



2015 Committee:

Geoff Dean (President & Treasurer), Margaret Cooper (Vice President), Liz Telford (Secretary), Fleur Rubens, Fran Henke, Ron Exiner, Jill Pickering, Susan Shaab.

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President's Report – Geoff Dean.



WE'RE STILL HERE!

Up to 400,000 polio survivors live in Australia. Post Polio Syndrome support and advocacy services will be needed for decades to come.

Following infection, many polio survivors lived in hospitals for medical treatment and rehabilitation. We returned to live at home as productive, creative members of our communities. As we age, many of us need devices to assist our mobility. Yet, we continue to lead in economic and social issues.

Polio Survivors are champions of ABILITY in Community, and co-operation with other disability and health service groups.

Therefore, after a long trial, and multi-level government negotiations, we welcome the Premiers' announcement that the National Disability Insurance Scheme is about to be rolled out in Victoria. Within the NDIS, thousands of people with a disability will be able to choose the care that best suits their needs. Look at the Premier's press release on page 3. The NDIS train will start rolling through Victoria on July 1st 2016.

This edition of PPV News also has information about:

- . PPV's AGM on Monday 23rd November.
- . Encouragement for new members to join Post Polio Victoria. It's EASY to join.
- . 2015 Polio Day in Melbourne on Saturday 24th October 2015.
- . Visits by Liz Telford and Margaret Cooper to politicians and advocacy work on behalf our members
- . Recent articles from our website;
- . PPV's letter to the Age in response to Julia Medew 's 15th August report on "preventable deaths in hospitals"
- Post Polio Victoria's Post Polio Health Education Campaign

It is that time of year again!

Yes, that's right- PPV's Annual General Meeting will be held at 10.30 on Monday 23rd of November 2015 at the Disabled Motorist's Association 2A Station St Coburg. You will have noticed it is on a weekday this year as we think this suits our membership better.

As well as needing you to vote on a change to the constitution which will make it easier to fill committee positions, we would like to hear your thoughts about what the advocacy priorities should be. After a power point presentation on our work to date by Margaret Cooper (Vice President), facilitator (and committee member) Ron Exiner, will guide the discussion. Maryann Liethoff will also be there to update us on Polio Australia's advocacy work.

Please come along. All welcome-members, supporters and the curious. RSVP Liz Telford at:

postpolio victoria@gmail.com
or by ringing 0417 006 455

A Reminder About Polio Day 2015

The focus will be on how polio survivors deal with changes within themselves, and external forces impacting on them.

Saturday 24 October 2015, 10:30 am until 3.30 pm
Supper Room, Springvale Town Hall
397 Springvale Rd, Springvale

IT'S EASY

Come Join Post Polio Victoria

FULL Membership of Post Polio Victoria is open to any person living in Victoria who has had polio. Associate Membership is available for people or organisations wanting to help with our work. It costs nothing to join PPV.

By joining Post Polio Victoria you will support and strengthen our efforts to increase awareness and education, ensuring that adequate services are provided. A strong membership reflects the real numbers of people with polio in the community.

You can join by:
• completing and submitting the membership form from our website: www.postpolio victoria.org.au
• emailing us at postpolio victoria@gmail.com
• ringing us on 0431 702 137
• writing to us at POST POLIO VICTORIA Inc. Ross House 247-251 Flinders Lane Melbourne 3000

We are also on

Facebook; Look us up. POST POLIO VICTORIA

Holiday Reading.



The Golden Age is a novel based in a real place of the same name; a polio rehabilitation home for children outside of Perth, for children of the Post World War II polio epidemics.

It devotes much to the relationships between the children and staff, where children are separated from their

families for many months.

For polio survivors it's an authentic account of children pushed to their own resources in helping one another, and of the personalities of staff caring for them. The children also feel estranged from their families even after their return home, since for them everything was forever changed; their bodies, their position in the family and their hopes for the future.

Woven within the Golden Age's rehabilitation story is that of post war Australia, where people of different war experiences, cultural backgrounds, and religions have to come to some common understanding of how to live together.

The Golden Age by Joan London published 2014 by Random House

Reviewed by Susan Shaab

NDIS Press release –The Hon. Daniel Andrews MP, Premier of Victoria

NDIS Press release by Daniel Andrews

Wednesday, 16 September, 2015

HISTORIC NDIS AGREEMENT TO IMPROVE THE LIVES OF OVER 100,000 VICTORIANS

The Andrews Labor Government today signed an historic bilateral agreement with the Commonwealth outlining the rollout of the National Disability Insurance Scheme (NDIS) in Victoria over the next three years.

Premier Daniel Andrews was in Canberra to sign the landmark agreement with Prime Minister Malcolm Turnbull and New South Wales Premier Mike Baird.

The Labor Government will contribute funding of \$2.5 billion per year, with the Commonwealth contributing \$2.6 billion, once the scheme is fully implemented – more than doubling the current funding for disability support.

Minister for Housing, Disability & Ageing Martin Foley joined disability advocates and stakeholders at the MCG to celebrate the achievement. The bilateral agreement will benefit an estimated 105,000 Victorians - more than the number expected to fill the stadium at next month's AFL Grand Final.

Following the successful Barwon pilot, the NDIS will be rolled out gradually across Victoria over the next three years starting July 1, 2016 in North East Melbourne, including Banyule, Darebin, Nillumbik, Whittlesea and Yarra.

The Central Highlands region will be next in January 2017 and the Greater Bendigo area in May 2017, with the rest of the state to follow. Victorian children under the age of six will receive priority help, in recognition of the developmental needs of young children.

The scheme will provide personalised care and support for people with a disability across the whole of Victoria by 1 July, 2019. Once fully rolled out, the NDIS will be the end of rationed services and waitlists for people with disability and their families.

Following today's crucial first step, the Government will continue to work closely with people with disabilities, their families, the disabilities sector and other stakeholders involved in the roll out of this significant reform.

Quotes attributable to Premier Daniel Andrews

"This is an historic day for Victoria and a victory for people with a disability, their families and loved ones who fought so hard for this reform."

"This provides certainty about how the NDIS will roll out across Victoria, and once fully rolled out it will mean a fairer system with no more waiting lists – it is about putting people with disability and their families first."

Quotes attributable to Minister for Housing, Disability & Ageing Martin Foley

"This agreement is life changing for the 105,000 people in Victoria to benefit from the scheme, and those who love them."

"People with a disability and their families deserve the control to live the life they choose, and get access to the support they need, when they need it - the NDIS will deliver that."

Victoria will roll out the NDIS in phases, from 1 July 2016.

Here's when the NDIS will be coming to your area.

NDIS Phases

Year One

1 Jul 2016 North East Melbourne: Banyule, Whittlesea, Yarra, Nillumbik, Darebin

1 Jan 2017 Central Highlands: Ararat, Ballarat, Golden Plains, Hepburn, Moorabool, Pyrenees

1 May 2017 Loddon: Campaspe, Central Goldfields, Greater Bendigo, Loddon, Macedon Ranges, Mount Alexander

Year Two

1 Oct 2017 Ovens Murray: Alpine, Benalla, Indigo, Mansfield, Towong, Wangaratta, Wodonga

1 Oct 2017 Inner Gippsland and Western District: Bass Coast, Baw Baw, Corangamite, Glenelg, Hindmarsh, Horsham, Latrobe City, Moyne, Northern Grampians, South Gippsland, Southern Grampians, Warrnambool, West Wimmera, Yarriambiack

1 Nov 2017 Inner Eastern Melbourne and Outer Eastern Melbourne: Boroondara, Knox, Manningham, Maroondah, Monash, Whitehorse, Yarra Ranges

1 Mar 2018 Hume Moreland: Hume, Moreland

1 Apr 2018 Bayside Peninsula: Bayside, Frankston, Glen Eira, Kingston, Mornington Peninsula, Port Phillip, Stonnington

Year Three

1 Sep 2018 Southern Melbourne: Cardinia, Casey, Greater Dandenong

1 Oct 2018 Brimbank Melton and Western Melbourne: Brimbank, Melton, Hobsons Bay, Maribynong, Melbourne, Mooney Valley, Wyndham

1 Jan 2019 Goulburn, Mallee and Outer Gippsland: Greater Shepparton, Mitchell, Moira, Murrindindi, Strathbogie, Buloke, Gannawarra, Mildura, Swan Hill, East Gippsland, Wellington

Post Polio Victoria's Post Polio Health Education Campaign on respiratory issues

Post polio is a complex condition that can amongst other things affect respiratory function particularly as the polio survivor ages. Lack of stamina in any of the muscles used to breathe can compromise breathing capacity and the patient with post polio may be more sensitive to drugs used for anaesthesia and for pain management. Some drugs are contra indicated and can have a depressive effect on respiratory function. (Selma Calmes, MD, Polio Health International; Lambert et al 2005)

Unexpected deaths have occurred due to lack of awareness of these issues.

Objectives

PPV's overall aim with this campaign is to improve health outcomes for people with post polio through enhanced awareness

- by doctors and other health professionals of post polio symptoms and risks
- in hospitals of surgery and post surgery issues for people with post polio
- by people who have post polio about their own respiratory health issues and management

Specific strategies

1. Post polio management protocols in hospitals such as the Polio Alert model (St Vincent's Hospital)
2. Protocols for respiratory health testing for people with polio to be developed
3. Respiratory testing to be a standard part of assessment and management of people with post polio
4. Seek support of Colleges of Surgeons, Anaesthetists, and General Practice organisations
5. Provide information via website and through newsletters to people with polio
6. Respond to articles in the media

Outcomes to date

1. One GP Forum held in conjunction with General Practice Victoria (not followed up due to dismantling of GPV which was replaced with Medicare Locals, now also replaced.)
2. Polio Alert adopted by St. Vincent's Hospital
3. PPV website developed to include Polio Alert and selected articles
4. Polio education forum for staff held by and for staff at St Vincent's Hospital
5. College of Anaesthetists Quality and Safety Committee is writing an article for its' newsletter
6. Austin Hospital is developing information brochure

Selma H. Calmes, MD, (shcmd@ucla.edu) Chairman and Professor, (retired) Department of Anaesthesiology, Olive View-UCLA Medical Center, Sylmar, California, Summary of Anaesthesia Issues <http://www.post-polio.org/edu/hpros/sum-anes.htm>
Lambert DA1, Giannouli E, Schmidt BJ. Anaesthesiology. 2005 Sep;103(3):638-44. Post polio syndrome and anaesthesia.

Advocating in the Dining Room at Parliament House

With the NDIS (due in some parts of Victoria in 2016) and the Commonwealth Home Support Package pending, PPV's campaign to ensure equity of services for all people with polio, has kept us busy this year. We have written to and met with a number of politicians and advisers.

Last month we met Mary-Anne Thomas MP, Member for Macedon and Parliamentary Secretary to Jill Hennessy, Victorian Minister for Health. Mary-Anne's portfolio covers the Department of Health and Human Services, which is responsible for Polio Services Victoria, and also information services to people with disabilities. However, she was not aware of post polio issues. We informed her about the increased need for these services with post-polio effects appearing and/or increasing decades after the initial bout of polio.

Our main message for this meeting was our health and information needs. We informed Mary-Anne about the pressures on PSV, the need for greater medical awareness and the loss of the Independence Australia polio information worker to work on these issues, and the impacts of the changes to disability and aged services on people with polio over the age of 65.

We met in the parliamentarians' dining room as Mary-Anne's office was inaccessible and this had an unexpected benefit. While discussing the 2016 International Post Polio Conference, and the lack of research in Australia, Mary-Anne Thomas took the opportunity to speak to Frank McGuire MP, Parliamentary Secretary for Medical Research, who just happened to walk past at that moment. She suggested that we follow up her brief discussion with him.

As with all of our meetings with politicians, our goal is to raise awareness of our presence and needs and to advocate for services to enable us to live life to the full. We felt that Mary-Anne Thomas showed interest and openness to the information we gave and we left feeling it had been a positive meeting.

PPV's letter to The Age in response to a report on preventable deaths

Polio alert is critical
The Age 18 August 2015

Julia Medew highlights errors in clinical management that have occurred in our hospitals with some devastating outcomes ("Hundreds of patients' deaths preventable", 15/8). A lack of medical knowledge is another cause. Here is a real example. In 2011, a man died unexpectedly in a major hospital a month after surgery. He had a history of polio. A surgical error considered minor (as it is for someone without post polio) combined with inappropriate post-surgery care (due to hospital ignorance of post-polio management) resulted in respiratory failure. The cause of death was given as "post polio", although it was not the disease process but clinical management that caused this man's preventable death. Anyone who contracted polio, whether paralysed or not (an estimated 400,000 Australians) may develop post polio, a condition that may affect the central nervous and respiratory systems. One Victorian hospital now has a polio medical alert for patients known to have had polio. All hospitals need to do the same, and patients should alert staff if they ever contracted polio. Despite the successful global polio eradication campaign, post polio will be around for decades to come and hospital staff must be educated.

[Liz Telford and Fleur Rubens, Post Polio Victoria Inc.](#)