



Volume 10, Issue 1

## Polio Oz News

March 2020-Autumn Edition

### Celebrating On The High Seas

### **By Gillian Thomas**

President, Polio Australia

Just over two years during the Christmas break I went out to dinner with Maryann who happened to be spending some of her holiday in Sydney. We chatted about my upcoming 70th birthday in 2020, and I said I'd like to go on a cruise to celebrate. Quick as a flash, Maryann said she'd come with me! The seed was sown – by the time a booking was due our party had grown to six (eager or cajoled!), including Board member Sue Mackenzie and her husband Graeme.

Receiving an OAM in the Australia Day Honours just a few days before we sailed gave me a double reason to celebrate and was the icing on the cake!

On a sunny Sydney afternoon we set sail to the South Pacific on Royal Caribbean's "Radiance of the Seas". Due to the corona virus scare, the ship was turned away from Mare, Lifou and Isle of Pines in Vanuatu, and instead we experienced Noumea, New Caledonia, twice. Fortunately, our cruise was not beset by the problems experienced by the "Diamond Princess" passengers in Japan.

I had previously cruised (Caribbean, Tasmania, Alaska's Inside Passage) and thoroughly enjoyed the varied experiences. However, my most recent cruise was 20 years ago, and my agility

and mobility have both decreased a lot in the intervening time. Although I had been looking forward to the cruise for two years, I confess to being nervous about how I would cope.

cruise All companies provide lot of а information on their websites about accessibility - well worth reading before you book. Royal Caribbean comprehensive \ has a Special Needs "Guest

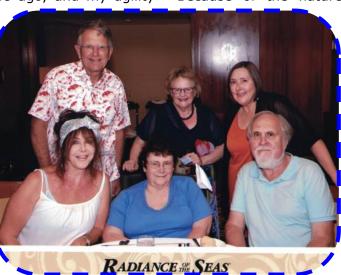
Form" which I duly completed. Since I was travelling with companions and my own manual wheelchair, I did not opt for wheelchair pier assistance (usually means a lot of sitting around waiting). Nevertheless, there was immediate assistance available at embarkation to take our luggage to the drop-off point (the same person helped us, our luggage and commode get to the taxi stand when we returned 10 days later in the pouring rain).

Once on-board the ship, moving around in a wheelchair both inside and on the outside decks is mostly easy. Occasionally, the thresholds that regularly appear in the floor between different sections can be a bit too high for small front wheelchair wheels to comfortably cross without help, but these were just minor inconveniences. The biggest challenge was waiting in front of a bank of lifts and heading to the right one fast enough when you heard a ping! During busy times, patience is a virtue as you wait for a lift with enough space to accommodate you and your wheels.

Having booked an accessible cabin (with a balcony!) I had decided early on that I would take my own bathroom commode. I included this on the Special Needs Form and requested a specific bed height to facilitate transfers. I was delighted to see that my request had been met.

Because of the nature of cruising, there are

usually quite a number of elderly people onboard. Some may need to use a wheelchair for longer distances, and are often accompanied equally elderly spouses. Dining staff and other always quick to offer only assistance. My quibble is that staff aren't always able to discriminate between frail occasional aged wheelchair users and those of us who are long -term wheelchair experts.



Cont'd page 2

## Polio Australia Representing polio survivors throughout Australia

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It is only the farmer who faithfully plants seeds in the Spring who reaps a harvest in the Autumn.

### Celebrating On The High Seas (cont'd from p1)

For example, if they insist on pushing me they will often go frontwards down a slope without even contemplating that this might cause a problem.

As I am only marginally able to use my legs to brace myself in this situation, I can easily slide straight out of the wheelchair! Some specific disability vs frail aged awareness training for staff would be very helpful.

Our original itinerary involved a few tender transfers if we wished to explore ashore. As it happened, the twice-revised itinerary meant we only had one tender transfer – Mystery Island. When booking, I had checked and confirmed that the tenders were accessible (restrictions apply for scooters and large electric wheelchairs). When the time came to board, however, they pulled us out of the line and said although they have a platform on the ship which lowers to tender height, we wouldn't be able to go to the island because there were steps from where the tender tied up. After much toing and froing, and repeatedly telling them steps weren't an issue (been going up them in my wheelchair for decades) we eventually negotiated that we would go in the tender, and if the steps turned out not to be do-able, then we would simply come back. An easy solution that really should not have taken at least half an hour of stress to negotiate!

In the end, the few steps were fine and although we could only wheel to the end of the jetty (there was sand beyond), at the very least I got off the ship and shared in the experience of the island, not to mention having a fun time riding in the little tender as it sped over the waves. I was reminded of the expression: "Don't decide what I can do by what you think I can't do".

Did I have a good time? Absolutely! Would I cruise again? Absolutely! Asking questions and checking things out beforehand is a must – let them know all your special needs. Then sit back and enjoy, and don't let the inevitable issues that are part and parcel of travelling with a disability interfere with your adventure.



#### **Photos:**

Above—"Radiance of the Seas" moored off Mystery Island

Right—tender transferring passengers from ship to Mystery Island jetty



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### President's Report



Gillian Thomas

It's a new year for Polio Australia and I was fortunate to have started it off with a great holiday. It was lovely being away from emails and phone calls. The problem with holidays, unfortunately, is that the "to do" list seems to grow exponentially while you are away, and then you have to work doubly hard to clear the backlog when you get back!

As reported on p4, in December we farewelled John Tierney as our National Patron, after 12 years sterling service in the role. John's efforts on behalf of polio survivors over this time have been inestimable. True to form, though, so as not to leave us without a Patron, John head-hunted his own replacement! Also on p4 we are therefore very pleased to introduce you to our new National Patron, Michael Lynch AO CBE.

Late last year we also regretfully farewelled Christine Tilley, one of our Queensland Board members representing Spinal Life Australia (SLA). Christine who was no longer able to give the time to contribute at the level she desired. In resigning, she wrote: "It has been a pleasure being a part of the Polio Australia Board. I am

proud to have been a part of what has been accomplished over the past three years. Furthermore, I have no doubt that the Board will continue their successes into the future." We will certainly miss your input, Christine.

At our February Board meeting, we welcomed two new members to the **Board**: Maryann Liethof (who I think you know!) who will have a special focus on operational matters, and Robyn Grote who is now our second SLA Board member. Robyn is a polio survivor and a physiotherapist, with extensive therapeutic experience advocacy experience supporting in development of better rehabilitation outcomes for Queenslanders. With extensive experience in Queensland Health, and as a research fellow, Robyn is well-placed to assist Polio Australia achieve our strategic aims.

To end this catalogue of comings and goings, the Board was very sorry to say goodbye to Rachel Ingram, our Health Promotions Officer (p6). Rachel's departure will inevitably have an impact on us achieving some goals in our Strategic Plan.

On the advocacy front, the inequities in access to the NDIS are gaining more exposure with recent media (p12). There are more articles in the pipeline, so keep your eyes and ears open.

### Gillian

### From the Editor



Maryann Liethof Editor

Here we are again! I'm not sure how 'retired' I feel after producing this edition of *Polio Oz News*; there's certainly a lot going on! Not least of which is the corona virus threat . . . It must bring up so many memories of polio epidemics. However, there is more than enough about *that* virus in other news forums, so I've stuck to things-polio.

As you can see on page 1, I was delighted to join Gillian and friends on a South-Pacific cruise earlier in February. I haven't been on a sea cruise before, so it was quite an experience. I spent a lot of time on my balcony reading and thinking of nothing much except when dinner time was. It was a great way to wind down.

Work goes on at Polio Australia, much of which has been reported in this edition. Clinical Health Educator, Michael Jackson, has been spending his 'down time' surveying our readers on their interactions with health professionals (p5 and 15), which he will present at the 3rd European Conference on PPS (p5) in June. Michael also produced another interesting article on Understanding Doctor's Learning (p10), which follows on from another article he wrote for the

Summer 2019 edition of Polio Oz News.

Steph Cantrill, our Community Engagement Officer, has also been busy organising information sessions in NSW (p6). She also found the time to write a piece on the difference between Polio Australia and the State Polio Networks, which some people still find a bit confusing (p7).

Darlene Felsch, the Resource Manager, put together some important data on Polio Australia's current financial situation on p9.

We have an update from Polio NSW (p8) and another from Spinal Life Australia (p14) which also highlights the resources available for NDIS vs My Aged Care recipients. This follows on from an interesting article which appeared in ABC News on the "Fight To End NDIS Funding Age Discrimination" (p12) featuring the issues faced by Victorian polio survivors Lyn Bates and Peter Willcocks.

Readers Esther Smart and Jan McDonald were both moved to write stories for this edition (p16 and 17), which many will relate to, I'm sure.

Additional articles on the NDIS, Aged Care Assessments, and polio news from abroad are also included. Hopefully, something of interest for everyone!

Maryann

### A Changing Of The Guard

At the end of 2019, Dr John Tierney AM PhD announced that he was standing down as Polio Australia's National Patron, enabling him to *fully* retire. John took on this role in 2008, also becoming President of Polio Australia from 2012 to 2017. During that time, John was one of the two Polio Australia Board members representing Polio NSW.

Polio Australia has so much to thank John for. Over the years, John has actively represented polio survivors in the halls of federal parliament, and in the media. Tapping into his many contacts, John enthusiastically promoted and participated in fundraising campaigns, raising much needed funds for Polio Australia.

As a polio survivor himself, John remains passionate about the ongoing welfare of the post -polio community, and Polio Australia's role in ensuring polio survivors continue to be supported into the future.

However, we are delighted to advise that John has not left a vacancy. This year, Polio Australia welcomes our new National Patron, Michael Lynch AO CBE.

Michael grew up in Maroubra, New South Wales, and contracted polio when he was 3 in 1953.

Michael has enjoyed a long and highly successful career, including being the General Manager of the Sydney Theatre Company from 1989-94. He went on to become General Manager of the Australia Council, the Federal Government's arts funding and advisory body from 1994-98. In 1998, he became Director of the Sydney Opera House.

From 2002 to 2009, Michael was Chief Executive of the South Bank Centre in London. He oversaw the successful rehabilitation of the Royal Festival Hall, which was re-opened in October 2007 by The Queen (King George VI having opened the original building in 1951).

In March 2009, Michael returned to Australia and was appointed a Director of the Australian Broadcasting Corporation. He is also a member of the Board of Film Victoria.

In 2011, Michael travelled abroad again to take up the Hong Kong Government appointment of CEO of the West Kowloon Cultural District Authority.

Michael returned to Sydney in 2015, and has since taken up a range of activities including becoming the Chair of the Sydney Community Foundation, working in Brisbane for Circa (a human circus company), and in the Northern Territory setting up an indigenous art gallery.

In 2018, Michael became a Co-Patron of Polio NSW.

In an email to Polio Australia, John said:

"Michael is a great find, and I believe there is a lot of potential in this new arrangement, both for new government and private funding for our cause. I did a similar thing at Lifeline Australia 10 years ago, and I hope that this changeover works out just as well.

I found my time as Polio Australia's National Patron and President challenging, rewarding and frustrating, particularly with it taking the Federal Government so long to act on our behalf. Hopefully, with Michael Lynch's influence and networks, in both the government and the private spheres, future funding and programs will be expanded quickly."

Polio Australia is extremely grateful for all the time, energy, generous funding support, experience, skills and wisdom that John has provided over the years. We know John will still be keeping a close eye on Polio Australia's progress. And we wish John luck in winding back his responsibilities; not an easy task for such an unrelenting achiever . . .

- Ed



Polio Australia is pleased to welcome Michael Lynch AO CBE as our new National Patron

### **Educating Health Professionals**



**By Michael Jackson** Clinical Health Educator

Michael has been invited as a Guest Presenter at the 3rd European Post-Polio Congress (see below) in June 2020. The following Abstract is the subject he will be presenting on. More details on the full survey results can be read on

page 15.

## A Descriptive Study on the Healthcare Interaction Perceptions of Australian Polio Survivors

#### INTRODUCTION

A frequently expressed frustration of Australian polio survivors is encountering knowledge and intervention barriers during interactions with their healthcare professionals. Survivors face risks with common health interventions, and express apprehension over potential loss of functional ability and mobility mode.

This descriptive study aimed to examine symptomatic survivors' (respondents): confidence with their healthcare professionals; expectations of healthcare professionals; and satisfaction with their General Practitioners' understanding of Late Effects of Polio.

### **METHODS**

An electronic survey was distributed to Polio Australia's contact list in December 2019, and was available for two months. 29 mandatory closed-ended questions and three optional openended questions were asked in the survey. Data was collated, filtered, and correlated to provide insight on survivors' perceptions.

#### **RESULTS**

734 survivors responded to the survey. The majority (>60%) characterised as 70-89 years old, living in a city, had polio before aged 6 years in Australia, had Late Effects of Polio onset beyond 30 years, and had one or no other chronic illnesses.

72% of respondents cited problems talking to health professionals. Respondents reported the most difficulty with doctors. When describing Late Effects of Polio problems to General Practitioners, respondents are less confident. Respondents reported average to low confidence in new health professionals being competent with the condition. Regarding interventional risks, most respondents had average confidence in their General Practitioner's knowledge.

'Activity and exercise' was the element of Late Effects of Polio which 72% of respondents deemed healthcare professionals should understand. 28% of respondents perceive their General Practitioner as both willing to learn and currently learning about the condition. 14% perceive their General Practitioner as both unwilling and not learning.

Respondents' education levels do not influence satisfaction with their General Practitioners, but those with four or more chronic conditions are less satisfied. Half the respondents were satisfied with their General Practitioner's answers and referrals regarding their condition.

### CONCLUSIONS

The frustrations and apprehensions which Australian polio survivors report elsewhere appear common and well founded. With education and training on Late Effects of Polio, current and emerging healthcare professionals would likely better serve this patient population.

### 3rd European Conference on Post-Polio Syndrome

Following the successful conference Amsterdam, the 3rd European Conference on Post -Polio Syndrome: "Improving care for Polio will be held in Vitoria, Gasteiz, Spain from June 10-12, 2020. This 3-day international conference aims to improve care for polio survivors who are confronted with post-polio syndrome, in Europe and worldwide. conference brings together an international polio of survivors, health care from disciplines, professionals multiple and and researchers, to exchange knowledge experiences.

### **Main conference topics:**

- Diagnosis and Therapy
- Symptom Management

- Multidisciplinary Rehabilitation
- Orthotic Devices
- Best Practices
- Latest Research Results

All accepted abstracts will be published in the <u>Journal of Rehabilitation Medicine</u>.

We are proud to inform you that world-renown speakers in the field of post-polio syndrome and polio eradication progress will lecture at the conference. Our conference website includes the scientific program, list of confirmed speakers, information about transportation and accommodation: <a href="https://www.postpoliocongress.com">www.postpoliocongress.com</a>

We invite you to attend this conference.

### Rachel's Farewell



### By Rachel Ingram

It is with great sadness that I am leaving the Polio Australia team this February. I joined the (at the time) one-(wo)manteam of Maryann in August of 2017, and WOW, we have certainly come a long way since! I remember researching the organisation prior to my job interview.

prior to my job interview, when I walked in and found out it was *just* Maryann in the office, I was gobsmacked! It always amazed me how far the organisation had come with so few resources.

I have thoroughly enjoyed my time at Polio Australia and working alongside the small close-knit team here in the office. I have also had the pleasure of meeting many polio survivors along the way. I want to thank Gillian, Maryann and the entire post-polio community for everything you have taught me (maybe even without knowing it!), both professionally and personally.

I truly hope that I have added value long into the future for the organisation and the lives of polio survivors in Australia. I am so proud of the "Living With Polio" information package which I coordinated after recognising a need for

symptom-specific information. I know this information package can be utilised for many years to come.

#### Footnote:

I'm sure I speak for the whole Polio Australia Team when I say that Rachel will be greatly missed—both personally and professionally! When Rachel joined us, she and I were the original office 'Team'. It was an absolute joy to have a young, vibrant, and progressive thinker like Rachel on board. Although she started as an Administration Officer, she was just about to complete her Degree in Health Promotions, so we were quick to utilise her more advanced skills, and she was promoted to the role of Health Promotions Officer. Rachel worked on web design, promoting Polio Awareness Month and other activities like fundraising campaigns. She also worked on streamlining internal and external communications, and so much more! The work she put into the "Living With Polio" Fact Sheets and associated videos, was absolutely exceptional.

Rachel has had a long-standing interest in eating disorders, and was successful in securing another job in this field. I wish her all the very best for her future career, and I know Rachel will be an asset wherever she goes.

Maryann Liethof

### Community Engagement



**By Steph Cantrill**Community Engagement
Officer

The New South Wales program outreach is continuing, and has been going really well. Each Community Information Session has new people in attendance, and even those who have "been there, done that" say they are getting

something out of them! People have said they appreciate the opportunity to connect, to encourage each other and to learn something new.

The following sessions are upcoming:

- Ballina, 16<sup>th</sup> March
- Coffs Harbour, 17<sup>th</sup> March
- Port Macquarie, 18th March
- Sydney, 20<sup>th</sup> March strictly RSVP only due to limited space

Of course, we are always looking for more funding so we can keep reaching out to polio survivors across the country. At the moment, we're particularly waiting on news from Grants SA regarding funding for Community Information Sessions in regional SA and Adelaide. And we'll just keep looking for funding opportunities – because we want to keep empowering polio survivors to manage their symptoms and access the help they need.

Check the website for more session details or contact Steph on: 03 9016 7678

### CAN YOU HELP STEPH GET TO THE 3RD EUROPEAN CONFERENCE ON PPS?

Polio Australia is keen for Steph to attend the <u>European Conference</u> in Spain in June. With a background in occupational therapy, together with her current role as Community Engagement Officer, Steph can present on Polio Australia's program areas, connect with key people, and share the information with Australia's post-polio community when she returns.

The budget is \$5,000 and we currently have \$2,900, thanks to a \$2,000 grant from Rotary District 9820 and a \$900 private donation. But **we need your help to raise the extra \$2,000**. Please consider donating here: <a href="www.polioaustralia.org.au/donations-bequests/">www.polioaustralia.org.au/donations-bequests/</a> or contact Polio Australia on Ph: 03 9016 7678 or Email: <a href="contact@polioaustralia.org.au">contact@polioaustralia.org.au</a>.

### Polio Australia And State Polio Networks



### Polio Australia and the State Polio Networks - what's the difference?

#### By Steph Cantrill

Community Engagement Officer

As I travel around metro or regional areas doing community information sessions, I often encounter confusion about who does what. When I'm asking for a person's name and address for our records, it's not uncommon to get a response like: "Oh, I'm already a member; you'll have all my details".

I then need to explain that Polio Australia doesn't have membership in that sense – the state networks are our members. So, while they may be a member of their state organisation, that doesn't mean we know who they are!

### So what's the difference? Why so many organisations?

I'm going to summarise this in a table (below), and then try to explain it in a bit more detail. I hope this helps to clarify things, because I know it can all be very confusing. To explain further:

### Membership

Polio Australia: Polio Australia's members are the State Networks. Individual people are not our 'members'. We do keep a database of people we come across though – for the purpose of sending you the newsletter, keeping you informed about

events in your area and so on.

State Networks: The States have members, usually with some form of annual payment. The states differ in what's available for their members, but there is always some level of support and connection. Membership with your State Network is highly encouraged!

### **Support for polio survivors**

This is the main priority of both Polio Australia and the States! Both organisations are available to answer your calls and emails. However, Polio Australia will often direct your query to your State Network for more localised advice and ongoing support.

*Polio Australia:* Polio Australia also exists to support the State Networks in doing what they do best – supporting polio survivors.

State Networks: The State Networks also oversee/coordinate the support groups. The States are your best contact to find out details of your local group.

### Information and resources for polio survivors

Polio Australia: Polio Australia has produced, and will continue to produce, a range of resources for both polio survivors and health professionals.

These are available to anyone (most of them free, but some at a small cost). While we would love to have enough money for them to be

	<u>Polio Australia</u>	State Networks*
Membership	State Polio Networks	Individuals
Support for polio survivors	Provide support to states.	<ul><li>Host support groups.</li><li>Also provide support to individual polio survivors.</li></ul>
Information and resources for polio survivors	<ul> <li>Production of <u>resources</u> available to anyone.</li> <li>Conferences/Retreats.</li> <li><u>Community information sessions</u>.</li> <li>National quarterly e-magazine, <u>Polio Oz News</u>.</li> </ul>	<ul> <li>Polio Australia resources available for use and distribution.</li> <li>May also produce locally-relevant resources.</li> <li>State-based newsletters (electronic or print), usually for members only.</li> <li>Local conferences or workshops including Polio Days.</li> </ul>
Health Professionals	<ul> <li>Department of Health funded clinical practice workshops for health professionals.</li> <li>Online Health Professionals Register.</li> </ul>	<ul> <li>Local knowledge, accumulated over many years.</li> <li>May work with Polio Australia to produce information for health professionals.</li> </ul>
Lobbying and advocacy	<ul> <li>Advocacy on national issues.</li> <li>Systemic advocacy on behalf of Australian polio survivors.</li> <li>The <u>Australian Polio</u> <u>Register</u>.</li> <li><u>Government lobbying</u> at national level.</li> </ul>	<ul> <li>Advocacy on state and local issues.</li> <li>May provide individual advocacy.</li> <li>Systemic advocacy on behalf of polio survivors in the state.</li> <li>State and local government lobbying.</li> </ul>

### Polio Australia And State Polio Networks (cont'd from p7)

available in hard copy, most of our resources are electronic.

National conferences, Retreats and community information sessions are also run by Polio Australia in various locations across the country. These exist to provide polio survivors and their families/carers with face-to-face opportunities to share and learn together.

In terms of regular information, *Polio Oz News* is Polio Australia's quarterly e-newsletter, available free to anyone who's interested.

#### State Networks:

As mentioned, the State Networks have polio survivors as members. They're available to the polio survivor community to provide information, resources and guidance.

The resources they share with the polio survivor community might include general resources produced by Polio Australia, their own state-based resources, or a combination of both.

State Networks may also have an extensive library of other resources available for purchase or loan.

The State Networks may also conduct conferences, seminars or other events to provide connection and information for polio survivors.

#### **Health professionals**

Polio Australia: Thanks to a Department of Health grant, Polio Australia is able to conduct Clinical Practice Workshops to educate health professionals about the Late Effects of Polio. The aim is to increase the post-polio awareness among the medical and allied health professional community, to promote better health outcomes for polio survivors. Bit by bit, our <u>register of knowledgeable health professionals</u> is growing – please feel free to use it to find someone in your area!

State Networks: The people you contact in your State Network will have a wealth of local knowledge. If they can't find a health professional in your area, they may be able to put you in touch with someone who can.

### **Lobbying and advocacy**

Polio Australia: Our national-level lobbying and advocacy activities have included:

- Successfully lobbying to obtain funding for health professional education
- Maintaining relationships with the Parliamentary Friends of Polio Survivors and Parliamentary Patrons
- Membership with two major alliances to advocate for the needs of polio survivors along with other illness and disability groups

   the Neurological Alliance of Australia and the Assistive Technology for All Alliance
- Submissions, position papers and press releases to promote the cause of polio survivors across Australia
- Maintaining a <u>national register of polio</u> <u>survivors</u> to increase our "voice"

State Networks: The states may also be involved in local-level advocacy campaigns, lobbying to MPs or other awareness-raising activities.

I hope that's cleared it up to some degree!

### Polio NSW Update

The Polio NSW Board met for its annual Planning Session on 21 February. While a significant proportion of the discussion focussed on governance and administration the plans for activities during the year were also a major element.

It was proposed that there be a mid-year seminar with two Board members and the office being charged with the responsibility to undertake initial planning for the date, venue and topics.

The other main activity for the year will be the Annual General Meeting in November which will be associated with a function involving either an after-lunch speaker or mini seminar.

Details of these events will be provided in upcoming issues of *Network News* and on the Polio NSW <u>website</u>.



Ella Gaffney, a Board member, recently participated in one of Polio Australia's community information sessions in Bathurst.

Two Board members will be "lived experts" at Polio Australia workshops during March. Vice President, Sue Ellis, will join Michael Jackson for the session at Royal North Shore Hospital and Secretary, Merle Thompson, will attend the session at Liverpool Hospital.

It is hoped that Merle will be able to travel to Spain to attend the European Polio Union's congress in Vitoria in northern Spain in June.

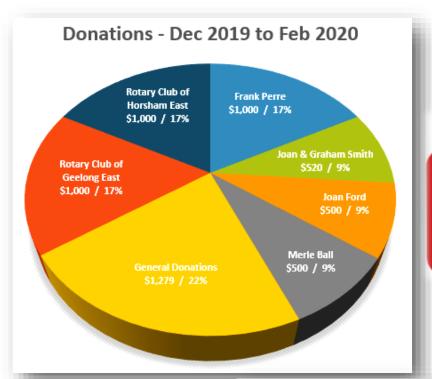
### Supporting Polio Australia

Polio Australia would like to thank the following individuals and organisations for their generous support from 1 December 2019 to 30 January 2020. Without you, we could not pay our rent, core operating expenses, or management staff!

Polio Australia has a life span of about 18 months if we don't urgently receive more grants and donations. For example, our 'Hall of Fame' donor, Jill Pickering, can only donate to salary of the Community Engagement Officer for one more year. Without new funding, after June 2021, engaging with, and running information sessions for, polio survivors around the country will no longer be possible.

Over several years, Jill Pickering has made this salary donation her 'living bequest', and many hundreds of polio survivors have benefited from her largesse.

If you would like to see how your 'living bequest' can support polio survivors now, click on the following link: <a href="www.polioaustralia.org.au/donations-bequests/">www.polioaustralia.org.au/donations-bequests/</a> or contact the Polio Australia office on Ph: 03 9016 7678 or Email: <a href="mailto:contact@polioaustralia.org.au">contact@polioaustralia.org.au</a>.



"I regularly donate to Polio Australia because it actively supports the unique needs of polio survivors. As a volunteer with Polio Australia, I am very aware of how they use every dollar received in the most practical and economical way." Jill P.





### Understanding Doctors' Learning

### **Preparation And Impetus**

### By Michael Jackson

Clinical Health Educator

In my December 2019 *Polio Oz News* article, I had delved into framing medical appointment interactions, understanding how doctors learn, and utilising the power of the written word. *Taking on the problem* is a key part of any doctor's learning cycle. I had indicated that this follow up article would examine patient-side aspects of being prepared for the *taking on the problem* barrier, and providing an impetus for doctors' learning.

The open ended questions at the end of the recent Polio Australia medical survey revealed many insights on this topic. Quite a few respondents offered advice on how to be prepared for and how to press for doctors to engage in learning about Late Effects of Polio (LEoP). It is worth noting the prevalence of the issue revealed by the survey: 3% of respondents denied having problems talking with health professionals, 25% offered no comment, and 72% of respondents reported one or more problems. This suggests that almost 3 in every 4 polio survivors experiences some sort of problem with healthcare professionals.

### Being prepared for a doctor not taking on the problem

Several position-based barriers of doctors were prevalent in our medical survey results, and have been reported elsewhere. These positions are: inexperience with the condition, attributing symptoms elsewhere, and disregard for the condition. Having fairly self-explanatory position titles, we can cut to the chase here with advice on how to be prepared for each of these positions.

*Inexperience with the condition?* This is an <u>information</u> barrier. Be prepared to:

- Summarise LEoP and/or PPS in a few concise sentences.
- Explain risk factors faced with usual medical interventions (exercise and activity, medications, surgery).
- Point the doctor towards resources (Polio Australia's website and professional workshops, HealthPathways, published articles and books, Polio Australia's Clinical Educator and Advisory Group professionals).
- Offer your assistance or guidance with education on LEoP.

Attributing symptoms elsewhere? This is a synthesis barrier. Be prepared to respond to:

• "It's your age": Compare your symptoms, health trends and abilities to others your age (siblings, spouse, friends). Highlight the

- underlying chronic aspect of having had polio. Mention your attention to your health.
- "It's that [health event] you had": Compare your recovery to 'usual' recovery. Compare your ability to previous ability. Highlight existing or long term trends on function and safety.
- "It's your [other diagnosed condition]": Highlight the difference in symptoms that you experience for each. Summarise LEoP and PPS. Ask for expected timelines for treatment and recovery for the attributed condition versus LEoP.

Disregard for the condition? This is a <u>belief-system</u> barrier. Be prepared to:

- Highlight the literature (300 published articles on this topic in the last 20 years)
- Highlight the prevalence of survivors (tens of thousands in Australia, mostly in the elderly who often use the healthcare system)
- Highlight the immediate context (you are their case study)
- Pose a "Would you..." question, e.g. "Would you disregard this condition if your parent was reporting it? Would you consult with your peers on my case?"
- Focus on symptom improvement in the interim, continuing to highlight the risks those with LEoP face.

Remember two things: it is the doctor who has the internal barrier, and yet the doctor may not be aware of the barrier. This is human. To boost your chances of reducing these barriers, you need to enlist some advocates – expand your education audience to include the doctor's staff. Doctors on their staff's anecdotal rely Staff information and observations. are influential advocates for your health, and can raise your doctor's awareness.

Also keep in mind that your delivery style is very important – despite any negative emotion or perception you may have towards a scenario, it is important to present your case in a proactive manner that looks towards positive health outcomes for you. Only both of you can make your case a success – success can be both contagious and motivating.

### **Impetus for Learning**

Let us now assume that your doctor has become aware of the barrier that has caused them *not to take on the problem* (LEoP, PPS) that you present to them. How can we now encourage them to take action and engage in the actual learning?

Some of the bulleted points previously described may be enough to trigger an episode of voluntary learning for a doctor. Try them and see what has an impact, but remember those

### Understanding Doctors' Learning (cont'd from p10)

strategies are mostly immediate and direct – the doctor is the captive audience in their own office! The doctor may not have chosen to be educated. You are the one prompting or delivering learning experiences.

At the threshold of voluntarily starting to learn, we need to understand and utilise some theory: Andragogy is the study of adult learning. Adults learn quite differently to children, although some characteristics can be shared. Most notably is the source of motivation – this being dominantly internal for adults.

Malcolm Knowles made five assumptions in his theory of andragogy, but we will only address three of them here:

As adults, doctors will prefer learning where there is a real world application. Is the topic relevant? It there a practical need? Are there ways to apply what is learned to other aspect of their work?

Prompt doctors to: find out how understanding LEoP will help their other patients; use the best evidence to treat you; explore Polio Australia's websites.

As adults, doctors will use experience as a resource for future learning. How have they learned about similar topics previously? How did they approach complex conditions as a junior doctor? What pre-existing context and knowledge do they have for LEoP?

Prompt doctors to: compare your LEoP to the symptoms other patients have; consider the patients they have treated who never revealed their polio history; contrast the LEoP condition with other disabling conditions they know.

As adults, doctors will learn by self-direction, preferring to be involved in choosing and planning their learning experiences. You can tell them what to do, but they ultimately decide upon action. You can provide avenues, ideas, and resources, but they have to choose to follow them. You are the same!

Prompt doctors to: state one LEoP symptom that they are most interested in; perform one literature search on LEoP on <a href="PubMed">PubMed</a>; ask you about the most interesting LEoP scenario you have heard about.

Self-direction is tied to motivation. When emotional content is added to a topic or desired action, motivation can be easier to engage. Put something at stake: describe your worst days; contrast their abilities to yours; describe your efforts and ask for reciprocal efforts. Tell them they can do it: be their cheer squad; act as your favourite teacher did towards you. I have modified our workshop promotional materials to include this approach – information can be bland and easily disregarded, but it can be hard to shrug off a triggered emotion.

To conclude, I will point out an interesting single point that was revealed in the medical survey:

One of the 734 survey respondents indicated that their GP was unwilling to learn, yet that GP was actively learning.

While this may seem an unusual scenario for an adult learner, it does highlight that doctors are human and can be influenced to take on your problem despite their internal resistance!

### Using The Health Professionals Register

By Michael Jackson

Clinical Health Educator

www.poliohealth.org.au/search-health-professionals-register

While delivering the Clinical Practice Workshops to healthcare professionals across Australia, Polio Australia has provided attendees with the opportunity to voluntarily join our professional register. Professionals who have not participated in a workshop who visit our website can also join on a voluntary basis. The register was established for the following reasons:

- To provide a means for healthcare professionals to advertise their skill set and availability to serve the Australian polio survivor population;
- To provide a means for polio survivors across Australia to find professionals with an interest in and/or training on the Late Effects of Polio; and
- To provide medical practitioners with a database of suitable professionals to refer their patients to.

To date there are 264 professionals listed (1 in NT, 7 in ACT, 16 in SA, 21 in TAS, 38 in WA, 56 in QLD, 58 in VIC, 66 in NSW). We hope to add to this list considerably this year, as we emphasize the need for connectedness between professionals, survivors, and the state networks.

Given the difficulty that polio survivors report regarding finding trained healthcare professionals, this resource should be an early point in your search for someone near you. If your GP, or any other healthcare professional you see, needs to refer you to someone, please mention this list to them.

### Fight To End NDIS Funding Age Discrimination

Disability advocates escalate fight to end NDIS funding age discrimination By James Hancock

**Source:** ABC News - 29 February 2020



**PHOTO:** Ms Bates said the NDIS discrimination was a bureaucratic mess that needed to be sorted out. (ABC News: James Hancock)

Lyn Bates is among hundreds of thousands of Australians with disabilities not covered by the National Disability Insurance Scheme (NDIS). "It's discrimination actually," she said.

### **Key points:**

- Lyn Bates and Peter Willcocks have to fund their own wheelchairs and other medical equipment
- They were both over the age of 65 when the NDIS was rolled out and are not covered by the insurance scheme
- A new alliance is pressuring the Federal Government to make funding available for those who have missed out on the NDIS

The 74-year-old cannot walk because of the effects of the polio virus, which she contracted as a child in the 1950s before a vaccine became available. She uses a powered wheelchair to get around her home in Melbourne's south-east and a hoist to lift her in and out of bed. The equipment cost Ms Bates \$14,000. But the NDIS would have picked up the tab if she was under the age of 65 when it was introduced. "It's not my fault the NDIS came here when I was over 65," she said.

The bureaucratic line in the sand means that those who were under 65 when the NDIS was rolled out will continue to receive coverage for the rest of their lives.

The chair and hoist would have set Ms Bates

back even more money if not for a Victorian Government subsidy to ease the financial pain. She said the federal My Aged Care program had no real funding for "assistive technology" and what home support funding was provided was quickly spent on other expenses like carers and maintenance.

Peter Willcocks is also covering the cost of his own assistive technology. Like Ms Bates, he has post-polio syndrome and relies on a powered wheelchair and leg braces to maintain his independence, along with other equipment like a home lift.

The braces, however, are old and put him in danger of falling over and the wheelchair has a worrying wobble. Mr Willcocks said replacements would not come cheap. "My immediate needs are around \$30,000," he said. One sixth of the cost will be covered by the state but the rest he needs to find himself. "It's going to hurt financially, it's really going to hurt," he said. "That's the sort of money that most people my age are able to use on holidays or new cars."

He is frustrated by the fact that if he was under 65 when the NDIS was rolled out, the disability aids would be paid for. "I would be assessed and I'd be sitting here right now in a new power chair and I'd have new leg braces on," he said. "I would be able to ambulate a lot safer than I can now."

### Not enough money to meet demand

Ms Bates and Mr Willcocks are among hundreds of thousands of disabled Australians aged over 65 struggling to get funding for assistive technology, according to Lauren Henley from the Council On The Ageing (COTA), Victoria.

"Funding for assistive technology outside the NDIS is currently spread across multiple departments at both the state and commonwealth level," she said. "There's about 46 different funding streams." Ms Henley said what money was available was not enough to meet the demand. "The funding is vastly insufficient, there are incredibly long waiting lists for support — we're talking upwards of 18 months to even get any sort of government funding," she said.

Ms Bates said it was a bureaucratic mess in urgent need of being sorted out. "You go to visit your local member, state or federal member — they don't know what's going on either," she said.

Disability and ageing groups are growing more frustrated with the situation and are stepping up their fight for reform. "We are increasingly concerned about the level of unmet need that exists for older people," Ms Henley said.

### NDIS Funding Age Discrimination (cont'd from p12)

More than 20 organisations, including COTA Victoria, have formed the *Assistive Technology for All* alliance. They want the Federal Government to make special funding available for assistive technology for those who missed out on the NDIS.

Ms Henley, who coordinates the alliance, said better organisation of existing funding streams would also go a significant way towards solving the problem. "We're certainly not advocating that the National Disability Insurance Scheme be expanded to cover everyone. We don't think that's feasible," she said. "All we're asking for is people to be given equitable access to the services they need."

### People over 65 can access the aged care system

An online petition has been launched and a delegation will travel to Canberra next month to lobby senior government ministers:

https://assistivetechforall.org.au/take-action/

In a response to questions from the ABC, the Commonwealth Department of Social Services did not specifically address the disability group's concerns.

But the department said financial support was available to people with disabilities over the age of 65. "People who begin receiving NDIS supports prior to turning 65 years of age can continue as scheme participants, or can elect to move to the Commonwealth aged care system, after they turn 65," the department said in a statement. "People aged 65 and over receive care and support from the Commonwealth aged care system."



**PHOTO:** The money Peter Willcocks has to spend on his equipment means the family's finances will take a hit. (ABC News: James Hancock)

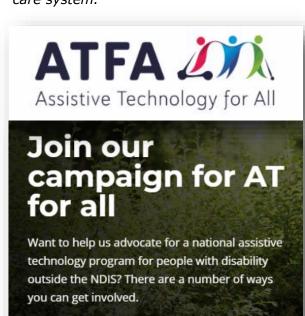
The Department of Health has commissioned a review examining "equity of access" to assistive technology for older Australians, with a final report due by the end of the financial year.

"To date, the review has identified more than 60 different national and state/territory assistive technology programs and sub-programs that support older people", a department spokesperson said.

### Note:

If you agree that assistive technology should be available for everyone, please click on the link to the AFTA petition (below left).

From the AFTA wegpage, you can also share your own story.





### Spinal Life Australia Update

The following article appeared in <u>The Advocate Summer 2019</u> edition, and is reproduced with kind permission from Spinal Life Australia.

### NDIS vs My Aged Care – what's the difference?

The NDIS is only available for people with disability who join the scheme before the age of 65, while Australians over 65 are eligible for the My Aged Care program.

While the NDIS is developed specifically for people with a disability, My Aged Care is for anyone over the age of 65 who requires extra support, regardless of level of disability.

Funding available for participants greatly varies between each scheme and people with a significant disability on My Aged Care are not likely to receive the same level of support as NDIS participants.

The National Disability Insurance Agency (NDIA) was granted an exemption to the Age Discrimination Act 2004 to allow the NDIS to made available only to people under 65.

### CASE STUDY

75-year-old member Mary\* sustained a spinal cord injury when she was 59, however by the time the NDIS was available in her area she was 65 years of age and not eligible to participate.

Through My Aged Care, Mary receives a maximum funding allowance of \$52,000 a year for personal care and support, community access, home maintenance and purchases of assistive devices.

If eligible for the NDIS, Mary could access the following support funding:

- > Personal Care \$148,498
- › Equipment budget \$25,000
- Consumables, daily living and transport expenses \$45,000
- TOTAL EXPENSES \$218,498 a year

If Mary was just one year younger, she could have been eligible for NDIS funding and would be likely to receive an extra estimated \$166,498 in funding a year for her support needs.

\*Name has been changed for privacy reasons

This case study is one of many pieces of information that will be submitted to the Disability Royal Commission and other processes to advocate for people over the age of 65 to be included in the NDIS.

The below updates are aimed at informing conversations with members, clients and the community. If you have any questions, please contact *Spinal Life Australia*.

**Healthy Living Centre opening** 

Our Spinal Life Healthy Living Centre in Cairns will welcome guests from 10 February, and our team has already moved from the Sheridan Street office into the Centre. We will also be hosting official opening celebrations on Thursday 19 March, with invitations to be sent out soon.

The Centre offers short-term accommodation, allied health services, a rehabilitation gym, hydrotherapy pool and community café. Visit the official website <a href="mailto:spinalhealthyliving.com.au">spinalhealthyliving.com.au</a> to find out more or make an enquiry.

#### **Inclusive Health Campaign**

As part of our 'Inclusive Health' campaign, Advocacy Officer Lachy Chapman has focused on access to radiology clinics. He has had some success so far, with QScan agreeing to make four clinics in SEQ more accessible including hoists, which are in the process of being confirmed so we can announce this further.

There is also a complaint under consideration by

the Anti-Discrimination Commission Queensland about radiology clinics that may influence improvements in all radiology clinics in the future. We are also developing a GP educational resource and have established an Inclusive Health Community Reference Group involving health professionals with lived experience. <a href="mailto:lchapman@spinal.com.au">lchapman@spinal.com.au</a> for more.

### **Inclusive Tourism Campaign**

Advocacy Officer Dane Cross recently conducted a review of accessible tourism in Cairns, joined by inclusive tourism advocate Bill Forrester from Travability. Their report includes seven recommendations on improvements that could be made across the Cairns region.

These recommendations will be presented in a forum on 3 March 2020 in partnership with Tourism Tropical North Queensland, bringing together local operators and community stakeholders. We are planning to conduct similar reviews in the Whitsundays and Townsville. We are also continuing to advocate for the introduction of an "Excellence in Tourism" award category in both the Queensland and Australian Tourism Awards programs.

dcross@spinal.com.au for more information.

### Spinal Life Australia Update (cont'd from p14)



### **Accessible app workshops**

We're developing an accessibility app for your smartphone which aims to provide accurate and up-to-date information on accessible accommodation, eating establishments, bathrooms, entertainment venues and more. The app will also allow users to submit their own reviews and experiences.

We will be hosting workshops over the coming months to hear feedback on what you would like to see in the app. <a href="mailto:jkretschmann@spinal.com.au">jkretschmann@spinal.com.au</a> for more details.

### Raising awareness of the late effects of polio

We are in the process of finalising our updated version of our information booklet for GPs, *The Late effects of polio: A guide to management for medical professionals*, after it was officially recognised as an Accepted Clinical Resource by The Royal Australian College of General Practitioners.

We will also be launching an online educational resource for GPs this year, as well as print more of our Medical Alert cards for polio survivors to carry in case of emergency. We are also in the final stages of confirming a conference in partnership with Polio Australia in Brisbane in May, with more details to be announced soon.

### Healthcare Interaction Survey

### By Michael Jackson

Clinical Health Educator

The following can now be reported based on the raw data obtained from the questions on the recent Australian polio survivor population survey. After two months, the total number of respondents who lived in Australia and responded to the survey was 734.

These figures should be taken on face value, as they are not presented in the context of a discussion or the intent of the question (besides the basic demographic data). The questions have not been correlated against each other in this list, except the two items marked with an \*, which are correlated to more accurately show the perception of GP learning. All items are reported as percentages.

The survey data, and the opportunities to correlate the data, lends itself to obtaining several insights separated into several papers. These will be shared once they are written.

### **Survey respondents:**

- 56% were female; 44% were male.
- 60% lived in a Metro/City area; 40% lived in a Regional/Country area.
- 24% representation by NSW; 18% representation each by QLD, VIC, SA; and 13% representation by WA.
- 64% of survivors were aged 70-89 years; 33% were aged 50-69 years.
- Education had a narrow range of 15%-22% for each level; all had gone to school.
- 90% had their acute polio below age of 11; 68% had their acute polio below age of 6.
- 76% had their acute polio infection in Australia.
- 80% had their onset of LEoP at >30 years later; 58% had their LEoP onset at >40 years.
- 54% have been officially diagnosed with PPS.
- 69% have either one chronic illness or no

- chronic illnesses, the number of chronic conditions compared inversely to the Australian population data.
- 23% meet with a local support group; 25% (180 survivors) are unaware of a support group but would like to join one.

### With regard to Healthcare interaction perceptions:

- 66% nominated doctors as the profession with which they had the most difficulty; 25% nominated allied health professionals.
- 48% were always confident describing LEoP symptoms to doctors; yet for describing their other health conditions 61% were always confident.
- 37% have not used complementary medicine to address their LEoP.
- 3% have not used a GP to address their LEoP.
- 60% say they usually or always have enough time in GP appointments to discuss/manage their LEoP.
- 52% are usually/always satisfied with GP answers to their LEoP questions; 48% are sometimes/never satisfied.
- Satisfaction with GP referrals to other professionals was split 50-50.
- 43% are sure their GP is willing to learn about LEoP, and 29% are sure their GP has engaged in learning on LEoP. \*28% say their GP is both willing and learning, this being 2 in 7.
- 15% are sure their GP is not willing to learn about LEoP, and 35% are sure their GP has not engaged in learning about LEoP. \*14% say their GP is both unwilling **and** not learning, this being 1 in 7.
- Undergoing surgery is the risk that more respondents are unsure about.
- 'Activity and exercise' was the risk factor ranked as most important for GPs, nurses and therapists to know.
- 37% nominated Polio Australia as the provider of the most useful information.

### Polio Schmolio

### By Esther Smart



I was born in 1950 in Berne, Switzerland. At age 5, I contracted Polio, along with many other children in our neighbourhood.

I have unpleasant memories of my stay in the children's hospital. A spinal tap, difficult therapies and home sickness made it all so traumatic for the little person I was. I was paralysed to the waist and I remember my legs being wrapped in hot cloths whilst being suspended in a type of sling to try and walk again.

My parents eventually took me home but I had to be taken for therapy every day for a long time. I am not sure how the progression took place but I eventually regained use of my legs. I had to wear 'sensible', ankle height boots for years and I hated them. I had to do strengthening exercises for years too and it was recommended that my parents take me to hot sand every summer to make me walk with resistance. My legs were weak and long hikes on school excursions were a problem for me.

I couldn't hike, I couldn't ski and I couldn't partake in any athletic type sports much to my teenage angst in those days.

Thankfully at age 16, the doctor declared that nothing further could be done and I put the very unpleasant experience to the furthest place in my mind. I studied visual arts and became a forensic photographer until I migrated to Australia in 1973. I have lived an exciting and varied adult life and took full advantage of the opportunities Australia offered me.

I eventually became a prison chaplain and worked for years in several prisons in NSW. I had a passion for my work but suddenly I started to notice vague symptoms of fatigue and shortness of breath. Investigations for Lupus, Multiple Sclerosis, and Chronic Fatigue proved negative and I was sent to a psychologist for stress relief.

Thankfully, somewhere, someone mentioned that there is such a thing as Late Effects of Polio and I immediately spent time researching and writing to Switzerland for further information. This led me to Polio Australia and, finally, recognition of what was happening to me. My body could no longer compensate for the damage incurred from the virus all those years ago.

In the last 10 years, I have had a steady decline in strength overall but in particular in the legs and the core muscles of the abdomen. I have been fortunate enough to spend two stays at <a href="Mtwlga-Rehabilitation Hospital">Mtwlga-Rehabilitation Hospital</a> where I have learned ways to manage the reality of my condition. I now have to live a paced, considerably slower way of life that includes a back brace, walking aids, shower chair and measured exercise just to get through my days.

Whilst, in my opinion, it is far too early for all of this, I also appreciate that I am lucky to be retired and able to make choices that suit my current situation. So, I spend quiet days at my studio painting or dabbling in all sorts of artistic pleasures including volunteering at the local school trying to enthuse the children that art is a worthwhile pursuit. In moments of joyful immersion in colour and texture I think "Polio, schmolio – who cares!"

### A Letter To My Legs—And Anti-Vaxxers

### By Jan McDonald

Dear Legs,

It is 4am, and after hours of sleeplessness, I thought I would write you this letter and tell you exactly what I think.

As you know, we have had a long association – over 65 years. In the early days we had a little setback – polio, I think they called it. Didn't make much difference initially, I was a baby so not particularly mobile. Then of course, when problems were noticed, you, Legs, were cosseted and fussed over – there were callipers, plaster casts and a special Foster frame to sleep in at night, weekly visits to the Royal Children's Hospital and Dame Jean Macnamara, and stays at Lady Duggan for more physio. Yes, Legs, you had it all. After all, we were blessed to be lucky people living in the lucky country.

Well, years went by, Legs, and admittedly, you pulled your weight more or less. I totally agree that you did get knocked around a bit due to a lot of childhood falls, but as a body we appeared to be relatively "normal" to the untrained eye.

But now, Legs, what are you doing to me???

For the last twenty years you have been letting things slip. You have become lazy. You are intolerant and fussy. Things are either too hot, too cold, too far to walk, or too difficult to remain vertical. I say, "Legs, it will be okay." We'll just keep doing the exercises, some form of which we have been doing all our lives. We'll just keep trying a little harder, as we've always done. We'll try more turmeric, magnesium, olive oil, anti-inflammatory foods, witches' brew from darkest Peru. We'll refuse the nasty foods that could inflame you more. We'll do hydrotherapy, buy a roller, use heat packs, exercise more, exercise less, meditate, do pilates, yoga, tai-chi, investigate whether we're imagining pain. Just work with me.

But what did you do, Legs? You let me down. For the last ten years you are not even happy if I lie down to sleep at night. You wake me up after a couple of hours. You tell me this muscle hurts, that muscle hurts – hurts too much to get back to sleep. If I ignore you, sometimes you even start throwing electric shock parties. So we stay awake for most of the night – and I have to tell you, Legs, you are not good company at 2 in the morning.

Now, Legs, this is not all about you. There is a whole body here that has to get on with itself. You are starting to play havoc with Brain. Brain is now often brain-dead. Not to mention Personality!! I don't like to say it but Personality has become quite staid and boring. Initiative, fortunately, is just a temporary tenant here, so Initiative did the only thing possible in an uneasy

body, and flew out the door. And as for Imagination! Imagination is long gone; I think Concentration and Endurance left at the same time. Energy tries hard to stick around, but now can't be depended on.

As these tenants move out Body is more likely to become a ghetto with unwelcome stayers – Frustration, Insomnia, Disillusion, Weight Gain and Depression are constantly applying for tenancy – after all they can see that there's a vacant space where Energy used to live. It's hard to keep stalling them!

Have you ever thought, Legs, that the rest of us have things that we would like to do – see more of the world, go on bushwalks, attend concerts, learn more via short courses, read more, spend more time with family and friends. Because of the damage that you have done to some of the other tenants (Brain, Initiative, and Energy, in particular) these things are not on. Besides, we already know that YOU don't like standing in queues, YOU aren't happy if we stay a little longer at an outing. YOU need another rest.

So, Legs, the rest of us are here together in the body corporate. We can't just run away. We have come to the conclusion we are stuck with you. But we would like to tell you a few home truths:

- 1. You are not a team player blow all the other body tenants.
- 2. You are princesses you think you are the most important.
- 3. There is very little we can do to make you happy.
- 4. You are not even grateful for the extra help you get.
- 5. You are very demanding and controlling life has to revolve around your wants.

In conclusion, Legs, though the body corporate generally puts on a pretty good front, you are letting us down. We dissociate ourselves from you and your demanding ways. Everyday life is a struggle, and often a real challenge. You made it that way. I just wonder how your contemporaries are allowing their bodies to get by in countries with less health assistance. Life is hard enough here with the help that we get.



### Federal Government Underspending On NDIS

### By Stephanie Dalzell

Source: ABC News - 21 Feb 2020

Two state governments from opposing sides of politics have teamed up to accuse the Federal Government of short-changing people with a disability.

#### **Key points:**

- NSW and Victoria are demanding the Federal Government release money to help people with a disability
- The last federal budget revealed a \$1.6 billion underspend in the NDIS
- The Federal Government dismissed suggestions it withheld funding from people with disabilities as "ridiculous"

In an extraordinary bipartisan attack, the New South Wales and Victorian governments have argued a \$1.6 billion underspend on the National Disability Insurance Scheme (NDIS) was being used to prop up a budget surplus.

Liberal NSW Disability Minister Gareth Ward and his Victorian counterpart Luke Donnellan have joined forces to demand the Commonwealth release the money.

The state ministers have penned a letter to the federal minister responsible for the NDIS, Stuart Robert, saying they had been trying to work collaboratively to access the funds.

Mr Ward said he had approached Mr Robert several times over the issue but had been unsuccessful in getting the money released.

"I want to make sure that money doesn't sit in a bank account offsetting the Commonwealth's budget, which is what it's doing," he said. "I want to see it improving the lives of people."

The last budget revealed a \$1.6 billion underspend in the NDIS, which boosted the Federal Government's bottom line for the 2019-20 financial year.

The Coalition has consistently said that was because of the transition of the scheme's rollout, and no eligible Australian was deprived of the funding they needed.

But Mr Ward said there were significant barriers for people outside of affluent areas in NSW to access NDIS assistance.

"I don't want postcodes to determine who receives support," he said. "Particularly in regional areas, Aboriginal people and people with disabilities from culturally and linguistically diverse backgrounds haven't been on the same level playing field as everybody. For example, if you have a disability and you live in Bronte, you'll have access to phenomenal opportunities.



But the further away from city and metropolitan areas you go — the less opportunities."

The states and the Commonwealth have agreed to establish a NDIS reserve fund, but documents from the last COAG disability reform council meeting show discussions around how the fund will operate are still taking place.

Mr Ward said the states have been told the reserve fund won't be finalised until after the May Budget.

The timing is significant, given the Federal Government's promised budget surplus is under threat as the country deals with the economic fallout from the coronavirus and a bushfire emergency that ravaged communities for months.

But Mr Ward said in the interim, people with disabilities were suffering.

"There's \$1.6 billion sitting on the Commonwealth balance sheet that we want to spend on people with disabilities," he said. "I've heard cases of people who sit in a room all day with no support, looking at the four walls. I've heard people who want and need things like occupational therapists, who need allied health supports and have not been able to find them. That is a product of a lack of action."

### Federal Minister refutes underspending allegations

Mr Robert dismissed suggestions his Government had withheld funding from people with disabilities.

"It is a ridiculous story from a ridiculous letter written by two governments that want money to spend on other projects," he told ABC Radio Melbourne. "I can't refute this more strongly than that. The New South Wales and Victorian governments just want their half of it so they can spend it to prop their budgets up. And that's not what it's designed for. It's designed to be spent over time."

### Government Underspending On NDIS (cont'd from p18)

On Sydney radio station 2GB, Mr Robert also accused Mr Ward of playing politics with the issue, saying he leaked the story after failing to obtain funding. But Mr Ward strongly refuted the allegations, describing them as an "unfortunate deflection."

Mr Ward, who is the only minister with a disability to hold the portfolio in the country, said he was unusually placed to fight for the funding.

"Unlike Minister Robert, I have lived experience of disability," he said. "I want people with disability to reach their full potential and I don't want this money sitting in a bank account anywhere."

Federal Labor NDIS spokesman Bill Shorten accused the Coalition of "stinginess" in failing to meet the needs of people with a disability.

"They have been sprung breaking a funding deal with Liberal and Labor state governments," he said. "It's time Stuart Robert stopped the handballing and obfuscating and started taking responsibility for people with disability."

### Aged Care Assessment Service Privatisation

#### **By Peter Willcocks**

Long-time volunteer and observer of aged care

It's 2021, the interviewer, powered by computerised clip board, excited and new to the job but well aware that there are too many in need, asks, "Did you shower yourself this morning?"

Important to be honest and wanting to maintain dignity the applicant smiles "Oh yes".

The box is ticked and further questions tumbled before there was a chance for the following to be asked or heard, "but my partner is there to make sure I'm OK and I'm really careful and I haven't fallen for a while ..."

The interviewer with five more assessments to log that day, had no time to notice no fruit in the bowl, blankets by the chair, hints of dystonia nor indeed the tangled garden hose.

I am writing to you to seek your action to contact those you know, who like you will be extremely concerned that aged care assessment is to be contracted to private enterprise. I am asking you to chat to your colleagues, your politicians and associations. I have hope that someone shared will have the knowledge and passion of persuasion to arrest the attention of our decisions makers to rethink the impact of privatising the Aged Care Assessment Service (ACAS), our independent advisor and comprehensive assessor of aged care services.

I fear consequences of the loss of the independence and expertise of ACAS assessors. I am extremely concerned that the quality of assessment will be further deteriorated to box ticking. As is often the case, through a lack of expertise, 'ability' boxes will be marked in such a way that will lead to supports that don't provide appropriate care for the individual, their families, their supports and their carers.

Most of us acknowledge that there have been many problems confronted by untimely delays due to assessment wait lists. Wait times, often of 6 months or more before an actionable determination are common, but we must also acknowledge that urgent assessments do happen and that this process no doubt has prolonged 'wait times' for others awaiting essential services.

The challenge for assessment does not seem to be one of quality of decision; current delays and pressure on the system are definitely one of under staffing. There are already unacceptable wait times for support via the already privatised Commonwealth Home Support Temporary Restorative Care Program, carer support, residential respite and 'permanent' residential care. The sadness is that once ACAS approved, access to the above mentioned support programs are further delayed, as they too are unfunded services with wait times for service implementation often of 12 months or more.

Legislated Review of Aged Care 2017 (David Tune AO PSM) recommended an amalgamation of ACAT and RAS (the Regional Assessment Service) in part to overcome undue wait times and duplication of assessment for services. There is also a recommendation that selfassessments would facilitate access to some services. The David Tune review is very comprehensive, gatekeepers became gateways; the link is below. It is best I don't interpret the review however; not so lucky the Royal Commission into Aged Care Quality and Safety where the commissioners were put into a position of recommending a monitor for the proposed amalgamated services. Chair of the Aged Care Royal Commission, Commissioner Gaeteno Pagone QC, released a statement denying the Interim Report released in October 2019 supported privatisation of the ACAT system.

### ACAS Privitisation (cont'd from p19)

Commissioner Pagone says, "Public concern has been expressed about statements made by the Minister for Aged Care and Senior Australians that we had decided to support the privatisation of the Aged Care Assessment Teams in our Interim Report ..."

The way I read it is that the Royal Commission is doing what they should, remain neutral until their final report but by then their advice will no doubt be irrelevant as the proposed government privatised contracts will be well advanced as services are to be implemented by April 2021.

A large number of people and organisations and people need our help and have spoken out against the ACAT privatisation. The New South Wales Health Minister Brad Hazzard, described the change as lacking "logic". Federal Shadow Minister for Ageing and Seniors, Julie Collins, described the Minister for Aged Care's ACAT/S changes being released just before Christmas as "sneaky" and "deeply concerning". The Doctors Reform Society passionately but accurately encapsulates many of our concerns.

"A privatised ACAT will be a race to the bottom. Poorly trained assessors will inadequately assess complex patient needs as they gouge Government fees for their private owners and force the dedicated assessors out of the system because they will not be profitable."

Dr Woodruff asks "Does this really sound like a way to improve the lives of our aging population?"

Perhaps a bit harsh but this move by government to privatise ACAS will not in itself lead to a better service. The current delays in ACAS triage to services are without doubt a result of under staffing. This critical area of health care requires senior assessors with a deep understanding of gerontology and an extensive history of hands on work in the provision of health care. Assessors need to able to recognise a wide range of both physical and neurological conditions. Assessors need to be able to recommend programs that provide appropriate supports and set support in process for care provision that will address ongoing health care needs.

Too many people are on wait lists for privatised home care and too many people are not provided the residential care that they need due to the already fast-tracked privatisation of their needs. We need a strong and independent watch dog.

ACAS is an essential clinical service that will best do its work independent of government and commercial interests

I ask you to please consider how you can raise

awareness of this crisis of decision. I ask that you join me and seek out those you know to join us on a campaign to build an amalgamated ACAS/RAS driven by medical expertise, free of whims of government and commercial need.

#### Further reading:

- Royal Commission into Aged Care Quality and Safety: Media Release ACAS <a href="https://agedcare.royalcommission.gov.au/news/Pages/media-releases/media-release-14-january-2020.aspx">https://agedcare.royalcommission.gov.au/news/Pages/media-releases/media-release-14-january-2020.aspx</a>
- Aged Care Guide https://www.agedcareguide.com.au/talking- aged-care/changes-to-acat-s-and-the-scepticism-around-the-decision
- SMH: NSW Health Minister Brad Hazzard has taken a shot at his federal colleagues for their decision to privatise aged-care assessments <a href="https://www.smh.com.au/politics/federal/not-a-lot-of-logic-nsw-minister-slams-federal-aged-care-move-20191230-p53npk.html">https://www.smh.com.au/politics/federal/not-a-lot-of-logic-nsw-minister-slams-federal-aged-care-move-20191230-p53npk.html</a>
- Doctors Reform Society

   https://www.drs.org.au/media releases/the-privatisation-obsession-aged-care-assessment-now-sold-down-the-river/
- Tony Broe Senior Principal Research Fellow, Neuroscience Research Australia. <a href="https://johnmenadue.com/tony-broe-privatising-aged-care-assessment-teams/">https://johnmenadue.com/tony-broe-privatising-aged-care-assessment-teams/</a>
- Council on the Aging (COTA): Future Reform

   an integrated care at home program to support older people
   https://www.cota.org.au/wp-content/uploads/2017/11/COTA-Response-DoHdiscussion-paper-Future-Reform-August-2017.pdf
- The National Aged Care Alliance submission to the Streamline Assessment consultation Feb.2019

  <a href="https://naca.asn.au/wp-content/uploads/2018/11/NACA-Streamlined-Consumer-Assessment-For-Aged-Care-Endorsed-21-Feb-2019.pdf">https://naca.asn.au/wp-content/uploads/2018/11/NACA-Streamlined-Consumer-Assessment-For-Aged-Care-Endorsed-21-Feb-2019.pdf</a>
- Legislated Review of Aged Care 2017 David Tune AO PSM <a href="https://www.health.gov.au/sites/default/files/legislated-review-of-aged-care-2017-report.pdf">https://www.health.gov.au/sites/default/files/legislated-review-of-aged-care-2017-report.pdf</a>

### **Update**

It appears that the privatisation of ACAS is no longer going ahead. However, please keep an eye on this important issue and be ready to speak to your MP.



### Intensified Polio Eradication Effort

**Source:** polioeradication.org – 10 February 2020

In face of challenging epidemiology, global health experts endorse new cVDPV2 response strategy



7 February 2020 – Meeting in Geneva, Switzerland, Member States of the Executive Board expressed overwhelming support to the global effort to eradicate polio, in the face of an alarming polio epidemiology which emerged in 2019.

Last year saw an upsurge of wild poliovirus cases in Pakistan and Afghanistan, and an unexpectedly large number of circulating vaccine -derived poliovirus outbreaks. To address the situation requires new energy, and Member States strongly asserted their support to urgently achieve a world free of all strains of poliovirus.

Addressing the delegations, WHO Director of the Global Polio Eradication Initiative Michel Zaffran noted the strong response of Member States to "Witnessing the efforts of 2019 setbacks: colleagues, and the commitment of national governments, I feel personally confident and optimistic that we have begun to turn things to ensure success. Ι see new commitments at country level. In Pakistan, a relaunch of the effort began midway through 2019. The programme undertook an in-depth analysis of the major area-specific challenges and their root causes, which they have now started to address."

Eradicating polio in the remaining global wild poliovirus transmission block in Afghanistan and Pakistan is critical, as failure could result in global resurgence of the disease. Modelling indicates that within ten years, 200,000 cases would be reported worldwide, every single year. The risk of global spread of communicable disease has this year been underlined by the

novel coronavirus (2019-nCoV) situation.

Member States also almost unanimously offered their support and commitment to closing outbreaks of vaccine-derived viruses (cVDPVs), endorsing new and concerted efforts. With Africa on the verge of being certified free of wild poliovirus, WHO Regional Director for Africa Dr Matshidiso Rebecca Moeti emphasised that the continent will continue to fully commit to eradication efforts until the cVDPV2 emergency is overcome. "New approaches and rapid response teams across the continent are intensifying their efforts in ensuring every child is reached during outbreak response, and that new outbreaks are rapidly detected and responded to."

To this effect, the Executive Board endorsed in a Decision a new cVDPV2 outbreak response strategy, including accelerated roll-out of novel oral polio vaccine type 2 (nOPV2) to more effectively address the cVDPV2 health emergency currently affecting parts of Africa, the Middle East and the Southeast Asia region. Novel OPV2 – a brand new tool to address outbreaks – could be available to address this health emergency as early as mid-2020 under WHO's Emergency Use Listing procedure.

The new vaccine, however, is only half the battle, cautioned Zaffran, stressing that resources and operational improvements are needed to ensure the vaccine reaches every last child. "We also need to implement stronger outbreak response and ensure comprehensive surveillance, both things that cost money. With thanks to the generosity of the international development community, we have mobilized pledges of US\$2.6 billion made at the Last Mile Forum in Abu Dhabi just two months ago. But this will not be enough to eradicate polio and tackle these increasing number of outbreaks. We are therefore calling on member states to mobilize domestic resources to respond to outbreaks, where possible.

Zaffran continued: "On the horizon I witness a new epidemiological situation slowly beginning to emerge. I see a new, re-launched programme which has the building blocks in place to lead us to success. Let us not be under illusions however. This will not happen overnight and this will not be easy. The nature of the virus is that every operational improvement will take several months longer to be reflected or epidemiology. This is the way polio eradication works: there is always a time-lag. So for now, need to measure our progress programmatic and operational success. We must continue our new commitments, action our new strategies, introduce new tools, monitor results and maintain our drive. Significant impact on epidemiology will subsequently follow."

### Intensified Polio Eradication Effort (cont'd from p21)

"We have a lot to do," Zaffran concluded. "But the programme is starting 2020 on a very strong footing. I am convinced 2020 will go down in history as the year which turned the programme around, and back onto the path towards lasting success."

Concluding the polio deliberations and speaking on behalf of 1.2 million Rotarians worldwide, Judith Diment, Chair of the Rotary Polio Advocacy Task Force, stated: "Rotary remains fully committed to the pursuit of a polio free world, as evidenced by our extended commitment to raise 50 million dollars annually through 2023. We urge all countries to devote the national financial and human resources needed to sustain high levels of population immunity through routine immunization, mitigate the risk of polio outbreaks and avoid significant unnecessary human and financial cost. The window of opportunity to achieve a polio-free world will not remain open forever. The time for urgent action is now."

### Shapari's Journey Of Resilience And Courage

### The story of a polio survivor By Nariman Bisma

**Source:** www.unhcrpk.org—28 November 2019

Unable to walk, run and play with her class fellows, Shapari could not wait for her father to pick her up from school and take her home. She did not enjoy a childhood like so many others did around her.

"I was 2 years old when I got severe fever and, in no time, I lost sensation and energy in both of my legs", said Shapari, with tears in her eyes.

Shapari had hardly come to terms with her condition when conflict broke out and forced her family to flee the province of Laghman in Afghanistan. She was in 5th grade when she left school and entered Pakistan as a disabled refugee child. Although her parents managed to enroll her in a school in Peshawar, getting familiar and adjusting to the new environment was not easy, especially due to the physical challenges that she had to overcome. As time went on, it became increasingly difficult to continue her education.

"My hands and feet got completely paralyzed in the 10th grade," said Shapari in a trembling voice.

Her mother kept motivating her and encouraged her to remain hopeful despite the daunting situation.

"I remember how my mother assured my teachers that I was a hard-working student with a passion to study at school with other children, but I was unable to hold a pen and write due to excessive weakness in my hands." Shapari recalls how school teachers supported her in Pakistan when learning of her condition.

Shapari managed to continue her education until she reached the 12th grade, but then, she started to lose hope. Reluctant to go out for fear of facing people who made fun of her condition, she sank into depression. Unable to socialize, she spent the next three years at home, in

seclusion.

Shapari's mother could not stand seeing her depressed and suggested her to spend some time with her sister. "As we were on our way to my sister's home in Hayatabad, an old bearded man saw my mother pushing me in a wheelchair. I do not know who he was, but to me, he was an angel," said Shapari with a twinkle in her eye.

The old man suggested that they visit Habib Physiotherapy Complex and consult its Founder and Managing Director, Dr. Mahboob Ur Rahman. Two weeks later, Shapari was taken to Habib Physiotherapy Complex, and from there, her life took a new turn. Dr. Mahboob not only initiated her treatment free of cost but also offered to support her education.

Dr. Mahboob assured her that he would take care of her like he would his own daughter. He later helped her get admitted in a Bachelor's degree programme in Physiotherapy. Shapari was not only enrolled in the physiotherapy course but also encouraged her sister to do so.

Shapari also received a DAFI scholarship through UNHCR. Funded by the Government of Germany and administered by UNHCR, the Albert Einstein German Academic Refugee initiative, known by its acronym DAFI, grants scholarships to deserving young refugees enrolled in Higher Education Commission (HEC) recognized universities, colleges and polytechnics in Pakistan. UNHCR has supported more than 1,700 refugee students in Pakistan through DAFI scholarships since 1992.

Dr. Mahboob Ur Rahman became her mentor, extending all of his support and treating her case for more than 6 months. "Rehabilitated through the Mahboob Power Evaluation and Therapeutic (MPET) chart, an effective tool/exercise in post-polio management, Shapari showed marked improvement as she got rid of crutches and orthotic support," shared Dr. Mahboob Ur Rahman. As a result, Shapari saw herself in a new light. "I told myself, I have

### Shapari's Journey (cont'd from p22)

polio, but polio does not have me," said Shapari.

Habib Physiotherapy Complex has been providing rehabilitation services to the Afghan refugees since a major influx in 1980's. UNHCR, the Commissionerate for Afghan Refugees and the International Rescue Committee have been instrumental in supporting its rehabilitation and physiotherapy training programme. In particular, UNHCR supported the training by covering tuition fees, course material costs, transportation and stipends for trainees.

Currently, UNHCR, in collaboration with its partner SHARP and Habib Physiotherapy Complex, is providing psychosocial counselling and assistive devices aiming at the rehabilitation of persons with disabilities who are refugees. There are currently 1.4 million registered Afghan refugees in Pakistan, most of whom live in urban settlements alongside Pakistanis.

With her head held high, Shapari decided she would tell the whole world that even a physically challenged person can live a better life and reach for the sky! Shapari was excited to study physiotherapy, but her struggle did not end here. She had to interrupt her studies again due to excessive weakness in her limbs during the last year of her Bachelor's degree.

Determined to fulfill her dreams, Shapari managed to resume her studies while seeking medical treatment. Her hard work finally bore fruit, and she graduated from the Faculty of Health Science, Gandhara University Peshawar in 2019.

"I am very happy to have graduated with a Bachelor's degree in Physiotherapy. I have no words to thank Dr. Mahboob, who helped me stand on my own feet today. Being a generous Pakistani, he treated me like family and helped me realize my potential," Shapari shared.

Shapari aspires to help physically challenged persons with the education and skills that she has acquired. "I want to follow in my mentor's footsteps to bring happiness and hope to others living with disabilities."

Shapari is seeking an employment that will earn her a decent living. She wants to work at a place where she would not be reminded of her disabilities and also wishes to continue her studies.

She noted that "women face many problems in our culture, but if a woman is physically challenged, her troubles become manifold." Her message for every disabled person is not to lose hope and not to give up. "Even though it will be hard and you may struggle through it all, let yourself fall."

Shapari also urges every disabled person to complete their education and make their place in the world, like others do.

"We too have a heart and deserve to live our life to the fullest," Shapari concluded with a smile.

"Shapari's hope, determination and success shows that with a little support from family and the community, and with access to professional services like Habib Physiotherapy, persons with disabilities can secure their future at par with the rest," said UNHCR Head of Sub-Office Peshawar, Mr. Dinesh Shrestha. He added that UNHCR is pleased to continue supporting Afghan refugees living with disabilities, both physical and psychological, as a part of its core protection activities.



### Polio This Week

**Source:** Polio Global Eradication Initiative — as of Wednesday 19 February 2020

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

Total cases	Year-to-	date 2020	Year-to-	date 2019	Total in 2019	
Total Cases	WPV	cVDPV	WPV	cVDPV	WPV	cVDPV
Globally	12	6	9	6	173	329
—In Endemic Countries	12	4	9	3	173	40
—In Non-Endemic Countries	0	2	0	3	0	289

### Case breakdown by country

Countries	Year-to-date 2020		Year-to-date 2019		Total in 2019		Onset of paralysis of most recent case	
	WPV	cVDPV	WPV	cVDPV	WPV	cVDPV	WPV	cVDPV
Afghanistan	0	0	2	0	29	0	7 Dec 2019	N/A
Angola	0	0	0	0	0	144	N/A	18 Dec 2019
Benin	0	0	0	0	0	7	N/A	6 Nov 2019
Burkina Faso	0	0	0	0	0	1	N/A	30 Nov 2019
Central African Republic	0	0	0	0	0	19	N/A	10 Dec 2019
Chad	0	0	0	0	0	3	N/A	28 Oct 2019
China	0	0	0	0	0	1	N/A	25 Apr 2019
Democratic Republic Of The Congo	0	0	0	2	0	84	N/A	5 Dec 2019
Ethiopia	0	1	0	1	0	11	N/A	1 Jan 2020
Ghana	0	0	0	0	0	12	N/A	29 Nov 2019
Myanmar	0	0	0	0	0	6	N/A	9 Aug 2019
Niger	0	0	0	0	0	1	N/A	3 Apr 2019
Nigeria	0	1	0	3	0	18	N/A	1 Jan 2020
Pakistan	12	3	7	0	144	22	22 Jan 2020	12 Jan 2020
Philippines	0	1	0	0	0	15	N/A	15 Jan 2020
Somalia	0	0	0	0	0	3	N/A	8 May 2019
Togo	0	0	0	0	0	7	N/A	20 Dec 2019
Zambia	0	0	0	0	0	2	N/A	25 Nov 2019

### 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



# Polic Australia Etonouring 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