

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 100th 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 25th 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> 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
	Total cost (out of pocket)	\$ 330

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 30th April

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

Friday 1st 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 2nd 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 3rd 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>

**Please call Mary-ann at Polio Australia at 03 9016 7678 with any queries
or email her at <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> 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 25th 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 25th 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 17th 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



2015 Health and Wellness Retreat and Polio NSW Seminar Program

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

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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>. 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.



Volume 4, Issue 4



Polio Oz News

December 2014—Summer Edition

New Film Tells Our Story

By Fran Henke

Bayside Polio Group, Victoria, has launched its film ["All Walks of Life"](#), plus a kit for allied health and care professionals to create awareness of post polio issues.

The lunchtime launch at Milano's, in Brighton, was conducted by Victoria's Disability Services Commissioner [Laurie Harkin](#), who spoke about the vulnerability of people with disabilities, urging everyone to speak up.

Mr Harkin outlined what he can and can't do as Disability Services Commissioner, saying there was nothing he couldn't look into; and given his standing, could be persuasive. Mr Harkin, a polio survivor, congratulated Bayside for its initiative in producing the film.

The film was produced in partnership with the [Rotary Club of Bentleigh Moorabbin Central](#) and [Individual Films](#).

The "All Walks of Life" film and awareness project was created by the group to illustrate the work of the polio community. As the project progressed, it was recognised that a tool could



be developed that could be of use to the wider community and the Post-Polio Awareness Pack was born.

Each pack includes a USB drive containing a high definition version of the film able to be screened on computers and television sets; digital copies of "Iron Wills, Victorian Polio Survivors Stories" and the Knox-Yarra Ranges group's book "Calliper Kids". The USB also includes Parliamentary enquiries and submissions; studies and papers with contributions from people who manage the late effects of polio; and support material around aged care and negotiating social inclusion and independence.

Paperback books in the comprehensive pack are: "The Late Effects of Polio: Introduction to Clinical Practice" (2012) and "The Late Effects of Polio: Managing Muscles and Mobility" (2014), both published by Polio Australia; "Iron Wills" (2012) published by Polio Network Victoria; and resource material from Victorian Polio Networks.

These Awareness Packs can now be ordered **on line** from [Polio Australia](#). (Australia only due to postage costs.)

The sale of 100 of awareness packs, for example, will raise \$5,000 towards the costs for hosting Polio Australia's 2016 Australasia-Pacific Post-Polio Conference, "Polio: Life Stage Matters".

cont'd p3

National Patron: Dr John Tierney, Ph.D, DAm

Polio Australia

Representing polio survivors
throughout Australia

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From the President

*Dr John Tierney
President*

This summer edition of Polio Oz News reports on the finish of one of our most productive years at Polio Australia and this has again been done with very few resources.

In late October we returned 30 strong to the Canberra halls of power and again we were prominent wearing our "We're Still Here" tee shirt. In this edition Joan Smith reports on her reflections on the day and what it achieved. The highlight of the day was the morning tea launch attended by MPs of the resource "Managing Muscles and Mobility". This world-class resource is the second in a series and was funded by private donation. Your lobbying team (John, Gillian and Mary-ann) also held a series of meetings with key health and disability decision makers in the parliament including a very productive meeting with the Health Minister's chief policy advisor. Thank you to all of you who went the extra mile to support this vital lobbying and profile raising work.

World Polio Day on the 24th October just preceded our descent on Canberra and we used this as a media opportunity to raise the profile of Australia's polio survivors and our needs. With the assistance of Kristy Rackham, we were able to set up some excellent media interviews and spread our messages far and wide across Australia at the press of a button.

October also marked the re-establishment of our connections

with our cousins across the ditch in New Zealand when I spoke at their 25th anniversary national polio conference in Christchurch. As a result of this contact, two of their senior executive took part in Polio Australia's three year strategic planning meeting in November. Already the Kiwis have embraced our "Walk with Me" program and gone one step further and plan to involve Rotary, which could be something to consider in future.

Probably the most exciting current development is the start of our planning for our September 2016 Australia-Pacific Post-Polio three day conference in Sydney. Please put this in your diaries because we want many polio survivors and their carers from Australia and beyond to be there. Our New Zealand friends are very aware of this conference and we are expecting strong support from that part of the Pacific region. Also when Mary-ann and I attended similar international conferences in Europe and the USA earlier this year, there was a lot of interest in supporting this conference. We are expecting input to our sessions at the Sydney conference from many of these health professionals and hopefully this will attract their Australian colleagues to also attend our conference.

So in this, our final edition for 2014, I am very pleased to report that Polio Australia is ending the year on a successful and progressive note. I would also like to take this opportunity to wish everyone the very best for the season and a happy and healthy new year. 🌟

John

From the Editor



Mary-ann Liethof
Editor

Well, I don't know about you, but I am REALLY looking forward to finishing up for the year! I've been so busy, busy, busy, it's sometimes hard to think!

As you will read in the following pages, we have been working hard to ensure that our post-polio community is being represented, especially in relation to informing health professionals about the particular needs of polio survivors.

Another exciting development is that we are launching a new clinical resource website for health professionals—www.poliohealth.org.au—which is currently under construction. This website should go 'live' sometime towards the end of December.

In addition to this, Polio Australia has a new resource for sale "*The Late Effects of Polio: Managing Muscles and Mobility*", and is in the early stages of planning an Australasian-Pacific Post-Polio Conference titled "Polio—Life Stage Matters".

We are also pleased to feature articles written by our readers including a review of the new film "*All Walks of Life*", "*Joan in Canberra*", and "*Learning to Walk Again*".

So, back to the time of year. Of course, we don't have a white Christmas (unless there is some freak weather pattern going on), but I saw this clip on YouTube recently and it made me smile. An oldie but a goodie. Just click on the picture to watch.

Hoping you enjoy all the trappings of the Season, then we can look forward to doing it all again next year! 🌟

Mary-ann Liethof



New Film Tells Our Story (cont'd from p1)

Orders will be packed and posted by Bayside Polio Group. Cost is:

\$50 = Single pack (collect)

\$64 = Single pack (post) – includes \$14.00 post & handling

\$117 = Triple pack (post) – includes \$17.00 post & handling

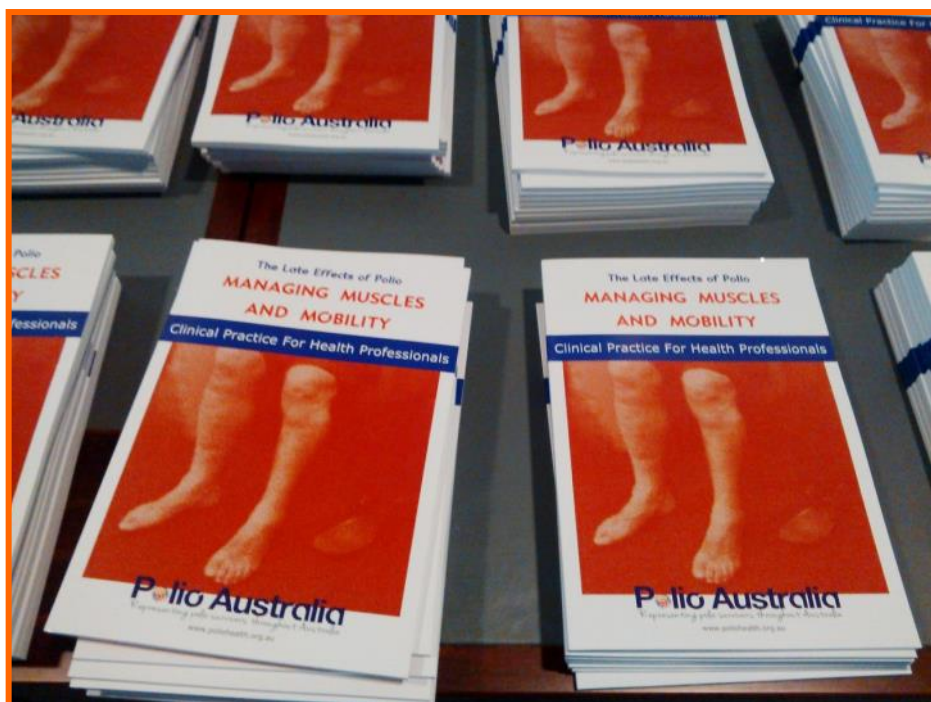
Buy two packs and one extra will be included to donate to local medical centres and community groups.

Payment methods to Polio Australia include:

- ⇒ **EFT:** Bank – Westpac / Branch – Parramatta, NSW / BSB – 032078 / Account Number – 555766 / Polio Australia Inc.
- ⇒ **Credit card:** payments will be processed through PayPal on behalf of Polio Australia
- ⇒ **Cheque:** made out to Polio Australia, posted to PO Box 500, Kew East, Vic, 3102 ([Order Form](#) required) 🌟



New Resource: Managing Muscles and Mobility



Polio Australia's clinical practice module project has been many years in the making. A number of telephone conference discussions between members of Polio Australia's [Clinical Advisory Group](#) throughout 2011 worked up the concept and decided what should be incorporated into a practical resource series for managing the Late Effects of Polio (LEoP) / Post-Polio Syndrome (PPS). However, the project's progress has been slow because of a lack of financial backing. Polio Australia receives no government funding, nor were we able to secure any philanthropic project grants for this work. Understandably, there is only so much time busy health professionals can contribute on a pro-bono basis.

In 2012, Polio Australia was able to launch the first of the series – a clinical practice 'overview' module titled "*The Late Effects of Polio: Introduction to Clinical Practice*", thanks to GSK

Australia's medical team, who took it on as a volunteer project. This overview was a compilation of LEoP / PPS symptoms and general explanatory notes, resourced from work produced by international experts. It proved to be a valuable resource, especially for polio survivors who were able to share a printed copy with their treating health professionals and/or direct them to the online version.

In early 2014, Polio Australia was approached by a private donor (who wishes to remain anonymous) looking to contribute to a discreet project. The donor agreed that "*The Late Effects of Polio: Managing Muscles and Mobility*" would be a worthy investment.

We were then able to engage one of our Clinical Advisory Group members, Dr Natasha Layton (OT), to work on producing this resource.

As a seasoned researcher, and proponent of evidence-based practice, her approach was based on:

- ♦ Rapid evidence reviews of the literature.
- ♦ Using methods to seek out, evaluate and privilege 'practice wisdom', that is, evidence and knowledge which is not contained in the refereed literature.
- ♦ Use of inclusive methodologies to embed the consumer experience and consumer-valued outcomes in any research endeavour.

A number of people from the post-polio community also contributed as "*Lived Experience Experts*", providing valuable insights into the practicalities of living and coping with their chronic condition.

The combination of skills, knowledge, experience, wisdom and energy has resulted in a rich and seminal resource that we can all be proud of. Most significantly, this module achieves its purpose of being a comprehensive, 'go-to' resource for Australian health professionals.

Paperback copies of this 90 page book are included in the "*All Walks of Life*" Awareness Pack (see pages 1 and 3). Alternatively, individual copies can be ordered by printing and completing the Order Form on page 21, or click [here](#) to download an Order Form.

An e-book version will also be available for sale in the near future.

General information can also be found on Polio Australia's website [here](#). 🌐

2016 Australasia-Pacific Post-Polio Conference



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

Polio Australia is pleased to announce that it is in the early stages of planning an inaugural Australasia-Pacific Post-Polio Conference: "*Polio—Life Stage Matters*", to be held from 20-22 September 2016 in Sydney.

There is clearly a growing need for health professionals with the knowledge to adequately treat the estimated 20 million people who are survivors of polio. Polio survivors can be found in every country around the world, although those in the Western World tend to be an ageing demographic, whereas those in developing countries are across the age spectrum.

The health issues for ageing polio survivors and young polio survivors differ. In young polio survivors the challenge is to prevent and treat severe deformities, to reduce disability, and to improve social participation. In ageing polio survivors, treatment focuses on Post-Polio Syndrome (predominantly neurological) and biomechanical decline due to consistent overuse (the Late Effects of Polio or Post-Polio Sequelae), with the aim of preserving independence and quality of life.

The aim of the proposed Conference is to exchange knowledge about the diagnosis and treatment of the post-polio condition in different age groups to best preserve functioning throughout life.

It is designed to facilitate better care and build international connections by bringing together

health care providers, researchers, polio survivors, their caregivers and patient organisation representatives from the Australasia-Pacific region, and worldwide.

The Conference would provide sessions for both polio survivors and health care providers, emphasising research results and gold standard evidence-based clinical practice. Since care for polio survivors involves many different disciplines, the Conference will target professionals in the fields of rehabilitation medicine, virology, neurology, respiratory, orthopaedic surgery, allied health, and students in these areas.

Polio Australia has been fortunate to have negotiated an Agreement with [Interpoint Events](#), who are taking on the logistics, marketing, and registration. Polio Australia will be responsible for bringing together the best presenters from the health care, research, and community sectors—both national and international—to address the range of issues impacting on people who survived polio through the various stages of their lives.

We have already had significant encouragement and support from [Post-Polio Health International](#) (USA) and the [European Polio Union](#), who have been promoting early notice of this Australasia-Pacific Post-Polio Conference through their bulletins.

Early in 2015, we will be meeting with members of our [Clinical Advisory Group](#) and other interested health professionals to establish a 'Scientific Committee' and hone the streams that will make up the Program.

So note September 20-22 in your diaries and start saving! More information will be released in the new year. 🌟



Joan in Canberra

Alan Tudge and Joan Smith



By Joan Smith

October, Polio Awareness Month, was also the occasion for the Canberra Campaign **"We're Still Here"**. Graeme and I attended, representing the Knox-Yarra Ranges Polio Support Group. We travelled over two days, joining some of the other campaigners in a Canberra Hotel, including Mary-ann Liethof and her fantastic assistant Kristy Rackham.

After going through the heightened security checks at Parliament House, we were issued with a very visual T-shirt in orange on white proclaiming **"We're Still Here! The legacy of polio lives on"**. Close to thirty of us assembled in the foyer for a group photograph before being escorted to the Sir Richard Baker Room for the morning activity.

Over morning tea, two of Polio Australia's [Parliamentary](#)

[Patrons](#) - Mark Coulton MP and Catherine King MP - launched the new publication *"The Late Effects of Polio: Managing Muscles and Mobility"*. They both referred to the across-party-support we had in our endeavours and congratulated Polio Australia on the excellent work achieved so far.

Dr John Tierney, President of Polio Australia and ex-Senator, spoke about the book as an example of Polio Australia achieving world best practice. The project costing \$30,000 was funded privately. He noted how much more could be achieved with adequate government funding, as the distribution was severely restricted due to cost. John also spoke about the quality programs Polio Australia has achieved, such as the annual Health and Wellness Retreats. About twelve politicians were able to attend the morning tea and learn more about our

issues. Overall, John noted, there was a lot of goodwill from politicians but no funding to support the goodwill.

Mary-ann presented an interesting ["Polio Timeline"](#) display depicting the history of polio and significant developments to date. Senator Rachel Siewert, another Parliamentary Patron, then spoke of 2014 and beyond. She referred to the 65 plus year age exclusion from NDIS and supports our inclusion. She also addressed the issue of the workforce needed to meet consumer directed care services and the Aged Care and Home Care requirements. Funding is urgently needed for the organisation and staffing of the new programs. Mark Coulton then concluded that meanwhile we need to continue to educate both the general public and medical professions.

Our group session was followed by individual appointments with local representatives. Graeme and I spoke to Alan Tudge MP. We mainly discussed the exclusion from NDIS based on age, not disability. He was surprised to learn that polio survivors are the largest physical disability group in Australia. Alan asked some good questions and said he would follow up with talks with Senator Mitch Fifield who has responsibility in the NDIS provision. I would like to have further discussion with Alan, perhaps in the New Year, to gauge his view of any change.

A very late lunch was then enjoyed in the Members and Guests Dining Room. The Polio Australia executive committee had further meetings that

Joan in Canberra (cont'd from p4)

afternoon and next morning to try for further progress and support. They certainly put in a lot of work supported by outstanding planning to make the most of our opportunity.

To finalise this report, I quote John Tierney from the Polio Australia press release: "The NDIS comes way too late for the majority of our polio survivors. It will not be fully

rolled out until 2020. Most polio survivors will be ineligible due to the cut off age of 65 years. People need help now because "We're Still Here!" and will be for decades to come. The personal cost of the late effects of polio and Post-Polio Syndrome for individuals, carers and families, is overwhelming. As the condition is not well known amongst health

practitioners, on a macro scale, the burden on the Australian health sector due to mis-diagnosis and inappropriate management also requires major financial contribution from the government. We continue to do everything we can to support people, but it is time for the government to step up and financially stand behind our work." 🌟

Vale Stella Young



Source: [ABC News](#) – 8 December 2014

Prominent disability activist, writer and comedian Stella Young has died aged 32. Ms Young was the former editor of the ABC's disability news and opinion website, Ramp Up. Her family said she passed away unexpectedly on Saturday evening [6 December 2014].

Ms Young was born in Stawell, in country Victoria, with Osteogenesis imperfecta, a genetic disorder that causes bones to break easily.

She campaigned hard against the idea that having a disability made her exceptional or brave. "Disability doesn't make you exceptional, but questioning what you think you know about it does."

Ms Young studied to become a teacher, before beginning a career in journalism. Read more [here](#).

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Supporting Polio Australia

Polio Australia would like to thank the following individuals and organisations for their generous support from 1 October to 28 November 2014:

Hall of Fame

Name	Donation
Jill Pickering	\$8,600
Dr John Tierney	\$4,000
	\$13,600

Significant Donations

Donation - General	
Jill Forsyth	Joan McGowan
Joan and Graeme Smith	Jill Burn
Pittsworth Crafty Quilters	Anonymous
The Australian Cloth Doll	Jeannette Thomson
Thomas Leresche	Kristin Gillies
Kay Blemings	Wesley School
Len Sheehan	
Total - \$2,986.45	

Walk With Me Fundraising Event

Name	Donations - Walk With Me
Polio Power NSW Walk	\$350

Rotary Donations

Name	Donations - Walk With Me
Rotary Club of Kew—Bunnings Sausage Sizzle	\$1,750

Become a Friend – Invest in Polio Australia and Make a Difference

Please invest in Polio Australia's work to help ensure that all polio survivors in Australia have access to appropriate health care and the support required to maintain independence and make informed lifestyle choices.

Polio Australia is endorsed by the Australian Taxation Office as a Health Promotion Charity and a Deductible Gift Recipient making all Australian donations over \$2 tax deductible. Polio Australia will issue an official receipt for all donations received.

Your Donation can be made via any of the following methods. Click [here](#) to see all the options.

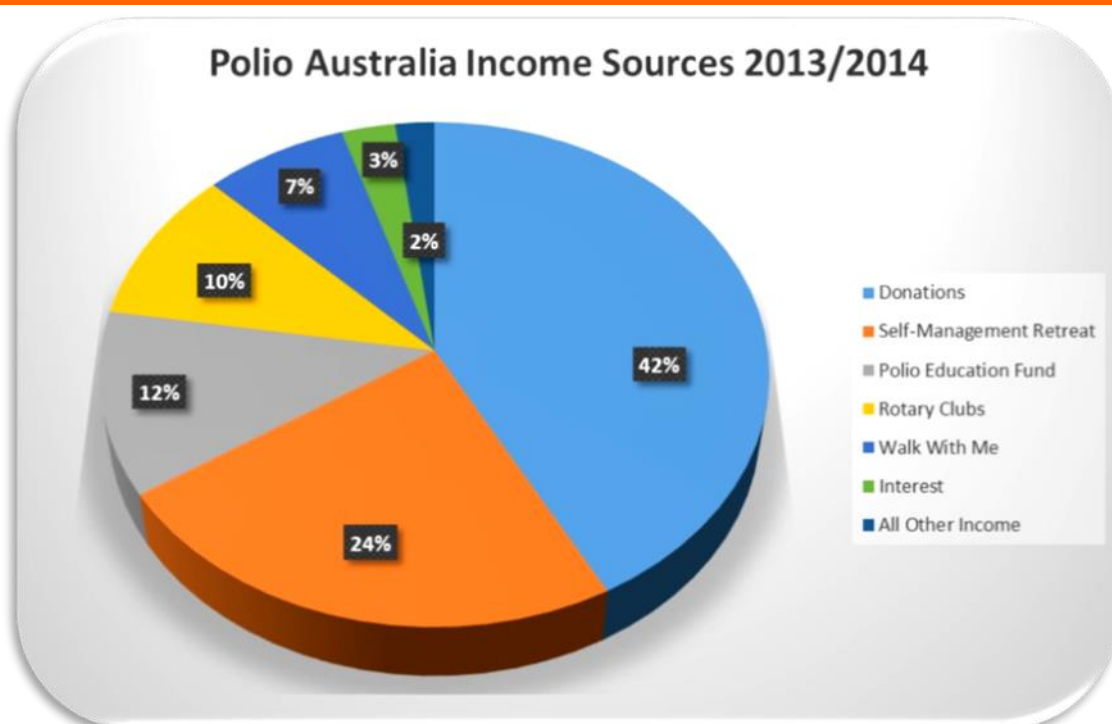
Bequests

Include a specific bequest to benefit Polio Australia in your Will. Consider making a bequest to Polio Australia and determine the type of bequest which best suits your circumstances and wishes. Check [here](#) for details.

2014—Year At A Glance

January	New promotional posters produced
February	Successful clinical training trial held in Victoria for 19 allied health professionals
March	Parliamentary Friends of Polio Survivors launched at a Morning Tea in Canberra
April	Work commenced on new clinical practise resource <i>"The Late Effects of Polio:"</i>
May	5th Polio Health and Wellness Retreat run in New South Wales
June	Presented at two International Post-Polio Conferences in St Louis, USA, and Amsterdam, The Netherlands
July	Discussions with International Post-Polio organisations regarding an Australian Post-Polio Conference in 2016
August	Presented to 1st Year Orthotics students at La Trobe University
September	Participated in <i>"Walk With Me"</i> fundraising events in New South Wales, South Australia, Victoria and Western Australia
October	Polio Awareness Month <i>"We're Still Here!"</i> Campaign and launch of <i>"The Late Effects of Polio: Managing Muscles and Mobility"</i>
November	Polio Australia's AGM and 3 year strategic planning meeting
December	Commencing work on 2016 Australasia-Pacific Post-Polio Conference and launching new health professional website www.poliohealth.org.au

Polio Australia Income Sources 2013/2014



2013-2014
[Annual Report](#)
 now available
 for viewing

World Polio Day at Spinal Injuries Australia

Source: Jeanette Kretschmann
Coordinator - Member
Networks, SIA

A hugely successful World Polio Day was held at the Brisbane office of [Spinal Injuries Australia](#) on 24 October. The day was attended by 36 members, staff and guests. Dr Pat Dorsett updated members on the research she is conducting involving three of the Post Polio network groups, while John Mayo stood in for Dr Margaret Peel to inform members about work progressing by Polio Australia.

Tony Fox from the Wynnum Manly Rotary Club gave a presentation on how Rotary International first became involved in the vaccination of children against polio in 1979 in the Philippines. With the success of this program Rotary worked with Dr Sabin to immunise all children against Polio giving rise to Rotary's Polio Plus program in 1985.



Tony presented evidence on how the gap in the world eradication program is closing fast, which is very exciting news.

to assist the group through this invaluable learning opportunity.

Keynote speaker Dr Ling Lan (pictured right), a rehabilitation specialist from Prince Charles Hospital who specialises in Post-Polio Syndrome, gave a PowerPoint presentation on Post-Polio Syndrome, "a life changing syndrome and how to adapt to it". The wealth of information was soaked up like a sponge by the audience who were full of praise for her efforts



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Becoming Part of Queensland Museum's Collection

Source: [Queensland Museum](#)

- 8 December 2014

Queensland Museum Senior Curator, Mark Clayton, writes about a toy car that was recently donated to the Museum and sheds some light on the accession process.

In common with other large collecting institutions, Queensland Museum periodically has to decline donation offers. Partly because of storage and display space limitations, offers are now being subject to ever more scrutiny with curators being increasingly called upon to provide long-term financial and policy justifications for proposed acquisitions.

Occasionally however we're presented with an offer so appealing, that it seems capable of effortlessly clearing all these administrative hurdles. Pictured here is one such object, a highly modified pedal car made by the Sydney-based toy-maker—[Peerless](#)—in the 1930s.



The donor in this instance was just three years old when, in 1952, he succumbed to the infantile paralysis (poliomyelitis) epidemic then ravaging Queensland. Keen to help him regain some of his lost mobility his uncle and father—an electrician and mechanic, respectively—set about modifying the pedal car so it could be safely operated by the driver, using just his left arm.

Motive power was provided by an electric motor salvaged from a disused washing machine. Both motor and battery were

housed within the large fairing behind the driver's seat. Since the donor at that time could only use his left arm (his right arm having also been paralysed), the car was operated via a lever—on the left side—which had a button on the top. Pushing it forward caused the vehicle to move forward, and pulling it back caused it to reverse. ●

[Read more . . .](#)

PHI's Post-Polio Medical Care Survey

Source: www.polioplace.org

Post-Polio Health International (PHI) created a survey asking polio survivors about their post-polio medical care. The survey, *"Post-Polio Medical Care: Post-Polio Specialists and Primary Care Physicians"*, was posted online and a version was also published in *Post-Polio Health* (Volume 30, Number 2).

Data was gathered from 632 people; 496 completed the survey online and 136 copies received by mail were entered manually. Partial information was also entered.

Several expressed frustration at having to choose on the survey between seeing a post-polio specialist or seeing a primary care physician. Sheila Michael, California, said, *"Over 20 years ago, I saw two post-polio clinic physicians (because of living in two separate locations) for evaluations and recommendations. These were shared (by me) with my primary physicians, as well as providing them information about the late effects of polio. Since then, my primary physicians have managed my post-polio care/needs with my input."*

The results show that 53% have been seen by a post-polio specialist. Twenty-nine percent heard about the specialist at a support group meeting while 21% were referred by their primary care physician. Location proved to be the main reason a specialist was chosen, with 58% visiting the closest one geographically. *"Heard they were the best"* was the second reason given (38%).

Read the full article on PHI's "Polio Place" website [here](#). ●

Learning To Walk Again



By Christopher Tia

Report on the trial of Cyberdyne's HAL exoskeleton device, a potential walking aid for polio survivors

As I sat filling in a post-trial evaluation form, I was somewhat bemused by one of the questions – “How long did it take you to travel to the venue?” I wrote ‘10 hours’.

It had indeed been a long way to travel – from Sydney to Tokyo – just to experience something for such a short period of time. But it was worth it. A major bucket list moment if there ever was one. Trying Cyberdyne's [HAL](#) exoskeleton suit was something I had wanted to do for a very long time, having spotted it many years before as it was being developed.

HAL (which stands for Hybrid Assisted Limb) is essentially a wearable device to support and enhance limb movement. It reads bioelectric signals from

the brain through sensors attached to your limbs. These tell the device to move and react accordingly. The simplest non-technical way to explain how it works is perhaps to think of the comic hero ‘Ironman’. Same idea. Science fiction now very much a reality.

A Bit About Me

I am a polio survivor, having contracted it when I was 3 years old – now 37 years old. Luckier than most, I had regained much of my movement but the disease had left both my legs fairly weak. I get around pretty easily and am very mobile by most people's standards. Like many polio survivors though, the dream to be able to independently walk again is somewhat of a constant. The later effects of polio have also started to be felt, so the prospect of a device that could assist to mitigate its impact was obviously something I wanted to at least try.

In test driving the device I also wanted to provide some perspective for fellow polio sufferers on what the experience is like. Moreover, as a tech-buff, I am perhaps in a better position than most to evaluate the technology on an objective basis. With these goals in mind, hopefully people will be able to decide for themselves whether to try it out after reading the rest of this report.

Use of the Technology as a Medical Device

HAL is certified as a medical device in the EU and has been used to treat different cerebral, nervous and muscle disorders. The company has some fairly interesting case studies,

including of someone who recovered the ability to walk from a spinal cord injury by using it as a rehabilitation device. As I understand it, the company also has several ongoing clinical trials with medical research institutions in the US.

In terms of polio specifically, staff at the company said that they have treated polio survivors previously with good success. One example being of a patient who ended up drastically reducing their need for major walking aids, requiring only a simple walking cane after several months of rehabilitation.

The HAL Experience – what's it's like to be ‘Ironman’?

The best way to describe my experience using HAL is like suddenly being given the keys to a Lamborghini after having driven a sturdy Toyota Corolla for the last 20 years. You know there's a lot of power available but you are not quite sure if you'll be able to gain full control of it.

After you put it on, the heaviness of the device (weighing in at about 12kg) quickly fades away as the sensors kick in to assist your movements. It can however be somewhat jerky at first as you learn to ‘fire’ and coordinate different parts of the device to take each step.

For long term polio survivors like myself (accustomed to compensating for the weakness in my legs, by relying on and using muscles the average person would not normally use in walking), it is also quite disorienting. The process to remember which muscle

Learning To Walk Again *(cont'd from p5)*

controls which movement, flexing it, then coordinating it to create a smooth stride required a lot of concentration. At the end of the one and a half hour session I had actually worked up quite a sweat.

The lack of confidence in being able to fully control the device also adds to the sense that you still need support systems in place to balance and prevent falls – in my case, it is normally the security of my crutches. HAL staff are however very considerate of this and initiate you by trialling the device first with support hand rails and secondly through the use of a harness device to offset your body weight while you learn to walk. I found the latter particularly useful as it allowed me to solely focus on using the correct muscles as I learnt how to walk again, rather than having to constantly worry about whether I would fall.

I found the more I used it, the easier it was to control. Sensors also tracked every movement and muscle flexed, so you can

easily figure out whether or not you are walking 'properly'. I found this helped a lot as old habits and reflexes take a while to overcome. After several laps with the device on, you get a pretty good sense of when and how assistance would be provided. This helped me increase the pace and length of my strides. Watch this [video](#) of the actual trial.

Final Thoughts

Extremely impressed is probably an understatement of my perspective on how far this type of technology has come in just a short space of time. The obvious potential for assisting people across a broad spectrum of applications is breathtaking.

In terms of medical application, I think it is particularly useful within a rehabilitation context. As discussed above, there is very much a learning curve involved in using the device though. For long term sufferers of a medical condition, such as polio survivors, this is likely to be significant as quite a bit of time may be required to learn

'how to walk again'. HAL training staff mentioned a typical timeframe of 3-6 months to see a significant difference.

So ... is it worth trying for polio survivors? I would say yes, with a couple of caveats. Firstly, the device relies on reading your bioelectric signals from muscles so it essentially amplifies rather than substitutes. In other words, the more existing control you have over your muscles the better the device will work for you. Secondly, the device is currently used and certified for rehabilitation purposes only. So unfortunately you won't be able to take one home with you just at the moment.

Further Info

Hopefully the above has been helpful for anyone curious about the technology. For those interested in further info and updates on this emerging area, this [Facebook](#) page has been created to assist. Feel free to post questions and share your experience, especially if you do end up deciding to try out the technology for yourself! 🌟

Congratulations Bill Bradley!

Source: [Polio NSW](#) - 25 November 2014

Winners of the National Disability Awards were announced tonight [25 November], with 23 finalists from across Australia present at the ceremony in Canberra. Some of Australia's most exceptional individuals, organisations and programs were among the finalists, drawn from the mainstream and disability and community services sector. Finalists were chosen from more than 200 nominations across eight categories by a 12-strong judging panel representing a wide range of community organisations.

The awards are Australia's foremost celebration of the efforts and achievements of people of all abilities, and are a major part of the Australian Government's acknowledgment of the International Day of People with Disability (IDPWD) which is celebrated on 3 December each year.

The *Lesley Hall Award for Lifetime Achievement in Disability* was named to honour Lesley Hall, a powerful advocate who fought for the equal rights of people with disability for several decades of her life, and who sadly passed away in 2013.

Three exceptional candidates were finalists for the Lesley Hall Award in 2014. There could only be one winner, and we were thrilled to learn that Polio NSW member, **Bill Bradley**, received the Award. **Congratulations, Bill!** 🌟 [Read more . . .](#)

Australia-NZ Relations

Source: www.polio.org.nz

Excerpt from Polio NZ Inc's "Polio News" December 2014 Edition

How has our big sister organisation managed to become so effective on behalf of its members?

National Patron and President of Polio Australia Dr John Tierney OAM gave conference 2014 a fascinating insight into the long-term strategic planning that has reaped such rewards.

The critical point was being able to employ professional staff, he said.

Dr John has served in the Australian Senate. He therefore brings a politician's experience to his role, which was very apparent in his descriptions of the patient ways the Australian

polio networks educated politicians over many years.

For example they ran a cunningly well publicised 'We're Still Here!' campaign, for example, with a who's-who of upcoming politicians posing with campaigners wearing eye-catching tee-shirts. This both established credibility and built relationships for the future. In politics key people change, and it's best to have them well-primed long before they become the go-to person in power, he explained. After that it's too late, they're too busy and take all their advice from bureaucrats.

The strategies grew out of a



Trans-Tasman presidents: John Tierney (L) and Barry Holland (R)

2007 "Design a Future" conference, which was attended by representatives from all Australian states and from NZ. Since then Polio Australia has developed extensive websites; a national polio register; post-polio clinical resource modules; and specific programmes such as the annual Health and Wellness Retreats. By as early as 2010 only 0.5% of the budget came from membership, with 53% from philanthropy, and 34% from project grants. ●

Australia's First Digital Hospital

Source: [Joint Media Release](#)
- 8 December 2014

The Hon Peter Dutton MP

Minister for Health
Minister for Sport
and

Keith Pitt MP

Federal Member for Hinkler

Australia's first hospital with fully integrated, digital eHealth capability was officially opened today.

St Stephen's Private Hospital, operated by UnitingCare Health in Hervey Bay, has been created by expanding the regional hospital with a new, three storey inpatient hospital with 96 acute care inpatient beds and three additional operating theatres.

Health Minister Peter Dutton said St Stephen's was a world class hospital which showcased the future of health care.

"St Stephen's has raised the bar for all healthcare providers by embracing the technology literally before the foundations were laid", Mr Dutton said.

"It will be a showcase for the improvements that eHealth information technology can make for health care and patient outcomes.

"Digital technology can make health care far more efficient and more effective for patients and providers.

"Given the demands on our health system - from an ageing population, rising levels of

chronic disease and ever-rising consumer expectations - creating new efficiencies is essential."

The Federal Member for Hinkler Keith Pitt said having the first fully digital hospital in Hervey Bay was a huge benefit to the people in the Hinkler electorate. *"State-of-the-art facilities such as these enable regional people to stay close to home when ill or injured.*

"This facility will create new jobs and attract medical specialists to our community", Mr Pitt said.

The hospital's digital features include patient, community and medical web portals, and information linkages with Hervey Bay Public Hospital,

The Man In The Iron Lung



By **Barry Hoffman**
HealthDay Founding Editor

Source: [HealthDay News](#)
- 1 December 2014

Paul Alexander's most impressive accomplishment is something most people never think about. He taught himself how to breathe.

Alexander, 67, is a victim of the

worst that polio had to offer children in the late 1940s and early 1950s. At the age of 6, he was completely paralyzed by the disease, his lungs stopped working, and he was literally thrown into an iron lung.

Alexander has been in that iron lung for 61 years because he remains almost totally paralyzed, able to move only his head, neck and mouth. He is one of an estimated seven people in the United States who are still living in an iron lung, and yet he has had a long and successful career as a lawyer.

"Over the years, I've been able to escape this machine for a few hours at a time by teaching myself voluntary breathing," Alexander said recently as he lay in the iron lung at his home in Dallas, Texas. "I have to consciously push air into my lungs, something that's done involuntarily by just about

everyone else. It's hard work, but it allows me to escape this infernal device, if only for a little while."

Alexander "escapes" the machine most often when he is litigating a case - his specialty is family law - or gives a speech.

While he sometimes condemns the contraption that keeps him alive, Alexander is most grateful for his iron lung, whose machinery is essentially unchanged from the first ones that were put in use in the late 1930s. His machine, in fact, is the same one he entered 61 years ago.

"It is my cage, but it's also my cocoon," he said, as the iron lung issued a noticeable whishing sound, an almost uncanny replication of normal breathing.

But we're getting ahead of the story. Read more [here](#). ●

Australia's First Digital Hospital (cont'd from p14)

medical practitioners, other UnitingCare Health hospitals, universities and diagnostic providers.

The patient-centred clinical systems include automatic record feed, automated care pathways, alerts, and medication management.

The Government has provided special authorisation under Section 100 of the National Health Act 1953, to enable St Stephen's to undertake a "Paperless Prescribing, Dispensing and Claiming Trial".

Instead of paper scripts, all medication transactions will be done electronically.

The Australian Government

provided \$25.9 million for the construction of the new hospital building and \$21.2 million to equip the expanded hospital with state of the art eHealth technology.

"My department will continue to work with St Stephen's to monitor the effectiveness of the electronic system, and pick up on the benefits to inform future changes", Mr Dutton said.

"We will use the lessons learned from St Stephen's paperless prescribing, dispensing and claiming trial to refine the hospital electronic medication chart, which will soon be in widespread use in Australian hospitals."

Electronic medication charts will start to be introduced in private and public hospitals this financial year (2014-15).

"This is a great example of the major contribution that private providers, including not-for-profit operators, make to our health care system", Mr Dutton said. ●



The Impact of Not Getting Vaccinated



By Nicole Gregory

Source: [GOOD Magazine](#)
- 8 December 2014

You would think governments and individuals would make vaccinating citizens against harmful diseases a high priority. But this video (above), [based off a map created by the Council on Foreign Relations](#), shows that this isn't always the case—and as a result, whooping cough, measles, and polio have returned in epidemic proportions in some areas.

Why do people shun vaccines for life-threatening diseases? The reasons are heartbreaking and confounding.

In Pakistan, polio vaccination workers have been attacked and killed by members of the Taliban, who distrust the Western countries involved in providing the vaccine—leaving large numbers of people unvaccinated. Consequently, this year Pakistan reported 202 polio cases so far.

Meanwhile, in middle-class

communities across the U.S., most notably California, parents who believe vaccines are unsafe are refusing to get their babies and toddlers vaccinated against whooping cough, measles, and mumps. For instance, in 2010, there were 12,000 cases of whooping cough reported worldwide, with 5,000 in California alone. According to a report released by the California Department of Public Health this fall, that number had risen to nearly 8,000 cases for the year.

Read more [here](#). 🌐

Next-Gen Polio Vaccine Tackles Wild Virus Emergency

Source: [University of Queensland](#)
- 13 November 2014

Vaccine technology being developed at [The University of Queensland](#) could hold the key to completely eradicating polio by removing live virus from the vaccine production process.

A polio inoculation in use since the 1950s has all-but eradicated the crippling disease in the developed world, but 'wild polio' strains are running rampant in some poorer countries.

The World Health Organisation has described the current polio situation in developing countries is an 'emergency'.

Researcher [Dr Natalie Connors](#) visited the WHO in Geneva last month to brief researchers on the 'modular virus-like particles' her team is developing at UQ's [Australian Institute for Bioengineering and Nanotechnology](#).

"These particles resemble viruses but they are not infectious and only use the safe part of the virus", Dr Connors said.

"They are made by producing protein, not the virus. However, being a good mimic of the infectious virus, they raise an excellent immune response."

Dr Connors uses computational modelling and simulation to predict the best design of virus-like particles to obtain the optimal immune response.

"There is no cure for polio. It can only be prevented", she said.

"This is why polio vaccination is so important, and why developing a polio virus-like

Next-Gen Polio Vaccine *(cont'd from p16)*



Dr Natalie Connors

"This work will lead to a range of safer and more effective vaccines", she said.

Dr Connors is a Postdoctoral Research Fellow at AIBN working with UQ's Acting Deputy Vice-Chancellor (Research) and Vice-President (Research) [Professor Anton Middelberg](#) and Protein Expression Facility Director [Dr Linda Lua](#).

"Visiting the World Health Organisation was a great opportunity for Natalie, and her work is playing an important part in addressing a global health emergency", Professor Middelberg said.

"We are confident research into virus-like particles done by Dr Connors and others at UQ will help the World Health Organisation develop a new-generation vaccine for polio."

Dr Connors was one of the Young Researchers Driving Change at the G20 Brisbane [Global Café](#) Youth Forum yesterday (Wednesday 12 November) ahead of the G20 Leaders' Summit.

Watch the UQ video [New weapons in war on polio](#).

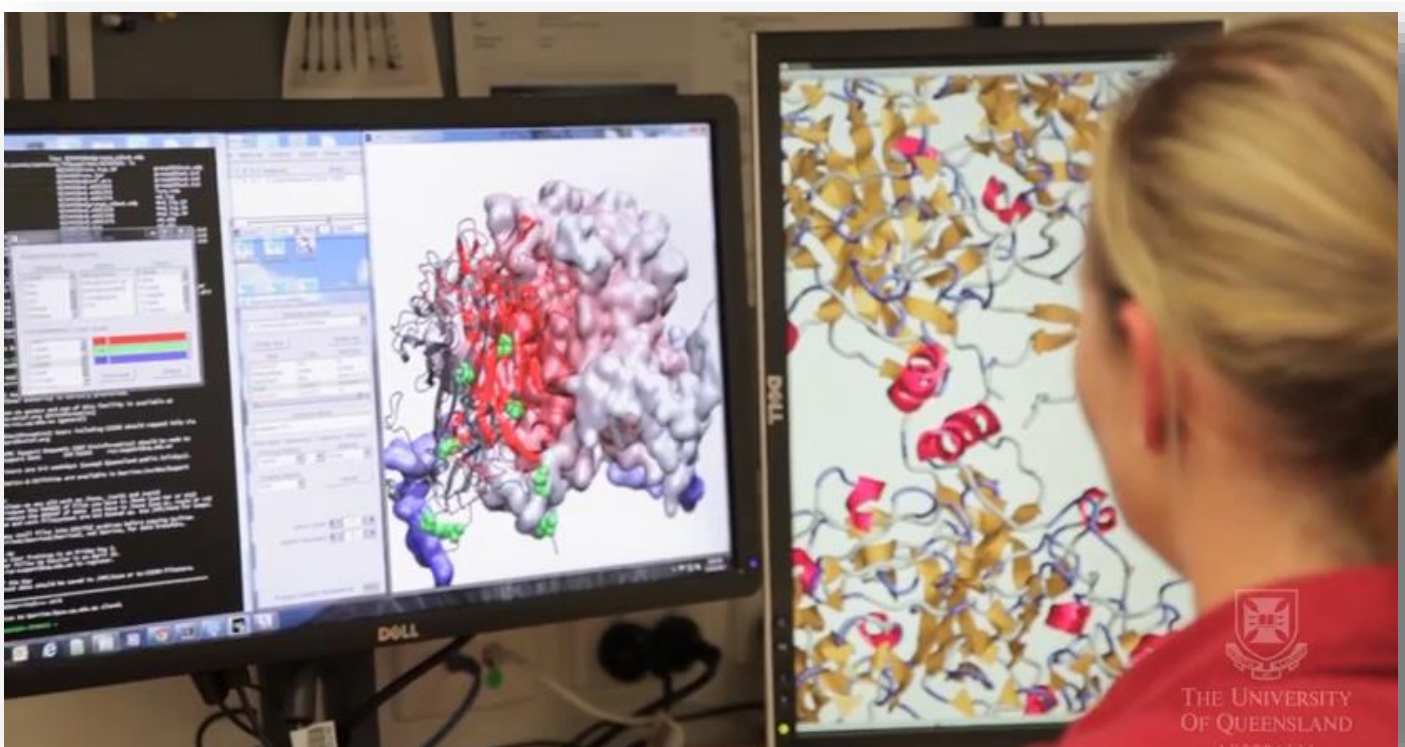
[World Polio Week](#) 2014 recognised the progress made towards the global eradication of polio. This year, South East Asia was certified as polio-free for the first time. 🇵🇰

particle vaccine would be the final step for eradication.

"The current live-attenuated polio vaccines, taken orally, can lead to circulation of vaccine-derived strains of polio-causing infection.

"Polio virus-like particle vaccines will be important for the post-eradication era, to maintain protection across the world without live virus production."

Dr Connors' research includes modelling the bioengineering of virus-like particles as a vaccine technology to fight other infectious and chronic diseases, including influenza and rotavirus.



"I Kept On Screaming, Begging For Help"

Source: [The Age](#)

—27 November 2014

Gunmen target polio vaccinators in Pakistan, killing four

Gunmen killed four members of a polio vaccination team in Pakistan's restive south-west on Wednesday, and one survivor recounted screaming at police and dozens of passers-by for help before it finally arrived.

The attack—the latest in a series by militants in Pakistan—happened on the eastern outskirts of Quetta, the capital of Baluchistan province.

Thousands of other polio vaccinators will refuse to go back to work unless they are assured of greater security, a representative said.

"A team of seven polio workers was getting ready to launch the fourth and final day of the campaign when two men riding a motorbike opened fire on their vehicle", provincial home secretary Akbar Durrani said.

Militants have in the past claimed that the polio vaccination is a cover for espionage or a Western conspiracy to sterilise Muslims. Opposition to immunisation increased after the US Central Intelligence Agency orchestrated a fake vaccination campaign to help catch al-Qaeda chief Osama Bin Laden.

The Quetta vaccination team leader, who wished to be identified by her first name 'Rubi', said the driver of her minivan fled when the men on the motorbike pulled out in front and flashed a gun.

"Then they started firing from

the front, I received bullets and fell down, I was bleeding. Then they went to the side of the vehicle and started firing", she said.

Rubi and others got out of the minivan after the gunmen fled the scene—but minutes passed before they could flag down help.

"I was bleeding and feeling so weak but I struggled to get down and saw a policeman nearby. I screamed for help but he walked away and disappeared down a street", she said.

"I kept on screaming, begging for help but vehicles wouldn't stop."

A motorcycle rider finally came to their aid. But two more workers, a husband and wife, died of their injuries on their way to hospital.

The attack was later condemned by Federal Information Minister Pervez Rashid, who said militants would not succeed in their 'nefarious designs'.

Poor security

Haleem Shah, President of the Polio Workers Association of Baluchistan, said his colleagues would not go back to work until they were assured of greater security.

"The government provides security for one day and if nothing bad happens then they take the security back", he said. *"We are in contact with the government and we have demanded that we won't participate in the campaign until we are provided security."*

Pakistan is one of only three countries where polio remains

endemic. Attempts to stamp it out have been badly hit by opposition from militants and attacks on immunisation teams, which have claimed more than 60 lives in the last two years.

District Health Officer Sher Muhammad said the campaign was launched in eight districts of Baluchistan including Quetta three days ago.

"It was the last day of the campaign to administer drops to the remaining children", he said, adding that the campaign was stopped in Quetta after the attack.

Officials say the number of polio cases recorded in Pakistan has reached 246 for the year—a 14-year high and more than double the total for the whole of 2013.

Among the new cases detected, 136 are in the troubled northwestern tribal areas that border Afghanistan and are the stronghold of Taliban and al-Qaeda militants.

The outbreak led the World Health Organisation earlier this year to ask Pakistan to impose mandatory vaccinations on travellers leaving the country.

Baluchistan, Pakistan's largest but least developed and most sparsely populated province, is racked by Islamist militants, banditry, a separatist revolt and sectarian violence between Sunnis and Shiites. 🌐

AFP

Polio This Week

Source: [Polio Global Eradication Initiative](#) - as of Wednesday 10 December 2014

Wild Poliovirus (WPV) Cases

Total cases	Year-to-date 2014	Year-to-date 2013	Total in 2013
Globally	325	359	416
- in endemic countries	306	135	160
- in non-endemic countries	19	224	256

Case Breakdown by Country

Countries	Year-to-date 2014				Year-to-date 2013				Total in 2013	Date of most recent case
	WPV1	WPV3	W1W3	Total	WPV1	WPV3	W1W3	Total		
Pakistan	276			276	74			74	93	22-Nov-14
Afghanistan	24			24	11			11	14	05-Nov-14
Nigeria	6			6	50			50	53	24-Jul-14
Somalia	5			5	183			183	194	11-Aug-14
Equatorial Guinea	5			5				0	0	03-May-14
Iraq	2			2				0	0	07-Apr-14
Cameroon	5			5	4			4	4	09-Jul-14
Syria	1			1	17			17	35	21-Jan-14
Ethiopia	1			1	6			6	9	05-Jan-14
Kenya				0	14			14	14	14-Jul-13
Total	325	0	0	325	359	0		359	416	
Total in endemic countries	306	0	0	306	135	0		135	160	
Total out-break	19	0	0	19	224	0	0	224	256	

Data in WHO as of 10 December 2013 for 2013 data and 09 December 2014 for 2014 data.