I heard ...

I vaguely recall sometime being in this box with just my head on the outside and hearing thunkerty thunk, thunkerty thunk.

They had apparently put me in an iron lung until such time as I could breathe unassisted.

I woke up one morning about two months later and even though I couldn't really move my head I could see I was in a place where I was surrounded by other beds that had lots of little kids like me in them.

I was encouraged to go to the toilet by having this rubber pan thing put under me and I had to drink masses of this yukky liquorice sort of stuff to start me going, boy did I hate that stuff.

Sand bags were laid along each side of my body to stop any movement, not that I was able to move, and I virtually just had to lay there.

We were only allowed visitors once a week and that was for an hour on Sundays and that was only through a glass window.

I remember the first time I saw my dad after all that time he had been away and all the time I had been away from home, it was the first time in my life I remember having received a shock.

Before dad went to hospital he had black wavy curly hair and here was this stranger standing there weeks later with streaks of grey, he just didn't look like my dad.

I can only imagine now how mum and dad must have felt thinking they might lose their son.

Polio not only affected me but all those around me who loved me as well.

One day as I just lay there the ward sister came with my mum, actually right up to my bed the nearest I had been to mum for weeks and I remember crying as I felt mum's hand on my arm.

The news was that mum was there to accompany me in the ambulance where I was to be taken to St George Hospital at Kogarah which was much closer to home for visiting, and visiting was three times a week there.

Could it get any better than that?

I spent almost two years there and most of it was strapped to an iron frame to keep my body stable.

Sister Murray who was in charge of the children's ward was really terrific when I look back, even though the nurses thought of her as a tyrant.

She went out of her way for me by having the hospital engineer make me a piece of equipment similar to a periscope so as I could look out the window and had them make a glass top frame for me which books could be opened and laid across so I could read.

The nurses always prayed I would be given thin golden books so as they wouldn't have to turn over too many pages.

Every day a physiotherapist, Miss Temperley, would come and undo each of my limbs and try to get them mobile. It used to pain like the dickens and I used to scream the place down and call her for everything, yet it was Miss Temperley who got me walking and it was Miss Temperley who sent me Christmas presents for the next ten years.

When I finally left hospital I had a calliper on each leg, a steel body brace and walked with the aid of crutches, a true man of steel.

For the next three years that I attended primary school I was picked up from home three mornings a week by ambulance, transported to St George for physio then taken back to school.

Most times I wouldn't arrive back at school until about 1:30 pm and because I was considered to be somewhat of a cheeky devil and always caused chaos in the class by disrupting everybody at the time of my arrival, the teachers thought it more appropriate if I went straight to the library instead of class after hospital and assist by covering and repairing books.

I never ceased to be amazed that in reality with only two days a week education I was able to finish primary school with marks that enabled me to be accepted by Sutherland High and put in 1A, a two language class. I even got to be voted as class captain.

If I thought this was how life was I was wrong as at the completion of first year my specialist decided to have me admitted to hospital for a spinal fusion operation, due to the problem I had developed because of throwing my leg out while walking with my large calliper which had in turn thrown my hip and spine out.

I remember arriving at hospital at the ripe old age of thirteen and immediately being harnessed in yet again another steel frame with weights off each end to stretch me. The session on the rack lasted for three months when the doctor realised that I had not quite as yet stopped growing and my operation would have to be deferred for another two years in his estimation.

This was all very well except during those next two years I had to wear a full plaster cast from my neck to over my hips to stop any further deterioration to my spine and hips after their fine stretching job.

During the summer months it was agony I remember with my cast being soaked with perspiration and not being able to scratch the unbearable itchiness.

The cast was only changed every six months by suspending me from the ceiling by a support under my neck and once it was removed each time believe me you couldn't get too close to it as it was really on the nose.

For the first year of this period I was able to continue my schooling by correspondence from a place called Blackfriars College which wasn't too bad but the following year back at school with the plaster cast was hell.

Ultimately at the age of fifteen I was again admitted to hospital for the spinal fusion but not before another stretch session.

At the time of this latest stretch session I developed an allergy to the elastoplast that secured my leg weights so that all the weights had to be transferred to hang off my neck over the head of the bed.

The nurses would have to manually ease off the weights during meal time so that the pressure could be eased off from under my chin and I could eat and those five minutes three times a day felt like heaven.

Eventually the operation was performed and even though I contracted pneumonia afterwards and nearly died I came through fighting fit.

The relief of not having a plaster cast any more I could not put into words, but then at the age of sixteen I did a very stupid thing and threw away my callipers as I did not consider them to be chic magnets, something which I have deeply regretted.

At sixteen years old I was fortunate to obtain a job on my first application and joined a printing company as a trainee accountant which necessitated three nights of college a week in accountancy class.

The managing director Mr Colin Begg, God love him, decided after three years my personality did not suit the serious attitude an accountant should possess and had me trained in management.

At the ripe old age of twenty-five I had attained the position of Assistant Manager, Office Manager at thirty, Production Manager at thirty-five, and General Manager at thirty-nine.

Upon the death of the managing director the other directors voted that while the company was in a viable situation it should be sold, so we were purchased by a Printing Group which at the time owned nineteen other printing businesses and of which I was given the position of Sales Administrator overall.

I was forty years old at the time, had been happily married for the past five years, and thought my life is now secure.

Roughly though about six years further down the track things started to go wrong. I began suffering pain constantly and falling for no apparent reason as well as not being able to sleep.

My doctors were not able to help me and were at a loss as to what was happening.

By the time I turned forty-nine I was unfortunately forced to quit my position due to continued pain and unexplained physical failings.

My wife though who is a very astute little person decided there must be an answer and came upon in her investigations a condition called Post-Polio Syndrome.

She located an organisation called Post-Polio Network (NSW) Inc and made it her business to attend all their meetings to learn all she could about this newly discovered condition.

She became so engrossed with the organisation she is now serving on the committee as their Publicity Officer and I must say does a great job even though we have entirely different outlooks on most things.

My physical condition continues to deteriorate but as I now know the reason, I accept it more readily with a greater understanding as to what is happening to me.

I would personally like to thank the Post-Polio Network as well as the American Disability Board for their continued support, and I still can remember that I used to jump puddles.



AGM Seminar Report - 21.11.2018

By Susan Ellis

Pain Management - Margaret Knight

Introduction:



Margaret's background is teaching. Students ranged from Playgroup toddlers, through school aged children, to adult piano students, and interviewers for market research projects. She currently holds a Certificate IV in Workplace Training and Assessment and A.Mus.A. (AMEB). Since 1993 Margaret has used these teaching skills facilitating Support Groups in Pain Management Programmes for people with chronic pain to help maintain abilities acquired.

In 1990, Margaret suffered a back injury, three ruptured lumbar discs. The next three years were spent learning how to negotiate the maze of the health system while undergoing many invasive procedures and surgeries. She was left with chronic pain and took part in the pilot of ADAPT (the pain management programme used now by Royal North Shore Hospital). The key message she learnt was that people need to be pro-active in their treatment and they need a support team to help them negotiate a long, difficult, road.

Twenty-five years on Margaret is pain free and experienced in all aspects of peer support – phone support (including suicide prevention), she continues to support and encourage people in pain, undertakes community speaking, and organises seminars and forums. She is an active consumer representative and advocate. She has worked with NSW Health Committees and a range of not-for-profit organisations. She is a consumer representative with the Agency for Clinical Innovation, a coordinator of the Northern Sydney Persistent Pain Professional Mental Health Group and facilitates a number of pain support groups.

Margaret feels that she has found a way to escape from the trials and limitations imposed by chronic pain and aims to help others to also improve their quality of life.

Report:

Being invited to speak to Polio NSW had brought back memories for Margaret of when she grew up in Brisbane in the 1950s; all around her were children who she went to school with who were suffering from polio. The Brisbane Show was cancelled for a couple of years for fear of catching polio. Sister Elizabeth Kenny was working out of the Darling Downs with her wonderful and controversial treatment where she would massage and flex people's limbs. In the Woman's Weekly, the local paper and the Courier Mail there were pictures and stories of kids in iron lungs. It was a terrible, terrible time.

She recalled when thinking about the massaging that from 2-4 years old she had callipers on her legs and she could remember the gnawing hollow pain in her bones that she used to get. Her parents used to massage her legs using Sister Kenny's methods, flexing her legs and for some reason metho was involved, they used to rub her down with metho and if she smells it today she recalls those days.

When Margaret was looking for pictures for her power point presentation she discovered a picture of some little boots with callipers attached and you can imagine that at age 2-4 hers must have been very, very tiny. She remembered them hanging up on a nail in the garage. However, she doesn't know if she actually had polio, she thinks maybe she did. Margaret's parents would have known and her brother arrived after she got the boots off and she

never asked her parents but just got on with her life. She doesn't really know why she had the callipers on but she can't think of anything else that it could have been.

Margaret happily got on with her life as we all do. She worked in market research in radio ratings and during this time injured her spine after carrying heavy boxes and twisting. This resulted in a prolapsed disc in her spine followed by three years of all sorts of surgeries and injections of pawpaw enzymes with the result that her back problem got fixed with screws and rods in her spine. All of this trauma to her spine over-sensitised her nervous system. Even the roots of her hair and teeth and even her toes would just ache. All of this interrupted her life, as polio did for us when once again polio came back into our lives and we didn't like it!



This picture shows how Margaret felt, she was glowing with pain and her whole body was sensitised. There wasn't a lot known about pain back in the 1980s; with the help of pain clinics and physios and psychologists, lots of reading and researching herself and a lot of hard work swimming and exercising she found out how to manage her pain. It took a lot of years. There were also a lot of drugs involved but this wasn't the important thing. **Margaret learnt how to turn down the volume of her pain.**

The main thing is to know what you can do to help yourself. The important thing is that you can learn how to turn the volume down on your pain. Just from do-it-yourself methods such as emotional management, movement and pacing.

So where does pain come from? Your brain is in charge of you, it is trying to guard and protect your body and it has sensors everywhere, in your teeth, fingers, in your hair, as well as internal senses. If the brain finds any threats it will give some sort of alarm and the alarm is often pain. The alarm could also be that you are cold, or breathless or you detect a sour taste in your mouth. The brain has a memory and it will tell you not to touch that, the last time that we touched that you got burnt. 24/7 your brain is on alert to protect you, it detects for threats everywhere and tries to remember those threats but sometimes it gets too enthusiastic and it can give you a bit of a false message (gets confused) and is very over-zealous in trying to protect you.



If you look at this picture, see if you can taste the lemon - is your mouth watering? Try to remember the taste of a lemon and your brain should produce saliva in your mouth. This is part of the warning system to tell you that this is tart.

Sometimes people are told that their pain is just in their head. Well it is but it is not your imagination, it is your brain using its senses to get a message to you to guard your body. It can make mistakes, however, as illustrated by this story

There is a pain specialist called Lorimer Moseley – he was walking through the bush pushing through some long grass and he thought he got his leg caught on a thorn but he kept walking and the next minute he was on the ground and dying. He had been bitten by a brown snake. His brain had processed the data as that he had been scratched by a thorn. He nearly lost his life, he was in intensive care and it took him a long time to recover. Eventually he got back to bush walking again and this day he was walking through the

bush and he felt a sensation to his leg and his brain immediately threw him down on the ground put him in agonising pain and he thought he'd been bitten by a brown snake again. This time it **was** a thorn.

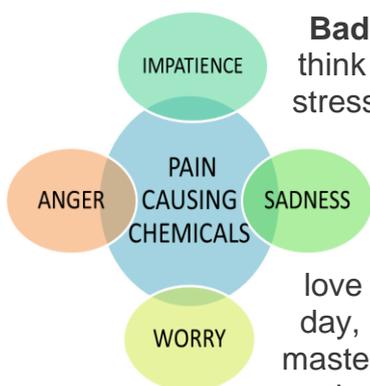
His brain was so over-protective that it didn't want him dying so it reproduced the sensation that he had when he had been bitten. So the brain can get a bit over-zealous sometimes.

One of the ways that you can learn to turn down the volume of your pain, whether it be a migraine, a broken leg, arthritis, polio pain (i.e. muscle and joint pain, muscle cramps and spasm, over-use aching pain, fatigue) is to be aware of things that can make the pain worse and, if we can manage to control those things, to a certain extent we can turn the volume down.

One of those things is **emotions**. When Margaret's pain was bad such as when she would be trying to get the dinner, leaning against the kitchen cupboard hardly being able to stand up because her back was aching so much whilst doing her best and struggling on and on. She remembered when her husband came home one night, he dumped his bag down, knocked over a vase which smashed, so there was glass and water and flowers everywhere and the cat was walking through it and the chips were burning – her pain just went through the roof. Stress can make your pain worse and if you are coping with pain problems, family problems, trying to meet a deadline for work, something like that, all of those sorts of things can exacerbate the pain. So if you can plan daily with what has to be done by looking over things the night before, writing it down in a notebook so you don't worry about it during the night, then leave the problems until the morning.

Also, before you go to bed it is a good idea if you can list five nice things that happened during the day, happy things, like you've had enough to eat, you are safe, your daughter rang you up, a flower came out – SO you can go to sleep in a nice frame of mind. You can talk to your brain! Margaret talks to her brain all the time. She might say 'look you have told me about that pain, you don't have to make it as strong as that, just tone it down'. Margaret now has arthritic pain to deal with.

Look after your emotions:



Bad emotions: Impatience, Sadness, Worry, Anger. You might think that you've got lots to do – kids, the dog, work – people get totally stressed. You might be impatient, sad or worried or think that life is not fair and you'd like your normal life back. When you stress about those things there are pain-causing chemicals that are produced and they can make your pain worse. So if you can manage to dampen these thoughts and encourage good thoughts ie your love of grandchildren or pets, something to be happy about, a lovely day, going on a holiday, perhaps some exercise that you have mastered, an achievement of some sort, a recipe – all those good emotions produces **pain lowering chemicals** and that is another way to turn the pain volume down.

You might also like to think about taking control of your life and get involved. When polio reared its head again you might have thought that you'd already defeated it once and this isn't fair – this can knock you about a bit and it can feel like you've got no control over your life, over your pain. Margaret did feel like this with her pain. If you can take active control over your life and find out information for yourself, question your doctor – be firm about wanting an answer about issues, "I'm not leaving here until you tell me about ...".



Taking control really encourages good pain chemicals and makes you feel like you are more in charge of things.

Remember when you said that when you grew up you'd do whatever you wanted, well you are grown up, you are the boss of you, you don't have to make everybody happy. Women especially think that they have to make everyone happy BUT you deserve a bit of priority too. So try and take care of your feelings daily, **REMEMBER TO BE KIND TO YOURSELF.**

Check list:

Don't sweat the small things – if you are caught in traffic put on some music, have a coffee.

Take a few deep breaths if you are in a stressful situation.

Count to ten – relax to reduce pain.

Know you are capable and brave – braver than you thought, look back at all the things in your life that you have managed to get through, you ARE very brave.

Don't hold grudges, it doesn't do you any good, try to forgive people.

Adopt an attitude of gratitude, we live in a lucky country, no wars, plenty of food.

You are allowed to say NO – if you feel that you can't do something, you don't have to give an explanation just say "*I'm very sorry but I can't do that*". It is very hard to do sometimes but it's a good thing to remember.

We are all made to **move**. If you can stand up ONCE an hour all day it adds up to 15 mins on the treadmill, so if you are watching TV, stand up once an hour, you'll be doing yourself some good. Moving is good for you, it produces endorphins which chase pain away – yet another way to turn down the pain volume. Going to a gym is great for formal stuff but moving for fun is just as good. When you are watching TV, try wriggling your legs or arms, it all uses up calories and gets your circulation going. You can go for a walk but remember you have to get home again so don't go too far and don't carry stuff. Get out into nature – go to the park, garden (even in pots), it gives you a lot of satisfaction being out in the fresh air. Go for a swim or paddle, it is good for your soul. Dance in the kitchen, dance with the dogs, turn the music up loud in the car, singing is good for your lungs, wave your arms – conduct an orchestra, it's good for your arms, play with your grandchildren, throw a ball against a wall, play totem tennis. However, with polio be aware and don't exceed your fatigue limit, just know your body and know how much you can do. Just have fun, no one's going to see you!!

For three years Margaret had been asking for a kayak and last Christmas she got one. She has it in her swimming pool. She paddles five strokes forward, turns and 5 strokes backwards, it gets her moving, it's fun. She also takes a glass of wine with her!

Pacing: Horses do it, expectant fathers do it, athletes do it and you should definitely do it. Athletes do it, we can't swim 1500 metres, can't run a marathon, it takes planning and pacing to achieve it. Pacing is vital to pain management, if you go flat out you will run out of puff and make your pain worse, especially as you have had polio. We might say that we need to clean the house, visitors are coming, so we keep pushing through, pushing through, the visitors come, you've got no energy left and you just feel like going to bed. Same with Christmas, shopping, etc. etc. and in the end you can't enjoy it. So just remember you are the boss of you, you are grown up now, you can do what you want. If you can't do something, you just say "*I'm sorry I can't do that, we are going to buy the pudding this year, I am not going to make it. We are going to have a picnic in the backyard. I'm not going to clean my place (or perhaps I'm going to come to your place and you can clean your place!)*."

Perhaps you want to mow the lawn; you don't have to mow the whole lawn all at once.

Think about everything that you want to do as a 'smorgasbord' – it is hard to learn to do this – and do two strips of lawn, go and wash your car, you can sit down and peel the beans using a different set of muscles with each task so you don't wear yourself out. Or if your body is telling you then just have a rest for half an hour. There is no crime in having a rest. If you can conserve your energy by pacing you can accomplish your goals.

Margaret reminded us of the story of the hare and the tortoise. The hare was once boasting about his speed before the other animals, "*I've never yet been beaten when I put forth my full speed. I challenge anyone here to race with me*". The tortoise said quietly "*I'll accept your challenge*". "*That's a good joke*", said the hare, "*I could dance around you all the way*". "*Keep your boasting until you've won*", said the tortoise – "*Shall we race?!*". A course was fixed and a start was made. The hare darted almost out of sight at once but soon stopped and, to show his contempt for the whole tournament, he laid down to have a nap. The tortoise plodded on and plodded on and when the hare awoke from his nap he saw the tortoise just near the winning post and he could not run up in time to save the race. Then the children said – "*Slow but steady progress wins the race*". So we need to be tortoises and then we will win.

**REMEMBER:
Manage your emotions
Keep Moving
Pace yourself**

YOU WILL KEEP THE VOLUME TURNED DOWN ON YOUR PAIN

Polio survivors self-report on the impact of impairments and fatigue

Paul Cavendish, Clinical Educator for Polio Australia, has forwarded the following request to take part in a survey he is conducting regarding the late effects of polio (LEoP). Your input will be appreciated.

I am forwarding a survey to measure the impacts of the late effects of polio (LEoP) on everyday life and fatigue. I would appreciate your support in completing this survey and/or forwarding it on to polio survivors you know who may be interested in completing this.

Survey Link: <<https://goo.gl/forms/YOfrr9q18iZan1pu1>>

This information helps us when we advocate for polio survivors' needs within the areas of health and disability. We also continue to educate health professionals with current and specific information. By giving health professionals more details on the impacts of LEoP, it will help them understand how to treat and manage fatigue (and your overall health). Providing results of this survey to health professionals also encourages further research by universities and professional peak health bodies regarding LEoP.

The survey should take approximately 8 minutes to complete. We do not collect any personal information with this survey. Your responses are anonymous.

If you would like any further information about this survey or for a printed copy, please contact me via 0466 719 013 or <paul@polioaustralia.org.au>.

Thank you in advance for your support. Kind regards, Paul Cavendish



Call for submissions: Growing Up Disabled in Australia

Posted December 3, 2018

A new anthology is open for submissions from all writers in Australia who identify as disabled, deaf, Deaf or chronically ill (under the social model of disability). The collection will be edited by blogger and appearance activist Carly Findlay, author of the forthcoming memoir “*Say Hello*”.

Submissions should be between 1000 and 4000 words of non-fiction pieces that deal with any aspect of growing up chronically ill, deaf, Deaf or disabled. Submissions can be in any manner, tone or style, but should not be academic or scholarly. They should be written in first-person and be honest accounts of lived experience – positive, negative or anything in between.

Frequently asked questions and details on how to apply can be found via the link below. For further questions, enquiries should be addressed to Kirstie Innes-Will:

Email: kirstie@blackincbooks.com

Closing Date: Fri 31st May, 2019

www.daru.org.au/resource/call-for-submissions-growing-up-disabled-in-australia

FAQ

What is the social model of disability?

According to the social model of disability, disability is socially constructed. This is in contrast to the medical model, where a ‘disability’ is a health condition managed by medical practitioners. According to People with Disability Australia: ‘The social model sees “disability” is the result of the interaction between people living with impairments and an environment filled with physical, attitudinal, communication and social barriers. It therefore carries the implication that the physical, attitudinal, communication and social environment must change to enable people living with impairments to participate in society on an equal basis with others.’

What if I have an impairment or chronic illness but don’t like being called ‘disabled’ / don’t identify as ‘disabled’?

Please submit anyway – and feel free to discuss this in your piece. We know that not everyone agrees on what terms should be used.

Do I need to have been born in Australia?

No – but you should either live here currently or have spent a substantial part of your life here.

What does ‘growing up’ mean?

‘Growing up’ can refer to childhood, adolescence or your evolving identity as an adult.

I’ve never been published before. Does this matter?

No.

Will you accept poetry?

Yes, as long as it is based on your lived experience. Poems should be no longer than seventy lines.

Should I avoid writing about abuse / self-harm / sex / illegal drugs, etc?

We encourage all contributors to write honestly about their experiences. As the anthology is partly aimed at teenagers, during the edit process we may suggest some modifications to avoid unnecessarily explicit content but pieces will not be excluded on this basis.

Where can I go for help to write my story?

The following organisations can offer advice and support:

- **Accessible Arts NSW** <www.aarts.net.au>
- **Writers Victoria – Write-ability** <writersvictoria.org.au/writeability/>
- **Access 2 Arts SA** <access2arts.org.au/project/writing-me/>
- **Arts Access Australia** <artsaccessaustralia.org>
- **Belconnen Arts Centre** <www.belconnenartscentre.com.au>
- **Arts Access Victoria** <www.artsaccess.com.au>
- **Arts Access Darwin** <artsaccessdarwinblog.wordpress.com>
- **Access Arts QLD** <accessarts.org.au>
- **DADAA WA** <www.dadaa.org.au>
- **Incite Arts** <incitearts.org.au>
- **Writing NSW** <writingnsw.org.au/support/writers-with-disability/>
- **Scope Australia writers program (2015)**
<www.scopeaust.org.au/news-event/calling-writers-artists/>

Can I write under a pseudonym?

Yes, but you must sign your contract using your real name so please give us both on submission.

Will I receive payment if my piece is accepted?

Yes, all contributors will be paid.

When will I find out if my piece has been accepted?

Due to the large number of submissions, selection can take quite a long time. You will receive a response letting you know if your piece has been accepted or not by 1 October 2019.

Polio Post



Rose Cogger-Collins, who is a member of the Hunter Polio Support Group, wrote to Polio Australia recently. Her email was passed onto Paul Cavendish, Clinical Health Educator; his response is included. Information about **Medical Energy rebates** follows on from this. Rose was also part of an ABC story about post-polio. <www.abc.net.au/news/2018-03-18/the-modern-fight-against-post-polio/9544276> Rose and Paul have kindly given their permission to include these emails in this newsletter.

In the last few years I have been diagnosed with having had polio in my childhood (my sister was paralysed with it) but it affected my lungs, I only have 90% oxygen in my blood, throat muscles and the Hypothalamus in the brain. After several years of tests and investigations I was advised I would have suffered from polio.

The damage to the Hypothalamus causes me to suffer severely from the heat, I tend to go semi-conscious and carry a small fan and chill towel or have ice cubes on my chest when they are available. It is a major concern to me, my husband and family as this happens frequently, even in the Doctor's surgery if it is too hot.

I have found information on it from Dr Bruno's website but wondered if there was any more information regarding this. I am a member of the Hunter Polio Network, attend their meetings and other people have complained of this problem.

Due to the fact that it took Doctors so long to diagnose my condition I wondered if it would be a good idea to have University medical school students and nurses educated on the late effects of polio and to make them aware of the number of people who were never diagnosed at the time they contracted polio, but in their senior years now suffer from having it. *Regards, Rose Cogger-Collins*

Paul's Reply:

Thanks for your email. Can I please check that it was you that was interviewed by Nancy Notzon from the ABC earlier this year?

It must be very concerning for you and your family, especially now we are in summer.

Regarding the symptoms, I want to check you have had respiratory function tests? This should pick up any issues with muscles that may be compromised around the neck (innervated from the brain stem) and any compromise with muscle innervation at the chest (if you were assessed sitting and lying down).

We are familiar with many polio survivors who have thermal regulation issues, and this has been acknowledged by state governments, including NSW, with discounts available on power bills:
<www.service.nsw.gov.au/transaction/apply-medical-energy-rebate-retail-customers>

Bruno has indeed reported many issues regarding brain stem issues that can relate to damage to the hypothalamus. This is certainly something that Rehabilitation Physicians monitor and seek further investigation with managing thermoregulation. It is difficult for anyone to adequately assess the true loss of neurones. This is very much the case with issues at, or near, the brain stem unfortunately.

We are trying to get the word out regarding the late effects of polio, but we do have more work to do. We deliver workshops to health professionals, explaining the breadth of effects (e.g. limb weakness/paralysis, respiratory issues and or bulbar/brain stem effects). We also explain there are people who were initially diagnosed with "infantile paralysis" or "paralytic polio" and others who were never diagnosed, such as yourself, but all people have experienced motor neurone loss in the body.

We have run workshops at John Hunter Hospital and Port Macquarie Hospital, as well as at Gosford and Wyong last year. We have also developed slides for universities to include into their courses on the late effects of polio to explain the details I briefly described above so medical, nursing and health professional students are more aware of the existence of the late effects of polio.

I am happy to discuss any aspect of this email with you in more detail at your convenience.

Kind regards, Paul

Rose's Response:

Thank you for the work you are doing to educate the medical profession on the late effects of polio, I know this is a slow process but at last you and Polio Australia can run workshops to health professionals.

I was interviewed by Nancy Notzon from the ABC earlier in the year and she saw first-hand my reaction to heat as the strong light on me at the interview was too much and I went into the semi-conscious state but she put my chill towel around my neck and put a fan on me and I came good I also find if ice cubes can be put into my chill towel and lay it on my chest it really helps.

I had several years of respiratory function tests, both sitting and lying; the Respiratory Specialist even did one and advised me never to go in the surf as I wouldn't be able to save myself. He also referred me to the John Hunter Hospital Speech Pathology Department due to the throat muscle problem, this has really helped me.

I am a little insecure about going out on my own because when I have the heat turns I can't talk and I am unable to open my eyes however I can hear people talking and they always want to get an ambulance My doctor prefers I don't go to hospital as it only takes a little while for me to be able to talk again. My GP is very well educated on the late effects of polio and this has really helped me.

Thank you for providing universities with information to include in their courses on the late effects of polio as there must be many people who ignored their respiratory problems for years until it became worse as mine did and I did something about it.

Kind regards, Rose Cogger-Collins



Medical Energy Rebate

The Medical Energy Rebate helps eligible NSW households cover the costs of their energy bills. The rebate is for NSW customers who have an inability to self-regulate body temperature when exposed to extreme hot or cold environmental temperatures. To be eligible for the rebate, you'll need to have a diagnosis that you're **unable to self-regulate your body temperature.**

Note: Retail customers receive their energy bills directly from the retailer.

What you'll need

- the PDF form – 'NSW Medical Energy Rebate Application Form Retail Customers'
- your pensioner concession, health care or gold card details
- your personal and contact details
- your medical practitioner to complete and sign the relevant sections of the form
- your energy account details.

How to apply

- Check the eligibility requirements (*see below*)
- Select the 'Download PDF form' button.
- Complete the form.
- Ask your medical practitioner (GP or specialist) to complete and sign the relevant sections of the form.
- Send your completed form directly to your energy retailer.

Who's eligible?

You can apply for the Medical Energy Rebate if you or someone living at the address of the eligible customer:

- is a NSW resident
- is an account holder named on the bill of an energy retailer
- has an inability to self-regulate body temperature
- has been assessed by a registered medical practitioner (who is not the applicant) who has been treating them for at least 3 months
- meets at least one Primary Qualifying Condition and at least one Secondary Qualifying Condition
- holds one of the following concession cards:
 - Pensioner Concession Card issued by the Department of Veterans' Affairs (DVA) or Department of Human Services (DHS),
 - Health Care Card issued by the DHS, or
 - DVA Gold Card.

Things to keep in mind ...

- If you've been treated by different doctors from the Royal Flying Doctor Service (RFDS) for at least 3 months, you may still be eligible for the rebate.
- If you change your energy supplier, tell them you receive the rebate, so you can continue to receive it.
- You'll receive the rebate as approximately \$71.00 credit on each quarterly energy bill, up to a total of \$285.00/year. The amount is calculated daily from the day you apply.
- Commonwealth Seniors Health Card holders are not eligible for this rebate.

To download the PDF form (retail customers) go to:

www.service.nsw.gov.au/transaction/apply-medical-energy-rebate-retail-customers

If you are an "on supply" household (*you receive your energy bill from a strata manager or community/village operator*), please visit this page instead where you can apply online:

www.service.nsw.gov.au/transaction/apply-medical-energy-rebate-supply-customers

or phone 137788 between 7am -7pm or visit your nearest Service NSW Centre





2019 Polio Program Activities

With the 4-day Retreat being held in NSW in October,
there will not be a mid-year Seminar this year

Thursday 17 th to Sunday 20 th October	St Joseph's Baulkham Hills	Polio Australia's 9 th Polio Health and Wellness Retreat < www.polioaustralia.org.au/retreat-2019/ >
Wednesday 27 th November	Burwood RSL 96 Shaftesbury Road Burwood	Polio NSW AGM and 30 th Anniversary Celebration <i>Introduced by President, Gillian Thomas</i>

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Have you added your details to the Australian Polio Register?
www.australianpolioregister.org.au



Polio Oz News

December 2018 – Summer Edition

Bound For South Australia

By Jan McDonald, Geelong Polio Support Group (Vic)

Well, didn't we have another amazing Retreat!!! This year's annual Polio Health and Wellness Retreat was held at the beautiful seaside town of Glenelg, just out of Adelaide.

Winnie, Denise with her husband, Doug, and I took the trip West from Geelong. Once again, we were treated to 3½ days filled with information, friendship, and fun.

The site of the Retreat was also the venue for the annual "Walk With Me" event to raise money for the work of Polio Australia. So on Thursday afternoon we lolloped, tottered, strode, wheeled, and shuffled our way along the delightful waterfront, and thoroughly enjoyed the camaraderie along the way.

Each one of the three main days had a different focus; the Body, Mind and Spirit.

Friday's 'menu' centred on "The Body". We had a choice of several sessions including Myofascial Release, Balance, Breathing and Stretching Exercises, Meditation, Hydrotherapy, Fatigue, Muscle Loss, Foot Care, Sleep Health, Partnering Polio . . . the list goes on.

On Saturday, it was time to focus on "The Mind". This included activities to keep our minds activated, as well as having fun. Such a variety;

Maximising Independence, Chair Dancing, Finances, Making Mosaics, Early Polio Memories, and more.

Sunday's offering was around "The Spirit". Maryann Liethof, Polio Australia's National Program Manager, took us on a journey exploring "What makes your whole body light up?". This provoked quite a discussion amongst us – God, music, nature, art, family, what?? We then had a choice of discussion groups on Christianity, Buddhism, and Aboriginal Spirituality.

A highlight of the weekend was the Celtic Music Club of South Australia, which entertained us with tunes while we had dinner on Saturday night.

Of course, we did arrive back home utterly exhausted. We thoroughly enjoyed the days, and emerged armed with a few more hints and tools to help us feel "well-rounded" physically, mentally and spiritually.

A Retreat like this also makes us aware that without the planning, commitment and goodwill of Polio Australia organisers, as well as our local group leaders, we would not have this, and all the other help we get. Without the cohesiveness of all polio survivors, our voice will become silent, and we could easily become conveniently forgotten by government. So, a BIG thank you to all who do their bit to allow us to be recognised. 🌟



2018 Retreat and "Walk With Me" participants wearing orange bandanas. All Retreat photos can be viewed online [here](#).

Polio Australia

Representing polio survivors
throughout Australia

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“I love how summer just wraps its arms around you like a warm blanket.”

~ Kellie Elmore ~

President's Report



Gillian Thomas

As December rolls around it is time to reflect on the year's achievements, enjoy some down time over the holidays and, through both processes, get reinvigorated to do it all again next year!

Having received some funding from both the Department of Health and Spinal Life Australia, it was a pleasure to start 2018 with staff available to expand our services in the directions we had long dreamed of. At our team meeting early in the year, the meat was put on the bones of the 2018-2020 strategic plan developed by the Board at our 2017 AGM. To recap, our strategic priorities are:

- **Education** (raising public awareness of, and educating health professionals and polio survivors about, the Late Effects of Polio);
- **Capacity Building** (future proofing Polio Australia to ensure sustainability);
- **Partnership Development** (enhancing internal and external relationships); and
- **Advocacy and Visibility** (lobbying and advocating, whilst creating positive visibility in the community).

Our work throughout 2018 furthered these priorities.

Forty-three [Clinical Practice Workshops](#) were held, providing education to more than 580 health professionals, across every state and territory. The impact of the training on the lives of Australia's polio survivors is inestimable. As polio survivors we should encourage our own health professionals to attend a workshop when it reaches our area. Entries on the [Health Professionals Register](#) also grew apace – there are now 197 entries, across many professions

and in every state and territory. In the last six months, there have been eight well-attended [Community Information Sessions](#) on the Late Effects of Polio in Victoria and South Australia, with more to come in 2019 in these states as well as Tasmania. Funding is currently being sought to employ a second Community Development Worker to service New South Wales.

We reached a significant milestone this year, celebrating our tenth anniversary in August. In 2005, when I first proposed the idea of a national body to the State Polio Networks, little did I know that we would be thriving in 2018.

Our [Polio Health and Wellness Retreat](#) in October returned to South Australia. In a first this year, we held our AGM and a [Walk With Me](#) event in conjunction with the Retreat. Walk With Me is our major fundraising drive each year, with the beneficiaries being both Polio Australia and the State Polio Networks who participate.

Other highlights of the year included:

- Revamping the Polio Australia and *Still Here* websites to keep them topical, interesting, and easier to navigate;
- Expanding our social media activity and building a solid and engaged following through regular posts and discussion starters;
- Launching the [Next Generation Polio Survivors](#) project (including a new [Facebook Group](#)); and
- In 2019, we hope to introduce our fun, new 'Splish, Slish, Splash' education activity to schools across Victoria—see p23.

What a difference 10 years of effort, a growing funding base, and increased staffing can make!

In closing, on behalf of the Board, I wish you all a very Merry Christmas, and a healthy and peaceful New Year. 🌟

Gillian

From the Editor



Maryann Liethof
Editor

Blue skies, longer days, warmer weather, beaches, crazy-hot cars, flies, bush fires, drought . . . Aahhh, summer in Australia!

We were lucky to have a taste of this in Adelaide for Polio Australia's annual Health and Wellness Retreat and *Walk With Me* fundraiser in October—it's not too late to donate! 64 polio survivors and

their family/friends joined us from across Australia, as well as New Zealand and Taiwan! Jan McDonald's article on p1 provides an overview, whilst you will see more photos of our 'walkers' on p9. All photos of the Retreat are online here: www.polioaustralia.org.au/retreat-2018/. In October 2019, the Retreat will return to New South Wales; details will be updated on our website, as they become available.

Throughout this edition, you will see how Paul, Polio Australia's Clinical Health Educator, and Steph, our Community Engagement Officer, are both contributing to educating health professionals, and the community, respectively. You can read the results of a survey on the use of orthoses, as well as participate in a current one we have (below) on your experience of the NDIS (for those people under the age of 65).

October's Polio Awareness Month was also a busy time for Polio Australia, as we joined in with Global Citizen (and others) at Parliament House, ACT, where we also met with our Parliamentary

NDIS Survey

Polio Australia is interested in receiving feedback from eligible polio survivors on how you have found working through the NDIS process.

We are seeking information to better understand the experiences of people who have applied for the NDIS (successfully or not), and those currently registered with the NDIS.

Your feedback will help Polio Australia provide other polio survivors with practical information on possible problems when applying for the NDIS, and how they might be overcome.

The responses will be shared with polio survivors, and also provide feedback for the disability sector. The survey is anonymous and there is no identification of individual comments or names.

If you have any questions related to this survey, please contact: Paul Cavendish, Clinical Health Educator, Polio Australia, T: 0466 719 013 / E: paul@polioaustralia.org.au

Thank you for taking the time to complete the survey: <http://bit.ly/PA-NDIS-Survey>



Patrons, see p4. Steph was also invited to speak to around 70 participants at Polio Network Victoria's annual Polio Day.

There are many more program areas we've been working on, including a makeover of the www.stillhere.org.au website. Take a look!

A couple of articles will be of interest to people using motors scooters on p11, or anyone requiring accessible housing on p13—and who doesn't?

Dr John Tierney has been busy in his 'retirement', submitting two articles on p14-15; one on his visit to Sister Elizabeth Kenny's Memorial in Nobby, Queensland; and the other on his experience of growing up with polio in the 1950's.

Many people may have read about the 'polio-like' illness that is sweeping across the USA. Whilst it's definitely *not* the poliovirus, the condition is just as frightening—see p18 for an update.

There is also an inspiring look at how 3 polio survivors are now helping to eradicate polio in Pakistan on p20, and a link to a report on PNG's polio outbreak response on p21.

It has been a real delight for me to have been able to work with a fabulous 'Team' during 2018. And on behalf of all of us, I'd like to wish our readers all the very best for the Season, and a healthy and fulfilling New Year. 🌟

 Maryann



HAVE YOUR SAY

Complete the survey on
the National Disability
Insurance Scheme (NDIS)
for polio survivors

ndis

Polio Australia
Supporting polio survivors through a lifetime

next
generation

CLICK HERE TO COMPLETE

World Polio Day And Meetings With Parliamentarians

World Polio Day—24th October—was established by Rotary International over a decade ago to commemorate the birth of Jonas Salk, who led the first team to develop a vaccine against poliomyelitis.

Polio Australia joined forces with [Global Citizen Australia](#), [UNICEF](#), [RESULTS Australia](#), [Rotary International](#) and [UNICEF Australia](#) for a World Polio Day 2018 event, acknowledging the efforts to date, and the task ahead, in finally seeing polio eradicated from the world.

This World Polio Day event was held early on the 18th of October at Parliament House, to ensure as many parliamentarians as possible could attend. Polio Australia was represented by Gillian Thomas (President), Alan Cameron (Treasurer) and Paul Cavendish (Clinical Health Educator).

To read more or watch the video, go to: www.stillhere.org.au.



Gillian Thomas (front) flanked by MPs, Catherine King and Greg Hunt (PA's Parliamentary Patrons), and other attendees

Whilst in Canberra, Gillian, Alan and Paul Cavendish also met with Polio Australia's [Parliamentary Patrons](#), presenting them with two documents:

- [Clinical Practice Workshops: The last 12 months overview](#)
- [Polio vaccine recommendations regarding travel to Papua New Guinea for Australian travellers](#)

This included an important meeting with Health Minister Greg Hunt, who requested a Proposal from Polio Australia for a 3 year extension on Paul's Clinical Health Education Program. The current contract with the Department of Health ends at the end of June 2019.



Photo L-R:

Paul Cavendish,
Alan Cameron,
Gillian Thomas,
Hon Mark
Coulton MP and
Peter Garde.

Mark is Co-
Convenor of the
Parliamentary
Friends of Polio
Survivors
Friendship
Group, together
with Steve
Georganas, MP.

Polio Day In Victoria

On Saturday, 20th of October 2018, Polio Network Victoria hosted Polio Day at the Hawthorn Arts Centre. Approximately 70 polio survivors, their family and carers, and health and aged care representatives attended the lunch.

The theme was "We're Still Here", and included speakers presenting information to assist with navigating post-polio and the MyAgedCare system.

Steph Cantrill, Polio Australia's Community Engagement Officer, gave a presentation titled "What's New In The World Of Polio", where she provided an update on: Polio Australia's Clinical Practice Workshops; her own Community Information Sessions; various conference presentations; and the ["Next Generation"](#) project.



Program Updates

By Steph Cantrill, Community Engagement Officer

I have now been working with Polio Australia for six months. In some ways it's hard to believe it's been that long, and in other ways I can't quite believe it's only been that long!

The last six months have definitely been a time of learning. It's been great to have met with a number of polio survivors through the existing networks, and to have come across some 'new' people when they attended my community information sessions on the Late Effects of Polio. This has been a really valuable opportunity to connect these new people with other polio survivors, let them know that they're not alone in what they're experiencing, and help to guide them towards the support they need.

I've also had the opportunity to get the word out about the fact that polio survivors are "still here", through presenting at conferences and meeting with organisations such as service providers and local community organisations. "*Forgive my ignorance, but is polio still around?*" is something I'm getting more and more accustomed to hearing!

Moving into the new year, I'm looking forward to: expanding the information sessions into South Australia and Tasmania, finding ways to ensure that partners and carers are well-informed about the Late Effects of Polio, further advocating for the needs of older people with disability through the ATOP (Assistive Technology for Older People) Alliance, building networks with other community organisations, and continuing to learn as I go. 🌟



Orthoses Survey

Update on Polio Australia's survey on use, capacity and satisfaction with orthoses.

HOW ARE POLIO SURVIVORS GETTING AROUND?

58% of people used a customised shoe or prescription orthotic. There were 38% of total respondents who also used an orthotic device (i.e. a calliper, or knee/ankle-foot orthoses). The most common device used to provide assistance with walking was a cane (42%), followed by a 'wheelie walker' (25%), then scooter (24%). The importance of getting prescription right for avoiding pain, abrasions and general comfort is highlighted by the vast majority of people spending 80-100% of their day wearing their shoe/orthotic.

WHAT LEVEL OF MUSCLE STRENGTH IS THERE IN THE LEGS (AND BODY)?

70% of respondents reported weakness in the whole leg. While it is important to distinguish between weakness and need for further support at the knee or hip joint, there was a continual sub-set of respondents that reported difficulty with tasks that would indicate the need for re-assessment at the very least. The reliance on an assistive aid for balance, the extra energy involved and the work required by remaining muscles to weight bear or balance is a very important consideration. 38% reported forearm or hand weakness, which is important to point out for usability/independence with an orthotic device. 46% of respondents found it difficult to get their orthotic on or off, and 3% were unable to do this task.



By Paul Cavendish, Clinical Health Educator

Thank you to the 127 people who participated in the recent Polio Australia orthotics survey. We used a standardised tool called the "Orthotics and Prosthetics User Survey" to find out information and present the results at a national conference in Adelaide on customised footwear and prescription shoe orthotics. Please see the presentation [here](#). These surveys assist

us greatly with providing information back to health professionals to help them improve the way they do things.

Program Updates: Orthoses Survey (cont'd from p5)

WHAT'S THE FUNCTIONAL CHANGE WITH WEARING AN ORTHOTIC?

The two findings that really stood out related to balance and walking. The majority (72%) who were wearing their orthotic found it difficult to stand and balance. Given this result, I thought dynamic balance would be harder again, however, this may not be the case. Looking at the task of getting on/off the escalator, only 55% found this difficult. While there were more people who stated they could not do this activity (as expected), there was also an increase of over 100% in the number of people who identified this task as easy to perform. Finding the right orthotic that allows someone to feel balanced in their shoes is still a key challenge.

The difference between ease of walking indoors as opposed to outdoors was more in line with assumptions, while 48% of people reported it was easy to walk indoors. This fell to 7% when they were asked about walking outside. It is interesting to consider this result with emerging diagnostic tools that allow you to place insoles inside your shoe to map pressure as you walk. Often, walking is only recorded at a clinical setting with a flat floor. Perhaps in the meantime it will be worthwhile for a polio survivor to provide a video of walking outside at the next review or assessment to help clinicians improve in this area.

OTHER MESSAGES TO HEALTH PROFESSIONALS

I have heard from both sides of the fence that it's not easy to get the right fit when it comes to orthotics. While there is work to be done, polio survivors were, on the whole, appreciative of what their health professionals were doing. 8% of people didn't feel they were a partner in the decision-making process for the prescription of orthotics and 3% felt they were not given the appropriate level of respect. Lastly, we highlighted at the conference that only a third of respondents felt there was sufficient sharing and coordination of information with other health professionals and GPs.

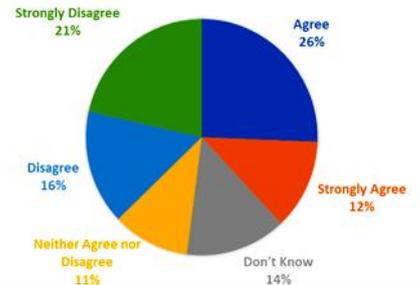
THE YEAR THAT WAS AND THE YEAR AHEAD

2018 saw over 580 health professionals trained with our workshops. We have started to deliver education to GPs, with two conferences at Brisbane and Melbourne. Next year, in conjunction with our workshop series, we have supplied universities with material and are in the process of developing an online course. There will be increased opportunity for health professionals to learn about the late effects of polio and assist polio survivors.

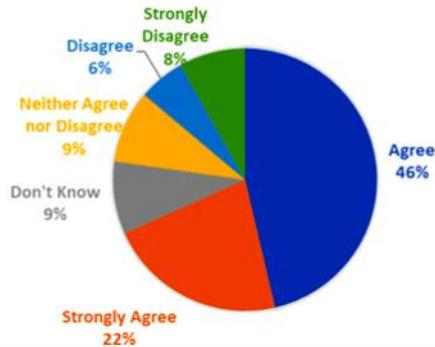
PS: The next survey we will be doing is on 'Fatigue'. . . 🌟



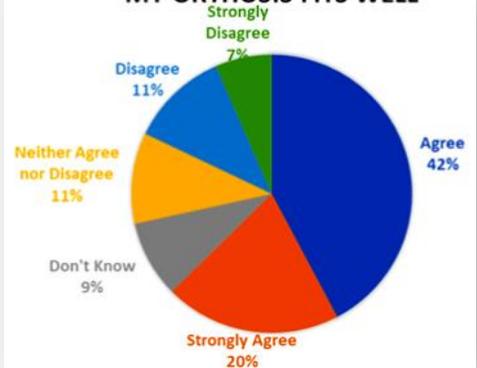
SELF-REPORTED CAPACITY TO AFFORD THE COSTS TO PURCHASE AND MAINTAIN ORTHOSIS



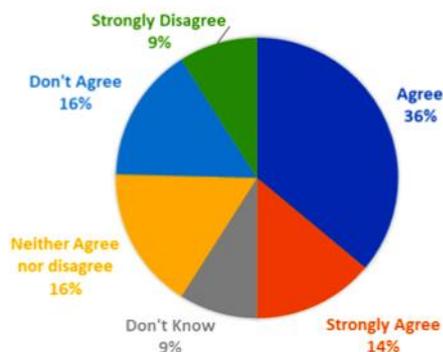
THE WEIGHT OF MY ORTHOSIS IS MANAGEABLE



"MY ORTHOSIS FITS WELL"



MY ORTHOSIS IS COMFORTABLE THROUGHOUT THE DAY



Australian Assistive Technology Conference

By Steph Cantrill

The Australian Assistive Technology Conference was held from Wednesday 14th to Friday 16th of November 2018.

The conference provided health professionals, developers and consumers with the opportunity to learn, share and discuss the importance of assistive technology (AT) as an enabler to independence and community participation. Technological advances were showcased, users gave their personal experiences of the importance of AT, and people were able to build their social and professional networks.



Polio Australia's Steph Cantrill, along with polio survivor and advocate Peter Willcocks, presented at the conference, with the topic: *"Still here and still needing AT: the complex needs of polio survivors."* The session was well received, and led to a few interesting conversations afterwards. It was a great opportunity to get the message out that there are still thousands of polio survivors in Australia, many of whom are experiencing the Late Effects of Polio, and that their needs for AT are many and varied. 🌟

Pedorthics: Striding Ahead Conference



Polio Australia's Steph Cantrill also presented on *"Getting the Assessment and Prescription Right with Polio Survivors"*, including some preliminary results of the recent Orthotic Users' Survey, at the *Pedorthics: Striding Ahead* conference on 22 September 2018.

This presentation was made on behalf of Clinical Educator, Paul Cavendish, and provided a great opportunity to talk about the unique needs of polio survivors with a group of pedorthists and podiatrists. 🌟

Brisbane General Practice Convention and Exhibition

In the meantime, Paul and Jake Malsbury, PA Admin Officer, attended the [Brisbane General Practice Convention & Exhibition](#) on 14-16th of September 2018.

With the chance to network with various health professionals from across the state of Queensland, Paul and Jake were able to educate delegates on the Late Effects of Polio and the work we do at Polio Australia.

They received great interest from many GP's as well as significant positive feedback for Paul's talk on the Late Effects of Polio. Great job Paul and Jake! 🌟



Jake Malsbury tending Polio Australia's Exhibition Stall

Supporting Polio Australia

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

Hall of Fame

Jill Pickering—\$20,000

Total—\$20,000

General and Regular Donations

Myrith Barr Jill Burn Simone Cassidy Barbara Cunningham Kim Duong

Joyce Hay S Langford-Wilson Wilf MacBeth Retreat Raffle Shepparton Info Session

George Seabrook Isolina Stansfield Liz Telford Gillian Thomas

Total—\$2,128.32

Rotary Club Donations For *Walk With Me*

Rotoract Club of Brisbane CBD (Qld)—\$500

Rotary Club of New Farm (Qld)—\$300

Total—\$800

Walk With Me

Glenselg, South Australia

11th October 2018

Polio Australia's annual fundraising event

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.

As of November 2018, 55 people have generously donated \$8,619.55



\$4,184.55 to Team Polio Australia (includes Rotary above)
 \$4,235.00 to Team Polio NSW
 \$400.00 to Team Victoria/PNV
 \$250.00 to Team Victoria/PPV
 \$250.00 to Team SA
 \$100.00 to Team QLD

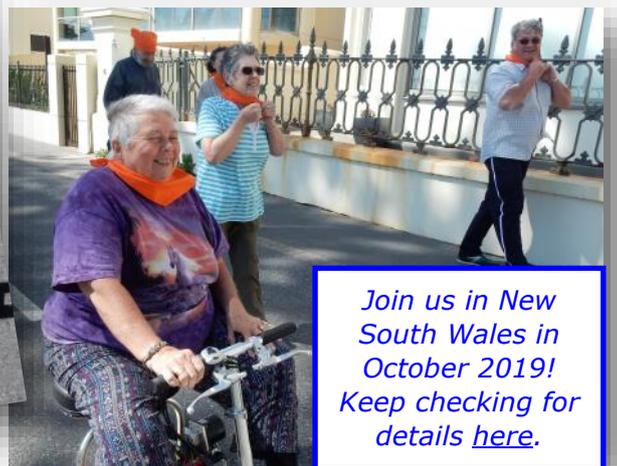
Donations for this event will be accepted until 31 December 2018.

www.polioaustralia.org.au/walk-with-me-2018/

Where agreed, 50% of donations raised by participating state networks will be allocated to those states to enhance their support for polio survivors.

Grand Total—\$31,547.87

Walk With Me Pictorial Highlights



Join us in New South Wales in October 2019! Keep checking for details [here](#).

Dare To Dream

By Steph Cantrill
Community Information Officer

At a recent ARATA (Australian Rehabilitation & Assistive Technology Association) [Australian Assistive Technology Conference](#), there was a presentation by an engineer from New Zealand who customises equipment to meet the specific needs of people with various disabilities. Some examples were wheelchair modifications, an electric toothbrush with an extra-large power button, and a hospital-friendly arcade game made from salvaged and recycled materials.

I gave a presentation titled *"Still Here and Still Needing AT: The complex needs of Polio Survivors"* on behalf of Polio Australia, along with a polio survivor to share his lived experience.

After our presentation, the impressive inventor-engineer approached my polio survivor associate, and asked him an interesting question: *"What is your dream piece of equipment?"* This was a great question, I thought. Why not get people to think big? So much of what we call assistive technology – all the gadgets, contraptions, and adaptations to everyday equipment that make life easier for people – must have come about from somebody daring to utter *"I wish..."*

Without much hesitation, the polio survivor gave his answer: *"A programmable wheelchair"*. Upon request for clarification, he added, *"It's been a long day and I'm tired. I need to get to the station after this. I wish I could just enter the name of the station into my wheelchair, sit back and have the chair take me there."*

This got me thinking. Really, the age of self-driving cars is almost upon us, so why should self-driving wheelchairs be far away? It wouldn't take too much technological advance beyond what's already at our fingertips. It just needs someone to come along and make it happen. Watch this space, I reckon!

And then the next question is – if you could have any piece of equipment, to help you do anything at all, what would it be? 🌟



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SCA33002

Senate Report On Motor Scooters

By **Kymerly Martin**

Source: www.freedom2live.com.au
—3 October 2018

A nationally consistent regulatory framework for motorised mobility devices (MMDs) was one of the key recommendations to emerge from a Senate inquiry. The Senate Standing Committee on Rural and Regional Affairs and Transport also noted that any future regulation of mobility scooters and motorised wheelchairs needed to be evidence-based and recognise the importance of safety of users and others, but not add any additional barriers or make access and inclusion more difficult for a frequently marginalised section of the community.

There was general consensus around the continuation of a 5 km/h minimum speed and a 10 km/h maximum speed. The committee suggested that this evidence be taken into consideration by Austroads as part of its future deliberations. The committee also recommended that Austroads take the report, and the evidence provided to the inquiry, into account for the purposes of its deliberations, in particular, education of users as well as licensing and registration arrangements and third party insurance.

From the very early stages of the inquiry, submissions from road transport and traffic agencies, community organisations and individuals expressed clear support for the development of a nationally consistent approach. Submitters also stressed the importance of finding a way to achieve both consistency and clarity in relation to the use and safety of mobility scooters and motorised wheelchairs.

Stakeholders acknowledged that achieving this outcome represented a challenge, from both a policy and legislative perspective. Researchers also concluded that motorised mobility device users, vendors and health professionals needed to work together to identify mobility devices that best fulfilled users' needs, were reliable and safe.

While the weight of mobility devices was raised throughout the inquiry, it was not identified as a key safety concern by submitters. However, the committee did have concerns about the lack of clarity in regard to weight limits and was of the view that further research is required to determine whether weight limits have any major impact on safety, and whether it is necessary to set limits in future regulations.



The inquiry has determined that there is considerable agreement around the need to develop less complex, nationally consistent rules and regulations relating to the use of motorised mobility devices. Based on evidence provided to the committee during its inquiry, the committee suggests that there is a high level of agreement amongst stakeholders in relation to:

- the need for individuals to be assessed by a medical professional, such as an occupational therapist (OT), prior to purchasing a motorised mobility device;
- the need for individuals to purchase a motorised mobility device that is suitable for both their needs and their (physical and mental) abilities;
- the need for users of motorised mobility devices to have access to appropriate training;
- the need for consistency in relation to the speeds at which motorised mobility devices are permitted to travel (including a maximum speed of 10 km/h);
- the need for further consideration to be given to implementing a simple, low-cost system which covers the licensing, registration and insurance of motorised mobility devices, including mobility scooters and motorised wheelchairs;
- the need for individuals to have met both medical and training requirements prior to being permitted to purchase, register and insure their motorised mobility device.

The committee was also of the view that the current lack of up-to-date data makes it very difficult, if not impossible, for authorities to determine exactly what the specific problems are that they need to mitigate against and supported the call for additional research.

Read full story [here](#) and to access the Government Report, click [this link](#).

Austrroads MD Rejects Prosecution Claim For MMDs

By Kimberley Martin

Source: www.freedom2live.com.au
- 17 October 2018

The suggestion that up to 30 per cent of wheelchair and scooter users could face prosecution if these devices were used on public footpaths because of their instability has been strongly rejected by Austrroads managing director, Nick Koukoulas, describing it as "absolutely inaccurate".

Koukoulas was responding to a media release from Scooters Australia managing director, Peter Fraser that Austrroads is proposing to make it illegal for any Class A scooter or wheelchair to be used in a public place on footpaths in Australia. The Class A category includes portable and collapsible mobility scooters and electric wheelchairs which are estimated to be used by nearly a third of mobility scooter users. The devices have been available for 20 years and can be purchased through the National Disability Insurance Scheme (NDIS).

According to Koukoulas the issue is devices that are designed specifically for indoor use are being passed off as suitable for use on footpaths and other public infrastructure. Their lightweight design, accompanied by small wheels and a high centre of gravity, makes them significantly more likely to topple over on gradients or navigating bumps on a path.

"The technical specifications will allow many small portable devices to meet the requirements for a blue or white label. These will need to be tested to the existing class B requirements for indoor/outdoor devices. However many devices that have been specifically manufactured for indoor use won't meet the requirements for a label. These are not designed for use on footpaths and won't be offered for sale as being suitable for use on such infrastructure", he said. "The labelling system is designed to make it clearer for persons at the point of purchase about the suitability of the device being purchased for its intended use".

Koukoulas said that further to this is the belief that standards are legal mandates when they are not. *"There are Australian and international standards that can be referenced regarding motorised mobility devices (MMDs), but none of the standards are law. The idea that legislation might be put in place to reference a non-binding standard is incorrect."*

According to Fraser, the Austrroads proposal does not prohibit the sale of these products, but proposes to ban them for use in all public areas which are under the control of state transport ministers. *"Portable scooters and powerchairs have become the most popular segment of the mobility market in Australia and around the world, simply because they have such broad applications. They can be taken on aircraft and cruise ships and fit easily into a car boot", he said.*

Changes To Accessibility Housing Standards

By Lizzie Hunter

Source: www.freedom2live.com.au
- 30 October 2018

Further evidence is needed to justify any regulatory changes to the National Construction Code when it comes to accessible housing. Speaking at the Australian Building Codes Board's Accessible Housing National Consultation forum in Sydney, ABCB senior project officer, Kieran O'Donnell said there has to be an identified need for change to happen. *"And we are trying to figure out what that need is."*

The national forums that took place this month provided an opportunity for the community to have their say on the ABCB's Accessible Housing Options Paper. Released in September, it provided a preliminary menu of options and costings on the possible inclusion of a minimum accessibility standard for housing in the National Construction Code (NCC).



The release of the paper followed calls from designers, researchers, people with disability and seniors for the government to introduce regulations mandating that new houses meet accessibility standards.

Accessibility Housing Standards *(cont'd from p11)*

O'Donnell told delegates attending the forum that the ABCB is looking at the level of unmet need for accessibility features within housing, rather than saying there's a problem with including those features.

"There are a few different figures as to how that unmet need is quantified", he said. "One figure we will use at this stage of the process came from Liveable Housing Australia where it was estimated around 5 per cent of housing that was being constructed complied with their guidelines.

"While that's not a large figure, it's worth noting that it does not mean that the other 95 per cent of houses are inaccessible. It simply means that within that 95 per cent, there is a portion of people who have made their own arrangements; another that will be supported through the NDIS and other programs or schemes; and finally those where the occupants have been unable to find housing appropriate to their needs, and these are the people we are looking to address through this project.

"We need further evidence and information if we're going to be able to justify advising a regulatory change to the National Construction Code."

Read full article [here](#).

International Pain Awareness Month

September was International Pain Awareness Month. Chronic pain is an issue that affects many people worldwide as a direct or indirect feature of numerous long-term diseases. However, despite affecting a huge and diverse patient population over many disease areas, the enormity of the challenges faced by patients living with chronic pain is often under-appreciated globally.

Read more in Pain Australia's e-news here: www.painaustralia.org.au/media/enews

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Australia's pain burden: a snapshot

- 1 in 5** GP consultations involve a patient with chronic pain.
- 40%** of forced early retirements in people of working age are due to chronic pain.
- Chronic pain costs the Australian economy **\$34+ billion** per year.
- Effective and timely treatment could reduce this cost by **50%**.
- 1 in 5** Australians (including kids and teens) are affected by chronic pain.
- 1 in 3** over 65 are affected by chronic pain.
- 80%** of aged care residents are affected by chronic pain.
- 30-40%** of Australians with chronic pain presenting for treatment have major depression.
- Suicidal behaviour is **2-3** times higher in people with chronic pain than the general population worldwide.

For help with ongoing pain visit: www.painaustralia.org.au

CHRONIC PAIN RESULTS IN COSTS TO QUALITY OF LIFE AND OUR ECONOMY

- Effective and timely treatment could reduce this cost by **50%**.
- \$34+ billion** in costs.
- 40%** of forced early retirements in people of working age are due to chronic pain.
- The annual cost of pelvic pain alone in Australia is **\$6 billion**. It affects **5%** of girls and women and equates to **11 hours** of productivity a week.
- Productivity costs associated with arthritis and other musculoskeletal conditions alone were estimated to cost the economy more than **\$7.4 billion** in 2012.

painaustralia

Barriers To Accessing Quality Palliative Care

Australian Healthcare Associates (AHA) has been engaged by the Australian Government Department of Health to explore the barriers that people may experience in accessing quality palliative care.

What is palliative care?

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness. This is done through the prevention and relief of suffering by early identification, assessment and treatment of pain and other physical, psychosocial and spiritual problems (World Health Organization).

The project focusses on nine groups of people who are under-served or have complex needs.

If you are from one (or more) of these groups, AHA would like to hear from you – whether you have experience of palliative care services or not.

- **People with a disability**
- People who are lesbian, gay, bisexual, transgender or intersex (LGBTI)
- People from culturally and linguistically diverse backgrounds

- Aboriginal and Torres Strait Islander people
- People experiencing homelessness
- Veterans
- Refugees
- People who have been incarcerated
- Care leavers (which includes Forgotten Australians, Former Child Migrants and Stolen Generations) and people affected by forced adoption or removal.

We'd like to hear your thoughts on end of life and palliative care, barriers to access, and how services could be improved. You can talk to us on the phone or in person, or be part of a group discussion. Anything you tell us will be kept anonymous.

Participants will be reimbursed with a \$30 gift voucher and we will also provide light refreshments.

To be involved, or for more information, please ring Greer or Shae at AHA to book an appointment or telephone interview on 1300 788 667 (local call cost) or email palliativecare@ahaconsulting.com.au.

Visiting Sister Kenny's Memorial

Visiting Sister Kenny's Memorial at Nobby, Darling Downs, Queensland

Dr John Tierney OAM National Patron Polio Australia

Driving back from Brisbane to Newcastle recently, Pam and I took the inland route via the Darling Downs and there in the run-down hamlet of Nobby in rural Queensland, stood a modern brick building housing a memorial to the work of Sister Kenny, the pioneer of the most effective treatment for polio survivors in the first half of the last century.

For her ground-breaking work, Sister Kenny received many honours from the medical community overseas but nothing from Australia, where her treatments were opposed by the 'experts'. It was only when her adopted daughter, who also became a polio therapist, took the initiative, that this memorial was

created by private donation and the support of the Country Women's Association.

Why the hamlet of Nobby? It was here, on the rich soils of the Darling Downs, that the Kenny family finally settled and farmed at the turn of the twentieth century and where Sister Kenny grew up. The creators of the local memorial building have done her proud. As the [photos](#) show, around the building interior is memorabilia including large posters that are testament to the width and depth of her work for polio survivors world-wide and the international communities' recognition of her contribution.

In one touching document is recorded stories about what Sister Kenny did for individual survivors, in their own words or that of their descendants. Sister Kenny died aged 72 in nearby Toowoomba in 1952 and so didn't live to see the Salk vaccine largely rid the world of the scourge of polio.



Have you visited Polio Australia's "Still Here!" website yet?

You can read more stories like Dr John Tierney's visit to Sister Kenny's Memorial, complete with photos. You can also catch up on various polio-

related newspaper articles and radio interviews. And much, much more!

www.stillhere.org.au

Growing Up With Polio In Australia In The 1950s

By Dr John Tierney

On a hot January afternoon in 1946, the country doctor hurried from attending a polio case at a home in Cooma, to the local hospital to deliver me. Ten years before the Salk vaccine became available, he brought with him the poliovirus on his fingers. It was a pity that he didn't wash his hand more thoroughly! Ten thoughtless seconds dramatically switched the direction of my future life path, to one of slow deteriorating physical disability over seventy plus years – so far.

I spent my first three weeks of life in the hospital, strapped to a board placed at a 45 degree angle to assist my breathing. The poliovirus attacks the nervous system and disables, in varying degrees, the muscle movements that the nerves control.

Only people over seventy years old now would recall the terror that families felt during the polio epidemics that blighted Australia about every ten years between 1910 and 1960, before the widespread use of the Salk vaccine. The poliovirus presents like flu, but overnight it can do irreversible damage to the body's nerves, muscles and eventually joints. The fear of the spread of polio in the Australian population in the first half of the 20th century was like the fear that is currently generated by the Ebola virus in Africa.

I was born into a family of athletes when I contracted this condition. My mother was a Riverina region athletics champion. My brother, Jeff, carried the Olympic torch on the road to Melbourne in 1956. My other brother, Michael, was an even better athlete, and with minimum practice, took out many Blues at the Illawarra regional sports carnivals every year that we were at high school. There is a family photo which shows my brother Michael wearing a chest full of blue and red ribbons.

In my entire 'athletics career', I managed one yellow ribbon (with nothing written on it). I think that I received this award for 'having a go', and it was presented to me at the Eden District sports carnival in 1951, when I finished well behind the field in the five year old 100 yard dash.

More than 50 years later, when I retired from the Australian Senate, I received a letter of thanks for my service to the community from a man who had watched me run in this race on the south coast of NSW all those years ago. What had caught the crowd's attention, it seems, was that I took part in the race with a caliper strapped onto my polio leg. This wasn't made of light titanium steel, but of railway track grade iron! "You came a very bad last", he wrote, "but you were first in the hearts of all those who watched."

My parents allowed me to be in the race as part of their 'normalisation' program. Such an approach fits in quite well with the typical polio survivor's 'A Type' personality. As a group, we tend to be overachievers, because polio couldn't stop us, and neither will anything else. My two older brothers also took up the normalisation cause with great gusto. Our home in Eden was near the cliffs above Aslings Beach. They didn't really care that a six year old with a severe disability was following them down the cliff face to the beach far below. I remember being stuck on the side of the cliff at one point but they didn't come back to help. They probably thought that the near death experience would toughen me up.

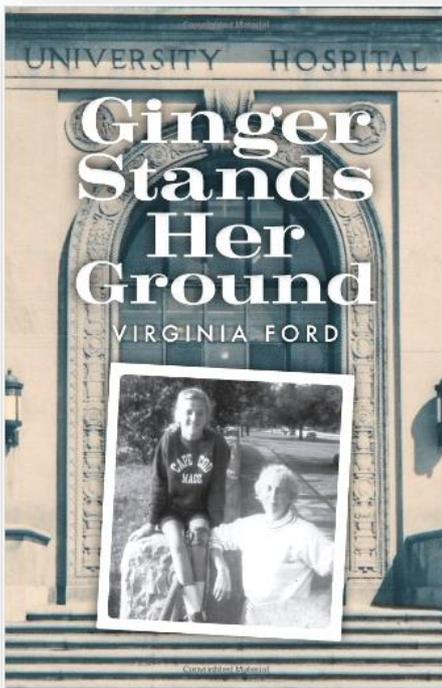
In a similar vein, my brothers really excelled themselves one day when, as a six year old, they gave me the job of 'chief mole' to test if their new hand-made underground tunnel, which was dug to connect two cubby house caverns, was wide enough. As one brother pushed from one end and the second one pulled from the other, I became stuck in my earth tomb. This must have created PTSD (post-traumatic stress disorder), as I can still vividly recall the smell and feel of fresh earth all around my head and body.

In my 1950's childhood, hospitals were part of an annual routine for tracking my ongoing disability caused by polio. I was one of the lucky ones because I only went for checkups. Many years later, I heard horror stories from fellow polio survivors who had been kept in hospitals for years of ongoing therapy. Some of it, such as the use of the notorious *Double Thomas Splint* (a cross shape frame), was designed to keep the child's body limbs immobilized and straight.

Our foundation President of Polio Australia, who now is virtually quadriplegic, as a baby spent almost 24 hours a day on this device for about twelve months! Medieval torture chambers would have been proud of such an invention. Also in the polio children's wards, parental visits were often not encouraged because, for these preschool children, it was felt that the departures of the parents after the visits could be 'upsetting'. Sometimes parents could only ever see their young crippled children through glass screens. Even now, PTSD counselling is needed for many of these polio survivors in their latter years.

I was unaware of such horrors as I made my pilgrimage from Eden on the far south coast of NSW to the Camperdown Children's Hospital in Sydney for my annual checkups. I still vividly recall entering that hospital with its squeaky green lino and the ever present smell of disinfectant.

Book Review



Ginger Visel contracted polio in the winter of 1950, when she was not yet five years old. Her life would never be the same. By the time the virus was through with her, she had a withered leg, weak muscles, and hip trouble that required multiple surgeries.

The University of Michigan Hospital became a second home, the March of Dimes a reliable support system, and leg braces an everyday part of her wardrobe. In the era before ramps and automatic doors, Ginger had to learn to adapt to a world not built for her.

Surrounded by ten siblings and guided by an unstoppable mother, she met every challenge with determination and an unshakable faith in God. With equal parts cheerful humor and honest vulnerability, Ginger recalls desperately trying to fit in at school, the terror of learning to drive a hand-controlled car, the near-impossibility of finding an accessible college, and the worry that she'd never get married and have a family of her own.

Both a universal coming of age story and a look at the complexities of being disabled before the ADA, *Ginger Stands Her Ground* is an inspiring story of the meaning of family, the importance of faith, and the ultimate triumph of love.

Available through [Amazon](#).

Growing Up With Polio In The 1950s *(cont'd from p15)*

The visits through the wards containing dozens of young polio survivors were traumatic. Many were in iron lungs because they would die within ten minutes if they were taken out of these breathing machines. The luckier ones were immobilized in hospital beds. Each year, the doctors would lay me down on a couch and measure the length and dimensions of my limbs and compare these readings to those taken in previous years, to track the ongoing development of my disability. There has never been any treatment to cure polio or its deadly after effects, just monitoring.

However, there were some useful techniques for stopping the limbs becoming more distorted, but these were uncomfortable, painful, and sometimes had long lasting effects. Even now, I never sleep on my back. Why? Because between the ages of two and seven, I had to sleep in this position with my left leg in a fitted plaster cast. This could be easily slipped on at night and was lined with soft cloth. However, with the weight of the plaster, I couldn't turn on my left or right side during the night.

Why was it necessary to put this instrument of torture on every night? When polio strikes, it kills off many of the nerve connections [which innervate] the muscles. [The resulting muscle contracture can affect joints, ligaments and tendons, distorting the skeletal frame]. Polio will also do more damage to either the left or right side and to either the top half or the bottom half of the body. In my case, it was lower and left. My worst damage from polio was initially in my lower left leg and foot, leaving me with a thinner and shorter leg. During the day, to also assist with keeping the leg straight, I wore an iron calliper on my left leg until the age of 12.



Continue reading John's anthology on Polio Australia's www.stillhere.org.au website [here](#).

New Polio Vaccine

This New Polio Vaccine Has One Crucial Difference, And It Could Finally End The Disease For Good

By Mike McRae

Source: www.sciencealert.com

– 28 November 2018

Just 22 people contracted polio in 2017. It's a whisper away from eradication, but due to the challenges involved in getting the vaccine to where it's needed most, the extinction of the polio virus in the wild remains just out of reach.

The end might finally be in sight thanks to a new method for preserving the preferred inactivated form of the vaccine – this new method requires no refrigeration. As a freeze-dried powder, the vaccine can now be shipped into places previously off limits, to provide much needed immunity to the handful of populations that are still at risk from this devastating illness.

Scientists from the University of Southern California worked with researchers from the drug manufacturer Integrity Bio to develop a process that removes the moisture from inactivated poliovirus vaccines (IPVs) without affecting their effectiveness, improving their stability at ambient temperatures.

"However, no matter how wonderful a drug or vaccine is, if it isn't stable enough to be transported, it doesn't do anyone much good", says the study's first author, Woo-Jin Shin.

Polio vaccines come in two varieties. The first was famously developed by Jonas Salk in the 1950s, and involves an injection of broken-up poliovirus particles. A second method was developed the following decade by the Russian-born medical researcher Albert Sabin. Though it requires no needles, his easy-to-deliver oral vaccine is based on a live, weakened form of the virus, so carries some risk of catching the disease.

That risk isn't exactly huge. Only 96 cases of vaccine-derived polio occurred in 2017, and the chances of those with the virus suffering its debilitating symptoms are also extremely small. Still, it's a risk we could do without. So the Global Polio Eradication Initiative is phasing out its use altogether and sticking to the injected vaccine.

Using IPV is certainly the safer bet, but as with most biological materials, light, temperature, and other environmental conditions make short work of its proteins, making it useless when it comes to inoculating against a disease. If kept at a chill 2 to 8 degrees Celsius (35 to 46 Fahrenheit), vials of IPV can be stored for up to four years. Otherwise, they go off like fish on a summer's day.



Freeze-drying the vaccine's ingredients can help stretch out their use-by date considerably, a method already used to ship vaccines for measles, typhoid and meningococcal disease into remote corners of the globe. But dehydrating IPV has proven more challenging, resulting in less than impressive stability at ambient temperatures.

Finding a new process isn't all that hard. At least, not in principle. *"Stabilisation is not rocket science, so most academics don't pay much attention to this field",* says Shin. What is hard is knowing which methods are winners, and which turn a potentially life-saving vaccine into an ineffective pile of dust.

So the team started by devising a new in vitro assay for determining the potency of IPV following its preparation. They then went about sifting through various formulations for freeze-drying using high performance liquid chromatography to rapidly sort which ones would still work their magic.

The result was an IPV that could be kept at temperatures of up to 37 degrees Celsius (99 degrees Fahrenheit) for four weeks and be just as effective as non-freeze-dried vaccines that had been kept at a chilly 4 degrees Celsius (39 degrees Fahrenheit). Tested on mice, the rehydrated form of the vaccine still provided the same level of immunity.

Polio is a disease most of us could be forgiven for thinking is already extinct. No cases have been recorded in the US since 1979. Prior to immunisation, annual cases could be as high as nearly 60,000 during outbreaks. Among adults with paralytic forms of the illness, up to nearly a third faced death.

There are three strains of the polio virus. One was officially declared wiped out in 2015, some 16 years after the last of its kind was detected in India. Another hasn't been seen since 2012. But that still leaves one variety persisting in communities in Pakistan and Afghanistan. If we're to truly see an end to it, and avoid a return to those epidemics, we'll need to overcome all obstacles. The world need this vaccine to finish the job.

This research was published in [mBio](https://doi.org/10.1126/science.1254444). 

Polio-Like Condition In U.S.

Cases of rare, polio-like condition in U.S. highest since 2016.

By Alex Dobuzinskis

Source: www.reuters.com
– 27 November 2018

(Reuters) - A rare, polio-like condition has sickened 116 people in the United States so far this year, the highest number of cases since 2016, the U.S. Centers for Disease Control and Prevention said on Monday.

CDC officials have said they do not know what causes acute flaccid myelitis or AFM, which affects the nervous system and triggers weakness and even paralysis in one or more limbs. The vast majority of patients are children.

In 2014, when 120 patients were diagnosed, the CDC began investigating cases of the disease, which it estimates affects one out of 1 million people in the United States.

Since 2014, the number of cases has spiked every two years in the United States. Last year, the nation had 33 confirmed cases, while in 2016 it had 149.

"It is pretty concerning that it's going up and we

still haven't figured out specifically how to prevent this or how to treat it", Dr. Emmanuelle Tiongson, pediatric neurologist at Children's Hospital Los Angeles who has evaluated and treated patients with the condition, said in a phone interview.

One phenomenon researchers have observed is the illness is particularly prevalent between August and October, a period when many viruses commonly circulate, according to the CDC.

The disease could be spread through infection, which would explain why there have been clusters of cases in certain states, Tiongson said.

The CDC on Monday provided a state-by-state breakdown of cases for the first time this year.

Colorado reported 15 confirmed cases of the disease and Texas had 14, followed by Pennsylvania, Ohio, Washington state and Minnesota, which each had eight cases, according to the CDC.

States with large populations or good methods for reporting the disease are more likely to have a larger number of cases, according to the CDC.

In some patients, the partial paralysis they suffer due to the illness will be a lifelong condition, Tiongson said. ●

A World Without Polio

What Must Be Done to Create a World Without Polio?

By Barry Rassin, Tedros Adhanom Ghebreyesus

Source: time.com — 24 October 2018

Rassin is President of Rotary International; Dr. Adhanom Ghebreyesus is Director-General of the World Health Organization; both organizations are members of the Global Polio Eradication Initiative.

Thirty years ago, the world united under a bold promise: a future free from polio.

In the decades since, organizations from across the world have worked alongside dedicated governments and health workers to make good on that promise. In addition to developments like improved access to clean water, vaccination efforts like those led by the Global Polio Eradication Initiative have yielded an incredible drop in wild poliovirus cases: from 1,000 a day in 1988, to 22 in all of 2017. If we finish the job, polio will become only the second human disease, after smallpox, to be wiped from the face of the earth.

But the road to eradication has been longer and harder than expected. While last year saw a record-low number of wild polio cases, we have fallen short of stopping the disease completely. One child affected is too many, and so far this year there have been 20 children paralyzed by wild poliovirus.

At the same time, there have been outbreaks of vaccine-derived polio, which occurs in rare instances when the weakened virus in the oral vaccine mutates to virulence, and can spread easily in large, unvaccinated populations. These outbreaks have occurred in high-risk countries like the Democratic Republic of Congo, Papua New Guinea, Somalia and Niger, and indicate that we are failing to reach enough children.

No matter the setting or viral strain, these challenges share a common cause: barriers to reaching every child. In Afghanistan, for example, nomadic populations, cross-border movement, insecurity and difficult terrain mean that many vulnerable communities remain inaccessible to polio vaccinators.

Though where we do gain access, the impact has been profound.

A World Without Polio *(cont'd from p18)*

In Pakistan and Nigeria — which, along with Afghanistan, make up the world's three final polio-endemic countries, down from 125 countries in 1988 — we are steadily reaching more children and the number of polio cases is dwindling, showing what is possible when we gain new ground.

For the children and families affected, contracting polio is a tragedy. For us, every new case is also a lesson — pointing to where we need to intensify our efforts and reminding us how quickly polio can come surging back if we aren't vigilant.

For every paralyzed child, there are an estimated 200 others who carry the virus without any symptoms. This is why, even as the world sees just a handful of cases, we must reach millions of children each year to prevent a massive resurgence of polio. If these vaccination efforts ceased, the consequences would be catastrophic. Within 10 years, polio could be back on every family's doorstep, paralyzing as many as 200,000 children each year.

We understand that delivering vaccines is no simple task. Polio has taken refuge in some of the most complex and dynamic environments in the world. But over time we've learned how to deliver health services in the face of extreme adversity, even in areas with almost no infrastructure.

We proved this in 2016, when the virus resurfaced in Nigeria after two years without a case. A critical front in the response was Lake Chad, a massive body of water that borders Nigeria, Chad, Cameroon and Niger. Health workers painstakingly mapped the many islands that dot the lake and traveled hours by canoe, reaching hundreds of settlements for the first time. Solar-powered refrigerators they brought along kept the vaccines cool.

Today, there are still parts of Nigeria where we can't reach children or properly track the virus, due to a combination of inadequate infrastructure, population movements and insecurity. But while we remain cautious, we have yet to see another case of wild polio since the 2016 outbreak.

Our partnership has also demonstrated its capacity to operate strategically, despite insecurity. Last year in

Syria, after conflict led to blockades that prevented health workers being able to reach cities, we responded quickly and effectively to an outbreak of vaccine-derived polio. We vaccinated fleeing children at transit centers and camps, and we partnered with local authorities to quickly administer vaccines during windows of safety — strategies we have used in conflict zones worldwide. As a result, Syria has seen a year without another child paralyzed.

We have also worked globally to strengthen local health systems and respond to community needs beyond polio vaccination. In Karachi, for example, Rotary International is working with local partners to install water-filtration systems in at-risk communities. Similar projects — including delivering bed nets, nutrition supplements and vaccines against measles, meningitis and tetanus — go on every day, anywhere that we fight polio. And this infrastructure will not disappear with the last poliovirus, but can be repurposed to fight other diseases and accelerate progress toward ambitious global goals like universal health coverage long after polio is eradicated.

These examples illustrate the tenacity of this coalition, which — thanks to committed vaccinators, donors and advocates around the world — has come so far since making that promise in 1988 to rid the world of polio. We are so close to keeping that promise. We have seen how readily the virus can push back, but we are more committed than ever before.

There was a livestream for Rotary's 2018 World Polio Day Event on October 24, at www.endpolio.org.

Read full article [here](#). Click on the picture below to watch the movie trailer. 🎬



From Polio Victims To Polio Eradicators

FROM POLIO VICTIMS TO POLIO ERADICATORS, ON THE FRONTLINES OF PAKISTAN'S BATTLE AGAINST POLIO

Source: polioeradication.org

- 23 October 2018

Polio frontline workers ensure that no child is left behind during door-to-door immunization campaigns.

For some of these workers, the cause of polio is very personal. They have been paralyzed by polio themselves, and today, they are the greatest champions and advocates of polio vaccines within their communities.

On World Polio Day, meet Rozi, Ashfaque and Bushra who are ensuring that no child succumbs to polio as they did.

Rozi Ahmed – Permanent Transit Point Supervisor, 31 Chaman, Kila Abdullah, Balochistan



Photo: Rozi Ahmed, 31, is using his exemplary tale as a polio victim to convince refusal parents to vaccinate their children. @whopakistan/Saima GulRozi Ahmed, 31, vaccinating a young girl at the Friendship Gate PTP. @whopakistan/Saima Gul

"I was only a year old when I contracted polio virus. The infection was almost immediate and within two days, I was paraplegic and also lost function of one of my arms. Afterwards, my parents took me to several doctors and "mullahs" (religious scholars), but the disease was irreversible.

Being a person with disability, studying in a regular government school was too much of a hindrance in terms of physical accessibility. Consequently, I dropped out of primary school because I felt the environment was not inclusive for people like me. Residing near the Pakistan-Afghanistan border, the Friendship Gate, I would always notice the workers administering polio drops at border. As inspiring as it was to see their commitment to vaccinate hundreds of

children every day, I noticed a lot of parents rejecting the vaccination as well. Seeing this, I resolved to work as a polio worker myself to raise awareness about the disease and the vaccination itself.

Today, I, along with 40 other workers at the Permanent Transit Point (PTP), vaccinate children every day. I hope that by doing so, my own example will serve as a cautionary tale for the parents and the larger community. I would not wish this disease on any child, which is why I am determined to end polio."

Ashfaque Naveed- Area Supervisor, 31 Pawakai, Peshawar, Khyber Pakhtunkhwa



Photo: ShoaibAshfaque Naveed, 31, from Khyber Pakhtunkhwa is a committed worker in fight against polio. @whopakistan/Muhammad Shoaib

"Belonging to rural Khyber Pakhtunkhwa (KP), the polio vaccinations were not considered vital for a child's health owing to misconceptions and myths. I was only a year old when polio virus left me paralyzed in my right leg. As a result, I could not walk or play like the other children.

Growing up, I was always on the outside looking in as I was never able to perform routine tasks with ease. Most of all, I was shunned by the community for being disabled. Determined to change my circumstances, thanks to my supportive family, I was able to get special corrective equipment and went on to not only stand on my own feet, but also completed my Bachelor's degree.

I quickly jumped on the opportunity to work as a Social Mobilizer in the Polio Eradication Initiative. Since then I have sought to not only vaccinate children, but also sensitize parents and the community about the irreparable dangers of polio and the importance of vaccinating all children under the age of five. I hope to see Pakistan rid of polio within my lifetime."

From Polio Victims To Polio Eradicators *(cont'd from p20)*

Bushra – Union Council Polio Officer, 34 Lahore, Punjab



Photo: Bushra, 34, determined to end polio to secure the future of children from permanent disability. @whopakistan/Anum Khan

"The biggest fear in a parent's life is seeing their child falling sick. One of my legs were paralyzed due to polio at just three months old. Since then, it has been an ordeal for my family and I.

Growing up, I was left out from sports, and being an avid sports fan, the experience was very isolating for me. The community members, my teachers, and fellow students often pitied my condition. These unfortunate circumstances made me all the more determined in fighting polio within my community.

For the past three years, I have been working as a Union Council Polio Officer in the Polio Eradication Team. Although the polio programme has made tremendous progress, the biggest threat to this programme is the lack of awareness and

convincing parents is a big challenge. By now, I have vaccinated hundreds of children, and I will continue to do so until we wipe off polio from within our country and communities." 🌟



**PAPUA NEW GUINEA
POLIO
OUTBREAK
RESPONSE
First 100 Days**

30 September 2018

It was early morning in late April 2018 when a six-year-old boy named Gafo woke up with hurting legs. He was excited to play with his friends so he ignored the pain. But he fell as soon as he got up from his bed – his legs were so weak that he could barely move.

In the next two days, Gafo's pain got worse, even with his mother Soya's constant massaging. On the third day, the family decided to bring Gafo to Angau Memorial General Hospital in Lae, Morobe, in the central northern coast of Papua New Guinea. After a series of tests, it was confirmed that polio was the cause of Gafo's paralysis. It was later discovered that the virus was circulating in the community.

For many weeks, Gafo was the nameless and faceless "first polio case in Papua New Guinea in 18 years" that was reported in the national and international media.

Read more [here](#). 🌟

Polio This Week

Source: [Polio Global Eradication Initiative](#) — as of Wednesday 20 November 2018

Polio this week in Papua New Guinea

- Three new cases of circulating vaccine-derived poliovirus type 1 (cVDPV1) were reported this week: one from East Sepik province and two from Enga province with onset of paralysis ranging from 17 August to 30 September.
- The total number of cases in the country in 2018 is now 25.
- Emergency Operation Centres are established and operational at the national level and in all affected provinces; environmental surveillance is functional in five sites in two major cities.

Travel advice

- WHO's International Travel and Health [recommends](#) that all travellers to polio-affected areas be fully vaccinated against polio.
- Residents (and visitors for more than 4 weeks) from infected areas should receive an additional dose of OPV or inactivated polio vaccine (IPV) within 4 weeks to 12 months of travel.

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	27	92	16	80	22	96
—In Endemic Countries	27	27	16	0	22	0
—In Non-Endemic Countries	0	65	0	80	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	19	0	11	0	14	0	2 Oct 2018	N/A
Democratic Republic Of The Congo	0	19	0	10	0	22	N/A	25 Sep 2018
Niger	0	8	0	0	0	0	N/A	14 Oct 2018
Nigeria	0	27	0	0	0	0	N/A	17 Oct 2018
Pakistan	8	0	5	0	8	0	7 Oct 2018	N/A
Papua New Guinea	0	25	0	0	0	0	N/A	30 Sep 2018
Somalia	0	13	0	0	0	0	N/A	7 Sep 2018
Syrian Arab Republic	0	0	0	70	0	74	N/A	21 Sep 2017