

## In This Issue

- Tributes to Dr Margaret Cooper OAM from Post Polio Victoria p. 2
- A farewell tribute to Liz Telford p. 3
- Background to PPV's Accessible Housing submission p. 5
- Quarterly Meeting Update p. 5
- Polio Oz's Health and Wellness retreat in New South Wales p. 6
- Making a submission to the Royal Commission into Aged Care Quality and Safety p.6
- Information on more cases of acute flaccid myelitis p. 7
- About polio achievements in Art and Sport – Running with Wilma Glodean Rudolph p. 8
- Intentionally discriminatory clauses – disadvantaging some polio survivors p. 10
- About the Late Effects Of Polio taken from *Christopher and Dana Reeve Foundation* website p. 12

## 2019 Committee

- Ron Bell (President)
- Robyn Abrahams
- Geoff Dean
- Barbary Clarke (Policy Working Group)
- Peter Freckleton
- Shirley Glance OAM (Secretary)
- Jill Pickering
- Mythili Srinivasan (Treasurer)
- Rangan Srinivasan
- Liz Telford (resigned May 2019)
- Susan Shaab

## President's Report



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As this is the first newsletter for 2019 after our 2018 AGM in November, when I was elected President, I thank my mate, predecessor, and Gippsland neighbour, Geoff Dean for his long devoted leadership of PPV's Management Committee. I also welcome the continuing Committee members and the newly elected Committee members. We now have a Committee of 10, with Barbary on our Policy Working Group. Readers can know something more about some of them with the snapshot bio of his/her interests offered. Readers will note that each act and advocate both locally and across boundaries on the issues that concern them. This adds diversity to Australia.

Last year ended on a sad note, with the sudden death on 27 October of Dr Margaret Cooper OAM a long-time member of PPV's founding Committee, and a tireless worker for the rights of people with disability, particularly women. Margaret died a month before our AGM. As a result it was both sad and a celebration of her life. PPV set up a memorial webpage so Margaret's admirers could share memories.

As we are already into winter, I hope that all PPV members are enjoying optimum health, and independence in getting out and about in their communities, whenever possible. This year had a frightening start for Judith and me, when the January bush fires came to within 800 metres of our home. As the fires circled around our small community, Yinnar South, we were compulsorily evacuated. We stayed in a motel, but ate many meals with other "displaced" people sheltering in the Community Hall. Because we have always been busy in our community, we knew the evacuees. We supported and entertained each other while waiting for news about the fate of our homes.

I thank all PPV Committee members for continuing the work during the 2 months I was out of action. Our home was saved, and no lives were lost because of the efforts of the fire-fighters, the police and the State Emergency Services. In atrocious conditions, they did a mighty job.

Between January and March, this year the Committee advocated on the issues concerning Victorian polio survivors with the following;

(i) Barbary Clarke followed up on PPV's submission to the Accessible Buildings Enquiry, she wrote on our behalf in December.

**Con't page 4**

# Tributes to Dr Margaret Cooper OAM from Post Polio Victoria

## From Geoff Dean's speech at PPV's 2018 AGM.

I accompanied Margaret on one her "pollie stirring" raids. As we left MP Russell Broadbent's office I enquired if there was a café handy to get a coffee and a sandwich.

At the doorway to the café was a 150mm step. This was a barrier to Margaret's wheelchair. We asked if we could have a table outside; but no their food-handling licence didn't allow anything so sensible. We had to make do with balancing our coffee cups on our laps. This was very difficult for Margaret who needed a longer straw. The waitress obligingly joined two small straws together to make one long straw, but the creamer failed to flow up the now long straw. All this while we sat on the footpath like lepers.

The politician's secretary who had directed us to the café happened to walk past. I pointed out the situation. He was very embarrassed and apologised. He had not given it a thought. People just don't think. Architects, shop owners, local government, politicians just don't think.

These embarrassing, frustrating situations would have happened to Margaret on an hourly basis and yet she just pressed on. Despite these regular frustrations she achieved an amazing amount of work for people with disabilities, and, in particular with polio. Her research and

advocacy has benefited us all and will remain a wonderful legacy."

The full script of Geoff's speech is on PPV's website.

## Susan Shaab writes;

I met Margaret Cooper in 1965. It was the year we both started studying social work at Melbourne University. In a sense Margaret was a year ahead of me, as she was in the 3-year diploma course, and I was in the combined degree/diploma stream.

I didn't see her much that year; we had only one common unit. At the end of that year, the Social Work School asked for volunteers (from those who had completed their first year) to plan Orientation Week for the new students in 1966. About half a dozen students volunteered. This meant we had to return to university, two weeks before the University's first day on March 12<sup>th</sup>. After more than 3 months in recess, Victorian universities curiously commenced on a public holiday. By the end of the first week of returning, the Committee was Margaret and myself.

So we planned activities for 60 new students each year, on a limited budget of \$100 for Orientation weeks of 1966 and 1967, producing campus maps, tours, times and spots for subject enrolments, lecture timetables, tertiary student clubs, and introductions to lecturers and

tutors. Getting around was difficult for Margaret. She had a wheelchair that she moved by hooks on her wrists, which she attached into the wheel spokes. Moreover, the Social Work School was in a tiny building in Royal Parade opposite the main campus. She never complained and rarely asked for help. She was a nuanced observer and commentator of campus consumer commodities.

I met the Orientation Committee of a large, male dominated faculty. They suggested that we go halves in ticket profits for the Thursday night Orientation Week Ball, no matter how many tickets we sold. Margaret said; "Agree. Any of our students who want to dress up and dance will find a free ticket!" On Friday, honouring their agreement, the male faculty OW committee handed over \$60.

"After the morning lectures, on March 12<sup>th</sup>, we will put on lunch at the Social Work School." Before lunch hour, students aplenty fronted to dash to shops for food, drinks, ice, chop vegetables, and, make sandwiches. It was a great meet and greet for students and staff. Sandwich, cheese and biscuit platters and pizzas were passed up and down the narrow stairways. To drink we had bowls of alcoholic and non- alcoholic pineapple fruit punch. People dropped in and out throughout the afternoon. Confusion reigned. Without a glance at labels, students grabbed bottles to top up

the punch bowls. Cherry brandy was put in the punch meant for the underage and teetotal students.

Happily sloshed students and staff talked for hours. The long lunch, born in Royal Parade concluded after 6.00 pm. Margaret's advice brought it to fruition.

Margaret went on to work full-time, to study, and, champion the rights of people with a disability to be able to live like everyone else. For this, we are all indebted to her.

### **Professor Rhonda Galbally AO**

Margaret Cooper OAM was one of the great pioneers of disability rights.

She worked tirelessly for access and inclusion. Margaret was an inspiration to me and to many others and she will be greatly missed.

### **Exerts from the tribute from Peter Willcocks, Bayside Polio Group:**

The Bayside Polio Group, a wide range of other groups and the thousands she has cheered through life have much thank Margaret for. It is likely that Margaret will be mostly remembered for her systematic advocacy for a more inclusive and caring world.

When we think of Margaret, we do not think of polio or disability; we think of those one on one quips that

left us wiser and feeling good.

Years ago, Margaret was organising a cruise with her father. I asked her why she needed three carers.

She smiled knowingly.

“One is going to fall in love and become heartbroken. Another is going to go out in sympathy and get drunk. I am hoping that at least one will be sober enough to help me get to bed.”

### ***Farewell Margaret and thank you.***

The full script of Peter's tribute is on PPV's website

## **A farewell tribute to our founding President Liz Telford**

In mid May, Liz Telford, who was the founding President of PPV, informed the PPV Committee that she was stepping down for health reasons. Liz has been an office holder and ordinary Committee member almost continuously since PPV was founded in 2011.

When Independence Australia closed down the its Polio Advisory Group in 2011, Liz and a group of other former PAC members (Ron Bell, Geoff Dean, Jill Pickering and Martin Grillo) decided that there was a need for a group to advocate on behalf of the polio community.

Liz was asked to be the initial President and was the driving force behind PPV's activities in the early years. The highlight was when Liz

represented PPV at the 2012 Parliamentary Committee Inquiry into Post Polio.

Liz led the Committee in advocacy and information dissemination and worked very hard to provide PPV with a strategic direction and goals. During her tenure. PPV became a well known and respected advocacy body.

Following her period as President, Liz served as Secretary for two years and then as an ordinary Committee member with a particular focus on advocacy.

She worked closely with Fleur Rubens and Margaret Cooper on matters including NDIS inclusion, polio triggers in hospital admission

forms and respiratory issues.

Liz was always focused on the need for PPV to act in a professional and strategic manner and also to be responsive to and engaged with PPV members and the general polio community.

She will be missed and the Committee would like to thank Liz for her unflinching dedication to the well being of PPV and the polio community and wishes her well for the next phase of her life.

## President's Report con't

The submission can be read on our website. The background to the need for this submission is in this newsletter.

(ii) In the run up to the Federal election, Barbary also led a 3-person delegation to the office of her local member, Peter Khalil to advise him about the unique needs of our members and asking his support for particular policies which would enhance our health and living care. Robyn Abrahams and Susan Shaab were the other delegates.

(iii) Liz Telford, Shirley Glance and Ron Bell co-ordinated stories for submissions to the Royal Commission into Ageing; these were about members' experiences with My Aged Care Packages and NDIS.

(iv) Susan Shaab attended a My Health Record information session, so PPV would be better informed before the extended opt-out date on 31 January 2019.

(v) Ruben (PPV administration) and Steph (Polio Australia) completed the flyer "Did you have Polio?" Copies have been distributed by the Committee to health clinics and hospitals around Victoria.

(vi) PPV and its members are making group and individual submissions to the Royal Commission into Aged Care Quality and Safety.

(vii) We contributed to the terms of reference of the Royal Commission on the Abuse of Disabled People, with partner organizations e.g. Women with Disabilities Victoria, Carers Victoria.

(viii) Three members of the Committee have attended the quarterly meetings with Polio Services Victoria, which Ron Exiner co-ordinates. I thank Barbary, Shirley, Liz, and Robyn for their determination that PSV provide a more patient focussed model for us.

In February and March, there were outbreaks of preventable diseases, measles, cholera, tetanus in parts of the world like Madagascar and Liberia where people were trapped in flood-waters.

In addition, in March a New York county declared Health Emergency measures, banning unvaccinated students from attending schools and anyone unvaccinated from entering public places. By the end of March, U.S. health departments around the country reported more than 300 cases of measles since the beginning of 2019. Closer to home, dozens of cases were reported in the Northern Territory, which spread to Melbourne by an unvaccinated airline traveller.

In relation to polio, there was an outbreak of poliovirus type1 in Indonesia, this year. Following this, WHO recommend that all travellers to polio-affected places, PNG, Afghanistan, Pakistan, Niger, Somalia the Democratic Republic of the Congo and Nigeria, be vaccinated against polio at least 4 weeks before travelling. It is also shocking that India has millions of young polio survivors-few have received any treatment. Thus, for at least 50 years, there will be millions of people on the sub-continent experiencing the Late Effects of Polio.

It is also concerning that in April the Red Cross which has been providing medical services

(including polio vaccines) to civilians in Afghanistan have withdrawn all their staff. The reason given was "staff and patient safety couldn't be ensured."

PPV has always stressed the importance of timely vaccinations. A lasting legacy of Dr Margaret Cooper OAM is her positive vaccination YouTube message on the Better Health Channel. She says, "All parents want their children to be able-bodied and independent." "It's better for parents to hear that they are doing their best for their children by having them vaccinated," and the children aren't disabled and in pain all their lives.

A main PPV goal is to inform the public of the Late Effects of Polio, (i.e. Post Polio Syndrome). Some people don't know they had polio. They quickly recovered from a short-lived child-hood fever. Decades later, they are inexplicably fatigued, and lacking sufficient muscle strength to move about.

There are people who although hospitalised for an infectious disease were wrongly diagnosed as having had rheumatic fever or muscular dystrophy, rather than polio.

In this edition we have published the first pages of the *Christopher and Dana Reeve Foundation* <https://www.christopherreeve.org> – about *Polio*. It's excellent on the symptoms of the Late Effects of Polio; so anyone can think about symptoms they are experiencing.

Readers able to connect to YouTube might also look at those I have been making, on Ron Bell-polio YouTube.

# Background to PPV's Accessible Housing submission

- The National Construction Code (NCC) - which governs all building in Australia – is currently silent on accessibility in housing.
  - Barbary's contact in the Australian Network for Universal Housing Design (ANUHD) alerted her to a consultation on accessible housing in late 2018
  - ANUHD had been advocating, for over 10 years, that accessibility standards must be regulated in the NCC
  - In 2010 the Council of Australian Governments (COAG) - made up of the Federal Government and all states and territories - met with ANUHD. COAG agreed to an 'aspirational goal' for 100% of new dwellings to be built to a minimum accessibility standard by 2020. By 2019 it is estimated that 5% of dwellings are built to a minimum accessibility standard.
  - The Master Builders' Association has argued strongly, for over a decade, that a self-regulatory regime is perfectly adequate regarding building accessibility into dwellings.
  - But the lack of progress between 2010 and 2019 on building accessibility into dwellings indicates that self-regulation has not worked. This may have something to do with the fact that builders can charge 22 times the amount for retro-fitting house modifications as they can for including accessibility features in initial builds.
  - In late 2018 the Australian Building Codes Board (ABCB) published an *Accessible Housing Options Paper* to which it invited all interested parties to respond, in the form of attendance at a consultation and/or by putting in a submission.
  - At the consultation the ABCB argued that there was little or no 'evidence' of unmet need in accessibility of housing. The presenter did not specify what 'evidence' would be acceptable to the ABCB during that consultation, but later issued a paper specifying a hierarchy of acceptable evidence, from peer-reviewed journal articles to the lived experience of people with disabilities who had requirements for various accessibility features to be built into their dwellings. There was an implicit assumption that quantitative evidence would be more highly regarded than qualitative evidence – although it was stated that qualitative evidence of lived experience would be taken into account.
  - To guide responses to the *Options Paper*, ABCB referred to a document on *Livable Housing Design Guidelines*, which specified Silver, Gold, and Platinum levels of accessibility. Respondents were requested to weigh up the features included in the different levels and to recommend which level(s) should be regulated as the minimum accessibility standard in a potentially revised National Construction Code.
  - Barbary drafted a submission on behalf of Post-Polio Victoria arguing that, since the Silver Level of accessibility did not even include any room dimensions (such as those required for successful manoeuvring of a wheelchair), the Gold Level must be regarded as the minimum standard to be regulated by the NCC.
  - The Post-Polio Victoria submission included eight case studies of housing modifications required and/or made to the dwellings of people with disabilities.
  - However, it also included quantitative evidence from SWEP and referenced numbers of peer-reviewed articles and, particularly, a very recent mixed quantitative-qualitative methods PhD by Niki Heath comparing and contrasting ageing with, and without, disability.
  - Some months after the consultation the Australian Building Codes Board issued a summary report of all the submissions it had received and the information gathered during the consultation(s). This listed the organisations which had made submissions – including Post-Polio Victoria. It also listed some of the references provided in the submissions made. Sadly, this reference list included none of the references supplied as 'evidence' by PPV – even the PhD. There was no reference in the body of its report to information contained in PPV's submission.
- A footnote about this from Barbary; "the next step is to give input to the Regulatory impact statement later this year or early next –date yet to be announced."

## 2019 Polio Health & Wellness Retreat



Body / Mind / Spirit

New South Wales in October  
17—20 2019

Registrations Now Open!

Polio Australia will be facilitating its LAST EVER 4 day/3 night day Polio Health and Wellness Retreat for polio survivors and their partners from Thursday 17 to Sunday 20 October, 2019 at St Joseph's Centre for Reflective Living in Baulkham Hills, New South Wales. Polio Australia has held two Retreats at this venue, which is a lovely, peaceful environment, and very conducive to sharing and learning new information. The holistic 'Body / Mind / Spirit' theme will continue and include sessions such as:

- Interactive group sessions and one-to-one consultation opportunities with a variety of allied health professionals
- Exercise options
- Latest orthotics, aids and equipment options
- Seated yoga and meditation sessions
- Activities to keep the Mind active
- Creative workshops
- Massage therapy

See details of previous Retreats at [www.polioaustralia.org.au/retreats/](http://www.polioaustralia.org.au/retreats/)

## Quarterly Meeting update

This is a meeting, convened by PPV, involving Polio Services Victoria, Polio Australia, Polio Network Victoria and PPV.

The aims of this meeting are to improve communication and support between these groups which in turn benefits the polio community.

We use this meeting to advocate to PSV, which is the key service provider in Victoria for people with polio, on behalf users and potential users of the services.

It also is a way for PSV to consult with representative groups about its services, initiatives and communication. We generally meet four times a year. Our last meeting was on 5 June.

Currently PSV is reviewing its physical layout in the Bolte wing at St Vincent's to create a more client friendly, efficient and pleasant environment for those people who are using their services.

The changes being made so far are to seating and signage. More substantial changes involving the reception area and access doors will depend on future capital budgets.

**If you have any feedback about the physical layout and/or PSV services, they would be very pleased to hear from you.**

We are working towards all Victorian hospitals having a polio alert as part of their admission procedures.

This is very important for people with polio, particularly with regard to anaesthesia. Anaesthetists need to know when patients have had polio.

St.Vincent's has a Polio Alert that is activated when an in patient informs the hospital that they have had polio.

We know that some hospitals have a type of polio alert as an automatic part of their admission procedures (i.e with a question about polio history on the in-take form) and we are looking to identify these and use them as a basis for approaching other hospitals. Polio Australia is trying to get a polio alert included in the My Health Records system.

**Remember that if you are admitted to hospital for any reason, always tell them you have had polio.**

**The PSV are reopening cases, please contact them directly on Tel: (03) 9231 3900 or 1800 030 324.**

## Making a submission to the Royal Commission into Aged Care Quality and Safety

### It's Important to Note;

The Royal Commission will receive submissions until the end of August 2019.

It is only interested in events that have taken place since July 1 2013, or issues that are ongoing.

It is against the law to provide false or misleading information to the royal commission.

It's easy to make a submission. It can be done in several ways, and there is no right or wrong way.

It can be set out as a letter, completed on line, posted, or told verbally on the Royal Commission Information Line on 1800 960 711.

While submissions are generally published on line, your submission can be kept private if you wish, by asking that it be "anonymous", or "not made public."

When writing your submission you need to include information about yourself, and, the type of aged care it relates to.

Something about the circumstances that led to you accessing aged care services.

Critical events that you want the royal commission to know about. Think about focussing on \*When, \*Where, \*Why, \*How, \*Who of the events.

How problems you have experienced could be avoided or the system improved.

The Royal Commission contact details are;

Phone 1800 960 711

Email: [ACRCenquiries@royalcommission.gov.au](mailto:ACRCenquiries@royalcommission.gov.au)

Web: <https://agedcare.royalcommission.gov.au>

Mail: Royal Commission into Aged Care Quality Care and Safety, GPO Box 1151, Adelaide SA 5001

## Information on more cases of acute flaccid myelitis

AFM: The Polio-Like Mystery Illness

As of January 2019, Federal health officials have confirmed over 200 cases of acute flaccid myelitis (AFM) in the United States a very rare but serious illness that can cause sudden polio-like symptoms such as weak muscles and paralysis. Most of these cases have been in children around 4 years old. The spike in the number of 2018 cases of AFM is similar to those in 2016 and 2014. However, the Centers for Disease Control and

Prevention (CDC) are investigating all suspected cases of AFM. A common thread linking the cases has not been found. While this sounds frightening, the American Academy of Pediatrics (AAP) reminds parents that AFM is very rare. The chances of a child getting it are less than one in a million.

In the last 3 editions of our newsletter we have detailed the rise in the numbers of children (mostly in the US) who have contracted

acute flaccid myelitis – the polio-like virus. In this edition we publish the latest news released in January. After a fall in reported cases in 2017, during 2018-19 the numbers rose again. However it is good news that doctors are finding ways of treating and reversing the symptoms of the virus.

## About polio achievements in Art and Sport

**Running with Wilma Glodean Rudolph - a polio survivor who became the fastest woman in the world, and nicknamed The Flash. She was born on 23/6/1940 and died on 12/11/1994.**

As a sixteen year-old, she came to the attention of the public at the 1956 Melbourne Olympics. As the youngest member of the American Team, she ran the third leg of the 4 x 100 metre relay, (time 44.9 seconds) only .4 of a second behind the Australian Gold medallists, anchored by gold medallist, Betty Cuthbert.

Wilma was a premature 2 kilo baby born in Saint Bethlehem, Tennessee. She was the 17<sup>th</sup> child of 19 surviving siblings from her father's 2 marriages. The family moved to Clarksville soon after her birth. Wilma recovered from pneumonia and scarlet fever in early childhood, but aged 5 contracted polio. Polio seriously affected her left leg and foot.

Doctors said she would not walk, unaided, again. Her leg was braced. Without any nearby treatment for black Americans, her family sought treatment at an all-black College hospital in Nashville, 50 miles from their home. For 2 years, her mother and Wilma took the weekly bus to Nashville, for treatment to regain the use of her leg. Then, for a further 2 years, family members gave her home massage treatments, four times each day. By the time she was 12, Wilma was able to walk unaided by a leg brace or orthopaedic shoe support.

In the eighth grade at Burt High School, she began to play all sorts of sports, basketball and track and field. She was spotted and mentored by Tennessee's State track and field coach, Ed Temple.



Still in junior high, she attended the 1956 track and field Olympic trials in Seattle, Washington, where she qualified to compete in the 200 metre individual event in Melbourne. She was defeated in her preliminary heat, but, with Wilma running the 3<sup>rd</sup> leg, the US team won bronze in the 4 x 100 metre relay. After returning home she continued to train and compete. In 1958, she had her first child, Yolanda.

While at Tennessee State, Wilma competed again in the US Olympic track and field trials in Texas. There she set a world record in the 200-metre dash that stood for 8 years, and, qualified for the 1960 Summer Olympics in the 100-metre dash.

At the Summer Olympics in Rome, Italy, she won gold in both the 100 metre and 200 metre sprints, and also in the 4x 100-metre relay. Being the first American woman to win 3 gold medals in a single Olympiad, she was greeted as "the fastest woman in history," by an adoring home crowd. Clarksville, Wilma's hometown celebrated a "Welcome Wilma Day" on October 4<sup>th</sup> 1960. A strong advocate for equal civil rights, Wilma insisted that the parade and banquet be integrated. Celebrations to honour Wilma were the first fully integrated events in the city's history.

When she was 22, Wilma retired from competition, and, did not compete in the 1964 Summer Olympics in Tokyo. At the time she retired, the 3 world records she held





for the times she ran in Rome had not been broken.

She returned to her studies at Tennessee State University, completing her degree in elementary education in 1963. That same year, she went to West Africa as a goodwill ambassador for the U.S. State Department, and was U.S. representative to 1963 Friendship Games in Senegal, and visited other African countries attending their schools and sporting events.

A few weeks after returning from Africa, she was involved in a civil rights protest in Clarksville aimed at desegregating a city restaurant. Shortly thereafter, Clarksville's Mayor announced that the city's public facilities, and, all restaurants would be fully integrated.

As an amateur athlete, she had not earned much from her track career. After her retirement her career shifted to teaching, coaching and working in both not for profit and government-sponsored athletic development programmes for American Children. By 1971, she had 4 children herself. She needed a busy career to support them.

Wilma's mother died 1994. In July, Wilma was diagnosed with cancer of the brain. Cancer had invaded other vital organs, and Wilma's health deteriorated rapidly. She died at home on November 12<sup>th</sup> 1994. She was survived by her 4 children, 8 grandchildren, many siblings and nieces and nephews, mourned by thousands across the United States, and, ultimately the world for her legacy to young people, life and peace.



After the U.S. withdrew its troops from Berlin in 1994, Berlin American High School was turned over to the people of Berlin. In 2000, the school was renamed the "Wilma Rudolph Oberschule."



In 2004, the U.S. Postal Service issued a 23-cent postage stamp, the fifth in its *Distinguished Americans'* series, recognising her accomplishments.

written by Susan Shaab after reading **WIKIPEDIA**.

**National**  
a **Women's** article by Arlisha R. Norwood  
**History**  
**Museum**

and, the book *100 Afro- Americans who shaped American History*, by Chrisanne Beckner, 1995 publication by Bluewood Books, California.

# Intentionally-discriminatory clauses inserted into Federal anti-discrimination legislation, disadvantaging some polio survivors

It is self-evidently unfair for Federal anti-discrimination legislation to be intentionally changed to actually *allow* discrimination.

On 23 May 2013 the *National Disability Insurance Scheme Legislation Amendment Act 2013* came into operation. This *Act* explicitly, and permanently (so far), exempted the NDIS from the provisions of the *Federal Age Discrimination Act 2004* in relation to people over the age of 65. The effect of this legislation was to prevent people over 65 years old from making legal complaints against the government for excluding them from the NDIS.

Almost simultaneously, section 41(1)(fba) was inserted into the *Age Discrimination Act 2004* to prevent action under the terms of the NDIS for unlawful discrimination against people over 65. Effectively, the government was protecting itself, doubly, in advance, against legal action for what is *prima facie* an offence under the *Age Discrimination Act*.

In its *First Report of 2013* to the federal Government the *Joint Parliamentary Committee on Human Rights* (a Committee made up of members of Federal Parliament from different political parties) asked the Government to clarify why a general exemption from the *Age Discrimination Act 2004* was justified \* (Clause 3.16).

The Government's original 'statement of compatibility' had suggested that excluding people over 65 was in accordance with 'the broader intent of an integrated

system of support operating nationally and providing seamless transition through different phases of life' (Statement of Compatibility, *National Disability Insurance Scheme Bill 2012*, p.4). It argued that the age-based exemptions had 'a legitimate aim' for the launching of new NDIS sites and were 'reasonable and proportionate' and, that 'Without a general exemption from the *Age Discrimination Act*, any temporary age-based restrictions for future launch sites *could constitute unlawful age discrimination*' (ibid, *my italics*), which proved that the Government was fully aware that its actions would be unlawful discrimination, if it did not change the legislation.

But the *Joint Parliamentary Committee* 'was concerned that the aged care system may not be designed with the same comprehensive and holistic approach to disability that would underpin the NDIS'\* (Clause 3.20)

On June 5, 2013 the *Joint Parliamentary Committee* sent a query on 'the breadth of a general exemption from the *Age Discrimination Act 2004*' to the Minister for Families, Community Services and Indigenous Affairs and the Minister for Disability Reform, who responded on 26<sup>th</sup> June that:

'The Government considered whether a more limited exemption would achieve its policy objective but considered that it would not and chose instead to seek a general exemption from the *Age Discrimination Act*'. This did not satisfy the *Committee*, partly because the Minister did not

explain what other, more limited exemptions had been considered. \* (Clause 3.23)

The Minister explained that 'the aged care system provided a number of supports consistent with those that would be delivered by the NDIS. In addition, recent changes to the aged care system would allow the system to "better meet the needs of individual consumers, including needs that relate to a person's disability"'\* (Clause 3.21)

This led the *Joint Parliamentary Committee* to understand 'that there would be some equivalence in the forms of assistance and support available between the NDIS and the aged care system [but it was brought to the attention of the *Committee*] that the types and levels of supports and services provided by Disability Care may be inadequately reflected in the aged care system, even taking into account the recent reforms to the system' \* (Clause 3.22)

The *Committee* expressed its concern that the amendments to the two pieces of legislation were designed as a '*general and permanent* exemption from the *Age Discrimination Act*' \* (Clause 3.25). It remained unconvinced, given the information provided, about potential 'substantial differences between the supports provided to individuals in the aged care system compared to those on the NDIS, which could result in the inequitable treatment of people over 65 years old who acquire a disability' \* (Clause 3.27).

There is now shown to be an undesirable two-tiered system where there is significant under-performance of My Aged Care in supporting people over 65 (witness submissions made to the *Royal Commission into Aged Care Quality and Safety*), compared even to the imperfect operation of the NDIS.

Post-Polio Victoria is exploring options for advocacy on this issue. Watch this space.

Source: *\*National Disability Insurance Scheme Legislation Amendment Bill 2013* and *DisabilityCare Australia Fund Bill 2013* and Eleven Related Bills. Available at:

[https://www.aph.gov.au/Parliamentary\\_Business/Committees/Joint/Human\\_Rights/Scrutiny\\_reports/2014/144/~/\\_media/Committees/Senate/committee/humanrights\\_ctte/reports/2013/1\\_44/d03.ashx](https://www.aph.gov.au/Parliamentary_Business/Committees/Joint/Human_Rights/Scrutiny_reports/2014/144/~/_media/Committees/Senate/committee/humanrights_ctte/reports/2013/1_44/d03.ashx)

By Peter Freckleton and Barbary Clarke

## Committee Biographies

### Robyn Abraham

I am a Registered nurse, midwife and critical care nurse. After a successful clinical career, I returned to



Melbourne University. I gained a degree that led me into Education and Training, Management and Human Resources in Health Care.

I have recently retired having worked all my life and juggled running a home and family with my professional life. My interests are my family, musical theatre, AFL, travel, museums and antiques. I like to cook and entertain.

I contracted polio in 1953. As a young child I was a patient at Fairfield and Yooralla. I had a busy professional and home life for years. I started getting post polio syndrome at about 40, and 15 years ago I was diagnosed as "best as able." I hope to contribute to the betterment of the management of PPS and LEOp through our advocacy initiatives.

### Barbary Clarke

Singing in harmony and finding la mot juste in my writing are two of my greatest pleasures in life; as is gathering with my feminist sisters. Sadly a crimp has recently been put in this, with the closure of Handsome Her café, our cultural hub in Brunswick.

I'm a member of Long Breast Press lesbian-feminist collective which has successfully published six books – some sold by Readings (quite a coup for a self-publisher!). First came *Willing Up* and *Keeling Over*, a handbook covering every aspect of making wills, planning & running funerals, and grieving the loss of loved ones. Surprisingly, to some, it's been our ongoing best-seller since 2007. As well as the serious side of writing on a subject no one wants to know about - until they need it! It was fun devising humorous chapter headings and including poetry, songs and stories.

My chequered career has included working in multi-nationals, latterly as a management consultant, until I escaped to reinvent myself as a restaurateur at Serendipity Sri Lankan restaurant and, later, as a grief counsellor.

Not content with that (maybe since I come from a line of female activists) for the past 20 something years I've been pursuing full-time (though, sadly, unpaid) human rights and health advocacy – with a PhD on the side.

I have a black familiar with 'cattitude'; a Toyota Prius that partly assuages my guilty reliance on my car; and a block with mature fruit trees, which are regularly stripped by urban wildlife.

Polio's been a speed bump, but I sometimes like to see if I can go over it so fast that I get airborne.

### Shirley Glance OAM

I contracted Polio at the age of just 14 months. I spent several months at Royal Children's Hospital and attended Yooralla school before joining mainstream schooling from the age of 7, when my family moved to the eastern suburbs from Carlton. I now suffer with Post Polio Syndrome/Late Effects of Polio.



My involvement within the Polio community is extensive and includes attendance at Polio Days. I have been an integral member of the Polio Day Committee one as a guest speaker. In 2007, I was involved in the Volunteer School Speaker Program (run by PolioNetwork a service of Independence Australia). In 2009, I attended the "Living with Polio in the 21st Century" conference in Atlanta, America.

In 2008, I helped regenerate the Bayside Polio Support group that hadn't been active for many years. I am the co-chair of this group to this day. In 2015, I completed a 'Fast Track Leadership' Program for people with disability.

con't p. 12

## Committee Biographies con't

In 2018, I became an active board member of Post Polio Victoria Inc., whose aim is to advocate for the services needed to ensure that health professionals are equipped with the necessary information to ensure the best possible care for people with Polio.

I am a strong advocate for people with disability. I was actively involved with National Council of Jewish Women of Australia (Vic) for over 30 years. Over those years I held various positions on the Board, Vice President, Co Chair of Israel Project. President of NCJWA (Vic) 2014-16.

Currently I am Co Vice President at the National level of NCJWA, I have held various positions on this Board, honorary secretary, chair of the ILAN foundation in Israel for disabled children and young adults.

In the 2018 Queen's Birthday

Honours list, I was proud to be awarded the Order of Australia (OAM) for my services to NCJWA and the Polio Communities.

### **Susan Shaab - newsletter editor**

I have been a PPV committee member for 4 years, and, committed to equal funding in health. I advocate and demonstrate for equality in housing, employment and education. I believe governments should fund and run public services only. My polio history began in 1950, after my third birthday. I spent 9 months at Fairfield Hospital. I wore a calliper on my left leg until I was 8. After a kindergarten year at the Yooralla School in Carlton, I started at my local primary school walking forty minutes each way every day with my younger brother.



I have some insight into the breathing difficulties of people with post-polio. My mother contracted polio at the same time I did. My father stopped working for two years to look after her at home. When she "recovered," mother was regularly rushed to hospital with breathing difficulties, diagnosed as asthma.

She had not suffered from asthma before. My parents were advised to move away from winter fogs coming from Merri Creek, to a suburb south of the Yarra. Mum's breathing did improve, after the move. Her emergency hospital visits reduced from a dozen per year to quarterly. Perhaps lung capacity is improved for some years with lung care. I was intrigued by my study of the life of Wilma Rudolph in that she was born prematurely; and how her under-developed lungs were trained to improve their air-capacity.

## *The Christopher and Dana Reeve Foundation*

<https://www.chistopherreeve.org>

information about Polio is excellent for polio survivors to study for the following reasons;

- It details fully the symptoms of the Late Effects of Polio (Post Polio Syndrome).
- It has information on what might be tried in order to live better with PPS; from diet, exercise, care, and social interaction. (Steph Cantrill is telling this locally in information sessions around Victoria.)
- It has a section devoted to myths around the onset and management of PPS.
- There is a list of books relating to all the above and more (i.e. novels about polio, also research articles about the spread and containment of polio, and related illnesses of spinal cord inflammation such as transverse myelitis).
- It informs us about the million survivors of polio in the USA, and extrapolates from that there are over 12 million survivors world – wide. Today the sub-continent has the most survivors. The majority are under 40. These people received little or no appropriate treatment after the acute phase of infection. This means that millions of people will for decades experience Post Polio Syndrome.