



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

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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 24<sup>th</sup> 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 25<sup>th</sup> 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](http://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](http://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
	<b>\$13,600</b>

### 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	
<b>Total - \$2,986.45</b>	

### 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.*

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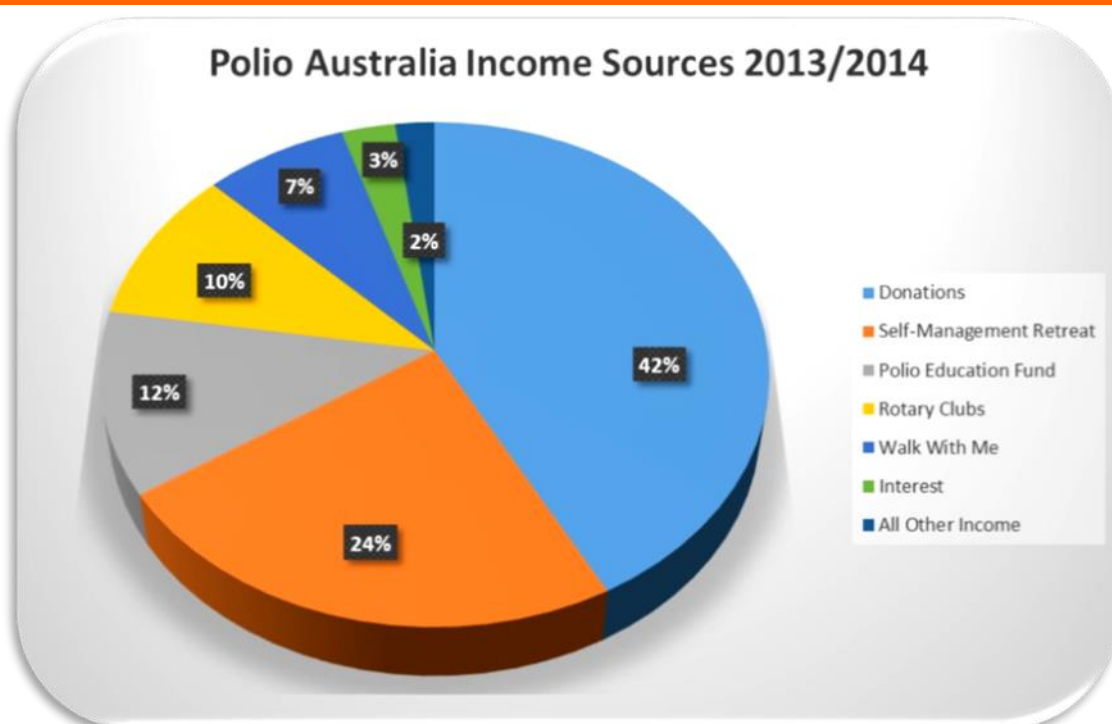
Include a specific bequest to benefit Polio Australia in your Will. Consider making a bequest to Polio Australia and determine the type of bequest which best suits your circumstances and wishes. Check [here](#) for details.



## 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 <a href="#">Polio Health and Wellness Retreat</a> run in New South Wales
June	Presented at two <a href="#">International Post-Polio Conferences</a> 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 <a href="http://www.poliohealth.org.au">www.poliohealth.org.au</a>

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](http://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](http://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."*

*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.*

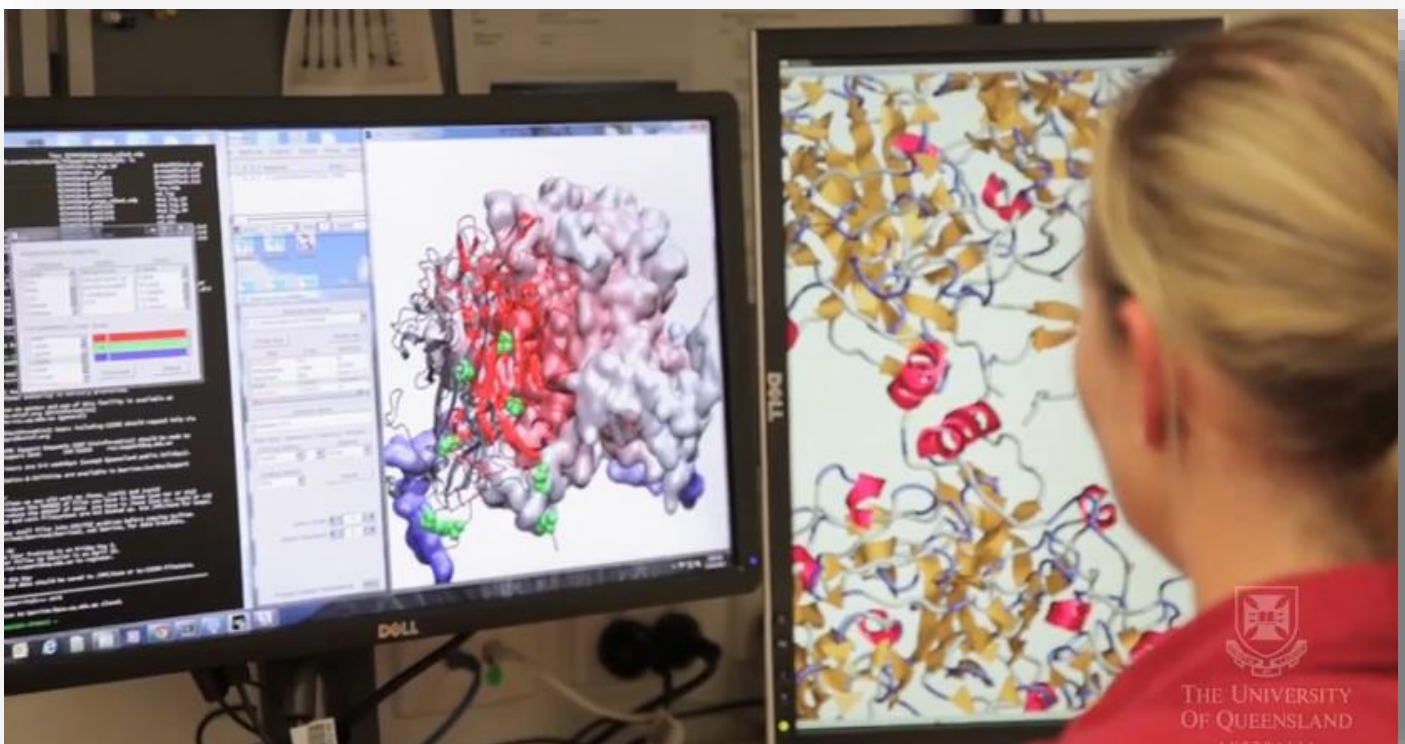
*"Polio virus-like particle vaccines will be important for the post-eradication era, to maintain protection across the world without live virus production."*

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.

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. 🇵🇰





## "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

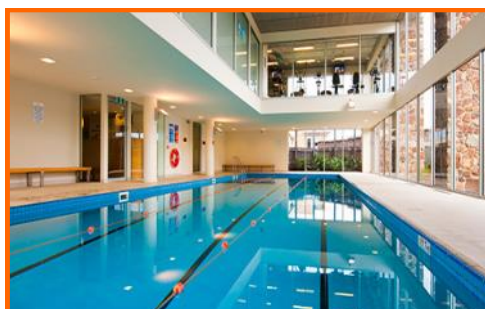
### Wild Poliovirus (WPV) Cases

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
<b>Total</b>	<b>325</b>	<b>0</b>	<b>0</b>	<b>325</b>	<b>359</b>	<b>0</b>		<b>359</b>	<b>416</b>	
<b>Total in endemic countries</b>	<b>306</b>	<b>0</b>	<b>0</b>	<b>306</b>	<b>135</b>	<b>0</b>		<b>135</b>	<b>160</b>	
<b>Total out-break</b>	<b>19</b>	<b>0</b>	<b>0</b>	<b>19</b>	<b>224</b>	<b>0</b>	<b>0</b>	<b>224</b>	<b>256</b>	

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



## 2015 Polio Health and Wellness Retreat

### Body / Mind / Spirit

#### *Expression of Interest*

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

Boasting a spectacular location along the pristine shores of Zeally Bay Beach on Victoria's Surf Coast, the Wyndham Resort Torquay is 90 minutes from Melbourne and enjoys stunning ocean views. Torquay itself is a vibrant seaside town that is the official starting point of the magnificent Great Ocean Road. The Resort has an outdoor 'lagoon' and an indoor heated pool, and plenty to see and do in the nearby areas, making it a great holiday destination.

Polio Australia's Health and Wellness Retreats provide an opportunity to:

- renew the mind, body and spirit
- have post-polio questions answered by unhurried medical experts
- spend custom-designed days enjoying recreational activities
- learn more about how to stay strong and healthy

Retreats offer ongoing wellness approaches that promise to improve overall health and quality of life through interactive group sessions, and one-to-one consultation opportunities with a variety of allied health professionals. See details of previous Retreats [here](#). Activities might include:

- ☆ Hydrotherapy and exercise options
- ☆ Latest orthotics, aids and equipment displays
- ☆ Seated Yoga and Meditation Sessions
- ☆ Activities To Keep The Mind Active
- ☆ Creative Workshops and Singing for Health
- ☆ Massage therapy

#### **Polio Australia's Health and Wellness Retreat—Victoria**

##### ***Expression of Interest only***

*(Registration fees for 3 nights accommodation, all meals and most activities  
= approx. \$400 pp double or twin share / \$450 single)*

**Please provide me with information on the 2015 Polio Health & Wellness Retreat when available.**

**Name:** \_\_\_\_\_

**Address:** \_\_\_\_\_

**Phone/s:** \_\_\_\_\_ **Email:** \_\_\_\_\_

**Return to:** Polio Health & Wellness Retreat, Polio Australia, PO Box 500, Kew East, VIC, 3102 or [Email](#)



## Book Order Form

The following clinical practice resource books published by Polio Australia can be purchased using this Order Form.

<b>Book</b>	<b>Cost Per Unit</b> <i>Inclusive of postage and handling</i>	<b>Number Ordered</b>	<b>Total AUD\$</b>
<i>The Late Effects of Polio: Introduction to Clinical Practice (2012)</i>	Australia & New Zealand <b>\$15.00</b>  Worldwide <b>\$25.00</b>		
<i>The Late Effects of Polio: Managing Muscles And Mobility (2014)</i>	Australia & New Zealand <b>\$34.95</b>  Worldwide <b>\$44.95</b>		
		<b>Total</b>	

### POSTAGE DETAILS

Name: .....

Address: .....

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### PAYMENT METHODS

**Cheque:** Please make cheques out to **Polio Australia Inc** and post to:  
 PO Box 500, Kew East, Victoria, 3102

**Electronic Funds Transfer:**  
 Include a reference (*your family name*) and also return this completed Order Form to the above address.

**Bank:** Westpac      **Branch:** Parramatta, NSW      **BSB:** 032-078  
**Account Number:** 555766      **Account Name:** Polio Australia Incorporated

***Thank you - an official receipt will be forwarded as soon as possible.***