

PPViews

No. 18 September 2017

In This Newsletter

- Saving Subsidised Taxis
- President's Report
- Awards for September
- Breast Cancer Resource
- Save the Date
- PPV Needs you
- Aids and Equipment Issues
- PPV collaborations
- Polio Health International
- Please Like Us
- Wayne and Ravy In Cambodia
- PSV Update September 2017

Saving Subsidised Taxis



Every Community should get behind efforts to save the subsidised Taxi Scheme, the only truly universal scheme available to all Australians with a disability who are unable to use public transport.

With the NDIS rollout the Federal government is limiting funds for transport for NDIS recipients. South Australia and Tasmania have announced that it will scrap subsidised Taxis for people taking up NDIS packages. PPV is lobbying to keep the scheme in Victoria, but hasn't yet received a reply to our letter to Minister Jacinta Allan

on 29/3/17, requesting a meeting with her and her advisors.

Similar lobbying resulted in the Queensland Government guaranteeing the scheme for a further year to the end of the 2019. New South Wales has indefinitely guaranteed their scheme.

By contacting your local State Member of Parliament to tell them how necessary having the scheme is to us all, is the way you can help to save the scheme.

2017 Committee

Geoff Dean (President)
Ron Bell (Treasurer)
Ron Exiner (Secretary)
Margaret Cooper
Jill Pickering
Liz Telford
Fleur Rubens
Susan Shaab

Ross House
247-251 Flinders Lane, VIC, 3000

postpolio victoria@gmail.com
www.postpolio victoria.org.au

Jill Pickering
ponders the big
question...
can one ever have
too many options?



President's Report



Following last year's Post Polio conference in Sydney, 2017 has been a busy one for Post Polio Victoria, continuing discussions with polio people we met there, and meeting locally. New members joined Post Polio Victoria, most from referral from Polio Australia's Registry. We welcome them, and any of family and friends who would like to join Post Polio Victoria as Associate members.

Post Polio Victoria committee members have attended their local polio support networks to give presentations and share information. Your Post Polio Victoria Committee met five times as the importance of lobbying and advocacy for polio survivors increased with governments across Australia trying to spend less on health care.

Health practice considerations for polio survivors will be with the

world for decades. The June edition of Post Polio Health International reported that though this year saw few cases of victims of wild polio virus, the world is far from reaching the required ratio of vaccinated children to eliminate the disease. Children in war ravaged regions have not been vaccinated. Children in places like Syria, Chad and Sierra Leone have been found with untreated polio.

However, there is better news for eliminating polio in these regions. The BBC and the Australian recently reported that scientists in Norfolk have discovered a plant (from the tobacco genus) that can mimic the polio virus. WHO is funding the research. The scientists hope that it will lead to the production of a cheap and widely available vaccine so that all the world's children can be vaccinated. For the full report log onto www.bbc.com/news/health-40925343.

Awards and commendations galore for Polios!



Congratulations to Trish Malowney who was awarded an OAM for service to people with a disability through advocacy roles. This honour followed on from Trish winning Victoria's Inspire award for her advocacy work.



Margaret Cooper and Fran Henke were nominees for respective Inspire awards for Human Rights – best achiever and best achievement in Writing.

Bravo to three fighters for Truth, Justice, and, Equality!

BREAST CANCER NETWORK AUSTRALIA RELEASES NEW DVD STARRING BAYSIDE SUPPORT GROUP CO-COORDINATOR and PPV MEMBER SHIRLEY GLANCE



It was really great to attend this launch recently. One of the DVD's is aimed at people with a disability who have a diagnosis of breast cancer.

"Always take someone with you to appointments. There is a lot to take in." That was one piece of advice given by Shirley Glance at the DVD launch "I am so used to saying I am fine when I am not, so when I saw the oncologist I was glad Howard was there to say how I really was, and my treatment was then adjusted".

Australians living with a disability who have been diagnosed with breast cancer, and their carers will now have improved access to information and support appropriate to their individual needs, with the launch of new disability inclusive resources.

Recent research undertaken by Breast Cancer Network (BCNA) found that existing breast cancer resources were not available in appropriate adaptive formats, did not provide sufficient information on the interaction between a person's disability and breast cancer and did not adequately prepare people with a disability or their carers for the process and impact

treatment may have on their disability. This does not only impact the treatment experience, but can also affect the individual's quality of life following active treatment for breast cancer.

To help support and improve survivorship outcomes for people with a disability and breast cancer, BCNA has developed a suite of resources in a range of accessible formats which can now be ordered through its website bcna.org.au, downloaded as a PDF document, viewed in HTML, streamed in audio or ordered as a hard copy.

Shirley spoke very directly about her experiences of having polio and other health issues explaining to the audience the challenges she then faced dealing with the diagnosis of breast cancer, and the treatments of chemotherapy and radiotherapy, as well as surgery.

"Everyone with a disability has their own individual story" said Shirley who described how she wrote POLIO in texta down her leg before surgery to remind the staff which side was affected. What a great idea!

Liz Telford

SAVE THE DATE

PPV'S ANNUAL GENERAL MEETING

will be held at 11 am on Monday
November 27th 2017 at the same
venue as last year,

The Disabled Motorists Australia
(DMA) at 2A Station St Coburg

The venue provides plenty of
disabled parking spots and is a
short walk from the Moreland
Metro Station.

Light refreshments are provided,
with time to discuss together the
issues facing us individually
and as a group.



A good discussion at the 2016 AGM



Healthy and delicious food and
good coffee is a feature at PPV's AGMs

Members of Post Polio Victoria Your Committee

NEEDS YOU!

PPV needs your help if we are going to continue to provide information to, and advocate effectively on behalf of the Polio Community. A couple of the Committee have flagged that after a number of years of involvement, they plan to step down at our forthcoming Annual General Meeting in November.

PPV is managed by a Management Committee of people with Polio, and others involved with them. The Committee has a range of activities that need to be done, and, for which many of you have the relevant skills and experience.

Retiring Committee Members include the VITAL role of Secretary to the Committee. Our need for a Secretary for 2018 is URGENT. If no member

steps forward before or at the AGM to take on the Secretarial role, Post Polio Victoria would have to disband for a period.

We try to make participation as convenient as possible, by conducting most of our meetings by teleconference, so Committee Members can meet in the comfort of their own homes.

I am available to talk to anyone about the role of PPV Secretary or any other Management position.

Please contact me on 0417 392 078 (Ron) or by email postpoliovictoria@gmail.com to discuss how you might become more involved with PPV.

RON EXINER
Secretary

AIDS AND EQUIPMENT ISSUES

Replacement of aids and equipment like calipers, walking frames and power chairs happens all too often. Then there is the need to modify our homes to accommodate increasing physical problems. The maze of documents put out by NDIS, My Aged Care and all the government departments which appear to be involved in our lives, is difficult to get through. We need to know who can assist us financially with what we need as these aids and equipment are quite expensive.

Finding a therapist who understands polio and will write a prescription for what we want and need is not easy either.

Imagine how difficult it is for older people, who haven't lived with disability, who acquire a condition like arthritis, and now need to find aids

and equipment, but who have little or no experience in negotiating the maze.

Post Polio Victoria has two representatives, Peter Willcocks and Margaret Cooper, who are involved in some promising discussions about a possible national Aids and Equipment Strategy. Peter is a member of the Policy Council advising the Council on the Ageing Victoria. COTAVIC has chaired two meetings to talk about the whole area. Representatives from the National Council on the Ageing, MS Australia, Motor Neurone Disease, Blind Citizens Australia, National Disability Services, Polio Australia, and National Ageing Research Institute are among the participants. Of course our friend Natasha Layton is involved too. We'll let you know what happens next.

Disabled Motorists Association
President (and PPV member)
Emilio Savle together with PPV
member (and champion sausage roll
maker) Jill Burn, heading into our
2016 AGM. If you want to sample
these sausage rolls, come to our
2017 AGM on November 28



ELABORATION ON PPV'S COLLABORATIONS

LIAISON WITH POLIO NETWORK VICTORIA

PPV and Polio Network Victoria have recently started to attend each other's Committee meetings with the aim of improving how we work together in the interests of the Polio Community.

PPV appreciates the very good work that Support Group Coordinators do in keeping the support groups going and providing the important liaison and contact that people in the community appreciate and need. We try to support Coordinators by distributing information and attending meetings to speak when invited.

A strong sense that has arisen from the opportunity to attend each other's meetings is that we share the same goals and issues and we look forward to ongoing cooperation so that we can support the important work that each of us does.

On that note-please join Polio Network Victoria in Bendigo for Polio Day on October 21st. See the notice in this edition.

CONTINUING OUR WORK WITH ST VINCENT'S HOSPITAL

As previously reported, PPV has been facilitating quarterly meetings with Polio Services Victoria (St Vincent's Hospital). Polio Australia, Polio Network Victoria and Bayside Support Group also participate in these meetings. A meeting will be held during the production time of this newsletter. An Update from PSV is attached.

The aim of these meetings is to engage with PSV to ensure that PSV services are as relevant and responsive as possible to the needs of people with Polio. Our next meeting is scheduled for mid September, which is about when this newsletter is being published.

We need to hear about your experiences with accessing and using PSV services, so that we can provide feedback (anonymously of course), to St Vincent's. Please contact us via our email address postpoliovictoria@gmail.com, by mail (c/- Ross House 247-251 Flinders Lane Melbourne 3000 or by ring us on 0431 702 137. We look forward to hearing from you.

REPRESENTING PPV ON POLIO AUSTRALIA

Post Polio Victoria is one of the two state based organisations (the other is PNV) which make up the Victorian representation on Polio Australia. Our Secretary, Ron Exiner, is PPV's representative on PA's Board.

PA has had a lot of exciting news recently. It has received Federal Government funding for three years to enable it to run a national pilot of clinical practice workshops. This will result in many more professionals who have been educated on Polio and Post Polio issues which in turn should result in quicker diagnosis and more effective treatment of people with these conditions.

It has also received sponsorship from its Queensland association, Spinal Life Australia, with a view to help-

ing PA become more sustainable into the future. This sponsorship is enabling PA to employ more staff, and particularly a fundraiser to ensure that PA can operate long term in the interests of the Polio Community.

PA is also in the process of established a Buddy Call Register of people who are willing and keen to support each other via phone calls. This program recognises that it is useful and supportive to for people with post Polio to talk to to each other, but this it can be increasingly difficult for people to get out and about to attend Polio support group meetings (and in fact a number of Polio support groups are no longer meeting regularly. If you want more information about this, please contact PA by email or by phoning 9016 7678.

New Polio Health International New Executive Director

The Board of Directors of Post-Polio Health International (PHI) is pleased to announce the appointment of Brian M. Tiburzi as Executive Director of PHI, including International Ventilators Users Network (IVUN), effective September 1, 2017.

Board President William Stothers said that Brian Tiburzi has been assistant to PHI's retiring Executive Director Joan L. Headley for more than nine years. "He has been a critical link between PHI and its Members, providing them with information and services."

"I want to thank everyone on the board for placing their trust in me," Brian said. "I think we all realize just how dedicated, intelligent and hard-working Joan was in her 30 years of tireless advocacy on behalf of polio survivors and users of home mechanical ventilation. I'm somewhat in awe of her and what she accomplished here."

Brian has also represented PHI at past conferences in Toronto, Copenhagen, and, most recently, Sydney. He helped coordinate two of PHI's conferences, when he was able to meet many of our members face-to-face. In addition,

he met leaders of national organizations and local support groups, and many health professionals with expertise in managing the late effects of polio.

"During the past nine years," Brian said, "I've communicated with many of them on the phone and through email and that has given me a sense of what our members are looking for from PHI as an organization. I believe this familiarity will aid in the transition by providing a sense of continuity for our membership."

Brian has been very involved in the design and management of Polio Place (www.polioplace.org), as well as the new IVUN site, www.ventnews.org.

"With so much incorrect or misleading information floating around on the web," he said, "the role of PHI as a source of trusted, accurate information cannot be overstated. PHI plays a vital role in helping polio survivors and ventilator users maintain their health and independence, and I am excited to carry on that legacy."

POST-POLIO HEALTH
INTERNATIONAL

POST-POLIO HEALTH INTERNATIONAL
INCLUDING INTERNATIONAL VENTILATOR USERS NETWORK



Please Like Us!

PPV is on Facebook and if you are too we'd like you to connect with us. It would help us reach more people if you would not only look at the page but "like" or comment on what you see.

We have Facebook friends as far away as Spain and Pakistan. It is another way for people with polio to connect so please, share your thoughts and ideas about issues relating to polio and disability.

Administrators at present are Liz Telford and Fran Henke.

If you aren't on Facebook but your friends or family are, maybe you can ask them to show you our page? Perhaps they might like it...?



The 2016 PPV Executive hard at work



Mary-ann speaking to us about the International Conference

WAYNE AND RAVY GET BUSY IN CAMBODIA

PPV members Ravy Leang-Slaterry and Wayne Slaterry have established a community school in Ansaong Village, Prey Veng – a rural area with subsistence farming-one of the poorest parts of a poor country.

The school is an independent organization with a disability focus. Many of the students have disabilities and both teachers employed have a disability. The project teaches English and computer skills to over 200 village children, free of charge. This will help them gain better employment escape the poverty trap.

Wayne explains "We have hired 2 teachers –they are young graduates or due to graduate. Very bright, enthusiastic and have a good rapport with students and family. They live in our house as part of the family. We pay a salary of US\$150 to

each. This is part of an agreement we have with another NGO (Veterans International)- they provided assistance and subsidized accommodation to disabled students to enable them to complete their tertiary education. We then arrange either permanent or temporary/voluntary positions for them to gain work experience. The agreement is that one of the teachers will be permanent with us and that the other position will rotated every 3 or 4 months. These two teachers will stay with us until we return from Australia to ensure continuity."

Some material help needed at the moment are the replacement of 3 PCs at a cost of around \$200-\$300 each. The school currently has 13 PC stations operational.

Not only this, but Wayne and Ravy have produced twins born in July this year! PPV congratulates Wayne and Ravy and welcome Pitou and Marlis their new son and daughter.

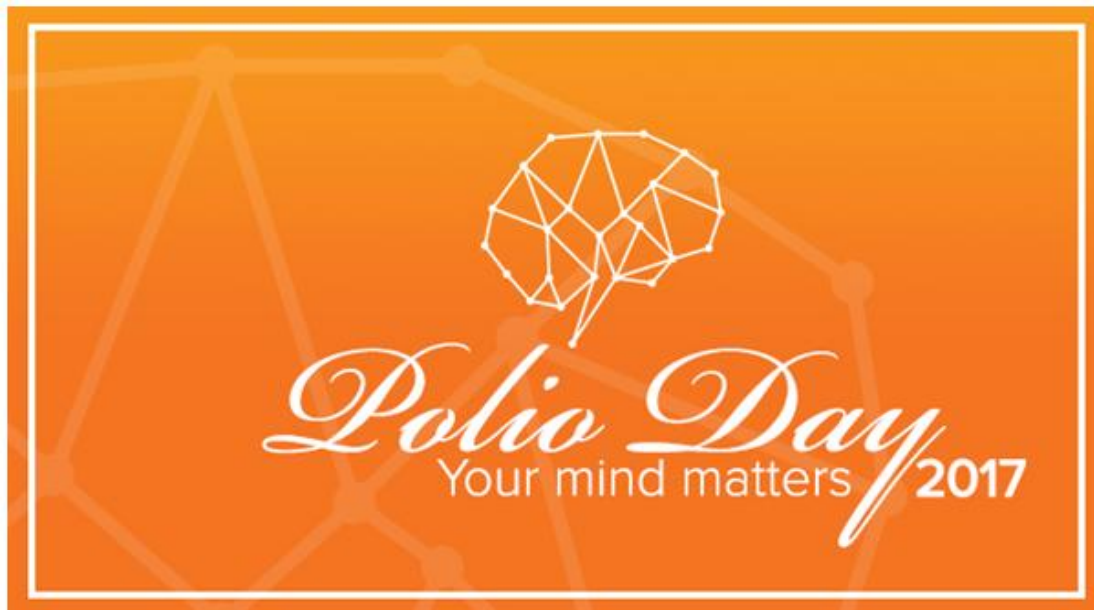
PPV has donated \$250 to assist. If you would like to know more or to support the project go to <https://www.generosity.com/education-fundraising/dreams-come-true-community-education-center>



The Twins



Wayne at the school



Polio Network Victoria invites you to join them in Bendigo for Polio Day 2017.

Polio Day 2017 will celebrate the theme 'Your Mind Matters' and provide information and strategies to assist with maintaining good mental health.

Held at the Bendigo Town Hall, Polio Day will showcase a range of speakers highlighting how good mental health and general well-being are vital to staying positive and active and to be able to continue your life journey as a Polio survivor.

Join us to listen to informative speakers, meet new friends and catch up with local Polio networks.

Polio survivors, family, carers and health professionals are all welcome.

Saturday 21st October, 2017, 10am for a 10.30am start

Bendigo Town Hall

189-193 Hargreaves St

Bendigo VIC 3550

Tickets: \$35.50

Includes morning tea, lunch and afternoon tea

Bookings and enquiries

To book please visit: <https://www.trybooking.com/QCCA>

For enquiries please contact: georgie@fetchingevents.com.au or ph 03 8600 9660

Bookings essential

Polio Network Victoria (PNV) is a free service of Independence Australia

Polio Services Victoria Update

Sept 2017

Staffing

- Additional 2 days week physiotherapy commenced in Jan 2017
 - Running hydrotherapy and new gym group and supporting transition from these programs to local facilities
 - Attends Wednesday metro clinic with medical staff
- Additional P&O hours for 2 months to address Gait and Balance wait list
- Additional Occupational Therapy hours for 2 months to address wait list
- New Allied Health Assistant role to follow up clients about their action plans and any issues with implementing
- Denise Currie has been appointed as the new dedicated Team Leader (0.6) appointed until started 18/9/17

Service Development

- Changes to the Hydrotherapy program (rolling 6 week program) now embedded and attendance has increased as a result.
- Exercise Program in Collingwood Recreation Centre (community gym) has commenced with 80% of clients transitioning to their local gyms.
- Fatigue Workshops being run both at St V's and regionally.
- Purchased a G walk (funded by Rotary) for the Gait and Balance clinic. It gives detailed readings about the gait pattern to both monitor and guide prescription of aids.
- The Polio Health Pathway (web portal for GPs and health professionals to access evidence based guidelines) for a range of health conditions goes live late September
- Social Worker and Psychologist attending the metro clinics where from triage it is thought that their services would be beneficial

- Moving to mailing out some of the assessments forms for the metro clinics pre appointment date so can be completed at home and therefore not making the metro clinic time as rushed
- Developed a referral pathway to the SVHM Optimal Health Program - an 8 week 1:1 program to support clients in addressing long term health needs

Capacity Building

- Lunch/discussion/presentation delivered at each of the regional clinic
- Regional Gait and Balance clinics are now being held in addition to the multidisciplinary clinic due to demand (ie regional clinics have been extended form 1 day to 1½ -2 days)
- Telehealth has been successfully used for regional patients and with regional allied health professionals for joint consultations.
- Joint sessions have taken place with therapists from St Vincent's, RMH and Northern to support clinicians treating polio survivors.
- Assisted NZ group in setting up their service. Likely to be potential for future collaboration together.

Consumer engagement

- New PSV brochures developed with input from current clients.
- Annual 1 month survey of polio clients attending service in March 2017 completed – looking at how to improve wheelchair access to toilets
- Joint project with RMIT marketing program to provide suggestions re promoting service amongst healthcare professionals
- Polio survivors and anaesthetic risk pamphlet – printed and displayed.

Research

- Research project underway to look at whether polio survivors are achieving the Department of Health physical activity guidelines and barriers. Information will be used to inform future service development as a sedentary lifestyle and impact such things as heart disease. Research Endowment Fund grant submission 'The effect of provision of orthotics to polio survivors on gait, balance and quality of life'.