



Volume 9, Issue 4

# Polio Oz News

December 2019-Summer Edition

### Pandemic: Margaret's Experience

#### **By Margaret Saunders**



My husband, Fred, and I were 2 of the original members of our Newcastle/Lake Macquarie Post Polio Support Group, which we attend every month in Toronto (NSW). I am happy for you to use my story in any way you can in order to get the message out that "We're Still Here!".

I met Fred in 1952, just 18 months after having polio, and we married in March 1954. We raised 5 children, and now have 24 grandchildren – the youngest is 10 years old – and 28 great grandchildren – who are all under 11.

In 1989, Fred and I moved into a Children's Home which was owned by our Church. I was the House Mother, caring for up to 8 children at any given time. Over the year we were there, we looked after around 20 children. The Home was sold once we left. I have also been a near to full-time Leader in The Girls' Brigade, working with girls of all ages from 6 years to 18 (photo right).

I was very fortunate for 50 years, until the Late Effects of Polio came upon me in 1998. There are some people I've come across who dispute that my disability originated from having had polio. I have had to watch my every step, and pick myself up when I fall, which is quite often. One lady tells me that it is only old age, as she has not seen me with any disability in younger years.

I told her that she needs to be in my body and then she would know.

As well as polio, I had level 4 melanoma taken from the front of my 'bad' leg back in 2002, along with losing 2 lymph nodes from my groin. I also needed to have my left knee replaced in 2004, as it crumbled after doing all the work for my polio-affected right leg.

Early this year, I saw a request from a young fellow named Jacob, who wanted to hear from people over 75 with stories from the 'early days'. As I was 84 at the time, I decided to contact him with my story of having had polio when I was 16 years of age. Out of all stories received, he chose mine.

Jacob wanted to make a short film for his major work for his Higher School Certificate (HSC). He came out to our home with his camera, sound recorder, and an umbrella to get the right lighting for his film. Over the months he was in touch with me by e-mail letting me know how things were progressing. By September, the film was ready to be submitted to the HSC board for marking. His teacher had given him 50/50, and suggested he enter his film into the Blue Heelers Short Movie Festival, which was coming up in October. His film came first and he received \$3,000 plus a new laptop, which he was very pleased about.

The film, titled "Pandemic: Margaret's Story" can now be viewed on YouTube: www.youtube.com/watch?v=eNcfdtocwws



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Representing polio survivors throughout Australia

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Pain Services Directory Launch

News From Abroad

Polio This Week

>>> Charles Bowden ∼

### Polio Australia's Websites

## Polio Australia



Representing polio survivors throughout Australia

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

www.polioaustralia.org.au

## Polio Australia



Improving health outcomes for Australia's polio survivors

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

www.poliohealth.org.au

## Australian Polio Register

Have you added your polio details?

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

www.australianpolioregister.org.au

## Polio Australia



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

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

www.stillhere.org.au

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## President's Report



At the end of the year it is time to look back and reflect on what was achieved in 2019 and what we can look forward to in 2020.

It is not only the end of the year but the end of an era as Maryann retires after working with Polio Australia since 2010. Although she will not be totally gone and will certainly not be forgotten, she will definitely be

Gillian Thomas

missed by the Board, staff and the community.

Unusually, there were a number of staff changes this year – besides Maryann's imminent retirement, we have farewelled Jake (June), Bonnie (July) and Paul (November). I have previously acknowledged the contributions of Maryann, Jake and Bonnie. Paul spent two years with us, and I greatly enjoyed working with him over this time and seeing the difference he made to the knowledge level of health professionals around the country who are working with polio survivors. During the year, we also welcomed Darlene (August) and Michael (November) to the team. They both hit the ground running and their skills complement the existing team skills. We certainly are very well served by our staff.

## From the Editor



Maryann Liethof Editor

Whilst this is my last newsletter as the National Program Manager for Polio Australia, you haven't seen the last of me yet!

My retirement date beckons, and there is still much to do before I leave at the end of December. However, over the past couple of years, I have been able to engage skilled people, who have evolved to

become an <u>amazing team</u>. They are going to be just fine without me! They have already expanded Polio Australia's services beyond anything I could have hoped for, and are all passionate about their work on behalf of Australia's polio survivors.

Rachel Ingram and Darlene Felsch will be sharing the management role as Program Operations Manager and Resource Manager, respectively. Steph Cantrill continues her fine work as Community Engagement Officer, and we have a new Clinical Health Educator, Michael Jackson (he's heard them all!). Short reports from the Team can be read in this edition.

We were sorry to see Paul Cavendish leave in November, but travelling across Australia can be The Board had its usual annual face-to-face meeting in October as we came together for the AGM. This year we reviewed our 2018-2020 strategic plan to update it in view of staff and program changes. The updated plan will be presented to the Board for approval at its next meeting and will then be available on our website.

Our biggest challenge remains ongoing funding to maintain our core operations. We were very pleased this year to receive a 3-year extension to our Department of Health grant to enable the Clinical Practice Workshop program to continue until 30 June 2022. Similarly to this program, most of the available funding sources are directed towards discrete projects. Such funding is vital to maintain and expand the services we can provide to Australia's polio survivors and the state networks who support them. However, it doesn't pay the rent or other operating costs – such expenses must be met through other sources, primarily donations and bequests.

After another busy year it will be good for all to have some downtime to recharge our batteries and return invigorated to meet what 2020 has to offer.

Best wishes to all for a healthy and peaceful festive season.

Gillian

challenging for a young family. Paul made great inroads in his two years with Polio Australia, and we wish him all the very best. Hundreds more health professionals are now educated in the Late Effects of Polio thanks to his efforts.

I will continue to edit *Polio Oz News* for the foreseeable future. I have also put myself forward to serve as a Board member for Polio Australia. I have accumulated a lot of information in my head which could be useful. A summary of my involvement with the post-polio community can be seen in this edition.

As usual, there are also many stories and articles I have collated over the past few months, which I am sure will be of interest. Our cover story is proof that 'ordinary people' do amazing things, especially polio survivors!

Perhaps some of our readers will benefit from the fresh injection of federal government funding in response to the Aged Care Royal Commission's Interim Report (p 17).

And a reminder that we must remain vigilant with polio (and other) immunisation, with the return of polio to the Philippines (p 22).

As we are rapidly approaching the end of 2019, I offer Seasons Greetings to all, however you choose to celebrate!



### Rachel Ingram



Program Operations Manager

Polio Awareness Month and the Launch of Clinical Advisory Group

October was Polio Awareness Month, and this year we focused on

"Equality—Inclusion— Access"

highlighting the desire for all polio survivors to:

- have appropriate access to services;
- feel included in all aspects of society; and
- have equality in all areas of life.

We also used Polio Awareness Month to launch our new-look <u>Clinical Advisory Group</u>. The purpose of this assembly of polio-savvy health professionals is to support Polio Australia to achieve organisational goals. We utilise the knowledge, skills and expertise of these health and medical professionals to advise on key health issues. This includes contributing to Polio Australia's <u>Fact Sheets</u> series and informing key projects such as our <u>Clinical Practice Workshops</u>).

The Polio Australia team also participated in a Polio Awareness Month fundraising activity, <a href="Two">Two</a> O'Clock Around The Block. The office staff completed a daily walk "around the block" at 2pm every workday in October. Why?

- To build/maintain fitness so we can stay strong and functional;
- To give us clear space to think creatively and share ideas outside the normal office routine;
- To reenergise our bodies and minds with fresh oxygen before we get back to work;

 Because we can? We acknowledge that not everyone is able to do a walk around the block, but we invite everyone to participate in any way that works for them.

#### **Grant Seeking Update**

Polio Australia relies primarily on philanthropic grants to fund its programs/projects. The Polio Australia team have been busily applying for grants, and despite the highly competitive nature of grants, are excited about six pending applications:

- Gambling Community Benefit Fund: to run a Polio Health and Wellness Conference in Queensland.
- 2. ILC Individual Capacity Building (ICB) Program Grant Opportunity 2019-2020: to fund Community Development Workers in each State.
- Aurizon Community Giving Fund: to deliver Community Information Sessions in Western Australia.
- 4. Grants SA Major Grants: to run a Polio Health and Wellness Conference in Adelaide (partnering with Polio SA).
- 5. EastWeb Grants: to translate key resources into various community languages.
- Budget Direct Sponsorships: Printing of resources.

The team out and about on one of our Two O'Clock Around The Block walks.



#### Darlene Felsch



#### **Resource Manager**

I joined Polio Australia three (3) months ago and I am enjoying the role immensely.

In the time I've been here, I have:

- automated payroll using the MYOB payroll module;
- implemented Single Touch payroll to comply with ATO requirements;
- introduced Salary Packaging for the staff, which takes advantage of the tax concessions available to staff who work for a charity; and
- attended the AGM and the October Board meeting.

I am providing ongoing support for our bookkeeper to record transactions in MYOB.

During October's World Polio Awareness month, I enjoyed attending an event in Warrnambool, run by Polio Network Victoria. I got to meet polio survivors and their families and listened to their stories and how they were dealing with the Late Effects of Polio.

I am looking forward to all that we will achieve together next year. •

#### Welcome Michael Jackson



#### **Hello All!**

I'd like to introduce myself as the new Clinical Educator for Polio Australia. I am stepping into the role that Paul Cavendish has performed since its inception in 2017. While I feel I have some big shoes to fill, given the amazing efforts of Paul expanding

the program from the initial pilot workshop, there is still much to be done to improve polio education levels amongst health professionals across Australia.

My professional background lies in two fields—education and physiotherapy. I spent about four years primary teaching in the Wide Bay area in Queensland, before transferring to a Brisbane school for a few years. Needing a change, and taking the opportunity to pursue a shelved dream, I headed to the US to travel and study for a few years. (I am fortunate enough to be a dual citizen, thanks to my mother.) A few years in the US turned into sixteen years. These years included obtaining my Physical Therapy degree in California, getting married, moving to Colorado,

working in a rehabilitation hospital in Northern Colorado, and raising a young child.

During my physio training I successfully applied for, and then spent twelve clinical weeks at, Rancho Los Amigos Rehabilitation National Hospital, in Downey, California. It was there that I found my calling for managing and treating complex patients, and where I had some invaluable time in their Polio Clinic.

Serving as the therapy department clinical educator for a number of years in Colorado, I noted a lack of awareness about Post Polio Syndrome amongst our staff. This, and the relief expressed by patients who I spoke to that "at least someone knew" about their condition, led me to educate our staff on the topic.

Recently, I had the opportunity to meet with those attending Polio Australia's Health and Wellness Retreat, and to present a session on "Falls", which serendipitously led me to accepting this role and writing this introduction!

I look forward to meeting you when I am in your area, and helping those who care for you to do so from a position of knowledge and understanding.

Michael Jackson M.P.T., B.Ed.

## Community Engagement



**By Steph Cantrill**Community Engagement
Officer

It's been an interesting few months. With such a small team, you don't expect to say too many good-byes, we've but already farewelled our outgoing Clinical Educator (Paul) and welcomed able his replacement (Michael)

and the next person to leave will be our very own Maryann. It's hard to say how much our organisation will miss her, but as I'm sure you can imagine things are going to be very different after the end of this year. It's a lot of change for a small team to handle, but we can do this!

My recent trip into New South Wales was very rewarding. Most of the sessions had a few "new" people – polio survivors who had not previously been connected with support groups, Polio NSW or Polio Australia. Hopefully that will lead to an increase in membership with Polio NSW, and a few new people meeting up with others regularly for support. And, of course, we hope that people

now feel more informed, and better able to manage their condition and communicate with their health professionals.

Something we've been discussing lately as a team is that, as Polio Australia is a national organisation and exists to supports the state networks across the country, it's important for the Community Engagement role to have a national focus. Up until now, I have mostly travelled to areas I can get to by car. This has kept costs down, but has limited the scope of my outreach. As our finances stand at the moment, it isn't possible for me to travel everywhere unless we get grant funding. While it's rather limiting to let the grants guide our work, the reality is that we can't spend money we don't have! Therefore, we have been concentrating on fundraising through grant applications, and my work will focus on the locations and priorities of successful grants.

Due to one such grant, from the James Kirby Foundation, I am working my way through NSW. The aim is to complete a total of 15 community information sessions around the state including the four sessions we had in October.

#### Community Engagement (cont'd from p5)

While they are by no means set in stone, the draft schedule for early 2020 looks like this (please check <a href="www.polioaustralia.org.au/community-information-sessions">www.polioaustralia.org.au/community-information-sessions</a> as details will be added when things are confirmed):

3<sup>rd</sup> February Bathurst Library, 3pm Orange Senior Citizens' Centre, 10.30am 4<sup>th</sup> February 5<sup>th</sup> February <u>Dubbo, Milestone Hotel</u>, 10.30am 6<sup>th</sup> February Tamworth (venue and time TBC) 7<sup>th</sup> February Newcastle/Maitland (venue and time TBC) 16<sup>th</sup> March Ballina (TBC) 17<sup>th</sup> March Coffs Harbour (TBC) 18<sup>th</sup> March Port Macquarie (TBC) 30<sup>th</sup> March Bairnsdale (VIC - TBC) 31<sup>st</sup> March Eden/Bega (TBC) 1<sup>st</sup> April 2<sup>nd</sup> April Ulladulla area (TBC) Wollongong (TBC) 3<sup>rd</sup> April possibly Sydney (TBC)

So, exciting things ahead! While fundraising continues to be a challenge, it's been so worthwhile connecting with polio survivors around the South-East of Australia, and I look forward to bringing the community outreach programs further afield.

### Clinical Practice Workshop Review

#### And Communication in Healthcare By Michael Jackson

Clinical Health Educator, M.P.T, B.Ed.

With the Polio Australia Clinical Practice Workshop (CPW) program changing hands, it is a good time to reflect upon Paul Cavendish's achievements in building and establishing the program with Polio Australia. It is also time to look at what we need to solve and modify to continue to bring impactful workshops to Australian healthcare professionals.

The CPWs are designed to bridge the *information* gap that exists between healthcare providers and polio survivors, on the topic of the Late Effects of Polio (LEoP). In my recent meeting with the members of Polio NSW, we also discussed the *generation* gap that exists between the same stakeholders. The following summary of the CPWs essentially reveals the way Polio Australia, with Paul at the program's helm, has been bridging these two gaps.

The table opposite shows the raw numbers of workshops held and number of attendees. Growth is certainly evident, and you can see that in 2019, the program targets were almost reached.

The program has reached metropolitan and regional facilities in all six states and territories. NSW accounts for about 30% of the attendees to date – with other states each accounting for 10% to 15% of attendees.

The majority of attendees are from allied health professions, with 45% being physios, 20% nurses, and 18% occupational therapists. As a group, medical professionals account for about

WORK- SHOPS	Count	Attendees	Mean Attendees	
2017	5	74	15	
2018	43	514	12	
2019	50	728	15	
TOTALS:	98	1316	14	
DoH TARGET:	55/yr	800/yr	14	

2% of our attendees. This is a known and expected problem, and the solution requires a creative multifaceted approach.

97% of attendees would recommend or highly recommend the CPW. This tells us that the topic, content and delivery is hitting the mark - attendees see value and want to share it.

96% of attendees state they have a good to better understanding of LEoP after completing the CPW. This tells us that we are getting the message across, and that the presentation is effective and provides adequate topic learning.

48% elect to join the <u>Health Professionals Register</u>, which you can find on the Polio Australia website. While this is below 50%, we should consider a few factors: we did expand our professional register with the 48%; a healthcare professional can be reluctant to label themselves expert enough to be on a register; and identity security concerns can occur with freely accessible registers.

Looking to 2020, there are numerous projects on the CPW horizon: consistently targeting hospitals

### Clinical Practice Workshop Review (cont'd from p6)

and utilising the resources that their systems offer; increasing the number of workshops at aged care facilities; solving medical professional learning and education barriers; and forming partnerships for building programs.

Reaching and subsequently educating medical professionals has proven to be challenging. Given that medical professionals' insufficient education and awareness of LEoP and PPS is a recurring complaint, and a reason for healthcare dissatisfaction amongst survivors, it is worth addressing this with some perspective as we enter 2020 and beyond.

While the CPW is certainly building an army of allied health professionals able and willing to advocate for you, it is still essential that you – the polio survivor – continue to self-advocate. Ideally, you shouldn't have to be your own advocate – your doctor should fully understand your post-polio needs and how to address them because accessible training and materials exist for LEoP.

There are many ways to approach self-advocacy, and we will explore several over the remainder of this article. Knowledge is a useful tool we possess (and wish to share!) – it is particularly impactful when handled both wisely and timely.

Understanding the consult or appointment interaction, is helpful for patients. These interactions usually occur in an environment in which we have little control. In non-medical terminology and simply put, there are three main elements of the interaction from the professional's position:

- INPUT: your history, the medical condition/ topic, your status, your needs. These four things are consistently needed in order to act in the next element.
- PROCESS: decision-making, trials or testing, diagnosing, establishing locus of control. These are variable based on the initial input information.
- OUTPUT: improvement, monitoring, something solved, closure. These are variable based on the character of the input and process elements.

If you are able to help the practitioner in front of you clearly define all the INPUT items, the consultation is on its way to being impactful and meaningful.

**Understanding** *How Doctors Learn* (Slotnick, 1999 article) can help a patient present information and their case more effectively. A doctor needs to quickly decide if the problem you are presenting is:

Specific (requires hot action; fast response), or General (requires reflection; time to respond).

In the case of presenting and discussing LEoP and PPS during a consultation, we want the doctor to think of the problem as general (because it is).

The next stage – taking the problem on – is the tricky stage. This stage is where patients with less prominent conditions (or an unclearly defined primary concern) can get verifiably frustrated by a lack of response or interest. Doctors, as people, are influenced by many personal and workplace factors and pressures. We want our doctors to learn new skills and gain knowledge, because it will be better for our outcome, and the next polio survivor's outcome.

Taking the problem on is the stage where the CPWs hit a barrier in obtaining the attendance of medical professionals. While Polio Australia (and other organisations!) are trialling strategies to overcome this, as a patient the best thing to do is be prepared for it and provide an *impetus for learning*. (This will be the topic for my next article in *Polio Oz News*.)

In the meantime, it is useful to remember to "teach one thing, not everything", when leading a doctor to educationally invest in your condition. Giving them the key to the most pertinent entry door is better than describing the whole house – they will find what they need if they have an entry point and are motivated to learn.

**Understanding the persistent power of the written word is useful.** You can deploy writing at various instances in your healthcare experience to procure attention and create influence.

- Write appreciation, thank you, positive, or encouragement letters, to show goodwill and optimism to the doctor (and their staff).
- Write additional notes on any form that both you and your doctor sign, to show attention to detail, and the inclusion of anything they may not be considering (but you are).
- Keep a diary of 'your end of the deal', related to what you were asked to do on previous interactions, and produce it to show your proactivity and accountability.

Also remember to write down (and bring!) your questions to your consultations with doctors. It is easy to be overwhelmed by the interaction and environment, and forget an important reason for being there. Exit the consultation with a list of answers and what you need to do.

## My Rotary Story



Oooh – OK – sounded a bit brutal . . . but off I went! (We all know that Maryann gives her help unconditionally.)

By 2015, I was presenting talks using the "We're Still Here!" campaign information provided by Maryann. I followed the script to the letter, with emphasis on raising much needed funds to help maintain the running of the Polio Australia office and Maryann's salary.

Five years later, and after more than 25 presentations to Rotary Clubs in Cairns, Tablelands, Townsville, Sunshine Coast, Gold Coast, and Brisbane (to name a few), I am pleased to report that I have contributed significantly towards generating funds for the Polio Australia office. This also includes organising several successful fundraising events.

Gaining public support was hard at first, with the usual comment "but polio has gone, hasn't it?" However, the fund and awareness raising

#### By Sue Mackenzie

Polio Australia Board Member

I contracted polio at the age of 2 in NZ. Like everyone, I managed life as best I could.

In 2012, I started having nasty falls (more than usual). I thought my polio leg was causing the falls but the doctors' comment was, "Polio? But that's gone!"

I Googled 'Polio in Australia' and discovered . . . I was not alone! Never in my 65 years had I spoken to another polio person. At my first Polio Retreat in 2013, I learned, and am still learning, how to manage the Late Effects of Polio.

My question to Maryann Liethof was, "How can I help?" She responded with, "Go talk to Rotary Clubs, Sue. We need to reconnect. Oh, and don't expect any help from me!"

campaigns grew. I am proud to say that I can now gather together a crowd of 100 plus people for an event. And all those people are now more familiar with the concept of polio and its late effects.

Stepping out of my 'polio zone' – or even acknowledging it – was hard. I had managed to hide it most of my life, so no one knew I had a 'polio leg'.

It has been hugely therapeutic for me, and I am privileged to have worked with Maryann, Gillian Thomas, John Tierney and others connected to Polio Australia.

Rotary has gone full circle for me, from childhood Rotary picnics, to sharing the "We're Still Here!" story with Rotarians. And now, to complete the circle, I am a proud Rotarian myself!

Merry Christmas!

## My Dealings With Rotary

#### And why I talk about POLIO!

#### By Gary Newton

Polio Australia Board Member

My journey as a Rotarian officially started on July 3<sup>rd</sup> last year when I was inducted into the Rotary Club of Geelong East. However, previous to this, in January I had been a Rotary Ambassador and travelled to India with my wife and 3 polio survivors to help Rotary's PolioPlus program (the Global Polio Eradication Initiative) and to talk to polio survivors in India about forming support networks with Rotary help.

Also last year, I spoke at two Rotary District Conferences (Sale, Victoria and Mt Gambier, South Australia) about my polio journey and the impact polio is having on its survivors. In particular, its late effects and the need for Rotary to refocus on its original resolution over 30 years ago: "the eradication of polio and the alleviation of its consequences" so as to provide support to polio survivors via Polio Australia's Clinical Healthcare Workshops.

## Clinical Practice Workshop Review (cont'd from p7)



Ideally, we would like all our doctors, therapists – all our healthcare providers – to sound like this at the mention of LEoP:

"What I want to do, is be able to make any modification that you are interested in that would help you have a more comfortable, enjoyable life." Intelligent words indeed, and undoubtedly experienced ones, given that they are from Dr Lauro Halstead (an advocate and campaigner of polio survivors for many decades).

Ultimately, healthcare is an interaction, with communication and some type of transaction. We can't choose the personalities and stressors that our healthcare providers have, but we can choose to be informed about how the system and the people working in that system operate.

The CPW program is one part of the multifaceted approach mentioned earlier, that is striving to reduce the information and communication gaps between healthcare providers and polio survivors. Your part is just as important: The ongoing interaction of many individuals prompting their healthcare providers to learn, and patients having reasonable expectations of informed treatment, adds weight and immediacy to the goal we share.

## My Dealings With Rotary (cont'd from p8)

Over the past 12 months I have continued to grow in the role, giving talks to Rotary, Probus and school groups about polio, my lived experience and its lifelong impact, so as to help the wider community gain a greater understanding and awareness of polio.

During October's Polio Awareness Month, I gave four talks including Horsham, Boronia, Mt Gambier, as well as a MUNA guest talk to students at Berwick Grammar in Officer, near Dandenong.

MUNA is yet another of Rotary's many projects involving young people, and stands for Model United Nations Assembly. I feel it is so important to talk to tertiary students about polio and the value of vaccines.

Response to my talks has been very encouraging, with many in the room moved at times to tears when they hear about polio and its influence on the world, many for the very first time.

I enjoy being that 'switch', taking the often unfamiliar word 'polio' and turning it into something more by providing a 'human face' to create awareness.

Following my presentation, many of the Rotary clubs have made significant donations to both the Rotary PolioPlus eradication effort and to Polio Australia, in support of their vital education workshops.

The Rotary path is an interesting one and well worth exploring because Rotary takes ordinary

people and provides them with an opportunity to do something extraordinary, like eradicating polio.

As I see it, there's much to be gained by fostering a solid relationship with Rotary, such as: travel/educational scholarships; supporting clinical workshops and more; plus renewed energy for Rotarians when they learn firsthand what their hard work is achieving.

I'm enjoying my time in Rotary, spreading the word about polio and the fact that "We're Still Here!", so I shall continue locally, nationally and internationally doing so for as long as I am able.



#### Polio Health And Wellness Retreat 2019

#### By Maryann Liethof, National Program Manager

Polio Australia ran its final Polio Health and Wellness Retreat from Thursday 17 to Sunday 20 October, for 55 participants. Details of the sessions and available handouts, presenters, and photos can be found online here: <a href="www.polioaustralia.org.au/retreat-2019/">www.polioaustralia.org.au/retreat-2019/</a>. Thanks for the memories!

Feedback comments included:

#### **Polio Survivors**

- Another magic day the facility, the outside environment, the program and support/attitude of staff are magic. I've had a ball – learnt a lot about myself and others. Enjoyed meeting people and sharing. Thank you all for your work and commitment to making this Retreat the meaningful experience it is for me and, I'm sure, everyone else. Many thanks for the new learnings and memory.
- Each presentation contains information that is applicable to me or if implemented would be beneficial. Getting the idea that LEoP can be complex and that regular exposure to information is required to maximise its usefulness and benefits.
- Excellent professionally organised, peacefully executed loved it!! Thank you for the experience.
- I've gained help in some way from each Retreat and look forward to what the new team can do to help us.
- Thank you first time very informative and well organised. Gave me directions to follow up.
- I don't know how you do it. Every year has been a 'pure gift'. Thank you from the bottom of my heart. I loath to think where we would be if not for our incredible Retreats and professional and personal input! Thank you! Thank you!!
- Thank you for allowing me to walk along God's Highway with other Retreaters.
- Excellent opportunity to meet other polio survivors and exchange information and history.

#### **Carers**

- The usual informative, uplifting occasion. It will be sad to see them go, but I can see the advantages of the day information sessions, particularly the names of local doctors and physios, etc, who know about polio.
- As the partner of a polio survivor, I have found this Retreat, its organisers and the beautiful people I have met, as a rewarding, life-long experience.

• In general, another well run, well presented event. Sorry it's the last, but looking forward to other new things to come.



#### Polio Australia's Life Fellows

## Submission to the Board of Polio Australia at the 2019 AGM By Brett Howard Vice President, Polio Australia



After more than 10 years of Polio Australia since Incorporation in the 2008/2009 financial year, there are some changes happening in the future. There has come a time when we MUST recognise the input of four very important people in the history of Polio Australia. I would like to speak to our official recognition of these four toilers.

Other organisations would offer "Life Membership", but Polio Australia Membership consists of States only, so individuals cannot be offered "Life Membership". Our four Superstars will be presented with a "Life Fellow" pin in recognition of service to Polio Australia.

So, to the nominees for the much-deserved accolades:

**Gillian Thomas** has been advocating for an Australia wide organisation to support survivors of polio since before a meeting in Victoria in 1991 which included input from New Zealanders, so people were beginning to talk about LEoP. There were almost annual attempts to get a single group to represent all Australians enduring LEoP. In 2005 at Polio Network Victoria's Polio Day, Gillian floated the idea of a "Think Tank". In May 2007 all networks met in Sydney and from this gathering a Memorandum of Understanding and Constitution were developed with agreement from all States, and incorporation followed. So, over the next 11 years Gillian almost needed an address in Canberra with the amount of time spent there lobbying Members of all political persuasions to support polio survivors. Gillian has also been President or Vice President of polio Australia since 2008 as well as being 'defacto' Treasurer and 'go to' person for any queries re Polio in Australia.

Dr John Tierney AM, our esteemed Patron and the First Parliamentary Friend of Polio Australia even before the title was adopted. John was a Member of the Australian Senate from 1991-2005 and was a special Parliamentary Advisor to the Minister for Community Services on Disability matters. He was also advisor to Polio Australia on the 'correct' way to apply for funding so that Government Departments would actually take notice of what was being requested. In December 2012, John was elected President of Polio Australia at the Annual Board Meeting, John served in this position until the Board Meeting in November 2017. John continues as Patron and Elder Statesman for Polio Australia.

Now we come to one of the most indefatigable people I have had the honour of meeting. After working at Polio Network Victoria from 2004 and representing Victoria on the Management Committee of Polio Australia, after a small

philanthropic donation, Maryann Liethof became the National Program Manager of Polio Australia in 2010. In 2007 Maryann was awarded a Churchill Fellowship which enabled her to tour North America to study "techniques to better manage the Late Effects of Polio" in 2008. The following year, in 2009, Maryann returned to Springs in Georgia for Post-Polio International's Health and Wellness Retreat and 10th International Conference. The Warm Springs Retreat enabled Maryann to learn the benefits of the holistic self-management model for chronic conditions. From this experience came Polio Australia's first Health and Wellness Retreat in 2010 which of course was coordinated by Maryann. Wellness Retreats became an annual event except in 2016 when Australia Australasian Pacific Post-Polio The Conference. The input for the Conference by Maryann again was immeasurable. Sadly, the final in this series of Wellness Retreats will be held at St Josephs from 17th-20th October. The editor of Polio Oz News keeps us all in Australia informed as to what is happening in the Polio world from around the world. Following a Board Meeting a few years ago which approved a pay rise in recognition of her work, Maryann made the decision to 'refund' it by way of an annual donation back to Polio Australia, stating the job provided its own rewards. In short Maryann has dedicated her working hours (and plenty more besides) to educating survivors about the LEoP and presenting Polio Australia as a very professional organisation.

Last but by no means least, Jill Pickering has been a very 'anonymous' philanthropist for Polio Australia since it began. Also from Victoria, Jill believes that brumbies in the Alpine National Parks need to be protected, but her second love is support of Polio Australia. Jill accompanied Maryann on her Churchill Fellowship tour. As a trained Occupational Therapist and survivor, Jill had informed insights to assist in understanding what was being shown to Maryann. Polio Australia simply wouldn't be the organisation it is today without Jill's unflagging generosity; her ongoing donations have paid for Polio Australia's office space and equipment, and now for Steph Cantrill's salary.

To finish, if the world were different there would be two more people on this list, and I would like to mention these friends of mine. **Neil von Schill** was the Treasurer for Polio Australia until his untimely passing in May 2014. Neil was one of the posse who haunted Parliament House, lobbying for better support for Polio Survivors. The other is **Peter Garde**, the partner/carer of our esteemed President, Gillian. Peter has accompanied Gillian on all of her lobbying trips to Canberra and to all the Wellness Retreats and all other polio events that Gillian has attended. Peter has supported Polio Australia in a selfless way.

#### Polio NSW Celebrates 30 Years

In 1987 a number of Australians attended the Fourth International Polio and Independent Living Conference in St Louis USA at which some 800 people were present. Many of these people were polio survivors and a high percentage reported noticing recent signs of one or more of undue muscle fatigue, muscle and joint pain, respiratory and muscle weakness.

In 1988 Professor Irving Zola, a member of the International Polio Network and himself a polio survivor, accepted an invitation to be keynote speaker at Australia's first post-polio seminar which was held in Sydney. The seminar elected a working committee of polio survivors to establish the Network with the aims of:

- Establishing support groups for polio survivors
- Providing information on polio and its late effects
- · Encouraging research into the late effects of polio



The Network (now known as Polio NSW) was officially established in 1989. Fast forward thirty years and "we're still here!", continuing to provide information and support to polio survivors, their families and carers.

Picture caption: 30<sup>th</sup> Anniversary birthday cake, cut by three Polio NSW Life Members (I to r) Nola Buck, Gillian Thomas and Merle Thompson

## What Are You Going To Do When You Retire?

#### By Maryann Liethof

This is a question I have been asked numerous times since I announced my retirement at the end of 2019. And fair enough, too! After all, I'm only turning 60 this month, and there's a lot of living left to do. However, I am very much looking forward to exploring my leisure options, and spending time with my older partner, Bill. Oh, and travel—LOTS of travel!

As mentioned in my Editor's piece on page 3, I will continue editing *Polio Oz News* as a volunteer, as well as become an independent Board member, i.e. not representing any of the state Polio Networks. Having worked with the post-polio community since 2004, I think I have something to offer in this space.

There are many polio survivors I have met along the way who have supported my 16 year journey in this career. Many have become friends, and the collective community, a kind of 'tribe' that adopted me. I have laughed and cried with people, and quickly developed a strong passion for advocating on behalf of the post-polio community. Although I have had many jobs since entering the workforce at the age of 17, supporting polio survivors has been both a calling and my life's work.

I joined ParaQuad Victoria in May 2004 as Polio Network Victoria's 4th Polio Community Officer. I

knew nothing about polio, but I was a qualified Community Development Officer. The work involved supporting 16 support groups, writing the Polio Perspectives newsletter, working with a very active Community Advisory Group, running the annual Polio Day, and more. I thought I had the best job in the world! A couple of years later, ParaQuad Vic became Independence Australia (IA), and strategic priorities changed, effectively reducing polio-related services and the scope of my role.

However, during my five years at IA, I was encouraged by a savvy polio survivor to apply for a Churchill Fellowship, which I was fortunate enough to get. Fellowships are awarded to individuals based on projects that can help improve the lives of Australians. My project was "To identify techniques to better manage the late effects of polio—USA, Canada". In 2008, I took off to North America for a 6 week tour of polio-related groups, institutions, and appointments with key individuals. I was joined by my volunteer and polio survivor, Jill Pickering.

This was a fantastic learning and networking opportunity, and an excellent insight into travelling with someone with a disability. (The time spent travelling was a combination of annual leave and leave without pay.)

## What Are You Going To Do When You Retire? (contid from p11)

When I returned to Australia, I organised 8 separate Polio Days across Victoria, where I shared my experience and vision for our postpolio community. I was also invited to speak to groups in Tasmania, New South Wales, South Australia and Queensland, which was a real joy.

In 2009, I successfully applied for a grant which enabled me to return to Warm Springs, Georgia, to attend Polio Health International's Health and Wellness Retreat, immediately followed by a major post-polio conference. On this occasion, I was joined by 4 other Australian polio survivors. It was this trip that inspired me to introduce the Polio Health and Wellness Retreats to Australia.

In 2008, Polio Australia was incorporated with a vision to represent Australian polio survivors at a national level. I was on the Board of Polio Australia, representing Victoria. However, although all the state Polio Networks were keen to progress this vision, there was no paid staff to perform tasks. It is very difficult to realise organisational goals without dedicated workers!

So in 2009, as my role at IA was dissolving, I spoke to the President of Polio Australia and Polio NSW, Gillian Thomas, to discuss if funding could be obtained to pay a salary. Polio NSW successfully applied for a \$35,000 grant, and I subsequently resigned from IA in December.

I got to work immediately to set up an office for Polio Australia in January 2010. For the first year, I worked part-time; then we received a 3 year grant from the Balnaves Foundation, which enabled me to become full-time. Of course, the first activity I facilitated was a Polio Health and Wellness Retreat. Having now run 9 successful Retreats—according to the participants, that is—I can confirm that the Warm Springs trip was worth it!

In 2010, the connections I'd made during my 2 visits to North America notified me of a European Polio Union (EPU) Conference being held in Copenhagen in 2011. There was a lot of new research being done by the Europeans, so this was very appealing. With Polio Australia being a self-funded charity, we agreed to jointly fund the trip. I put in an abstract to do an oral presentation on Polio Australia's Health and Wellness Retreats, which was accepted. As with the Warm Springs Retreat and Conference in 2009, a few of the same Australian polio survivors also attended.

Both Post-Polio Health International and the EPU scheduled international conferences in June 2014. What to do? Go to both, of course! I flew to St Louis at the beginning of June, then up to Canada to see my relatives, before heading over to Amsterdam. It was an amazing trip. Those keen Australian survivors I'd travelled with previously, also came to Amsterdam. We have now become firm friends.

These trips provided the latest post-polio research and management strategies, and also informed me in what to aim for in Australia. However, they provided vital links to the real 'movers and shakers' in post-polio services, research and management. Many expressed an interest in coming to Australia, if a conference could be arranged. But how could our small self-funded charity possibly afford it? On recommendation, I approached Simon from Interpoint Media, who magnanimously agreed to take on our 'charity project'. The result was the highly successful 2016 Asia-Pacific Post-Polio Conference in Sydney. This was definitely a career highlight for me. Hundreds attended from Australia and beyond, and the key presenters were world-renowned experts from Australia, New Zealand, the USA, and Europe.

Information on all the conferences mentioned can be found online here:

www.poliohealth.org.au/post-polio-conferences/

From 2010 to 2017, I was the only full-time, paid staff member for Polio Australia, which was both challenging and limiting. However, after years of lobbying federal government—led by Dr John Tierney AM (Polio Australia's Patron and past President), we were finally awarded a modest grant by The Hon Greg Hunt, the (then) new Minister for Health. It was enough for me to be able to employ Rachel Ingram, Health Promotions Officer, and Paul Cavendish, Clinical Health Educator, who established the muchanticipated Clinical Health Education Program. A further generous 'living legacy' donation from Jill Pickering, meant we could also employ Steph Cantrill as Community Engagement Officer. I finally had a TEAM! In 2017, we received another generous 2 year largesse from Spinal Life Australia to employ Bonnie Douglas to work on fundraising, and Samantha, a casual Bequest Officer. Jake joined us for a while as an Administration Officer, Samantha finished up in 2018, and Bonnie and Jake's contracts ended in 2019. This year, Paul has been succeeded by Michael Jackson, and we now have a Resource Manager, Darlene Felsch.

On my departure from the office, Rachel is stepping up to the role of Program Operations Manager, and she and Darlene will jointly manage Polio Australia's operations. Michael will be educating health professionals, and Steph will continue to work with the community.

I know Polio Australia is in safe hands with this passionate and proactive team, and I do believe the organisation is ready for the next phase in its development.

I am truly blessed to have found stimulating work that I have felt passionate about. I have done my best to help achieve better outcomes for Australia's polio survivors, who have always been my inspiration. It has been a pleasure and my honour to serve.

## Supporting Polio Australia

Polio Australia would like to thank the following individuals and organisations for their generous support from 1 August to 30 November 2019. Without you, we could not pay our rent, core operating expenses, or management staff!

#### Hall Of Fame

Jill Pickering

Dr Christine Tilley

Joan and Graeme Smith

Pam Tierney

#### Total-\$64,200

#### **General and Regular Donations**

Anonymous x 3 Jill Burn Liz Telford Gillian Thomas Timothy Rowley

Bruce May Margaret Schneider Jeannette Aldridge Wyndham Ladies' Probus Club

#### Total-\$2,054

#### **Rotary Donations**

Rotary Club of Central Melbourne / Rotary Club of Horsham

Rotary Club of Mount Gambier West / Rotary Club of Boronia

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Walk With Me and Rotary Club of New Farm Wine With Me Donations

Total-\$4,957.75

#### Grand Total-\$74,581.35



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## Post-Polio, My Wife, and My Dog

#### By Alpheus Williams

**Source:** <u>Seniors' Stories</u> – Volume 5, p131 *Reprinted with permission from the author.* 

Four am, two days ago, I fell on my way to the office, walking down the ramp in the dark. I released the grip on my forearm crutches to open the door and collapsed. It was an unprotected fall. I went down like a puppet with cut strings. I didn't have time to protect myself. Hurts like hell especially falling on concrete. I fell on concrete. I don't think I broke anything this time but everything hurts.

Today I'm in the office, messing around on social media, I should be writing. My wife comes in at six am to take the dog for a walk on the reserve running along the river. I take my walking bike.

I modified the bike about five or six years ago. I bought it cheap. It's just a kids BMX bike. One of those short ones. I knocked the sprocket and peddles out of it, so I could take the weight off my body but still get around by using my legs. It works a treat and I can go for walks with my wife and dog in the morning. We walk a couple of blocks, cross the road and enter the reserve. 'J' lets the dog off her lead. She runs and gambols across the grass. We can't help but share her joie de vivre.

'G' stands at the boat ramp looking out over the river. He sips from a giant cup of coffee. He's on his own, all full of quiet and thought. Our dog runs up to him, says hello, gets a pat on the head. She sprints back to us, her tail is a happy blur as she bounds back to us with her mouth open and tongue hanging out in a smile gone all goofy.

The grass is wet with dew and the sun is coming up over the ocean at the river mouth. The sky is all flushed pink, purple and red. It's a beautiful thing. Three black faced spoonbills fly across the sky, graceful and white. They float like dreams, land across the river on the sandbank and wade in the shallows. Small fish scatter at their approach, ripples of retreat on the water. Our dog, a border collie, loaded with fun and energy sprints out in front of us and returns as if on some sort of giant rubber band.

The morning is mild enough to sit out on the deck for breakfast and why would you want to sit anywhere else on a day like this? Butcher birds sing in a large pine tree that looms over the neighbours' roofs. I've cooked *okonomiyaki*, or at least my version of it. J sets the omelets on the table. I lean my crutches against the wall and open the fridge to get the ice water and go down again. At least this time it's on the timber deck and not as painful, but it's painful enough. I roll around on the ground like a worm on a hot tile.

It hurts. The dog commando crawls on her belly towards me, I can feel her breath on my face. The eternal empath, she's concerned. I'm touched. My wife is there too. I don't know who hurts most, me, the dog or my wife. I manage to get into the chair. Swallow the pain and settle in for breakfast. I feel a lot better after coffee.

After breakfast we drive into town and J does the shopping. I sit in the front seat and roll the windows down. The dog crosses from the back into the front and settles in next to me.

When J finishes the shopping and loads the car, I drive us back to the village. We stop at the little shop to pick up our mail. The river looks lovely. It's warm enough. We drive to the cottage and I change into swimmers. J drives me back to the river. She and dog sit at a picnic table as I go in the river. The tide is on the way out and the water is crystal clear. Small bream scatter beneath as I swim against the current for a time. When I finish, I join J and the dog at the bench and dry off. We drive home and prepare lunch. Eat out on the deck, watch birds flit in and out of the giant pine.

I haven't fallen in at least a couple of years. Twice in so many days is a bit unsettling. I weighed this morning and have put on a few kilos. It's essential that I lose them. Everything is different now. When you get polio you fight like hell to do what others can do, to stay mobile, to be independent. When you get postpolio syndrome you can no longer do that. The more the push the more damage so the less we can do. It's like mass murder on nerves cells. It's all about pace and planning.

I will think things out. Lose a little weight. Do what needs to be done. This is my life now. I love my wife. I love my dog. I love my life.



## My Positive NDIS Experience

#### By Jan Williams

Contracted polio 1955—age 18 months

The National Disability Insurance Scheme (NDIS) in south east Queensland came online early in 2018. However, it was not until early July, just 3 months before my 65th birthday, that I telephoned the National Disability Insurance Agency (NDIA) to enquire about my eligibility for the scheme. And I must say, from the beginning my experience has been an extremely positive one.

For ease of explanation, I will dot point my journey through the system:

- Following my initial telephone call NDIA posted me the appropriate application paperwork for completion (received within a few days).
- I completed my section (surprisingly not as much paperwork as I expected). Then a visit to my GP for him to complete the relevant paperwork.
- Duly completed, I returned this to NDIA.
- Mid-August, I received a phone call advising that my application had been accepted and that I would be contacted in due course by an NDIA representative in my local area to arrange a meeting to discuss my needs and set up my plan.
- This meeting took place in early September in an unhurried (about 2.30 hours) session where my current and possible future needs were discussed with me at length, my entitlements under the system clearly explained, and a plan for the next 12 months set up.
- As I am self managing my plan, it was explained that the plan drawn up at that meeting now needed to go to NDIA assessor for approval, that I would be advised when this was done, and would have an area coordinator assigned.
- I received a call mid-October confirming approval of my plan and making an appointment to meet with my NDIS Area Coordinator. At this meeting, the self management of my plan was gone through in detail and my access to the NDIS online Portal explained.
- From here, it was over to me. My plan included a couple of items for which I needed an assessment by an occupational therapist, including relevant quotes from suppliers. The items were a replacement chair unit for my (20 year old) internal stair lift, and replacement of my much used and worn travel mobility scooter. NDIS website lists registered providers in my area and I arranged for a local Occupational Therapist to undertake these assessments. This was done promptly and the OT sent the necessary paperwork directly to

- NDIA for approval. This happened early in January.
- By early March, approval had come through from NDIA and I had the items shortly thereafter.

A third item listed by NDIA as considered necessary, was the replacement of my 43 year old right, below knee orthotic, made in Melbourne in 1976. To this end, I required an assessment and quote by a registered orthotist. I elected to travel to Melbourne to meet with Darren Pereira at Neuro-Muscular Orthotics in Clayton. Prior to attending this appointment, I contacted my NDIA Planner to advise what I was arranging. I asked what timeframe I might be looking at for approval, particularly in light of the fact that I live in Brisbane (I point out here that travel to Melbourne was at my expense, as it was my choice to select this particular provider). My planner indicated that if the assessment and quote could be emailed from the provider while I was in Melbourne, every effort would be made to get approval almost immediately so I wouldn't have to make a second trip.

Long story short, this is exactly what happened! Hence, following a week in Melbourne, fitting, manufacture and trialling my new 'leg', I returned home.

The above covers the three things considered most important to assist with my daily life, and I cannot stress enough how impressed I have been with the assistance and support I have received. I do feel that being self managed is advantageous as it is up to me to make sure appointments for assessments are made, ensuring follow up with quotes etc.

I also believe that keeping both my NDIA and NDIS co-ordinators in the loop (in the main via email) with progress of what I was undertaking, was extremely valuable.

My plan continues to be monitored and I receive a phone call from my NDIS co-ordinator about every 8 weeks to check whether I need any further assistance.

All in all, my experience with NDIS has been extremely positive. Having said this, I must add that each State and Territory are independently managing the scheme, so I am only able to comment from a Queensland perspective.

Click below for Polio Australia's NDIS Fact Sheet.



## Acting To Improve Aged Care

#### By Greg Hunt MP

Federal Member for Flinders Federal Minister for Health

**Source:** Media Release – 25 November 2019

The Morrison Government is taking strong action to respond to the three priority areas identified in the Aged Care Royal Commission's Interim Report released on October 31, by increasing home care packages, reducing chemical restraints, and getting younger people out of residential aged care.

The Royal Commission's interim report is clear – as a country, the Government, the Aged Care Sector and the entire Australian community, we can and must do better in providing improved support for our older Australians.

In response to this interim report, we will deliver a \$537 million funding package across the identified three priority areas, including:

- investing \$496.3 million for an additional 10,000 home care packages;
- providing \$25.5 million to improve medication management programs to reduce the use of medication as a chemical restraint on aged care residents and at home, and new restrictions and education for prescribers on the use of medication as a chemical restraint;
- delivering \$10 million for additional dementia training and support for aged care workers and providers, including to reduce the use of chemical restraint; and
- investing \$4.7 million to help meet new targets to remove younger people with disabilities from residential aged care.

## Increasing the number of Home Care packages

The additional 10,000 home care packages will be focused on the Royal Commission's identified areas of need and is strongly weighted towards level 3 and level 4 packages, which provide a high level of care. These packages will be rolled out from 1 December 2019.

Since the 2018-19 Budget, the Government has invested \$2.7 billion in 44,000 new home care packages.

## Better medication management and dementia training

The Royal Commission has identified an overreliance on chemical restraint in aged care, therefore from 1 January 2020, we will also establish stronger safeguards and restrictions for the prescribing of repeat prescriptions of risperidone.

Doctors will still be able to prescribe it but will be required to apply for additional approval if



risperidone is to be prescribed beyond an initial 12 week period. These changes have been developed following recommendations from the Pharmaceutical Benefits Advisory Committee, and in collaboration with doctors' groups and the broader health sector.

Education resources for prescribers will also be developed to support the appropriate use of antipsychotics and benzodiazepines in residential aged care and targeted letters will be sent to high prescribers.

Funding for medication management programs will be increased by \$25.5 million, including support for pharmacists to ensure more frequent medication reviews can occur.

The Royal Commission directed that restraint must only be used as a last resort, and amendments to regulations will make this clear.

The Government is also providing an additional \$10 million over two years from 2019–20 to increase dementia training and support for aged care workers and health sector staff.

This will better equip them to manage behavioural and psychological symptoms of dementia, deliver best practice dementia care and comply with the new standards for reducing the use of physical and chemical restraints in aged care.

We have also responded immediately to the Royal Commission's findings on antipsychotics in aged care facilities by declaring "Quality Use of Medicines and Medicines Safety" a National Health Priority.

#### Younger people in residential aged care

In March, the Government announced the Younger People in Residential Aged Care Action Plan. Since this time there has been a reduction in the number of younger people in residential aged care, including a decline in the number of younger people entering the aged-care system.

### Acting To Improve Aged Care (cont'd from p17)

However, in response to the Royal Commission, the Government will strengthen the initial targets of the Younger People in Residential Aged Care Action Plan.

The new targets, apart from in exceptional circumstances, will seek to ensure there are:

- no people under the age of 65 entering residential aged care by 2022;
- no people under the age of 45 living in residential aged care by 2022; and
- no people under the age of 65 living in residential aged care by 2025.

The Government will invest \$4.7 million to help remove young people from residential aged care and further support these goals by:

- establishing a Joint Agency Taskforce (JATF) between the Department of Social Services, Department of Health and National Disability Insurance Agency (NDIA) to develop a new strategy that builds on the Action Plan and takes action to ensure these new targets are met;
- establishing a specialist team within the NDIA to prevent younger people with a disability who are eligible for the National Disability Insurance Scheme from entering aged care. The specialist team will grow to 80 complex support needs planners by end March 2020 to find suitable accommodation and match participants to vacancies;
- working with industry to identify all available Specialist Disability Accommodation and Supported Independent Living supports across the country to develop a database of existing and new housing options available now and in the future; and
- undertaking a detailed analysis of younger people currently living in aged care, as well as up to 2,000 young people at risk of entering aged care, to better inform new policies and pathways to find alternate accommodation.

#### **Building on longer term reforms**

These measures will complement the major reforms the Morrison Government has been undertaking to improve standards, oversight, funding and transparency in the care of older Australians.

In line with the long-term direction as identified by the Royal Commission, we will also progress further measures, including:

- providing simpler aged care assessments by creating a single assessment workforce and network; and
- establishing a single unified system for care of our elderly in the home.

We will unify the Home Care and Commonwealth Home Support Programs, in line with the Royal Commission's direction to deliver a seamless system of care, tailoring services to the needs of the individual.

These changes will be guided by the final recommendations of the Royal Commission and will have the goal of improving care and ending the wait for home care packages.

#### Simplifying the system for consumers

The Government will streamline assessment by creating a single assessment workforce and a single network of assessment organisations that are able to undertake all aged care eligibility assessments.

This will help people to be connected to care sooner, reduce duplication and inefficiencies, and stop a revolving door of assessments where vulnerable older people get sent to multiple organisations depending on the programs for which they are eligible.

#### **Key reforms continue**

The Royal Commission's final report is due on 12 November 2020, however the Government's rigorous oversight of the sector and reform program continues.

The Government has established a new independent aged care watchdog in the Aged Care Quality and Safety Commission, upgraded Aged Care Quality Standards and introduced regulations to minimise the use of restraints, and we are developing a Serious Incident Response Scheme.

The Government is also expanding the powers of the Commission, with the new Commissioner responsible for the approval of aged care providers, compliance and enforcement actions in relation to the care being provided, and the administration of the responsibilities of approved providers to report assaults.

While we undertake these reforms we will continue to deliver record funding for older Australians of \$21.7 billion in 2019-20, growing to an estimated \$25.4 billion in 2022-23, up from \$13.3 billion in 2012-13.

There will be more work to do across aged care as we continue to listen and respond to the issues raised by the Royal Commission.

Like every Australian, we were appalled by the revelations of the Interim Report, however we will do everything we can to build an aged care system of the highest quality.



## Telehealth Changes

#### **Telehealth Changes Improve Remote Australians' Access To A Doctor**

**The Hon Greg Hunt MP**Minister for Health

**Source:** Media release—29 October 2019

Australians in some of the most remote parts of the country will soon have greater access to a doctor, with the Morrison Government investing \$45.5 million in GP telehealth consultations.

Minister for Health Greg Hunt said, "From 1 November 2019, GPs will be able to conduct regular telehealth consultations with their patients in remote areas, with rebates available through the Medicare Benefits Schedule."

"This expansion of Medicare rebates for telehealth will help improve the quality and continuity of care for patients in areas classified as Modified Monash Model 6 and 7, which encompasses remote parts of Western Australia, the Northern Territory, Queensland, New South Wales, Victoria, South Australia and Tasmania."

The Government will invest \$45.5 million over three years from 2019-20 for this initiative, which aims to encourage patients to maintain a strong relationship with their existing GP.

Minister for Regional Services, Decentralisation and Local Government, Mark Coulton said, "This initiative demonstrates the Government's determination to ensure that Australians who live in remote areas are able to access world-class health services."

"These changes will be implemented through 12 new telehealth specific items being included on the MBS. Expanding the range of services means that patients will get more access to health care," Minister Coulton said.

To be eligible for subsidised telehealth consultations, patients are required to:

- live in a Modified Monash Model 6 or 7 location;
- have an existing clinical relationship with the GP providing the telehealth consultation (defined as three face-to-face consultations in the past 12 months); and
- be at least 15 kilometres by road from the GP.

"A range of existing MBS telehealth arrangements are already in place, including extra telehealth support for people in drought-affected areas," Minister Coulton said.

Minister Coulton said Medicare also supports specialists, consultation physicians and psychiatrists to conduct telehealth consultations with eligible patients in non-metropolitan areas.

"Another telehealth program enables psychologists, GPs, social workers and occupational therapists to provide mental health consultations under the Better Access initiative," Minister Coulton said.

In the eight years to 30 June 2019, the Liberal National Government has funded more than one million telehealth episodes of care, representing an investment of \$155.9 million in the health of Australians living in regional areas.



## New Pain Services Directory Launch

#### By Carol Bennett, CEO, Pain Australia

Source: Painaustralia Blog - 23 October 2019

Living in constant pain day in and day out, pain so all-consuming that it affects your ability to think, communicate, to move. A pain that seems to impact all aspects of your life. It would be an unbearable situation. You want to get help, you want to regain your life. What path might you take to get help?

You might go see your GP. Chances are (3 out of 4 times), she/he will give you a script for a medication. That might help you in the short term, it will dull your brain's perception to the pain, and for a while you will regain function and what may appear to be a measure of normality.

However, the medicine only targets the pain receptors in your brain, not the underlying condition that causes the pain. Over time you may need more, higher doses, as your body builds tolerance to the medicines or your brain becomes more sensitive to the pain. And like all medications, pain relief medicines come with side effects. You could find yourself on a long road, one that many consumers find themselves on, only to find way down in their journey that you are probably heading in the wrong direction.

Only 15% of all GP consultations end with a referral to another health practitioner. This situation is problematic on two fronts. Not only are we pushing millions of Australians towards a pharmacological pathway of pain management, we are also not providing them with an evidence -based way of best practice pain management.

The one consistent question Painaustralia has heard from many people living with chronic pain over the years is not surprising: How can I get the right help?

As always, the answer to the complicated question of chronic pain is never straightforward. For many years we have grappled with the complexities of chronic pain. Sometimes pain cannot be 'treated', cannot be explained, cannot be 'killed' with medication. Effective pain management, the way we respond to chronic and persistent pain, has now become one of those glaring public health challenges. Like pain itself, this challenge is often overlooked or invisible to the public eye.

Fortunately there is a way forward. We know that like all complex conditions, such as diabetes and heart disease, we need to build a team of health professionals around the person living with the condition. You may need a physiotherapist who helps you regain function and mobility for your osteoarthritis, you may

need a psychologist who can help you with the anxiety you experience every month living with endometriosis. It could be a dietitian who assists you in managing your rheumatoid arthritis, or a pharmacist who helps you juggle all the other chronic conditions you deal with along with your complex regional pain syndrome. It may be one, or more, or all of these allied health professions, but having access to them is the best possible chance that you can have at managing your complex chronic pain condition that is unique to you.

This approach to pain management, the psychosocial-bio approach, is central to the aims of both the National Pain Strategy and the National Strategic Action Plan for Pain Management. Both these visionary documents provide a blueprint for the treatment of pain, recommending an interdisciplinary approach to deliver best practice pain management which takes into account the complex physical, psychological and environmental factors that underpin pain conditions.

This is why today, Painaustralia and the Federal Government have taken a step back to basics and provided consumers with the support they need to make informed decisions around their pain management options and pathways.

The <u>new interactive directory</u> launched by Minister Greg Hunt today includes a geographical location tool that can visually show the pain services nearest to your postcode. The Directory lists over 200 facilities both public and private, as well as offering the list of services provided by each facility.

Categorised by 3 levels, based on the International Association for the Study of Pain's (IASP) recommendations for Pain Treatment Services, the Directory lists Multidisciplinary Pain Clinics, Pain Management Services as well as pain practices. With a focus on providing pain management and specialist care, these services are guided by an understanding that pain is influenced by biomedical, psychological, and social/environmental factors, and treatment that is evidence-based and safe.

The Directory takes us and each of the 3.24 million people living with chronic pain one step closer to achieving greater awareness of pain and pain management, and more timely access to consumer-centred multidisciplinary services, the gold standard in pain treatments available today.

If you can imagine constant pain, you can begin to imagine how useful it might be to find a pathway to best practice care.

#### Two Out Of Three Wild Polio Strains Eradicated

## Global eradication of wild poliovirus type 3 declared on World Polio Day

**Source:** www.who.int—24 October 2019

In an historic announcement on World Polio Day, an independent commission of experts concluded that wild poliovirus type 3 (WPV3) has been eradicated worldwide. Following the eradication of smallpox and wild poliovirus type 2, this news represents a historic achievement for humanity.

"The achievement of polio eradication will be a milestone for health. global Commitment from partners and countries, coupled with innovation, means of the three wild polio serotypes, remains," one said Dr Tedros Adhanom Ghebreyesus, Director -General of the World Health Organization and Chair of the Global Eradication Initiative (GPEI) Polio Oversight Board. "We fully

committed to ensuring that all necessary resources are made available to eradicate all poliovirus strains. We urge all our other stakeholders and partners to also stay the course until final success is achieved," he added.

There are three individual and immunologically-distinct wild poliovirus strains: wild poliovirus type 1 (WPV1), wild poliovirus type 2 (WPV2) and wild poliovirus type 3 (WPV3). Symptomatically, all three strains are identical, in that they cause irreversible paralysis or even death. But there are genetic and virologic differences which make these three strains three separate viruses that must each be eradicated individually.

WPV3 is the second strain of the poliovirus to be wiped out, following the certification of the eradication of WPV2 in 2015. The last case of WPV3 was detected in northern Nigeria in 2012. Since then, the strength and reach of the eradication programme's global surveillance system has been critical to verify that this strain is truly gone. Investments in skilled workers, innovative tools and a global network of laboratories have helped determine that no WPV3 exists anywhere in the world, apart from specimens locked in secure containment.

At a celebration event at the headquarters of the World Health Organization in Geneva, Switzerland, Professor David Salisbury, chair of the independent Global Commission for the Certification of Poliomyelitis Eradication, presented the official certificate of WPV3 eradication to Dr Adhanom Ghebreyesus. "Wild poliovirus type 3 is globally eradicated," said "This is a significant Professor Salisbury. achievement that should reinvigorate the eradication process and provides motivation for the final step - the eradication of wild poliovirus

> type 1. This virus remains in circulation in just two countries: Afghanistan and Pakistan. We cannot stop our efforts now: we must eradicate all remaining strains of all polioviruses. We do have good news from Africa: no wild poliovirus type 1 has been detected anvwhere on the continent since 2016 in the face of ever improving surveillance. Although

> the region is affected by circulating vaccinederived polioviruses, which must urgently

which must urgently be stopped, it does appear as if the continent is free of all wild polioviruses, a tremendous achievement."

Eradicating WPV3 proves that a polio-free world is achievable. Key to success will be the ongoing commitment of the international development community. To this effect, as part of a Global Week in Abu Dhabi, United Arab Emirates, in November 2019, the Reaching the Last Mile Forum will focus international attention on eradication of the world's deadliest diseases and provide an opportunity for world leaders and civil society organizations, notably Rotary International which is at the origin of this effort, to contribute to the last mile of polio eradication. The GPEI 2019-2023 Investment Case lays out the impact of investing in polio eradication. The polio eradication efforts have saved the world more than US\$27 billion in health costs since 1988. A sustained polio-free world will generate further US\$14 billion in savings by 2050, compared to the cost countries would incur for controlling the virus indefinitely.



## Travelling To The Philippines Soon?

#### Please get a dose of polio vaccine. By Mae Yen Yap

**Source:** <u>sea.mashable.com</u>—30 October 2019

Polio has returned to the Philippines. And if you plan to travel to and from the country, it is definitely a good plan to get a dose of polio vaccine.

In particular, Filipinos planning to travel to Indonesia are strongly advised to get a dose of the polio vaccine before taking their flights.

If you plan to travel between Indonesia and the Philippines, both embassies highly recommend getting polio vaccination before flying.

Indonesian authorities have recently instructed the Philippine Embassy in Jakarta to increase strict supervision and precautionary measures against Polio Vaccine Derived Polio Virus (VDPV) Type 2, according to ABS-CBN.

Travelers who don't heed the advice and arrive in Indonesia without the immunization requirements will be given polio vaccination on site. They will be charged roughly US\$3 (IRP45,000) for the vaccination.

The embassy also emphasized that travellers who refuse to be vaccinated will be prevented from entering Indonesia and may face deportation from the country.

The Philippines's <u>third polio case</u> has been reported by the country's Department of Health just recently over the weekend.

Health Secretary Francisco T. Duque III confirmed that the latest case is a four-year old child from the Maguindanao who did not receive any dose of the oral polio vaccine (OPV).

"I enjoin all parents and guardians, to ensure that all of your children are protected from all vaccine-preventable diseases," Duque said.



Samples from another suspected case is currently undergoing examinations at the National Institute of Infectious Diseases in Japan.

If you're planning to travel soon, the Philippines DOH has released an advisory that can assist you.

- All travellers of all ages going to countries with ongoing poliovirus outbreaks should receive a dose of oral poliovirus vaccine (OPV) or inactivated poliovirus vaccine (IPV) between four weeks and 12 months prior to travel.
- Those undertaking urgent travel who have not received a dose of OPV or IPV in the previous four weeks to 12 months, should receive a dose of polio vaccine at least by the time of departure as this will still provide benefit, particularly for frequent travellers.
- Travelers must secure a Certificate of Vaccination that will serve as proof of vaccination prior to departure.

If you or a loved one haven't gotten a vaccination, please do so as soon as possible.

## Surge In Polio Cases Predictable

#### By Faiza Ilyas

**Source:** Dawn.com - 30 November 2019

https://www.dawn.com/news/1519610/surge-in-polio-cases-this-vear-predictable-says-expert

KARACHI: The surge in polio cases the country has seen this year was not entirely unpredictable given the fact that the environmental samples collected from across the country from March last year till now have shown presence of the polio virus in many districts.

Also, it is important to note that out of 91 polio cases that have surfaced so far, routine immunisation coverage was not found in 60 cases.

These points were highlighted by Dr Ali Faisal Saleem, paediatric infectious diseases specialist at the Aga Khan University (AKU), at a presser organised at the press club on Friday. The event was organised by the Medical Microbiology and Infectious Diseases Society of Pakistan (MMIDSP).

## Surge In Polio Cases Predictable (cont'd from p22)



"While the country reported only 12 polio cases last year, the test results of sewage samples collected from 35 districts came out positive, suggesting that the situation could be bad this year," said Dr Saleem.

This year, 91 polio cases had been reported in the country, five times higher than last year. Of them, 66 were from Khyber Pakhtunkhwa, most from Bannu district, whereas Sindh had 13 cases.

"The good news, however, is that we have been able to eliminate type two and type three strains of polio," he said.

Speaking about the challenges being faced in polio eradication, he regretted public misconceptions about the safety and efficacy of

polio vaccine and contended one shouldn't have any ambiguity about the vaccine as other countries like Bangladesh and India used the same vaccine to eliminate the crippling disease.

Dr Saleem emphasised the need for strengthening the Expanded Programme for Immunisation and argued that success in the polio programme couldn't be achieved without enhancing the coverage of routine immunisation.

"Out of the 91 polio cases [that have] surfaced so far, 60 cases had no history of routine immunisation," he told journalists, adding that the government's commitments to the programme could be assessed from the fact that it's the first time that it was using its own funds on the cause.

Replying to another question about the negative report on Pakistan's polio programme by an international body, he said the government was engaging all stakeholders now and had set up committees in which all provinces had representation.

"All fears about the vaccine are unjustified and there is a strong need to create awareness and mobilise communities especially the educated segments of society showing hesitance and resistance towards the campaign," he said, adding that the government needed to focus on children being missed in campaigns.

#### Polio This Week

Source: Polio Global Eradication Initiative — as of Wednesday 27 November 2019

- A four-day regional emergency preparedness workshop is currently underway in Lomé, Togo, for senior public health officials to strengthen the capabilities within West African countries to respond to polio outbreaks. Read more about the workshop.
- "It was good to know that a country like India could eradicate polio. It gives us hope that Pakistan can do it too, and we will soon be polio free." These are the words of Aziz Memon, a Rotarian who has dedicated his life to fight polio in Pakistan. Read about his journey.
- Summary of new viruses this week (AFP cases and ES positives): Pakistan— five WPV1 cases, two cVDPV2 cases and one cVDPV2 positive environmental sample; Democratic Republic of the Congo (DR Congo)- five cVDPV2 cases; Benin four cVDPV2 cases; Ghana— four cVDPV2 cases and two cVDPV2 positive environmental samples; Philippines three cVDPV2 cases and five cVDPV2 positive environmental samples; Togo two cVDPV2 cases.



## Polio This Week

**Source:** Polio Global Eradication Initiative — as of Wednesday 4 December 2019

## Wild poliovirus type 1 and Circulating vaccine-derived poliovirus cases

Total cases	Year-to-	date 2019	Year-to-	date 2018	Total in 2018	
Total Cases	WPV	cVDPV	WPV	cVDPV	WPV	cVDPV
Globally	113	195	29	104	33	104
—In Endemic Countries	113	29	29	34	33	34
—In Non-Endemic Countries	0	166	0	70	0	70

## Case breakdown by country

Countries	Year-to-date 2019		Year-to-date 2018		Total in 2018		Onset of paralysis of most recent case	
	WPV	cVDPV	WPV	cVDPV	WPV	cVDPV	WPV	cVDPV
Afghanistan	21	0	21	0	21	0	17 Oct 2019	N/A
Angola	0	60	0	0	0	0	N/A	21 Oct 2019
Benin	0	6	0	0	0	0	N/A	15 Oct 2019
Central African Republic	0	16	0	0	0	0	N/A	6 Oct 2019
Chad	0	1	0	0	0	0	N/A	9 Sep 2019
China	0	1	0	0	0	0	N/A	25 Apr 2019
Democratic Republic Of The Congo	0	50	0	20	0	20	N/A	7 Oct 2019
Ethiopia	0	3	0	0	0	0	N/A	8 Aug 2019
Ghana	0	9	0	0	0	0	N/A	23 Oct 2019
Indonesia	0	0	0	1	0	1	N/A	27 Nov 2018
Mozambique	0	0	0	1	0	1	N/A	21 Oct 2018
Myanmar	0	6	0	0	0	0	N/A	9 Aug 2019
Niger	0	1	0	9	0	10	N/A	3 Apr 2019
Nigeria	0	18	0	33	0	34	N/A	9 Oct 2019
Pakistan	91	11	8	0	12	0	7 Nov 2019	3 Nov 2019
Papua New Guinea	0	0	0	26	0	26	N/A	18 Oct 2018
Philippines	0	6	0	0	0	0	N/A	2 Oct 2019
Somalia	0	3	0	12	0	12	N/A	8 May 2019
Togo	0	3	0	0	0	0	N/A	16 Oct 2019
Zambia	0	1	0	0	0	0	N/A	16 Jul 2019