

PPViews

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2020 Committee

Robyn Abrahams
Ron Bell
Judith Bell
Geoff Dean
Peter Freckleton
Shirley Glance OAM (President)
Nimo Hersi (Secretary)
Lan Huynh (Treasurer)
Nanette Morel
Susan Shaab (Vice-President &
PPViews Editor
Anne Wright

Presidents Report



It is hard to believe that we in Melbourne have been in lock down for

three months, and as I share my report with you the numbers are rising in Victoria. We have all faced challenges during this time and many of us will compare this pandemic to the polio epidemic. The similarities are quite staggering, the isolation, schools being locked down just to name a few.

In April ABC reporter
Larissa Romensky
contacted PPV regarding
the similarities of polio
epidemics and the Corona
virus, which bought back
memories. 'State borders,
schools, pools and theatres
closed, and travel
restrictions and quarantine
measures were introduced',
much the same as we are
experiencing today.

Senior Rehabilitation Physician Stephen De Graaff told the ABC 'if post polio survivors were to contract COVID-19 they were at more risk of serious illness."

This prompted Liz Telford to prepare a one page document, reviewed by Dr Stephen de Graaff" should you need to be admitted to hospital during this time. (see page 3). As we are now having cluster outbreaks in Victoria we may be more vulnerable than before!

We have written letters to State and Federal leaders and health ministers regarding our 'concerns, that we be given full treatment if infected with COVID-19, including the use of ventilators and that we not be subject to what could amount to enforced euthanasia as a result of best practice treatment always be used'.

Continued on page 2

Presidents Report (Continued)

In November 2019 PPV endorsed the "Assistive Technology for All Alliance Submission to the Royal Commission into Aged Care Quality and Safety" which called for people with disability over the age of 65 to have the same access to assistive technology as younger people who qualify for the NDIS.

In March 2020 we managed to sneak in our strategic review and I would like to thank Anne Wright for facilitating the day and also thank and acknowledge everyone who participated We covered a lot of ground and I am so pleased that we have made a good start and look forward to sharing this with you in the near future.

November 2019 we held a very successful Annual General Meeting, and I would like to thank Ron Bell for his leadership over the years. Ron will remain a committee member and we welcome his wisdom and input at our meetings. I would like to acknowledge our outgoing Treasurer Mytill Srinivasan for her work and commitment, Jill Pickering

for her support over the years and also Rangan Shrinivasan.

I am delighted to welcome new committee members as of November 2019, Lan Huynh – Treasurer, Nimo Hersi – Secretary, Nanette Morel and Anne Wright (May 2020).

Thank you to Robyn Abrahams, Judith Bell, Geoff Dean, Peter Freckleton and Susan Shaab for their continued support over the last eight months, and who continue as committee members.

I am so pleased to share with you that in this year's Queens Birthdays' honour list our founding President Liz Telford OAM was awarded the Order of Australia for her services to people living with polio, and to the community. This is truly a well deserved honour for her dedication and commitment to polios.

Sincerely, Shirley Glance OAM

Melbourne University Project

Melbourne Universities project - "Post polio syndrome: Knowledge translation and professional development for GP's and other health professionals" is progressing well.

Petra Quinlan-Turner, Prof McVilly, Dr Phyllis Lau, Liz Telford and Shirley Glance had a Zoom meeting on the 22nd of April. Data collection has been completed with a good response rate from health professionals (11 interviews), along with the focus group. The data is now being analysed, and depending on the COVID situation, presentations mid to late October may take place.



Petra has been working with PPV creating professional development materials for health professionals.

Coronavirus and advocating for our rights

People with polio, and especially the older of those among us, may be especially vulnerable to coronavirus. However there are concerns that during a pandemic, our treatment may be treated as a lower priority than able-bodied people.

In April we wrote to the Prime Minister Scott Morrison, the Health Minister Greg Hunt, The Premier of Victoria Daniel Andrews, The Victorian Health Minister ,Jenny Mikakos David Southwick MP, Georgie Crozier MP and Prof Brett Sutton, Victoria's Chief Health Officer, to voice our concerns:

"PPV insists that polio survivors be given as of right full treatment for coronavirus infection, including use of ventilators.

Moreover, PPV insists that polio survivors not be subject to enforced euthanasia through failure to provide best-practice treatment, or in any other way.

It is self-evident that the medical treatment of polio survivors must not be compromised by reason of age and/or disability or on any grounds whatsoever.

We acknowledge the return letter from Victorian Minister for Health Jenny Mikakos MP, assuring equitable access to care facilities in accordance with the Australia and New Zealand Intensive Care Society guidelines.

Coronavirus and Post-Polio Medical Advisory

PPV prepared a medical advisory for patients presenting with coronavirus to provide to their medical practitioners.

Polio causes muscle weakness, including of the diaphragm, larynx and other muscles involved in breathing. Therefore, while lung function is not affected by polio, people with post polio may have respiratory conditions eg sleep apnea.

Polio survivors may also have restriction in chest wall movement due to scoliosis and chest wall muscle weakness.

Oxygen therapy may not be tolerated as it requires breathing stamina which may be affected by these issues. Oxygen tolerance would need close monitoring to avoid carbon dioxide buildup. The patient should be propped and not completely lying flat so that there is less pressure to breathe against.

Ask the patient for specific information about the effects of polio on their muscular skeletal and respiratory health, and contact their specialist.

To download and print a copy of this letter go to postpoliovictoria.org.au/coronavirus-letter



Congratulation Liz Telford - PPV founder and Order of Australia Medalist!

Liz Telford, PPV's inaugural president, was awarded an OAM in the 2020 Queens Birthday Honours list for services to people with polio and the community. PPV is delighted that Liz' years of contribution and service have been recognised in this way.

Liz, what got you involved with advocacy about polio?

It was a way for me learn about the condition, the services and issues while also contributing. When I developed symptoms in my late forties, it took at least 6 years for any health professional to recognise that my health issues were related to my polio history and that was only after I had contacted Maryann Liethof who was the Polio Information Officer (employed by Independence Australia formerly ParaQuad) and sought out information. A way for me to deal with the changes that were going on for me was to get involved so I joined the Polio Advisory Committee, Maryann's reference group.

You also went to a Retreat at Warm Springs?

At around the same time, I was lucky enough to attend a Polio Retreat and International Polio Conference at Warm Springs, Georgia, USA, along with Maryann, Shirley Glance (current President of PPV) and Fran Henke. John and Pam Tierney were also there. This retreat formed the model for the highly successful Polio Australia retreats that followed. We had a great time and some strong friendships developed. I learned a great deal from the presentations but it was being with so many other polio survivors from around the world that was the really powerful experience for me. I was inspired to continue to work for better services, information and more inclusivity.



Post Polio Victoria was formed as an advocacy group. Why?

We were very aware of the reduction of the polio health services funding in the 1990s with the move from Fairfield Hospital and we tried to prevent the loss of the information service, then auspiced by Independence Australia, which was changing its direction. After this (lost) battle, five of us, Jill Pickering, Martin Grillo, Geoff Dean, Ron Bell and I saw a need for an advocacy group as we knew that polio health had specific issues. I was Interim Chairperson then inaugural President and over the next few years we were involved in education and advocacy projects at a state and national level that showed that there was a place for a group like PPV.

Many people with polio were socialised into being compliant patients, as doctors and physiotherapists expected us, and even at times ordered us and our parents to accept the treatments without question. So PPV may have been a challenge to that thinking for some.

What influences your approach to advocacy and leadership?

My belief has always been that everyone should be able to participate equally in all aspects of life, without discrimination. I was raised this way and also trained as a social worker. There is a strong disability advocacy history in Australia which I have also learned from, and this has been my aim with PPV. Good organisational processes are important as I believe that this enables everyone to have a voice, not just the most confident.

Your award also was for work outside of polio advocacy. What was that?

This was in the areas of relationship and family counselling and community work. I was a social worker and therapist and served for a number of years as President, Secretary and Committee member of the Victorian Branch of the Australian Association of Relationship Counsellors. AARC served to develop and maintain high standards of practice and accountability in the profession.

Finally, Liz what does the OAM mean to you?

I am very honoured to receive it and I thank my nominator and referees. I also thank my husband Ron who has joined PPV, contributing in many ways and supporting our work.

I think this award is a recognition of the important work that is being done by all of us in PPV and other polio organisations.

Polio back to bite its victims

Better health training essential

by KIRSTY STEIN

NEW Australian doctors are not NEW Australian doctors are not being trained to diagnose or treat the late effects of polio, even though about 150,000 people across the country are at risk of suffering ongoing consequences. The House of Representatives Health and Ageing Committee has now called for measures including training for health professionals and professional development for existing GPs in the

opment for existing GPs in the ate effects of polio and post polio

syndrome. The committee also recom-mended a program of community education particularly targeted at older people and people from non-English speaking back-grounds, and for the Australian Bureau of Statistics or the Australian Institute of Health and Welfare to gather data on the prevalence of late effects of polio.

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At a specially-convened roundtable, Liz Telford from Post Polio
Victoria told the committee a
large proportion of Australian
polio survivors had contracted the
disease before the 1950s and were



BETTER TRAINING NEEDED – Liz Telford, a polio survivo the 1956 epidemic, is advocating for people experiencing effects of polio.

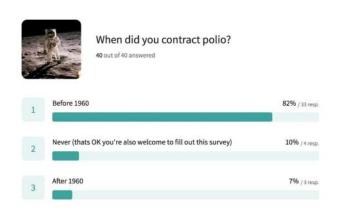
Liz featured in the Senior Newspaper in October 2012, at the beginnings of PPV

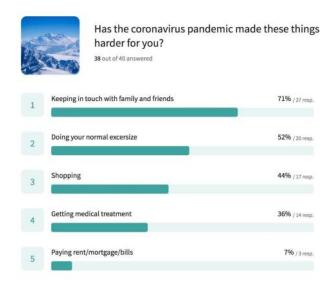


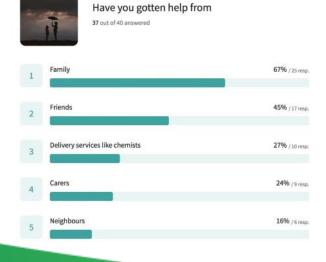
Liz (bottom centre) rejoined our June Committee Meeting

Post Polio and Corona Virus Survey Results

We wanted to find out how everybody has been going during this very challenging time and share our stories. During the lockdown in Victoria, we surveyed our members online to find out more about how coronavirus has been affecting people with histories of polio. 40 people completed the survey between the 3rd of May and the 19th of May 2020.







The Results

Most of our respondents had contracted polio before 1960, with just three younger people who had contracted polio after 1960. Some other supporters and community members also filled in the survey. We believe these numbers reflect our general membership demographic, a good reminder to invite and welcome more younger people and recent arrivals to join PPV too!

Challenges of the coronavirus pandemic

For most of us, the lockdown made it a lot harder to keep in touch with family and friends – but others are used to staying home, or have learned to use technology to keep in touch.

A great concern for many people with polio is regular exercise, and just over half of respondents were having difficulty with that, with access to hydrotherapy, pools, gyms and other sports facilities interrupted.

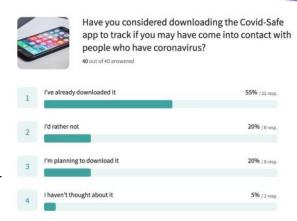
Getting medical treatment has also become significantly more difficult. Of great concern are 3 respondents who are having increased difficulties paying the bills and keeping a roof over their head.

Getting Help

Thankfully, family, friends, carers, neighbours have all come to our assistance. Other responses were food deliveries, nurse on call, and 'husband' also came in handy a couple of times. One person called on a charity to help, and one person who may have needed help didn't receive any. Its a good reminder to reach out to people in our communities who may need it.

The Covid-Safe App

As the Covid-Safe App was rolling out, we wanted to know if people were using it, and what they thought. While the 55% of people who had installed it on their phone already was very significantly higher than the population of Australia as a whole, contention around the apps security and privacy was still a major issue - even for many of those who did download the app.



Echoes of Polio

People were asked "Do you think that your experience of polio has made it harder or easier for you to adapt during this pandemic?" – and the responses were decidedly split. Some people had a chance to let the world catch up to their slower pace of life. Others felt used to it and had survived worse, but for many there were added challenges, especially the difficult memories of childhood polio.

"Its been much harder as bringing back buried memories of my 6 years in hospital and the devasting personal and financial effect on my family" Rosemary

"Brought back very difficult memories."

"Its been much easier, I was in isolation when I got polio, had schooling via mail etc. I was kept away from other people but coped with it then" Lyn

"Much easier. Less appointments to go to when over-tired. Can take things slowly which suits pained body and lack of sleep due to pain. Have spent all my lifetime finding alternative ways of entertaining myself, pacing and being patient with a tired pained body, so much easier now with less external demands. Can go at my own pace." Jan

People were also asked Does this pandemic bring back memories of the time that you or others around you had polio? A much clearer majority said it did, other than for those who had polio as a baby, or not at all.

"Yes many awful memories. Isolation the noise of ventilators and being deemed dirty and contagious" - Robyn

"The memories are seldom from my mind what very few I have but it has increased the fear of catching the virus." - Allen

Our stories

The survey was a good opportunity to share stories and have a discussion with members from across the state, and one as far away as the Kimberley in Western Australia. We couldn't fit them all here but you can find the full results, and share stories of your own at postpoliovictoria.org.au/survey-results

The coronavirus pandemic and people with disabilities

On the 6th of May the United Nations Secretary General António Guterres launched the UN's "Policy Brief on Persons with Disabilities and COVID-19".

The policy brief called on governments to "guarantee the equal rights of people with disabilities to access healthcare and lifesaving procedures during the pandemic."

They called for measures with relevance to Australia including:

- Strengthen national legislation and policies on health care in line with the Convention on the Rights of People with Disablities.
- Identify and eliminate obstacles and barriers to accessibility in health-care facilities.
- Improve health-care coverage and affordability for persons with disabilities as part of universal approaches to health care.
- Prohibit discriminatory practices in health insurance and promote health insurance coverage for assistive products and rehabilitation services.

Secretary General Guterres said:

"I urge governments to place people with disabilities at the center of COVID-19 response and recovery efforts and to consult and engage people with disabilities."

"Looking to the future, we have a unique opportunity to design and implement more inclusive and accessible societies to achieve the Sustainable Development Goals.

Last year, I launched the United Nations Disability Inclusion Strategy to ensure the UN system is doing its part.

The Strategy represents the UN's commitment to achieve transformative and lasting change. When we secure the rights of people with disabilities, we are investing in our common future."

https://www.un.org/en/coronavirus/we-haveunique-opportunity-design-and-implementmore-inclusive-and-accessible-societies

These are interesting and indeed exciting developments for PPV members and the disability community generally. Our stances on the right to full Covid treatment and resources inclusiveness are in tune with current international thinking, and we can hope for some good changes in official policies and attitudes in Australia as well.

There is so much going on, it is getting hard to keep abreast of it, so as well as formal PPV submissions, as individuals we may find ad hoc opportunities to influence discussion, particularly with so much happening online.



Meetings with Polio Services Victoria

Polio Services Victoria, part of St Vincent's Hospital, provides services and support for people who have had polio. PPV has been facilitating meetings involving PSV, Polio Australia and Polio Network Victoria with the aim of advocating to PSV to improve the quality and quantity of its services and to better understand the needs of people with polio.

The first Quarterly meeting for 2020 was held on 11 March 2020 (and probably was the last face to face meeting for most of the participants before the Coronavirus shut down).

PPV has key goals for 2020 to improve the level of polio knowledge amongst health professionals and to make hospitals more proactive in identifying when a patient has a history of polio and then having protocols and advice to improve the safety and well being of these patients. St Vincent's Hospital has updated its polio alert (which it presented at the meeting) and we plan to use the Quarterly meeting to support our advocacy for all hospitals in Victoria to identify people with polio and have an alert as to what their needs are, as part of their admission procedures.

PPV is also aiming to educate anaesthetists about the needs of people with polio. Our President Shirley, has a contact, Dr Peter Roessler from the College of Anaesthetists, and the meeting asked her to follow up with him. Shirley, Liz Telford and I subsequently met with Dr Roessler and he has organised for us to write an article for the College's journal and to present to one of their scientific meetings once these resume in 2021. Liz is preparing a draft of the article for presentation and discussion at the next Quarterly meeting which is on July 15.

All groups represented at the meeting provided updates. Some of the highlights were:

- Polio Services Victoria (PSV) reported that their data shows that there are 40 new cases per year presenting
- PSV has updated its polio alert. One drawback is that it only works if the person being admitted to hospital is or has been a PSV client. Otherwise, it relies on patient disclosure. It is very important that if you are being admitted to hospital for any reason, you inform them that you have had polio.
- There is also information on the PPV
 website which you can present to the
 hospital aimed at anaesthetists and focus
 on the anaesthesia risks to people with
 polio. PPV will start work on this and
 bring our thoughts to the next meeting for
 discussion.

Dr. Roessler said he was impressed with our commitment to supporting the polio community and that he felt privileged to be working with us.

As Chair of the Quarterly meeting, I would also like to congratulate our Group member, Liz Telford, on receiving a very well deserved Order of Australia medal in the Queens Birthday Honours List, for her leadership and contribution on behalf of people with polio and the community.

Ron Exiner
Chair, Quarterly meeting
To get in touch with Polio Services Victoria
contact 1800 020 324

Member profile - Nimo Hersi - Polio Parenting in Victoria and afar



I was born in Mogadishu the largest city in Somalia and its capital. I was the youngest of 6 children. I was 3 when I caught polio. I remember being sick, but not much else. I was the only one in the family to get polio. There was no clinical diagnosis, nor treatment, to be had. People

considered it to be a "misfortune," and tried to solve it by religious readings, purgatives or herbal remedies.

In 1991, our family fled from the war in Somalia, and we were the first refugees to enter the Kenyan refugee camp. My mother died soon after our arrival there.

My family built our own home from plastic and from wood which we sourced from the bush surrounding the camp. Eventually, thousands of people settled in the camp, which became a pandemic-place for cholera, dysentery, mosquito -borne malaria, pneumonia and polio.

I was about 5 years old when a polio clinic came to the camp, which confirmed that I had had polio. My father was particularly kind to me. Until the day he died, he tried "to make it better." Eventually, he died a few years after my mother.

I was 13 or 14, when me and other siblings migrated to Australia via a refugee visa. We were first settled in Townsville, where, for the first time I saw a polio specialist. Later, we moved to Brisbane for further education.

My brother finished a sociology degree and became a researcher at Brisbane Uni. He has moved back to Africa and works for the IGAD (Intergovernmental Authority in Development) based in East Africa. I have always worked for non-profit organisations. In Brisbane, I worked for Lifeline and for the cerebral palsy league of Queensland.

Since moving to Melbourne several years ago, I have worked part-time with a number of organizations. I now work in Women's Health as a bi-lingual worker, to help women with financial literacy. And, I also work part-time as an interpreter.

In my spare time, I do a lot of advocacy for the Somali community in Australia, with a special interest in women and children.

In addition to working part-time, I am studying Community Service, part-time.

Whatever I do, establishing good working relationships is important to me.

I joined PPV's 2020 committee because PPV is moving positively in many ways to advocate for people with polio.

Because of past difficulties trying to explain to hospitals what a polio survivor needs going home with a new baby, I was recently offered a project partnership with the Australian Catholic University, Polio Services Victoria, and Polio Australia. We hope to provide an Information Package to support future parents with polio. When it is finished, I hope it will be beneficial to myself and other members of the polio community.

I love spending time with my friends and family. Long drives are my thing! Once a year, I take my family for a trip round the scenic drive of The Great Ocean Road. We spend a couple of days on the road; of course, with stopovers. I enjoy living in Victoria; the best place in the world!

Member profile - Nanette aka Mrs. Chocolate Frog



I joined the 2020 Committee of PPV because I believe that all people with a disability should be treated equally, and, advocacy has an important role in achieving this.

I caught polio when I was 5. I was in ward 9 at Fairfield. I remember little about my time there. I recall my grandpa and auntie visiting me sometimes; little else.

My parents never came. I was the eldest of 8 children. I guess mum and dad were too busy. Also, parents were not encouraged to visit because visits made younger children difficult to handle. From Fairfield's records, I was in an iron lung for nearly 12 months, and went in and out of hospital for 5 years to learn to walk. I left hospital in 1955 when a vaccine against polio became available.

I was discharged to my parents' home in Elsternwick. My parents moved frequently because my father was a German refugee. Before I finished my schooling, I went to at least 15 different schools. I wore callipers on both legs until I was 12, and visible as a newcomer and "disabled."

After I left school, I went to Melbourne University to study medicine, but after 3 years I couldn't cope and left. During those 3 years, I met my husband, a lovely man, who was very supportive of me returning to study. He did all the housework so that I could study. Because of the severity of my polio, doctors predicted I couldn't have children. During those study years, we had 2 young sons so finishing my degree took longer.

Eventually, I graduated as a child psychologist and began working from home, a clinic in East Melbourne, and the Children's Hospital with children who were dying from blood cancers. I only worked with children. They don't tell lies.

For every child, I brought a chocolate frog present as thanks for allowing me to visit. They called me Mrs Chocolate Frog. My work was helping children and parents say goodbye. It was emotive work listening to children until they were ready to say their goodbyes. Children always asked, "Will I go to heaven?" I told them I had never met anyone from heaven, but "I think it's a place where people are really happy and eat lots of chocolate frogs."

I have many ideas and interests. I hate racism of any kind, especially the anti-Chinese sentiment, which sadly features in the "people blabber" today.

I am a member of "Friends of the Kororoit Creek." Until recently, I was volunteer planter along its' bank, and in the regular rubbish clean ups using a long pick up stick.

For some time, post polio syndrome has curtailed my activities. Brittle bones have seen me in and out of hospital with broken legs from falls. I have a disability scooter. Our neighbourhood is highly multicultural. During the time of Covid-19 lockdown, I have made a hobby of learning greetings in the languages in our community. My goal is to learn forty. When I go out on my scooter people are so happy hearing me say "hello" in their language. One Somali lady told me that I was the first white person to speak to her.

I am saddened by the militarization of America and what seems like empire building. Surely the world learned from history about the Nazis and the murders they committed in their empire building?

Update on Accessible Housing consultation

Barbary Clarke and Margaret Ward

In December, 2018 PPV made a submission to the Australian Building Codes Board's (ABCB's) consultation on whether minimum standards of housing accessibility should be regulated within the National Construction Code, which governs building in Australia. Previously the Master Builders' Association had argued, strenuously and successfully, that standards should be self-regulated by the building industry.

However, this has been shown not to work, with only around 5% of new dwellings being 'accessible' to people with disabilities. The wheels of change grind slowly

The reference to COAG (Council of Australian Governments) refers to the body which commissioned ABCB to hold the consultation. The following is an update on developments to date, provided by Margaret Ward of ANUHD: The Consultation (draft) Regulatory Impact Statement was to be released on 3 April 2020, but on the advice of the Disability Discrimination Commissioner [when he] saw it, it was delayed for a major rewrite.

On the 4 June [2020], the ABCB has informed us that:

Regarding the delay on release of the Consultation RIS

The Disability Discrimination Commissioner has provided the ABCB with further information, which is currently being reviewed. Allied to this they are completing some follow -up leads and hope to have the final version of the Consultation RIS available for the Board to release sometime in June 2020. This timing will still provide for the eightweek consultation period, which has been envisaged from the outset.

Regarding the abolition of COAG

There has been no advice to the ABCB as to the consequences of the abolition of COAG in favour of a National Cabinet—the Building Ministers Forum was never a formal COAG Ministerial Committee because it is the creation of an Intergovernmental Agreement. The ABCB consider there is no reason to believe that this or any other COAG Intergovernmental Agreement is made void through replacing COAG with the National Cabinet. The announcement is a change of intergovernment process, not a universal change of inter-government co-operative arrangements or pre-existing policy directions. There appears to be no reason as to why this announcement has any effect on the ABCB's work program and therefore the work they are doing on the RIS for accessible housing.

Our work on this issue seeks to remind decision makers of this maxim

Accessibility is getting in the door;

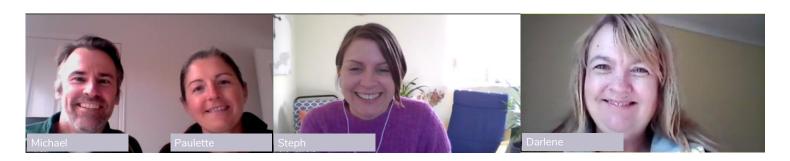
Diversity is being invited to the table;

Inclusion is having a voice at the table;

Belonging is when your voice is heard;

Universal is everyone, everywhere, every time.

Polio Australia Updates



There's been lots of changes and updates from our partner organization, Polio Australia.

Staffing

In the second half of 2019 and the start of 2020, we have had a lot of staff changes at Polio Australia:

- We welcomed Darlene, our Resources Manager, in August 2019, to help us manage office systems and organisation, and to help Maryann ease into retirement.
- Paul resigned from his role as Clinical Educator in October, and was replaced by Michael. Michael commenced his work doing Clinical Practice Workshops for health professionals late last year, and did a few more workshops early in 2020 before being held back by the COVID-19 pandemic.
- Maryann, our Program Manager, left us at the end of 2019 after many years of tireless service to the post-polio community. We hope she is enjoying her well-earned rest!
- We said good-bye to our Health Promotions Officer, Rachel, in February, and were very pleased to welcome Paulette as our Admin Officer in March. Paulette will mainly be supporting the clinical education program.

Due to the pandemic situation, all staff are working from home at the moment - the picture above shows them working at home using online teleconferencing.

Health Professional Education

All face-to-face workshops are currently on hold. Michael has been conducting a series of webinars - see www.facebook.com/ PolioAustralia and go to "Events" for details. As restrictions continue to lift, Michael is hopeful that he will be able to return to conducting Clinical Practice Workshops soon.

Polio Survivor Education

Community Information Sessions are also currently on hold. However, we've held virtual meetings with great turnouts around the country around the country. Additionally, we're posting videos on a range of topics on our Facebook page - www.facebook.com/ PolioAustralia. Please like our page if you haven't already!

Please stay well and safe, and we look forward to connecting with you when things settle down.

Polio Australia Factsheets

Polio Australia has developed factsheets to assist with our understanding of living with polio. These factsheets, and others, are available on our Polio Australia website.

You can find all these factsheets online at <u>polioaustralia.org.au/living-with-polio</u> or call 03 9016 7678 to request a printed copy

Health

- Anaesthesia and Surgery
- Bone Density & Health
- Continence
- Physical Activity and Exercise
- Fatigue
- Womens Health
- Footwear/Pedorthics
- Pain management
- Sleep and Breathing
- Cold and Heat Intolerance

Lifestyle

- Aids & Equipment
- Falls What to do if you have a fall
- Speech and swallowing
- Medication
- Driving & Vehicle Mods
- Orthoses

Services

- Disability Services
- NDIS
- MyAgedCare

Providers

 Types of Health Professionals



Movie Reviews - Recalling our activist history during time of lockdown

Susan Shaab recommends to two excellent documentaries to see in the wintry stay at home. locked down months.

Crip Camp

"Crip Camp" is a 2020 documentary about a New York summer camp (Camp Jened) for people with disabilities which inspired activist movements in the 1970's.



This recently released, Netflix, production is directed by Nicole Newnham and Jim Lebrecht. The film shows interviews with campers about a wide range of topics; their treatment outside the camp, their need for privacy and sexual experiences which were not acknowledged. It also shows happy people expected to play sports instead of sitting and watching on the sidelines.

After the camp, Jim and fellow campers, become activists in the disability rights movement, which led to the 1977 504 Sit-in at HEW (the United States Department of Health, Education and Welfare) offices all around the country. Finally, after years of Government prevarication, this led to big changes in the 1973 Rehabilitation Act.

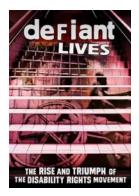
One of the sitters recalled years later that the 26 - day Sit-in drew support from other activists. "Out of solidarity, the Black Panthers arrived with free meals for us.

The protests were the culmination of a long period of effort among people with different disabilities in supporting legislation to benefit all disabled people. The changes included

accessible public transport, housing, equality in employment and enshrining mainstream schooling.

Defiant Lives

"Defiant Lives" is an Australian film produced by Sarah Barton and Liz Burke in 2017, exploring the same human rights issues for disabled people. The 90minute film reviews the



decades after WW2 when activists in Australia, the UK and the USA demanded structural changes in society to ensure the human rights of people with a disability.

Sarah Barton spent 8 years of research to complete the film, which includes archival footage of activists' own camera work, as well as media clips of protests with a definitive start in Melbourne with the de-institutionalisation movement.

A DVD version of "Defiant Lives" has just been released, and should reach our libraries when they reopen.

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If you'd like to donate to keep PPV working to advocate for people with polio, and keep our bi-annual newsletter coming out to you, you can donate online at postpoliovictoria.org.au/ <u>donate</u>

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