



**POLIO NSW INC**

*formerly Post-Polio Network (NSW) Inc*

# NETWORK NEWS

*Incorporating – Polio Oz News*

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## President's Corner

Gillian Thomas

Welcome to another year of *Network News*, and I note with some pride that we are fast approaching our 100<sup>th</sup> issue.

**Our very exciting news in this issue is the establishment of a Late Effects of Polio Assessment Clinic at Mr Wilga Private Hospital in Hornsby.** Our Secretary, Merle Thompson, has provided detailed information about the Clinic, and the steps to take to access it, in her article on pages 2 to 4. You will see that your Committee has been working very hard to make the establishment of this Clinic a reality, and we strongly encourage members to take advantage of all the Clinic has to offer. **If we don't use it, we'll lose it.**

Polio NSW's **mid-year Seminar on Wednesday, 3 June**, will take a close look at retirement living choices. Preliminary details are on page 4 – full registration information will be posted out in May.

Polio Australia's **2015 Polio Health and Wellness Retreat** is being held from **30 April to 3 May**, in **Torquay, Victoria**. If you haven't yet experienced a Retreat don't miss the opportunity to snap up one of the few remaining places. See the article on page 5 for brief details of the program. Also on page 5 is the first announcement of Polio Australia's **international post-polio conference, Polio: Life Stage Matters**, to be held in **Sydney on 20-22 September, 2016**. Save the date!



Finally, it is with sadness that we advise of the death late last year of past Committee Member, **Dr Elizabeth Joyner**.

Elizabeth served 5 years on the Management Committee, in two terms, from 1999 to 2002, and from 2004 to 2006. Elizabeth contributed greatly to the work of Polio NSW during her time on the Committee, particularly with regard to developing a Medical Resource Register. With her medical training, Elizabeth also brought detailed and accurate synopses of presentations to members through her informative Seminar Reports published in *Network News* over a number of years.

Even after she stood down from the Committee, Elizabeth remained available to advise us on medical matters, and also contributed articles to *Network News*. We passed on our condolences to Elizabeth's husband, Kerry, and family when we learnt of her passing.

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# STOP PRESS!! IMPORTANT ANNOUNCEMENT

## LATE EFFECTS of POLIO ASSESSMENT CLINIC FOR NEW SOUTH WALES

by Merle Thompson, Secretary

**AT LAST**, after something like 15 years of trying we can announce that we have a clinic established in New South Wales which will provide an assessment program for polio survivors.

### Background

Some members will remember that back in the 1990s there was a clinic at Prince Henry Hospital with Dr Jill Middleton as a rehabilitation specialist. Dr Middleton was later joined by Dr Pesi Katrak. This was not a multi-disciplinary service and referrals had to be made for any other assessments or treatments. Dr Middleton was able to join us for our 25<sup>th</sup> Anniversary Lunch in December and those of us who had benefited from her assessment and advice were thrilled to catch up with her.

When I went to Amsterdam last year to the European Polio Conference one of the most significant issues for me was the realisation that most of the polio survivors and the medical and allied health professionals who were there, particularly those from across western Europe, all took it for granted that everyone had an outpatient clinic in which there was a multi-disciplinary team with knowledge of the Late Effects of Polio. Many were researching the needs of polio survivors and considering new techniques to assist them.

The Polio NSW Management Committee has been trying over the years to interest successive governments in providing a clinic but without any positive result. I was asked to consider other options and was wondering about approaching the private sector then in a “great minds think alike experience” Nola Buck attended Mt Wilga Private Hospital, a rehabilitation hospital, and realised there might be a possibility of a polio clinic in that setting.

Nola and I have exchanged documents and met with Dr Helen Mackie and Dr Joanna Murray who are rehabilitation physicians. Dr Mackie has submitted a proposal to the hospital board and they have accepted it. The Polio NSW Management Committee has also endorsed the proposal. **Now the clinic can become a reality!!!**

Mt Wilga Private Hospital is a private specialist rehabilitation hospital in Hornsby providing Inpatient and Day Patient (Ambulatory) and Neuro-rehabilitation programs. Personnel include neuro and ortho-physiotherapists, occupational therapists, dieticians, psychologists, speech therapists and exercise physiologists. Orthotic consultations can be arranged.

[Visit <[www.mtwilgaprivate.com.au](http://www.mtwilgaprivate.com.au)> or search for “Mt Wilga Private Hospital” on YouTube]



## What is being offered?

The initial assessment is a three-hour process involving sessions with:

- Rehabilitation physician
- Physiotherapist
- Occupational therapist

The aim of the assessment is to give you a comprehensive review of your physical and functional abilities and to make recommendations for maintaining or improving those abilities.

## What will it cost?

The costs for the initial assessment would be:

a. Rehabilitation Physician Prolonged Assessment under Medicare Item 132:	bulk billed
b. Physiotherapy Initial Assessment: Outpatient cost	\$ 120
c. Occupational Initial Assessment: Outpatient cost	\$ 140
Report cost	\$ 70
<b>Total cost (out of pocket)</b>	<b>\$ 330</b>

These costs can be offset if you have a GP Chronic Condition form for Allied Health sessions or you have private health fund membership with extras cover. The actual amount you pay will depend on the type and level of health fund cover you have or other assistance to which you are entitled. With some health funds it might be no cost or there might be a co-payment as low as \$50.

If you are covered by the Enhanced Primary Care Scheme you may be able to access additional services or get them at a reduced rate.

## What happens after the assessment?

A **Combined Multidisciplinary Clinic Report** including recommendations will be forwarded to you and your GP.

- If the report recommends associated services which Mt Wilga can provide, you would be able to access these services. The cost would be as per your individual private health fund cover or as per an individual quote for self-funded services. These services include dietician; speech pathologist; psychologist; social worker; orthotist. Similar conditions apply if you need radiology or pathology.
- Admission as an in-patient can be arranged if necessary. Again the costs would depend on the type and level of your private health fund or would need to be self-funded.
- On-going and periodic therapy with return visits can be possible.
- If the report recommends on-going and periodic therapy and you do not live where you can easily access Mt Wilga, referrals can be made to services, such as a physiotherapist, in your own area. In these circumstances, the Mt Wilga staff will be able to consult with your therapist and discuss the polio-specific issues of your treatment.
- Catered accommodation is available at a cost of \$70 per night. Unfortunately this is not wheelchair accessible.

## How do I access the clinic?

- Step 1:** Ring Mt Wilga with an enquiry for assessment in the LEOp Clinic - phone Lara on 9847 5016.
- Step 2:** An Information Sheet about the LEOp Assessment Clinic and Questionnaire will be sent by post or email.  
The questionnaire includes a request for GP referral to Dr Joanna Murray.
- Step 3:** Arrange an appointment with your GP and obtain a referral to Dr Joanna Murray.
- Step 4:** If you are eligible, obtain a GP Chronic Condition form for Allied Health sessions.
- Step 5:** Return the Questionnaire and GP referral to the Clinic.
- Step 6:** Ring Lara again and make an appointment.
- Step 7:** After your assessment go back to your GP to discuss your Report and plan any required services.

Note: It is possible to have a referral from a physiotherapist but it wouldn't be valid for as long and is not adequate for Medicare. However, if you are currently having physio treatment it would be helpful to take information provided by your physiotherapist.

I told my own GP that we were finalising arrangements for the establishment of the clinic and that I would like to be the "first cab off the rank". She was very pleased to hear of the Clinic and said she would definitely give me a referral. "*Just find out what they would like in the referral and come back and I will write it*". Why not have a chat with your GP?

I have agreed with Dr Mackie that I will assist by being the contact person for members who go to the clinic to give me feedback which will help Mt Wilga assess the success of the Clinic.

As the process goes further we will keep you informed.



## 2015 Mid-Year Seminar Notification

by Anne O'Halloran, Seminar Co-ordinator

"**Retirement Living Choices for People with a Disability**" is the title of our Mid-Year Metropolitan Seminar to be held on Wednesday, 3rd June 2015, at Northcott in Parramatta.

The theme for this Seminar will cover issues that arise when we are considering future living choices so that we can maintain a level of independence when day-to-day living becomes more of a challenge. We may be thinking of downsizing to smaller, more manageable, accommodation, or a retirement village or just considering more in-home services so that we can stay in our present home.

The Seminar will include speakers from State and Commonwealth government departments to inform us about services available and imminent changes. These presentations will be in the morning sessions.

The afternoon session will take the form of a panel of speakers from our membership, some of whom have moved in recent years to a retirement village and who will talk briefly about their experiences.

We are hoping that members in the audience who have downsized, or chosen services for home, will contribute to the afternoon session by sharing their experiences and comments.

## Victorian Polio Health and Wellness Retreat – 30 April to 3 May 2015

### 2015 Polio Health and Wellness Retreat Body / Mind / Spirit Wyndham Resort Torquay

**ONLY A FEW PLACES LEFT – BOOK NOW!**

Polio Australia will once again be facilitating its 4 day / 3 night Polio Health and Wellness Retreat for polio survivors and their partners, this time from **Thursday 30 April to Sunday 3 May 2015** at the delightful **Wyndham Resort Torquay**, 100 The Esplanade, Torquay, Victoria, 3228. 🌊

#### *The Program At a Glance*

##### **Thursday 30<sup>th</sup> April**

- ◆ Registration
- ◆ Program Overview
- ◆ Introductions & orientation
- ◆ Guest Speaker

##### **Friday 1<sup>st</sup> May (Body)**

- ◆ Plenary – The Polio Body
- ◆ Pain and Fatigue Management
- ◆ Take A Deep Breath: Respiratory Issues
- ◆ Holistic Health Parts 1 and 2
- ◆ Exercise Options
- ◆ To Brace or Not To Brace
- ◆ Hearing, Listening and Communication
- ◆ Let's Talk About Self Care
- ◆ Healthy Eating
- ◆ Managing Mobility
- ◆ Being Medicine Wise
- ◆ Partnering Polio

##### **Saturday 2<sup>nd</sup> May (Mind)**

- ◆ Plenary – Healthy Mind / Healthy Body?
- ◆ Mindful Self Compassion
- ◆ Mindful Movement
- ◆ Early Polio Memories
- ◆ Mind Your Mind
- ◆ Cryptic Crosswords
- ◆ What's Your 'Type'?
- ◆ Creative Writing
- ◆ Exploring the Share Market
- ◆ Ikebana
- ◆ Neuroflow: Creative Drawing
- ◆ Find Your Voice
- ◆ Why Family History?
- ◆ Partnering Polio

##### **Sunday 3<sup>rd</sup> May (Spirit)**

- ◆ The Healthy Spirit
- ◆ Worship Through Music
- ◆ Philosophy
- ◆ Connecting with Spirit Through Meditation

**CLICK [HERE](#) TO DOWNLOAD THE PROGRAM, PRESENTERS LIST, AND REGISTRATION FORMS.**



**Download the detailed program, presenters list, and registration form from:**  
<[www.polioaustralia.org.au/retreat-2015](http://www.polioaustralia.org.au/retreat-2015)>

Please call Mary-ann at Polio Australia at 03 9016 7678 with any queries  
or email her at <[office@polioaustralia.org.au](mailto:office@polioaustralia.org.au)>



**2016 Australasia-Pacific  
Post-Polio Conference  
Polio - Life Stage Matters**

**20-22  
SEPT  
2016**

**FOUR  
SEASONS  
HOTEL  
SYDNEY**

**SAVE  
THE  
DATE**

The first ever Australasia-Pacific Post-Polio Conference – “*Polio: Life Stage Matters*” – to be held in Sydney in September 2016 will facilitate better care and build international connections by bringing together health care providers, researchers, polio survivors, their caregivers, and patient organisation representatives, not only from the Australasia-Pacific region, but worldwide.

Visit <[www.postpolioconference.org.au](http://www.postpolioconference.org.au)> for more information.

# Polio NSW 25th Anniversary Lunch

by Susan Ellis

I can confidently report that all who attended the lunch had an enjoyable time celebrating Polio NSW's 25<sup>th</sup> Anniversary and reconnecting with old acquaintances. Burwood RSL did a magnificent job of catering which included a delicious official anniversary cake. The committee and office staff all pulled together to organise the day which was attended by 42 members and guests.

Many members who attended had a long history with Polio NSW, some had served as past committee members or support group convenors as well as a number who had been around from our early beginnings. There were so many familiar faces who had contributed to the success of the organisation over our 25 year history, an organisation that has proved to be a vital support for all of us who are surviving with polio. Congratulations!

## **Merle Thompson welcomed our special guests:**

*"The fact that we have survived as an organisation on our own resources without government funding is somewhat remarkable. Along the way there have been people and organisations who have provided support and encouragement. We invited some the 'special' ones to be our guests today as a way of acknowledging them and it is my pleasant role to welcome those who are here and to present the apologies of those who could not join us today.*

*Firstly, I would like to acknowledge Professor Richard Jones who has been a source of encouragement throughout our history. We sent him a formal invitation even though we knew he couldn't come. I would like to read you his reply.*

*"You quite rightly recall my strong interest in the previous Polio Network and Polio NSW and of the times when I have been more intimately involved with the provision of services for those remarkable people usually self-rehabilitated who suffered the long term effects of poliomyelitis.*

*I have never ceased to admire your group and at many occasions reiterate the fondness with which I hold your members. From time to time you may recall my talking to the organisation and of the research that I and my colleagues undertook into the Post-Polio syndrome which resulted in publications and supported our efforts in the Post-Polio Clinics."*

*The organisation which has given us the most support is the Northcott Society which, in its previous guise as The NSW Society for Crippled Children helped so many of our people decades ago or perhaps for decades. Glenn Gardner was the CEO when we first discussed having our office in their premises. He is our guest speaker today. Kerry Stubbs is the current CEO. Thank you to Northcott as an organisation and to the two of you as individuals for all your support.*

*Not all our support is polio or disability related. Welcome to Peter Roebuck. My experience in other organisations tells me that annual audits in 2014 dollars cost anything from \$2,500 to perhaps \$8-10,000 plus GST. For our size organisation \$3,000 would be standard. Peter has done our audit for free for 24 of our 25 years. Thank you Peter.*

*As individuals, rather than as an organisation, many of us were assisted in understanding and dealing with our polio-related problems when, for just a brief time, we had a clinic at Prince Henry Hospital. The person who initially conducted the clinic and to whom so many of us are grateful is Dr Jill Middleton who is with us today. Jill was joined in the clinic by Dr Pesi Katrak who has sent us this message:*

“Please pass on my congratulations to Gillian and other members of the committee for many years of commendable service to the Polio community.”

*From a research perspective, Prof Simon Gandevia is one of the only people who has attempted neurological research to try to understand post-polio. Simon could not join us but has written:*

“I congratulate you and the Society on reaching the quarter of a century milestone and I wish you well in your next 25 years!”

*Of course the most on-going work for the Network has been carried out by our own members and their families. We have honoured six of the longest serving and hardest working members with life membership. Three of us, Nola, Gillian and myself are here not as guests but as continuing members of the Committee. Bernie O’Grady who was a long-term support group convenor and then co-ordinator has travelled from his home up north to be with us. Welcome Bernie and Irene.*

*Along with Nola the first life membership was presented to Dr Mary Westbrook whose keen intellect, extensive knowledge and research skills were used to our benefit for so long and her gift for friendship meant so much to us. Mary is disappointed that she is unable to attend today due to health issues.*

*The other life member was our very, very special friend Neil von Schill, the indefatigable support group convenor and co-ordinator and later Secretary whose death we are grieving. It hurts to be here without his cheerful face and outgoing personality welcoming and supporting us all.” Merle then proposed a toast to Polio NSW which was enthusiastically endorsed.*



**Glenn Gardner** was Managing Director and CEO of Northcott Disability Services (formerly The NSW Society for Crippled Children) for over 20 years. Under Glenn's leadership, Northcott experienced considerable growth and is now one of NSW's major providers of disability services.

Polio NSW has had a long and friendly relationship with Glenn and it was our pleasure to ask him to be our 25<sup>th</sup> Anniversary Lunch guest speaker.

Glenn became the CEO of The NSW Society for Crippled Children in 1989, the year our Post-Polio Network commenced (*he was able to provide us with the names of prospective members from his polio client list*). Up until then his only contact with disability had been when he sold badges for The NSW Society for Crippled Children at Wynyard Station while he was at school, he really knew nothing about disability. We all remember the blue forget-me-not.

He quickly started to develop friendships with two local CEOs of disability agencies within Sydney, then within a year or two, 1991 or 1992, he tried to get some of the Crippled Children’s Societies CEOs in other states, Melbourne and Adelaide, to meet regularly and eventually included two or three more and they came together and started Ability First Australia in 2003.

Glenn has always had an interest in history, gaining a Bachelor of Arts degree majoring in history. As he got into the work of Northcott he became intrigued by its own story so he started to read more and to interview people so he could learn more about it.

In 1928 The Rotary Club of Sydney conducted an extensive door knock of houses around Sydney to see how many children there were who had contracted polio during the epidemics. They simply asked, “*Are there any crippled children here?*” This is how the first list of clients of what became The NSW Society for Crippled Children developed.

On 17<sup>th</sup> December 1929, The Rotary Club of Sydney held a meeting of concerned citizens in the Sydney Town Hall. A resolution was put that a society for the welfare and support of crippled children be established and The NSW Society for Crippled Children was formed. This was during the depression but still, within months, sufficient funds were raised to begin the Fred Birks School for Crippled Children in the old Royal Alexandra Hospital for Children at Camperdown; it was to become the first of seven special schools that the Society ran. The government was not involved in the education of children with disabilities so the Society provided the funds, employed the teachers and ran the show and that went on until mainstream schooling became the order of the day and slowly those special schools closed. However, the Fred Birks Activity Centre at the Hospital continues until this day.

In 1992, the Board sent Glenn on a study tour to the United States where he met people who ran the Easter Seals [stamps] (then known as The National Society for Crippled Children). These ‘stamps’ were sold to companies who put them on their mail outs which raised money and even today still raises \$15M each year for people with disabilities. Glenn returned to the United States three years later to see how he could develop a relationship between the American crippled children societies and our own here in Australia.

On his return, Glenn wondered why the Rotary Club of Sydney suddenly became so interested in crippled children in Australia back in 1929. He spoke to the staff librarian, Judi Lipp, who was also an Archivist. He was keen to find something in The NSW Society for Crippled Children’s archives to explain why the Rotary Club of Sydney got so passionate about its cause. She found an original letter from the International Society for Crippled Children written by Edgar F Allen (President) to Paul Harris, the founder of Rotary International. The letter thanks Paul Harris for the introduction to a Mr BR Gelling of the Rotary Club of Sydney.

Mr Gelling was a member of the Board of the Rotary Club of Sydney, he was able to observe what was happening in the United States, how the crippled children societies in America were really tackling the movement to provide care and education to every crippled child, and how particularly Rotary was at the beginning of most of this movement around the United States. Gelling obviously convinced the Rotary board members back in Australia and in 1929 The NSW Society for Crippled Children was officially incorporated. The then President of Rotary, Sir Henry Braddon, became the first president of The NSW Society for Crippled Children and he was joined by other members from the Rotary Club board.

Around that time when Glenn was still deputy he was given the job of developing strategic plans. Instead of separate departments for physiotherapy, occupational therapy etc. multidisciplinary age-specific teams were developed which was revolutionary. Slowly the institutions started to close. This was in the early ‘90s. Things were changing.

The Society moved premises to the old Northcott School where it had emblazoned above the door, “The Parramatta and District School for Spastic or Crippled Children”, a reminder every time kids walked through the door that they were either spastic or crippled. Glenn remembered thinking that this just wasn’t right.

There was someone on the Board at the time who had been a client of Northcott, he was the first to get a scholarship to go to the University of Sydney, and he gained an economics degree; he was quite a character, a very bright man, severely disabled, and he became the Financial Advisor to Lang Hancock on the eastern seaboard of Australia. He showed

Glenn his business card and it said after his name, BEc, PBC. Glenn understood Bachelor of Economics, but what was PBC? *“Poor bloody cripple”*, he said!

However, things had changed; Northcott now of course really exists so that people with disabilities are provided support services from the beginning, and indeed in their own homes, to keep them out of institutions.

The day came when a change of name was needed; the name had grown considerably to, The NSW Society for Children and Young Adults with Physical Disabilities. Northcott was suggested – Northcott had been the name of their school, John Northcott had been the Governor of NSW in 1946-57 and Patron of the Society from 1947. It is a coincidence that Glenn’s eldest brother, a professional soldier, when he was a young captain had been the aide de camp to Lieutenant General Sir John Northcott. Glenn asked his brother how to go about changing the name and so permission was sought and today the Society is known as Northcott.

Glenn is really proud of the fact that an organisation like Northcott is rooted in history and the beginnings of its history had to do with people who contracted polio at a time when there was virtually nothing for them.

In more recent years, at a time when he would have been *“put out to spell in a paddock for the rest of my time”*, Glenn got linked up with Polio Australia and they have been trying to re-establish those links with Rotary. It is a long and tedious battle. It is a process of the re-education of Rotarians. Rotary has this fantastic program called Polio Plus (the global eradication of polio) but what Polio Australia is talking about are those who have survived polio. Glenn and others are trying to get Rotary and Polio Australia together. It is slow and it is not always encouraging. However, Glenn was terribly encouraged at Polio Australia’s AGM to see in the finances that Rotary now provides 10% of the operating expenditure budget for Polio Australia whereas a couple of years ago it was zilch. Now it needs to be raised to 50% over the next couple of years and even beyond that. Glenn’s dream has been to try and get Rotary to set up some kind of fund that wealthy individuals and companies might contribute to, so income from the proceeds of the corps of investments would be enough for the running of Polio Australia.

Glenn still wants to encourage us. Although he knows it is hard, as we are not covered by the NDIS because we are mostly over 65, he thinks within the Rotary community there are still people there that we need to talk to in order to stir their memories. Glenn and John Tierney and others have spoken at Rotary Clubs and the moment you start talking about Polio, a light comes on and they will say, *“Oh yeah, I was at school with a kid, or my cousin....”*. So we have to stir their memories a bit as there are people who want to support us and that will continue to be so.

Glenn is really proud of the fact that the beginnings of Northcott, the beginnings of Easter Seals, the beginnings of Ability First Australia were all because of the polio epidemics of the last century.

Glenn wanted to encourage us to keep on keeping on, keep on supporting each other and keep on supporting whoever we can to get the message out there that over 400,000 Australians are still living having survived the epidemics and something has to be done about it.

Glenn was thanked by past President, Nola Buck, for his entertaining and informative speech and presented with a gift of appreciation.



# A Polio Journey

Reprinted with permission from *Rotary Down Under*, Issue 568, Dec / Jan 2014-15, page 28.

For Monica Saville, Rotary's polio eradication campaign is personal. Saville, who survived the disease as a child in Australia, has helped raise money to fight polio and has vaccinated children in India. A member of the Rotary Club of Epping, NSW, she is a regional Rotary Foundation coordinator and a past governor of District 9685.

**THE ROTARIAN:** *What was your own experience with polio like?*

**SAVILLE:** I was raised about 300 miles from Sydney in Junee, a small rural community that had a lot of sheep and wheat. In 1951, when I was 11, a farmer died of polio. The whole town was reeling. We were a fairly isolated place. Just after that, I was at school one day feeling very sick. Flu-like symptoms, aching back – I will never forget the pain. I went home, and my mother called the doctor. He checked my arms and legs, and then he said, “*Put your chin on your chest*”, and I couldn't, because my neck was paralysed. I couldn't swallow. I couldn't eat very well and couldn't talk properly. He told my mother, “*You need to take her to the nearest large hospital*”, which was 25 miles away in Wagga Wagga. There was no treatment, but I was able to go home after three weeks, and I went back to school after another three weeks. Mine is a good-news story in that I'm now 74, and I'm fit and well. But for millions of other children, it's been either death or lifelong disability.

**TR:** *How did you become involved with Rotary's fight against polio?*

**SAVILLE:** I had put the whole childhood episode behind me until I became a Rotarian in 1993 and learned that the eradication of polio was Rotary's most ambitious project. You know how you feel compelled to do something? I felt a huge need to vaccinate children against polio.

I was in Andhra Pradesh, a very poor part of India, in 2010. We started off early in the morning in a bus, then we transferred into jeeps. Along the way, we were vaccinating children. The Indian parents ran out to meet us, and the children were terrific. It must have seemed strange to them – these were isolated communities – but they knew their parents wanted them to have these two vital drops.

Then we transferred into an old boat and went out on a lake with rocky shores. It was night, we'd been vaccinating all day, and we had only the light of flashlights and phones. I remember thinking, “*If we start to sink, I should keep my shoes on*”, because the shores were so rocky. We'd pull ashore, scramble over the rocks, and vaccinate children. One family jumped in a coracle and frantically paddled out to us so their children could be vaccinated before we went away.

**TR:** *What are Australian Rotarians doing these days to help end polio?*

**SAVILLE:** We have a project for World Polio Day on October 24, the Ribbon of Gold. The idea is that clubs can put a yellow strip of tape on the ground at their local shopping centres and people can line up gold coins on it. And at the International Convention in Sydney, our Prime Minister announced that the Australian Government would give \$100 million to help eradicate polio. For a small country, that's a large amount.

Anne Ford, *The Rotarian*



*Anne Grove is a member of Polio NSW. She has written the following in response to the above article that was published in Rotary Down Under. An abridged version of this article will also appear in the next issue of Rotary Down Under. She hopes that it may get the message across that polios are surviving with the late effects of polio without support from government or Rotary.*

My husband Barry is a member of the Rotary Club of Engadine. I usually read *Rotary Down Under* and was very interested to read an article by Anne Ford, The Rotarian quoting Monica Saville and titled “A Polio Journey”.

I am afraid that this article does not reflect the journey that most polio survivors in Australia are experiencing in their later years.

Monica was very lucky to be able to leave hospital after three weeks, and then go back to school after another three weeks. I admire Monica for the work she is doing as a Rotarian to eradicate polio in parts of the world where polio is still rampant.

I am a member of Polio NSW. In the general business section of Polio NSW’s 2013 AGM minutes, I would draw your attention to comments made by a committee member: *“It is rather perplexing that Rotary sends money overseas to eradicate polio but thinks little of its survivors in Australia. Members of Polio NSW have approached Rotary and are encouraging cooperation between Rotary and Polio Australia regarding polio survivors in Australia.”*

My polio journey is still continuing. I was born in the Far North Coast country town of Kyogle. Now approaching 80, I am a member of the group that contracted polio in one of the major epidemics which occurred in the thirties and forties. One other person in that small town contracted this devastating disease at the same time. He was a young man who then lived his remaining years in an iron lung.

This was also at a time of the Depression, so my parents, with the help of the local Catholic priest, Father Nicoll, managed to send me to Camperdown Children’s Hospital, where I remained for nearly two years. My parents could not afford to travel to Sydney. Apparently when I finally went home, my mother told me that my cry was *“You are not my mother – I want nurse”*.

Then followed years of me wearing a calliper and trips to Manly to the Far West Children’s Home. At high school, I experienced comments such as *“here comes hop along”* and also *“stick leg”*.

There was no such thing as counselling – or a shoulder to cry on – in those days. I had an operation back in Sydney as an early teenager to try and help bad foot drop. There have been years of buying two pairs of shoes to get one pair, as one foot takes a 3½ fitting, the other, 5½ . One shoe has to be built up.

There were fairly normal years in later life - getting married, having two lovely daughters and moving to Engadine. Then there was the onset of what is now called *“Post-Polio Syndrome”*. It is not the onset of old age, as some would suggest. Ask any person who has lived with the results of polio. They will tell you this is not the case.

Physiotherapists who have never treated survivors of polio sometimes do more damage than good. I have had that experience myself.

The leg without polio has undergone a complete knee replacement, and then the polio leg could not cope – and the circle is complete. Now it is back to wearing a calliper again.

Other polio survivors could tell you the same sort of story. The creeping feeling of weakness all over, the lack of confidence, balance just about gone and periods of depression, needing help to get out of a chair. When I go out, these questions crop up:

How far do I have to walk? Are there stairs? Getting in and out of a car is an issue. All these turn into major problems.

Walking stick ... wheelchairs ... calliper ... now an electric scooter, when wanting to shop - and concern when a lot of walking is involved.

Luckily, in Sydney I managed to find a shoe outlet which can order odd-size shoes for me but they have to come from Germany. Then one of the shoes has to be built up. To buy handmade shoes in Australia is very expensive. The shoes from Germany are expensive but our health insurance scheme allows me to purchase one pair a year – and gives a refund for part of the cost.

The National Disability Insurance Scheme cuts out at the age of 65, so is of no help to the dwindling and older survivors of polio. Luckily my circumstances have allowed me to have various items which make life bearable, such as having inclinators installed in our home and a government-subsidised scheme for assistance with house cleaning. There are many others who do not have this advantage.

I am sorry that this story is so long but I feel strongly that a lot of polio survivors have been struggling and are continuing to battle on, with little help from our government or from Rotary in Australia.



## Demerit point to target low lifes

**Duncan Gay MLC, Minister for Roads & Freight, Minister for the North Coast**  
Leader of the Government Legislative Council  
**MEDIA RELEASE - Friday 28 November 2014**

Minister for Roads and Freight, Duncan Gay, today announced the introduction of a demerit point penalty, on top of the existing fine, for able bodied people found guilty of abusing disabled car parking spaces. Mr Gay said he won't stand for the irresponsible and rude actions of people who deny disabled people the right to park in these critical car parks.

*"I have made it very clear I'm outraged by able bodied people who steal disabled car parks just to make their life easier", Mr Gay said. "These people selfishly deny vulnerable members of our community close access to buildings and sufficient room to get in and out of their vehicles – they are low lifes, simple. Clearly, hitting their back pocket doesn't stop this behaviour so I'll hit them where it really hurts, their licence."*

*"From Monday, anyone caught parking in a disabled car park without holding a valid mobility parking sticker will not only get a \$519 fine – the highest fine for this offence in the country – they'll also receive a demerit point penalty. Wherever disabled parking offences are currently enforced, whether on a public road or in a car park, the demerit point will apply."*

*"Drivers who think about parking illegally in disabled car parks need to know the demerit point penalty can contribute towards licence suspension and also make drivers ineligible for discounted driver's licence renewal fees and reduced insurance premiums."*

*"The demerit point will hopefully help people use their moral compass and think twice before choosing to park their vehicles illegally in a disabled car park", Mr Gay said.*

The public can report abuse of the NSW Mobility Parking Scheme by phoning **1300 884 899**  
More information on the Mobility Parking Scheme is available at:  
**[www.rms.nsw.gov.au/roads/using-roads/mobility-parking/index.html](http://www.rms.nsw.gov.au/roads/using-roads/mobility-parking/index.html)**



## 2015 Health and Wellness Retreat and Polio NSW Seminar Program

<b>Thursday 30th April to Sun 3rd May</b>	Wyndham Resort Torquay, Victoria	<b>Polio Australia Health and Wellness Retreat</b> <i>Only a few places left – see page 5</i>
<b>Wednesday 3rd June</b>	Northcott 1 Fennell Street North Parramatta	<b>Retirement Living Choices for People with a Disability</b> Preliminary details are on page 4 Full details will be mailed out in May
<b>Saturday 5th December</b>	Burwood RSL Club 96 Shaftesbury Road Burwood	<b>Annual General Meeting and Seminar</b>

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### Have You Included Your Polio Details on the Australian Polio Register?

The Australian Polio Register was established by Polio Australia in October 2010 to gather information on the numbers of polio survivors living in Australia today, whether or not they contracted polio in this country. There are currently more than 2,000 polio survivors on the Register and this number increases daily. To make the Register truly reflective of the unmet need for polio services throughout Australia, all State polio networks are urging every Australian polio survivor to join the Register which is available on Polio Australia's website at <[www.polioaustralia.org.au](http://www.polioaustralia.org.au)>. The Australian Polio Register form can either be completed online or downloaded (by you, or a friend with internet access) for completion and subsequent return to Polio Australia.