Post Polio Victoria Inc.
a voice for people with polio

PPViews

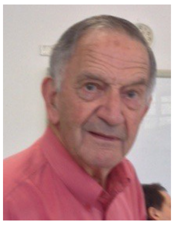
No. 22, September 2019

In This Issue

2019 Committee

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

President’s Report



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It’s pleasing to report that our support of polio survivors has paid recent dividends.

Dr Margaret Cooper’s papers are being archived by Melbourne University. Dr Petra Quinlan- Turner has gained a scholarship for a Masters in Public Health Policy from the same school of Population and Global Health run by Professor Keith McVilly. Dr Petra has commenced initial consultations about polio survivors in Australia to firm up her research proposal.

In spite of Committee members having more than their share of health issues to deal with, advocacy continues. Barbary Clarke at the forefront of equality of accessibility, Robyn Abrahams and Peter Freckleton with safe management of and hospital procedures.

Barbary informed us that in May 2020 Melbourne would host a conference on Universal Design in Buildings, and asking for expressions of interest and an abstract of presenting papers by October 21st. The theme is “Thriving with Universal Design, everyone, everywhere, everyday.”

Measles return to the USA

On September 3rd, SBS’s Dateline began a series of investigations into how anti-vaxers have infiltrated and divided close-knit communities in America, and the struggle of their religious leaders to acknowledge correct science and bring the communities together. Catch up with this episodes from dateline at **www.bit.ly/35tUa0I**

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Freckleton in France

Peter Freckelton had just returned from two months in France where he was impressed by how planners and populous ensure that people with a disability can access all forms of transport, buildings theatres etc; there are special moving platforms at airports, immediate access and seating in theatres and exhibitions, and fatigue seating everywhere.

Peter also informed us that the Committee on the Rights of Persons with Disability met in Geneva between 26th of August and 20th of September.

Ageing with Care, Quality and Safety?

Ron Bell, Peter Freckleton, Liz Telford and Stephanie Cantrill made a submission on behalf of PPV to the Royal Commission on Aged Care Quality and Safety. The submission is concerned with the inequality of the support provided to people with disabilities. People with disabilities over the age of sixty-five are not given the same access to funding to meet their support, rehabilitation and assistive technology needs as is received by their younger counter parts, who are eligible for the National Disability Insurance Scheme

PPV has also joined an Alliance of several organizations calling for a national assisted technology scheme to be funded separately from the NDIS, because the costs for each individual within NDIS are prohibitive.

The submission appears in this newsletter. Include the whole submission or just a link

www.bit.ly/33o5ZDW

PPV AGM 2019 - Have people with a disability been included in today's society?

Our AGM will be held on Monday 25th November 2019 at Disabled Motorists Australia at 2 Station St, Coburg Vic 3058. Lunch will be served. Everyone welcome.

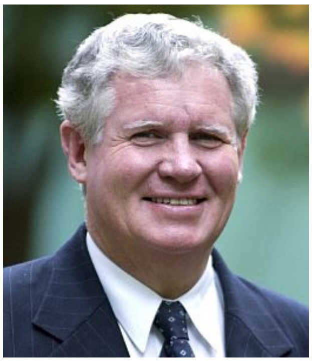
Our Keynote speaker will be Professor Keith McVilly, the Foundation Professorial Fellow for Disability & Inclusion, in the School of Social & Political Sciences at the University of Melbourne.

Professor McVilly has been leading the project of archiving our late member Dr Margeret Cooper's papers on the emergent disability rights movement in Australia.

The AGM is a great opportunity to get together with other members from around the state. It's also an important day to ensure the continued existence of our organisation and our work for the rights and inclusion of people with polio.

Go Doctor John, OAM

Congratulations go to Dr John Tierney (not the famous climate denialist) who was made a member of the Order of Australia in the Queen's Birthday Honours, for significant services to people with polio and in his roles as Polio Australia's patron and its' president from 2012-2017.



Polly Farmer, Footballer with Polio

Vale to the great Polly Farmer MBE (10 march 1935-14th August 2019) who survived polio and with his left leg shorter than the right, yet still played a balanced brand of footy. He was as strong, skilled mobile ruckman who leapt high and changed handballing into a forward offensive strategy. Up there, Polly Farmer.

"Women To The Front"

Women to the Front by Heather Sheard and Ruth Lee tells extraordinary stories of twenty-six Australian Women Doctors who went to provide medical services at the battlefields. Some of them died from diseases including polio, typhoid, tetanus and influenza for which there were then no known preventions or cures. For the women doctors who survived and returned to live in Australia or the British dominions, despite having performed extraordinary surgeries on the battlefields, they were again locked out of what was considered a men's only profession.

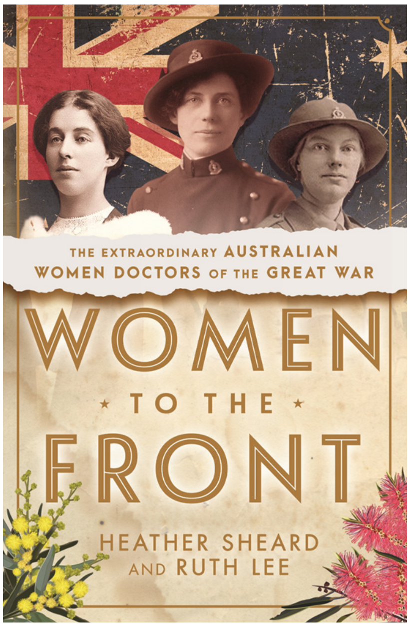
Dr Hilda Wagner Bull (Esso, Dale) (1856-1953) earned world fame for her research into poliomyelitis.

Dr Elsie Jean Dalyell (1881-1948) returned to work for the New South Wales Department of Public Health in the prevention of venereal diseases to benefit women and children.

Dr Mary Clementina De Garis (1881-1963) travelled around Australia as a medical officer after graduating from Melbourne University in 1905. After the war, she settled in Geelong and was responsible for a dedicated maternity ward at the new Geelong Hospital, where she delivered 1000 babies without the loss of a single mother. These were times when there were no antibiotics and infant and maternal mortality rates remained high.

Dr Vera Scantlebury (Brown) (1889-1946) eventually returned to Victoria where she was instrumental in the Government establish a Department of Infant Welfare, and Infant Welfare Centres throughout the State.

Despite some of them having had political affiliations before the war, all the women doctors who returned home became dedicated pacifists, having witnessed first hand the "utter waste of lives."



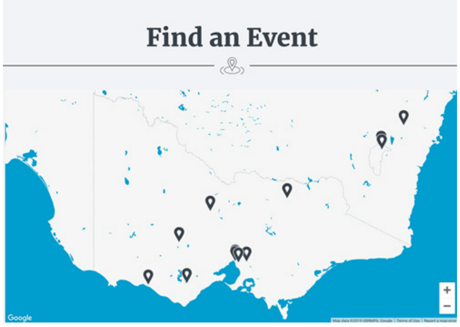
These doctors and the nurses they chose to go with them, gave medical help to captured enemy soldiers, civilians who were under fire from both sides, as well as wounded allies. These medical teams were gentle with the children, especially those they put into isolation while they nursed them through the fevers of the raging pandemic diseases. They assisted birthing women in the battlefront towns. The knowledge the medics gained there about how to help women and their babies was put to good use when they returned to Australia. Foreign Governments honoured some of the doctors for their work in saving civilian lives and the next generation of children.

Polio Day, Worldwide

On World Polio Day on Thursday, 24th October 2019, thousands of community groups around the world will hold events and fundraisers to recognize our progress in the global fight to end polio, and for those of us who've had polio ourselves, our stubborn determination to stay alive.

Events around Victoria

More details about events held by Rotary can be seen on their website endpolio.org/world-polio-day



Lighting up the Melbourne Town Hall

Melbourne, Australia
On World Polio day the Melbourne Town Hall will be lit up in End Polio red to create awareness of the day.

Walk Your Way - Rotary Walk to End Polio

Rotary Club of Albert Park
Albert Park Rotary club are walking at two locations, with one focus and that is to End Polio.

Dinner to End Polio

Rotary Club of Boronia
The Rotary Club of Boronia invites you to join them for a dinner to mark World Polio Day. 7:00pm Wednesday 23rd October 2019 at The Knox Club, cnr Stud Road and Boronia Roads, Wantirna

World Polio Day Breakfast

Rotary Club of Warrnambool Daybreak
A breakfast fundraising event organized by the Rotary Club of Warrnambool Daybreak with invitations extended to all D9780 Rotary Clubs. Includes a guest speaker from Polio Network Victoria

Purple for Polio in Beaufort,

Rotary club of Beaufort
Inviting businesses to have their team wear purple long with local residents and children. Having a coin circle around our Band Rotunda, series of articles on Polio in local paper and social media.

Walk to End Polio

Rotary Club of Eaglehawk
The local Rotary clubs will come together for the End Polio Campaign by participating in a Walk to End Polio - 5 laps of the local lake concluding with a BBQ - all proceeds to the End Polio Campaign.

Worlds greatest meal to end Polio Nigerian feast

Rotary Club of Milawa Oxley
Worlds Greatest Meal to end Polio as a Nigerian feast to celebrate the milestone of 3 years without wild Polio.

Quarterly Meeting update

As you may know, PPV facilitates meetings involving Polio Services Victoria, Polio Australia and Polio Network Victoria. The aims of this meeting are to advocate for more and better services generally, provide feedback to and lobby PSV to improve services to people with polio and to provide a forum for the organisations to communicate and plan together.

At the last meeting in June, PPV, PA and PNV agreed to write to two Ramsey Group hospitals which we believe have a polio alert as part of their intake procedures. We are seeking further information on how these operate as part of our campaign to have polio alerts introduced at all Victorian hospitals. We believe that this is very important for people with polio who have to go to hospital, particularly when anaesthesia is involved.

PSV is also reviewing and seeking to improve the physical environment from which it delivers its services. The aims are to make a for a better, easier to navigate and more pleasant environment. Some work has already commenced while other changes involving capital expenditure will depend on future budgets. We would be very interested to hear if you have noticed any changes and what you think.

We also discussed the work that PSV is doing to get feedback on their services. PSV states that it is eager to get further feedback and we encourage everyone who has previously or is currently using PSV services to provide feedback, and to let us know as well so that we can continue to advocate to PSV on your behalf.

You can contact PPV via our website (www.postpoliovictoria.org.au), by email (postpoliovictoria@gmail.com), by phone (0437 702 137) or by writing to us c/- Ross House 247-251 Flinders Lane Melbourne 3000.

The Inequality of the Disability System hits those with Polio

There is now a two tiered disability system in Australia. PPV has sent a submission to the Royal Commission into Aged Care Quality and Safety, arguing that the care of people over the age of sixty-five with a disability, is inadequate and discriminatory. It should be as equal to that provided to people under 65.

The Federal Government talks about supporting people to stay in their own homes for as long as possible. That may apply if you are a younger person with a disability or an older person without one. But it certainly does not apply to an older person with a disability.

People over 65 when the NDIS came in, who were on Individual Support Packages (ISPs) (in the days when there was a Disability Service in the State Government's Department of Human Services,) were promised that they would not lose funding. "Continuity of Service" (CoS) was put into place for these people but it was revealed that this was not to continue for long. They were soon told to register for My Aged Care (MAC).

The highest MAC package (Level 4) is $50,250 per year, reduced by at least 25% administration fees. The participant also loses access to SWEP, so repairs or new equipment must come out of that. It is also means tested, unlike the NDIS.

One person told PPV that she lived an independent and active life, using Support Workers eight hours a week for nightly transfers and some domestic work (at $45 an hour that's about $49,000 per year). She was put on CoS (Continuity of Service) and soon told she had to be assessed for My Aged Care. During those assessments she was told she ought to go into a nursing home! If eligible for the NDIS the cost of Support Workers would be covered to enable her to live at home. As would be the costs of her equipment repairs and new equipment, any therapies she might need and home modifications.

However, unlike the NDIS, My Aged Care is not geared towards the individual with disability. Here is another example. Ron B. has a level 2 package, which provides approximately $15,000 a year, minus mandatory fees (approximately $6700-not much left!) allocated for garden maintenance and domestic assistance. But he also needed new equipment to enable his continued walking-two new braces each costing $15,000. There was no flexibility in the package for this. He had funding enough for half a brace and nothing else. If he was eligible, the NDIS would cover the full cost of the two braces, along with the other services he needed.

In Victoria we have seen services to people with polio whittled away until there is now no treatment provided, only assessment. Now those who are not on the NDIS are losing access to disability services, the meagre contribution of the State Wide Equipment Service and any equality with other younger people with the same condition. We do not think this is right and we are doing what we can to voice this and seek change. If you have a similar story, please let us know. And tell your local member, taking this article along!

WHO race to prevent a polio epidemic in the Pacific

Following a June outbreak of polio in Papua New Guinea, that health authorities have hopefully contained, two children living on the outskirts of Manila have contracted polio.

The Philippines had been free of polio for nearly two decades, with polio declared an eliminated disease there. Unfortunately, in the last 3 years, child vaccination rates plunged from 70+% to the low 20's.

So now the race is on to vaccinate tens of thousands of children under 5, in a city that has the population of Australia. The World Health Organisation and chapters of the Philippine's Red Cross are mobilising to vaccinate 1.2 million children throughout the country.

Travellers to the Philippines will also be required to get booster injections before they leave home.

Regulatory Impact Statement for a minimum access standard in housing

IN 2017, the Building Ministers Forum called for a Regulatory Impact Statement for a minimum access standard in all new housing construction.

A Regulatory Impact Statement must ask: "What is the net societal benefit for the Australian community?" This means you.

You can have your say by responding to the Australian Building Codes Board (ABCB)'s Consultation Regulatory Impact Statement to be released early in 2020.

Why do we need a minimum access standard in all new housing construction?

Social

Our home is where we seek privacy, rest and recuperation from daily life, share family values and traditions, raise children, provide support to each other, and solve everyday problems. It is the most important building in our lives.

Accessibility in housing allows everyone to participate in these important activities in community and family life. Everyone has something important to contribute.

Economic

Access features are cost-neutral and easy to provide at design stage. They cost 19 times more if added after the home is built.

It is estimated that over 90% of homes can expect to require access by a disabled, aged or injured resident or visitor sometime in its life.

Governments are planning for people to live in their own homes, remain at home if they have a disability, as they age and to recover at home after an illness. This works best for everyone.

Human Rights

As a signatory of UN Convention on the Rights of Persons with Disabilities Australia is obliged to promote equal access to all aspects of our physical and social environment.

The 2010-2020 National Disability Strategy supports the aspirational target that all new homes will be of a minimum access standard by 2020.

The voluntary approach favoured by the housing industry has failed. Without regulation in the National Construction Code, this target will not be met.

Australian Network for Universal Housing Design recommends Livable Housing Design Gold level* access standard for all housing construction in the National Construction Code.

*See http://www.livablehousingaustralia.org.au/

For more information, visit:
Australian Network for Universal Housing Design: www.anuhd.org
Australian Building Codes Board: www.abcb.gov.au/Initiatives/All/Accessible-Housing

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Australian Network for Universal Housing Design

What is a Regulatory Impact Statement?

The National Construction Code (NCC) provides the minimum necessary requirements in the design, construction, performance and livability of new buildings (and new building work in existing buildings) throughout Australia.

Any potential change to the NCC, such as a minimum accessibility standard for housing, must generate a *net societal benefit*, which is outlined in a Regulatory Impact Statement.

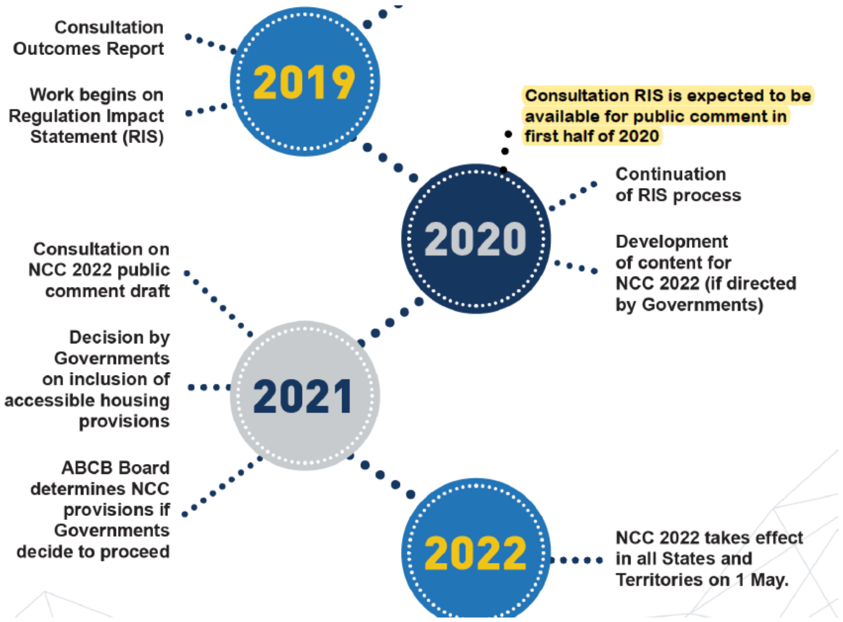
Who benefits from an access standard for housing?

There are five broad areas of *societal benefit*. With an access standard in the NCC:

1. **Buyers and renters of new housing**
   People buying or renting a new house or apartment can expect a minimum standard of access to be included at no extra cost, like smoke detectors, handrails on stairs and electrical safety switches.
2. **Residents and visitors throughout the life of the dwelling**
   Homeowners and renters will be able to stay in their existing home as their needs change through life stages, or if they are ill or injured. People will find it easier to visit neighbours, family and friends if their homes are accessible.
3. **Health and support services, including hospitals, and in-home care**
   There will be fewer home-based slips, trips and falls, experienced most frequently by older women and small children. There will be fewer avoidable hospital stays because patients can leave hospital earlier, receive support and treatment at home more readily, and even avoid being admitted to hospital in the first place. Workers will be able to provide more cost-effective and individualised health services, home care and rehabilitation in people's homes.
4. **Housing services**
   People in social housing, crisis or specialist aged or disability accommodation will have more options to find housing that suits them. There will be less demand for housing support to find accessible dwellings to buy and rent. Homes will be cheaper and easier to modify to people's individual needs.
5. **Australian governments and communities**
   Everyone will benefit from more inclusive residential communities, through greater participation of its citizens in family, work and community life, and fewer people excluded from the mainstream residential environments.

When can you have your say?

The next public consultation is expected in the first half of 2020. The ABCB timetable is below:



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Australian Network for Universal Housing Design

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"The Stolen Marriage" is written In memory of Lydia Lee Green, fellow author and loving friend who battled polio as a child and went on to do so much and be so kind.

"The Stolen Marriage" by Dianne Chamberlain - St Martin 's Press: New York: October 2017.

Review by Susan Shaab

"The Stolen Marriage" was written around the true story of the townspeople in a small town (**Hickory, North Carolina**) who came together to build, equip, and staff a fully functioning polio hospital in fifty-four hours.

While the hospital was open for only 9 months to deal with the 1944 polio epidemic, in that time staff assessed, treated, and, restored , 663 people to better health.

Around its' true core of the Hickory polio hospital, Chamberlain creates a myriad of fictional characters in **Hickory** in the South, and **Baltimore, Maryland** in the North of the **U.S.**

The novel's heroine Tess (Theresa DeMello) grows up a naive, only child in **Little Italy, Baltimore**. She is training to be a nurse while engaged to her childhood sweet heart Dr. Vincent Russo. They have a date to be married in the summer of 1944…

Meanwhile down South in economically depressed **Hickory, North Carolina**, the main male character, Henry Kraft, supplies the army from a furniture factory his family has owned and operated for generations. Henry's life has been privileged. The factory is the main employer in a town, that owes its' wealth to owning slaves. **Little Italy**, and **Hickory**, despite the religious divide between Catholic Italians and Protestant Americans, are united in their patriarchal, racist, and homo-phobic beliefs. **Hickory** has a social system where married women, despite having black servants to do every conceivable form of domestic duty, even as nannies to their children, do not work and spend their time in useless leisure pursuits and/or "good works."

When polio hits **Hickory**, Tess does all she can to help. She works long shifts nursing at the hospital saving the lives of the Mayor's daughter and her premature child. During this time, Tess learns Henry's ultimate secret. Since his teens, he had been in a mutually loving relationship with Honor Johnson, one of the house servants.

As a contemporary book about an historic polio epidemic, this work informs readers of changing treatments for polio during that epidemic. Survivors had enduring physical effects, poorer for those with affected respiratory muscles, (a clue to the difficulties with anaesthesia for people experiencing the Late Effects of Polio, today). It tells those too young to know of the concerted efforts to find a preventative vaccine. Communities divided by class, colour, creed, or occupation came together to fight the disease. In many communities, this enhanced movements for greater equality between rich and poor that commenced after the Great Depression.

I think one can draw parallels between some of the novel's characters and themes, to moves to political extremes today. Arguably this has worsened health- care in poor countries as well as for poor people in rich countries, and, in those same communities, an increase in preventable diseases. American trade sanctions on medicines and vaccines, anti-vaccination lobbyists, the destruction of the natural environment, factory- farming practices, together with the lack of clean air and water, have exacerbated the problems. Governments around the world withdrawing from the provision of public services, and selling them off to private enterprise also markedly increase inequity in health care. This is happening at an alarming rate in the so-called "richest" country in the world, the **United States of America**. The USA is now experiencing a spike in acute flaccid myelitis, a polio-like disease, pneumonia, tuberculosis and measles.

Around the country, deaths in dozens have been recorded, as well as people permanently disabled by disease side effects. Herd immunity is threatened in previously unaffected places. Outbreaks of polio in the Pacific may mean the USA may not remain immune from the same tragic outcomes.

Diane Chamberlain's inspiration to research and write this novel came from seeing her dear friend battle polio as a child. It's a battle that polio survivors do each day.